

THE POSITIVE SIDE

HEALTH INFORMATION & VIEWS

SPRING 2008
VOLUME 10 ISSUE 1

Sandy Lambert
talks about his journey
to AIDS activism

SOARING SPIRIT

DOUBLE DUTY

Living with HIV and hepatitis C

TRANS CANADA

HIV and the transgendered

FACING THE FUTURE

Surgery for facial lipoatrophy



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EDITORS' LETTER

Welcome to the spring issue of *The Positive Side*. In it, we present stories on issues surrounding two distinct groups within the HIV community: those who are HIV positive and transgendered, and those who are co-infected with the hepatitis C virus.

In *Double Duty* on page 19, author Colleen Price explains why living with two viruses requires twice as much determination. A survivor of trauma, addiction, hepatitis C and HIV, Price found the strength and the support to undergo 48 weeks of therapy and turn her life around. Now a tireless advocate for the rights of the co-infected, Price shares her story and introduces one other co-infected individual. She also discusses treatment and other issues.

In *Trans Canada* on page 11, Nora Underwood tackles HIV infection in the transgendered community. Although these men and women often face relentless challenges that make them vulnerable to HIV infection, a growing number of specialized programs are working to better meet their needs.

As always, you'll find lots of other inspirational stories. A profile of Sandy Lambert, the PHA who graces our cover, is one of those stories. Despite the odds, Lambert turned a personal health-care struggle into a victory that can potentially benefit every PHA living in British Columbia. Read about his journey to AIDS activism on page 8.

Need inspiration in an everyday kind of way? You'll find it in *Chatty CATIE* on page 6, where four PHAs share their secrets for finding the joy in every day. And speaking of every day, if your diet leaves something to be desired, check out *Conquer the Kitchen* on page 15. David McLay explains how to take your diet from downtrodden to triumphant (and you along with it!).

For those who are looking to get away from it all, escape with some fiction from author and PHA Laurette Lévy. You'll find a translated excerpt from her novel, *Debout en clair-obscur* (Standing in the half light), on page 28.

If you or someone you know is struggling with facial wasting, you can learn more about the pros and cons of reconstruction for lipoatrophy in *Ask the Experts* on page 23. Then, on page 26, Derek Thaczuk shares an inside view of what having the procedure is all about.

We hope you enjoy this issue. Happy spring!

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FROM THE FRONT LINES

What's happening at AIDS service organizations across Canada

PACIFIC

New grassroots initiatives mentor positive women leaders

In spite of excellent services for HIV-positive women in British Columbia, opportunities for these women to be leaders in their own communities have been few and far between. Until now.

Two new grassroots initiatives—the **Positive Advocacy Project of British Columbia (PAPBC)** and **SAHWANYA** for African women living with HIV—are by positive women, for positive women.

PAPBC

The brainchild of the Vancouver-based Positive Women's Network (PWN), PAPBC was formed in response to the increasing diversity of PWN's membership and the clear need in B.C. for a committee made up entirely of positive women. "PWN is trying to be responsive to women where they're at," says PWN board member Margarite Sanchez.

PAPBC members currently include Aboriginal women, recent immigrant women, urban and rural women and women living in Northern B.C., the Interior and on Vancouver Island.

Under the leadership of Sanchez, PAPBC recently completed a client evaluation of the Oak Tree Clinic, which provides specialized HIV care for positive women, children and families. PAPBC's long-term goal: to create a community of leaders by providing training and mentoring opportunities for positive women.

New members are welcome and all meetings are confidential. For more information, contact PWN at pwn@pwn.bc.ca or 1.866.692.3001.

SAHWANYA

SAHWANYA is run by and for African women living with HIV in the B.C. Lower Mainland. It first began meeting in June 2007. Jeanne Nzeyimana founded the group when she heard from a doctor that African PHAs were dying in Vancouver not from lack of access to HIV treatment, but from isolation. "It is difficult for immigrant and refugee women to integrate because of poverty, illness, language barriers and

stigma in their communities," explains Nzeyimana. Women who have recently arrived in Canada and who speak little English often have difficulty gaining access to services.

With the support of AIDS Vancouver, PWN, the Oak Tree Clinic and the Bridge Clinic, which provides health care services to newcomers, SAHWANYA is currently meeting every two months for a Community Kitchen. Members bring their children and cook and eat together. Having a safe space to meet, support and educate one another helps them discuss common issues such as treatment, how to disclose to their children and how to prevent HIV transmission. Members also provide translation support for each other at medical appointments.

For more information or to join, e-mail sahwanya_ck@yahoo.com or call 778.998.2692.

THE PRAIRIES

Focus on diversity, service delivery

Like all regions across Canada, the Prairies has its share of funding and staffing challenges. With a growing immigrant and refugee population, many ASOs are rising to the challenge by partnering with translators and ethnocultural-based organizations. At the *Faces of HIV/AIDS in Manitoba—Past, Present and Future* conference, speakers focused on issues of diversity within HIV care, such as culturally appropriate ways to work with Muslim clients. And now, Nine Circles Community Health Centre in Winnipeg has started working with translators to better serve its Spanish-speaking clients.

A vast geography continues to dictate service delivery across the Prairies. Population density shrinks the further north one goes, and as such, so do resources for services.

To address these challenges, service providers and advocates, representing 13 organizations across Manitoba and Saskatchewan, came together in mid-January to discuss how to

best share resources and build upon collective expertise. Historically, Manitoba and Saskatchewan have been home to some of the largest populations of First Nations and Métis peoples, as well as a growing number of Inuit. For this reason, discussions around best practices of service delivery across large regions went on to acknowledge the important role of Aboriginal service providers and leaders in these areas.

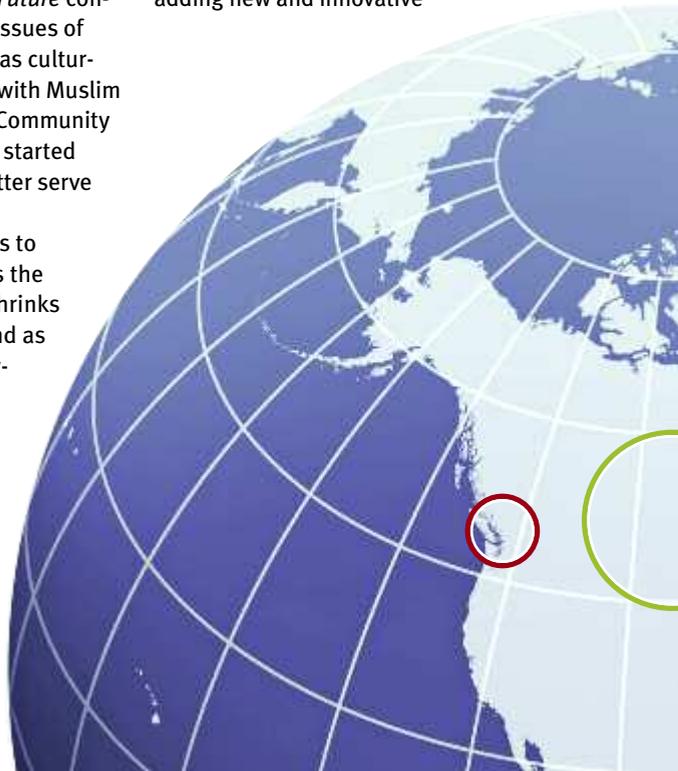
For more information about the network, contact Sugandhi Wickremarachchi: swickremar@catie.ca or 1.800.263.1638 ext. 246.

ONTARIO

New services and programs

The Toronto People with AIDS Foundation (TPWAF) has added two new services: interpretation services and a program for seniors. In partnership with Multilingual Community Interpreter Services (MCIS), TPWAF will provide an on-site interpretation service in more than 85 languages. The service is available in person and on the phone. A second new program, the Positive Seniors Fund, will cater to those who are 65 years of age and older. For more information, go to www.pwatoronto.org or call Pamela Beavis at 416.506.8606 ext. 630.

The AIDS Committee of London is adding new and innovative



programs to help people with HIV/AIDS (PHAs) living in rural areas access services. The programs include Stories of HIV & AIDS Related Experiences (SHARE), a PHA peer volunteer program as well as an initiative to build Internet resources to support on-line education. For more information, call 519.434.1601 or go to www.aidslondon.com

AIDS Thunder Bay (ATB) has extended its Positive Prevention campaign. In early March, ATB held a special town-hall workshop on health and housing and the decision has been made to hire three new staff: a front-line support worker/IDU outreach worker; someone to head the education department; and a full-time nurse practitioner focused on hepatitis C. For more information, go to www.aidsthunderbay.org or call 807.345.1516.

The AIDS Network, Hamilton, has launched a series of new agency posters. The Network also had its second annual Oscar gala, "Play It Again Sam," on Feb. 23. A two-day workshop on community-based research and knowledge transfer for PHAs will be presented in partnership with McMaster University on April 9 & 10. For more information, go to www.aidsnetwork.ca or call 905.528.0854.

The Ontario AIDS Network (OAN) launched the Leadership Level III in January and will be providing ongoing skills leadership training Level II in April and Level I in June. Check

www.ontarioaidsnetwork.on.ca for details of current and ongoing course descriptions.

QUEBEC First Learning Institute focuses on increasing community treatment knowledge

On March 5 & 6, CATIE and COCQ-Sida invited 20 workers and volunteers from AIDS service organizations across Quebec for *L'Institut d'apprentissage des info-traitements VIH* held at the Sheraton Hotel in Montreal.

This first Learning Institute in Quebec focused on increasing community knowledge of clinical trials and basic pharmacology so that participants could benefit from *La 8ième Journées québécoises VIH*. The opening reception featured a presentation by AIDES, the French national HIV/AIDS organization, on its work providing HIV treatment information and advocacy in France. *L'Institut d'apprentissage* ended with an overview of the upcoming conference.

