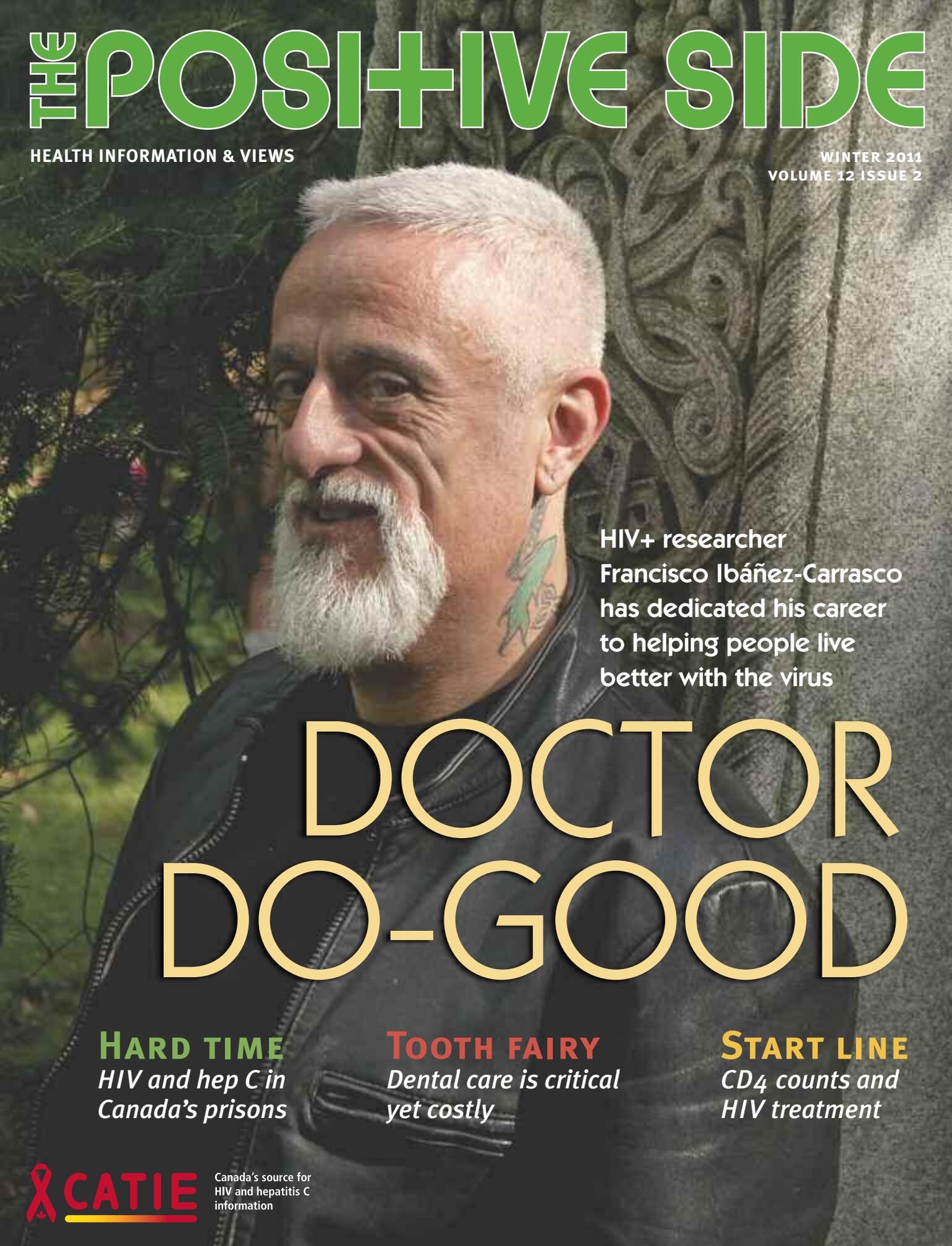


THE POSITIVE SIDE

HEALTH INFORMATION & VIEWS

WINTER 2011
VOLUME 12 ISSUE 2



HIV+ researcher
Francisco Ibáñez-Carrasco
has dedicated his career
to helping people live
better with the virus

DOCTOR DO-GOOD

HARD TIME
*HIV and hep C in
Canada's prisons*

TOOTH FAIRY
*Dental care is critical
yet costly*

START LINE
*CD4 counts and
HIV treatment*



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EDITOR'S LETTER

Let's begin at the end this time—the end of the issue, that is. On the last page you'll find highlights from the readership survey we conducted this past summer. First off, a sincere thanks to all of you *Positive Side* readers who took the time to share your thoughts about the magazine. We strive to represent all people living with HIV in Canada and your feedback guides us.

Perhaps the most consistent message was that you love the mix of personal stories from people living with HIV and useful information on all aspects of holistic health. In this issue, we keep it coming. We share the personal stories of a diverse group of people with HIV: academic Francisco Ibáñez-Carrasco, Montreal artist Shayo, and Doug Foreman and Mavis Daniels, who have both spent time in prison. Ron Rosenes writes about his experience getting dental care and we look at a variety of things you can do to keep your heart healthy and protect yourself from food-borne infections.

You also told us that the magazine often helps you feel more connected to other people living with HIV. Knowing that we can help break down isolation and promote empowerment is deeply satisfying for the team here. It motivates us to keep exploring issues and writing articles that interest you—and, of course, to continue creating the professional and positive visuals you so enjoy.

With all the information from the survey, we're fired up to make *The Positive Side* an even better magazine. Watch for changes in the coming issues. In the meantime, you don't need to wait for the next survey to tell us what you think. Send your stars and cherry bombs to dmclay@catie.ca.

—David McLay

PS. You will notice that the binding on this issue uses no staples, which should allow the magazine easier access into correctional facilities. A small change, but an important one for reaching *all* people living with HIV in Canada.

From the Front Lines 4
Canadian ASOs have seen the future—
and it's online

Chatty CATIE 6
4 PHAs express their gratitude

Profile 8
Francisco Ibáñez-Carrasco not only lives with
HIV, he's devoted his life to researching it

Food Safety Facts 11
4 steps to avoid food-borne infections

Million-Dollar Smile 12
Good dental care is critical for PHAs,
but why does it cost so much?

Views from Vienna 14
5 impressions of the XVIII International
AIDS Conference



Behind the Walls 18
The unique challenges of living with
HIV in prison

Keep Your Ticker Tocking 23
Information and tips to take to heart

Ask the Experts 26
4 doctors weigh in on when to start
antiretroviral therapy

Freedom by Expression 28
Shayo's HIV status is central to her art, but
she's more than just an HIV-positive artist

We Asked, You Answered 30
Results from *The Positive Side* survey
(You like us! You really like us!)

THE POSITIVE SIDE

www.positiveside.ca

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calling 1.800.263.1638.

FROM THE FRONT LINES

What's happening across Canada



ASOs Go Viral

Canadian AIDS service organizations are using online social media to connect with their clients. CATIE educator **Melissa Egan** shares her favourites folder.

AIDS service organizations (ASOs) have seen the future—and it's online. On the way out are newsletter-mailing parties with free pizza. Keeping in touch and connecting with clients and community are getting easier with the widespread use of online social media such as Facebook, Twitter and YouTube. This issue of From the Front Lines goes online and points you to ASOs from your region and across the country.

Facebook



After becoming one of the most popular social networking sites on the Web, Facebook is growing in popularity as a way for ASOs to promote their events, fundraise and build community—both virtual and real. Once a person or group has signed up for a free account, they can create pages that are then used to post information, make connections and interact with other users.

Vancouver-based **YouthCO AIDS Society** uses Facebook to announce its events. Fresh graphics and detailed information on activities are available to all and it's tough to resist their sweet and sassy invitations, such as the one to their 16th anniversary party Acquired Taste. The group doesn't just promote sexual health and HIV/AIDS awareness through near-daily status updates, it also uses this virtual world to make real-world changes, as when it gave away a year's supply of condoms (365 to be exact) through the page.

www.facebook.com and then search for **YouthCo**

AIDS Saskatoon's Facebook page has more than 400 fans. The tight-knit community keeps in touch through the site's status updates and members frequently post messages to each other, maintaining a vibrant and connected volunteer base. Updates include enthusiastic calls to join the agency at local events such as Saskatoon Pride and tempting tickets for raffles and other fundraising efforts. Posting pictures of agency activities, such as its volunteer party or annual community needle cleanup day, makes everyone want to stop by the page to see the action!

www.facebook.com/aidssaskatoon



Blogs

Blogging, a unique approach to online writing, hit the Net in the late 1990s, with people posting what were often personal diaries. While no longer created only by individuals, blogs still provide a personal perspective on a topic. Several ASOs write blogs that provide both information and an HIV-positive view on life. The ability for readers to add a comment on each post allows people with HIV to share their experiences and for a community to form around the storytellers.

Vancouver's **Positive Women's Network (PWN)** has an appealing blog on its sunny website. Blog posts are consistently interesting, informative and inspiring. The blog is written by Monique, Janet and Miriam—three women who each bring their unique experience of HIV to the site. Monique posts stories about online dating as a positive person and moving beyond survival and learning to thrive. Janet, PWN's communications coordinator, keeps the blog lively with links to other websites and new support groups available in the city. Miriam brings a thoughtful analysis of multiculturalism and posts notices of events for women with HIV.

pwn.bc.ca/blog

A vital and energetic community of HIV-positive bloggers can be found at positivelite.com, a website by Toronto's Brian Finch, whose vision has created a robust roundup of resources and personal stories. Finch shares his experience of everything from improv workshops to facial fillers with honesty and humour. Each contributor to the site, aimed at positive gay men and their friends, writes with their own unique style and personality. Don Short, an artist and case worker at AIDS Durham Region, is one of the bloggers. He muses on happiness and travel and frequently shares his artwork with readers.

www.positivelite.com



Twitter

Twitter is one of the newest forms of social media, and it pushes the boundary of short and sweet. With Twitter, messages—called “tweets”—contain just 140 characters and are sent out to subscribers. To follow your favourite ASO all you need to do is set up a free account on twitter.com

The **AIDS Committee of Toronto** uses Twitter to stay in touch with its community members and volunteers via creative one-liners. Updates about recent HIV-related news stories from local and national media, callouts for help at events and even job postings are sung by this creative birdie. Whoever’s in charge of those 140 characters uses them well!

twitter.com/ACToronto

AIDS Moncton has personalized its Twitter page with a laundry line of colourful condoms, and the breezy updates are a perfect match. Subscribers receive links to HIV news and information, invitations to events such as the annual AIDS walk fundraiser and updates about other sexual health resources. Known to her Twitter subscribers simply as Kate, special events coordinator Kate Doyle’s talky tweets make the organization’s twitter feed a handy way to keep up with this energetic group.

twitter.com/AIDSMoncton



YouTube

Home to millions of videos, this site is the most popular online video community. A quick search will turn up film clips, music videos, home movies and the incredible work coming out of ASOs in Canada and around the world.

