

# THE POSITIVE SIDE

HEALTH INFORMATION & VIEWS

SPRING/SUMMER 2006

VOLUME 8 ISSUE 1

## USER FRIENDLY

PHAs Wayne and Carla  
are regulars at Canada's  
only safe injection site

**HAVE VIRUS, WILL TRAVEL**  
**TREATMENT INFO = POWER**  
**Q & A WITH STEPHEN LEWIS**  
**HIV+ IN A NEW LAND**



Canadian AIDS Treatment Information Exchange  
Réseau canadien d'info-traitements sida



## AIDS 2006

*Time to Deliver • Passons aux actes*

# This August, the World is coming to Canada ...and CATIE will be there to greet it

The Canadian AIDS Treatment Information Exchange—just call us CATIE (everybody does)—is committed to playing an important role in helping our members, partners and visitors get everything they can from this year's International AIDS Conference in Toronto.

Here's some of what we are offering:

**The Learning Institute:** We have devised an innovative pre-, during and post-conference program of strategies, techniques and lessons to ensure you get the most out of your time at the conference. This includes advanced preparatory work, specialized ongoing "reporting streams" and guidance on post-conference knowledge-sharing...it's all about getting everything you can from the event.

**CATIE International Satellite:** We are pleased and proud to host a satellite designed to foster international cooperation and meaningful networking. The focus of the program is to share best practices from around the world in developing treatment literacy.

**Skills-Building Opportunities:** With everything from techniques for training peer treatment information volunteers to the art and therapy of body mapping, CATIE is offering conference delegates the chance to expand their knowledge and increase their effectiveness.

**Plus: Positive Youth Outreach, art posi+ive, free materials and much more**

Canadian AIDS Treatment  
Information Exchange, Suite 505,  
555 Richmond Street West,  
Toronto, Ontario M5V 3B1



To learn more about CATIE  
and the work we do, visit our  
Web site at [www.catie.ca](http://www.catie.ca)  
or call **1.800.263.1638**.

**Drop by to see us at our booth!**

## EDITORS' LETTER

Welcome to a special AIDS 2006 edition of *The Positive Side*. Among other reasons, it's special because we are extending our reach well beyond our usual readership to include many of the 20,000 or more attendees of the XVI International AIDS Conference in Toronto this summer. It is special too because we are devoting our pages to content somewhat different from our usual offerings: more international articles and more about the Canadian experience.

This becomes immediately clear as one reads Tim McCaskell's history of AIDS action in Canada. Perhaps it is not surprising that many of us remain unaware of the fear and desperation, the anger and activism of those early days when there was no effective medical response to a barely understood killer and when government seemed indifferent. That was, after all, a long time ago, and many of the leaders of those struggles did not survive. But some veterans of those battles and the ideas that inspired them do survive and they inform the present, through national and regional groups like the Canadian Treatment Action Council (CTAC), the B.C. Persons With AIDS Society (BCPWA), le Comité des Personnes Atteintes du VIH du Québec (CPAVIH) and, of course, CATIE.

For many, Stephen Lewis is the current flag-bearer for this same activist impulse, albeit in a different part of the world and on a different scale. Indeed, as the United Nations Special Envoy for HIV/AIDS in Africa, he has become a heroic figure in the battle here and now as a result of his years of passionate dedication and persuasive eloquence. We are very pleased to have a lengthy interview with him in this issue.

Having a conference of the scope and magnitude of AIDS 2006 right in your own backyard means a lot: a lot of work to be sure, but also a lot of opportunity to share experiences and insights across geographic and cultural divides. To the thousands of delegates who are gathering in Toronto in August, we welcome you and hope your time here is productive, pleasant and rewarding. We look forward to meeting you. To all of our readers who will not be attending, CATIE's Web site and *e-Bulletin* will be chock full of news leading up to and following the event.

—The Editors

## THE POSITIVE SIDE

Spring/Summer 2006

Publisher:

Canadian AIDS

Treatment Information  
Exchange (CATIE)

505-555 Richmond St W  
Box 1104

Toronto ON M5V 3B1

Canada

© 2006, CATIE.

All rights reserved.

ISSN: 1191-9809

Publications Agreement

Number 1707361

Editors:

Matthew Church,

Sean Hosein, Anna

Kohn, RonniLyn Pustil,

Tim Rogers

Contributors:

Beverly Deutsch,

Diana Johansen, Susan

Massarella, David McLay,

Devan Nambiar, Jacob

Peters, Darien Taylor,

Derek Thaczuk

Creative Direction

and Design:

David Vereschagin,

Quadrat Communications

For expert review,  
thank you to:

Bill Cameron, MD,

Ann McCarthy, MD,

Ottawa Hospital

Cover Photograph:

Elaine Brière

## Chatty CATIE

If you could turn back time, would you do anything differently after your diagnosis? 5 PHAs reflect Interviews by **Maggie Atkinson**

4

## To the Heart of Africa

Stephen Lewis won't stop talking about AIDS in Africa. That's why he matters Interview by **Ann Silversides**

6

## Uprooted Lives

The unique struggles of immigrants and refugees with HIV... and what's being done to help them By **Diane Peters**

9



## Out of Harm's Way

An up-close-and-personal look at how harm reduction is saving lives in Vancouver By **Elaine Brière**

13

## Power to the People

The history of treatment information in the battle to save lives in Canada, as told by one of our original AIDS activists By **Tim McCaskell**

20

## Vacationing with the Virus

Pack your bags. Here's all you need to know about travelling with HIV By **Walter Armstrong**

25

## Putting Hope on the Map

Body mapping—art therapy for the body and soul By **David McLay**

30

## What is the one thing you wish you had known when you were first diagnosed with HIV?

And, if you knew then what you know now, would you have done anything differently when it came to your treatment, care, attitude, outlook, or anything else? What advice would you have for someone newly diagnosed?

Interviews by **Maggie Atkinson**

We asked five people living with HIV/AIDS (PHAs) from across Canada to share their opinions. They discuss disclosure, support, becoming informed, finding a specialist and getting on with life. Some have many regrets, one has none. They all share a message of hope.

### **TERRY CHRETIEN**, 29

Licensed practical nurse  
Regina, Saskatchewan  
Diagnosed in 2003  
Viral load: 560  
CD4 count: 414

**I wish I had known that the AIDS service organization (ASO) was there** and that they were so approachable. Before I was diagnosed I hadn't really heard people talking about AIDS and I didn't know there was a support program for people with HIV, even though I'm a nurse. I found the number in the phone book about eight months after I was diagnosed. It took me a long time to get the courage to call.

When I found out my boyfriend was cheating on me, I got tested for every sexually transmitted infection under the sun. My general practitioner (GP) did no counselling prior to my HIV test. She said, "You have nothing to worry about, I shouldn't even test you." When I went in for a regular follow-up appointment she said, "Well, your HIV test results have come in and it's not good—it's

positive." Then she handed me the forms from Public Health to fill out. She didn't give me any information. I cried in her office for an hour, and had to call my sister to come and get me. My GP had warned me not to tell

anyone. She said that my friends would reject me. She made me feel dirty and shameful.

I became very depressed over the next year and felt suicidal, but I realized that I did have some close friends who really cared for me, and that stopped me. If I had made contact with the ASO earlier I might not have spiralled into such a deep depression.

Although I am very open about my status now, I still feel shame around the HIV. My parents support me, but they are unsure about my being so open. Most of my friends have supported me. For the first year I didn't tell anyone outside of a few girlfriends and family. My co-workers have been surprisingly supportive. I am more assertive and stronger now because of the HIV. I feel that I have to stand up for myself because no one else will.

**ADVICE:** Don't be scared. Reach out for support.

### **JEAN**, 47

Volunteer, AIDS Community  
Care Montreal (ACCM)  
Montreal, Quebec  
Diagnosed in 1992  
Viral load: undetectable  
CD4 count: 300-400

**I wish that I had disclosed to my friends and family earlier.** I was afraid that they might reject me, so it took me a few years before I could tell my sister and a few more years before I told my parents. I found out I had a lot of support that I didn't know was there.

I could have used that support because I had tuberculosis (TB) and a CD4 count of about 60 when I was diagnosed. When I recovered from the TB a few months later, I considered

returning to work as an accountant, but I am glad that I went on disability because I went on to develop serious infections like MAC (*Mycobacterium avium* complex) and cryptosporidiosis. My CD4 count eventually dropped to zero. Although I was getting some counselling around the HIV, I wish I had tried to find out more information about healthier foods and supplements, because I think that might have helped me.

I wish I had joined a support group earlier. It was three or four years before I came out to meet other people in my situation.

There were years when I couldn't work, but I wish I had gotten involved in volunteering earlier to feel more useful—it can have a positive effect on your health and your outlook on life.

**ADVICE:** The important thing is not to panic. There are various treatments available and there is a lot of information you can obtain as to what the best options are for you. In the past there was one treatment and that was it. There are more choices now. Make sure you are starting on the best regimen for you. Lead a healthy lifestyle. Eat properly, exercise and avoid stress. Join a support group—it helps to talk to others like yourself.

### **CRISTIAN SARMIENTO-BARRAZA**, 53

Flight attendant  
Toronto, Ontario  
Diagnosed in 1987  
Viral load: undetectable  
CD4 count: 540

When I tested positive in the '80s, there wasn't much hope. There was no medication available. It was a death sentence. You had maybe a few

"Don't be scared. Reach out for support."



TERRY CHRETIEN



## “Keep on living.”

CRISTIAN SARMIENTO-BARRAZA

years. **I wish I had known then that researchers were working on medications that would mean that you could one day lead a somewhat normal and productive life.** That you could hold onto your dreams. I just moved on. I planned for the next couple of years, but I didn't think I had a future beyond that. When I was diagnosed, I had just completed my degree in architecture at UBC, but I thought, “What's the point?” I had put myself through my final years of university by working as a flight attendant. I had medical and disability coverage, so I decided to stay with the airline. I didn't pursue my dreams.

I would have planned a little better for the future, had I known then what I know now. I wasn't thinking of retirement. I stopped making contributions to my RRSP and pension plan. Instead, I spent time with friends and family and I travelled. I thought it made more sense to spend the money rather than save it for a future I didn't think I had.

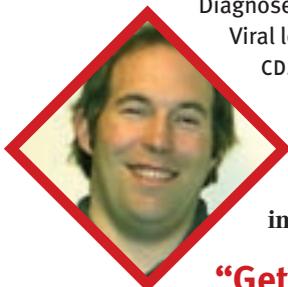
**ADVICE:** Keep on living. It's not the end of your life, plans and dreams. Don't forget your responsibilities—to yourself and those you are having sex with. Educate yourself about HIV and the treatments. Look after yourself. Get a good doctor. I hear people saying it's OK to have unsafe sex because there are drugs now, but there is no cure for AIDS and not everyone reacts well to the medication or succeeds on it. That said, there is hope that things will be even better in the future—that the drugs won't have the same side effects and will be more effective.

### **JAMES EDWARDS, 40**

Support supervisor, call centre  
Saint John, New Brunswick  
Diagnosed in 1996

Viral load: undetectable  
CD4 count: 550

**I wish I had known that there were HIV specialists in Halifax.** I was



## “Get informed.”

JAMES EDWARDS

diagnosed in Montreal, where I was seen at Clinique l'Actuel. A year later I moved back to my home city of Halifax. I got a GP, who only had about 10 HIV-positive patients in his practice. He was pushing meds on me even though my counts were fine. Fortunately, I had been told at Clinique l'Actuel that I didn't need to go on drugs as long as my counts were OK. Also, my father has diabetes and has to take insulin every day, and he said, “Don't go on medication if you can possibly avoid it.” About a year later I heard about the HIV clinic and asked my doctor to refer me there. The doctors at the HIV clinic had more experience in treating PHAS, and they listened to what I said. I was able to go almost nine years without meds. I'm afraid that I might have become resistant if I had taken them earlier.

**ADVICE:** Two things: 1) Get informed. Local ASOs can provide information about clinics, doctors and meds—don't just try to sort it out on your own. Get informed about how to talk to your doctor. Get the number for CATIE [1.800.263.1638] and find out about meds and when to start them. The more info you have, the easier it is to communicate with your doctor. There are so few clinics in the Maritimes that people are afraid to speak out and disagree with their doctors. But because I had the information when it came time to start meds, I was able to explain to my specialist what my needs were as a person who had to work full-time. 2) Get referred to an HIV specialist immediately. In the Maritimes, especially if you're not in Halifax, many doctors don't have a large number of cases, so they don't have the experience.

### **MIKE FULTON, 39**

Volunteer peer treatment counsellor,  
British Columbia Persons With AIDS  
Vancouver, B.C.  
Diagnosed in 1990  
Viral load: undetectable  
CD4 count: 320

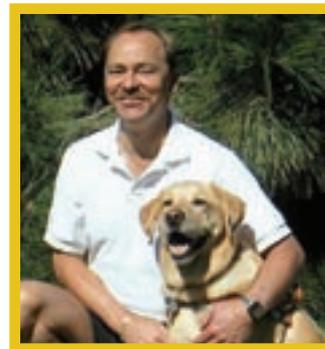
There isn't really anything that I wish I had known. **I wouldn't do anything**

**differently.** I didn't know much about HIV when I was diagnosed: I had only been out for two years and I was in a monogamous relationship. But I was well informed from day one by my doctors. My original GP referred me to the immunodeficiency clinic at St. Paul's Hospital. I did research on whom to see there and Julio Montaner was at the top of the list. I didn't have any misconceptions about the illness.

