

inside  
▶▶▶

**05 ▶ COMMUNITY REPRESENTATION AND ENGAGEMENT**

The BC government finally agrees to provide safe infant formula to all HIV-positive mothers.

**06 ▶ EMERGENCY PREPAREDNESS**

A group of disability organizations is researching emergency plans to determine how they can be improved for people with disabilities.

**08 ▶ THE TANZANIA DIARIES**

In the first of four installments, a BCPWA staffer recounts her two-month stint helping fight the HIV/AIDS battle in Africa.

**12 ▶ WORKPLACE ISSUES**

Being HIV-positive and holding down a full-time job can be challenging—as well as rewarding for all involved.

**14 ▶ PREVENTION**

A holistic perspective on positive prevention.

**16 ▶ GOVERNMENT FUNDING**

What happened to that extra public health funding the BC government promised?

**40 ▶ LAST BLAST**

A story with a sweet beginning and an even sweeter ending.

features  
▶

**09 ▶ HIV ACTIVISM, THEN AND NOW**

HIV activism has changed dramatically since the early days, and now it's more about advocacy work. Louise Binder and Ron Rosenes provide an overview.

**20 ▶ COMPLEMENTARY AND ALTERNATIVE MEDICINE**

- ▶ A beginner's guide to alternative therapies.
- ▶ How to choose a complementary therapy and find the right practitioner.

**17 ▶ CO-INFECTION**

Lung cancer is showing up at increasing rates among PWAs.

**25 ▶ COMPLEMENTARY THERAPIES**

Nourishing foods and herbs that can soothe your nervous system and help you sleep.

**27 ▶ DRUG ACCESS**

- ▶ A survey of the different antiretroviral drug plans for each provincial and territorial health ministry.
- ▶ Four years later, the federal government still isn't providing catastrophic drug coverage.

**30 ▶ STRAIGHT FROM THE SOURCE**

What is anal dysplasia?

**31 ▶ LET'S GET CLINICAL**

The latest trials at the Canadian HIV Trials Network.

**32 ▶ OPPORTUNISTIC INFECTIONS**

A report from the 14th Conference on Retroviruses and Opportunistic Infections.

**34 ▶ FOOD SECURITY**

Research projects are tackling the interconnected relationship between HIV/AIDS and food security.

treatment  
information  
▶▶▶

*living* is published by the British Columbia Persons With AIDS Society. This publication may report on experimental and alternative therapies, but the Society does not recommend any particular therapy. Opinions expressed are those of the individual authors and not necessarily those of the Society.



**British Columbia  
Persons With AIDS Society**

The British Columbia Persons With AIDS Society seeks to empower persons living with HIV disease and AIDS through mutual support and collective action. The Society has over 4400 HIV+ members.

**living ⊕ editorial board**

Wayne Campbell – chair,  
Kenn Blais, Michael Connidis,  
Sam Friedman, Rob Gair, Neil Self,  
Derek Thaczuk, Glyn Townson

**Managing editor** Jeff Rotin

**Design / production** Britt Permien

**Copyediting** Alexandra Wilson

**Contributing writers**

Denise Becker, Louise Binder,  
Dave Boyack, Moffatt Clarke,  
Dr. Jennifer Hillier, Sean Hosein,  
Audrey Le, Dr. Natasha Press,  
Ron Rosenes, Julie Schneiderman,  
Carley Taylor, Katolen Yardley

**Photography** Britt Permien

**Cover Photograph** John Kozachenko

**Acting director of communications & education**  
Melissa Davis

**Director of treatment information & advocacy**  
Jane Talbot

**Coordinator of treatment information**  
Zoran Stjepanovic

**Director of positive prevention**  
Elgin Lim

**Subscriptions / distribution**  
Ryan Kyle, Joe LeBlanc

Funding for *living* ⊕ is provided by the BC Gaming Policy & Enforcement Branch and by subscription and donations

**living** ⊕ magazine

1107 Seymour St., 2nd Floor  
Vancouver BC V6B 5S8

TEL 604.893.2206 FAX 604.893.2251

EMAIL [living@bcpwa.org](mailto:living@bcpwa.org)

BCPWA ONLINE [www.bcpwa.org](http://www.bcpwa.org)

© 2007 *living* ⊕

**Permission to reproduce:**

All *living* ⊕ articles are copyrighted. Non-commercial reproduction is welcomed. For permission to reprint articles, either in part or in whole, please email [living@bcpwa.org](mailto:living@bcpwa.org).



# think ⊕

opinion & editorial . . .

## Standing up for what's right

by **Paul Lewand**

**I**t was a shocker.

On December 3, 2003, Abbott Laboratories announced it was boosting the US price of Norvir (ritonavir) by 400 percent (it also boosted the Canadian price by the maximum allowable 5 percent).

AIDS activists in the US smelled a rat. They noted the quadrupled US price for ritonavir could cripple Bristol-Myers Squibb's new protease inhibitor, Reyataz (atazanavir), the chief competitor to Abbott's Kaletra (lopinavir/ritonavir) combination, because Reyataz relied on Norvir as a booster. Abbott didn't increase the price it paid for using Norvir as a booster in its own Kaletra product.

So, by early 2004, the American Treatment Activists Coalition and the Organization of HIV Healthcare Providers called for a boycott of Abbott.

The BCPWA Society responded. After extensive discussion and debate, the BCPWA Board of Directors endorsed the boycott on February 18, 2004—and, to make it real, decided to forego any sponsorship or grant money from Abbott until the boycott ended. In 2004, that cost BCPWA \$35,000.

(It actually cost more. That fall, the Positive Women's Network (PWN) AIDS Walk team, as part of their sponsorship agreement with Abbott, wanted to bring helium-filled Abbott balloons to the Walk. BCPWA said no. Abbott then pulled their \$5,000 AIDS Walk sponsorship from PWN. Not wanting anyone else to suffer unwillingly because of its own boycott decisions, BCPWA gave PWN \$5,000 out of its own AIDS Walk receipts.)

The Canadian Treatment Action Council and AIDS Vancouver also endorsed the boycott. However, when

BCPWA took the boycott to that year's meeting of the Canadian AIDS Society, the majority of AIDS organizations at the meeting rejected the boycott call.

Eventually, the boycott worked. Abbott announced in November 2004 that it would roll back the price increase for Medicaid and Medicare recipients, for all state-run AIDS Drug Assistance Programs, and for anyone not covered by these programs but requiring the drug and unable to pay the high price. The boycott was called off, and the BCPWA Board of Directors ended its part in the boycott on January 5, 2005.

But there was always the lingering suspicion among some—including those at the CAS meeting—that the whole thing had been a ridiculous overreaction to a legitimate corporate decision, a bit of shrill grandstanding rather than a principled response to an intolerable provocation.

So it is that an article by John Carreyrou in the January 3, 2007 edition of the *Wall Street Journal*, "Inside Abbott's tactics to protect AIDS drugs," was so welcome. It laid out the whole story in well-documented detail. And it showed, in retrospect, that the AIDS activists had it right all along.

The lesson? As ever: activism works, and it's essential to stand up for what's right.

To read John Carreyrou's article, visit [www.aegis.com/news/wsj/2007/WJ070101.html](http://www.aegis.com/news/wsj/2007/WJ070101.html). ⊕



**Paul Lewand**  
is the chair of BCPWA.



## Vancouver hospital move draws fire

The battle over moving St. Paul's Hospital from downtown Vancouver to the False Creek Flats near the train station is heating up.

The coalition that is trying to keep the hospital at its current location on Burrard Street says the decision to move has already been made, despite promises to hold community consultations. It claims that hospital staff were told by Providence Health Care that the plans to move have been finalized.

But Neil McConnell of Providence Health Care said the plans to move have not been finalized. McConnell says the public consultations will take place in the spring and summer.

The current plan calls for part of the current St. Paul's site to be redeveloped for commercial and residential use. Some services including urgent, primary, and secondary care would also continue to be offered at the downtown location.

*Source: [www.cbc.ca](http://www.cbc.ca)*

## Legal Network releases plan to fix drug access

The Canadian HIV/AIDS Legal Network has called on Ottawa to take concrete steps to fix Canada's Access to Medicines Regime and get affordable drugs to people in developing countries who desperately need them.

Originally passed in May 2004 as the Jean Chrétien Pledge to Africa, the Regime was intended to allow generic drug companies in Canada to produce and export much-needed lower-cost versions of brand-name drugs to developing countries. To date, however, not a single pill has left Canada.

The cornerstone of the 13 recommendations in the Legal Network's brief is a proposal to authorize any pharmaceutical firm to produce generic versions of any drug patented in Canada for export to any eligible developing country listed in the law.

The full text of the brief, entitled "Getting the Regime Right: Compulsory Licensing of Pharmaceuticals for Export," is available at [www.AIDSlaw.ca](http://www.AIDSlaw.ca).

## Resistance emerges in first months of treatment

A small, intensive German study has found that the emergence of drug resistance is already detectable in the first months of HIV treatment even if viral load is falling, and is especially pronounced in people who experience slower viral load declines.

As selection of drug-resistant virus correlated significantly with the length of time until viral load became undetectable, the researchers recommend therapy intensification during the early treatment phase to be considered as a strategy to control replication.

In this study, published in the March 30 edition of *AIDS*, 15 mainly chronically-infected patients were followed just prior to and during the early months of anti-retroviral therapy.

*Source: [aidsmap.com](http://aidsmap.com)*

## China holds first gay HIV clinic

Free HIV/AIDS tests attracted more than 200 gay men to a Beijing hospital in April in what is being called a first for China's capital city. The clinic was organized by Chaoyang—the Chinese AIDS Volunteer Group.

Most of the men who turned up were in their thirties, although there were

some older men and college students. Each was given a number and a password to the Chaoyang website so they could easily retrieve their test results. In addition, safe-sex booklets were distributed and psychologists were on hand for anyone needing help.

That the clinic was held at all is seen as part of a new awakening to the reality of men-having-sex-with men in China. The Joint UN Program on HIV/AIDS has warned that up to 10 million people in China could be infected by 2010 without more aggressive prevention measures.

*Source: [www.365Gay.com](http://www.365Gay.com)*

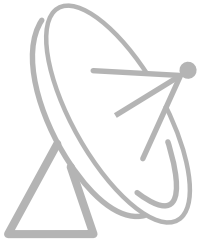
## Researchers find protein that blocks HIV

German scientists have discovered a protein in human blood that can block HIV entry into immune system cells, potentially offering a new type of HIV fusion inhibitor that is non-toxic even at high concentrations. The findings were published in the April 20, 2007 issue of the journal *Cell*.

The protein, named virus inhibitor peptide, or VIRIP, is a fragment of a naturally occurring serine protease inhibitor whose main function is to protect the lungs against damage from neutrophils.

"The findings reveal a new target for inhibiting HIV that remains fully active against viral strains that are resistant to other drugs," said study author Frank Kirchhoff of the University of Ulm in Germany.

It was identified after the researchers sifted through a comprehensive library of small peptides that had been filtered from the blood of patients with chronic kidney failure during dialysis, in search of those with anti-HIV activity.



# REALITYBITES

News from home & around the world



VIRIP is being developed by IPF Pharmaceuticals GmbH, a German company.

Source: [aidsmap.com](http://aidsmap.com)

## Australian PM backs down over ban

Australian Prime Minister John Howard has been forced to abandon plans to refuse entry to HIV-positive migrants and refugees.

A government spokesman has said that the commitment made by Prime Minister Howard will be “quietly dishonoured,” after he came under fire from HIV/AIDS groups.

The HIV/AIDS Legal Centre said that HIV-positive patients were already barred from entry into Australia in most cases, as was anyone else with a chronic medical condition who could be a drain on the system.

The centre slammed Mr. Howard for comparing HIV with tuberculosis, an airborne disease that is more easily passed on. A spokesman for the centre added that Mr. Howard’s comments could be in breach of Australia’s anti-discrimination legislation. The Prime Minister was also slammed by state AIDS bodies and HIV medical specialists.

The Prime Minister is an opponent of gay marriage and other rights for gay couples.

Source: [www.pinknews.co.uk](http://www.pinknews.co.uk)

## NYC to promote circumcision to gay men

New York City’s Health Department is reportedly preparing a campaign promoting circumcision as a means of reducing HIV/AIDS among high-risk groups.

The *New York Times* reported that the Department of Health and Mental Hygiene campaign is aimed at gay men,

Hispanics, and African Americans. The department began working on the campaign after the World Health Organization (WHO) last month cited “compelling” evidence that circumcision can reduce their chances of contracting HIV by up to 60 percent.

Some AIDS activists are urging caution in implementing the program. Peter Staley, a co-founder of AIDSmeds.com, ACT-UP New York, and the Treatment Action Group, noted the WHO study bore little relation to New York’s risk groups. And there are questions about how effective circumcision would be in preventing HIV/AIDS among men who have sex with men.