The YouTube page of **AIDS Community Care Montreal** is actually a channel, meaning it’s updated regularly. You’re encouraged to subscribe so when a new chapter of its “Safer Sex News You Need” series is online, you’ll be the first to know. The videos, which begin with a tongue-in-cheek history of sex, are refreshing in their approach to sexual health education. Snappy dialogue, bold visuals and great music all come together successfully to make safer sex interesting and entertaining.

www.youtube.com/user/ACCMontreal



iPhone Apps

Apple’s iPhone has taken the cell phone market by storm and the applications (or “apps”)—programs that make use of the phone’s computing ability—used with them have turned the cell phone into a rich source of mobile information.

Toronto Public Health has come up with an original application that’s sexy and informative. M2Men is a health resource for gay men. Install the application on your iPhone and quickly locate local ASOs, popular clubs and bars with free condom dispensers and access lots of great information, ranging from which sexually transmitted infections can be transmitted during specific sex acts to tips on HIV disclosure. The application is well designed, easy to use and, above all, right at your fingertips!

Search for M2Men in the App store.

This is not a complete overview. If there’s an ASO using social media that you think we should know about, send the info our way at info@catie.ca.

Other Online Resources and Communities



AIDS Calgary blog
aidscalgary.blogspot.com

Health Initiative for Men
www.checkhimout.ca

AIDS Committee of London
Twitter feed
twitter.com/AIDSLondon

The following ASOs have Facebook pages. Search for them by name on www.facebook.com:

- **AIDS Committee of Guelph and Wellington County**
- **AIDS PEI**
- **AIDS Vancouver Island**
- **HIV Edmonton**
- **Rézo**

CHATTY CATIE

Thank You Notes

Studies show that gratitude can improve both your health and happiness by strengthening your immune system and increasing your level of optimism. Here, four people with HIV count their blessings. What are *you* grateful for?

INTERVIEWS BY RONNILYN PUSTIL



The single thing that I am most grateful for is my partner.

JOHN BISHOP, 62

Vancouver

Diagnosed with HIV in 1999

CD4 count: 500

Viral load: undetectable

I have a good life. I am fortunate enough to have very good people around me. That's one of the things I value the most—my family and friends. They keep me sane and they're there for me when I'm in need of support. As we get older, our support network is critical for our well-being.

I'm grateful that I live in a time when HIV medications are at where they are. When I first seroconverted in 1999, I went on medications right away. They made me sick, so I stopped meds and continued to monitor my blood work. Two years ago my CD4 count hit 250, and so I restarted medications. Other than a bit of diarrhea,

I've had no problems. I have a quality of life that I never imagined back in 1999. I feel that if I take care of myself today, I can have a full and rich life. I expect to live another 20 years.

I'm grateful for living in British Columbia. Our health-care system is the best in North America and, I believe, in the world. My doctor, the hospital and the immunodeficiency clinic are all within walking distance of my home. There's a very strong sense of community here.

I express my gratitude by being involved with my community. Volunteering at British Columbia Persons With AIDS Society (BCPWA) is one of the cornerstones of my well-being. It gives me a purpose in life. I'm fortunate enough to have a full benefit pension from my employer, which has allowed me the freedom to give back to my community without worrying about income.

The single thing that I am most grateful for is my partner, Barry. He is incredibly supportive and he takes care of a lot of household duties, giving me the freedom to do my volunteering. I don't tell him often enough how much I love him.

BELIEVE MABHINDU DHLIWAYO, 39

Mississauga, Ontario

Diagnosed with HIV in 1993

CD4 count: more than 650

Viral load: undetectable

I am grateful for the opportunities I have had here in Canada, which have made it easier for me to live with HIV. However, living with the virus is still not easy and never will be. Learning to

live with HIV is an art that you learn over time. Some have failed to live with it due to various challenges and factors. So am I grateful? YES! Especially for the following things:

An opportunity to live – I lost most of my friends who were living with AIDS back home in Africa. I am grateful that the government of Canada provides resources that enable individuals to live healthy, fulfilling lives. I have friends and a life partner who are very supportive. I always wanted to settle down, get married and go to university. I am grateful that I have a family, despite the stigma that HIV-positive people should not marry and have children. And I am determined to complete my studies and live life to the fullest.

The availability of resources – I am grateful that the basic resources (food, housing and job opportunities) have

I am very grateful for the opportunity to access treatment.



been made available, though systemic barriers are still sometimes present.

Access to treatment – I am very grateful for the opportunity to access treatment. When I came to Canada in 2005, my CD4 count was 90 and my viral load was higher than 1,200. The doctors took their time to explain and convince me that it was important to take care of myself so I could continue taking care of others.

Diversity and integration – I have met wonderful people from across the globe and have worked with them to address HIV/AIDS. I have been to places for conferences that I could not have traveled to if I were not living with HIV.

I express my gratitude by spending time with my family, giving to the community my time and energy to scale up prevention efforts and promoting effective ways of addressing HIV/AIDS in the minority communities of Toronto. I will never be too busy to help or assist newcomer people with HIV in need.



I am grateful for the example set by my mother.

MICHAEL BURTCH, 28

Ottawa

Diagnosed with HIV in 2005

CD4 count: 426

Viral load: undetectable

I am my mother's son, and for that I am grateful. My mother, Heather, is a

steely divorcée of the '80s, a working single mother of three and a thrift-store clothes horse. She stocked her closet with sparkling clip-on earrings, high-heeled shoes and everything else a gay boy of five needed to do drag and to celebrate the strong women in his family. My mother showed me what it meant to be a woman, and she taught me how to be a man, too.

What I learned from witnessing her strength and composure, her struggles combating sexism and chauvinism, and her love of teaching became translatable when I tested positive. If not for absorbing her numerous displays of gumption, I could have lost my sense of identity and myself at the hands of HIV.

Instead, I did what my mother did 26 years ago when she left a bad marriage. I pulled myself up by my bootstraps and soldiered on. I became engaged in fundraising and activism around agencies and issues that impacted my community, and I started blogging about my experiences as an openly HIV-positive gay man on *positivelite.com*. I have met people who I admire and who inspire me to be better. I am grateful to be acquainted with all of them. Mostly though, I am grateful for the example set by my mother. She is, and always will be, my hero.

JOANNE SCHINGH, 44

Windsor, Ontario

Diagnosed with HIV in 1997

CD4 count: 864

Viral load: undetectable

There are so many things I am grateful for.

I have a beautiful daughter and a good son who are with me. I'm in a wonderful relationship with a man who loves and supports me. I have a close family that is always there when I need them. I have friends with HIV who inspire me, keep me strong and remind me that I'm not alone.

I have a great house that keeps the cold outside and a warm bed for when my body can't hold out. I've got my hands that do good work, and I have my eyes, though they don't see as far as I would like. I have a good heart

that I show to the people I'm close to.

After 13 years of being positive, I am still healthy. I'm always grateful to God for granting me another day. Having HIV has made me more grateful for so many things. I don't take anything for granted.

I express my gratitude by giving back to my community: I am a peer mentor, I sit on the board of directors at my local AIDS service organization, I do education and prevention work and more.

I thank the AIDS Committee of Ottawa, which opened its arms to me and made me feel safe. I met a lot of wonderful ladies there. One woman became my mentor. She was there to



I'm always grateful to God for granting me another day.

show me that everything would be all right. She introduced me to many other AIDS organizations, including Voices of Positive Women. What an eye-opener that was—I was amazed by how much work these women did to make sure our voices were heard. That's where I learned to get involved.

I am who I am because of these organizations and all the friends I've met along this path. I thank you all. There may not be a cure at this time, but I have the power and strength to endure. +



Professor Poz

Whoever says HIV researchers are boring has never met **Francisco Ibáñez-Carrasco**.

BY JENNIFER MCPHEE

PHOTOGRAPH BY JOHN PHILLIPS



One of the first things you notice about Francisco Ibáñez-Carrasco, 47, is the multicoloured fish tattoo on his neck. In his early twenties, getting inked was his way of side-stepping a boring, conventional life. “The idea was that no one would hire me to work in an office,” explains the cheerful HIV researcher over a plate of nachos at Hair of the Dog pub in downtown Toronto’s gay village. “Now, of course, I work in an office.”

But that’s not all Ibáñez-Carrasco does; these days he spends just as much time teaching in a virtual classroom as he does working in an office. Inspiring the next generation of HIV researchers at the national training program Universities Without Walls, he tells up-and-coming scientists that they probably won’t get rich studying HIV, but they’ll never be bored.

Few can claim to know the history of AIDS more intimately than Ibáñez-Carrasco. Not only is he a longtime survivor—he’s been living with HIV for 25 years—but he has also devoted his life to researching ways to improve the lives of people with HIV. And his efforts have not gone unnoticed. In June, he received the 2010 Award of Excellence in HIV and Rehabilitation,

awarded by the Canadian Working Group on HIV and Rehabilitation (CWGHR) in recognition of his contributions and leadership in the field.

When Ibáñez-Carrasco was diagnosed with HIV in 1985, months after migrating to Canada from Chile, having the virus didn’t mean much to him. He was 22 years old and still felt invincible. Most of the friends he arrived with in Vancouver moved on to New York City, which was “kind of a gay Mecca in our imaginations,” he says. “We were all young gay men who didn’t know anything about AIDS. We all got infected and they all died. Some of them died of HIV-related complications; some of them died undocumented. So, yeah, there’s a trail of dead people behind me, whom I honour, of course, all the time.”

BEAUTIFUL CHALLENGES

As people around him died, Ibáñez-Carrasco developed a consciousness around HIV/AIDS, eventually applying to do his Masters in AIDS education at Simon Fraser University in Vancouver in 1989. Back then, there were very few openly gay students and even fewer HIV-positive ones. The university sent him a rejection letter, explaining

that AIDS education was not something that existed within the school’s Faculty of Education. His mentor, professor Suzanne De Castell, took up his fight and the university eventually reversed its decision. Ibáñez-Carrasco earned his Masters degree in 1993 and then decided to pursue a doctorate.

Then, 10 years after his own diagnosis and around the same time as the AIDS-related death of his second partner—his first partner also died of AIDS—Ibáñez-Carrasco was hospitalized at St. Paul’s Hospital in Vancouver. He was battling multiple opportunistic infections and covered in Kaposi’s sarcoma lesions. Believing the end was near, Ibáñez-Carrasco wrote his autobiographic first novel, *Flesh Wounds and Purple Flowers*, which was nominated for a Commonwealth Writers’ Prize.

Not expecting him to live, Simon Fraser University decided to drop Ibáñez-Carrasco from its doctoral program. Again, his mentor successfully battled that decision. Then, in 1996, Ibáñez-Carrasco came back from disfigurement and the brink of death, thanks to the arrival of the first protease inhibitors and the advent of effective combination therapy. Following his

recovery, he went on to resume his studies at Simon Fraser, obtaining a PhD in Education with a focus on health and sexuality in 1999, making him one of the first Canadians with HIV to earn a doctoral degree. “I was an oddity,” he says. “A PhD is something you earn in order to have a career. But what kind of career could you have when you were [still] expecting to die?”

Looking back, Ibáñez-Carrasco views the obstacles created by Simon Fraser University as beautiful challenges. “It only demonstrated to many people, and to myself, that you can fight back.”

REHABILITATING RESEARCH

After earning his PhD, Ibáñez-Carrasco went on to hold a variety of research, teaching and volunteer positions, continually impressing colleagues with his creativity, enthusiasm and ability to create a bridge between academia and grassroots organizations.