I told my mom within five minutes of finding out. I had already told my family that I was gay. My family was supportive.

I was 23, working in computers, and I kept working as long as I could. HIV threw my diabetes out of whack. I developed peripheral neuropathy and my blood sugar was on a rollercoaster. I had been diagnosed with diabetes at 18, and I think this may have helped me deal with HIV. I had already coped with a life-altering situation that required taking meds at a designated time. I went blind in December 1998 as a result of the diabetes. In February 1999, I got necrotizing fasciitis (flesh-eating bacteria) in my foot, and in June my kidneys failed. I was on dialysis for six years until I became the first HIV-positive person in British Columbia to have a kidney transplant about a year ago. Through it all, I have kept a positive attitude. I still have a lot to accomplish in this life.

**ADVICE:** It's not the end of the world, given all the innovations in HIV therapy coming out almost on a daily basis. A positive attitude is so important. Bernie Siegel's book, *Love, Medicine and Miracles*, helped me with everything: diabetes, blindness, kidney disease, dialysis. Hold on, keep going. +



“A positive attitude is so important.”

MIKE FULTON



PHOTOGRAPH: TAMELA HULTMAN/ALLAFRICA.COM

# To the Heart of Africa

Night and day, in as many places as he's invited, Stephen Lewis works away at the issues surrounding HIV/AIDS in Africa. His hope? To help build momentum for change

## INTERVIEW BY ANN SILVERSIDES

NAMED ONE OF THE 100 MOST INFLUENTIAL people in the world by *Time* magazine in 2005, Canadian diplomat Stephen Lewis has emerged as arguably the best-known non-African advocate for people living with HIV/AIDS (PHAs) in Africa. He is an eloquent and compelling public speaker whose advocacy as United Nations Secretary-General's special envoy for HIV/AIDS in Africa galvanizes audiences. Lewis's message gained a much

wider audience when a series of his talks were broadcast on CBC Radio as the 2005 Massey Lectures and subsequently published in his best-selling book *Race Against Time*. The book's dedication reads: "To the women living with AIDS in Africa. Indomitable. Resilient. Courageous. One day the world will come to its senses." Several years ago, when Canadians began to spontaneously send him donations to address the AIDS crisis in Africa, he set

up the Stephen Lewis Foundation ([www.stephenlewisfoundation.org](http://www.stephenlewisfoundation.org)) to put the money to work supporting grassroots organizations. Donations to the foundation—none solicited—total \$10 million to date. An astonishing 95 percent of that has been donated by individual Canadians.

Journalist and author Ann Silversides interviewed Stephen Lewis for CATIE in his Toronto home.

**SILVERSIDES: What is your job description?**

LEWIS: There was no definition—the job defined itself as I did it. It is primarily an advocacy role. It is a job of exploration of issues, reporting back, finding the themes that need advocacy (treatment, capacity, women, orphans—the obvious areas of emphasis) and doing that advocacy night and day everywhere, in as many places as I am invited. I've just been pounding away at the issues, hoping that it will help build the momentum for change.

I spend as much time on the envoy role as I possibly can, but if it were a full-time job, I'd be spending even more time in Africa. I try to get there roughly once a month. In the interim I do a lot of speaking in Europe, America and Canada about the issues.

When I visit a country I try to meet with the political leadership, the civil society leadership, the UN family, the diplomatic community and always—as a matter of principle—with groups of PHAs whose position I promote as strongly as possible during my visit. I ask them what they need, what questions they have, and then I take their questions to the various political leaders I meet as I travel. Before I leave, I report back to them because it is really important that they recognize that they have friends in the UN who will treat them with the kind of respect

vigorously or effectively support the work that governments are doing.

**Tell me more about your interaction with PHAs in African countries.**

They pour their hearts out. One of the things they always say is that no one listens to them. They are the experts—they know more about the virus than anyone else—and no one listens to them. They are treated so often with indifference and contempt, and it is really unacceptable because they are so courageous, so strong, and they do such magnificent prevention work. They're moving through schools, community centres, religious groups. PHAs do a tremendous job of prevention; it even extends to the commercial sex workers who wave condoms above their heads and go out into the community and talk about preventing infection. A government that doesn't pay attention to PHAs, or that diminishes them, demeans them or disregards them, is making a terrible mistake in judgment. Boy, they are a powerful crew in every country!

Canada has made important contributions to the World Health Organization's "3 by 5" initiative (to get 3 million PHAs in the developing world on treatment by 2005), the International AIDS Vaccine Initiative, and the Global Fund to Fight AIDS,

been admirable, in part because the JCPAA legislation may turn out to be a real breakthrough. [Médecins Sans Frontières (MSF) has placed the first order under the JCPAA for a fixed-dose combination drug.] Canada provided the core of the money to make 3 by 5 possible and I continue to regard it as an extraordinarily inspired intervention which broke the logjam of inertia and made hope and momentum possible. I am sorry we didn't make the 3 million, but we have set in process a treatment rollout that is irreversible. Everything had been so immobilized that it was really important that there be a visionary breakthrough of the 3 by 5 kind—so that finally the world would understand that there had to be targets.

So now everyone talks about universal access. Country after country is asked to set realistic targets—how many people to be tested and counselled, how many pregnant women to have access to drugs to prevent transmission to the child, how many to be in treatment, how many kids to be in pediatric treatment.

**Do you agree with those who argue that Canada has not stood up to the United States on key issues such as patent laws and harm reduction?**

We should have been standing up to the U.S. not just on patent issues but on

**"People living with HIV/AIDS in African countries are the experts—they know more about the virus than anyone else—and no one listens to them."**



that governments frequently don't display. I also try to spend roughly 50 percent of my time in the field, visiting projects. I then do an exit press conference in the country to lay out exactly what I have seen.

Back in New York I do a briefing with the international press at the UN. I try on an intermittent basis to see the Secretary General [Kofi Annan] and we talk about how the UN might more

Malaria and Tuberculosis. And you were instrumental in lobbying for the 2004 Jean Chretien Pledge to Africa Act (JCPAA), so that generic [less expensive] versions of AIDS drugs still under patent can be manufactured here for use in the developing world. How are we doing as a country?

Relatively speaking, Canada's contribution to the fight against AIDS has

the question of abstinence and condoms. Canada's voice should be heard on these things, but then, to be fair, no one stands up to the U.S. on these issues or about the amount of money they give to the Global Fund or many of the serious limitations around PEPFAR [U.S. President's Emergency Plan for AIDS Relief]. I got in tremendous trouble with the U.S.—I think for a while my job was on the line—over criticisms

PHOTOGRAPH: MÉDECINS SANS FRONTIÈRES, 2004

of the disproportionate emphasis on abstinence in situations where it makes no sense, like marriage.

You argue in your book that Canada's contribution to fighting AIDS has been undermined because Canada has not set a timetable to reach a target of contributing .7 percent of gross domestic product to foreign aid—a target that has already been surpassed by the Nordic countries.

The inability to meet .7 has compromised our integrity on everything else, even though we have done good stuff on AIDS. We were the authors [of this goal, in 1969] and we are the only G7 country with budgetary surpluses. Everyone thinks we are just a bunch of hypocrites.

I assume .7 is important because you see the issues and needs in the developing world going far beyond AIDS.

Poverty lies at the heart of it all.

And AIDS?

I see AIDS as the centrepiece of the human dilemma in southern Africa at this moment in time. Everything is

I was struck by what you said in your book about AIDS treatment bringing along AIDS prevention, about treatment and prevention being inseparable.

I'm not going to make any apologies for this simple truth: People are dying unnecessarily in huge numbers and one of the things a civilized society does is to keep people alive. I consider that the strongest of imperatives. I will not retreat from it. And it is an utterly false dichotomy to pit prevention against treatment, or to pit AIDS against any other disease. You are not diminishing anything by treatment. In fact, you are opening doors everywhere. Treatment gives hope. People come to get tested because they know there is the possibility of a prolonged life. With treatment can come openness and an end to stigma.

How is treatment progressing in Africa?

The numbers of people who have access are growing all the time because treatment is moving out of the urban centres into the rural hinterland, and out of hospitals into the districts. The critical problem is capacity—every-

were seen to be the objects of life's passion—to reverse them, turn them around, eradicate them. From the age of 5 that is all I heard: Social injustice was bad, poverty shouldn't exist, inequality shouldn't exist, racism shouldn't exist, and you are on this planet to fight those things.

For me, what's happening in the pandemic is the ultimate expression of inequality and social injustice and poverty, and therefore everything that I believe comes into play. I probably have as much compassion as the next person, but it is much more ideological. The anger and rage I feel is an anger and rage at—I have to phrase it this way—at capitalism, at the way the world is organized, at the way in which the privileged and powerful care hardly at all for the uprooted and disinherited. And that is for me what this is all about. As well, I live in a feminist family. Feminism is an absolute bulwark of the convictions of this family, and the gender inequality of the pandemic is the ultimate violation of the feminist impulse for the rights of women.

What lies ahead for you?

At the moment, the assumption is that my job as special envoy will end at the end of 2006. There are a number of avenues [opening up], including a "scholar-in-residence" role at McMaster University. But whatever I do, Africa and AIDS will remain a centrepiece. I don't intend for a minute to relinquish that. I am also working on another book. I love the UN, but I'm happy to anticipate a more unencumbered platform. I am allowed now an unusual amount of freedom to speak forthrightly, but I'd like even more. I'd like to be able to say some things that I now have to bite my tongue about, choke back, and I'll feel a moment of significant liberation when the end comes and I can speak even more frankly. +

Ann Silversides is the author of *AIDS Activist: Michael Lynch and the Politics of Community* (2003, *Between the Lines*), a history of the early days of AIDS activism in Toronto and Canada.



"Whatever I do, Africa and AIDS will remain a centrepiece."

linked to everything else and poverty lies at the heart. I recognize that you can't address the other dimensions until you address AIDS. Or, alongside everything else, AIDS must be dealt with. Orphan children have to go to school, so you deal with school fees and uniforms. You can't do treatment if people are malnourished. They need nutritious foods. If you have opportunistic infections everywhere then sanitation and latrines are going to be important—after all, you don't die of AIDS but from whatever disease or complication afflicts the dismantled immune system.

where, absolutely everywhere. The flow of drugs is a problem, the continued sustainability of resources is a problem, and capacity is an overwhelming problem.

What keeps you from becoming jaded or burnt out?

I think the explanation is simple, and I don't think it reflects on any particular qualities I have. It is ideological. My entire period of growing up was in a family, a democratic socialist family, where social injustice was considered to be the great evil of the world. Inequality, indignity and injustice



# Uprooted Lives

Immigrating can be daunting at the best of times, but add HIV to the mix and the difficulties multiply. Increasingly, AIDS service organizations are called upon to help newcomers deal with the challenges—and the isolation

BY DIANE PETERS

WHEN MARIA APPLIED TO CANADA FOR LANDED IMMIGRANT status in 2002, she was asked to take a blood test. It came back positive for HIV. But the mother of two was already personally familiar with the illness. Her teenage son had contracted it from a blood transfusion in Southeast Asia at the age of 5.

The boy had been born in Canada, back when Maria was living here in the 1980s with her then husband. In Southeast Asia, reaction to her son's HIV status was so bad that when he was initially diagnosed Maria and her children were thrown out of her parents' home, where they had been living. And later, when her son was in his teens, taunting at school left him contemplating suicide. Canada

was a solution. To get the health care her son needed and to leave behind the powerful stigma in the community, Maria chose to return her family to Canada. But a problem remained; while her son and daughter had a legal right to be here, Maria did not.

Thus began years of stress and waiting. While Maria has been living in Toronto since 2002 on a tourist visa, she has to renew it every six months, a hassle at best. And while her children's drugs eventually became fully covered through Ontario Works—a social assistance program—she herself has no basic health care coverage for simply visiting the doctor or getting a blood test.

Variations on Maria's situation abound. Many people living with HIV/AIDS (PHAs) new to Canada struggle to see a doctor, find a pamphlet in a language they can read, get the right meds or manage to pay for them. It's a growing problem, mainly because every year more newcomers to Canada are HIV positive. Of the 15,876 new HIV cases reported in Canada between 1998 and 2004, 467 involved people born in countries where the disease is endemic—spread through the general population mainly through heterosexual sex. And the numbers are on the rise. In 1998, just 34 new HIV diagnoses came from these newcomers, versus 98 in 2004.

Helping these people is a growing priority for AIDS service organizations (ASOs). But the challenges that newcomers face are so numerous and complex that it can be hard to know where to begin. "It's stressful, it's depressing. It's really a lot to handle," Maria says. When she first brought her family back to Canada, even her children were denied full health coverage despite having been born here, because, according to a provincial rule, the mother must have coverage in order for her children to receive it.