More than 100,000 of New York’s 8.2 million residents have HIV/AIDS.

Source: [www.365gay.com](http://www.365gay.com)

## Chinese company to develop CCR5 inhibitor

The Shanghai-based Target Pharmaceutical company has signed the first stage of an international development and marketing agreement for an investigational CCR5 inhibitor, nifeviroc, with the Australian drug company Avexa.

CCR5 is a receptor on the surface of cells that HIV can use in order to gain entry. Blockade of the CCR5 receptor is an important target for drug discovery, but so far, only one company, Pfizer, has been able to bring a CCR5 inhibitor project to fruition.

Pfizer’s product, maraviroc, is now in phase III studies and is expected to receive a license for use in treatment-experienced patients before the end of 2007 in Europe and the US.

Nifeviroc was developed by the Shanghai Life Sciences Institute and the

Shanghai Institute of Organic Sciences. Phase I human studies are expected to begin next year. Avexa is already testing a nucleoside analogue called apricitabine in phase IIb studies and has an HIV integrase inhibitor discovery program.

Source: [aidsmap.com](http://aidsmap.com)

## Green tea has anti-HIV effect in test tube

An ingredient in green tea may reduce HIV binding to human CD4 cells by approximately 40 percent within an hour of drinking two to three cups of green tea, according to a test tube study conducted at the University of Sheffield, England, published in the *Journal of Allergy and Clinical Immunology*.

Further research is needed to show whether drinking green tea protects against HIV infection or disease progression.

Recent research has shown that green tea contains flavonoids with anti-bacterial, anti-tumour, and anti-viral effects in the test tube. Several studies have now demonstrated that derivatives of a flavonoid in green tea can reduce HIV replication in the test tube, and that epigallocatechin gallate (EGCG), the main flavonoid in green tea, can occupy the CD4 receptor on CD4 lymphocytes and prevent HIV’s gp120 protein from binding to the receptor.

This latest study shows that EGCG can prevent HIV from binding to the CD4 receptor at levels that are “physiologically relevant.”

Source: [aidsmap.com](http://aidsmap.com) ☉

# FIGHTING WORDS



## A winning formula

**BC government finally agrees to provide safe infant formula to all HIV-positive mothers** *by Jane Talbot*

It's been a long time coming, but there's been a significant development in the struggle to secure infant formula to all HIV-positive mothers in British Columbia. After over one year of advocacy efforts, numerous meetings, one rejected proposal and an urgent letter to BC Health Minister George Abbott requesting the government's support on this initiative, the Provincial Health Service Authority (PHSA) announced on April 11, 2007 that it would provide full funding for the 2007-2008 fiscal year. Finally, all HIV-positive mothers in BC will immediately be eligible to receive infant formula at no cost.

In May 2005, BCPWA's Advocacy Program received a request from Oak Tree Clinic in Vancouver to research what could be done to ensure all HIV-positive mothers, regardless of income level, could be eligible to receive infant formula for the first 12 months of their child's life. Currently only mothers who receive assistance from the Ministry of Employment and Income Assistance (MEIA) are eligible to receive formula. It seemed a logical and straightforward request: we know that HIV can be transmitted from mother to child through breastfeeding and we know the human heartbreak and subsequently high and prolonged medical costs associated with treating HIV when infants become infected.

With this in mind, it seemed incomprehensible that the BC government would forfeit the opportunity to provide infant formula to HIV-positive new mothers. Yes, there would be an immediate cost of \$1,920 per child for 12 months of formula. But the total cost of action, when juxtaposed against the consequences of inaction, seemed quite modest. As well, if a child contracted HIV through breast milk, the cost for medication alone for each child would exceed \$14,000 per year *for the rest of his or her life*. From a cost-saving measure alone, it made perfect sense.

In partnership with Oak Tree Clinic, BCPWA conducted further research demonstrating that only 30 to 50 percent of HIV-positive mothers with newborns received formula through MEIA. The remaining HIV-positive mothers in BC faced the

choice of breastfeeding or purchasing infant formula on their own. Many women not receiving MEIA live on extremely limited incomes and lack the financial means to buy infant formula, and all were painfully aware that simply breastfeeding their hungry child put their child at grave risk.

**It seemed a logical and straightforward request: we know the human heartbreak and subsequently high and prolonged medical costs associated with treating HIV when infants become infected.**

In November 2005, BCPWA, Oak Tree Clinic, and Positive Women's Network submitted a joint proposal to the Provincial Health Services Authority to authorize funds for infant formula for all HIV-positive new mothers. After a full year of deliberation, the proposal was officially declined in December 2006.

Determined to resolve this matter, the agencies didn't give up. In February 2007, they submitted a revised proposal, followed by a letter and information package to Health Minister Abbott on April 5. One week later, PHSA announced full funding for the year.

While the announcement is indeed good news, in lieu of the protracted process to date, many people remain cautiously optimistic about the prospect of securing sustainable funding beyond 2007-2008. ☺

*Jane Talbot is BCPWA's director of treatment information and advocacy.*



# Be prepared Part II

***A group of disability organizations is researching emergency plans to determine how they can be improved for people with disabilities***

*by Glyn Townson*

Emergency preparedness in the event of a natural disaster continues to be a hot issue in the Lower Mainland. It's a particular concern for persons living with disabilities (see "Be prepared" in the July/August 2006 issue of *living* ☉), because there are still weaknesses and voids in our current emergency response systems. That's why a group of disability organizations is researching current emergency plans to determine how they might be corrected or improved for persons living with disabilities (PWDs).

People with disabilities make up approximately 15 percent of BC's population. To date, emergency planning hasn't addressed disability-specific needs in various emergency or disaster situations.

In Vancouver, the bulk of emergency services in the event of a major catastrophe (such as an earthquake), are tasked out to local volunteer groups with key staff from the government left to organize communications. If a person is displaced from his or her home, the designated shelters and collection centres are primarily housed in the city's community centres throughout the city. Other municipalities and areas have similar designated areas depending on the emergency scenario unfolding.

## **An ad hoc committee**

Last fall, the BC Coalition of People with Disabilities (BCCPD) put out a call for groups interested in participating in emergency planning specific for persons living with disabilities. Representatives from the health authorities, Provincial Emergency Program (PEP), and municipal emergency personnel have also been invited to the

conversation, as well as fire departments, St John's Ambulance, and the Red Cross. The purpose is to identify issues facing PWDs in emergency and disaster situations, with the goal of working together with emergency personnel to create plans tailored to the needs of PWDs. This critical work has no precedent in BC.

**The group determined that specific training for the needs of PWDs must be added to core training of emergency volunteers.**

The first meeting was in September 2006. The ad hoc committee of various disability groups—working in community living, mental health, cerebral palsy, sight impaired, deaf, and HIV/AIDS—met to discuss the needs of their specific groups and to identify what services currently exist and what areas might need to be strengthened. The group also discussed who actually provides emergency supports on the municipal level, and who provides those specific services.

Based on reports from major disasters in other areas—such as New Orleans in the aftermath of Katrina, and closer to home, the floods on the Chilliwack River late last year—the group determined that specific training for the needs of PWDs must be added to core training of emergency volunteers. That

way, in the event of a major disaster, people involved in dispatching emergency protocols will have some basic knowledge and sensitivity training around disability issues and what services are necessary. Currently, community volunteers perform most of the services in emergency situations, and while they have some basic training, they often have no background in dealing with PWDs.

A second meeting was held at Vancouver's E-Comm Centre, which provides emergency communications for southwest British Columbia; it includes a 9-1-1 call centre and radio and dispatch systems. At the meeting, the committee set up sub-committees: Accessibility, Awareness and Preparedness, Communications, Medical Supplies and Supports, Network Training, and Volunteer Registry.

### Getting life-saving mechanisms in place

The sub-committees presented reports and recommendations at a subsequent meeting. The group decided that their purpose was "to work collaboratively with various stakeholders in order to develop comprehensive emergency planning strategies and crucial life-saving mechanisms that will assist and support people with disabilities during emergencies and disasters throughout British Columbia."

Since no Canadian government agency has formal emergency preparedness plans available for persons with disabilities, the committee decided to use the American Red Cross's *Disaster Preparedness for People with Disabilities* handbook as the basis for a BC-centric model. The group recognized the need for materials in various mediums, such as Braille and American Sign Language. The group is working on the training deficits of current emergency preparedness volunteers and designated government officials. Currently, there are no official emergency protocols in place for PWDs.

The committee intends to apply for various streams of funding to accomplish this important and timely work. BCCPD will

research and apply for grants from the Vancouver Foundation, City of Vancouver, WorkSafeBC, BC Paraplegic Foundation, and the Public Health Agency of Canada.

### Create your own plan of action

If you're a person living with a disability, you need detailed plans for a variety of emergency scenarios. Create a support network consisting of several different people. Emergency and crisis situations can vary, so it's important to have a variety of people and contacts lined up; some people on your list may not be available or unable to reach you. That's why relying on only one or two people isn't a good idea.

Some points to consider in your emergency preparations:

- ▷ Have evacuation plans mapped out for your home, school, and/or work.
- ▷ Prepare three days of emergency food and water supplies.
- ▷ Make a list of your personal needs, such as medications, assistive devices, battery packs, and prepare for seven days' of supplies.

Until local BC resources are available, refer to the American Red Cross manual for Emergency Planning for persons with disabilities at [www.redcross.org/services/disaster/beprepared/disability.pdf](http://www.redcross.org/services/disaster/beprepared/disability.pdf). ☺



Glyn Townson is the vice-chair of BCPWA.

### Get involved

If you're interested in participating in the emergency preparedness committee for PWDs, contact Karen at the BCCPD at [bod@bccpd.bc.ca](mailto:bod@bccpd.bc.ca). Meetings take place monthly; sub-committees meet as required.



**BCPWA  
Advocacy  
gets  
results!**

The BCPWA Society's Advocacy Program continues to work hard to secure funds and benefits for our members. The income secured for December 2006 and January 2007 is:

- **\$0** in debt forgiveness.
- **\$11,000** in housing, health benefits, dental and long-term disability benefits.
- **\$51,520** monthly nutritional supplement benefits
- **\$2,250** in ongoing monthly nutritional supplement benefit for children

# The Tanzania diaries

**In the first of four installments, a BCPWA staffer recounts her two-month stint helping fight the HIV/AIDS battle in Africa**

by Jane Talbot

**T**wo months in Africa humbles an individual. I arrived in Arusha, Tanzania on November 11, 2006 all bright-eyed and bushy-tailed, and ready to contribute what I could to the ongoing HIV/AIDS battle in Sub-Saharan Africa. I didn't go in search of myself, I had no intentions of changing the world or anything else for that matter, and I didn't leave home with any preconceived or romanticized ideas of what AIDS work in Africa might be like. However, I did want to be challenged and to be of service.

I learned very quickly that for all Africa lacks, there is an immediate abundance of challenges and opportunities to be of service. Upon arrival, both my attitude and ability to stay positive were quickly put to test.

Lost luggage that did not arrive for three days? No problem—who needs a change of clothes when what I was wearing could be washed in a creek or a bucket of water? Stolen wallet on day two? A slightly bigger issue but nothing that couldn't be replaced. Warnings of vigilante law, public beatings, and possibly death for petty theft? Just words and nothing I felt I would witness. Going for a walk that very afternoon and witnessing such a beating? Yes, that was difficult, and even today, sitting at my computer, I close my eyes to block out the sights and sounds of the pick-up truck that arrived full of men carrying batons, and worse, the sounds the clubs made as they connected to a human body.

After just three days, I was wide-eyed as opposed to bright-eyed, and that bushy tail was already filthy, wilted, and fighting the urge to tuck itself away in self-protection. And I had yet to begin my AIDS work.

After a few short days of orientation, my work began. First up: providing instruction to 30 secondary education students. The teenagers, we would learn, were considered high risk and in need of basic HIV and prevention training. For the next five days,



Jane Talbot with students at a school in Arusha.

my fellow volunteers and I worked with the same group of teens, and in doing so, began to understand how complex and disastrous the AIDS pandemic in Africa is.

Feelings of frustration and helplessness were ever present. Without a concerted effort to remain positive, it was entirely too easy to slip into a negative and defeated mindset. We trained the students, but unless we brought pens and paper, they couldn't write anything down. We spoke to them about prevention and the importance of using a condom each and every time they engaged in high-risk activities, but with so many young girls experiencing sexual abuse, often by their teachers, we knew the likelihood of any of them insisting on a condom was extremely small. We talked about the importance of antiretrovirals even though most Tanzanians have little hope of accessing treatment. We discussed the importance of testing, but although services are available, most Tanzanians have no idea how to access these programs; even if they did know, many expressed a clear desire to avoid testing.