Perhaps motivated by his own experiences of regaining his health and picking up the pieces of his life, Ibáñez-Carrasco chose to focus his research on HIV and rehabilitation. The choice put him in a field that continues to be one of practical importance for people with HIV, especially now that effective treatments mean that HIV is viewed more and more as a chronic manageable condition.

The practical benefits of his work are many. One of the large-scale research studies he worked on looked at the positive impact of alternative medicine and therapies on the lives of people with HIV; a smaller-scale project engaged marginalized people with HIV in innovative nutritious cooking workshops held in Vancouver’s impoverished Downtown Eastside.

All along, it’s been clear from his work that Ibáñez-Carrasco connects with people from different walks of life without being condescending or judgmental. This ability comes from respecting people who struggle and work hard, including drug users and sex workers. “You and I can sit here

and discuss what’s legal or illegal, but that’s not terrain where I like to go,” he explains. “Morality is for people who can afford it.”

Ibáñez-Carrasco’s perspective is partly rooted in his life experience. He was raised by a poor, single mother who earned her living cleaning rich people’s houses. As a child he was molested by Catholic priests, and as a teenager he traded sex for cash. “I get

“Because of its history, HIV has been ‘queered’... That makes the field scary, intensely quirky and interesting.”

along with people with an edge, with difficult lives,” he says, “because I see myself reflected in them.”

Unwavering optimism is another of his strengths, a trait that Ibáñez-Carrasco cheerfully refers to as his survival strategy. “He’s optimistic in the sense that he refuses to let the world get the better of him,” says Elisse Zack, CWGHR’s executive director. “When things seem overwhelming, he says, ‘There’s got to be a way through this.’”

STUDYING STIGMA

Ibáñez-Carrasco still studies HIV and rehabilitation, and he has started looking at the impact of aging as well. These days, he is also particularly interested in the health and sexuality of HIV-positive queer men. He is currently collaborating on several research studies about the physical and mental health impacts of living with HIV for many years. One project involves studying factors, such as stigma, that prevent gay and bisexual men with HIV from accessing mental health services in Ontario.

Ibáñez-Carrasco believes that the stigma associated with homosexuality carries over to people with HIV regardless of their sexual orientation and that this stigma permeates all aspects of people’s lives. For instance, he points out that it’s still harder for people to ask their employers to accommodate HIV-related health problems, compared with people suffering from, say, diabetes. Many people are made to feel so ashamed of having HIV, he says, that they hide themselves from other people. As a result, many become chronically depressed but don’t seek help.

Studying this stigma is what makes his chosen field so intriguing to Ibáñez-Carrasco, and he shares his enthusiasm with young HIV researchers through University Without Walls. “Because of its history, HIV has been ‘queered’ compared to very straight-laced health areas,” he says. “That makes the field scary, intensely quirky and interesting. We need to reinvigorate a new generation of HIV researchers to understand that.” +

Ibáñez-Carrasco is working on his third book, *Giving It Raw: 25 Years with AIDS*, a memoir that incorporates some of his past published writing.

Jennifer McPhee is a Toronto-based freelance writer who contributes regularly to *The Positive Side*. Her work has appeared in numerous publications including *Chate-laine*, *The Globe and Mail* and *Childview*.

Food Safety Facts

Knowing how to properly handle and prepare food can help you avoid foodborne illnesses and stay on good terms with your digestive system.



Did you know that there are about 11 million cases of foodborne illnesses in Canada every year? People with HIV can be particularly at risk, so read on to see how you can avoid being one of these cases.

FOOD SAFETY 101 – A CRASH COURSE

Foodborne illness, sometimes called food poisoning, happens when you eat food contaminated with disease-causing germs, such as bacteria, viruses and parasites.

Symptoms of foodborne illness include stomach cramps, nausea, vomiting, diarrhea, headache and fever.

Depending on the type of germ you ate, you could start feeling sick a few hours after consuming contaminated food, or even a few days or weeks later! People often think it's the last thing they ate, but this is not always true.

If you have a weakened immune system for whatever reason—HIV or alcoholism, cancer, diabetes or organ transplantation—it can be more difficult for you to fight off infections. To reduce your risk of getting a foodborne illness, it's important to take extra care when handling, storing, preparing and shopping for food.

Some food can be more risky because of the way it is produced and the conditions and length of time it is stored. You can reduce your risk by avoiding certain foods, such as sushi or unpasteurized dairy products,

and by choosing safer alternatives, such as fully cooked fish or pasteurized dairy products.

FOLLOW THE FOOD SAFETY STEPS

Following the four key steps to food safety is the best way to protect yourself from foodborne illness:

- **Separate:** Separate your raw foods, such as meat and eggs, from cooked foods, fruits and vegetables to avoid cross-contamination.
- **Clean:** Wash your hands, kitchen surfaces, utensils and reusable shopping bags often with warm, soapy water.
- **Chill:** Refrigerate your food and leftovers promptly at 4°C or below.
- **Cook:** You can't tell by looking. Use a digital thermometer to be sure! Cook your food to safe internal temperatures. +

Check out www.healthycanadians.ca for lots of useful info on safe food handling at home and in the grocery store. The site features a **Select the Safer Alternative** chart, which offers many safer options to common foods that can be riskier for people with weakened immune systems, and a **Safe Cooking Internal Temperature** chart, which lists the safe internal temperatures for meats and egg dishes.

You can also call Health Canada toll-free at 1.866.225.0709 or TTY at 1.800.276.1245.

BEWARE THE “BAD BUGS”

These types of foodborne illnesses are dangerous for people with weakened immune systems:

***E. coli* O157:H7** infection – caused by bacteria that may be found in foods such as:

- raw and undercooked ground beef
- unpasteurized fruit juice or cider
- sprouts
- unpasteurized dairy products

Listeria infection – caused by bacteria that may be found in a wide variety of refrigerated **ready-to-eat foods**, such as:

- raw and unpasteurized dairy products
- non-dried deli meats
- hot dogs straight from the package

Vibrio infection – caused by bacteria that may be found in **raw and undercooked shellfish**, such as:

- oysters
- clams
- mussels

Salmonella infection – caused by bacteria that may be found in a variety of foods but especially in:

- raw and undercooked chicken
- raw eggs
- raw milk



MILLION-DOLLAR SMILE

Ron Rosenes knows that good dental care is critical for people with HIV, but the cost has him grimacing.

ILLUSTRATION BY JOHN WEBSTER

As if trying to age gracefully with HIV—at 63, I have lived with the virus for 29 years now—weren't a sufficient challenge, I find myself facing a growing effort and cost to maintain the health of my teeth and gums. And there is good reason to put my money where my mouth is: Good oral health is integral to our overall health and well-being.

A case in point: At a recent visit to my doctor, we noticed that my PSA antigen, a marker for prostate health, had started to go up after being stable and within normal range for many years. Soon after, I went to the dentist for a routine examination and cleaning (\$185). An initial X-ray (\$23) revealed the need for a root canal (\$1,000, ka-ching ka-ching!) on the upper right side and showed evidence of infection.

The root canal was one of the most painful experiences of my life. The residual pain lasted for days and I resorted to the prescription painkiller Percocet and cold compresses for relief. I was also put on antibiotics for the infection. I am happy to report that everything returned to normal after about two weeks.

Two months later when I asked my doctor to repeat the PSA antigen test, the results came back with my old numbers. The lesson for me? The mouth is connected to the butt in ways I never imagined. I had read somewhere that infections in the mouth could cause the PSA antigen marker to rise, and while my doctor was somewhat skeptical, he could not find another explanation for the return to normal levels.

TOOTH FAIRY, WHERE ARE YOU?

Now, I must add here that I've been phenomenally fortunate in having a dentist who has cared for me since 1977. I was among his first patients diagnosed with HIV and he took it upon himself to study the new disease and learn techniques that would keep everyone safe. Unfortunately, this is not always the case: Although having HIV is not a reason to be denied dental care, some practitioners still refuse to treat people with HIV/AIDS (PHAs).

I dutifully returned to the dentist last week for a follow-up appointment. I am now the proud owner of a gold crown (another \$1,200)—and not the kind you wear on your head.

All told, this dental adventure has cost me just over \$2,400.

Like so many fellow PHAs, I have no dental insurance and have had to pay for these costs out of my own pocket. Any time I've looked into supplemental dental insurance, pre-existing condition clauses made it unaffordable. Yet I consider myself among the lucky ones. After all, even though I don't have insurance, I do have better income than the average PHA, thanks to private long-term disability insurance that I purchased before my diagnosis.

Many PHAs access their drugs and dental care through provincial or territorial social assistance or disability programs. These programs might allow you to get your teeth cleaned once a year and have a bad tooth pulled, but root canals and crowns? Forget it! Bridges and implants? I don't think so! The result is that many people in our community cannot afford to see a dentist or a hygienist—and their health may be at risk because of it. (See "Open Wide" for a discussion of common dental issues for PHAs.)

ORAL HEALTH = OVERALL HEALTH

After my dentist fitted me with my new crown, the hygienist began a new program to monitor my gum health over time because of the relationship between gum disease and heart disease. Results of the Scottish Health Survey have shown a link between tooth-brushing behaviour and cardiovascular disease. Researchers think that the lax dental practices that often result in poor gum health can foster buildup of bacteria and lead to low-level inflammation. This chronic low-level inflammation can increase your risk of cardiovascular disease. (See "Inflammation Information" in the Summer 2010 issue for more on HIV, inflammation and heart disease.)

Although it seems a no-brainer that good oral health is integral to our

overall health, government officials often say there is no money to improve oral health care for those on social assistance. This should not stop us from advocating for the health-care system to improve coverage for medically necessary dental care, and as a community, we should have a say in defining what that means. Benefits and coverage for people on assistance programs need to be greatly

Many people in our community cannot afford to see a dentist or a hygienist—and their health may be at risk because of it.

expanded. In some cases, people would be able to return to work if their dental needs were met.

In the meantime, if you're looking for more affordable dental care, consider asking whether your dentist has a sliding fee structure for people on limited incomes. Also, some dental schools offer clinics with reduced fees. Finally, don't be afraid to discuss your dental health problems with your doctor. Some physicians may be able to treat infections or act as an advocate with a dentist they refer you to. +

Ron Rosenes has lived with HIV for almost three decades and has worked tirelessly for access to proper health care for all PHAs during that time. He believes in the African proverb: The best time to plant a tree is 20 years ago. The second-best time is now.

Open Wide

Finding a dentist who has experience with HIV and being open about your HIV status with him or her will help you get the best care. There are several oral conditions that are more common among PHAs and sometimes the first signs of advancing HIV disease appear in mouth.

Dry mouth, common among PHAs, can be caused by the virus, certain drugs and some foods and drinks. Saliva protects teeth and gums, and a dry mouth can lead to infections and decay in the teeth and gums. **Canker sores** (aphthous ulcers) can also be an issue. These small round sores can be quite painful. Check out CATIE's *Practical Guide to Nutrition* for tips on how to deal with problems in the mouth or throat. If they persist, talk to your dentist or doctor.