At the time, Maria turned to the Alliance for South Asian AIDS Prevention (ASAAP) and the HIV & AIDS Legal Clinic of Ontario (HALCO). Staff at these organizations sorted out the coverage issue for her kids and found her doctors who see her for free. When Maria had to be hospitalized for two weeks in 2003 and the bill came to \$35,000, a social worker at the hospital navigated channels that somehow allowed her to get rid of the entire bill. "You've got to know the right connections," Maria says. "If you don't know them, you're out."

## THE COMMON FACTORS

All PHAs new to Canada share common obstacles, the most powerful being stigma. "The stigma can be so great, there are people who are living in fear all the time,"



**"Many of my clients tell me that if news of their being HIV positive ever got back to Rwanda or Burundi, it could jeopardize the safety of their family members," says Claire Duchesneau, a social worker at the Montreal Chest Institute's Immunodeficiency Service.**

says Rounak Khan, PHA support coordinator with ASAAP. "That can create a barrier in coming out and getting help."

Often, the best places to get help are service organizations devoted to newcomers from certain communities such as Asia, Africa or the Caribbean. But fear of running into someone they know prevents many from accessing these services. Those who brave showing up in public often hide their status, despite the obvious. At the Immunodeficiency Clinic at the Ottawa Hospital, for instance, women in the waiting room often tell each other they're seeing the doctor for a hurt foot or a cold. "It's an HIV clinic. Why don't these women seek support from each other and disclose to each other?" Dr. Paul MacPherson says. "They won't. They're trying to protect themselves."

Some stay silent out of a very real fear, says Claire Duchesneau, a social worker at the Montreal Chest Institute's Immunodeficiency Service, whose clients are mainly African refugees. "Many of them tell me that if it ever got back to Rwanda or Burundi, it could jeopardize the safety of their family members," she says. Disclosure can be an issue, even within families. Many PHAs request meds that don't have to be refrigerated so family members or others in the household won't see evidence of the disease.

Although privacy is critical, it's not always respected by the Canadian immigration system. When HIV and AIDS activist Believe Dhliwayo came from Zimbabwe last October and applied for refugee status, he was sent by Citizenship and Immigration Canada to a clinic for a physical. Right in the middle of the waiting room, a nurse naively asked him personal medical questions, including whether he'd ever had TB, as well as his HIV status. "There wasn't any confidentiality," he recalls. "I could see other people looking at me while I was being asked."

These government-referred clinics are where many newcomers receive blood tests and later find out, via phone, that they're HIV positive. "They just phone and tell it to you. It's world shattering and there's no counselling," says Khan, who notes that PHAs in this situation are also not given any written information or guidance about where to turn for support.

That support is not always available, however, if you live outside the major centres. Dhliwayo has been staying in Barrie, Ontario, but he has to travel to a Toronto hospital, one hour away, for care. "There's only one doctor here for people with HIV, and he's not taking on any new clients," he says.

Often, immigrants don't realize there are doctors who specialize in HIV/AIDS, and that if their doctor is not well informed, it's important to find one who is. But many Canadians—not just newcomers or those with HIV—have a hard time finding any doctor because of the national shortage.

New Canadian PHAs also struggle with our complex legal and health care system. "It took me three months to figure out where to find services," Dhliwayo says. The problem is compounded when newcomers don't have a firm grasp of English or French. Big city ASOs may have translators and some information printed in languages from Tamil to Cantonese to Creole but, for the most part, very little information for PHAs is available in non-European languages. "You can't have a translator at your side all the time," Duchesneau says. There's so much to read and understand: from printed drug information to travelling directions to what the nurse is telling you at the doctor's office.

Add to these obstacles the strain of moving to a new country. "I'm already stressed that I can't go back to my home," Dhliwayo says. "For me to concentrate enough to go through a thick volume of information, that's a bit of a problem." That stress can turn to depression, further keeping people from taking care of themselves. And stress is compounded by money problems, which almost anyone starting a new life here has. "A lot of them are dealing with immeasurable poverty," Duchesneau says. It's not uncommon for a newcomer to be working more than one job, or collecting a small welfare cheque and sending most of the money home to family. Eating right, taking supplements and exploring complementary medicine are just not options for most people in this situation. As well, it's common for newcomers to postpone taking meds, fearing that the side effects will make them too sick to work or necessitate their having to turn to expensive alternative treatments.

## REFUGEE CHALLENGES

While many PHAs apply for protected status in Canada because of the hazards of stigma back home, others have come here because of war, sexism or homophobia. For those who have left home for reasons unrelated to their HIV status, concerns about disclosure remain an issue. "They fear they will be deported because of their HIV, which won't happen, but a lot of people don't know that," says Patrick Truong, support program coordinator for Asian Community AIDS Services (ACAS) in Toronto. This

fear leads some refugee claimants to put off applying for health coverage and taking meds, sometimes until they end up quite ill.

Sometimes the circumstances back home can cause other serious health problems as well. "The average person we see has witnessed multiple deaths and horrific crimes you would not believe," says Duchesneau, who often applies for special health coverage to get African refugees treatment for post-traumatic stress disorder.

Another source of stress can come from the way refugees are treated by others here. "If you are a refugee who is HIV positive, you suffer two stigmas—one related to HIV and the other related to being a refugee, the stereotype that you don't have education and you're on social assistance. Both stigmas together really affect the emotional state of the individual. And that can affect people's treatment and adherence to meds," says Victor Inigo, who works at Toronto's Regent Park Community Health Centre to help refugees and immigrants living with HIV gain access to services.

MacPherson, however, says his refugee patients are usually very committed to taking their drugs, particularly if meds are scarce back home. But significant obstacles remain. He may help refugees build up their immune systems with meds, but sometimes their claims are later rejected and they are sent home. Back home [in Africa], if you're "too well"—usually that means having a CD4 count of more than 200—you are denied treatment because of the scarcity of meds. "We've made them healthy," he says, "and then send them back, virtually disqualifying them from getting meds."

For refugees, finding out the outcome of their claim takes a minimum of a year, but often much longer. Meanwhile, they are eligible for the Interim Federal Health program, which provides health coverage and pays for medications. But, Inigo says, acquiring protected status can take a long time. "I know people who have been waiting 10 years." And there's no way of predicting if a person's claim will be rejected or accepted. "This uncertainty and the long period of waiting are what make the process very hard. It affects the individual in many different ways, not just emotional. They feel no sense of belonging to the community." Until the claim is resolved, people can't truly settle themselves and do what they need to do to stay well long term. "With my clients I've seen that

**When Believe Dhliwayo underwent a physical exam while applying for refugee status, a nurse asked him his HIV status in the middle of the waiting room. "There wasn't any confidentiality," recalls Dhliwayo, an HIV/AIDS activist. "I could see other people looking at me while I was being asked."**



## AIDS SERVICE ORGANIZATIONS

- African and Caribbean Council on HIV/AIDS in Ontario (ACCHO), [www.accho.ca](http://www.accho.ca)
- Africans in Partnership Against HIV/AIDS (APAA), 416.924.5256, [www.apaa.ca](http://www.apaa.ca)
- Alliance for South Asian AIDS Prevention (ASAAP), 416.599.2727, [www.asaap.ca](http://www.asaap.ca)
- Asian Community AIDS Services (ACAS), 416.963.4300, [www.acas.org](http://www.acas.org)
- Asian Society for the Intervention of AIDS (ASIA), 604.669.5567 [www.asia.bc.ca](http://www.asia.bc.ca)
- Black Coalition for AIDS Prevention (Black-CAP), 416.977.9955, [www.black-cap.com](http://www.black-cap.com)
- Canadian HIV/AIDS Legal Network, 416.595.1666, [www.aidslaw.ca](http://www.aidslaw.ca)
- Centre of Resources, Interventions and Services in Sexual Health (CRISS), 514.855.8991, [www.criiss.org](http://www.criiss.org)
- Centre for Spanish Speaking Peoples AIDS Support Program, 416.925.2800, [www.spanishservices.org](http://www.spanishservices.org)
- Committee for Accessible AIDS Treatment, 416.364.2261, [www.regentparkchc.org/CAAT.htm](http://www.regentparkchc.org/CAAT.htm)
- Group d'Action pour la Prévention de la transmission du VIH et l'Eradication du Sida (GAP-VIES), 514.722.5655, [www.aihc.ca/CCRI/gapvies.html](http://www.aihc.ca/CCRI/gapvies.html)
- HIV & AIDS Legal Clinic of Ontario (HALCO), 416.340.7790, [www.halco.org](http://www.halco.org)
- Women's Health in Women's Hands, 416.593.7655, [www.whiwh.com](http://www.whiwh.com)

## MULTILINGUAL HIV TREATMENT INFORMATION

Fact sheets in Asian and African languages: [languages.catie.ca](http://languages.catie.ca), [www.acas.org/treatment](http://www.acas.org/treatment) or call CATIE at 1.800.263.1638

People working to get immigrant status in Canada often deal with immigration consultants. Some are “quite bad,” Truong says. Scams happen often, with consultants charging exorbitant fees for things like filling out basic forms for health coverage. “Especially for people who come into the country illegally, there’s always a chance they can be cheated.”

## HELP IS AVAILABLE

Since Canada’s immigration and refugee system does not cater to PHAS, ASOs fill in the gaps. People at these organizations call the federal and provincial governments directly to clear up coverage issues, they contact pharmaceutical companies to get free meds, and they find or develop information in different languages and source translators. Khan even takes her clients to the doctor personally when they need extra support.

These groups are constantly looking for ways to better serve newcomers. At the Montreal Chest Institute, Duchesneau and her staff have started following the news in Rwanda and Burundi, as events there affect their clients here. “It took us years to understand what religion meant to our clients,” Duchesneau says. “Now we hold a mass at the hospital once a month just for women from Africa who have HIV.”

Sharing information has become a new mandate for many of these groups. Large city groups often receive calls from smaller centres, and they send off pamphlets in various languages and offer advice.

In Toronto, the Ethnoracial Treatment Support Network has been formed, which brings together ACAS, ASAAP, the Black Coalition for AIDS Prevention, the Centre for Spanish Speaking Peoples, Africans in Partnership Against HIV/AIDS and CATIE. One of their projects is to develop a peer-based counselling system to provide multilingual treatment information and support to new immigrants and refugees living with HIV.

The HIV/AIDS and Immigration Services Access Project is another collaboration looking at ways to improve services for newcomers and suggest changes to Canada’s immigration system. They want immigration-referred doctors to deal with testing and disclosure more sensitively; a complete information package to be given to all PHAS newly arrived in Canada; and to send out the message, as strongly as possible, that HIV is a treatable illness, not a death sentence. Helping newcomers stay well with HIV/AIDS will be an ongoing challenge, no matter how dedicated service providers are or how the rules change. Yet, despite everything, many newcomer PHAS do overcome their difficulties and receive treatment. Most work when they can, volunteer to help others and still find the energy to assist family back home. “People who come here are highly resourceful,” MacPherson says. “They didn’t survive this long without being really smart.” +