Drs. Mark Wainberg and Jean-Guy Baril opened *La 8ième Journées québécoises VIH* with an interactive discussion on important research presented at CROI 2008, moderated by Lyse Pinault, Executive Director of COCQ-Sida. During the two days that followed, epidemiology, basic science, prevention and clinical research on HIV as well as hepatitis C were presented from the perspective of clinical practice in Quebec.

For participants attending *L'Institut d'apprentissage* and *La 8ième Journées québécoises VIH*, it was an intense and rewarding learning experience as they gathered important HIV treatment information to be reported to their communities across Quebec. CATIE and COCQ-Sida feel that *L'Institut d'apprentissage* was a great success in keeping community members updated on the state of HIV treatment information and transmission knowledge in Quebec. The two organizations are planning a similar Learning Institute to precede the 14^e *Symposium sur les aspects cliniques de l'infection par le VIH* to be held at the end of November.

For more information, contact Michael Bailey:

mbailey@catie.ca or 1.800.263.1638 ext. 260.

ATLANTIC Charlottetown RAAN meeting coming in May

The Canadian Institutes of Health Research (CIHR) has awarded CATIE funding to host the first official meeting of the Regional Atlantic AIDS Network (RAAN) in Charlottetown, P.E.I. in May.

This is both exciting and newsworthy as the Atlantic region is one of the only regions in Canada that doesn't have a community-based HIV/AIDS network. A meeting to discuss the possibility of forming this network was held in March 2007 and 17 participants from Atlantic ASOs attended. CATIE staff facilitated a discussion with participants, which determined that a community-based HIV/AIDS network could:

- assist all participants to share skills and knowledge;
- build and strengthen the Atlantic region's response to HIV/AIDS;
- provide continuity and allow regional shared projects to be developed;
- build capacity for PHA leadership;
- improve communication and build a collaborative vision of HIV prevention, treatment and support; and
- provide professional peer support.

Organizations from the four Atlantic provinces that will make up RAAN include:

- AIDS Committee of Newfoundland and Labrador
- AIDS P.E.I.
- AIDS New Brunswick
- AIDS Saint John
- SIDA/AIDS Moncton
- AIDS Coalition of Nova Scotia
- AIDS Coalition of Cape Breton
- Healing our Nations
- AIDS Committee of Western Newfoundland
- Nova Scotia Advisory Commission on AIDS

Membership in RAAN will consist of two members per ASO: an executive director (or other appointed staff person) and a PHA who volunteers or works with the organization.

For more information, contact Tricia Smith: tsmith@catie.ca or 1.800.263.1638 ext. 230. +

How I find the **JOY** in every day

by **Ronnilyn Pustil**



HIV may have led me to the love of my life. Within two years of my diagnosis, I was engaged.

LAURA, 37

Board Member of GNP+NA (Global Network of People Living with HIV/AIDS North America) and Member of PASF (Projet action sida femmes), Montreal
Diagnosed in 2005

I find joy in thinking and doing and planning and imagining all sorts of possibilities.

Being diagnosed with HIV is life altering. For me, the diagnosis ushered in a range of positive implications. I now actively think about joy. I crave and cultivate moments of happiness. I'm moved by things that at one time might not have stirred my spirit. Lightning struck me and in its wake is a light within me. I let life happen, savouring all sorts of opportunities. At the same time, I am motion, forging straight ahead. Accepting, valuing and being easy on myself are catalysts for joy.

HIV may have led me to the love of my life. Within two years of my diagnosis I was engaged. We're currently planning our wedding. This is a journey (more like an odyssey!) that gives us immense joy.

One thing that makes me hopeful is the prospect of creating a family. This is a contemplative joy. You can't know how many kids you'll be blessed with—

not specifically because of HIV, but biologically, cosmically—so it's a point of true wonder.

HIV has led me to discover and join a sorority of sisters around the world who collaborate and find strength in collective action and support. I glean joy from close friends who generously support me and whom I support, taking an avid interest in their milestones and achievements.

Life is short, and I intend to keep it sweet.

ROBERTA ALLEN, 68

Private tutor; Volunteer
Halifax
Diagnosed in 1999

My own power and control over my life is my joy. I didn't always have that, but now I'm hanging on to it with my fingernails and my toenails and my teeth.

I'm a survivor. I've had many hardships in my life, which have made me strong and determined to be the best I can be and not take anything less than the best. If I don't get good treatment from one doctor, I will find

another one. I encourage other people to do the same. I don't allow anyone to tell me what I can't do—whether it's medical or whatever.

Just getting up every morning and doing my daily routine brings me joy. I curl my hair every day because it's as straight as a stick, I eat a healthy breakfast, I tutor two mornings a week, I sew and do crafts, and I walk 100 miles a month. Walking invigorates me. I am grateful for the awesome support of family and friends. This also brings me joy.

I found a naturopath who is absolutely fabulous. She is helping me detoxify my liver, and I finally feel good. I wasn't always able to say that because of the fear that I might be sick in the next few minutes, but now, when somebody asks me, "How are you?" I can say, "Good, thank you." And that brings me great joy.

I walk 100 miles a month. Walking invigorates me.



TOM PANKRIL, 39

Teacher

Toronto

Diagnosed in 1998

One of the things that having HIV has made me really conscious of is nutrition—what I put into my body. I find a certain amount of joy every day in eating something healthy, whether it's taking the time to prepare an awesome meal made with fresh ingredients or choosing a bran muffin over a double chocolate chip muffin. I feel that with each food choice I make every day I'm doing something good for myself.

I find great joy in the ritual of going to the grocery store or fruit market and choosing healthy products: fresh tomatoes over canned, fresh green beans over frozen. And when I get home there is another layer of joy in preparing the food. There is nothing like the luxury of taking time to prepare my meal, and, for instance, steaming fresh vegetables instead of microwaving frozen ones.

I'm especially lucky if I have an opportunity to sit down and eat with company, whether it's lunch with a co-worker or a sit-down meal with my family.

Other than my dog, this is my greatest joy.

For more info on how to boost the nutrition quotient of your meals, see "Conquer the Kitchen" on page 15.

BOITUMELO, 31

(Boi, for short)

Marketing and Sales

British Columbia

Diagnosed in 2005

I find joy in putting my health and myself first.

I find joy in knowing that it is actually possible to accomplish my mission of putting myself first.

I find joy in getting enough sleep and waking up refreshed.

I find joy in being surrounded by understanding people. Being an HIV-positive immigrant is one of the most difficult things I ever had to deal with. I was

There is nothing like the luxury of taking time to prepare my meal.



scared and confused, but now it gives me joy to know that there is help out there. I've connected with HIV organizations, a specialist and lots of other people living with HIV/AIDS (PHAs). Some of these people are now my "family."

I find joy and peace in practicing yoga and meditation and dancing to my Botswana music, belly dance and salsa.

I find joy in wearing my sexy high-heeled shoes and little black dress, doing my hair and make up, and looking fabulous.

I find joy in getting together with my girlfriends—talking, laughing, connecting and forgetting for a moment that I'm a PHA.

I find joy in looking at pictures of my sister, who's in Botswana, before I go to bed.

I find joy in looking at myself in the mirror and saying: "*Gatela pele*

ngwana wa mosetsana!" ("Keep going, girl!")

I find joy in being in Canada—a safe place where I trust I have the best medical attention, a place where someone will do something if I ever experience any type of abuse. I was raped back home and for a long time I was very angry. I worked very hard to get to where I am. I'll never forget the incident but I've put the anger aside and look forward to great things to come.

I find joy in sharing my story. A while back I could not say the words *rape* or *HIV*.

I find joy in understanding that I deserve joy and that I don't owe anybody any explanation of what happened to me and what's going on at the moment.

I find joy in knowing I got my power back.

Above all, I am so overjoyed to have this understanding: Look forward, don't look back. +



I find joy in wearing my sexy high-heeled shoes and little black dress and looking fabulous.



HAPPY DAYS: Sandy Lambert
at his home in Vancouver

OVER THE HUMP

BY CHARLENE CATCHPOLE
AND KRISTIN JENKINS

Whether he's speaking out on foster care or fostering AIDS awareness and activism, **Sandy Lambert** doesn't take 'no' for an answer. Just ask B.C. Health.

For almost 20 years, Sandy Lambert's family doctor told him, "If you feel well, don't get an HIV test."

He doesn't have that doctor anymore.

It wasn't until 1996 when Lambert underwent surgery for an out-of-control staph infection in his thigh that he got tested for HIV. The circumference of his infected leg had shrunk to half the size of his other leg and he was in excruciating pain and couldn't walk. "My doctor told me that she thought my immune system was compromised," recalls Lambert, an Aboriginal man from the Tall Cree First Nations in Alberta.

Getting the results was an emotional rollercoaster ride: the first HIV test came back positive; the second came back negative; and the third came back positive. "The last time the doctor came in she said, 'You know why I am here.' I said, 'Yes, I know what you're going to tell me and I need my partner here.'"

Through the tears and the talk about the new antiretrovirals (ARVs), Lambert's partner reassured him that he would stand by his man. "He's still with me," says Lambert, proudly.

Within two weeks of starting his first regimen, Lambert became deathly ill once again. The vomiting and diarrhea were so severe that Lambert's weight plunged to 125 pounds. (He is 6 foot 1 inch tall.) His skin started peeling "like a snake" and he became dangerously dehydrated.

Back in hospital, Lambert was sure he was dying. "They started doing all these tests and I thought, 'I am leaving this earth. I need to get all my friends in. It's critical.'"

It turned out Lambert had Steven Johnson syndrome—a severe allergy caused by the drugs Dapsone and co-trimoxazole (Septra) that he was taking for PCP (pneumocystis pneumonia).