Gum disease is inflammation of the gums. It can result in receding gums and loose teeth, which might even fall out. Smoking and dry mouth can make gum disease worse, and there is new evidence that the inflammation seen in gum disease can lead to increased risk of heart disease. Gum disease has also been linked to an increased risk of diabetes and perhaps to pre-term births. Good oral hygiene—including regular brushing, flossing and visits to the dentist—can keep gum disease from developing.

Infections in the mouth can be a sign that the immune system is being weakened by HIV. They sometimes lead to someone being tested and diagnosed with the virus. Thrush (or candidiasis), hairy leukoplakia and oral Kaposi's sarcoma are seen in advancing HIV disease. PHAs should also be on the lookout for other infections, including cold sores (herpes simplex), shingles (herpes zoster) and oral warts (human papillomavirus).

Views *from* Vienna

Five attendees offer their impressions of the recent XVIII International AIDS Conference.

Vienna city hall plays backdrop to the city's annual Life Ball fundraiser, which coincided with the conference opening.



Murray Jose

Living with HIV since 1991

The conference appeared to me to be full of dichotomies. Topics often seemed to have two strongly opposed or simply distinct positions.

For example, the call for earlier treatment and even the idea of “test and treat”—which suggests everyone should start treatment early, perhaps right after diagnosis—were juxtaposed with research presentations highlighting the impacts of the long-term side effects of HIV medications and our lack of knowledge of the consequences over many decades of use. There was also a focus on the need for new ways to support people with HIV/AIDS (PHAs) as we live longer and get older. At the same time, mounting evidence suggests that living long term with HIV leads to a sort of accelerated aging.

It frustrated me that many researchers and physicians at the conference didn't seem to notice (or at least have any desire to discuss) these contradictions.

During the week, former U.S. President Bill Clinton spoke on the idea of false choices. He said that we can too easily see a situation as presenting apparently opposing choices, but in reality this opposi-

tion is fictitious. For example, in promoting women's health, it's a false choice to think we must choose between programs for women living with HIV and programs for broader groups. The choice is a false one because both programs can improve the health of women living with HIV and their families.

As the conference progressed, I reflected on Clinton's words. Perhaps the apparent dichotomies I saw were just false choices. In looking at the issues from this perspective, maybe we can find the connections that indicate where solutions lie and guide us forward in a way that will further support our living well and whole as PHAs.

Kath Webster

Living with HIV since 1995

I loved the conference—a huge global, intelligent, dynamic community came together for a week full of presentations, protests, discussions, performance, research, art, debate and more.

I was particularly intrigued by sessions on treatment as prevention, criminalization and harm reduction. The theme of human rights was prominent and peaked with a midweek march through the city streets that ended with a robust rally and a concert by Annie Lennox. She proved to be a well-informed and passionate spokesperson on HIV issues, particularly those affecting African women.

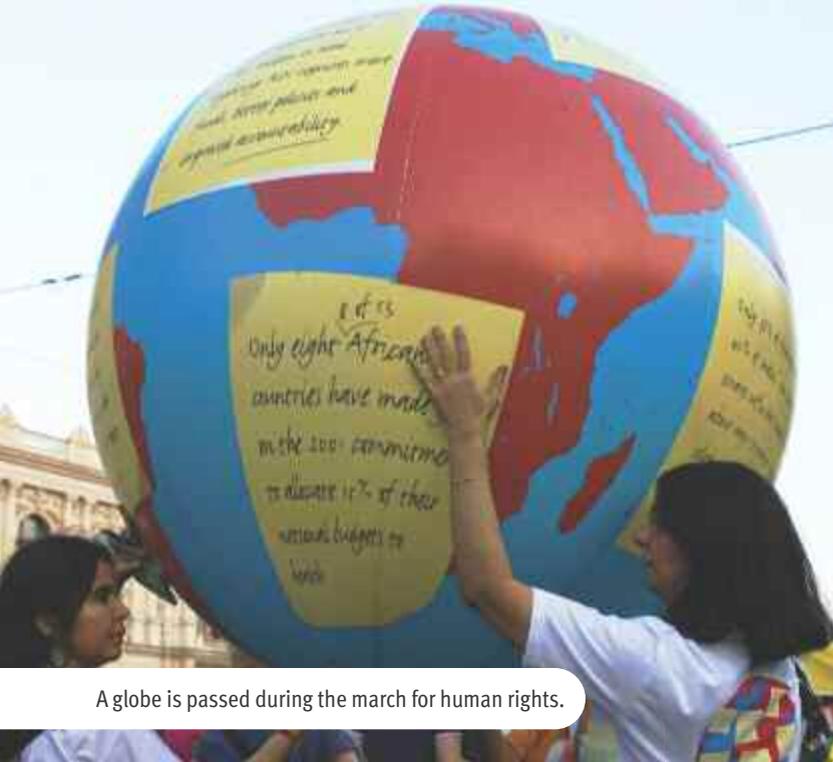
The most hopeful and exciting news was about a new microbicide—a vaginal gel used to prevent HIV. It has been a long wait for an effective prevention tool that women can control. When I heard that the gel is 54 percent effective in the best-case scenario, I thought: “Why are people so excited about something that's only effective slightly more than half the time?” However, I learned that the good news is that the trial is proof of a new concept,

namely using an HIV drug (tenofovir/Viread) as the active agent in the microbicide. There is great optimism that further developments will very likely improve its effectiveness. It is a true milestone.

The level of involvement of people with HIV at this conference was impressive. I witnessed HIV-positive folks in a multitude of roles: as conference organizers, speakers, delegates and moderators. It inspires me to no end. I came home more informed on local and global HIV issues, and, more importantly, I am acutely aware and feel a part of the thousands of dedicated people working to improve the lives of those living with and at risk of HIV.



Raising red umbrellas, protesters call for rights for sex workers.



A globe is passed during the march for human rights.

Alex McClelland

Living with HIV since 1998

For me, this year's conference provided a platform to let the world know that Canadian HIV, hepatitis C and harm reduction activists have had enough of the current government's regressive policies and inaction.

The conference saw the launch of the Vienna Declaration, which calls for science-based drug policy and an end

to the "war on drugs." Canadian government officials at the conference refused to endorse the declaration and openly deny the overwhelming scientific consensus on the value of harm reduction approaches.

Our epidemic is still growing and I see a link between the government's policies and the alarming rates of HIV in Canada. The prevalence of HIV in federal prisons is as high as the generalized epidemic in some sub-Saharan African countries.

While at the conference, a group of us felt we needed to hold our government accountable, so we did what any angry activists would do: We held a demonstration! Led by Toronto harm reduction activist Zoë Dodd, 50 of us walked across the conference venue chanting: "The war on drugs is a war on us!" We marched into the exhibition hall to shut down the Canada exhibition booth—the symbol of our country's presence at the event.

Our action brought attention to the issue. We got press coverage in Canada and abroad. Many people said they had

no idea about the Canadian government's anti-harm-reduction stance. Many people from the Canadian HIV response thanked us.

While these kinds of actions can make some people uncomfortable (especially us polite Canadians), people in Canada are still dying from HIV and hepatitis C. And while people lose their lives because of what I see as the inaction of decision makers, I will continue to feel the responsibility to act. This is why we did what we did in Vienna and why we will continue to act until these policies change.



In the main conference venue, balloons advocate for increased AIDS funding.

Tim Rogers

CATIE

At this conference I think we witnessed the long-awaited marriage of treatment and prevention.

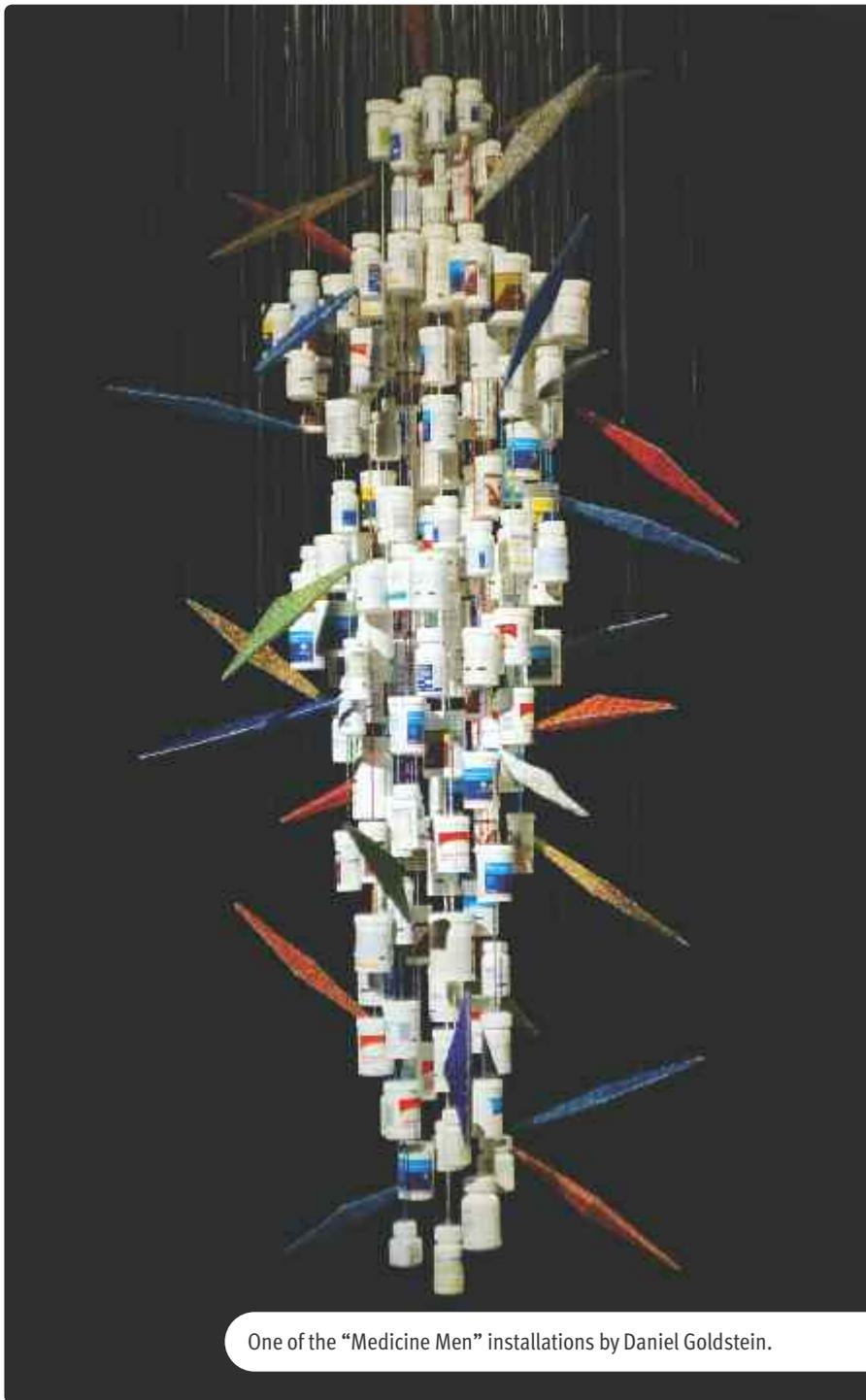
Researchers from South Africa led the way with results from a clinical trial of a microbicide containing an anti-HIV drug that was used by people who are HIV negative. They found that tenofovir gel applied vaginally can reduce HIV transmission on average by 39 percent in women. It was a modest result, but the standing ovation for the researchers showed how excited people are about this potentially new approach to prevention.