We tried to teach empowerment and communication skills, especially to the girls, but the culture made much of our instruction feel like a bunch of foreign

words. Still, we remained focused. At the end of the week, most students could tell us how HIV is transmitted, how it isn't, why condoms are necessary, where to get them, how to put them on, and how to discard them so they're never used again. As well, most students were able to identify high-risk behaviours from low-risk ones, and could distinguish between many facts and myths.

Through my first and second week, my greatest enjoyment proved to be living as a local among the locals. Each day I found immense pleasure completing tasks and activities that pose very few challenges to most of us in Canada. My friends and I would high-five each other for something as ridiculous as managing to get to the other side of a street as a group and in one piece. The moment that I successfully withdrew 100,000 Tanzanian shillings from a bank machine that gave promptings only in Swahili was liberating and empowering. By far, however, my greatest daily achievement was successfully navigating the public transportation system and arriving to work on time and with all of my personal belongings.

Two weeks into my trip, I was dirty, tired, and at times bewildered and overwhelmed. I wasn't homesick—there was no time for it—but I did long for answers. How did the situation ever get this bad? What can possibly be done to fix it? How can I really help? Where does all the money go that is sent to this country for this cause? I didn't have the answers then and I don't have them now. The only thing I knew for sure was that my time in Africa would teach me more than I, the educator, could ever teach my students. ☺

**Jane Talbot** is BCPWA's director of treatment information and advocacy.





# Tough work— but someone's gotta do it

***HIV activism has changed dramatically since the early days, and now it's more about advocacy work***

by Louise Binder and Ron Rosenes

***“Whoever you are, wherever you are, start there.” —Phil Wilson, Black AIDS Institute***

We must never forget the nightmare of the early 1980s when gay men in North America and Europe became ill and started to die in great numbers from what would turn out to be a sexually transmitted virus. Gay men were the canaries in the coalmine for AIDS, the greatest challenge facing mankind today—not just a medical problem, but also a social, political, economic, and deeply cultural one.

When we look at how far we've come in Canada and the developed world, at how much we've learned about this virus and its ability to take hold among the most vulnerable, it's worth remembering that the majority of women, children, youth, and men living with HIV today

are in exactly the same place they were 25 years ago: they have almost no access to prevention information and technologies, care, treatment, or support.

Change only occurred when the voices of activists were raised. Our early voices were loud and radical because we felt so powerless. Over time, we have gained power through our ability to advocate from within the existing power structure. Has the time for activism passed? Is it all up to the advocates today?

## **Activism then: fighting to be heard**

It's difficult to examine our accomplishments without a feeling of collective guilt about how far we have to go, both in our own society and abroad. Yet our accomplishments are many and we can be proud of them. Articles written by

long-term survivors and activists like Tim McCaskell chronicle the early years of gay men and their supporters fighting to be heard by government, struggling to bring change to the pharmaceutical industry, to the medical establishment, to health care.

Access to treatment and treatment information played an early and pivotal role as it does to this day. Organizations like AIDS ACTION NOW! that began in Toronto were joined over time by national organizations like the Canadian Treatment Advocates Council (CTAC; now the Canadian Treatment Action Council), which focuses on access to treatment, and the Canadian AIDS Treatment Information Exchange which provides treatment information to all Canadians through a variety of media.

*continued on next page*



March on Victoria 3/26/86

Kevin Brown, a founder of 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 US. BCPWA established its own Treatment Information Program, and today, *living* regularly combines information on treatment issues with news, political issues, and practical advice on the challenges of living with HIV. The Comité des personnes atteintes du VIH du Québec (CPAVIH) in Montreal and the AIDS Committee of Toronto hold regular forums on treatment issues that attract large numbers of women and men.

The GIPA principles (Greater Involvement of People with AIDS) that have come to guide the community-based model of care and support were first articulated in documents like the Denver Principles as early as 1983 in which PWAs demanded a central role in setting the agenda. Similarly, The Montreal Manifesto was released at the International AIDS Conference in 1989. It advocated for an international code of rights to promote the “active involvement of affected communities of people with HIV disease in decision-making that may affect them.”

### **Playing a role in policy making**

In the years following the advent of highly active antiretroviral therapy (HAART) and in some measure due to the success of triple therapy, the need for direct action diminished. It signaled the era of the advocate. Whereas activists worked from outside the system, advocates began increasingly to occupy seats at a variety of decision and policy-making tables with government and industry.

The work today takes place in a complex landscape of local, provincial, and national organizations that have increasingly become “professionalized”; in the eyes of some, they’re at risk of losing the connection to the lived experience of PWAs.

Fortunately, that isn’t always the case. “One group that has bucked this trend, however, still combining treatment information and in-your-face treatment activism, is Montreal’s LIPO-ACTION!” notes Canadian activist Tim McCaskell. “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.”

### **Advocacy now: more complex issues**

Certainly, things have changed since the early days of HIV. There has been a significant change to the social and political environment. Both in Canada and in the US, a wave of conservative thinking has affected policy-making by federal governments. In part, this is a reflection of the mood of the electorate since 9/11. These governments generally don’t respond to public actions in a positive way and they see activists who engage in public displays as “special interest groups.” While this tactic still has some value in raising public awareness—for example, International Women’s Day and World AIDS Day—public displays of criticism are not generally as successful as they used to be. In fact, they can backfire. Provinces are more likely to react in varying degrees to such public actions as press releases, conferences, and demonstrations, but only if used sparingly.

The issues have become increasingly complex, so advocates now need to be more knowledgeable in a number of areas. Treatment and prevention (including microbicides and vaccine) advocacy requires in-depth knowledge of complex science. People need background in the social and behavioural sciences when advocating for policy change in prevention and for the needs of vulnerable groups that are overrepresented in the epidemic. As well, advocates may need to understand health systems, health budgeting, and international pricing and regulations.

It isn’t easy to jump into advocacy work without a good grounding, mentorship, and strong community connections. Advocates usually gain trust and authority when they’re elected representatives of the communities on whose behalf they speak.

**“Diplomacy works.  
We need to strike a  
balance between radical  
activism and diplomacy.”—  
Dorothy Odhiambo, Kenyan  
branch of the Network of  
African People Living with  
HIV and AIDS.**

With different populations becoming infected, there’s a growing complexity to the work of advocacy to ensure that discrete social and cultural needs are taken into consideration. Often the role of the advocate is to coach and teach others how to advocate for themselves. Capacity building is therefore essential to the work.

### **Fewer new advocates to do the dirty work**

Fewer people living with HIV are prepared to dedicate the time and resources to doing advocacy. Many long-time advocates have stopped doing the work or in many cases, they’ve died. Those who remain are over-extended. Fewer new advocates are coming along. If people can stay in the workplace, they often choose to; if they’re unable to work, then stigma, discrimination, family requirements, and cultural or religious concerns may prevent them from becoming more involved. Many have more pressing concurrent issues than HIV, such as substance addictions, mental health problems, poverty, and/or homelessness. The complexity of systemic issues may be intimidating or simply not of interest.

Where activism viewed through the mists of time now appears romantic and exciting, advocacy today consists of the more sober and mundane work of analyzing government policies; attending meetings, consultations, and panels; presenting position papers; giving speeches; and working with media. The gains and progress are incremental and can be harder to measure.

**“When we weave our lives together like threads, we create a strong and comfortable fabric that is community, and the value of this is vast and immeasurable”—  
anonymous PWA**

Today, at the national level, advocacy is specialized among such non-governmental organizations as CTAC (access to treatment), the Canadian AIDS Society (prevention, medical marijuana), the Canadian Aboriginal AIDS Network (issues facing Aboriginal communities), and the Canadian Working Group on HIV and Rehabilitation (workplace and employment issues), to cite some examples.

The GIPA principle is becoming lost in HIV advocacy, as fewer people are available or being trained to understand the issues and do the work. This creates a great challenge to ensure that advocates continue to represent the will of communities and not the wishes of the advocate. Fewer resources to train and build capacity are being made available, particularly at the federal level where this is “out of fashion” with a government that seems to fear criticism no matter how constructive.

Over \$12 million was lost last year to the voluntary sector due to the cancellation of federal support. The cost of doing advocacy prevents many from participating. Without the backing of a well-funded organization, it can be very difficult to get to the table.

Let’s face it: the average Canadian no longer sees HIV in this country as a serious health threat, making it much harder to raise funds and generate public support despite the enormous ignorance, stigma, and discrimination that continue to hobble our ability to slow the advance of HIV. The media are less interested in publishing stories on HIV in Canada, except through the lens of “criminal behaviour.” The issues are harder to explain and interest has shifted, not surprisingly, to the devastation occurring in developing countries.

This may explain the renewed interest in activism since the International AIDS Conference in Toronto and the resurgence of groups like AIDS ACTION NOW! New people, emerging leaders with loud voices, are needed and welcome to support the work being done every day by advocates in our national and local organizations. The greatest challenge may be for the advocate to remain an activist and for the activist to learn the art of advocacy. Both skill sets are required, though not necessarily in the same individual at the same time.

### **Working in partnerships**

As the first consumer-driven health movement in the world, HIV activism and advocacy have had a strong influence on the work of other disease and disability groups. We are perceived as leaders when it comes to getting a seat for consumers at decision

and policy-making tables. Other diseases such as cancer, arthritis, and hepatitis have taken a page from our book in seeking discrete funding.

Coalitions that have sprung up, often including or led by the HIV community, include Best Medicines Coalition, the HIV/Hep C Working Group, and Get it Right for Patients (GRIP) in Ontario. HIV advocates are often asked to do capacity building, for example, with breast cancer advocates and representatives of rare diseases. There are also new coalitions of disease groups with professional associations working on joint advocacy platforms. For example, a coalition of groups including the Canadian Pharmacists Association, provincial pharmacists associations, the Canadian Medical Association, nurses associations, and the Canadian Health Coalition is working on the cross-border Internet pharmacies issue.

**“The lens of HIV is a great revealer of the problems that existed before we got HIV”—**

**Lynde Francis, founder of  
The Centre in Harare, Zimbabwe**

The challenge we face today is to ensure respect for GIPA so that the voices of people living with HIV/AIDS continue to be heard at every table where decisions are being made about our lives. We have moved to tables that are no longer just talking about HIV but about broader health-related issues and the sustainability of the healthcare system. In order to continue to be a strong presence, we must turn our efforts towards developing new leadership and developing the skills of emerging activists and advocates. Our governments and the organizations we have built to serve us would do well to invest in mentorship programs that would ensure our ability to participate in the increasingly complex world that spans the continuum from research and prevention, to care, treatment, and support.

Together, we need both activism and advocacy to ensure that the political will and the funds are in place to build strong voices for the future. And not just for ourselves, but for our sisters and brothers in communities around the world. ☺

***Louise Binder** is chair of the Canadian Treatment Action Council, co-chair of the federal Ministerial Council on HIV/AIDS, vice-chair of Voices of Positive Women, and member of the Global Coalition on Women and AIDS Leadership Council.*



***Ron Rosenes** is co-chair of the Canadian Treatment Action Council, co-chair of the Community Network Advisory Committee of the Ontario HIV Treatment Network, and a board member of AIDS Action Now!*



# Working it out

**Being HIV-positive and holding down a full-time job can be challenging—as well as rewarding for all involved**

by Moffatt Clarke



So, what's it like if you're HIV-positive and you work full-time? It's a great question—one that doesn't seem to get asked very much, let alone answered. Here are some of the key issues and concerns, along with a few ideas to make your life, on and off the job, fuller and more manageable.

## **A healthy workplace**

First of all, there's a need to create healthy workplaces for PWAs. Many organizations, including my own, are concerned with poor employee retention and with employees taking stress leave. Employers are looking to address these issues by implementing a variety of initiatives to address work-life balance, including health promotion and healthy living programs, for all staff. Employees living with HIV and other episodic conditions can benefit from these initiatives. Some examples include:

**Supporting disclosure of HIV status when appropriate.** At the top of the list of concerns is the question: Do you disclose your HIV status to your manager, your co-workers, your clients, and customers? The answer is always situation-specific. Being open is prudent in some cases. For me, however, if I'm feeling well and productive, it doesn't need to be an issue in the workplace.

**Promoting flexible work arrangements.** Modernized human resource policies that make working arrangements more flexible often benefit HIV-positive staff. Flexible arrangements include compressed workweeks, variable workday hours, self-funded leave, leave with income averaging, and working from home.

**Responding to the duty to accommodate.** Increasing focus is being paid to "duty to accommodate" policies for employees with disabilities, with a view to removing barriers that prevent your full participation in the workplace. Examples include identifying and removing barriers to employment, career development, and promotion.