TOUGH TIMES

Lambert is no stranger to tough times. Born in Dawson Creek, B.C., he was taken from his family and placed in foster care when he was just one month old. He never saw his

mother or father again. Or five of his six siblings.

By the age of six, Lambert had been in and out of six foster homes. He knew he was different from the Caucasian families he was placed with but nobody would tell him why. It wasn't until he was 19 and down in Wyoming that a Native American asked him a question that changed the course of his life. "He asked me what tribe I was from and told me, 'You look like our people.'"

It turned out that Lambert's "people" came from Alberta but their territory extended down into the U.S. "What he said piqued my curiosity," says Lambert. Fuelled by the realization that he had to be Aboriginal, Lambert set out to find answers. All he could unearth was a government file that held an old school report card, a handful of photos and some meeting reports from social workers. Still, it was enough to set the wheels in motion to obtain a status card and find out more about his roots.

Lambert's need to know propelled him forward. He talked to local organizations in Vancouver where he was living. He went to the University of Alberta in Edmonton to look for any records that would help him put together a family tree. "I figured if anybody knew, they would, because that was where I came from," Lambert says.

In Dawson Creek, he got a copy of his birth certificate, went into a local hospital and "started asking a lot of questions." Eventually he was put in touch with a cousin who tried to reunite Lambert with his mother. But it proved too much for him. "I didn't want to go down that path," he says. Shortly after, he had a face-to-face meeting with his older sister. "It's weird to see your own blood," says Lambert, "same features, same bone structure."

That was 15 years ago and Lambert has long since moved on. These days, he says, his claim to fame is getting rid of his buffalo hump—or rather, humps—a side effect of anti-HIV therapy that resulted in fat gain in his neck. This side effect is known as lipodystrophy and it can also lead to fat wasting or atrophy in the face, arms and

legs. (For more on facial lipoatrophy, see page 23.)

The larger of the two unsightly fat deposits sat across the top of his shoulders; the smaller one protruded from the base of his skull. There was just enough room in between the two to insert an index finger. “I didn’t like it and knew that somehow, I had to make it go away,” says Lambert.

At first, his doctor prescribed the diabetes drug metformin, but Lambert couldn’t take the nightmares that were a side effect of drug therapy. Lambert was finally put on human growth hormone, a horrendously expensive drug. “It cost about \$6,000 a box for 12 vials; one vial a night,” notes Lambert, wryly. “You do the math.”

FROM HUMP TO HIP

After much campaigning on his own behalf, Lambert got the provincial Ministry of Health to cover the drug under the provincial health insurance plan—the B.C. Health Plan, First Nations Inuit Branch. Unfortunately, after all that effort, the drug didn’t make much of an impact on the size of Lambert’s humps. “Not enough for me to feel comfortable,” he says.

Then, before anything more could be done about his hump, Lambert’s hip blew. The staph infection had gobbled up 75 percent of the cartilage in his leg, leaving nothing left to support his weight. Lambert was using a wheelchair, unable to walk. To make matters worse, the hospital refused to fast-track him for total hip replacement, calling his situation a “non-emergency.”

In all, Lambert waited about a year for surgery, during which time he was forced to make a lot of changes. One of them was selling his beloved Jaguar XJS. He could no longer get in or out of it, and besides, there was no room to stow the wheelchair.

The struggle to get hip surgery turned out to be just a warm-up for another round in the ongoing battle with B.C. Health. Lambert learned from his doctor that surgery for removal of his buffalo hump wasn’t covered under the provincial health insurance plan—and never would be. Knowing he’d have to step up to the challenge again, Lambert told his doctor, “You just wait.”

Lambert started a letter campaign and involved everyone in HIV treatment he could think of: his chiropractor, his dermatologist, the pharmacist who filled his prescriptions, even a supporter from the B.C. Aboriginal Health Coalition. In all, he gathered eight letters.

He was rejected twice. Finally, B.C. Health requested X-rays to see how much the humps were affecting Lambert’s cervical and upper-thoracic spine. Then, just before Christmas, his surgeon called and gave Lambert the good news: B.C. Health was going to cover the cost of removing the humps. It had been three long years. “I started crying and told him, ‘This is the best Christmas present I’ve ever had.’”

I don’t sit in the back of the class and expect somebody else to ask the question or wait until later. I want to know now.

Lambert’s case set a precedent on a provincial level, paving the way for other HIV-positive people to undergo the same kind of surgery at no cost. With the date for his hip surgery approaching, Lambert told his surgeon: “First the hip, then the hump.”

Now back on his feet and standing tall, Lambert misses no opportunity to spread the news about provincial health insurance

coverage for hump removal. “I’ve always been an activist,” says Lambert matter-of-factly. “Anything I wanted or thought other people needed, I always went for it.”

Lambert speaks with great passion about everyone’s duty to speak out, whatever their heritage. “Ask questions and if you get ‘no’ the first time, go back. It’s like sales and marketing: For every 10 calls you will get one back. I don’t sit in the back of the class and expect somebody else to ask the question or wait until later. I want to know now.”

People with HIV are all on a learning curve, he points out. And more people need to step up instead of relying on others. “The same handful of people can’t keep doing it over and over. Everybody needs to get involved.”

Now Lambert is working to bring better access to HIV/AIDS information and treatment to Aboriginal people living on reserves and in rural areas. He’s also outspoken about the need to support Aboriginal people who, like himself, have been raised in foster care.

As well, Lambert is helping those who are struggling with treatment and side effects of medication. “Some people think, ‘Oh well, I’ll just take a pill and everything will be fine.’ They don’t understand the side effects.” Lambert knows about side effects firsthand: “I have gout, which I take a pill for; I have high blood pressure, which I take a pill for; and I get rashes maybe once or twice a year. Your skin becomes much more sensitive once you start taking anti-retroviral drugs.”

Lambert also got involved in other ways, and now sits on the boards of many organizations devoted to HIV/AIDS. He’s a director at the British Columbia Persons with AIDS Society (BCPWA), where he also does treatment information peer counselling. He’s the Aboriginal representative for the Canadian Treatment Action Council (CTAC) and is Aboriginal-at-Large on the board of directors for CATIE. He’s also director and co-chair of the Red Road HIV Society Network.

Lambert is grateful to his “real” family—his partner and his friends. “They’ve been there from bad to good,” he says. In the end, Lambert remains an optimist, counting his lucky stars.

“I have both worlds—the white world and the Aboriginal world,” says Lambert. “We all need to help each other and learn from each other. And that’s one thing I believe the Creator has left me on this planet to do.

“There were two times for me to go—when I had the staph infection and then the allergic reaction to the meds. But it turned out that it wasn’t time for me to go after all. It turned out I have work to do.” +

TRANS CANADA

Many transgendered men and women face unique challenges that make them highly vulnerable to violence, mental illness, substance abuse, poverty and HIV infection.

Now, a growing number of specialized programs are working to support one of society's most marginalized communities.

By Nora Underwood



PHOTOGRAPH: TODD PEARSON / DIGITAL VISION



years ago, Christine was diagnosed with HIV. But learning to live with the virus was just one of many challenges she faced. Then in her mid-30s, Christine was living in a man's body—specifically, a gay man's body. Outside of the gay community, she was almost

always mistaken for a woman.

In 1998, during a trip to Atlantic City with her mother and some friends, Christine went to the men's washroom in the casino. The custodian told her she was in the wrong place. "I came out of there and said, 'I can't do this anymore. I can't live in this world and that world,'" she now recalls. Her family was extremely supportive of her decision to make a full transformation into a woman (though "Mother had trouble with the pronouns," she says) and Christine, now 55, does public speaking about her life and about HIV.

Many other trans men and women—people who cannot identify with their birth gender and who take any of a number of steps to live as the gender they identify with—are not as fortunate. Even in cities like Toronto, Montreal and Vancouver, many trans men and women face unique and relentless challenges every day—challenges that render them far more vulnerable to violence, mental illness, substance abuse, poverty and more.

And though there is little in the way of trans-specific statistics gathering, the trans community also appears to be more vulnerable to HIV than the general population. Some U.S. studies indicate that rates of HIV may be as high as 20 percent among trans women in New York, Chicago and Los Angeles, and as high as 30 percent among trans women in San Francisco and Washington. Another study, of trans women sex workers in Atlanta, found HIV rates soaring to 68 percent.

When you step back and look at the reality of many trans peoples' lives, it might be surprising that the numbers aren't higher. Trans men and women are one of the most marginalized communities. Many aren't embraced by the gender with which they identify. Neither are they heartily embraced by—nor do they necessarily identify with—the gay and lesbian community.

According to Anna Travers, manager of the LGBTTT (lesbian, gay, bisexual, transsexual and transgendered) program at the Sherbourne Health Centre in Toronto, it is important to ask what world the person comes from.

"There are quite a number of MTF [males to females] who have come out of a straight marriage," points out Travers. "If you have lived in a straight world and you transition and you're still into women, in some ways you're going to be perceived as lesbian, but you have no experience of that community and you may not fit into that."

The program at the Sherbourne Health Centre, which has hundreds of trans clients, is one of a small but growing number of specialized programs across the country. These safe spaces are still largely associated with the gay and lesbian community, however, and are confined to Canada's largest cities (see *Highway to health* on page 14).

THE PASSING LANE

Out in the broader community, the single most important key to a successful transition is whether or not you "pass." Almost everything follows from that. But passing is complicated. Many of those who are most successful have gone through their transformations at a younger age.

Not passing can be devastating for trans men and women: many will be overlooked by prospective employers and, as a result, some will end up without money or a home. It's a vicious cycle, because a loss of income makes it harder to follow through on the medical steps—from hormones to surgery—that make it possible for many trans people to pass. Not passing can also present a real problem at shelters and on the street, and trans men and women are at much higher risk for experiencing violence. "It's a domino effect," says Christine. "Once you've been refused employment and housing, everything goes kaplooeey."