Interestingly, adherence was one of the big issues in the trial. Women who were able to maintain high levels of adherence received the maximum benefit of 54 percent reduction in HIV risk. Unfortunately, the longer women used the gel the less effective it became, and researchers think this is because it was hard to keep using it consistently. The challenges of long-term adherence are something PHAs have known for a long time.

A lot of evidence about treating PHAs with anti-HIV drugs as a method of prevention was presented and debated. How well does it work? Should treatment be considered for the sake of prevention? Will this approach undermine existing prevention work? What about the idea that the responsibility for preventing infection is shared by both HIV-positive and HIV-negative people?

Beneath the controversies, there seemed to be consensus that providing optimal diagnosis, care and treatment for PHAs is an important and underappreciated prevention tool. There were also a number of presentations around the theme that supporting healthy sexuality is just as important for PHAs as it is for those who are negative.

This convergence of treatment and prevention is exciting, but it also brings new challenges. It was fantastic to see the leadership of PHAs at the conference, but I worry that communities in Canada are still not engaged enough in the research and debates, especially considering what is at stake. +



One of the "Medicine Men" installations by Daniel Goldstein.

Photographs by
Jacob Peters

Living with HIV since 1984



Behind the Walls

Living with HIV in prison comes with its own set of challenges, and some aren't the ones you'd expect.

BY DAVID MCLAY AND ANN SILVERSIDES

ILLUSTRATIONS BY RAYMOND BIESINGER

Douglas Foreman knows firsthand what it is like to live with HIV in prison. At 52, he is a veteran of the Canadian correctional system, incarcerated in 11 different institutions since his first sentence in 1978. A gay man who contracted HIV through sex in the 1980s, Foreman was also diagnosed with hepatitis C virus (HCV) in 1991, although he isn't sure how or when he became infected with it.

That may have happened 32 years ago, during his first year in detention. He was in Quebec's Archambault Institution, at the time a maximum-security penitentiary, when he one day found himself being shot up by a fellow prisoner. "He was sitting beside me and I watched him prepare his hit, then he prepared one for me," recalls Foreman in a telephone interview from his current residence, a medium-security institution in Quebec. "I didn't even know I would shoot up... I would never have known how to."

After more than three decades in the system, Foreman is well aware that being HIV positive in prison comes with its own challenges—ones never faced by people with HIV outside prison or by prisoners who are HIV negative. Access to proper medical care is an obvious concern. As well, the HIV stigma and discrimination common in society can be worse inside prison walls. But Foreman's story points to another issue: Because rates of hepatitis C in Canada's prisons are high and access to prevention tools is

limited, many prisoners with HIV face the heavy health burden of being co-infected with HCV.

According to published data, between two and eight percent of prisoners in Canada are living with HIV, which is at least 10 times higher than the prevalence of the virus in the general population. Even so, Foreman says, "Rates of HIV in prison are much higher than people say. I was in a minimum security prison three years ago where there were 250 prisoners. At a seminar on HIV, I declared who I was and afterwards 25 men came up and told me they were also HIV positive."

HCV infection is even more prevalent, according to official reports, affecting 19 to 40 percent of prisoners, which is at least 20 times the prevalence in the general population. Most prisoners say they became infected with HIV or HCV through sharing needles and equipment to inject drugs. Perhaps Foreman became infected with HCV through that single time he shared a needle. Or perhaps it was through sex—there is mounting evidence that HCV may pass sexually, especially among HIV-positive men who have sex with other men.

Mavis Daniels, 33, is a Cree woman living in Prince Albert, Saskatchewan. She was diagnosed with hepatitis C

in 1996 and with HIV in 2003. Daniels injected drugs for many years before stopping three years ago. She says she contracted HIV through sex with a former partner. The man, a hemophiliac who contracted HIV in the 1980s during a blood transfusion, never told her of his status. She says that after hearing rumours, she asked him, “Are you sick? You need to tell me this.” He said, “No, I’m not. I don’t know who’s telling you this bullshit.” The relationship continued and the couple even decided to try to become pregnant. Eventually, a mutual friend told the truth to Daniels. “My heart jumped because I was already having unprotected sex with him for a year.” An HIV test came back positive.

Daniels has also spent time in prison, twice—once in the late 1990s and again from 2007 to 2009—in Saskatchewan’s Pine Grove Correctional Centre. She is a very real face of some startling statistics, including the fact that the Prairies has nearly half of all HIV-positive federal female prisoners in the country. Aboriginal women in prison are particularly affected—in a 2007 anonymous survey conducted in federal prisons, about one in 10 (or 11.7 percent) Aboriginal female prisoners was HIV positive and a shocking one in two (49.1 percent) was HCV positive.

One of the most important aspects of living with any chronic medical condition, including HIV, is getting good medical care. In Canada, people have the right to “essential health care” while in prison, which includes treatment for HIV.

Generally, HIV-positive prisoners have at least occasional access to specialist care. Barb Bowditch, HIV case manager and consultant with the Prince Albert Hepatitis C Program in northern Saskatchewan since 2006, says that HIV-positive prisoners in the region’s three institutions see an HIV doctor regularly—about every one to three months depending on the institution—either at clinics held in the prison or by being escorted to the Prince Albert clinic. Support and clinical services are offered on an ongoing basis. (Between appointments with the HIV specialist, prisoners can request to see a prison doctor. All requests are evaluated by the prison nursing unit and then forwarded or not.)

National data show that about six out of every 10 HIV-positive prisoners is on anti-HIV therapy. In the federal system, people get two weeks’ worth of HIV meds at a time, in blister packs that they keep in their cells. People can start HIV therapy while inside if it’s necessary and if they are ready. At the Prince Albert clinic, Bowditch says, “it’s a decision that’s made by the doctor, the patient and one of the nurses. Some may not want to start HIV meds right away and that’s OK. But, say their CD4 counts are dropping,

we’ll at least start them on Septra and azithromycin” to give them some protection from other infections.

Unfortunately, security can trump health in prison. “For three months,” Daniels recalls, “I complained to nursing staff that something’s wrong with me. I could not eat. Every time I woke up in the morning, I threw up. I told the nurses and they did nothing. I think they assumed that I wanted to make a trip out to the hospital so that someone could come meet me there with drugs.” The situation deteriorated and one morning Daniels had a seizure. “When I woke up in the ambulance they said the sleeping meds collided with my HIV meds, Kaletra and Combivir, and it caused a reaction to the brain.”

Given stories such as Daniels’, prison may not seem like the most obvious place to get healthy, but the stability of the daily routine can make it easier to stick with anti-HIV therapy. It was during her second stay in Pine Grove that Daniels got serious about her anti-HIV therapy. She had been taking it on and off for years, but the dependable routines of prison allowed her to take the medications regularly. Still, a majority

of people on HIV treatment have reported missing at least one day of therapy while in prison. Sometimes they missed because they decided to stop therapy or forgot to refill their prescription, other times because the prison pharmacy did not have the meds in stock or because treatment was interrupted while they were transferred between prisons.

Treating the symptoms and side effects of HIV and HIV treatment is also trickier in prison. Prisoners with HIV—who sometimes take medications such as Gravol (dimenhydratate) to counteract nausea and gabapentin (Neurontin) to treat neuropathy—can be intimidated into handing these over to fellow prisoners who inject them to get high. “What I hear and see is much more abuse of medications. People are injecting garbage like Gravol, and this didn’t used to happen,” says Dr. Peter Ford, a retired HIV specialist with more than 20 years of experience treating prisoners with HIV in federal institutions in Ontario. As a result, prescriptions written by HIV specialists are sometimes ignored by the prison doctors, who have the final say on which prescriptions are filled.

Just as in the wider community, HIV carries stigma in prisons, so many HIV-positive prisoners keep their status secret or at least try to do so. Mooky Cherman, provincial prison program coordinator at Prisoners’ HIV/AIDS Support Action Network (PASAN), an Ontario-based AIDS service organization for HIV-positive prisoners, says that anything, including HIV, that labels someone as weak or vulnerable can lead to problems on the range. During his work in the men’s provincial system in Ontario, Cherman has heard many stories of men



with HIV whose status becomes known and who then face ostracism and aggression from fellow prisoners.

Bowditch says her impression is that the experience in the prisons in northern Saskatchewan is different. “The prisoners are very open about their status within the walls. Probably about eight years ago I heard a lot of this [stories of stigma], but I think people are becoming more comfortable,” perhaps due to a growing awareness of the epidemic in the region.

Stigma combined with the power imbalance inherent in prisons can give rise to the potential for abuse by staff as well. Cherian, who sees clients in several provincial prisons in Ontario, recounts the story of one man who because of his HIV status receives canned nutrition drinks to help him stay healthy. (While needed, these drinks can be a sign to others of the person’s health status.) The man says that guards on occasion take the can from his food tray and drink it in front of him before tossing back the empty can. This kind of intimidation may explain why two-thirds of HIV-positive federal prisoners fear discrimination.

Canada has only one AIDS service organization (ASO) whose sole mandate is to serve prisoners with HIV and advocate on their behalf: PASAN, established in 1991. Because it’s the only one, even though it is officially an Ontario organization, PASAN is often thought of as a federal one. It has also taken on work with hepatitis C-infected prisoners. Other ASOs that have broader mandates—such as the British Columbia Persons with AIDS Society (BCPWA), Centre Action Sida Montréal (CASM) and HIV/AIDS Regional Services in Kingston—provide prison outreach workers.

Workers from these agencies supply information to prisoners, advocate for access to services within the prison and lend a compassionate ear. To ensure confidentiality to their clients, programs often do not refer to HIV explicitly. Instead, services are offered under the umbrella of sexual health or harm or risk reduction. That way, no one can be sure of a prisoner’s HIV status.

Front-line workers are often involved in organizing social services, health care or housing for prisoners who have been discharged. In Daniels’ case, the system worked well. “Six months before my release date,” she recalls, “I asked Barb [Bowditch] if she could find me a place to stay and a job.” As luck would have it, Bowditch knew the director of the local youth centre where Daniels once worked. A few phone calls and Daniels had work at the centre doing outreach. “What I do here is go out in the outreach van and we give out sandwiches, juice, condoms and needles.”

The Prince Albert clinic also provides health care to people returning to the community, though that can present challenges. “We have their housing information when they get released,” Bowditch says, “but we sometimes lose

them, especially if they are homeless or have an addiction issue. We may see them out on the street and try to connect with them there.”

It’s no surprise that prisoner infection rates for HIV and for HCV are so much higher than those in the general Canadian population. Injection drug use is common in prisons and sharing needles is generally accepted to be the main way HIV and HCV are transmitted there. According to the 2007 national survey, 16 percent of men and 15 percent of women say they have injected drugs while incarcerated. Anecdotal evidence from prisoners puts that percentage higher, often around 30 percent. There’s a multitude of reasons for using drugs: drug dependence, mental health issues, the desire to escape the boredom or difficulty of prison life and pressure from other prisoners. “It’s a stress-filled environment,” Foreman deadpans.