## **Making sure other supports are in place**

Many group disability insurance plans were designed decades ago when many diseases or conditions either didn't exist or weren't disclosed. Disability insurance plans need to be revised so they're more compatible with the needs of people with episodic conditions like HIV. Flexible coverage would enable people to work when well enough, and know they'll have coverage when they're not. (See the sidebar for the stories of two PWAs and their experiences with part-time disability insurance.)

# The ups and downs of dealing with disability insurance: two first-hand stories

## Bruce's story

"In 1995, I spoke with my doctor who had expressed concerns regarding the amount of stress my job entailed. I asked pointblank if he would support me in a request to either take time off or to work less. He agreed immediately, so I sat down and drafted a letter to my employer. For financial reasons as well as a personal belief that the regular routine of work was a good thing for me, I didn't want to go on full-time disability. Since my particular disability plan wasn't tax free, I would have ended up in financial difficulty had I pursued that avenue.

"Instead, I asked that I work a nine-day fortnight, with my disability plan covering the remaining one day every two weeks. My doctor provided a supporting letter and very soon thereafter the plan was accepted. I have nothing but praise for the Human Resources department of Pacific Newspaper Group (PNG) in all of this. They've been amazing.

"Over the past seven years, I have gone to a four-day work week, with insurance covering one day a week, expanding to more days as needed if I have a bout of bad drug reactions. This has continued through several insurance companies.

"Human Resources at PNG have explained that, with my 25 years of experience with the company, I am valuable to them. They know full well I could be off on full-time disability anytime I so choose."

## Ian's story

"For the last seven years, I have worked at my job on a 40 percent basis. This was made possible by a provision in my disability insurance coverage that allowed for partial disability coverage. With the consent of my doctor, I returned to work part-time after being completely away from it for a period of about five months. This arrangement has now continued through two insurance carriers and will probably continue through a third.

"The drawback to this situation is that I'm being paid disability payments based on my 1996 salary. Any increases in funds or salary increases that may be forthcoming from my employer are deducted directly from the tax-free payments from the disability plan. The paradox is that if I get a raise, I am worse off financially.

"The other dilemma is my pension fund: it's being contributed to on the basis of a 40 percent salary and therefore is correspondingly small. So the opportunity to keep my hand in and to have a reduced work week, while welcome from a health point of view, does have some strong economic downsides. These are becoming more worrisome as I contemplate that I might make retirement age, when all payments from the disability insurance would stop. I would then be required to retire and would have a very modest pension."

People with HIV need to support efforts to reform health care so that it remains accessible, for example by ensuring there is access to primary and specialty medical services on weekends or in the evenings for people who are working. Models such as community health centres, local community service centres (centre local de services communautaires, or CLSCs) in Quebec and Spectrum Health in Vancouver serve PWAs well: doctors provide care in integrated community-based primary care settings in conjunction with healthcare practitioners, including nurse practitioners, pharmacists, social workers, and dietitians.

## Community organizations accommodating working PWAs

There are also ways that community-based organizations could better respond to the needs of working clients by developing healthy living programs and services and by improving existing programs. Examples include ensuring that programs and services are available outside of the typical 9 to 5 office hours, and building partnerships with fitness centres and community centres to offer fitness classes and programs for PWAs that are accessible to those who are working.

Community-based organizations could also explore ways for busy single working people to eat nutritious meals. Ideas include community kitchens for working PWAs who need to eat well but are too tired to shop and cook when they get home from work, and buyers clubs or co-ops with bulk groceries, vitamins, and supplements, in order to lower consumer costs.

These are just some of the questions and a few of the answers that might contribute to an ongoing discussion about living and working full-time with HIV.

Supporting HIV-positive people to stay at work is a win/win situation. Fewer people will be dependent on income security programs, employers will get to retain their investment in human resources, and more HIV-positive people will continue to contribute to the workforce. ☺

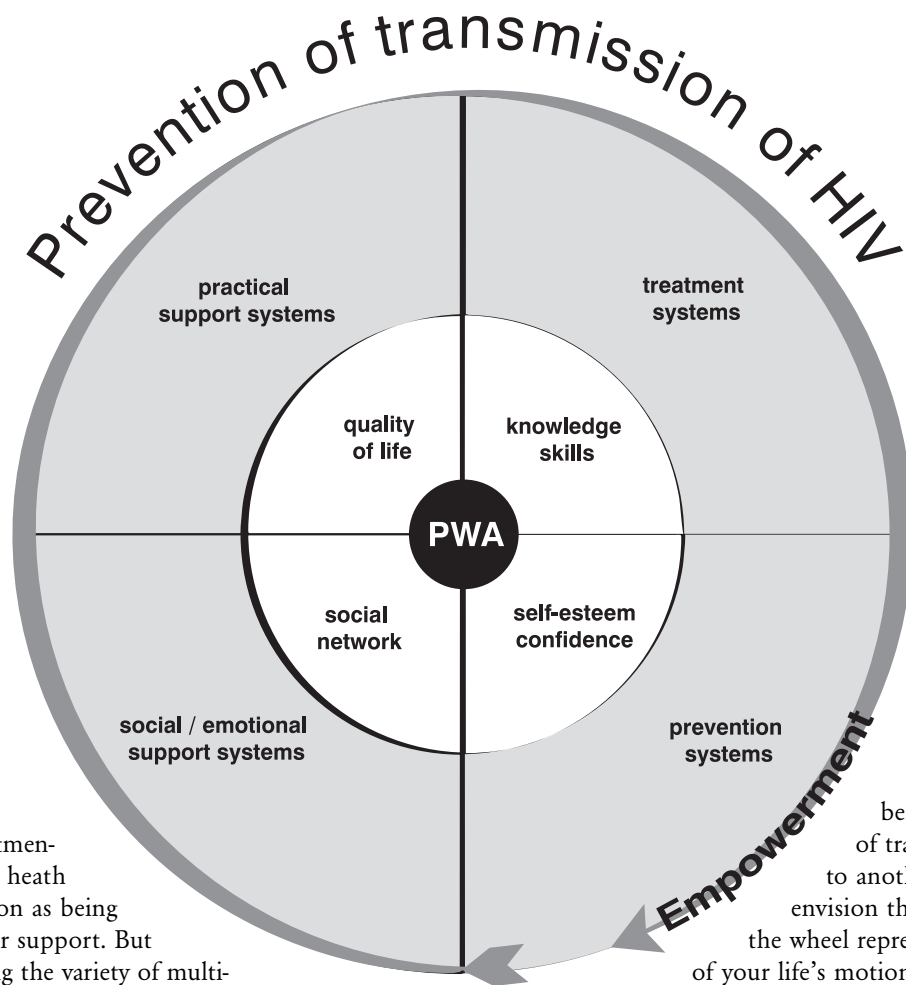
*Moffatt Clarke works for the Public Health Agency of Canada.*



# Setting the wheels in motion

*A holistic perspective on positive prevention*

by Neil Self



**T**oo often, we artificially compartmentalize our lives and health care. We look at prevention as being discrete from treatment or support. But there's value in recognizing the variety of multi-cultural and alternative perspectives on current social issues. One such valuable perspective is the notion of the holistic approach to living with HIV. Recently, we've begun to look at prevention, treatment, and support in a linear continuum of care—that is, from prevention to treatment and then to support.

The concept of a holistic positive prevention circle is in the spirit of the First Nations' medicine wheels and healing circles. Envision yourself at the centre of the circle, with the goal

being the prevention of transmission of HIV to another person. Also envision that the motion of the wheel represents a metaphor of your life's motion—an area of the wheel that is undeveloped or not balanced with the rest of the wheel will result in either a bumpy ride or a complete blowout.

## The inner circle

The initial work of positive prevention is to ensure that the four areas of the inner circle are developed, balanced, and expanding. These include knowledge and skills (related to prevention and treatment), self-esteem and confidence, social

networks, and quality of life. All four areas are crucial to helping PWAs prevent transmission of their HIV to others.

Knowledge of HIV transmission, and skills about how to negotiate safer sex and drug practices, are traditional focuses of prevention, while self-esteem and confidence are also generally accepted as factors affecting behaviour such as safer practices. Quality of life and social networks are also important, as poor quality of life—poverty, lack of housing, inadequate nutrition—can lead to declining health, poor treatment adherence, higher viral loads, lower self-esteem, use of unhealthy coping mechanisms such as alcohol or street drugs, and increasingly risky sex and drug practices. Healthy social networks reduce isolation and can provide a crucial element of support, which can directly or indirectly contribute to the prevention of the spread of HIV.

### The outer circle

The outer circle consists of four broadly labeled areas of systems that you interact with to support your life-long journey of preventing the spread of HIV: prevention, treatment, practical support, and social/emotional support. When you're newly-diagnosed, you may feel overwhelmed by your sudden interactions with the various systems; you may need formal assistance, such as advocacy or case management, or informal assistance, through friends, family, and support groups. Your most significant interaction is with the medical system, for treatment. In addition, at various times throughout your life, you may interact with a range of other systems: AIDS service organizations (ASOs) or community-based organizations like BCPWA; employment, training, or

unemployment; welfare or income assistance; pension or disability insurance; housing; nutrition; complementary therapies; and the legal system.

### Support systems

BCPWA's Positive Prevention department, in conjunction with other BCPWA departments and other ASOs, helps PWAs navigate this prevention journey. BCPWA's Treatment Information Program, Internet Café, and library help you make informed choices on treatment, and that treatment has implications in prevention. Advocacy and case management can help with quality of life issues such as housing, income security, and legal issues and referrals. BCPWA and other ASOs offer numerous supports and services to provide both practical and social/emotional support.

Prevention programs must continue to educate PWAs on new potential and emerging prevention technologies and concepts, such as microbicides, highly active antiretroviral therapy (HAART) as prevention, circumcision, and harm reduction.

This holistic approach of the positive prevention wheel can empower you to make healthy and responsible choices in your life and stop the spread of HIV. ☺



**Neil Self** is a social worker and BCPWA board member.

**We need people like you.** BCPWA has volunteer opportunities in the following areas:

*Web site maintenance* > Communications

*Administration* > Internet research, filing, database management, reception, etc.

*Special events* > AccoIAIDS Awards Gala and WALK for LIFE

*Writers* > *living* ☺ magazine, Communications

*Workshop development and delivery* > Communications and *living* ☺ magazine

### Benefits of becoming a volunteer:

- ◆ *Make a difference in the Society and someone's life*
- ◆ *Gain work experience and upgrade job skills*
- ◆ *Find out more about HIV disease*

If you are interested in becoming a volunteer and/or to obtain a volunteer application form, please email [volunteer@bcpwa.org](mailto:volunteer@bcpwa.org), call 604.893.2298 or visit [www.bcpwa.org](http://www.bcpwa.org).

**volunteer @**  
**BCPWA**



# Grin and bear it

## **An update on what happened to that extra public health funding the BC government promised** *by Ross Harvey*

**BC** Health Minister George Abbott must be a fan of Lewis Carroll's *Alice in Wonderland*.

Like that famous book's Cheshire Cat, Abbott's November 2005 promise of new HIV/AIDS funding as part of a larger \$60 million public health initiative has slowly diminished until almost nothing is left but his smile.

Abbott had insisted in a 2005 speech that "HIV/AIDS organizations play an important role" in helping the government deal with the challenge of HIV/AIDS, and the \$60 million had been added "for health authorities to work with AIDS organizations to assist the government in meeting the goals of its *Priorities for Action in Managing the Epidemic*. Abbott was careful to add, "The \$60 million is for public health, not just for AIDS, but AIDS is an important part of it."

How important? As previously noted in "No cash flow" in the November/December 2006 issue of *living* ☉, Fraser Health reported that, of the \$1,874,000 it initially received, \$200,000 went to new funding for Surrey HIV/AIDS Society. An additional \$150,000 was slated in 2006/07 for public health nursing within the Fraser Health bureaucracy to develop an HIV/AIDS case management system. Interior Health declared that existing contracts with AIDS organizations were unaffected, and no new contracts were awarded upon receiving its first \$1,199,000 share.

Provincial Health Services Authority (PHSA)—which funds the BCPWA Society, among others—wrote that their preliminary \$622,000 share was allocated to support West Nile virus, environmental health, and lab surveillance, and that funds have been directed to the PHSA laboratories and BC Centre for Disease Control to support these initiatives. Nothing was directed to HIV/AIDS organizations.

Vancouver Island Health Authority (VIHA) reported that it used \$350,000 of its \$1,568,000 initial share to make a one-time contribution to AIDS Vancouver Island (AVI), Vancouver Island Persons Living with HIV/AIDS, Victoria AIDS Respite Care Society (VARCS), and one other unidentified organization. Yet ironically, earlier this year VIHA announced it was now going to cut funding to agencies like AVI and VARCS by up to \$450,000.