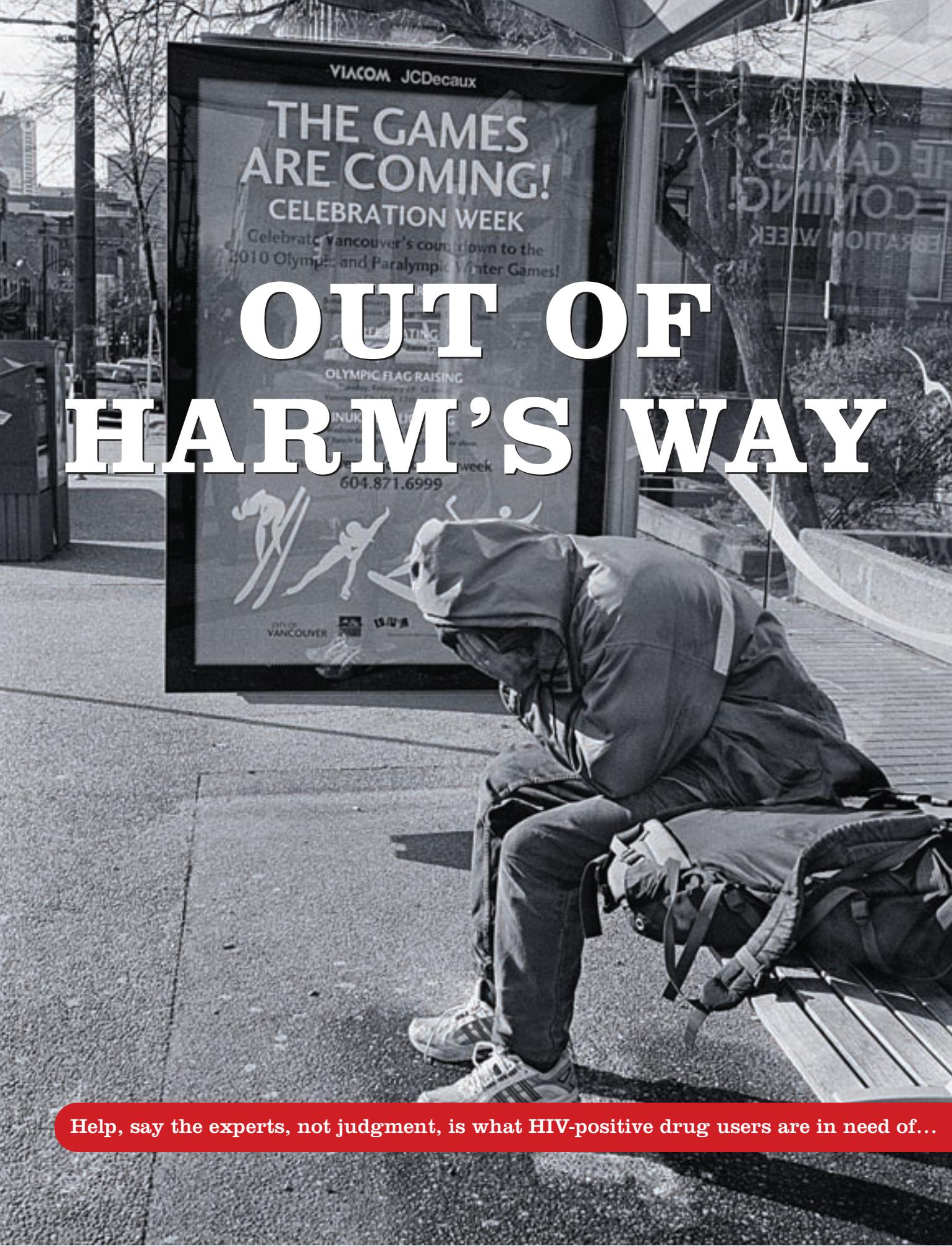
Diane Peters is a Toronto-based writer who has written extensively about health, including HIV/AIDS, for *Chatelaine*, *Reader’s Digest Canada*, *POZ* and *Today’s Parent*.

once a person is accepted, everything changes. They really move on and make huge changes and long-term decisions.”

## IMMIGRANT CHALLENGES

In addition to all the stresses of living with HIV in a new country, many immigrants feel they need to prove their value to Canada, so they work numerous jobs and refuse social assistance even when they’re sick.

But there are also people trying to immigrate to Canada who, like Maria, already live here—sometimes illegally—but are waiting for status. Many are refugees who have had their claims rejected. For these people, there are even more barriers to staying well.



# OUT OF HARM'S WAY

Help, say the experts, not judgment, is what HIV-positive drug users are in need of...

**TWO YEARS AGO, WHEN VANCOUVER BECAME** the first city in North America to open a safe injection site where people can use narcotics in a medically supervised setting, a storm of controversy ensued. Critics claimed that the facility, called InSite, would increase drug use and make taking drugs easier—that addicts from all over the country would move to Vancouver.

These days it's clear that by providing a benign environment for injection drug users, InSite (located on the infamous 100 block of East Hastings) has, if anything, reduced the harm and severity of the drug problem in the Downtown Eastside. "Given how new InSite is, the results are amazing," says Dr. Thomas Kerr, a research scientist with the B.C. Centre for Excellence in HIV/AIDS, which is overseeing the evaluation of InSite. "There has been a substantial reduction of people injecting in public, less discarded syringes on the streets, reductions in needle sharing and elevated rates of entry into detoxification services."

A pilot project funded by the Vancouver Coastal Health Authority, InSite also provides a point of contact for education, counselling and treatment. Its approach to street drug addiction is part of a philosophy and practice known as harm reduction. The central concept is to help people, without making judgments about their addiction or requir-

ing them to stop using before receiving help. As Dr. Kerr says, "We have to invest in strategies that keep people alive and as healthy as possible until they get to that place where they quit on their own or their use stabilizes so they can manage their lives better." Many say this is an approach whose time has come for North America.

At InSite, staff initially worried that people might be slow to use the facility, says coordinator Sarah Evans. "But after four months we were running at maximum capacity." With 12 booths open 18 hours a day, InSite can handle up to 800 visits—just a fraction of the number of injections happening daily in Vancouver. But many users, like Wayne and Carla, are willing to wait their turn for the measure of safety and security the site offers.

Both are injection drug users who travel from their apartment in Kitsilano to use the facilities at InSite. Because both are HIV and hepatitis C positive, infections and abscesses from unclean needles and paraphernalia could prove fatal for them. About 17 percent of users at the facility are HIV positive.

Carla is an attractive, articulate woman in her early fifties. She grew up in a small town near Montreal where her parents owned a hotel. "I was well taken care of," she says. "I had everything I wanted. We had money. We lived



by a lake. I skated. I skied. But I was a very high-strung kid; nervous and scared all the time. My mother didn't know what was wrong with me. I was afraid of airplanes. It was the time of the assassination of John F. Kennedy and they were saying scary things on television. . . I took it as being real. I had to tape down the blinds in my bedroom at night and tack the drapes to the wall."

When Carla was 11 her mother took her to a pediatrician who put her on Librium. Ever since, Carla has been taking drugs in the benzodiazepine family for anxiety and panic attacks. During the '70s she experimented with hard drugs off and on but never became addicted until 1983, when her first husband died in a head-on collision in Montreal. She was working in the film industry at the time. "When I lost my husband, I started going out with a bisexual guy and fixing coke with him . . . anything to take away the reality."

Her present husband, Wayne, is 38, but seems older. "Wayne is the best thing in my life," Carla says. "I don't know what I would do without him. . . my biggest fear is being alone and dying. . . with Wayne I can share my fears, someone to be honest with who sees every side of you and still accepts and loves you." Lean and stoic, he looks like a sailor straight off the deck of a WWII merchant ship. His heavily tattooed right arm is lifeless from the elbow down

**"Your life could be a total mess, a total disaster. You're at your wit's end and then you take the drug and none of these things bother you anymore. You feel that you can conquer anything."**

after he accidentally injected a nerve two years ago, and he has a steel bar from his left knee to his ankle from an assault in 1999 during a botched robbery attempt he was involved in.

Wayne first injected LSD at a party when he was 14. "To be honest," he says, "I was petrified of needles. There was a big party. I was coerced into it. I had very low self-esteem. I wanted to be cool. I come from a small town just outside of Winnipeg. All my family were big drinkers." That same year Wayne's life in prison also began.

"My first conviction, for robbery, was when I was 14 years old," Wayne says. "I got nine months in juvenile detention. From there it was nothing but prison. I matured very quickly in prison. The worst part was the loneliness; being locked down and nobody there. I've been in the prison system most of my life. I was in the penitentiary twice, once in Winnipeg, and once in Drumheller. I started with property crime—business, not residential—then it escalated. I have eight years' experience as an industrial spray painter, which I learned in jail, but I can't work now because of my health."

Carla was diagnosed HIV positive in 1998 and began to take HIV medications to fight the virus. At first she had a strong negative reaction. "A nurse came every day to my hotel to make sure I took it. I had nausea, headaches—like the flu—right away. But my numbers were great. Undetectable. It was like the operation was a success but the patient died. So I went off the meds and I got better. The ones I'm now on are great. I don't get sick at all."

Both Wayne and Carla take daily methadone, an oral synthetic opiate administered by a pharmacist. It has a long-lasting effect that stabilizes the nervous system but without the euphoric effect of heroin. Many people on methadone, which is a depressant, still use stimulants like cocaine and heroin to get high and overcome the slowing-down effect of the methadone. Wayne is not on antiretrovirals right now because they conflict with his methadone treatment—to find a solution for this problem, he is having blood work done.

Before the safe injection site opened, Wayne and Carla injected in the alleys on the Downtown Eastside. "I had a rat run over my feet when I had a needle in my arm," Carla tells me. "That's the power of addiction. I was more concerned with my injection than the rat. This is not me at all. I still think about it and quiver. It just blows me away that I didn't stop immediately and scream."

"When you take that drug," Wayne says, "whether you're smoking it or injecting it or snorting it, you get this euphoric feeling of 'nothing matters.' You could have a cable bill you haven't paid in three months, your life could be a total mess, a total disaster. You don't have a nickel in your pocket. You're at your wit's end and then you take the drug and none of these things bother you anymore. You have energy, you feel that you can conquer anything."

Using opiates continually over the long term creates opiate dependency—the drug is needed to generate an endor-



phin-like high. Bill Nelles, founder and director of The Methadone Alliance, a user-led group of activists and professionals in the United Kingdom (U.K.), talks about the long-term effect of opiate use on the brain. After six months or so of continual use, dependency takes place. “Opiates, unlike alcohol, are easy on the body,” he says, “but what does happen is that the brain shuts down the whole endorphin system . . . . In many, if not most users, these changes may not be reversible.”

The Alliance, which is funded by the British government, does educational work and lobbies for better treatment and services for addicts, such as safe injection sites, inhalation rooms, prescription narcotics and detox. The first harm reduction initiatives, Nelles says, were taken in the early '80s by Amsterdam drug users who were worried about the spread of HIV and hepatitis C. “We took the Dutch work and brought it to the notice of the English-speaking world.”

A former opiate addict now on methadone, Nelles became addicted while he was a student nurse involved in a relationship with a doctor who easily obtained the drugs. No methadone program existed in eastern Canada in 1977, although there was one in Vancouver. Because he had a British passport, Nelles chose to go to the U.K. to get into methadone treatment. “All of the people I started doing opiates with in Ottawa are dead now,” he says. “We have this lovely idea that people who are addicted can come off the

**In 2003, in response to a large-scale police crackdown and government inaction, the Vancouver Area Network of Drug Users, along with other like-minded organizations, opened an unsanctioned user-led safe injection site that operated for 181 days and supervised more than 3,000 injections.**



drugs if they want to ...that they are making a choice to stay addicted.”

It's the users themselves, Nelles says, who are the experts on drug use. He credits the work of the Vancouver Area Network of Drug Users (VANDU) and its feisty director, Ann Livingston, for taking the lead in pushing for a safe injection site in Vancouver. In 2003, in response to a large-scale police crackdown and government inaction, VANDU, along with other like-minded organizations, opened an unsanctioned user-led safe injection site that operated for 181 days and supervised more than 3,000 injections.

According to Livingston, novice users coming to the Downtown Eastside area contract HIV and/or hepatitis C within six months. “If you grab 100 addicts, 35 of them are likely to be HIV positive and Aboriginal people are seven or eight times more likely to be HIV positive.... Because this place is like a village, people won't out themselves about their HIV. Everyone from the community will know. Their lives are already hard enough.... But if nothing else is working for you, that's the last thing you'll do. Many have never taken AIDS meds. I call it dying with your boots on.”

Indeed, what Kerr calls “the most explosive outbreak of HIV infection in the Western world”—a 19 percent incidence rate—happened in Vancouver's Downtown Eastside in 1996–1997. The Vancouver Richmond Health Board declared it a public health emergency. Today, of the 12,000

people living in the area, approximately 5,000 inject or inhale drugs daily. Estimates are that 90 percent of drug users have hepatitis C and 35 percent are HIV positive.

Marcie Summers, director of the Positive Women's Network, echoes these concerns. “Seventy percent of the women who access our services are Aboriginal. This is an epidemic. Recently the Health Officer for Northern B.C. declared it a health crisis. Only a small percentage of women with HIV are on meds.” She adds that domestic violence and a lack of stable housing are the two biggest barriers for women seeking treatment. Funding from the province has remained flat though the disease is spreading to many parts of B.C. There are long waiting lists and few places where women can go for treatment with their children.

Livingston credits InSite with reducing harm but would like to see the facility open up an inhalation room for crack smokers and do something about the problem of assisted injections. Many older users have badly scarred veins or, like Wayne, injured limbs, and have a great deal of trouble injecting themselves. Present policy at InSite is for self-injection only. Many of the most vulnerable users, who are physically unable to inject themselves, cannot take advantage of the safer, more congenial atmosphere of InSite. And using in the alleys makes them easy prey for robbers and thugs.



InSite has saved lives. Because the drugs brought into the facility are obtained on the illegal market, they can be toxic and sometimes deadly. This past February Wayne almost died when he injected speed that he thought was cocaine. “I wouldn’t be here today if it wasn’t for InSite,” he says. “Thank God they had the medical staff to supply oxygen and keep me breathing. I came close to dying. I had nine seizures in 20 minutes.”

Compounding matters, prejudice abounds. As Marcie Summers puts it, “We see people with HIV/AIDS as marginal people, disposable people.” Kerr’s view is that from an ethical, legal and human rights perspective, society has to do something.

Apart from offering a safe injection site, InSite refers on a daily basis about four clients to addiction treatment and an average of two clients to methadone treatment. But most of the assistance the facility gives to people involves essentials such as housing and food. “You can’t even talk about detox until you have a home,” says Sarah Evans, InSite coordinator.

The number of homeless on Vancouver streets has doubled in the past year, according to The Vancouver Regional District. And many are inhalation or injection drug users. In an attempt to restore “public order,” Vancouver’s Police Chief Jamie Graham announced on February 22 that there would be a crackdown on open drug use in the Downtown Eastside.