For many reasons, a substantial number of trans women turn to sex work. For some, it's a way to make money to live or to put toward surgery. For others, it's a way of getting off the street at night. Still others choose sex work because they find it empowering. "It's incredibly powerful when you've been called a freak your whole life to then find yourself being desired," explains Rebecca Hammond, a researcher currently working on *TransPULSE*, a large community-based project examining the

challenges trans people face in accessing health and social services. (For more information on the project, go to www.transpulse.ca.)

Anecdotally, many people involved with the trans community agree that HIV infection rates are substantially higher among trans women sex workers than among other trans groups. The reasons are complicated. Certainly there are concerns that HIV education is lacking in the trans

Many people involved with the trans community agree that HIV infection rates are substantially higher among trans women sex workers than among other trans groups.



community but because solicitation is illegal, sex workers—trans or not—are often forced to get into a car quickly to avoid being picked up by police and before they have a chance to negotiate safer sex.

For groups of trans men, the issues may be somewhat different. “Some of them are vulnerable and have low self-esteem,” explains Kyle Scanlon, trans programs co-ordinator at The 519, a Toronto LGBT community centre. Scanlon is also working on the Gay Bi Queer Trans Men’s Working Group study, which involves interviews with trans men who identify as a gay or bisexual and have sex with men. “These men described how important it was for them to be accepted as men, to be desired as men, and that they might be willing to have unsafe sex to get it,” notes Scanlon. He adds that, “Self-esteem is one of the largest factors as to whether someone has safer sex or not.”

IN THE DRIVER’S SEAT

Access to health and social services is another huge issue for trans men and women, HIV positive or not. “Trans people get treated very badly even when they’re going for routine things,” says Travers. “They’re asked inappropriate questions; they have a sore throat and someone’s questioning them about genital surgery. It’s brutal...”

From the many trans men and women who use the Sherbourne Health Centre, Travers has heard that many health- and social-care providers are “extremely ambivalent, sometimes hostile, sometimes uncomfortable, sometimes unsure of themselves when working with trans people.” Such ordeals set up a dynamic in which trans people avoid using the health-care system unless they’re really desperate. “So you may not be getting health education, normal preventative tests and screenings and I guess it’s a whole environment in which there’s a feeling of a lack of entitlement to health,” Travers adds. “When you feel that marginalized by a system, it’s hard to have a substantial investment in it.”

Finding a doctor can be a real challenge. According to Hammond, many trans people in Ontario travel to Toronto just to get healthcare; in Ottawa, there is only one doctor who sees trans patients—and he’s 70 years old. But there are ways to get help. In Quebec, Montreal’s Project 10 maintains a trans health database of physicians, therapists and other providers who care for trans patients. HIV Edmonton maintains a similar list for trans people in Alberta. In British Columbia, Vancouver Coastal Health’s Transgender Health Program provides services to any trans man or woman in the province, giving priority to

those in an emergency or crisis situation, and to people who experience multiple barriers—physical, geographic, linguistic and so on.

To find a trans-positive doctor, particularly if you live in a smaller town or city, Scanlon suggests looking for practitioners who have worked with people with HIV/AIDS and with those from the lesbian, gay and bisexual communities. “They may not have any experience working with trans people yet, but often they have proven themselves to be patient-centred, progressive and willing to research what they don’t already know.”

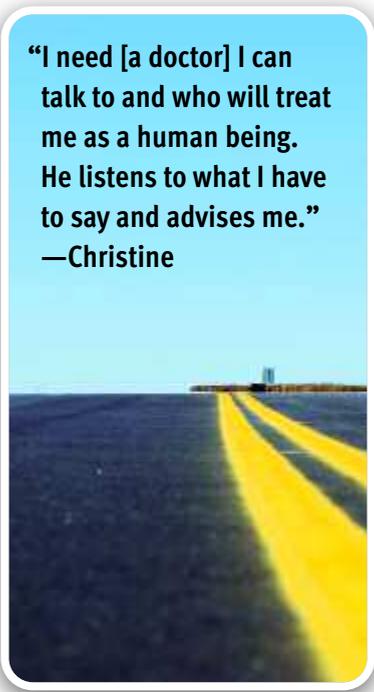
With some searching, HIV-knowledgable doctors can be found, says Christine, who has had an excellent specialist for five years. “I need someone I can talk to and who will treat me as a human being,” she says. “He listens to what I have to say and advises me.” Christine found that other doctors told her what to do; her current doctor gives her all the options and she makes the decisions. “If you’re HIV positive and have a doctor you don’t like, get rid of him,” she advises.

So, what happens when a trans person becomes HIV positive? Often, it’s just one more thing on a very long list of things to deal with. “For a lot of people,” Hammond says, “particularly given the number of challenges they experience, HIV is at the bottom of the list in terms of priorities.”

Unfortunately, there’s not a lot of information about how HIV and anti-HIV meds affect trans people specifically. Some anti-HIV meds are known

to interact with the female sex hormones that some MTF trans people take to promote body changes. And, points out Travers, little research has been done on the long-term effects of hormones on HIV-negative trans people, never mind those who are positive.

For his part, Scanlon feels positive steps are being taken to support the trans community to make healthier lifestyle choices. The 519 hands out condoms and lube, holds safer sex workshops and support groups, and has put together *The Happy Transsexual Hooker*, an HIV/AIDS resource guide for trans sex workers. Much of this progress is the direct result of the trans community creating services for itself, says Scanlon, and the result has been better access to housing, healthcare and legal support as well as a place for trans youth to hang out and feel normal. But there’s still a long way to go when it comes to meeting the needs of the trans community, he points out. “It’s a real challenge just to be trans.” +



For resources, see Highway to health on page 14.



Highway to health

Organizations across Canada that serve the trans community

The TransPULSE project has compiled a “TransPULSE Resource Guide” at www.transpulse.ca.

PACIFIC

The Centre – a community centre serving and supporting Vancouver’s LGBT community
www.lgtbcentrevancouver.com

Pride Health Services – weekly drop-in health services for LGBT people in Vancouver
604.633.4220

Prideline (support, information and referral)
604.684.6869 or toll-free at 1.800.566.1170

Vancouver Coastal Health Transgender Health Program
www.vch.ca/programs/transgender.htm
604.734.1514 or toll-free at 1.866.999.1514

THE PRAIRIES

Alberta Trans Peer Support Network
groups.yahoo.com/group/AlbertaTransPeerSupportNetwork

Albertatrans.org – an all-inclusive Web site for anyone on the transgender spectrum in Alberta

The Pride Centre of Edmonton – resources and support for the LGBT community
www.pridecentreofedmonton.org
780.488.3234

The Transitions Program at the Distinctive Employment Counselling Services Of Alberta (DECSA) – a program to promote and support leaving the sex trade
www.decsa.com/Programs/trans.php

Transgender Café – a Winnipeg support group for anyone wishing to explore issues of sexual identity
www.transgendercafe.com
204.284.5208

ONTARIO

The 519 Church Street Community Centre – with extensive peer-run trans programming
www.the519.org
416.392.6874

Sherbourne Health Centre – offering primary health care to LGBT individuals in Toronto
www.sherbourne.on.ca
416.324.4180 (Direct line to LGBT services)

Trans Support Toronto
www.transtoronto.com

Gender Mosaic – a transgendered support group in Ottawa
www.gendermosaic.ca

QUEBEC

Action Santé Travesties et Transsexuelles du Québec (ASTT(e)Q)
at Cactus Montréal
www.cactusmontreal.org/en/astteq.html
514.847.0067

Association des transsexuel(le)s du Québec (ATQ)
www.atq1980.org
514.254.9038

La Coalition des transsexuels et transsexuelles du Québec
www.cttq.org

Project 10 – a Montreal LGBT youth organization that maintains a trans health database
www.p10.qc.ca
514.989.4585

Stella – a group for and by sex workers, including transexual sex workers
www.chezstella.org
514.285.8889

ATLANTIC

The Youth Project – a Halifax program that offers a trans youth support group
www.youthproject.ns.ca/main2.htm
902.429.5429

FOR SERVICE PROVIDERS

The TransPULSE Project
www.transpulse.ca
1.877.54PULSE (547.8573)

TGStation – offering diversity training on issues of gender
www.tgstation.com
519.432.2323

UCSF Centre for AIDS Prevention Studies fact sheet “What Are the HIV Prevention Needs of Male-to-Female Transgender Persons (MTFs)?”
www.caps.ucsf.edu/pubs/FS/MTF.php

Trans Access Project, The 519 Church Street Community Centre – a trans team that delivers workshops and policy assistance to service providers to increase trans accessibility
www.the519.org/programs/trans/access_project/
416.392.6878 x 332

Conquer *the* Kitchen

Five steps that will take your diet from downtrodden to triumphant (and you along with it)

By **DAVID McLAY**



DOCS TELL US TO EAT BETTER; IT'S AN important way to keep your immune system strong, they say. Sounds simple, but when you try to put it into practice, it can be simply overwhelming. Where to start? What to do better?

First of all, good nutrition is not about counting every calorie or weighing each slice of bread. Nor does it involve a complete overhaul of your diet and eating habits. What you do need to become a triumphant warrior is a battle plan. In the case of nutrition, your battle plan is a menu.

So how do you conquer the kitchen? Fear not, CATIE is here to help you devise a plan to harness the forces of nutrition. In this article you'll find five steps for planning a daily menu that will meet your nutrition needs as well as a one-day sample menu and a list of good stuff to have on hand in your kitchen pantry. We've drawn the information from our *Practical Guide to Nutrition for People Living with HIV*, which also talks about vitamins, minerals and supplements as well as how to deal with symptoms, side effects and more.

Here's how it works: Start with one of the numbered steps and keep at it until it sticks. Then, move on to another step. Don't get discouraged if you stray from the plan. The next meal is always another chance to do better.