Since this information was received last year, BCPWA has heard from the remaining two health authorities. Vancouver Coastal Health reported that, of its first \$2,305,000, "none of this funding has gone directly to AIDS programs. None of the contracted agencies working with AIDS patients in our region have received any of this money either."

Northern Health, which received a \$431,000 initial share, reported that it had directed an additional \$40,000 to Positive Living Northwest in Smithers

and \$180,000 to Positive Living North in Prince George. As well, \$73,000 went towards increasing capacity in the AIDS prevention programs, dedicating public staff to HIV/AIDS work, supporting an Aboriginal Leaders forum, training for Aboriginal nurses in testing and pre- and post-test counselling, support to the regional Aboriginal Task Group on HIV/AIDS, education of physicians, and conducting community readiness assessments. This appears to be the best record of any of the health authorities.

The bottom line? The most generous possible interpretation is that, of Mr. Abbott's initial \$8 million disbursement for new public health initiatives, roughly \$843,000 went to new or enhanced HIV/AIDS work. A bit more than 10 percent. Three of the six health authorities spent nothing on new or improved HIV/AIDS work. Worst of all, one of the health authorities that did advance new money appears ready now to claw back an even greater sum.

Which leaves Abbott's cheery contention that "AIDS is an important part" of public health sounding very hollow indeed. Reminiscent of that last, lingering, mocking smile. ☉

**Ross Harvey** is BCPWA's executive director.







# treatment. information

## TREATMENT INFORMATION PROGRAM MANDATE & DISCLAIMER

In accordance with our mandate to provide support activities and facilities for members for the purpose of self-help and self-care, the BCPWA Society operates a Treatment Information Program to make available to members up-to-date research and information on treatments, therapies, tests, clinical trials, and medical models associated with AIDS and HIV-related conditions. The intent of this project is to make available to members information they can access as they choose to become knowledgeable partners with their physicians and medical care team in making decisions to promote their health.

The Treatment Information Program endeavours to provide all research and information to members without judgment or prejudice. The program does not recommend, advocate, or endorse the use of any particular treatment or therapy provided as information. The Board, staff, and volunteers of the BCPWA Society do not accept the risk of, or the responsibility for, damages, costs, or consequences of any kind which may arise or result from the use of information disseminated through this program. Persons using the information provided do so by their own decisions and hold the Society's Board, staff, and volunteers harmless. Accepting information from this program is deemed to be accepting the terms of this disclaimer.



*by Carley Taylor*

**L**ung cancer is an increasing problem among people living with HIV. Studies estimate that the risk of lung cancer is two to seven times higher among HIV-positive people compared to those in the general population. What's more, lung cancer survival rates appear to be worse among PWAs, with only 10 percent surviving past one year. There are several possible factors in the recent increased risk of lung cancer among PWAs: smoking, immunodeficiencies, and highly active antiretroviral therapy (HAART).

Smoking is the number one cause of lung cancer. Roughly 85 percent of HIV-positive individuals who develop lung cancer are smokers. Sixty to 80 percent of PWAs smoke, which is significantly higher compared to the general population at 20 -

30 percent. In that regard, lung cancer rates are highest among HIV-positive injection drug users, likely due to heavy smoking rates among this group.

However, differences in smoking habits aren't the only explanation for the higher rate of lung cancer among PWAs. Studies show that the most common type of lung cancer in HIV-positive individuals is adenocarcinoma, a type that is least associated with smoking.

Several studies have also suggested that chronic reduced efficiency of the immune system is a risk factor. Researchers have found that there is a significant increased risk of lung cancer in men with AIDS, and that lung cancer rates were significantly higher in the period surrounding an AIDS diagnosis than before the men developed AIDS.

*continued on next page*

## What are the symptoms?

People who have lung cancer frequently experience symptoms such as:

- ▷ cough
- ▷ shortness of breath
- ▷ wheezing
- ▷ chest pain
- ▷ hemoptysis (bloody, coughed-up sputum)
- ▷ loss of appetite
- ▷ weight loss
- ▷ pneumonia (inflammation of the lungs)

A number of other symptoms are associated with lung cancer:

- ▷ weakness
- ▷ chills

- ▷ swallowing difficulties
- ▷ speech difficulties or changes (such as hoarseness)
- ▷ finger/nail abnormalities (such as overgrowth of the fingertip tissue)
- ▷ skin paleness or bluish discoloration
- ▷ muscle contractions or atrophy (shrinkage)
- ▷ joint pain or swelling
- ▷ facial swelling or paralysis
- ▷ eyelid drooping
- ▷ bone pain/tenderness
- ▷ breast development in men

Other studies have found that the increased risk of lung cancer is higher now than it was prior to HAART. Some data suggests that PWAs developing lung cancer are older; possible reasons for this are increased life expectancy and the decline in AIDS-related deaths since the advent of HAART.

But the treatment regimens could be a factor, too. Some researchers have found that two nucleoside analogue reverse transcriptase inhibitors, AZT (Retrovir) and lamivudine (3TC), are conceivably co-carcinogens (although they haven't been shown as carcinogens in humans) that, along with tobacco smoke, could cause increased rates of lung cancer.

**Roughly 85 percent of HIV-positive individuals who develop lung cancer are smokers.**

Researchers are finding that most of the fatalities associated with lung cancer are due to late diagnosis. It's estimated that as many as 80 percent of the deaths in the general population might have been prevented by screening to find the tumours early.

If you or your doctor suspect you may have lung cancer, you should have a thorough physical examination. In addition,

your physician may ask you to provide a sample of sputum. The sputum sample will be sent for testing to see if it contains bacteria, other infectious organisms, or cancer cells. Cancer cells may be present in the sputum in certain types of lung cancer. If sputum analysis doesn't provide a definite diagnosis, you'll need more tests.

Treatment options include surgery, chemotherapy, and radiotherapy. Surgery remains the treatment of choice for localized disease in people with adequate pulmonary function and general good health, regardless of their immune status.

The reasons why HIV infection is associated with poorer outcomes remains unclear. Neither CD4 cell count nor AIDS status at lung cancer diagnosis seem to influence prognosis, and there doesn't appear to be a correlation between the stage of lung cancer and CD4 counts. Regardless, as people with HIV live longer and grow older, lung cancer will likely increase as a cause of morbidity and mortality. ☹



*Carley Taylor is a volunteer with BCPWA's Treatment Information Program.*



Look for your AGM package in the mail beginning July 10, 2007.

## Notice of Annual General Meeting

The membership will meet to receive the Annual Report of the Directors, consider amendments to the by-laws of the Society, if any, and conduct other such business as is deemed necessary in accordance with the constitution and by-laws of the Society.

Please note that SIX two-year term positions on the Board of Directors of the Society are to be elected for the period 2007-2009.

**WHEN:**

Saturday, August 18, 2007 at 11:00AM

**WHERE:**

The Training Room,  
1107 Seymour Street, Vancouver

**REGISTRATION:**

10:00 – 11:00AM

**MEETING BEGINS AT:**

11:00 AM (sharp)

### IMPORTANT DATES TO REMEMBER

By June 11, 2007

Resolutions from the Members to be submitted to the Secretary of BCPWA

Not later than July 20, 2007

Mail out of AGM Packages

On July 31, 2007

For individuals who do not receive mail, AGM Packages will be ready for pick up from Member Services (Reception) Desk

August 3, 2007

Last day Proxies are Mailed

August 10, 2007

Last Day Proxies May be Requested for Pick up

Members wishing to have business placed on the agenda for the Annual General Meeting should submit it prior to June 11, 2007. A letter to the Secretary of the Society containing:

- (1) a brief paragraph describing the specific intent of the business, and
- (2) a properly worded motion pertaining to the business should be sent to the Society's registered office at: 1107 Seymour Street, Vancouver, BC, V6B 5S8

If you have any questions or would like to receive a copy of the Society's Annual Report, please call Wayne Campbell, Secretary, at 604.646.5350 and leave a confidential message. To ensure accuracy, please spell your last name slowly and leave a contact phone number.

If you require ASL interpretation, please contact the Secretary of the Society.

**A lunch will be served.**



# CAM primer

## Navigating the vast field of complementary and alternative medicine

by Dr. Jennifer Hillier

Open any magazine or watch television these days and you're inundated by ads for herbal remedies, immune boosters, and alternatives to drugs that promise unbelievable results. From fat busters to sleep aids, this slick marketing of alternative therapies is often the first thing people think of when asked about natural health. Unfortunately, in the world of alternative therapies, there are as many roadblocks as there are paths to wellness.

Complementary and alternative medicine (CAM) is a vast field of health care that seems to encompass everything that isn't traditionally defined as Western medicine. Within this field, some therapies are more prevalent and better researched than others.

### A handy overview

It can get confusing, so here's a handy overview of some of the main options available in BC. Some of the therapies have been discussed in greater detail in past issues of *living* magazine.

**Traditional Chinese Medicine (TCM):** Working with ancient teachings and modern research, TCM is based upon the movement of energy along channels in the body. Disease develops when this energy is disrupted in some way. By supporting the healthy flow of this energy through the use of acupuncture, herbs, and bodywork, symptoms can be decreased and health restored. TCM is practiced by doctors of TCM, naturopathic physicians, and occasionally by other medical professionals like medical doctors, chiropractors, and physiotherapists.

**Ayurvedic medicine:** Ayurveda is a holistic system of medicine from India that uses a whole body model. Its aim

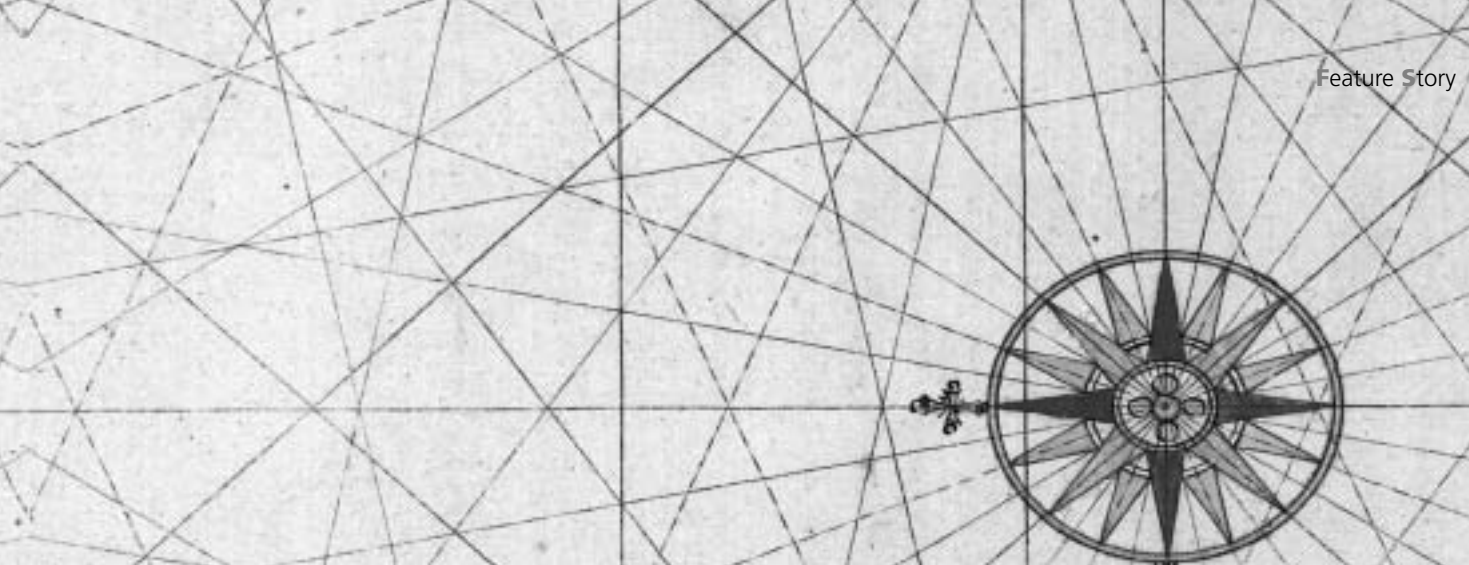
is to provide guidance on food and lifestyle in order to balance the body. Ayurveda is practiced by specialized ayurvedic practitioners.

**Homeopathic medicine:** Working with dilute concentrations of plant, mineral, and animal substances, homeopathy affects the body on the physical, mental, and emotional planes to stimulate healing on a deep level. Homeopathy is practiced by homeopathic doctors and naturopathic doctors.

**Unfortunately, in the world of alternative therapies, there are as many roadblocks as there are paths to wellness.**

**Botanical medicine:** This therapy uses fresh, dried, or concentrated plants to treat illness and disease. Botanical medicine is practiced by a variety of health professionals, including naturopathic doctors and herbalists.