Some people who smoked drugs on the outside begin to inject them while they are in prison because injection does not produce smoke, which might alert the guards. As well, random urine testing for drugs means that some people may switch from smoking marijuana, which can stay in the body for weeks, to injecting drugs like cocaine and heroin, which clear quickly from the body.

Because there is no official access to sterile syringes in prisons, people resort to sharing injection equipment and this increases the risk of HIV or HCV transmission. Given the high rates of HCV in prisons, the danger of co-infection is very real for people living with HIV. Co-infection comes with its own set of medical issues, including faster liver disease progression, more complicated treatment schedules for both HIV and HCV, and lower HCV treatment success rates. Making matters worse, in prisons, care for hepatitis C lags. Only four percent of

HCV-positive prisoners receive treatment. Ironically, as it was for Daniels and her HIV treatment, the routine and structure of prison life can help people succeed with the often year-long regimen of daily pills and weekly injections that make up HCV treatment.

HIV and, with greater difficulty, HCV also pass during sex, and sex is definitely happening in Canadian prisons. In the 2007 survey, 17 percent of male prisoners and 31 percent of female prisoners reported having oral, vaginal or anal sex in the past six months. Almost all reported at least one instance of unprotected sex and a significant proportion said they had sex with someone who was positive for HIV or HCV or whose status they didn’t know. A 2008 ban on tobacco in federal prisons may also be playing an indirect and unexpected role in the increased transmission of HIV. “Tobacco was the jail house currency,” Foreman explains.

Security can trump health in prison.

“Now any tobacco that comes in is sold at astronomical prices. What have taken its place [in everyday bartering] are sexual services.”

Experts realize that reducing HIV and HCV transmission in prisons is going to require programs to reduce the risks associated with injection drug use. Reducing drug use itself is one tactic, and prison programs do exist to help prisoners address their drug dependence. Harm reduction, an approach advocated by many experts and activists, supports such rehabilitation but also acknowledges that injection drug use happens in prisons and encourages looking for ways to make it safer.

Agencies that work with HIV-positive people in prisons

Prisoners' HIV/AIDS Support Action Network (PASAN)

416.920.9567 or 1.866.224.9978

(accepts collect calls from prisons in Canada)

www.pasan.org

Centre Action Sida Montréal Femmes (CASM)

514.495.0990

netrover.com/~casm

HIV/AIDS Regional Services, Kingston

613.545.3698 or 1.800.565.2209

www.hars.ca

Prince Albert Hepatitis C Program, Saskatchewan

HIV Case Manager – 306.960.4157

HIV Outreach Nurse – 306.765.6541

Hepatitis C Nurse – 306.765.6545

British Columbia Persons with AIDS Society (BCPWA)

604.893.2200 or 1.800.994.2437

www.bcpwa.org

Resources for people in prison

Cell Count – PASAN's magazine for and by prisoners; published four times a year, this bulletin is the only newsletter in Canada providing an uncensored forum for prisoners and young offenders to explore and share their own experiences, ideas and fears about HIV/AIDS. Contact PASAN to subscribe.

Prisoners' calendar – available through the CATIE Ordering Centre, www.catie.ca or 1.800.263.1638

Articles from *The Positive Side* with more info

“Path to Healing” (Winter 2010 issue) – inspiring stories of HIV-positive Aboriginal people from the Prairies

“Double Duty” (Spring 2008 issue) – HIV/HCV co-infection

“Hep C on the Radar” (Spring/Summer 2010 issue) – sexual transmission of hepatitis C

Additional reading from the Canadian HIV/AIDS Legal Network

Under the Skin: A People's Case for Prison Needle and Syringe Programs. 2010.

Clean Switch: The Case for Prison Needle and Syringe Programs in Canada. 2009.

These two publications are available at www.aidslaw.ca or through the CATIE Ordering Centre at www.catie.ca or 1.800.263.1638.

Needle and syringe programs seem an obvious solution, yet the Canadian prison system has not allowed their introduction. A zero-tolerance policy for drugs in prisons precludes any activity that would acknowledge drug use. It's true that other prevention and harm reduction measures—condoms, dental dams, bleach for needles—are in place. Douglas Foreman applauded their introduction into prisons in the early 1990s, but there's still a long way to go. For example, bleach can kill HIV—though Cherian points out there is no evidence that it is effective at killing HIV in the makeshift syringes normally found in prisons—but is not effective at killing HCV. What's more, research shows that even approved prevention tools are not consistently available in Canadian prisons.

As well, tattooing with improvised machines and unsterile equipment is common in prisons and carries the risk of transmitting HIV and HCV. A pilot prison tattooing program started in mid 2005 by Correctional Service of Canada was shut down in December 2006 by the then newly elected federal government, even though a draft report of an evaluation said the program had potential to reduce the risk of transmission.

For national-level research and advocacy about HIV in prisons, the Canadian HIV/AIDS Legal Network has long been at the forefront, holding conferences and producing important documents. “As a legal organization, we can focus on research and policy analysis and advocate for the health and human rights of people in prison in a way that complements the work of grassroots organizations,” says Sandra Ka Hon Chu, co-author of two of the organization's detailed reports on the need for needle and syringe programs in prisons. (See resources listed at left. The two reports contain many stories of prisoners living with HIV.)

While getting needle and syringe programs into prisons would help slow the spread of HIV and HCV, it might be the growing rates of hepatitis C that finally convince authorities to address the problem. Ford, the HIV specialist whose groundbreaking early research drew attention to the prevalence of HIV in Canadian prisons, argues that HCV is so rampant inside that it amounts to a “new epidemic.” In November 2009 he traveled to Ottawa to educate members of the federal Standing Committee on Public Safety and National Security about these issues. “What we're looking at,” he told the committee, “is a problem with a communicable blood-borne disease Corrections is going to find itself looking after people with terminal liver failure, and this is a very expensive prospect.”

For her part, Daniels has not yet taken treatment for hepatitis C. A few years ago, her friend begged her to wait until she was in a more stable place in her life before considering to undertake the often-grueling treatment. She thinks the time has come and has started talking with her doctor and collecting information. As for Foreman, he is also fighting to be treated for HCV. While both his HIV and HCV infections are critically important, he knows that, untreated, it's the HCV he acquired back in 1991 that poses the greatest risk to his health. +

t keep YOUR ticker tocking

As if living with HIV isn't enough, it's becoming increasingly clear that HIV-positive people have a higher risk of heart disease. Fortunately, there are many things you can do to keep your heart healthy.

Sean Hosein and **Debbie Koenig** chime in.



a few years back, 12 years after being diagnosed with HIV, Abel suffered a heart attack. He was 70 years old. Abel smoked, he did not exercise, and he loved his steak, burgers and fries.

Jean-Claude, 37, also suffered a massive heart attack. He had started anti-HIV therapy three years earlier and his doctor was perplexed: Jean-Claude didn't smoke, he wasn't overweight or physically inactive, he didn't have high blood pressure and he had no family history of heart disease. In short, he had no risk factors for heart disease.

While people like Jean-Claude can, and sometimes do, develop heart disease, the vast majority of people living with HIV/AIDS (PHAs) who have a heart attack or some other kind of heart trouble also have traditional risk factors for cardiovascular disease. In other words, cardiologists are far more accustomed to seeing people whose life situations resemble Abel's than Jean-Claude's. The upside is that there is much you can do to lower your risk.

risk factors for heart disease

Although you may not associate having HIV with heart disease and you may think of heart trouble as something that affects only older people, new research suggests that people with HIV, including relatively young people, are at greater risk than the general population. So, regular monitoring of your heart health should be part of your plan for living longer and living well.

During the first two decades of the HIV epidemic, doctors focused on preventing and treating life-threatening infections. However, now that more effective anti-retroviral therapy (ART) is widely available in high-income countries like Canada, deaths from life-threatening infections are uncommon here. As a result, HIV-positive people are living much longer, and as they get older, they become more vulnerable to diseases that can come with aging—including heart disease.

Another factor that's making heart disease more common among PHAs is the inflammation that occurs as a result of HIV infection, especially if HIV goes untreated. This happens because HIV can cause the immune system to be in a continuous state of inflammation. This inflammation damages the immune system, increases the risk of heart disease and harms other internal organs. It also accelerates the aging of blood vessels.

Taking ART can greatly decrease HIV-related inflammation. Indeed, studies have found that people who stop taking ART have a greatly increased risk for heart attacks and stroke. However, even when a person has a low or undetectable viral load, low-level inflammation triggered by HIV may heighten their risk for heart disease.

At the same time, some of the medicines used to treat HIV can raise lipid levels—fatty substances in the blood, such as cholesterol and triglycerides—which increase a person's risk for heart disease. This is why it's crucial that your doctor monitor your lipid levels regularly. Many HIV-positive people who use these medicines take other steps to ensure that their lipid levels stay as low as possible.

WHAT IS HEART DISEASE?

Think of your heart as a pump that moves blood through blood vessels to different parts of your body. Heart disease includes a long list of conditions that affect your heart and/or blood vessels, such as heart attack, stroke, aneurysm (the ballooning of a blood vessel) and angina (when an artery that supplies blood to the heart becomes narrowed or blocked and can no longer deliver the blood and oxygen your heart needs).

Smoking is the number one risk factor for heart disease among PHAs. You may also be at greater risk for heart disease if you: have parents or siblings who have had heart disease; have diabetes, high blood pressure or abnormal cholesterol levels; are a man older than 45 or a woman older than 55; carry around extra weight, particularly around your midsection; experience depression or high levels of stress; don't get enough physical exercise; or use street or party drugs such as cocaine, ecstasy, heroin or crystal meth.

It is important to discuss any and all of your risk factors with your doctor to determine your overall risk for heart disease.

what you can do

There's not much you can do about risk factors like your age or family history, but there are many risk factors you can control with help and advice from a doctor, nurse or dietitian. By making a few changes to your life, you won't only be doing your heart a big favour but you'll probably feel a lot better, too. You might start with just one or two of the following suggestions:

Butt out. Smokers are at far greater risk for cardiovascular disease. And smoking rates are significantly higher among PHAs than among the general population. So if you don't smoke, don't start! If you do smoke, quitting is *the single most important thing you can do* to reduce your risk of heart disease. Quitting smoking also reduces your risk of lung disease, cancer, thinning bones and many other health problems.

Once you butt out, your risk for heart disease will diminish as time goes by—it will be cut roughly in half three years after you quit.

Talk to your doctor or nurse for advice about quitting smoking. Nicotine replacements in the form of patches and gum are available. Certain medications and other therapies might also help you quit. Remember that quitting is a process that requires patience and perseverance. For many people, it takes several tries before they're successful. If you have friends and family members who also smoke, see if one of them will commit to kicking the habit with you.

Eat healthy. Studies have found that eating a diet rich in colourful fruit and vegetables, low-fat dairy products and whole grains can significantly reduce high blood pressure and cholesterol. Eating a handful of nuts (such as almonds, pistachios or walnuts) every day may also help improve your cholesterol levels. Reducing your intake of salt helps to lower blood pressure. And limiting the amount of saturated



**REGULAR
MONITORING OF YOUR
HEART HEALTH SHOULD
BE PART OF YOUR PLAN
FOR LIVING LONGER
AND LIVING WELL.**

and trans fats you consume will help keep your cholesterol down.