David Eby, a lawyer with the Pivot Legal Society, whose mandate is to advance the interests of marginalized persons, calls this a step back to police practices of the past. “Since the big HIV outbreak in the area 10 years ago the police backed off and quit arresting people for simple possession of narcotics,” he says. “This seems to be part of a strategy to clean up the area before the 2010 Olympics.... Everyone knows it’s a joke because there is no way the police could arrest everyone using drugs openly and ever have a chance of processing them. The courts couldn’t handle it, the judges couldn’t handle it. It would bring the system to a standstill.

“But what is happening is that users are hiding themselves away in a little nook or cranny in the alley where they won’t be found for hours if they overdose.” Since people are afraid of having needles and rigs on them, Eby continues, they toss them away instead of bringing them into the needle exchange, increasing disposal problems and the risk of accidental infection.

Incarceration in the wake of crackdowns leads to additional serious problems for people with HIV/AIDS (PHAs). According to Kerr, “Being in jail is one reason people stop taking their meds. Appointments with physicians are posted in public places and everybody will know that you’re HIV positive.... Also, in jail a syringe is shared between 20 and 30 people. If you declare, you won’t get access to the syringe that’s going around.”

**In 2001, the Auditor General's report on the problem of street drugs in Canada concluded that 94 percent of all federal resources directed toward the drug problem were spent on enforcement and incarceration—with no measurable benefits.**

Of course there are other reasons that half of those who are HIV positive and injection drug users discontinue treatment prematurely—reasons such as side effects. “Injection drug users have so many health issues,” Kerr says, “that adding antivirals can be too difficult to tolerate.”

Still, the crackdown has got a lot of people worried, since police cooperation is fundamental to effective harm reduction. With the exception of the NAOMI project, a trial heroin prescription program in the area, the only place to inject besides InSite is in the alleys.

And the violence that accompanies the street drug trade is a daily occurrence in this part of town. In March, a 44-year-old Aboriginal man was knifed to death on the corner of Hastings and Main over a \$5 crack transaction. As well, the criminal nature of the global drug trade is a growing issue in Europe, the U.S., Australia, Canada and in many Third World countries where the drugs are produced.

Yet in 2001, the Auditor General's report on the problem of street drugs in Canada concluded that 94 percent of all federal resources directed toward the drug problem were spent on enforcement and incarceration—with no measurable benefits. Society can't afford “no measurable benefits”—the costs are staggering: property crime, criminal gangs and the spread of bloodborne diseases like HIV and hepatitis C.

With an eye to combatting all these costs, the Health Officers' Council of British Columbia (2005) and The City of

Vancouver Prevention Report (2005) produced papers recommending experimenting with a regulated market for illegal drugs. This wouldn't be unprecedented. The countries most progressive in drug reform, such as Holland, Switzerland, Britain and Spain, are advancing harm reduction to include things like the sale and regulation of certain narcotics and soft drugs.

Mark Haden, an addictions expert who works for the Pacific Spirit Community Health Centre in upscale Kerrisdale, agrees. “If these drugs are available only on the black market, people become enormously engaged in the criminal system. They do a lot of crime to pay for the drugs... I think it is immoral of society to allow the existence of a black market that creates so many pathologies, criminalizes our youth and creates so many problems for society.”

VANDU's Ann Livingston estimates that at least \$150,000 a day is spent on illegal drugs in the 10-block area of the Downtown Eastside. The resulting expenses for society involve the police force, ambulances, medics and the like, she says. “The public needs to understand the cost to them; the risk that your children will get involved in injecting drugs. This risk is very high if you don't have a regulated market.” But it takes time for people to adjust their attitudes around prescription narcotics, particularly when Hollywood and the media reinforce the notion that abstinence is the only goal. And, as Livingston says, the public has to go at its own pace. “Harm reduction is a new idea that people often have to warm up to.”

Still, it may well be an idea whose time has come. “I think that Vancouver is so ready for someone to do something really radical to deal with the problems of the Downtown Eastside, up to and including the legalizing of prescription heroin and cocaine,” David Eby says. “To treat this as a health and social problem and not as a criminal problem.”

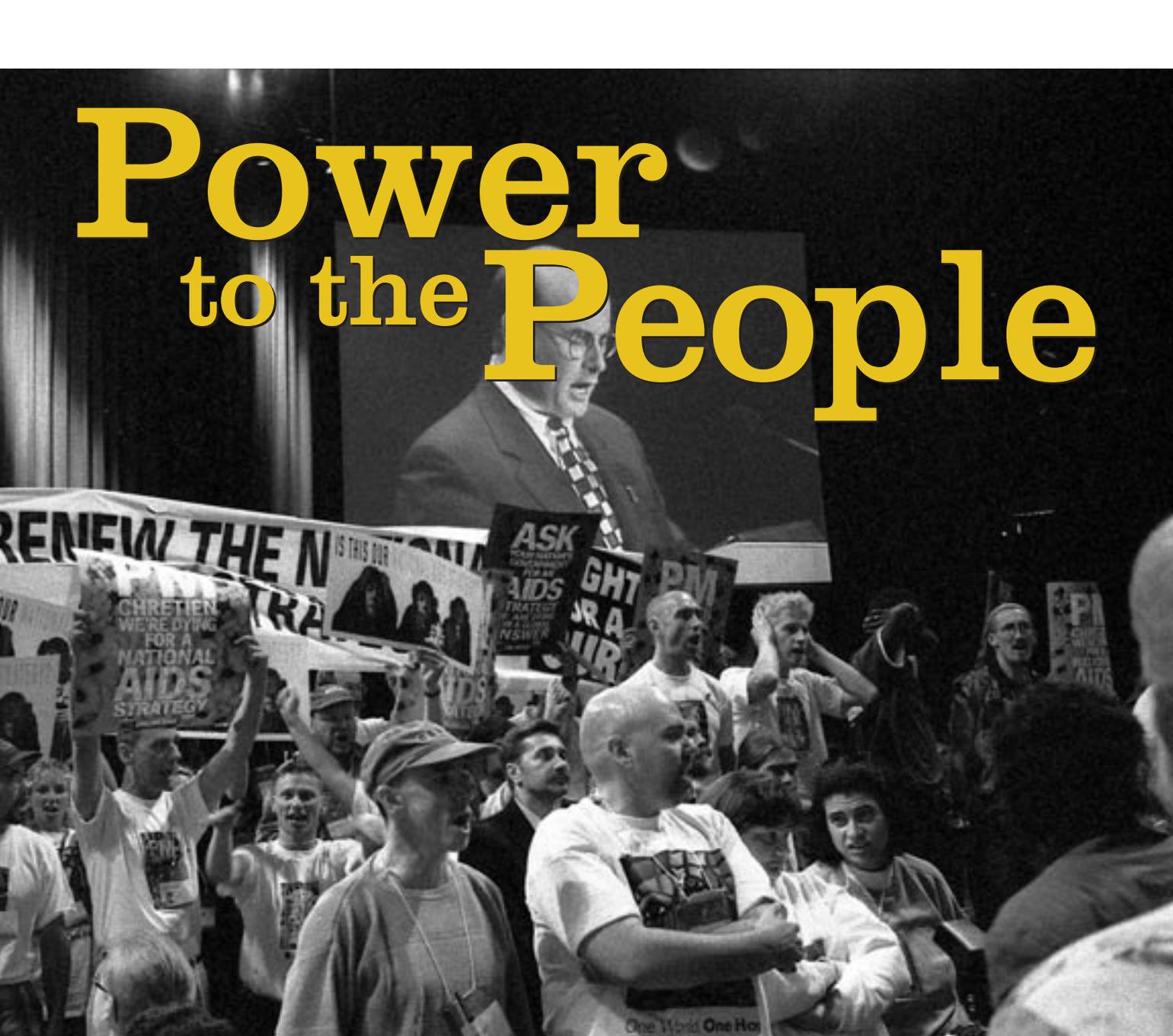
Carla and Wayne, like many others, would both like to see more safe injection sites as well as market control and regulation of the drugs they use. “Crime would decrease,” Wayne says. “Death would decrease. A lot of people would get their humanity back, their self-respect... People wouldn't look down on you and you would have a little bit more self-esteem so you might make that change to go over to the other side of the room, to recovery.”

The couple is thinking of going into detox through InSite. “I don't want my legacy to be on a billboard with a body count in an alley,” Carla says. “I'd like to change that.” +

Elaine Brière is a Vancouver writer, documentary photographer and filmmaker. She was the last photographer to visit East Timor before the Indonesian invasion of 1975. Her book *East Timor: Testimony* was published by Between the Lines, Toronto, in 2004.

CATIE's treatment guide for HIV-positive injection drug users and their caregivers, *pre\*fix: harm reduction for + users*, is available at [www.catie.ca/pdf/Prefix/ENprefix.pdf](http://www.catie.ca/pdf/Prefix/ENprefix.pdf) or by calling 1.800.263.1638. For more info on harm reduction, visit [www.canadianharmreduction.com](http://www.canadianharmreduction.com)

# Power to the People



**A look back at the issues, struggles and victories that defined the early age of AIDS activism in Canada**

**BY TIM McCASKELL**

## **EARLY TO MID-'80S: IGNITING HOPE**

IN THE EARLY 1980S, THE NIGHTMARE OF AIDS BROKE LIKE A tsunami over gay communities in Canada's major cities. Young, healthy men were suddenly and inexplicably dying across the country. No one knew the cause of the epidemic, and even after the identification of HIV in 1984, there was ongoing controversy over the role of the virus in the syndrome. No cure existed for the underlying immune dysfunction, and treatments for the opportunistic infections that came in its wake were largely ineffective.

With medical science impotent and in disarray, gay communities were largely thrown back on their own resources. They established organizations offering support and counselling, set up hospices to care for the dying and, once HIV had been identified, launched prevention campaigns urging safer sex. But with “only” marginalized groups such as gay men dying, government efforts, what little there were, tended to be restricted to preventing the virus from spreading to the “general population.”

Some 25 years later, it's illuminating to trace the course of events that ensued—the outcry, struggles and victories of early AIDS activists in their efforts to force key changes within the medical establishment, the pharmaceutical industry, the government and the health care system—and to look at the role that treatment information played in those struggles.

In 1987, impatience with government inaction and lack of research for treatments and a cure finally erupted in the U.S. The AIDS Coalition to Unleash Power in New York (ACT UP NY) emerged, quickly leading to the formation of chapters across the U.S. Canadians soon followed ACT UP NY's example of in-your-face activism, drawing on the women's health movement's healthy skepticism of the medical establishment and the strategies and tactics of lesbian and gay liberation, with its demonstrations and street theatre.

That same year, Kevin Brown, a founder of the B.C. Persons With AIDS Society (BCPWA), began lobbying the federal government for speedy access to AZT, which had just been approved as the first treatment for HIV infection in the U.S. And in early 1988, inspired by the example of American activists, AIDS ACTION NOW! formed in Toronto. Most of AAN!'s activists were HIV positive. Treatment quickly emerged as a key issue, as did criticism of the Public Health approach, which was so focused on prevention that it ignored the needs of those already infected.

When AAN! published its first treatment information broadsheet, *Treatment AIDS*, and distributed thousands of copies at Toronto's Lesbian and Gay Pride day in June 1988, there was little distinction between “alternative” and mainstream approaches, and minimal scientific rigour. The medical establishment might have warned against raising “false hopes,” but to activists, trying anything made more sense than waiting around to die.

### INFORMATION AND ACCESS

In this context, treatment information was the foundational element of treatment activism. If they were going to mobilize and fight back, people needed hope. The idea that treatment, or even a cure, might be within reach helped combat the resignation and despair that had seized many people living with HIV/AIDS (PHAs), convinced that they faced an imminent death sentence. It also raised expectations and focused attention on the barriers to

treatment—government red tape and inaction, and lack of research and information. The virus might be incurable but, according to treatment activists, people were not so much dying of a virus as they were dying of neglect and indifference. That, we could do something about. The goal was to empower PHAs to make demands on the health care system, the government and the pharmaceutical industry.

At this point, activists confronted the incomprehension of most people in positions of authority. It took time for doctors to recognize that their patients often knew as much as they did about the new and mysterious disease, and that a much more collaborative approach was necessary. Governments were blind to the fact that the glacial pace of standard drug approval and a laissez-faire approach to



1991 – Early AIDS ACTION NOW! battles commemorated.

research were inappropriate in the face of crisis. The pharmaceutical industry was befuddled by unprecedented demands for immediate access to experimental treatments and trial designs that didn't use PHAs as expendable guinea pigs. They were all oblivious to what BC Civil Liberties Association President John Dixon began to call the “catastrophic rights” to treatment for those facing major illness.

Pentamidine was a case in point. When the drug was used in a nebulizer that turned it into a fine mist breathed directly into the lungs, pentamidine trials in the U.S. had shown dramatic results in preventing PCP (*Pneumocystis pneumonia*), at the time the major AIDS-related killer. But the drug, although available in most hospital pharmacies, had not been approved for aerosolized use in Canada and Canadians could not get access. Activists demanded the opening up of the federal Emergency Drug Release Program (EDRP) to allow PHAs access to a range of experimental treatments from around the globe.