**Nutritional and diet therapy:** By tailoring your diet and introducing, eliminating, or increasing specific foods, you can enhance the function of your body and decrease symptoms of illness while improving energy and vitality. Nutritional advice may be provided by nutritionists, TCM doctors, naturopathic doctors, and your MD.



**Energy work:** Manipulating the subtle energy fields of the body, this broad category may include reiki, craniosacral therapy, and yoga, among many others.

**Bodywork:** Including massage, manipulation, and stretching, this therapy can help to loosen tight muscles, improve flexibility, decrease pain, and enhance well-being. Traditionally offered by massage therapists, chiropractors, physiotherapists, and kinesiologists, this therapy may be used alone or as an addition to any treatment protocol.

**Naturopathic medicine:** Encompassing all of the above therapies, naturopathic medicine works to uncover the root of illness and treat the individual rather than the disease. By understanding the relationship between the side effects of medications and the effects of HIV itself, naturopathic doctors help you cope with the changes and balance the many reactions happening in your body.

Naturopathic doctors are trained in pharmacology (medications) so they understand the physical impact of the drugs and how these effects can be countered with a variety of therapies, including acupuncture, diet, nutrition, homeopathy, and plant medicine. To find a naturopathic doctor (ND) near you, visit the Canadian Association of Naturopathic Doctors website at [www.cand.ca](http://www.cand.ca).

## When to use CAM

The recent popularity and interest in CAM has led to a huge increase in people seeking out alternative therapies. From picking up something at a health food store to seeing a naturopathic doctor, the uses of CAM are widespread. Some of the most common complaints that naturopathic HIV/AIDS practices see include: digestive problems, including gas, bloating, diarrhea, and indigestion; mood disorders, anxiety, depression, and grief; sleeping disorders, including problems falling or staying asleep; peripheral neuropathies (tingling or pins and needles) in the hands and feet; and lipodystrophy and wasting of muscle mass.

Treatment for mental-emotional side effects of being HIV-positive tops the list of reasons why PWAs seek CAM

## So, why would you use CAM?

- If you're experiencing uncomfortable symptoms of HIV/AIDS or side effects from your medications.
- If you'd like to take a more proactive role in your health care and do something to preserve or enhance your health.
- If you'd like to experience individualized support while working on physical, mental, and spiritual issues related to your health.
- If you'd like to strengthen your body before, during, and after undergoing therapies with your primary care physician.

treatment. The stress related to the diagnosis, the medications, and the stigma is overwhelming and can often lead to anxiety, insomnia, and depression. Naturopathic physicians take into account your health history, your medications, any treatments you're undergoing, and your health goals, both in the short and long term. By understanding all aspects of your health, they can tailor a treatment plan to your needs.

With the many claims out there for improved health through CAM, it's important to do your homework. By following the suggestions in this article and the next article, and by listening to the advice of your current health professionals, you're well on your way to making the best use of the many benefits that are available to you through CAM. ☺

*Dr. Jennifer Hillier, ND, is a researcher with the Living Well Lab, a founder of the BCPWA Naturopathic Clinic, and has a private practice in Mississauga, Ontario.*



# CAM primer

## How to choose a complementary therapy and find the right practitioner

by Dave Boyack

Some days it's hard just to get out of bed. When you have a life-threatening illness and you suffer from a number of ailments and symptoms, it can slow you down—or even leave you bedridden. Living with HIV/AIDS, it's often challenging to maintain your general health. Your symptoms can be compounded by both your disease and the medications you're taking.

While many people rely on their doctor for medical advice, there are other trained health practitioners who can help you maintain and improve your overall health as well as treat your health problems.

Complementary health therapists are an overlooked resource. Complementary and alternative medicine (CAM) includes a wide range of healing methods, including massage, reiki, shiatsu, reflexology, aromatherapy, naturopathy, traditional Chinese medicine, acupuncture, and meditation. Many of these healing therapies are centuries old, and many qualified practitioners today must complete years of education and training before being certified in their discipline.

Because many of us grew up in the Western-based medical system, we may not be familiar with the centuries-old traditional healing methods of other cultures. Western medicine tends to focus on the external factors or symptoms of illness and therefore relies on medicines, drugs, and other forms of treatment to treat the symptoms. CAM focuses on maintaining a balance of the body's internal energies. CAM restores the balance between a person's physical, mental, social, and spiritual well-being. Unlike Western medicine, complementary therapies are not clinically tested in a lab, but are learned from centuries of practical experience.

CAM is much more than just the odd massage or an annual visit to the acupuncturist. It's more than taking your vitamins, attending support groups, or meditating; it's about engaging your mind, body, and spirit in the healing process. Our bodies have amazing powers to heal. Complementary therapists know

that our mind and body are inseparable, and therefore they take a whole-person or holistic approach to healing.

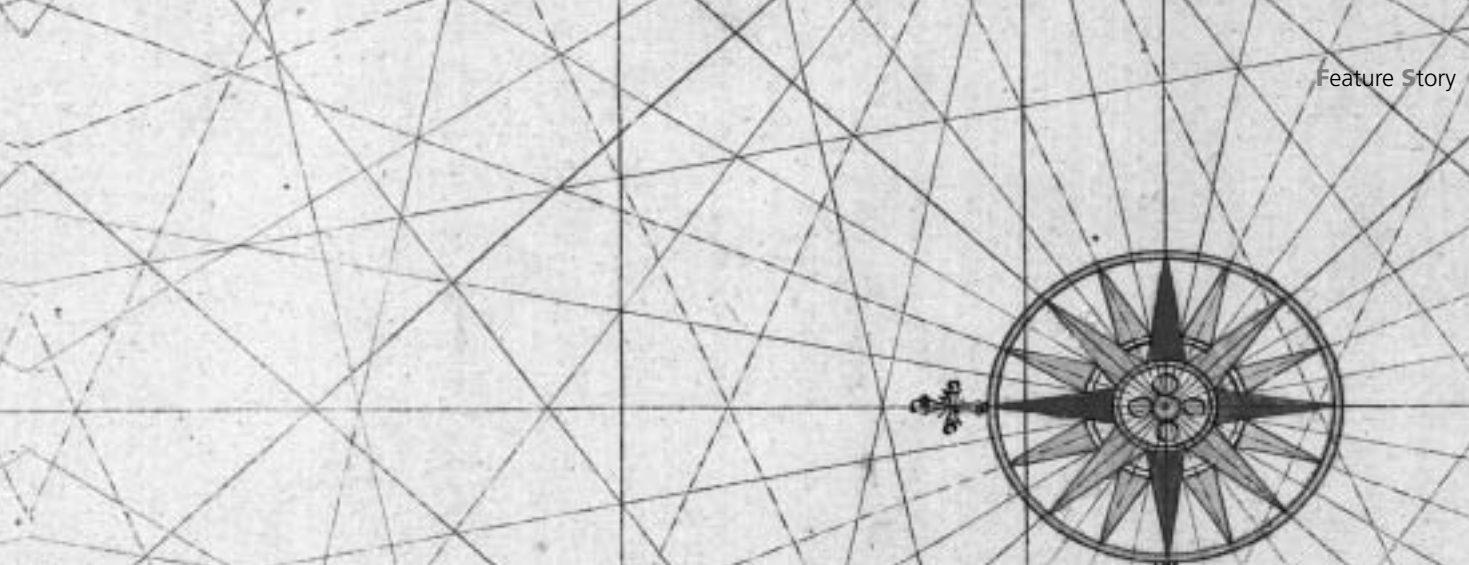
People who seek complementary therapy often feel a sense of empowerment because they're involved in maintaining their own health. You're left with a greater sense of being in control of your wellness.

### Referrals and personal research go a long way

If you're considering complementary therapies, make sure you know exactly what you're getting into before you book an appointment. Ask yourself why you're considering complementary therapy. Do some research on the procedure or treatment you're considering. Despite centuries of use, there's often very little scientific evidence on the safety or effectiveness of CAM, so it's always a good idea to consult with your medical doctor. Contact the different complementary therapy professional associations for information. These organizations often have standards of practice and might provide referrals to practitioners. If you know people who have used the treatment, ask them if and how they benefited.

Have realistic expectations about the outcomes of a treatment. CAM is often used to treat chronic, long-term conditions or to enhance wellness and the overall immune system—but they're not a cure-all. Consider the benefits of a therapy, and if your time and money are well spent, since some complementary therapies aren't covered by BC's provincial health plan or by private health care insurance plans.

If you do visit a CAM practitioner, be prepared to answer some personal questions. You may, for example, be asked about your health history, major illnesses, your medications, and other important information. Many therapists and practitioners can take up to an hour asking questions about your lifestyle, habits, and background, in order to better understand your overall health; this is part of the whole-person approach. Also, many therapies involve touching, so you'll need to be comfortable with that.



### Ask the practitioner plenty of questions

As the name implies, complementary therapists offer treatments that complement or support the medical care you may already be receiving from your medical doctor. It's important, therefore, to tell your doctor and your complementary therapist about the different kinds of treatments you're using.

So, how do you find a knowledgeable and sensitive complementary therapist? First, find out if the therapy that interests you is regulated by a professional organization. Regulated organizations generally require therapists to be trained and qualified in order to practice.

Check therapists' credentials or licenses. Ask them where they received their training. A therapist should have a diploma from an accredited school. Some countries require certain standards for training, but other countries don't require licenses or certification.

If you're interested in a therapy that isn't regulated, be prepared to do more research. Don't be afraid to ask a lot of questions. If you know other people who have used a particular therapist, ask them about their experiences. And if you can, find a CAM therapist with training and experience in working with people with HIV/AIDS.

Before your first visit to a CAM therapist, make sure you

ask about the cost and the length of treatment. Also write down, in advance, a list of questions to ask the practitioner during your first visit or consultation. Questions might include:

- ▶ What are the risks?
- ▶ What benefits can I expect from this therapy?
- ▶ Do the benefits outweigh the risks for my disease?
- ▶ How long will I need to undergo this treatment?
- ▶ Could the therapy interact with the conventional medications I'm taking?

After your first visit, evaluate if the treatment was beneficial to you. Ask yourself: Was the therapist easy to talk to? Did the therapist make me feel comfortable? Did the therapist get to know me and ask me about my condition? Did the therapist seem knowledgeable? Was the treatment reasonable and acceptable?

If you're at all uncomfortable with the therapist, then seek another one—or another form of complementary therapy. ☺



**Dave Boyack** is a volunteer with BCPWA's Education and Communications.

### Watch out for the scam artists

Most complementary therapists are professional, qualified people. However, that's not always the case. There tends to be less regulation of complementary medicine compared to Western-based medicine. So it pays to be careful when selecting a CAM practitioner.

Be wary of a practitioner who:

- ▶ asks for large payments
- ▶ promises quick fixes and/or miraculous results—such as curing HIV/AIDS or cancer
- ▶ warns you not to trust your primary doctor
- ▶ tells you to stop seeing your doctor or primary caregiver

- ▶ has credentials from a school you can't find online
- ▶ sells products that you must buy as part of your therapy

Some CAM practitioners may legitimately recommend products as part of their therapy. Acupuncturists, for example, sometimes use Traditional Chinese Medicine. And homeopathy specifically involves using low concentrations of plant, animal, and mineral substances to stimulate the immune system. But if you're getting an uneasy sense that a practitioner is trying to hawk unnecessary products—this is where background research comes in handy—then you should think twice.

# EVENING HOURS

**NOW  
OPEN LATE**

# AT BCPWA

**TO BETTER SERVE  
OUR MEMBERS  
TUESDAYS & THURSDAYS  
UNTIL 9PM**

Visit [WWW.BCPWA.ORG](http://WWW.BCPWA.ORG)  
or phone 604-893-2200  
for more information



## **Drop in and...**

- o Join as a member or volunteer
- o Register for & attend information workshops or support groups
- o Collect Complementary Health Fund forms or cheques
- o Speak with an HIV treatment information counsellor
- o Access advocacy services for financial, medical, or housing issues
- o And much, much, more

**THE BCPWA LOUNGE  
IS NOT OPEN  
FOR EVENING  
DROP-INS**





# From panic to peace

**Natural ways to soothe your nerves and help you sleep** *by Katolen Yardley*

The effects of a fast-paced life are evident throughout North America. Without daily practices of emptying the mind, your head can become full of thoughts, worries, and anxieties; in this mental state, it's challenging for the body to simply be calm. No wonder so many people suffer from insomnia.

There are a number of factors that can lead to insomnia: constant thoughts, pain, low blood glucose, the overuse of stimulants, certain medications, and underlying anxiety or depression. Anxiety occurs when your thoughts rest on the pains of the past and indulge in fears about the future. By bringing attention to your mind and identifying what thoughts you're fixating on, you can realize that you can choose positive, joyful thoughts. That creates a space for your anxiety to dissolve.