1

Start with fruits and vegetables

7 servings each day

- Include fresh, frozen, canned or dried vegetables and fruits as well as vegetable or real fruit juice. Eat more whole fruit and drink less juice.
- There are many healthy foods to choose from in this category. The serving sizes are quite small (about ½ cup/125 mL) so you might choose two servings of the same food (e.g. 1 cup/250 mL of cooked carrots).
- If you currently eat one serving per day, try to add a few more servings even if you don't get up to seven. Spread the fruits and vegetables throughout your meals and snacks.
- Look for lots of different colours. Try to include one dark green (e.g. broccoli, spinach, kale) and one orange (e.g. carrot, squash, sweet potato, pepper) vegetable each day.
- Some people with HIV may not be able to tolerate this many servings of fruits and vegetables because of the high fibre content. Eat what you can. (You can learn more about fibre in the *Practical Guide to Nutrition*.)



2

Then add grains

6 servings for women each day, 8 for men

- Include foods such as bread or bagels, pasta, hot and cold cereals, rice, barley, quinoa and couscous. A serving is about 1 slice of bread, ½ of a pita, or ½ cup/125 mL of rice, pasta or couscous.
- Spread the servings throughout your meals. For example, you might want to have two servings at each of breakfast, lunch and dinner. Extras can be added as snacks.
- Make most of your choices whole grain (e.g. whole wheat, oat, flax, millet, buckwheat, spelt and brown or wild rice).



3

Combine with milk products and alternatives

2 to 3 servings each day

- Include cow's or goat's milk, cheese, yogurt, kefir and milk alternatives (such as soy, almond or rice milk). A serving of cheese is 1½ oz/50 g; yogurt is ¾ cup/175 mL; cow's milk or soy milk is 1 cup/250 mL.
- If you need extra protein or calories or if you have osteopenia (thinner-than-normal bones), you might need more than three servings. (*The Practical Guide To Nutrition* has a section on bone health.)
- When choosing a milk alternative make sure it is fortified with calcium and vitamin D.



4

Serve with meat and alternatives

2 to 3 servings each day

- Include food from animals, such as meat, fish, poultry and eggs, as well as legumes (dried peas, lentils and beans) tofu, peanut butter, nuts and seeds. (*The Practical Guide To Nutrition* provides a long list of animal and vegetarian sources of protein and their serving sizes.)
- Choose three or more servings if you need extra protein.

Sprinkle lightly with fats and oils

- Aim for about 2 to 3 tbsps (15 to 30 mL) of added fats daily. This includes butter, oil, salad dressing, margarine and mayonnaise.
- Examples of healthy oils and fats include olive oil, canola oil, flax oil, nut oils, nuts and avocados. These contain more monounsaturated fatty acids and omega-3 fatty acids.



5

A sample food plan for one day

	FRUITS AND VEGETABLES	GRAINS	MILK AND ALTERNATIVES	MEAT AND ALTERNATIVES	FATS AND OILS
Breakfast					
½ cup (125 mL) berries	1				
1 cup (250 mL) bran flakes		1			
1 cup (250 mL) milk or ¾ cup (175 mL) yogurt			1		
Lunch					
1 cup (250 mL) vegetable soup	1				
1 cup (250 mL) green salad	1				
Salad dressing					1 tbsp (15 mL)
Chicken breast sandwich		2		1	1 tbsp (15 mL)
Afternoon snack					
Apple, mango or orange	1				
1 container yogurt (175 g)			1		
Dinner					
½ cup (125 mL) cooked carrots	1				
½ cup (125 mL) cooked broccoli	1				
1 cup (250 mL) brown rice		2			
Grilled fish				1	
Evening snack (good with meds)					
Banana	1				
1 small whole grain bagel		2			
Cheese (increase or decrease fat depending on meds)			1		2 tbsp (30 mL)
TOTAL	7	7	3	2	4 tbsp (60 mL)

Practical tips for healthy eating

Plan ahead. Start with planning the main meal of the day for the next two or three days. Work up to making a weekly menu. Make a list of the groceries you'll need.

Bring the list to the grocery store and have a snack before you go. Both will help keep you from making impulse purchases.

Don't purchase large packages of unhealthy foods that you can't resist.

Read the nutrition information and ingredients on food packaging. Your dietitian can help you learn how to interpret the information.

Carry healthy snacks. This will decrease the likelihood of needing fast food or junk food to curb sudden hunger.

Focus on more unprocessed foods and whole grains. Over time, you might find you skip the grocery aisles filled with processed foods.

Think about brushing up on your cooking skills. Open a recipe book and start with the basics. Simple foods from natural ingredients are not only healthier and easier to cook, they are often cheaper.

If you get paid once a month, stock up on foods like oats, peanut butter, canned fish, brown rice, pasta, canned lentils, black beans, baked beans, pea soup and frozen vegetables.

No fridge or stove? These foods are nutritious, keep well and require little or no cooking:

- bread or bagels
- peanut butter and nuts
- cereal and granola bars
- powdered milk
- canned salmon, sardines and tuna
- canned beans, vegetables and fruit
- rice cakes and crackers
- raisins, bananas and apples
- nutrition drinks

Join a community kitchen if there is one nearby. This is a good way to learn how to cook and save money on meals by sharing the cost. Going to one also makes meals more social, an important benefit of good nutrition.

Read "KISS in the Kitchen – 15 food groups to pack in your pantry" in the Spring/Summer 2004 issue of CATIE's *The Positive Side*, available at www.positiveside.ca.

To get your free copy of CATIE's *A Practical Guide to Nutrition for People Living with HIV*, call 1.800.263.1638 or visit www.catie.ca/ng_e.nsf

David McLay, PhD, is a writer and editor at CATIE.

DOUBLE DUTY

For those co-infected with the hepatitis C virus (HCV) and HIV, living with two infections requires twice as much determination.

By Colleen Price

My story

The mind can transcend trauma, illness and addiction and I believe that everyone has this capacity to heal mind, body and soul. Sometimes, it just needs to be fostered.

I am a survivor of trauma, addiction, hepatitis C virus (HCV) and HIV. I no longer feel shame, guilt or fear. Instead, I found a way out of my depression, anger and despair by addressing issues of childhood trauma and that helped me heal for the first time.

It has been a long journey, but I have found acceptance, empowerment and hope, something that I never valued before being treated for HCV. In moving beyond my past, I chose to accept myself for who I am and found that I no longer need my addictions to survive. I also realize this will be an ongoing process, as I am in recovery and face chronic illness.

In June 2005, I completed 48 weeks of HCV treatment. It was not an easy process as I am infected with a strain of HCV known as HCV genotype 1, but I learned to cope.

I am grateful for all the support I received from my partner, Sandie, as well as from long-term survivors of HCV, HIV

Treatment tango

In Canada, it is estimated that more than 10,000 people living with HIV (PHAs) are also infected with the hepatitis C virus (HCV). That's about 20 percent of the estimated 58,000 PHAs in the country.

About 70 percent to 80 percent of people with HCV in Canada got the virus when they injected drugs, and shared needles or other drug-related equipment. Many people also get HIV this way, so it's little surprise that injection drug users are particularly vulnerable to co-infection (that is, infection by both viruses). It is estimated that between 50 percent to 90 percent of all PHAs who inject drugs also have HCV.

Sex appears to account for only a small percentage of new HCV infections, but the risk of transmission increases with the presence of sexually transmitted infections, HIV, menstruation or through rough sex, fisting, anal enemas, group sex or sex with multiple partners.

Perhaps the most worrisome part is that about 65 percent of all people with hepatitis C don't know they have it. (See *Are you at risk?* page 21.) The only way to know if you have HCV is to be tested. If there is a chance you could be co-infected, ask your doctor for testing for HIV and HCV, as each virus requires separate tests.

HCV is a virus that causes inflammation and scarring (fibrosis) of the liver and, in more serious cases, can lead to cirrhosis or liver cancer. There are six genotypes or strains and some people are infected with more than one genotype as a result of being exposed to HCV more than once. In Canada, the most common HCV infection is with genotype 1, which is also the most difficult to treat.

In most cases, HCV is a manageable, treatable disease, especially when it is diagnosed early. And while treatment for HCV/HIV co-infection tends to be more complex than therapy for either infection alone, the bottom line is that even when you are co-infected there is a lot you can do to stay as healthy as possible. In some cases, HCV can be treated prior to HIV therapy; in others, liver-friendly anti-HIV meds can be given and then the status of both HCV and HIV carefully monitored.

HCV treatment is a combination of two antiviral drugs: ribavirin (Pegetron capsules or Copegus) and a long-lasting form of interferon

called pegylated interferon (Pegetron or Pegasys). For co-infected people, both drugs are usually taken for 48 weeks. Ribavirin is a pill you take twice every day. The pegylated interferon is injected once a week. Once you start taking these medications, your doctor will monitor the level of virus in your blood (HCV viral load) regularly, just as with anti-HIV meds, to see whether or not the drugs are working. Also like HIV, HCV viral load can become undetectable, though with HCV, undetectable means fewer than 15–50 IU/mL, depending on the test. If your HCV viral load is undetectable six months after treatment, it's called sustained virological response (SVR) and you have cleared the virus. Many consider this a cure. However, you are not protected from HCV and you can be re-infected.

Note that some anti-HIV meds—specifically AZT (Retrovir and in Combivir and Trizivir), d4T (Zerit) and ddI (Videx EC)—can interact with anti-HCV meds. If you are taking any of these meds and you're considering HCV treatment, make sure you talk with your doctor.

Anti-HCV drugs come with side effects, including flu-like symptoms (headaches, fatigue and muscle pain), depression or irritability and low red blood cell counts (anemia), as well as low white blood cell counts (neutropenia). There are ways to manage them. For example, you might be able to cope better with the flu-like symptoms by doing interferon injections at night, taking an over-the-counter pain medication and sleeping through the worst side effects.