Also, in the face of increasing demand for action, a

placebo-controlled trial of aerosolized pentamidine was finally set up in Canada in 1988. It would enroll 750 participants, all of whom had had at least one bout of PCP and who were therefore at high risk for a second attack. But half the group, in a placebo arm, would receive nothing. The deaths in that group would be the measure of success of the drug among those who received treatment. AAN!'s first public action was a demonstration that marched on Toronto General Hospital, site of the trial in that city. The demonstrators demanded that the trial be halted and the treatment be made available to those who needed it. To hell with the regulations, lives were at stake.

The fall of 1988 saw a federal election. AIDS activists across the country dogged the ruling Progressive Conservatives for their lacklustre efforts against the epidemic. The message got through. Although the Conservatives were re-elected, one of the first announcements made by the new Health Minister, Perrin Beatty, was that Canadians would be able to access experimental AIDS treatments, including pentamidine, through EDRP (now renamed the Special Access Program, SAP). The unethical pentamidine trial was halted and a whole range of new treatments became available.

If the government had begun to move, the pharmaceutical industry was still slow to respond. It took a month-long



1990 – Pamphleteering at Toronto’s Gay Pride parade.

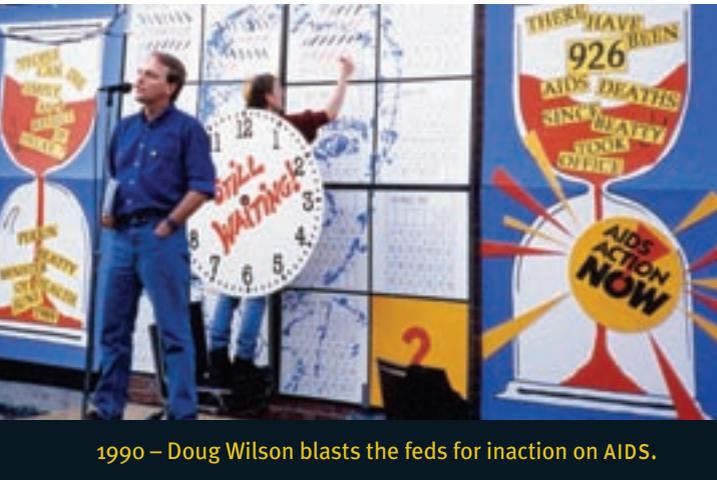
Exchange (TIE) in Toronto to make scientifically reliable information on cutting-edge treatments available. TIE took on the publication of AAN!'s *TreatmentUpdate/Traitement-Sida*, a low-budget summary of breaking treatment information written by Sean Hosein.

But activists also recognized the limitations of grassroots, local efforts in spreading the word. With what's now called the Special Access Program open for business, AAN! joined the Canadian AIDS Society to demand that the federal government establish a national treatment registry to provide information about treatment options and strategies for PHAs and their doctors across the country. When Health Minister Beatty announced funding for the country's first national AIDS strategy in April 1990, he also included funding to set up the registry.

But announcements and implementation are quite different animals. A year later, after several false starts, there was still no national treatment registry in sight. Rather than wait on the government, activists decided to do it themselves. In February 1991, AAN!'s TIE project became the Community AIDS Treatment Information Exchange (CATIE). As an independent, charitable organization, CATIE would be able to raise funds to put in place a credible infrastructure to gather, evaluate and distribute treatment information, at least on a local level.

By now the government, the research establishment and the pharmaceutical industry could no longer ignore the voices of PHAs. When the Canadian HIV Trials Network (CTN) began functioning in 1991, it included a Community Advisory Committee made up of activists from across the country. The Committee has veto power over any research protocol considered by the CTN. One of the great legacies of treatment activists was that they successfully pushed for the involvement of PHAs at all levels: public policy, research design, hospital advisory boards, AIDS service organizations (ASOs) and more.

PHOTOGRAPH: LINDA GARDNER



1990 – Doug Wilson blasts the feds for inaction on AIDS.

picket of the Bristol-Myers offices in Toronto by a mother demanding access to ddI for her seriously ill son, international news coverage and the arrest of AAN! activists occupying its offices in the summer of 1989 before the company gave in and agreed to make the drug available on a compassionate basis.

PHOTOGRAPH: LINDA GARDNER

## FOUNDATIONS OF AN INFRASTRUCTURE

Treatment information had proved itself a powerful weapon in mobilizing PHAs to demand change, and in the spring of 1989 AAN! set up the local Treatment Information

## NEW ACCESS ISSUES

By 1992, the face of AIDS was changing and so, too, were the strategies employed by treatment activists. The epidemic was no longer confined to the gay community. More

women were now infected. Treatment activists, many of them women themselves, struggled with understanding how the new therapies coming on line were affecting women's bodies since most had only been tested on men.

As well, as scientific understanding of AIDS deepened and more drugs and treatments were tested, enrollment in clinical trials of new antivirals became a major mode of access to treatment for PHAs. Suddenly, the design and ethics of clinical trials became a serious concern. In early 1992, AAN! published the information booklet *AIDS and HIV Drug Trials in Canada: What you need to know*. A major AAN! demand was that all trials include a compassionate arm so that those seeking treatment could participate in trials knowing that they were receiving the drug and not a placebo.

Increasingly, cost was also becoming a factor. Most provinces had originally established programs to pay for the early antivirals, but as time went on, the growing number of newer antivirals and treatments for opportunistic infections were not covered. In Ontario and Quebec, for example, more and more PHAs without adequate private drug coverage were forced to stop work and go on welfare in order to be eligible for a provincial drug card to pay for their medications. In a dramatic video broadcast shortly after his death in January 1993, AAN! Chair James Thatcher indicted the Ontario government, whose failure to establish a catastrophic drug program had prevented him from accessing treatments he needed to stay alive. The following year, in the face of persistent pressure, the government finally relented and established Ontario's Trillium Drug Program.

The role of treatment information continued to be an integral part of the struggle for access throughout the first half of the 1990s. Knowledge that options existed empowered PHAs to demand more from their doctors. It increased pressure on governments to cover the cost of expensive therapies and mobilized PHAs to demand that the pharmaceutical industry take their interests into account in the design of clinical trials.

### MID-'90S TO 2005: MANAGING SERVICE

In the summer of 1995, CATIE received the federal government contract to implement the national AIDS treatment information service [formerly called the national treatment registry], which had been floundering in successive agencies since its announcement in 1990. Much had changed since AAN! had made its first proposal for a national treatment registry in 1989. As CATIE struggled with transforming itself from a local to a national, bilingual organization over the next year, AIDS treatment in Canada was being transformed by the introduction of the first protease inhibitors. For the first time, effective combination therapies—highly active antiretroviral therapy (HAART)—and the dream of AIDS as a “chronic manageable infection,” a concept popularized by AAN!'s George Smith in 1988, were real possibilities.

But the emergence of new therapies also had unexpected results. As the dying diminished, so did the perception of AIDS as a crisis. One of the major activist fights at the

## MILESTONES

1987

Vancouver activist Kevin Brown lobbies the federal government for access to AZT.

1988

AIDS ACTION NOW! is founded in Toronto and publishes a broadsheet for Gay Pride day on possible treatments.

1989

AIDS ACTION NOW! publishes the first issue of *AIDS UPDATE* by Sean Hosein. In subsequent issues the publication becomes bilingual and is renamed *TreatmentUpdate/TraitementSida*.

AIDS activists seize the stage at the International AIDS Conference in Montreal. AAN! demands that the federal government establish a national treatment registry.

1990

AAN! establishes the Treatment Information Exchange, and Health Minister Perrin Beatty announces funding for a national treatment registry as part of the National AIDS Strategy. The Emergency Drug Release Program opens up to allow access to unapproved treatments for AIDS-related conditions.

1991

The Canadian HIV Trials Network establishes a Community Advisory Committee to vet all its trials.

AAN!'s Treatment Information Exchange project becomes the independent organization CATIE.

1995

After years of false starts, the national treatment registry project is taken over by CATIE, which then assumed a national role.

1996

International AIDS Conference is held in Vancouver, protease inhibitors are introduced. Canadian Treatment Action Council forms.

2003

LIPO-ACTION! forms in Montreal.

International AIDS Conference in Vancouver in July 1996, was to demand that the government renew the National AIDS Strategy with its dedicated funds for prevention, services and research. The Chretien government had previously announced its intention to let the strategy lapse.

A second development was that treatment information had become much more complex. The “exchange” of information among peers originally envisioned was increasingly

being superseded by the technical demands of information technology—managing, evaluating and disseminating huge amounts of complex information.

Finally, many of the demands for access by AIDS activists had been met. The Special Access Program was functioning and experimental drugs were available. Most clinical trials now included compassionate arms. And the provinces with the largest numbers of PHAs had programs in place to cover the cost of medications for those who were uninsured. As well, many of the original activists had died and many of those who survived were exhausted. The sense of crisis within the gay community diminished and groups like AAN! were unable to incorporate activists from the newer and often even more marginalized sectors of the population— injection drug users, Aboriginal communities, new immigrants and refugees, youth—now affected by the epidemic.



2005 – The fight continues: Montreal’s LIPO-ACTION!

PHOTOGRAPH: MARTIN MAILLOUX

One group that continued to pressure both government and the pharmaceutical industry on behalf of PHAs on a national level was the Canadian Treatment Action Council (CTAC). Founded in 1996, CTAC worked to orchestrate activists’ participation in pharmaceutical advisory committees and ensure that trial design and management committees were knowledgeable and accountable to the community. Today, CTAC provides policy and research related to treatment access directed at both pharmaceutical companies and government, and conducts related skills-building activities targeting CTAC members and PHAs across Canada.

The growing professionalization required of groups such as CATIE in order to effectively manage and evaluate huge amounts of data was accompanied by a decline in traditional activism. Treatment information became increasingly understood as a service to help patients and doctors deal with a range of confusing choices, rather than an

incitement to public action. One group that has bucked this trend, however, still combining treatment information and in-your-face treatment activism, is Montreal’s LIPO-ACTION! Since its launch in 2003, the group has used demonstrations, street theatre and lobbying to raise awareness and demand access to new therapies to combat lipodystrophy.

### BACK TO THE FUTURE

The growing complexity of AIDS treatment and the increasing marginalization of communities now affected by the virus have meant that power and expertise is once again shifting away from “patients” back to medical professionals and institutions.

In response, many ASOs are deepening the work of providing treatment information to their local communities, usually with electronic links to CATIE. BC Persons With AIDS Society (BCPWA), for example, established its own Treatment Information Project (TIP), and its bimonthly publication *Living Positive* regularly combines information on treatment issues with practical advice on the challenges of living with HIV, news and political issues.

In Montreal, the Comité des Personnes Atteintes du VIH du Québec (CPAVIH) holds regular forums on treatment issues, as does the Toronto People With AIDS Foundation, which established a treatment resources position as early as the late 1980s. Thanks to the work of the Committee for Accessible AIDS Treatment, that position now includes a component to assist individuals temporarily without access to HIV medications—people with a temporary lapse in coverage, refugees and others. [This program grew from earlier efforts to “recirculate” medications from PHAs who died or weren’t able to tolerate them, to others without access.] As well, a new Ethnoracial Treatment Support Network has been established in Toronto. The network trains peer treatment counsellors from immigrant and refugee communities to work with other HIV-positive community members struggling with cultural, linguistic or legal barriers to accessing treatment.

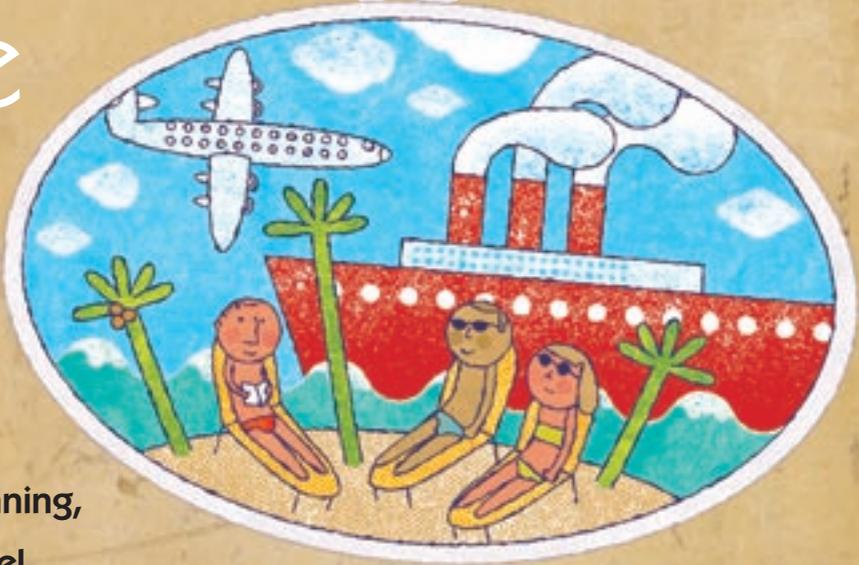
This last focus illustrates a major challenge facing the treatment information movement in Canada—how to target efforts to make highly complex and technical information about treatment options available to increasingly diverse, marginalized populations from a variety of cultural and linguistic backgrounds. One size can no longer fit all.