Depression and low spirits can be aggravated by a lack of nutrients. Junk food is a common cause of depression. Brain chemicals or neurotransmitters that regulate behaviour are greatly affected by the foods we eat. Take steps to avoid processed fast food, artificial colourings, sugar, fried foods, and caffeine—they all wreak havoc with the nervous system, contribute to scattered thinking and nervous energy. They also cause blood sugar fluctuations, which can further aggravate your emotional state.

Focus on whole grains such as brown rice, millet, and oatmeal. Porridge is one of the best foods for the nervous system. Choose steel-cut or Scottish oats for the highest nutritional value (avoid instant flavoured oatmeal, which is processed and often high in sugar). Choose proteins that offer important amino acids for the

brain and nervous system function. Turkey, bananas, tuna, and nut butters are sources of the amino acid *tryptophan*; this raises serotonin levels, which helps promote sleep and instill a calm, peaceful feeling in your body.

Calcium and magnesium deficiencies are also causes of frequent waking and difficulties in falling asleep. Supplements of these minerals can help calm tense muscles and relieve anxiety. Calcium citrate is one of the most absorbable forms of calcium on the market. Magnesium is used for restless leg syndrome, and it's a natural laxative to minimize the possible constipating effects of certain medications (if you're experiencing diarrhea, decrease the dose of this mineral).

There are also a number of herbal remedies that can relieve tension and stress:

- ▶ **Passionflower (*Passiflora incarnate*):** A nervine used to quiet the mind from constant mental thoughts and over-excitability.
- ▶ **Scullcap (*Scutellaria lateriflora*):** A nervous system restorative and relaxant herb used for stress, headache, anxiety, and insomnia.
- ▶ **Chamomile (*Chamomilla recutita*):** A gentle remedy for stress, mild inflammation, and digestive cramping. It promotes sleep and calms a nervous stomach.
- ▶ **Lemon balm (*Melissa officinalis*):** An herb used for upset stomachs, to soothe digestion, brighten the spirits, and lift melancholy and sadness. This herb also contains antiviral properties of benefit to people with HIV.

Combine the above herbs together in equal portions and use as a tea (3 - 4 cups a day): use one heaping teaspoon of



the herb mix per cup of water and steep 15 minutes before drinking. The herbs can also be used in tincture or capsule form (tea or tincture are best).

Another remedy for insomnia is lavender essential oil, a balancing oil used for lack of energy during the day and to promote sleep at night. Add 5 - 6 drops to a hot bath at night to promote sleep.

Herbs are a mild, gentle, and non-habit forming option to prescription medications for insomnia. It's possible to wean off prescriptions and use herbs in place of medication, however you should always do this under the clinical care of a medical herbalist, who can monitor your progress. ☺

**Katolen Yardley, MNIMH,** is a medical herbalist in private practice at *Alchemy and Elixir Health Group* in Vancouver and Coquitlam.



# LOON LAKE CAMP

June 11-14, 2007

September 4-7, 2007

## HEALING RETREATS FOR HIV+ PEOPLE

MEET NEW FRIENDS.

LEARN MORE ABOUT YOURSELF.

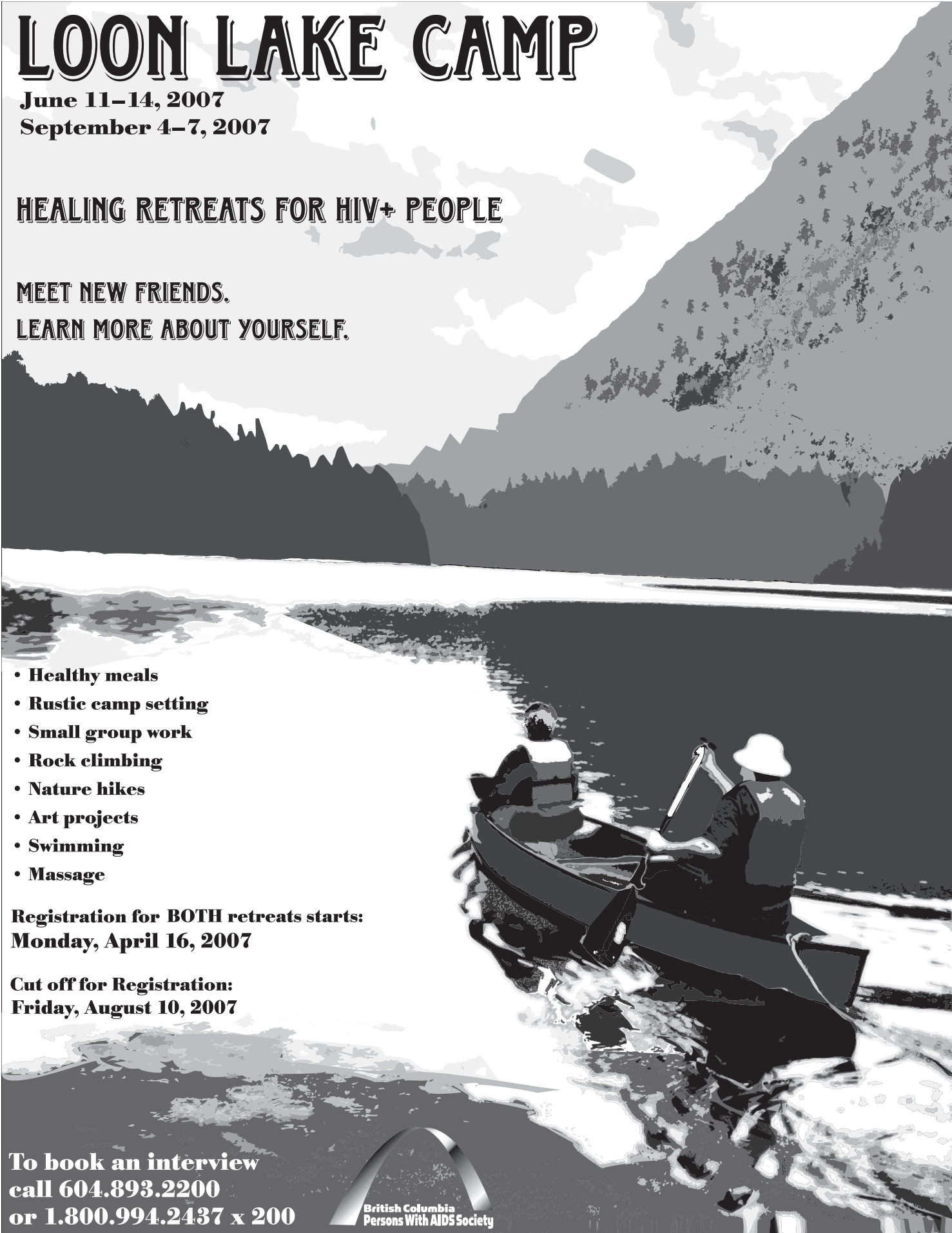
- Healthy meals
- Rustic camp setting
- Small group work
- Rock climbing
- Nature hikes
- Art projects
- Swimming
- Massage

Registration for BOTH retreats starts:  
Monday, April 16, 2007

Cut off for Registration:  
Friday, August 10, 2007

To book an interview  
call 604.893.2200  
or 1.800.994.2437 x 200

British Columbia  
Persons With AIDS Society



# Are you covered?

## A survey of the different antiretroviral drug plans for each provincial and territorial health ministry

by Rob Gair

People living with HIV today are much healthier thanks to advances in antiretroviral therapy. This means individuals are more mobile and can now consider moving to another province for work or personal reasons. If you're considering such a move, one of the deciding factors might be the extent of antiretroviral drug coverage you can expect elsewhere. With annual costs for HIV medications approaching or exceeding \$10,000, you can incur significant costs if you're moving to a province or territory where coverage is less generous.

Surveying Canadian provincial and territorial health ministries and their antiretroviral drug plans reveals the good news: all jurisdictions cover the majority of costs in one way or another, although the mechanism for coverage varies.

Most provinces require private employer-based insurers to pay first. Private plans generally pay about 80 percent of the drug cost, with the province covering the remainder after the patient pays a deductible (usually income-based). In other words, the private insurer is the first payor and the province is the last payor. People with low incomes or who lack private insurance may apply to their health ministry for additional coverage. Provinces that don't require payment by private insurers usually pay the full amount themselves—in which case the province is the first payor.

For example, BC is a first-payor province because medications are dispensed from a central pharmacy and prescription costs are covered 100 percent upfront. In last-payor provinces like Ontario, medications are dispensed from local community pharmacies and private insurers are expected to cover the majority of costs. In Ontario, you must pay the amount not covered by private insurance, then get reimbursed by the Trillium drug plan after you've paid your deductible.

The table to the right outlines some of the differences between the various provincial and territorial antiretroviral drug plans. It isn't a comprehensive summary of provincial drug plans. ☹



**Rob Gair** is a pharmacist at the BC Drug and Poison Information Centre in Vancouver.

### Drug coverage by province/territory

Province/territory	Private insurance	Drug plan	What the patient pays
British Columbia	No payment	First payor: 100%	Nothing
Alberta	No payment	First payor: 100%	Nothing
Saskatchewan	No payment	First payor after patient deductible	Income-based deductible (max. 3.4% of annual)
Manitoba	First payor	PharmaCare: Last payor	Income-based deductible
Ontario	First payor	Trillium: Last payor	Income-based deductible
Quebec	First payor	Public plan: Last payor	Maximum \$73.42/month
New Brunswick	First payor	Plan U: Last payor	Maximum \$500 per year
Nova Scotia	First payor	Special fund: Last payor	Dispensing fee
Prince Edward Island	No payment	First payor: 100%	Nothing
Newfoundland	First payor	Prescription Drug Program: Last payor	Income-based deductible
Nunavut/NWT	First payor	Extended health: Last payor	Nothing
Yukon	First payor	Chronic Disease Program: Last payor	\$250 per year (may be waived if low income)
First Nations/Inuit	Covered by Health Canada's Non-Insured Health Benefits (NIHB) Program		



# All talk, still no action

**Four years later, the federal government still isn't providing catastrophic drug coverage** *by Glyn Townson*

Catastrophic drug coverage has been in the news again. The federal government has formed another parliamentary committee to devise a plan to protect Canadians with serious health conditions and illnesses who face very high prescription drug costs, which can lead to a serious—or “catastrophic”—financial burden. This was the line towed with the 2003 First Ministers Accord, which promised to take measures by the end of 2006 to provide all Canadians with reasonable access to catastrophic drug coverage. It's now 2007, so where's the federal commitment to this coverage?

The release of the *Hall Royal Commission on Health Services Report* in 1963 launched the discussion on the government's role in providing individuals with compensation to cover the continually rising cost of pharmaceuticals to treat disease. In fact, the report stated: “Either the industry will itself make these drugs available at the lowest possible cost, or it will be necessary for agencies and devices of government to do so. We must not confuse the distribution of essential drugs with the distribution of cosmetics and sundries.” Clearly, it was a very strong statement to support the argument that life-saving medications should be universally available throughout the country.

At the time the report was released, pharmaceuticals were seen as a necessary part of the healthcare system. The report notes that “the expenditures on all drugs are equivalent to 95

percent of the outlay of physician's services with prescribed drugs representing about 43 percent of medical expenditures.”

Drug costs have increased steadily since then. They are now one of the fastest-growing components of total healthcare expenditures in Canada; in 1993, for the first time, drug costs exceeded payments to physicians. Canada spent about \$4 billion on drug costs in 1985, according to the Canadian Institute for Health Information. That number skyrocketed to \$25 billion in 2005 and it continues to rise, with few controls in place.

## **Conflicting federal and provincial policies**

From the late 1960s until the late 1980s, federal and provincial policies seemed to be working in the same direction. The federal policy of compulsory licensing made cheaper generics available earlier, and the provincial substitution laws directed physicians and pharmacists to switch to generic brands. The result was lower expenditures on drugs.

However, with the introduction of Bill C-22 in 1987—which gave pharmaceutical companies up to 10 years of protection from compulsory licensing for all marketed drugs—and then Bill C-91 in 1993, which abolished compulsory licensing completely, federal and provincial policies have moved in opposite directions. Federal regulations allow longer patent terms, higher prices, and less generic competition. At the same

time provincial policies, such as requiring a cost-effectiveness justification prior to formulary listing and reference pricing, seem to be attempting to contain higher drug acquisition costs.