Anti-HCV drugs can affect your mood, making you feel blue or even depressed. If you have a history of depression, mention it to your doctor while you are discussing HCV treatment. There are ways to manage depression before and during treatment. And it's really important that you let your doctor, nurse and other caregivers know if your mood changes once you start therapy.

How well you respond to HCV treatment depends on a number of factors, including the strain of HCV you are infected with, as well as the amount of damage the virus has caused to your liver. The good news here is that response rates to HCV treatment have generally improved. This means that even if therapy didn't work for you in the past, you might be able to undergo treatment again with better results. That's definitely something you'll want to talk with your doctor about.

and HCV/HIV co-infection who shared their stories and knowledge. Without it, I may not have stuck with treatment. Along the way, I learned that HCV/HIV co-infection is not a death sentence. Now, two-and-a-half years after treatment, I have tested “undetectable” for HCV and I am not on HIV medications.

People with HCV/HIV co-infection have unique social, treatment and support needs, but many fall between the cracks of HIV or HCV service organizations. Just who is responsible for the co-infected? Right now, it’s a grey area with no dedicated government support.

Co-infected people need to be identified as a special-needs population, and policy, program and support services developed accordingly. Most people living with HCV/HIV are former or current drug users and this can be a barrier to treatment. The kind of treatment that you have access to also depends very much on which province you live in, whether you’re in an urban or rural centre, on or off reserve, and whether or not you are incarcerated. Co-infection protocols that would standardize services and access to services are desperately needed.

We need comprehensive, multi-disciplinary treatment plans to support co-infected individuals. Healthcare professionals as well as mental-health and addictions specialists must be trained in HCV/HIV co-infection so that services can assist not only with prevention, but also help rebuild shattered lives.

Regressive government policies remain one of the greatest challenges in HCV-HIV co-infection, despite the vast amount of scientific research that supports the effectiveness

of harm reduction. Harm-reduction services help people change ingrained patterns of thinking, feeling and behaving, improving quality of life and increasing the chances they will stick with treatment.

More and better support services are also desperately needed. HCV treatment can cause psychiatric complications including depression, aggression and suicidal thoughts. Antidepressants, individual counselling and peer-support groups are often needed to reduce clinical and emotional side effects and to strengthen coping strategies. Diet, use of micronutrients and exercise are also important.

More needs to be done. This includes research on disease interaction, HCV and HIV drug interactions, interactions with street drugs and issues related to aging and organ transplantation. Everyone must have the opportunity to be tested and treated, and research must focus on those who are difficult to treat.

My experience with HCV treatment has motivated me to advocate for those who are HCV/HIV co-infected. I will never give up my fight against these devastating infections. I know firsthand that with dual diagnosis comes dual stigma and complex treatment options. I also know that treatments can and do work, so never give up hope, never give up on yourself. Keep positive and take care of your mental, physical and spiritual health.

Colleen Price is a board member of the Canadian Treatment Action Council (CTAC) and chair of the CTAC HCV/HIV Working Group.

Are you at risk?

Many of the behaviours that put people at risk for HCV are similar to those associated with HIV and many of the steps to prevent HCV also apply to preventing HIV.

Hepatitis C virus (HCV) is transmitted when the blood of an infected person comes in contact with the blood of someone else. The virus itself is quite resilient and can survive outside the body for four or more days. The activities with the highest risk are those that have the highest potential for blood-to-blood contact.

HIGH-RISK FACTORS/BEHAVIOURS

- **Sharing drug-use equipment:** Equipment for injection drug use, smoking crack, using steroids or snorting drugs can be contaminated with microscopic blood particles and transmit HCV. Even a single episode of sharing drug-use equipment (syringes, cookers, water, filters, tourniquets, straws or pipes) means that you should consider being tested for HCV.

- **Sharing tattoo or body-piercing equipment:** Needles, equipment and ink can be contaminated with infected blood and transmit HCV. This is most likely to happen when single-use equipment is re-used or proper sterilization techniques are not used.
- **Blood transfusions prior to 1992:** Blood transfusions received before blood screening began in 1992 are considered high risk.
- **Unsterilized medical equipment:** Shared medical or surgical equipment can transmit HCV.
- **Blood or cutting rituals:** Rituals that involve cutting with shared tools or the exchange of infected blood can also transmit HCV.
- **Unprotected anal intercourse if you are positive:** HIV-positive men who have unprotected anal intercourse with people who either have HCV or don’t know their HCV status.

MODERATE RISK

- **Sharing personal hygiene and grooming supplies:** Sharing razors, toothbrushes, nail

clippers and other household items contaminated with infected blood can transmit HCV.

- **Sexual intercourse:** HCV can be transmitted sexually when infected blood is present, such as during menstruation or when other sexually transmitted infections are present.
- **Mother-to-child transmission** during childbirth.
- **Needlestick injuries in health-care settings** when there is the possibility of exposure to HCV-infected blood.

NO RISK

- **Casual contact** with a person living with HCV, including sharing toilets, drinking glasses and eating utensils.
- **Hugging, kissing or touching** a person living with HCV.
- **Employing harm-reduction principles**, using new drug equipment for injecting, snorting or smoking drugs, or using new/sterile tattoo and piercing equipment.
- **Using new or sterilized medical equipment** during medical procedures.

Getting involved and giving back

I am passionate about volunteering with AIDS service organizations, sitting on the board of directors (AIDS Thunder Bay and Ontario AIDS Network) and public speaking. If I was not involved in these ways, I wouldn't feel the way I do now about my future. Now I understand what I need to do to have a long life.

—**Greg Simmons, 40, Toronto**

When I awoke early on Dec. 20, 2003, I knew my life had changed dramatically. Someone was injecting me with their blood. I didn't die from a drug overdose, but I realized that something much more profound had happened instead.

The next few months flew by in a blur as I self-medicated instead of trying to deal with what I knew—that I had been infected with HIV. The day I got my diagnosis, I tried to kill myself, but a friend found me and called an ambulance. When I learned that I had been diagnosed with HCV and HIV, I thought my life was over.

How wrong I was. Since that day, I have begun to live my life the way I dreamed of as a child. I applied to go back to school and I am on the board of directors for AIDS Thunder Bay and on the board of the Ontario AIDS Network. My volunteer work has been a source of pride for me, since I was incarcerated for several years when I was younger.

It feels good giving back to society and trying to help my fellow PHAS. It hasn't been easy and I couldn't have done this without the guidance of some remarkable people, as well as my ASO and the Canadian Mental Health Association. The Ontario AIDS Network Leadership training also assisted me and I recommend this training for people living with HIV/AIDS and those who are HCV/HIV co-infected. +

Where to find information about HCV/HIV co-infection online



www.hepcinfo.ca is part of CATIE's **Hepatitis C Key Messages Toolkit Project**. This new bilingual Web site contains downloadable **prevention education/harm reduction** resource materials for service providers and people living with and affected by hepatitis C virus (HCV).

"Infections and Bugs and Germs... Oh My!" in the Fall/Winter 2004 issue of *The Positive Side*, available at www.positiveside.ca, provides info about how to avoid all the hepatitis viruses.

www.catie.ca provides several resources on HCV/HIV co-infection, including:

- a brochure on co-infection
- pre*fix: harm reduction for + users
- in-depth fact sheets on hepatitis C and its treatment

www.hivandhepatitis.com

www.thebody.com/content/art44395.html – U.S.-based *The Body* provides an overview of HCV/HIV co-infection.

OTHER HCV RESOURCES

The Canadian Harm Reduction Network is the virtual meeting place for individuals and organizations dedicated to reducing the social, health and economic harms associated with drugs and drug policies.

- www.canadianharmreduction.com

The Hepatitis C Support Project (HCSP) is a registered non-profit organization that provides advocacy to communities affected by HCV and HCV/HIV co-infection, including medical providers.

- www.hcvadvocate.org

HepCBC is a non-profit organization that provides education, prevention and support to those living with HCV.

- www.hepcbc.ca

www.hemophilia.ca from the Canadian Hemophilia Society. (Look under "Infectious diseases" in the left-hand navigation bar.)

The Canadian Aboriginal AIDS Network (CAAN) has excellent resources and a paper on Aboriginal HCV/HIV co-infection.

- www.caan.ca

WHERE TO FIND INFO ABOUT SUPPORT

www.cmha.ca – Canadian Mental Health Association

About face

I have facial wasting and it's really depressing. When I walk down the street, I'm convinced people are staring at me and know that I'm positive. I've heard there's surgery to fix it. What can you tell me? —T.J., Halifax



DR. ANDREW DENTON

Director of Facial Plastic Surgery
Vancouver General Hospital

With facial lipoatrophy, the main problem is a loss of fat under the surface layers of the skin. We don't know what causes people with HIV/AIDS (PHAS) to get a gaunt, drawn appearance exactly, whether it's due to the medication alone or a combination of disease and medication. Facial lipoatrophy isn't dangerous to health but it can hurt psychologically and emotionally and it carries a huge social

stigma because it pinpoints you as HIV positive.

Typically, the problem we see with patients with HIV/AIDS is that the fat loss is quite substantial and a lot of filler is needed to replace it. This can make treatment too expensive for some people. Fortunately, there's financial support available for patients meeting certain economic criteria. The Face Forward Foundation provides a substantial subsidy to eligible patients and there are physicians like myself associated with the

program who perform the procedure almost at cost.

The treatment challenge is to replace the lost fat. This means injecting or surgically implanting some sort of agent or material. When the patient has shallow cheekbones in addition to lipoatrophy, an implant can be used to add volume to the cheek as well as to the area below the cheek.