The next decade will decide if the treatment information movement, born out of a ferment of patient empowerment and entitlement, will be able to continue to evolve to meet the challenges emerging from the changing face of AIDS. If the resilience that this movement has shown since the first dark days of the epidemic is any indication, however, there are grounds to hope that it will continue to thrive until a cure is found and the AIDS epidemic finally becomes history. +

Tim McCaskell is a longtime gay activist in Toronto. He was a founding member of AIDS ACTION NOW! in 1988, and a member of the Ontario Advisory Committee on HIV/AIDS for over a decade.

# Vacationing with the Virus

**Been denying  
your wanderlust?  
With some careful planning,  
the exhilaration of travel  
could be yours once more**



**BY WALTER ARMSTRONG**

WANT TO GET AWAY FROM IT ALL THIS summer? Go for it. Give the HIV-positive finger to global terrorism, avian flu and every other fear, and hop a plane to your dream destination. If you're lucky, you'll lose your tired old self in a strange new land—and come home, renewed, a citizen of the world.

Plus, it's what people with HIV do. Soon after testing positive in 1989, Arvin Thomas took a six-month leave of absence and went backpacking through Asia. "I was trying to sort out my head. It was the most amazing thing I ever did for myself. There was no fear—I found a complete sense of freedom," he says of his you-only-live-once adventure. "There is such a

liberating feeling to being in a foreign country. You can be anyone you want to be and do anything you want to do." But even more than that, he says, "It was a very humbling experience to meet so many people who had so much less than I had and yet invited me to share their home, their food. I realized how blessed I really am—and [decided] to stop whining about being positive."

Still, as always for the HIV enhanced, the stakes are raised. A routine setback, such as a bout of travellers' diarrhea in a lonely room far from home where you can't negotiate a local call or the local currency, can set off emergency sirens in your mind. But the flip side is, you can stroll down the Champs d'Elysées at twilight

dressed all in leather, lace or feathers and forget all about HIV.

What you can't forget is to take your meds. And that's where we at *The Positive Side* come in. Because we want your trip to be as safe and comfy as possible and, yes, because we love to nag. So prepare yourself for a crash course in Viral Vacationing 101.

## VACATION VAX

Part of the fun in travelling is dreaming up the trip. If you're looking for an HIV-savvy travel agent, it pays to go gay, since they will have had the most experience with positive peregrinators; check out the International Gay and Lesbian Travel Association at [www.iglta.org](http://www.iglta.org). For do-it-yourself planners, access to the Internet is



indispensable. While Googling the cheapest flights to your destination and sights not to miss, take note of health need-to-knows, starting with local diseases you *will* want to miss. (Keep in mind that the health problems travellers most commonly face are injuries from motor vehicle accidents, diarrhea and sexually transmitted diseases—not more exotic fare like Japanese encephalitis, malaria or avian flu.)

Still, you'll need to consider needle work. If you're heading to the U.S., Europe or Down Under, you're unlikely to have to roll up your sleeve for any particular vaccination. Canadians are usually immunized in childhood against such nasties as diphtheria, whooping cough, tetanus, polio, measles, mumps and rubella—but check with your doctor to see if you need a booster. Hepatitis A and B are vital vaccines for the wary traveller.

Vacations in the developing world, however, may call for some shots, depending on where and when; certain countries require specific vaccinations for entry. Check out the Public Health Agency of Canada's Travel Health Program (THP) at [www.TravelHealth.gc.ca](http://www.TravelHealth.gc.ca) for more info. Every year sees awful outbreaks of diseases that never make headlines, and THP provides updates. And, yes, there's a special avian-flu page, with recommendations for nervous nellys (sorry, no vaccine exists yet).

Two vax facts: 1. The immunization may take weeks to months to kick in,

so plan your visit to Doc accordingly. 2. People with HIV should avoid all "live" vaccines, including yellow fever and vaccinia, since a tiny case of said disease may be more than your immune system can handle.

### LA TRAVEL CLINIQUE

If you're short on time (but not on cash), drop by your local travel clinic. (For a national list, click on [www.phac-aspc.gc.ca/tmp-pmv/travel/clinic\\_e.html](http://www.phac-aspc.gc.ca/tmp-pmv/travel/clinic_e.html).) Many swear by these one-stop shops for health travel needs, where you'll find not only a specialist in tropical medicine and hygiene (who should be HIV savvy) but a blizzard of brochures and other information. Although your provincial health plan may not cover the visit, the initial consult shouldn't run you more than \$50, with specific vaccinations ranging anywhere from \$5 to \$250 (but you'd be paying for any travel-related vaccinations at any doctor's office, anyway).

Travel clinic or no, don't scrimp at the planning stage. A recent study by Dr. Irving Salit and his colleagues at Toronto General Hospital of Canadian PHAs who travelled internationally revealed some disturbing findings. Of the 290 folks interviewed, 18 percent got so sick during their trip that they needed medical care—a stat higher than their HIV-negative peers'. The top troubles? Pneumonia and other lung-related issues; malaria and other parasitic problems. Notably, fewer than half of the PHAs visiting such mosquito-rich regions as Latin America, Africa and Southeast Asia packed the recom-

mended antimalarial meds. (Ask your doctor about possible interactions between anti-parasite pills and your HIV combo.)

Not surprisingly, only 13 percent of the 290 had visited a travel clinic before their trip, and when asked why not, most said they viewed such medical advice as unnecessary. But you can bet that in retrospect, those PHAs who came home with memories of the holiday from hell thought the cost of a travel-clinic visit would have been money well spent.

To make your packing that much more mindless, we've provided a checklist of must-haves (see sidebar, page 28)—so there's no excuse for forgetting your meds. For Shari Margolese, PHA writer, speaker and activist, it's the med she *can't* take that causes her biggest travel headache. Margolese, a frequent flier to AIDS conferences worldwide, has to leave home without her beloved medical marijuana: "I travel all the time, but I can't take my weed across borders. I don't even like travelling in Canada with it. It's a problem because it's the only thing that controls my nausea and vomiting. Alternatives like Dramamine make me so tired that I end up sleeping most of the time."

### DON'T MISS THE DOSE

Marijuana aside, adhering to HIV medication is tricky for many travellers. In Salit's study, while half of the PHAs on combo therapy reported doing just fine with their dosing schedule, 30 percent either had difficulty taking their pills or quit taking them entirely. Only a handful had checked with Doc about interrupting their treatment before doing so. The point is not to get permission, but to confirm (1) that a break is safe and (2) whether to stop all meds at once or to phase out—certain drugs stay in your body much longer than others, and so to minimize the risk of resistance, it's best to keep the level of the entire combo as consistent as possible.

Last year, Margolese got married in Jamaica. After the wedding, she mistakenly packed her HIV meds in her son's luggage, and when he left,

she was forced to go med-free for the rest of her island honeymoon. Suffice it to say, it was not all cool runnin'. "As the week progressed, I began to feel increasingly tired and viralish," she says. "When I got home, I went to my doctor, got tested and found out I had developed resistance to Kaletra. In a single week! And despite the fact that I went off all my meds at the same time!"

Treatment interruption is risky business. That's why it's so disturbing that many of Salit's pill-stoppers went off their regimen either because they were afraid to cross borders with their meds or because they ran out of doses during their trip—poor excuses for rational treatment decision-making. If you want a vacation with Club Med-Free, plan it with your HIV specialist.

If you're crossing time zones, you need to address any potential dosing disruption before you get to your penthouse suite at the five-star. "Travel is very complicated for med adherence," says Louise Binder, chair of the Canadian Treatment Action Council. "I stay on my drug regimen, with the same times from home, and if that means I have to set an alarm in the middle of the night, I do that. I don't add an hour

for every time zone or anything like that." Binder's former three-times-a-day combo could have wreaked havoc with her schedule, but it taught her to keep plenty of food bars and bottles of water handy. Now that she's on a twice-a-day dose, med matters are easier, but with a new twist. "It's a protease-boosting regimen, so I have to refrigerate the ritonavir," she says. "That has been the peskiest thing. When I don't have a fridge in my room, I have to improvise with an ice bucket. And for the plane, I buy those ice packs and a little cooler and I carry the ritonavir with me."

Others may take a different approach. "I do not want to wake up in the middle of the night to take my meds," says one PHA emphatically. "If I'm going away for more than a few days, I like to take my meds on the local schedule." He adjusts to the new time during his first two travel doses, adding or subtracting half the time change to the first, half to the second. But whatever changes you're tempted to make, don't make any adjustment that veers off your usual meds routine without first getting the go-ahead from your doctor. Why risk bringing a mutation home as a souvenir?



### WATER AND FOOD 411

Eating adventurously is a favorite feature of foreign travel. "My biggest joy when I vacation is the food," Arvin Thomas says. "That's why I love travelling in Southeast Asia—because you can get almost any kind of food you want—Chinese, Thai, Indian, western food, Starbucks—24/7 and for a third the price." Not surprisingly, traveller's diarrhea is the most common health affliction of the intrepid traveller anywhere hygiene and sanitation leave something to be desired. Most cases are caused by bacteria in water or in raw or undercooked food, although even well-prepared food may contain evil toxins left by the bacteria killed by cooking.

You can't just guzzle from the tap and gobble street-vendor snacks like a native without expecting some gastrointestinal aftermath. A little vigilance is on order. You know the

safe-food-and-water drill: drink only bottled water with sealed caps in restaurants and on the road; be sure to stock the stuff in your room for downing meds and any middle-of-the-night refreshment. Wash and peel all fruit, and avoid cut fruit from local street vendors. Nix the water fountains and ice in restaurants. Speaking of which, the busier the restaurant, the better—but don't order from the raw-food section of the menu.

The good news about traveller's diarrhea is that bouts lasting a day or three won't ruin your entire vacation. But intense or prolonged diarrhea may indicate a serious problem that needs urgent medical attention. Some PHAs have found that mild diarrhea can be managed with meds of the Pepto-Bismol persuasion. But beware: Some anti-diarrhea drugs, particularly Imodium and Lomotil, increase the amount of time the offending germs



stay in the gut. Broad-spectrum antibiotics can beat back many bugs that cause diarrhea (don't you just love that word!). If you think your trip poses a high diarrhea danger, ask your doctor about packing antibiotics—just in case. “Because believe me,” Binder says, “you can get any bug anywhere, and you can't always find a doctor.”

Margolese swears that it's flying itself that poses the biggest risk. “I almost always end up with a cold after airplane travel,” she says. “Now with SARS and avian flu, I am much more conscious of picking up viruses on planes. I don't go to the extent of wearing a mask, but I'm very conscious of what I touch. And if the person next to me is coughing or sneezing, I look for an open seat elsewhere.”

By the way, if you need medical care while travelling, at best your provincial health plan will cover only limited emergency services and hospitalization. Plus, many foreign health facilities demand cash upfront—regardless of whether or not you have provincial coverage. If you want greater protection, buy single-trip health insurance, which will run you anywhere from, say, \$30 for emergency-only coverage to \$130 for all-inclusive coverage for a two-week vacation. However, many policies may exclude HIV and any other “pre-existing conditions,” covering only for ailments and accidents that afflict you on your great adventure. (For more info, check out the Canadian Life and Health Insurance Association at [www.clhia.ca](http://www.clhia.ca).)

Margolese is a true travel-insurance adherent, and like many tourists, she learned the hard way that an ounce of

prevention (and the premium) is worth a pound. . . . Years ago, on a trip to Mexico, an ectopic pregnancy sent her into emergency surgery, and without insurance she had to fork over \$5,000 in advance. Since then, she has put her travel insurance to good use. For example, on a second trip to Mexico, she was hit with a barrage of Crixivan-related kidney stones, and a local MD gave her two scripts—one for a pharmaceutical painkiller, the other for a special tea that she got from a *herbalita*, and that she still uses.

## A ROUGH CROSSING

As Salit's study reveals, traversing borders with HIV meds is a fraught issue for people with HIV, and no border illustrates this more acutely than the one between Canada and its southern neighbour. The U.S. bans the travel and immigration of all PHAs into the country. The Yanks welcome all guests with an arrival form that includes a question asking if you have a communicable disease (not HIV specifically); for short-term visitors, answering yes is unlikely to lead to denied entry, but there are no guarantees.