Ask your doctor or nurse for a referral to a registered dietitian who can give you the advice and support you need.

Bust a move. The “miracle drug” called exercise can help reduce inflammation, lower bad cholesterol levels, help control diabetes and lead to weight loss. Because of these benefits, regular exercise (four or more times per week) can reduce your risk for heart disease. Ideally, your exercise should cause you to break a sweat, make you somewhat breathless and significantly increase your heart rate for at least 30 minutes. Before doing anything more vigorous than walking, talk to your doctor or nurse about what kind of exercise is right for you.

Take it off. If you are overweight or have a large belly, gradually reducing your weight will help lower your risk for heart attacks (see *Eat healthy* and *Bust a move*).

De-stress. Easier said than done, but try to keep the stress in your life to a minimum. If avoiding stressful events isn't possible, acupuncture, massage, meditation, yoga and other relaxing activities can help you cope with stress. And make sure to get plenty of sleep.

Depression seems to increase a person's risk of heart disease, so let your doctor know if you feel unexpectedly tired or persistently sad or angry. He or she may be able to help or at least refer you to someone who can.

Quit or cut down on substance use. Cocaine, speed, crystal meth and ecstasy can increase your risk of a heart attack. Injecting substances such as heroin or cocaine can also cause serious life-threatening infections, and the resulting inflammation may affect your heart. If you use drugs and want to cut down, speak to a counsellor or someone who can support you.

Practice safer sex. Research suggests that sexually transmitted infections (STIs) heighten your risk for heart disease. Sex can and should be fun but there's no need to expose yourself to germs. Practicing safer sex, even if you are HIV positive and have sex with other HIV-positive people, helps reduce your risk of catching and passing on STIs. Talk to your doctor about testing for and treating STIs.

RESOURCES

From *The Positive Side* (www.positiveside.ca)

- “Inflammation Information” (Spring/Summer 2010) – an article that explains how chronic inflammation can affect PHAs and may contribute to a range of health problems, including cardiovascular disease
- “Up in Smoke” (Spring/Summer 2004) – an ex-smoker shares practical tips on how to butt out
- “Conquer the Kitchen” (Spring 2008) – an easy-to-read article about healthy eating for people with HIV
- “Let's Get Physical: The Benefits of Exercise” (Spring/Summer 2005) – a look at how regular exercise can promote the health and overall sense of well-being of PHAs
- “Work It!” (Spring/Summer 2009) – a physician, a dietitian, a yoga instructor and a personal trainer offer advice to PHAs who want to get active

Health Canada's *On the Road to Quitting* – a guide to help you in your journey to break free from tobacco
www.hc-sc.gc.ca/hc-ps/pubs/tobac-tabac/orq-svr/index-eng.php

The Heart & Stroke Foundation website – a wealth of information on heart disease, heart-healthy recipes, educational materials, current research, multicultural resources and more
www.heartandstroke.ca

For more info about HIV and heart health, contact CATIE at 1.800.263.1638 or go to www.catie.ca.

Reduce your exposure to germs.

Chronic exposure to germs may increase inflammation in your body, which is a risk factor for heart disease. Wash your hands often with soap and warm water. And visit your dentist regularly to maintain your dental health (see “Million-Dollar Smile” on page 12).

Because the flu also causes inflammation, if you have heart disease and get the flu, you are at heightened risk for a heart attack. Be sure to get a flu shot every fall.

Can nutritional supplements help? You may have heard about natural health products (vitamins, herbs and supplements) that are supposed to prevent or cure heart disease; unfortunately, there is no such magic bullet. If you do take supplements, let your doctor and pharmacist know what you are taking. Some natural health products can weaken the effects of HIV medications, make the side effects worse or cause their own side effects.

take heart

Dr. Julian Falutz, director of the HIV Metabolic Centre at the McGill University Health Centre in Montreal, tells his patients: “You can get the most bang for your buck by quitting smoking. Also, find simple ways to be more active in your daily life. Park your car farther away from where you're going. Stop taking the elevator—climb the stairs instead...” You get the idea.

After three months of doing this, you may notice a change: lower blood pressure, lower cholesterol, improved energy, weight loss. The

key is to keep it up. Falutz notes that the temptation is to think after a few months: “I've done it. I kicked the habit: I've quit smoking. I can have *one* cigarette.” Don't. Keep it up. The same goes for other lifestyle changes, too.

To empower his patients, Falutz points out that they've taken pills (ART) every day—in some cases, for decades—to keep their viral load undetectable. That takes commitment, work and discipline. “Don't short-change yourself. You can do it.” +

Debbie Koenig is a writer/editor at CATIE. This article is based on a CATIE fact sheet written by CATIE science and medicine editor Sean Hosein.

ASK THE EXPERTS

Get answers to your treatment questions

Time to Start?



The decision to start treatment is a joint one made by you and your doctor. You likely look to your doctor for expert medical advice. Doctors, in turn, rely on their training and experience and on HIV treatment guidelines. Here, four medical doctors discuss how last year's changes to the U.S.-based DHHS guidelines—the granddaddy of such guidelines—have affected their thinking about the best time to start antiretroviral therapy.

INTERVIEWS BY JENNIFER MCPHEE

JEAN-GUY BARIL, MD

Clinique médicale Quartier Latin,
Montreal

When effective therapies first appeared in the mid-1990s, HIV doctors followed a “treat early and treat hard” approach. However, as we used these early anti-HIV drugs, we learned that they caused many short- and

long-term side effects. To minimize these effects, physicians and people with HIV/AIDS (PHAs) began delaying treatment for as long as possible, generally until CD4 counts fell to 200 cells.

As drugs have improved, however, the pendulum has swung back toward earlier treatment. Since 2008, HIV treatment guidelines have recommended

starting therapy at the 350-cell mark, and most experts agree that evidence from cohort trials supports this recommendation.

Based on growing evidence that, even at high CD4 cell counts, not being on treatment can increase the risk of certain diseases, such as heart or kidney disease, the U.S.-based DHHS (Department of Human and Health Services) guidelines moved in 2009 to recommend even earlier treatment by also recommending therapy when CD4 counts are between 500 and 350 cells. The DHHS experts did not reach a consensus: 55 percent strongly recommended this change, while 45 percent gave it a moderate recommendation. *[For a summary of the changes, check out TreatmentUpdate 176, available online at www.catie.ca/tu.nsf.]*

Half the panel also recommended treatment above the 500-cell mark, which essentially means they recommend therapy for everyone with HIV. The remaining panel members felt that therapy at such a high cell count should be optional.

No national HIV guidelines exist in Canada, but Quebec and British Columbia both publish provincial guidelines. I am chair of the advisory board that approves Quebec's guidelines. In our latest guidelines, we continue to recommend treatment at the 350-cell mark, and we recommend even earlier treatment for certain categories of PHAs: those with viral loads above 100,000 copies; those with a CD4 decline of more than 100 cells per year; people co-infected with hepatitis B or C; pregnant women; and anyone with HIV symptoms. Currently, however, we feel that insufficient evidence exists to support recommending treating everyone with HIV.

DARRELL TAN, MD

Toronto General Hospital and
St. Michael's Hospital, Toronto

The data supporting an earlier start to treatment comes mostly from two observational cohort studies. In these studies, researchers tracked a group of people with HIV and observed that people who started treatment between

500 and 350 cells were less likely to get or die of AIDS-related illness.

Observational studies are useful for generating hypotheses to prove in more rigorous clinical studies called randomized controlled interventional trials. However, observational studies do not prove cause and effect because they cannot account for other factors that may explain the real reason these particular early-starters had better outcomes.

For this reason, I still generally wait until a person's CD4 count dips to around 350 cells before I recommend treatment. However, I begin talking to my patients about treatment as soon as I meet them. I start the conversation by explaining that they have a lifelong incurable infection that can jeopardize their health and even their life and that they will almost certainly require daily treatment someday. But I also stress that treatment is not something to fear. After all, treatment is what will allow them to continue living long, fulfilling lives.

Some people become very worried about side effects. I try to help them overcome this and other fears by giving them good information. For instance, I explain that even the most common side effects don't happen to most people. More often than not, side effects are temporary or we can find a way to minimize or solve the problem. I also help put their concerns in perspective by reminding them that treatment prevents them from experiencing much more serious health problems.

JOHN GILL, MB ChB, MSc

Southern Alberta HIV Clinic, Calgary

Debating whether people with HIV should begin treatment at the 350 or 500 CD4-cell mark is a nice academic exercise, but it's largely irrelevant in the real world. Like most other HIV care programs in the developed world, we struggle with the huge problem of people presenting late for care. Too often people arrive at their first appointment with CD4 counts so low that everyone would agree they need to be on

treatment. I would like to see more sexually active people undergo HIV testing during their annual medical exams because, right now, too many people aren't diagnosed soon enough.

It's also important to point out that the DHHS guidelines (and any other guidelines) are not rules. Equally wise experts have created other sets of guidelines and reached slightly different conclusions based on the same science. Personally, I feel that 350 is still the best threshold for starting treatment because the evidence used to support an even higher threshold is still somewhat speculative.

All this said, I keep all the various HIV guidelines in mind as I work with my HIV-positive patients on when to

start and what to take. The drug combination we most commonly prescribe consists of two nukes combined with either a non-nuke (usually efavirenz [Sustiva and in Atripla]) or a ritonavir (Norvir)-boosted protease inhibitor.

Of course, one size doesn't fit all, and my patients and I take other various factors into consideration, including drug resistance patterns, abacavir hypersensitivity tests and their underlying health. For example, one of my patients suffers from night terrors—a sleep disorder that causes him to awaken from sleep in a terrified state—so I would not suggest any drug that might make his condition worse.

WALTER SCHLECH, MD

Queen Elizabeth II Health Sciences Centre, Halifax

Current HIV therapies cause fewer side effects, and evidence does suggest that starting treatment at the 500- to 350-cell mark prolongs life. However, the DHHS experts were clearly divided in their opinions, and I suspect some of them were also influenced by new observational trial data that suggest that PHAs taking HIV treatment are less likely to pass on the virus during sex. [See the sidebar for more on the idea of treatment as prevention.]

The physicians at my clinic always reach a consensus about when we will encourage each PHA to start treatment. For now, we've agreed to recommend that our patients start treatment at the 350-cell mark. However, we may encourage people to consider beginning sooner if they have consistently high viral loads or if their CD4 count rapidly declines over several months.

We inform people about the medical evidence and debate surrounding the best time to start treatment. If someone wanted to start early, we would all discuss it and likely move forward with treatment. But this request is rare. Most people realize that treatment is a lifelong commitment and prefer to wait as long as possible. +

TREATMENT AS PREVENTION

Treatment as prevention is the idea that anti-HIV therapy may be able to reduce the risk of transmitting HIV. It's a debated topic right now because many experts find that the evidence supporting the idea is not yet convincing. The issue is made more contentious by the possible implications for PHAs, namely the possibility of starting treatment simply for the greater good, not for personal medical necessity.