Within the injectable-filler category, there are temporary fillers, which last for about one year, longer-lasting semi-permanent fillers that last from

one to two years, and permanent fillers. Each has its own advantages and disadvantages. In cases where the fat loss associated with HIV is not too severe (mild to moderate lipoatrophy), a study has shown that patients are very satisfied with injections of Perlane, a temporary filler that is a form of hyaluronic acid. In the study, results lasted for more than a year and there were only minor side effects.

Semi-permanent fillers such as Artefill and Sculptra are also available. I tend not to use these because of the expense to the patient. Other physicians say they get good results with these products.

The product that I use most is Bio-Alcamid, a semi-permanent filler in liquid form. If necessary, quite a lot of it can be injected into the soft tissues of the face, and the body forms a thin collagen capsule around it, keeping it in place.

Bio-Alcamid is also removable to an extent. However, there are still risks including infection and contour irregularities. These risks can be reduced somewhat with good care before and after treatment. I start all my patients on antibiotics the day before treatment and then continue for seven to eight days after treatment.

Treatment begins with photographing and marking the area that will be injected. Local anesthesia is used to numb the skin and reduce the amount of bruising. Then, filler is injected into the face at three to four different places, depending on the size of the area being treated. The material is massaged to smooth it out.

There is a bit of swelling for two to three days after treatment but patients say there is little or no pain. Patients are told not to do any heavy lifting, bending or straining for the first four days and to avoid direct sun exposure, including tanning beds, for four weeks.

After 40 to 50 days, touch-up injections may be needed to smooth out any

Facial lipoatrophy isn't dangerous to health but it can hurt psychologically and emotionally.

uneven places on either side of the face. Some minor asymmetries are normal even after a successful treatment and touch-up, however.

I perform two to three of these procedures each month and, overall, my patients have been very happy with the results. I have

never had a patient say that he would not have the treatment again.

JENNIFER HENDRICK, PhD
Psychologist, HIV Clinic
Queen Elizabeth II Health Sciences Centre, Halifax

I think that we are probably underestimating the impact of lipoatrophy. Those who come forward for help may represent only a fraction of the number affected. For the past two to three years, I've been asking people on anti-HIV meds how they feel about their appearance and I get the impression that it can affect PHAs of all ages, from those in their 20s right up to those in their 70s.

Anti-HIV meds have been very beneficial but they also come with a price. And while many clinicians treating PHAs for a long time feel encouraged by what these medications can do, we know meds can come with biological and psychological consequences because of lipoatrophy. We are taking it very seriously.

It's our job to encourage and facilitate the discussion around lipoatrophy with patients so they feel supported and won't try to pretend that it's not important. The impact of lipoatrophy is right up there with other psychological issues in HIV, including adherence, anxiety, depression and substance use.

There's not a lot of good research available about the psychological and emotional impact of lipoatrophy because it's a fairly new phenomenon.

But it seems that the amount of distress varies among individuals, based on things such as treatment history, life experience and self-esteem. For instance, some PHAs who have experienced a lot of change in their appearance are fine with it; others with minimal appearance-related side effects can be very distressed.

For some, facial changes make them feel more visible. Having HIV and being treated for it are one thing; being publically out about having HIV is another thing. Some PHAs feel more self-conscious, like they're outed against their will. If people who are self-conscious are also looking for romantic or sexual partners, they might feel lipoatrophy limits their opportunities. Some people consider stopping their anti-HIV meds or hesitate to start medication because of a fear of getting lipo. That's a real concern for health-care providers.

Sometimes, people respond to these concerns by isolating themselves socially. For a psychologist, that's a red flag because social isolation can lead to depression and anxiety. Even for those PHAs who are healthy—high CD4+ counts and undetectable viral load—visible side effects can force them to confront troubling issues, such as how people may have rejected them in the past.

Then there's the issue of self-esteem. Lipoatrophy can exacerbate low self-esteem, especially if a PHA's

It's our job to encourage and facilitate the discussion around lipoatrophy with patients so they feel supported and won't try to pretend that it's not important.

sense of self is largely based on appearance. This in turn can play a role in depression and anxiety and relationship problems.

It can also have an impact on a person's motivation and ability to take care of themselves. If a person doesn't feel good about himself, for instance, he may stop taking meds

and exercising. One patient I know stopped working out at the gym because he was embarrassed about changes in his face and body. And exercise had been a big coping strategy for him.

There's also the issue of guilt: guilt that you're alive while friends, lovers and co-workers may have died of AIDS. These PHAs appreciate what meds have done for them and don't feel they have the right to report any concern about appearance changes because they have their health.

But some *are* distressed. They're just not expressing this distress to their caregivers. I would encourage anyone who is feeling the effects of lipoatrophy to discuss it with their primary care physician or their HIV physician or nurse. I think most clinics now have access to mental health professionals, either psychologists or social workers or psychiatrists, and they can really help.

Being listened to and validated helps you realize that it's a problem that's affecting a lot of people, not just you. It's all right to feel concerned about your appearance because it affects how you feel about yourself and your relationships. You don't have to deal with this on your own.

Mental health professionals have the training and experience to help with some of the things that may be part of this: depression, anxiety, self-esteem, the impact on relationships. Even if you've had or are considering the surgical treatments for these symptoms, mental health professionals have a lot to offer as well.

Everybody is unique and reacts to HIV meds differently. We've come a long way from the one-size-fits-all approach to medication. PHAs are considered part of the team and part of the decision-making around their treatment.

DR. KEN DOLYNCHUK

Cosmetic and reconstructive plastic surgeon
Medical Director,
Ageless Cosmetic Clinic
Winnipeg

People with lipoatrophy don't like the way they look and there's also a social stigma. We do as much as we can to help patients get as close as possible to their pre-lipo features.

It's important for people to understand that they probably won't get back to exactly the way they used to look. They also need to know the risks associated with the procedure, including possible infection, nerve damage and even changes in muscle strength and function. Make sure you discuss

all of these possibilities with your doctor.

I usually do injections of Bio-Alcamid into one area and then allow things to settle. I ask my patients, most of whom are in their 30s and 40s, to come back in a couple of weeks for a checkup. Then we wait until the injection sites are healed—approximately six weeks—before they decide if there are other areas they want injected. Patients who have their upper cheeks done, for instance, often come back and want the brow done, or the lower cheek.

For people with lipoatrophy who are sure they want the procedure, reconstruction surgery is worthwhile.

CHRISTIE CHAPMAN

Director, Face Forward Foundation
Toronto

The Face Forward Foundation has a Bio-Alcamid subsidy program for people with HIV-related facial wasting/lipoatrophy who are in need of facial esthetic restoration and cannot afford it. We've been around for

almost two years now and have helped about 250 patients.

We've figured out a way to reduce the cost of treatment by about 50 percent for individuals who earn below \$30,000 a year. Each month, participating surgeons from across Canada treat an average of five patients at the reduced rate. The distributor provides the product to the doctor at cost and Face Forward manages the relationship between the patient, doctor and distributor.

The cost of the procedure is partially determined by how much product is needed. There's a chart on our Web site [www.faceforward.ca/financial.htm] but the minimum cost to the patient would be \$900. Without the Face Forward program, cost to the patient would be about \$1,800.

Each person who meets the eligibility criteria is placed on a waiting list and then contacted when an appointment becomes available, usually in about one to two months.

Deciding whether or not to have reconstruction lipo is such a personal thing. Getting support is important but it's a decision that you have to make on your own. We counsel patients on what to expect and we have a buddy system that makes it possible to speak to people who have had treatment and are willing to talk about their experi-

ence. We also ask everyone in the program to participate in a quality of life study after the surgery. +

It's important for people to understand that they probably won't get back to exactly the way they used to look.



We have a buddy system that makes it possible to speak to people who have had treatment and are willing to talk about their experience.



For more information and to apply online, visit www.faceforward.ca or call 416.509.2494.

For a personal account of one PHA's experience with facial reconstruction, see page 26.



APPY BIRTHDAY HANDSOME

Losing your looks to HIV can be devastating psychologically and emotionally. After a long time in denial, Derek Thaczuk decided to give himself the ultimate birthday present: reconstruction surgery for lipo. Here, he shares the details.

I spent a lot of time convincing myself that reconstruction surgery for lipo wasn't that important, that I didn't need it. So many other HIV-positive people I know have gotten really sick or died, so I gauged how I looked against that. It was like, "Look, you're a long-term survivor. You've made it through 14 years of this alive and well, so if your cheeks are a little sunken, just suck it up."

And yet, every time I looked in the mirror, I would play with my face, pulling my cheeks back and imagining how I might look with the treatment. I'd see pictures of myself and think, "You walk around looking like that?" Plus my outspoken aunt told me I looked awful.

I knew a fair bit about reconstruction for lipo in an academic way. But one night I attended an ACT (AIDS Committee of Toronto) educational forum where Dr. Mona Loutfy from the Maple Leaf Clinic gave a talk on the subject. I got so much positive information about the practicalities of the procedure, the cost and the results that I decided then and there that reconstruction lipo was going to be my birthday present to myself.

Through Face Forward (a non-profit organization that helps people manage lipoatrophy as well as the emotional effects of HIV/AIDS) I was able to get a partial subsidy toward the cost of the procedure. We're still talking thousands of dollars out of pocket, which is a lot for me and completely out of reach for many, I totally realize that. I don't know what the upper limit on cost might work out to but it's directly related to the severity of the lipoatrophy and how much filler is needed.

I had a total of four visits to Dr. Sammy Sliwin at Toronto's Forest Hill Institute of Aesthetic Plastic Surgery: a

preliminary assessment, the actual procedure and two follow-ups. On the first day, he sat me down and quickly sketched a few lines on my face with a magic marker, showing where the filler would go: a lot in the temples, some in my cheeks. Then we booked the next visit.

The procedure itself took less than an hour. I made the mistake of driving. Don't make that mistake! They couldn't sedate me because of the driving and you definitely want that sedation.