Many PHAs simply refuse to put a check in the little box on the form, although that can cause sweaty palms and anxious thoughts in the (inevitably long) line at customs. Binder has entered the U.S. many times without outing herself on the arrival form and never had any trouble. “I am a straight white woman and don't fit the stereotypical PHA image. If I were a gay man or a person of colour, things might be very different,” she says. “Still, I do not

## TRAVELLER'S CHECKLIST

Universal plastic and ATMs may have made traveller's cheques obsolete, but don't leave home without the following:

To carry on:

- 1 passport (valid for more than six months, with visas if necessary)
- 2 HIV meds
- 3 vaccinations against infectious diseases, including certificates thereof for entry (if required)

To pack:

- 4 aspirin, ibuprofen or a Tylenol-type painkiller
- 5 anti-diarrheals like good old Pepto-Bismol
- 6 antibiotics for traveller's diarrhea; rehydration salts for enduring it
- 7 antifungal creams
- 8 Benadryl-type antihistamines
- 9 sunscreen
- 10 iodine
- 11 Band-Aids
- 12 insect repellent and a mosquito net (if recommended)
- 13 a thermometer
- 14 a Swiss Army knife (for all those Indiana Jones-style improvisations)
- 15 condoms and lube
- 16 a camera . . . to bring it all back home with you!

advertise my HIV status. When asked the purpose of my trip, I will not say 'AIDS conference,' but 'health conference.'" A fellow leading Canadian AIDS activist, who requests anonymity because of these draconian travel restrictions, takes a similar tack on his frequent travels to the U.S. "I dress for success, like the average gay white male, no bling or hair products to make me conspicuous," he says. "I keep my answers very short. But the whole time, my heart is in my throat. I actually practice meditation while waiting in line."

Still, there's always the chance that you will be searched, and for Margolese, one of the most annoying issues is where to put her meds. "The risk is if I put them in my luggage, they may not arrive," she says. "But if I put it in my carry-on, I may be caught." Margolese errs on the side of health safety by always carrying them with her on the plane. On long trips, she asks her pharmacist to put the meds in generic bottles with a drug label omitting those two adorable acronyms *HIV* and *AIDS*.

Now that we've filled your head with all manner of fright and frustration, you may feel that, like Dorothy, for a PHA there's no place like home. But, hey, the international tourism industry is predicting a banner summer in foreign travel, marking a sustained rebound from the dog days triggered by 9/11 and the SARS outbreak. Doing its bit, Toronto will play host to the XVI International AIDS Conference—AIDS 2006—and what is likely to be the largest-ever get-together of the HIV community in the Americas. You don't want to miss out on all that, do you?

Or on this: "I have always had the travel bug," says our anonymous activist. "But when I became quite sick in the early '90s—no CD4 cells—I was afraid of food-borne illness. Suddenly seeing my horizons shrink was one of the worst parts of having HIV back then." These days he's planning a three-week trip to India that he once thought was forever closed to him and his depleted immune system. But now with an undetectable viral load, a CD4

count of 350 and a careful approach to what he puts in his body, he and his partner can voyage out. "We'll alternate between moving and resting, a few days in a city and then a few driving. I can't describe how it feels planning for all the places I had always wanted to visit but had given up hope of ever seeing," he says, a little teary-eyed. "And now I can go."

Now hurry up or you'll miss the plane. And don't forget your passport.



## CANADA WELCOMES PHAS

Some 20,000 scientists, advocates, doctors, officials and, of course, people with HIV/AIDS (PHAs) are descending on the Metro Toronto Convention Centre from August 13 to 18 for the XVI International AIDS Conference. Dubbed AIDS 2006, this biennial global summit is the single-most important event on the HIV community's social calendar, fixing the mainstream media's attention on a preventable pandemic that has infected more than 40 million people worldwide—and killed 25 million others. This year's theme is "Time to Deliver"—as in deliver on our promises of prevention and, in particular, treatment to the HIV-ravaged developing world.

AIDS 2006 is notably the third International AIDS Conference to be held in Canada—a frequency due in part to the conference's boycott of the U.S. and its discriminatory visa and immigration policies, namely the restriction on PHAs. And if the past suggests a pattern, Toronto '06 will make history, as did Montreal '89 when activists and PHAs seized the stage, and Vancouver '96 when the protease revolution was launched. In fact, one permanent change has already taken place: thanks to a collaborative effort by the conference organizers and the Canadian government, the Canadian visa application was revised last May and no longer demands that visitors disclose their HIV status.

"We asked the immigration department for a review of the visa application requiring that all people with any communicable and chronic health condition reveal their medical diagnosis on the form. They agreed that the question was much broader than it needed to be to meet Canadian law," says Joan Anderson, a senior advisor to the Toronto Local Host Committee. The result? The department made a permanent change to the visa application—not just for PHAs or for the conference. The temporary resident visa application now asks specifically only about tuberculosis and any expectation that treatment will be required for a physical or mental health condition that might place demands on Canada's healthcare system.

The principle that the conference organizers were backing, Anderson says, was that of freedom of travel for PHAs. But she is quick to point out that the revision doesn't affect immigrants applying for permanent residence, who still must be tested for HIV. "And for visitors, the immigration department still has concern that some people from developing countries coming to the conference may try to stay here once they arrive," Anderson says. "We are still concerned about problems entering the country, but not specifically for being HIV positive."

Meanwhile, the U.S. has granted the conference a "blanket waiver," to allow PHAs to travel to AIDS 2006 via the U.S., despite that country's travel ban against PHAs. Still, that army of empowered PHAs angry at the world's sole superpower not only for its ban on HIV travellers but for exporting anti-condom prevention, anti-generic treatment and any number of other policies may seize the conference's media spotlight with some loud and colourful demonstrations. Stay tuned.

For more info on AIDS 2006, check out [www.aids2006.org](http://www.aids2006.org)

Or your meds. Or... Oh, and have the time of your life! +

Walter Armstrong is a freelance writer and editor in New York City who covers HIV and medical issues.

For more info, see the presentation "Making Sure Your HIV Patients are Ready for Travel" by Dr. Gordon Arbess, available at [www.ohtn.on.ca/SMHHIVRounds.htm](http://www.ohtn.on.ca/SMHHIVRounds.htm) (click on "view" to find the presentation).



# Putting Hope on the Map

**In an art book of striking self-portraits called body maps, 12 South African women living with HIV reveal how the art form helped them regain their courage and dreams**

BY DAVID MCLAY

“WHEN I LOOK AT THIS BODY MAP I feel like my life is not finished,” says Babalwa Cekiso, a woman with HIV who shares her story in *Long Life ... Positive HIV Stories*. The 8×11-inch book recounts the tales of 12 South African people with HIV/AIDS (PHAs), told through reproductions of vibrant, full-size self portraits called body maps. “I feel good actually, explaining how I feel inside, certain feelings and memories that I don’t normally talk about.” In Cekiso’s body map, news clippings of South Africans’ struggle to obtain antiretrovirals surround her body’s outline. But inside, a deep red heart holds her fear of dying before her children are grown.

Jonathan Morgan, a clinical psychologist formerly at the University of Cape Town, and researcher Kylie Thomas were the driving force behind *Long Life*. After learning of body maps from Cape Town artist Jane Solomon, Morgan and Thomas understood that the maps could also empower PHAs to take control of their health. Under Solomon’s direction, Cekiso and other PHAs from the townships outside Cape Town completed the process of body mapping, the results of which went on to fill the pages of *Long Life*.

The women started by outlining their bodies on large sheets of paper. Then they added images and words to depict their lives and to express their thoughts and feelings about living with HIV. Although facing bad memories and fears often hurt, the result was therapeutic and beautiful. “This picture and this project tells the story of my life: the burns and the bites and the TB, but not only bad. Except for those marks, my body is jumping and shows I’m alright and I love people,” says Bulelwa Nokwe, describing her leaping blue silhouette with a strong tree growing inside (shown here).

As access to antiretrovirals has improved in South Africa, body maps have been adapted to meet the challenges of long-term therapy. Using a tracing book, which contains a small body map to be drawn on regularly, PHAs can draw changes in their health, such as a skin infection that grows or shrinks. They can refer to the drawings when visiting their doctor. In cases where the PHA and doctor speak different languages, tracing books could be life-savers.

Body maps know no boundaries and have travelled to North America. Here in Canada, Allison Cope at HIV/AIDS Regional Services in Kingston, Ontario, has led several local body mapping workshops. All PHAs have “a unique story to tell,” she says, “and body mapping facilitates this storytelling through art. Body mapping helps PHAs make visible that which ordinarily is invisible to others, and sometimes, invisible to themselves.”

CATIE and REPSSI (Regional Psychosocial Support Initiative for Children Affected by AIDS, poverty and conflict), where Jonathan Morgan now works, plan to collaborate—to connect CATIE’s vast HIV health and treatment resources to the power of body maps and tracing books.

Visitors to AIDS 2006 in Toronto can see slide presentations of the *Long Life* body maps by visiting the REPSSI booth in the exhibit hall. REPSSI promotes and develops resources and strategies to help children affected by HIV/AIDS, poverty and conflict in 13 countries in east and southern Africa. The body maps are also online at [www.bodymaps.co.za](http://www.bodymaps.co.za). +

# HIV Positive? Supporting someone who is?

## CATIE is here for you.

### In print, online and over the phone

The Canadian AIDS Treatment Information Exchange is Canada's national provider of treatment information in English and French to people living with HIV/AIDS, their care providers and community organizations.

CATIE is committed to improving the health and quality of life of all people living with HIV/AIDS in Canada, by providing accessible, accurate, unbiased and timely treatment information. Here's what we offer:

#### ■ FREE ONE-ON-ONE PHONE SESSIONS

**1.800.263.1638**

Speak anonymously with one of our trained Treatment Information Educators about your treatment questions. Find out about local resources anywhere in Canada.

#### ■ FREE E-MAIL INFORMATION

**questions@catie.ca**

Ask any HIV/AIDS treatment questions of our knowledgeable staff when it is convenient for you and we'll respond with the information, resources and links you need.

#### ■ CATIE WEB RESOURCES

**www.catie.ca**

Read or download treatment publications, current news and CATIE's many other resources. Plus, check out our links to other useful Internet sites.

## CATIE Publications

To order any of our materials (in English or French) or to become a subscriber of *The Positive Side*, please contact us at **1.800.263.1638** or download an order form from our Web site at **www.catie.ca**.

**A Practical Guide to HAART:** Up-to-date, reliable information on the various aspects of treatment, including a description of the virus and the immune system, the stages of HIV disease, the tests used to assess health status, and anti-HIV medications. A very useful guide.

**A Practical Guide to HIV Drug Side Effects:** What you need to know about various side effects related to treatment, from appetite loss to sexual difficulties, and tips for countering or preventing them.

**A Practical Guide to Complementary Therapies for People Living with HIV/AIDS:** An overview of many alternative therapies used by people living with HIV/AIDS, including massage, mind-body medicine and complementary medical systems such as Ayurveda and homeopathy. Includes lists of resources where you can find more information about various therapies throughout Canada.

**A Practical Guide to Herbal Therapies for People Living with HIV/AIDS:** An essential reference tool for people living with HIV/AIDS seeking information on understanding, using and choosing herbal medicines.

**Fact Sheets/ Supplement Sheets:** Concise, credible overviews of a wide variety of specific conditions, symptoms, medications, side effects, complementary therapies, vitamins and other treatment issues of interest to people living with HIV/AIDS.

**Managing Your Health:** A must-read guide for people living with HIV/AIDS, which addresses social, legal, health-related and practical issues comprehensively and from a national perspective. An outstanding primer.

**pre\*fix:** A harm reduction booklet for HIV-positive drug users.

### BECOME A CATIE MEMBER ...IT'S FREE!

More and more people and organizations are joining CATIE. Sign up now to receive updates on treatment information by e-mail or regular mail.

Visit **www.catie.ca** or phone **1.800.263.1638** to join.

**PERMISSION TO REPRODUCE:** This document is copyrighted. It may be reprinted and distributed in its entirety for non-commercial purposes without prior permission, but permission must be obtained to edit its content. The following credit must appear on any reprint: "This information was provided by the Canadian AIDS Treatment Information Exchange (CATIE). For more information, contact CATIE at 1.800.263.1638."

**ACKNOWLEDGEMENTS:** CATIE would like to thank the many people living with HIV/AIDS who volunteered their stories, making this truly a publication by and for Canadians living with HIV/AIDS. We would also like to thank our medical and alternative therapy advisors, researchers and contributors for their thoughtful comments and assistance.

**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.

The Canadian AIDS Treatment Information Exchange (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.

We do not guarantee the accuracy or completeness

of any information accessed through or published or provided by CATIE. Users relying on this information do so entirely at their own risk. Neither CATIE nor the Public Health Agency of Canada nor any of their employees, directors, officers or volunteers may be held liable for damages of any kind that may result from the use or misuse of any such information. The views expressed herein or in any article or publication accessed or published or provided by CATIE are solely those of the authors and do not reflect the policies or opinions of CATIE or the views of the Public Health Agency of Canada.

**Production of this magazine has been made possible through a financial contribution from the Public Health Agency of Canada.**

Disponible en français aussi.

Unbiased  
anonymous  
up-to-date  
practical  
**FREE**

In print, online, over the phone.

If you're looking for HIV/AIDS treatment information,  
then you should get to know us. [www.catie.ca](http://www.catie.ca) 1.800.263.1638



Canadian AIDS Treatment  
Information Exchange  
Réseau canadien  
d'info-traitements sida