The observational trials that have looked at this question are not able to prove that being on treatment actually causes a reduction in the risk of passing the virus. As well, it is not yet clear by how much the risk is lowered for heterosexual and homosexual sex—it might be different due to the differences between the two kinds of sex. A clinical trial currently underway will give us better answers to these questions. Results are expected in a few years.

To gain more perspective on the issue, here are some other readings:

- "Treatment as prevention: We've all heard about it but what does it really mean?" in the Winter 2010 issue of *Prevention in Focus*, available at www.catie.ca.
- "Sex, Drugs and Viral Load" in the Winter 2008 *Positive Side*, at www.positiveside.ca.



Performance "Symptôme #1," Shayo Detchema, Confluence Nocturne, Péristyle Nomade, *L'écho d'un fleuve*, summer 2010

Freedom by Expression

From painting to video to performance art, Montrealer **Shayo Detchema** moves beyond the label of HIV-positive artist.

BY LAURETTE LÉVY

PHOTOGRAPHS BY FÉLIX BOWLES

“The disease had become a painful cry and art was my only way out. As a multi-disciplinary artist, my work is a series of evolving self-portraits.”

These words from the artist sum up the artistic process of Shayo, a 30-year-old Montreal woman who has been living with HIV and hepatitis C for 16 years. Raised in a family and school environment focused on the arts, she had her first exhibition of oil and acrylic paintings at the age of 21. Since then, she has continued her exploration through installations involving mixed-media sculpture and assemblage. Throughout her varied works, Shayo has tried to come to grips with what has become her daily life—the disease, its symptoms and the medications she takes every day.

Most recently, Shayo has turned to video and performance art to express her frustrations and reflections on life with HIV. She felt a need to break down the isolation caused by having HIV and decided to express herself through her body—a very physical way of reaching out to others. The result of her experimentation was her first film, *Elisa+*, a series of tableaux of the artist filmed in 2009. By staging her own body, Shayo found she was able to communicate what had otherwise been incommunicable.

The première of *Elisa+* took place last fall at the inaugural edition of *VHsion*, an HIV/AIDS film festival organized by Shayo and other HIV artists and activists from Montreal. The two-day festival included performances and films from Canada, the United States and Africa. (Read more about *VHsion* in “Lights, Camera, Action” in the Winter 2010 *Positive Side*.)

Following this short film, Shayo was invited to participate in *L'Écho d'un fleuve*, an urban art event that took place this past June. For the occasion, she produced her first performance piece, “Symptôme #1.” Shayo, dressed in white, lied abandoned on a mattress covered with a white quilt (an allusion to the AIDS Memorial Quilt that began in San Francisco in 1987 and now includes additions from more than 35 countries). Viewers were invited to leave a comment or symbol using one of the markers attached to the edge of the quilt by red ribbons of varying lengths.



“Dying and falling asleep are definitely not the same thing.”

At the side, a small suitcase lay open with objects symbolizing Shayo's HIV status as well as a headset playing an unusual soundtrack. Photos were hung on a wall, and scattered on the floor were slips of paper with the evocative opening words from a song

by the great French singer Barbara (the stage name of Monique Serf): “Dying and falling asleep are definitely not the same thing.”

During the evening-long performance, many people wrote or drew messages of hope and tenderness on the fabric as well as on Shayo's clothes and the exposed parts of her body. Some curled up against her on the mattress. It was such an intense experience that it took Shayo more than a half-hour to regain a sense of reality after the performance. By creating such an intimate environment and allowing herself to be vulnerable, she felt the spontaneous comfort and love from audience members.

Until recently, Shayo has presented her work predominantly in the HIV community. “Symptôme #1” allowed her to enter the larger arts world. Shayo does not like to be labelled an “HIV-positive artist,” even though her status is central to her art and despite her involvement with different AIDS service organizations since 1994. She does not hide her HIV status, but she doesn't see it as the primary or defining part of who she is. She also rejects the label of “activist artist” although she acknowledges that disclosing her status is a deliberate act. She knows how important it is to get out from the shadows if you want to make a difference.

Encouraged by the success of “Symptôme #1,” Shayo plans to continue in this direction. She is working on several projects with another performance artist because, she says, “Performance has become essential for me, as it allows me to fulfil a desire to communicate with my audience.” +

Shayo invites you to visit her interactive website at www.shayo.ca

For more info about the *VHsion* film festival, go to www.vhsion.com

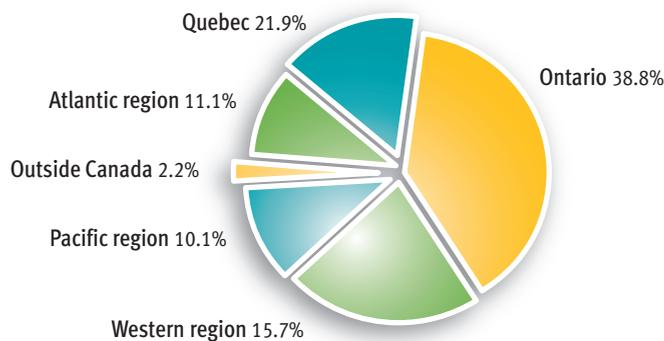
We Asked, You Answered

Last summer, we invited you, readers of *The Positive Side*, to tell us what you think of the magazine by completing our readership survey. More than 200 of you answered our call. Here's what you said.

TELL US A BIT ABOUT YOURSELF

The Positive Side reaches people living with HIV/AIDS (PHAs) and beyond. While a majority of readers are living with HIV or hepatitis C (HCV), the people who work with PHAs (including health-care providers and community workers) also turn to the magazine. Just over half (57 percent) of the respondents were men, with the remainder being women, and eight out of every 10 were older than 40.

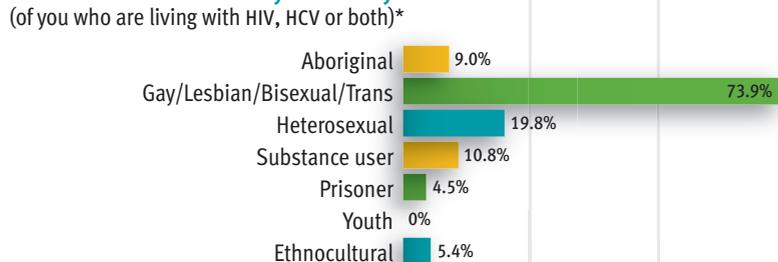
Where you live



Who you are (all readers)*



How you identify (of you who are living with HIV, HCV or both)*



*People could include themselves in more than one category, so the total is greater than 100 percent.

WHAT DO YOU LIKE?

Readers told us that the strong PHA voice is the most successful aspect of the magazine because personal stories pass on knowledge and help PHAs feel that they are not alone. And, readers pay it forward: Three-quarters share articles with other people. We love being passed along.

Many readers mentioned that they like the mix of personal stories with holistic health information. The two favourite regular columns are Chatty CATIE and Ask the Experts. We'll keep it coming with updates on the latest clinical findings, discussions of current health issues and loads of practical advice on how to live well with HIV.

Readers also love the visual aspect of *The Positive Side*, from the friendly faces of PHAs on the cover to the professional layout and colourful graphics that make the magazine easy to read. We've worked hard to keep the pages of the magazine fresh and we're glad people approve.

WHAT CAN WE DO BETTER?

We get fidgety at *The Positive Side* if we sit on our laurels—they poke our delicate derrieres!—and we know we can do better. Respondents told us to keep providing personal perspective and useful information, and many had suggestions on specific subjects—dealing with the effects of aging, getting access to care, going back to work, and many more. Some people want lighter, more fun articles. There were even suggestions to include a comic strip. We're listening! We want to continue to reach out to the diverse communities affected by the virus. We're also looking at how we can make the magazine more responsive and timely.

Although the survey is over, we still want to hear from you. Send your story ideas and comments to info@catie.ca or call 1.800.263.1638. +

CATIE is Canada's source for up-to-date, unbiased information about HIV and hepatitis C. We connect people living with HIV or hepatitis C, at-risk communities, healthcare providers and community organizations with the knowledge, resources and expertise to reduce transmission and improve quality of life. For details, please visit www.catie.ca or call 1.800.263.1638.

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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.

CATIE in good faith provides information resources to help people living with HIV/AIDS who wish to manage their own health care in partnership with their care providers. Information accessed through or published or provided by CATIE, however, is not to be considered medical advice. We do not recommend or advocate particular treatments and we urge users to consult as broad a range of sources as possible. We strongly urge users to consult with a qualified medical practitioner prior to undertaking any decision, use or action of a medical nature.

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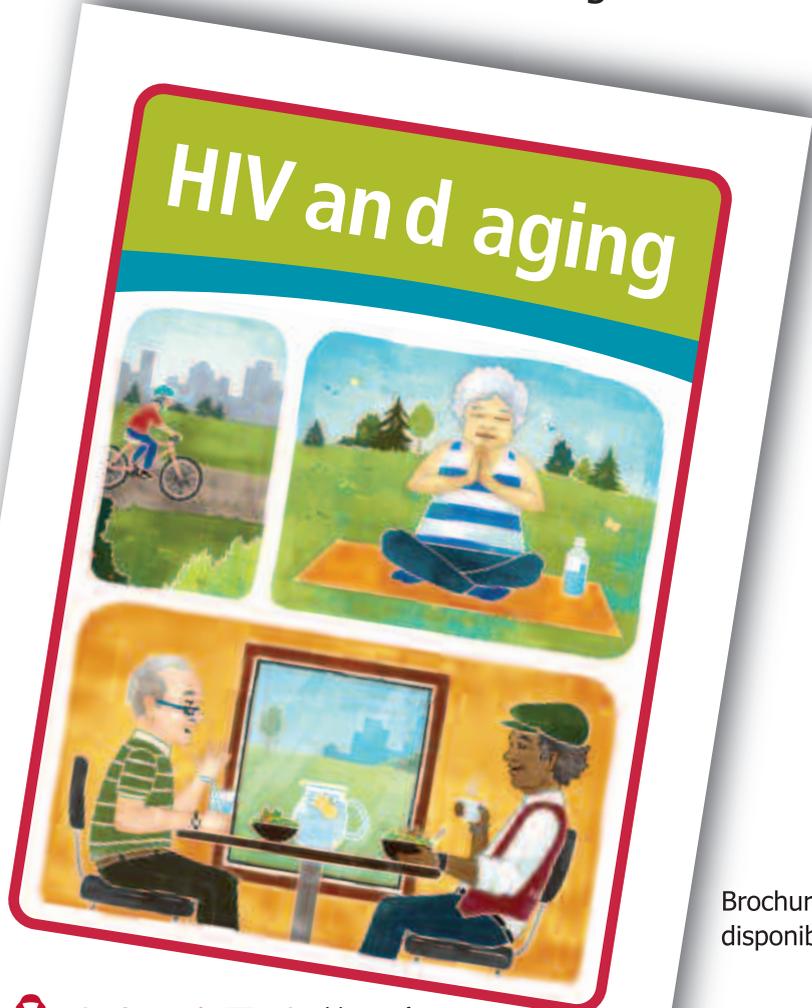
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