The worst part of the entire procedure was the anesthesia. They use the needle from your nightmares (about the size of a hot dog). It's filled with xylocaine that gets injected into about two dozen spots. I don't want to scare anyone, but if you have a problem with needles, this is going to bother you. It's a big scary needle, it hurts and it goes into your face.

I'm not sure why there wasn't any preliminary freezing. My understanding is that sometimes you can use a topical gel to freeze the skin first. You might want to ask about that.

At first it hurt, but not too badly. I meditate and practice yoga, so I just kept breathing my way through it. But with each new shot, the pain felt a little worse and it started to, let's say, damage my calm.

Luckily, that was the worst of it, and it was over in a few minutes. After the anesthetic, I was left to sit and numb out for about 20 minutes. When the doctor came back and I couldn't feel him poke my cheeks, it was needle time again.

Now, from where I was sitting, this did not seem like a delicate procedure. It was more like pumping up my face like a bicycle tire. I'd sort of pictured this Zen thing with ambient music, a little fountain tinkling somewhere. In

2002



2004



DEREK THACZUK 2008



reality, not so much. I'm sure it was done with great precision and skill, but from the corner of my eye, I could see stabbing motions I decided I'd rather not see. I pretty much kept my eyes shut; I couldn't feel a thing.

The procedure was over quickly; it didn't even hurt when the anesthetic wore off a couple of hours later. But I looked ridiculous. I had huge chipmunk cheeks: puffed out, red and swollen. I actually did go in to work; I wanted to show people. There were mixed opinions on that! After about 20 minutes, people told me, "You're all swollen, there's blood and magic marker on your face. Please do us a favour and go home."

At first the swelling went down quickly—but not completely. The whole process of "deflating" took a couple of months. That was longer than I'd expected, and there were times I thought, "uh-oh." As it turned out, the doctor knew just what he was doing, but it would have been nice to know.

The two follow-up visits were both very quick—one after a month, another after three. Dr. Sliwin simply checked that there were no complications. (There weren't. Five days of antibiotics following the procedure was a safeguard against infection.) And to make sure that I was happy with the results (I was) and whether I wanted anything else done (I didn't).

I didn't go in there to come out looking like Brad Pitt. I just wanted to look like myself again and now I do. I don't think about my appearance like I used to; I don't stand in the mirror and obsess. Just every once in a while I catch a glimpse and say, "Damn, I look good." And I have no problem with that at all!

Now that the problem is fixed, I can admit how much it bothered me. I put a lot of time and effort into denying and minimizing the psychological impact of lipoatrophy. It's there every time you look in a mirror.

Would I do it again? Absolutely, no question. Even if I had known exactly what I was in for. Again, I don't want this to scare anyone off but you should certainly talk about the procedure first, ask questions and find out what you're getting into, especially if you're spooked by needles! I think

I have a fairly good tolerance for stress and pain, and I got a bit rattled.

The cost—well, that's something to be reckoned with. (My credit card took a while to recover.) But as far as I'm concerned, it was worth every penny. If you're suffering from facial lipoatrophy and have the resources to do something about it, I'd say "Go for it." +

For information about lipoatrophy and its treatment, visit CATIE online at www.catie.ca or call 1.800.263.1638 and speak with an information educator.

For more information

Face Forward Foundation

416.509.2474; www.faceforward.ca
info@faceforward.ca

A Practical Guide to HIV Drug Side Effects

www.catie.ca/sideeffects_e.nsf

The Positive Side "The Lipo Files" Fall 2003

www.positiveside.ca/e/V613/Face_e.htm

PHOTOGRAPHS: 2002: IRENE THACZUK; 2004: RONNIVY PUSTIL; 2008: NELSON FRENCH





Debout en clair-obscur

A translated excerpt from the novel by **Laurette Lévy**

“I’M NEGATIVE! NEGATIVE! IT’S FANTASTIC!”
Yes, it was fantastic. Beatrice was profoundly happy. If she had infected Peter, it would have been hell.

During the weeks that followed, he beamed. Bea waited for a gesture or a few words. Nothing. Or next to nothing. Only: “Don’t worry, everything will be okay, honey.”

Bea struggled to get the resources she needed on her own. The nurse who revealed her status advised her to see a doctor quickly to have more blood tests done. Her friend Philippe, who had already gone through the same thing, helped her a lot. First, he reassured her by offering himself as an example: “Look at me, Bea, I’m in great shape. We’re going to get through this, you know. It’s not like it was in the early years. You’ll see, we’ll beat this thing.” He encouraged her to contact the AIDS Committee of Toronto (ACT), the city’s main organization, to be referred to a competent HIV doctor. During her first appointment, however, the doctor dealt a heavy blow: “You need to speak with your partner’s daughter. She needs to know. You have to prepare for anything.” Beatrice didn’t understand why she should disclose her illness right away to Emily, who was only seven, and her mother, Peter’s ex-wife. Why not write her will while she was at it? Bea’s intuition told her to wait and, most of all, to find another doctor who was less alarmist.

She couldn’t understand,
everything was falling
apart. Had he never
loved her? Had he lied to
her all this time? Had she
been deaf and blind
day after day?

Six months later, Peter dumped her. He had found a new girlfriend. Was she younger and prettier? Who knows? Bea had never met her. The only thing she knew for sure was that she was HIV negative.

The breakup occurred without a warning. Peter had just finished a long contract and wanted to relax for a few days at his friends Susan and Jack’s place near Trent River. Bea was supposed to join him for the weekend. The day after Peter left, she called him. She was already missing him

and wanted to talk to him. Susan told her Peter had gone out with Jack. She would give him the message and was sure he would call her back if they didn’t get home too late. Bea waited all evening long. The next day, as soon as she got home from work, she called him again to say she was planning on taking Friday afternoon off so she could join him sooner. Peter’s voice sounded strange as he answered:

— No, Bea, you shouldn’t come.

— Why, what’s happening?

What’s wrong?

— No, don’t come. It’s me.

Uh...it’s over, you and me.

— What, over? What are you saying? What’s going on? Faced with Bea’s persistent questions, he added:

— I’ve met someone. I’ve thought a lot about it, I can’t go on. It’s over, Bea, over.

Bea cried and pleaded. She assured him that she could understand and accept what she believed to be a passing

infidelity. Maybe they should take a break. What about a temporary separation? Naturally he was upset about her diagnosis, but surely that didn't change his feelings?

— But don't you understand? he replied. I don't love you, Bea, I never loved you.

Then he hung up. Bea was paralyzed, unable to react to this statement that denied the years they had spent together. She couldn't understand. Everything was falling apart. Had he never loved her? Had he lied to her all this time? Had she been deaf and blind day after day? Profoundly devastated, she stayed home, unable to face her colleagues and the questions they would inevitably ask upon seeing her eyes puffy from crying. With the phone off the hook, she sobbed for forty-eight hours, thinking she was the unhappiest person in the world, wondering what would go wrong next, screaming at Peter and all men who make women suffer, ruining their lives in a second. For forty-eight hours she howled with rage and jealousy. Where and when had he met this woman? How long had he been lying to her? How could she not have seen it coming? For forty-eight hours she replayed the dreams they had been building together: one day, Emily would have a little brother or sister; one day they would own their own home. Forty-eight hours remembering Peter's tender gestures, the kisses just behind her ear when she pulled her hair up, the party he had thrown for her birthday last year, the moments of beautiful and passionate lovemaking. She loved to grab his kinky hair and brush it away from his face so she could look at him as he leaned over to make love to her. Would it never happen again? It was unthinkable.

What a nightmare! Bea wondered if there was a limit to her pain and to what she could endure. The diagnosis, the breakup, would there be an end to all of this shit in her life?

Peter returned unmovable from his friends' house. He gathered together his and Emily's things and

moved out while Bea was at work. She found herself alone in the large High Park apartment they had chosen together that was now half empty and too expensive for her. Unable to relinquish all traces of hope, Bea swallowed her pride and attempted to contact him and persuade him to change his mind. His friends and family—even his mother who was always so sweet to her—repeated that she should not push things. Peter had made his decision and it was irrevocable.

Bea had the courage to carry on despite everything. A strength she did not know she had surged up from deep within to keep her standing amid the disaster that her life had become. No, she would not go under. She would rise above. She would show him, she would show the entire world that she was stronger than that. +

After working as a researcher at the Ontario Institute for Studies in Education (University of Toronto), Laurette Lévy has been focusing on writing over the past few years. In 2002, she published a collection of short stories called *Zig-Zag*. *Debout en clair-obscur* is her first novel.

Laurette has been volunteering with community AIDS organizations since the early 90s. Now living in Montreal, she is a member of PASF (Projet action sida femmes) and sits on CATIE's board of directors.

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Laurette Lévy talks about the art of writing a novel

It took me a good three years to write *Debout en clair-obscur* [*Standing in the half light*], which is set between 1993 and 2003. During this 10-year period, the arrival of antiretrovirals changed things dramatically for people living with HIV/AIDS. I wanted to show that even though all the characters' lives changed radically, they could still have normal lives in some ways.

I like all the characters even though I disagree with some of their decisions. They're like good friends: you acknowledge their mistakes and their shortcomings and love them anyway.

What surprises me is that I wrote this book so the general public would have a better understanding about what it means to live with HIV/AIDS for the rest of your life. I didn't think people with HIV/AIDS would like the book because it was too much about their own reality. But what happened was really the opposite: many people with HIV/AIDS are very taken with this book, especially women. One woman called to thank me for writing the book. So the fact that I touched people living with HIV came as a big surprise. I wasn't expecting it.



This column is part of art posi+ive, an initiative enabling HIV-positive artists to share their experiences of living with HIV through their artwork. The program was launched in 2005 by CATIE in partnership with Gilead Sciences Canada, Inc.



HIV positive? Supporting someone who is?

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