All provinces have some coverage for prescription drug programs, such as PharmaCare in BC. Unfortunately, coverage between the various provinces is far from consistent (see preceding article on page 27), and coverage for specific rare or catastrophic disease treatments has an even greater disparity. Although various parliamentary committees have discussed catastrophic coverage since the Hall Report was released, many provinces—Ontario, Quebec, Manitoba, Saskatchewan, Alberta, and BC—provide assistance under the Constitution and without a national plan. However, the specific medications covered vary greatly between the provinces.

**Although Ottawa regulates drug prices and patent terms, it doesn't face any of the consequences of its policies. The provinces and the public are the ones that pay the drug costs.**

That difference came to the forefront late last year, when news headlines drew attention to the inequities of treatment if you have cancer and you live in the wrong province. The Atlantic Provinces don't provide for catastrophic coverage outside of the hospital system. Since the Atlantic provinces account for only two percent of Canada's population, it would be more cost effective for them to adopt the same systems as other provinces and have a mechanism to partner with other jurisdictions that have greater buying power.

**Recent policy changes fuel the problem**

The costs of new medications continue to increase, and some of the problems of containing drug costs in Canada have been aggravated by recent government policy changes. The October 5, 2006 amendments to the *Food and Drug Regulations* provided brand-name drug companies with an eight-and-a-half-year ban on competition, even for non-patented drugs. The federal government's changes go far beyond the five years required under international trade agreements such as NAFTA and will add hundreds of millions to Canada's prescription drug costs.

The unfortunate reality facing the Canadian pharmaceutical marketplace is that although Ottawa regulates drug prices and patent terms, it doesn't face any of the consequences of its policies. The provinces and the public are the ones that pay the drug costs.

The Patented Medicine Prices Review Board (PMPRB) is supposed to set ceiling prices for pharmaceuticals. Part of Bill C-22 in 1987, the PMPRB was created as an independent, quasi-judicial body. The PMPRB serves two roles: it acts as a regulatory body to ensure that manufacturers don't charge excessive prices for patented medicines; and it is a contributor to policymaking by reporting on pharmaceutical trends and on research and development spending by pharmaceutical patentees.

The problem with the PMPRB setting ceiling prices is that the prices are linked to the consumer price index, and pharmaceutical companies are allowed to increase annually. However, many manufacturers have voluntarily given up their patents, which until recently allowed them to escape the jurisdiction of the PMPRB. At the same time, prescription prices have risen at about 12 percent each year, in part because older, less expensive drugs are being replaced by newer, more costly drugs.

**Pharmaceutical companies are reaping big profits**

The Canadian Centre for Policy Alternatives released a report in early January 2007 recommending aggressive measures to deal with the rising costs of prescription drugs in Canada, especially given that the pharmaceutical industry is reporting profits twice that of other manufacturing industries.

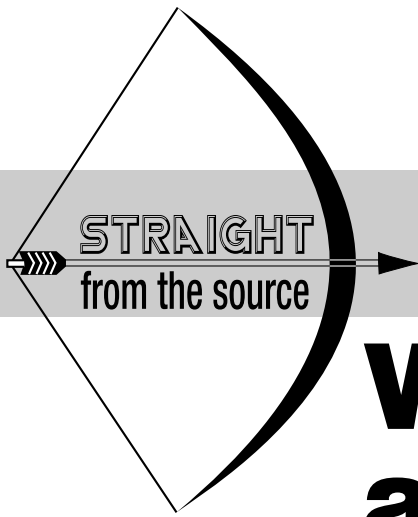
It's time for change, and a strong case can be made for the provinces combining to buy pharmaceuticals in bulk, nationwide, allowing for greater cost savings even in our less populous regions. Australia's pharmacare program has resulted in drug costs nine percent lower than Canada's, thanks to aggressive bargaining with drug companies. Canada's patchwork of provincial plans limits bargaining power, bulk buying, and administrative efficiencies.

A federal election is looming. We must challenge all candidates on to how they'll deal with this burgeoning problem, one that will continue to worsen if policies and ideology don't change. The provinces and the federal government must sit down together and work out the details to ensure Canadians in all regions have access to the medications they require, and that the system isn't bankrupted in the process. A national pharmacare strategy would be a good start. ☺

*Glyn Townson is the vice-chair of BCPWA.*

**Further reading**

To read the Canadian Centre for Policy Alternatives' report, *Canadian Drug Prices and Expenditures: Some Statistical Observations and Policy Implications*, visit [www.policyalternatives.ca/documents/National\\_Office\\_Pubs/2007/Canadian\\_Drug\\_Prices.pdf](http://www.policyalternatives.ca/documents/National_Office_Pubs/2007/Canadian_Drug_Prices.pdf).



what's new in research

# What is anal dysplasia?

**Cases of anal cancer continue to rise among HIV-positive gay men**

by *Natasha Press, MD*

**Men** who have sex with men (MSM) have a higher rate of anal cancer than those who don't, especially if they're HIV-positive. A pre-cancer area called dysplasia, which means abnormal cells, occurs first; over time, it may progress to cancer.

The pre-cancer area is caused by a virus called the human papilloma virus (HPV), which is a sexually transmitted disease. There are different types of HPV: some types cause warts, while other types cause dysplasia. Most HIV-positive MSM are infected with several of the different types of HPV. Therefore, warts and dysplasia are common. Although warts may cause symptoms, such as being able to feel a lump, dysplasia doesn't cause any symptoms, so you may not know you have it.

Unfortunately, dysplasia isn't prevented by taking antiretroviral therapy or by having an increase in CD4 count and a decrease in HIV viral load. Therefore, the risk of anal cancer continues to increase in HIV-positive MSM, despite better control of HIV infection. Presumably, as HIV-positive MSM live longer on antiretroviral therapy, the number of cases of anal cancer will continue to increase among this population.

To prevent an increase in anal cancer, some doctors are screening their HIV-positive MSM patients for dysplasia. Screening is still being researched and isn't yet part of recommended guidelines for treating HIV-infected individuals, so not all doctors are doing it.

Screening is done with an anal pap test. A swab, which looks like a Q-Tip, is inserted about one to two inches into the anal canal and is moved around against the mucosa—the skin inside the anal canal. This picks up cells off the mucosa, including abnormal (dysplastic) cells. If the results show that the anal pap is abnormal, then local patients can be sent to the Anal Dysplasia Clinic at St. Paul's Hospital in Vancouver.

St. Paul's Hospital, in collaboration with the BC Centre for Excellence in HIV/AIDS and the BC Cancer Agency, started the outpatient clinic in April 2003 as part of a research protocol.

The goal of the clinic is to find and treat dysplasia so that anal cancer doesn't develop.

HIV-positive MSM who come to the clinic have their anal canal inspected using a microscope to see whether any dysplasia is present. Doctors insert a small plastic tube, called an anoscope, into the anal canal, and then carefully inspect the mucosa through the microscope. If doctors see any abnormal areas, they take a biopsy. The biopsy is a small piece of mucosa, the size of a piece of rice, which is cut off and sent to the lab. If the biopsy result shows a lot of dysplasia, called high-grade dysplasia, then the individual returns to the clinic for treatment.

Different types of treatment are used for dysplasia. At the St. Paul's clinic, doctors use a strong acid that burns off the top of the mucosa, including the abnormal cells. This is similar to getting a sunburn, after which the skin peels off. Other clinics in North America are using laser-type treatments to burn off the dysplasia. It isn't known which type of treatment works best yet, but research is ongoing.

If dysplasia is detected and treated, hopefully anal cancer rates won't increase. However, the treatments used for dysplasia don't get rid of the HPV, so dysplasia can happen again even after being treated. As well, warts aren't treated at the Anal Dysplasia Clinic, so the types of HPV that cause warts are also still there. ⊕

**Dr. Natasha Press** is an infectious diseases physician working at St. Paul's Hospital and the BC Centre for Excellence in HIV/AIDS in Vancouver.

She does research on anal dysplasia in HIV, and runs the Anal Dysplasia Clinic at St. Paul's.



## Further reading in living⊕

"HIV + HPV = pain in the ass" Issue 35 (March/April 2005)

"A bum deal: Treating and diagnosing anal dysplasia" Issue 36 (May/June 2005)



# Early treatment put to the test

by Julie Schneiderman

Researchers have set out to attack HIV while the immune system is still intact to fight the virus. Dr. Brian Conway of Vancouver's Downtown Infectious Diseases Clinic (DIDC) and Dr. Joseph Margolick of Baltimore's Johns Hopkins Bloomberg School of Public Health are studying whether one year of highly active antiretroviral therapy (HAART) can slow the progression of HIV in adults who have been recently infected.

By hitting the virus with a course of therapy very early in its invasion of the body, the researchers are hoping to control HIV for a longer period, which means both preserving the immune system and allowing it to more easily handle the virus. Ultimately, this could lead to a delay in the need to start often difficult and expensive therapies. "Treating early might mean more than higher CD4 counts and a lower viral load," says Dr. Conway. "We could see long-term or potentially even life-long benefits for individuals, communities, and the bottom line."

Over the next three years, individuals presenting with either acute infection (within the past two months) or early infection (within the past two to 12 months) will be randomly assigned to receive treatment for one year, or will wait to receive treatment until they meet the standard guidelines for treating chronic HIV infection. The study will compare the viral load and CD4 cell counts of treated versus untreated participants at

two and three years following enrollment, and will also evaluate the toxicity of HAART in the recently infected.

The study team is sensitive to the fact that many eligible participants have only just been diagnosed with HIV. They are working closely with local and regional organizations to link individuals with counselling and other community resources. Dr. Conway plans to draw on the expertise of a team of on-call counsellors at the Pender Clinic, and to refer participants to the comprehensive information and services at BCPWA.

This study, CTN 214, expects to enroll 180 participants, with 132 participants between four clinics in BC and four other sites across Canada, and the balance in Baltimore. "Currently there is no right answer when dealing with recent infection," says Dr. Conway. He explains that some doctors are quick to treat, while others feel it's best to wait. "This study will help us generate the evidence to see who benefits most from treatment in this setting." ☉



*Julie Schneiderman is the communications manager at the Canadian HIV Trials Network in Vancouver.*

## Trials enrolling in BC

**CTN 147** — Early Versus Delayed Pneumococcal Vaccination  
*BC sites:* Downtown Infectious Disease Clinic (DIDC) and St. Paul's Hospital, Vancouver; Medical Arts Health Research Group, Kelowna General Hospital

**CTN 205** — Valproic Acid and HIV  
*BC sites:* St. Paul's Hospital, Vancouver

**CTN 214** — Effect of a One-Year Course of HAART in Acute/Early HIV  
*BC sites:* DIDC, Vancouver; Cool Aid Community Health Centre, Victoria

To find out more about these and other trials, check out the **Canadian HIV Trials database** at [www.hivnet.ubc.ca/ctn.html](http://www.hivnet.ubc.ca/ctn.html) or call Sophie at the CTN 1.800.661.4664.



# New drugs, new hope, old lessons

## **Report from the 14th Conference on Retroviruses and Opportunistic Infections**

by Sean Hosein

The annual Conference on Retroviruses and Opportunistic Infections (CROI) is North America's premier scientific meeting on HIV/AIDS. This year the conference took place from February 25 - 28 in Los Angeles. The meeting deals mostly with research and treatment of HIV/AIDS. But many other related issues were also addressed this year: vaccine development, treating complications of HIV infection, managing co-infections, how HIV gradually disables the immune system, and transmission of HIV. As well, coverage of treatment and HIV transmission issues in low-income countries has been gaining more attention at the conference for several years.

Advances in the treatment of HIV infection have always been an important aspect of CROI. In the mid-1990s, word

about the powerful and life-prolonging effect of protease inhibitor (PI)-based therapy first appeared at CROI. In 2007, attendees' expectations were largely met through presentations of results of emerging therapies. These therapies included the following new groups or classes of anti-HIV medications:

- ▶ Maraviroc, which works by blocking a receptor called CCR5 found on the surface of cells. HIV needs this receptor in order to get inside and infect a cell.
- ▶ Integrase inhibitors, which work by interfering with an enzyme used by HIV called integrase. One integrase inhibitor is called raltegravir (MK-0518) and is being developed by the pharmaceutical company Merck. Another company, Gilead Sciences, is developing another integrase inhibitor called elvitegravir (GS 9137).



When either maraviroc or raltegravir is used as part of combination therapy, the drugs have strong anti-HIV activity, resulting in rising CD4 cell counts, decreased viral load and consequently, improved health. There are many new anti-HIV therapies under development. However, maraviroc and raltegravir are most likely to become available in expanded access programs and later through formal approval by regulatory authorities in high-income countries. Before these expanded access programs are approved, both drugs may be requested by physicians through Health Canada's Special Access Program.

### **Proceed with caution**

Maraviroc and raltegravir have been tested for a relatively short period of time—less than one year in publicly released data. And so far, these drugs don't appear to cause serious side effects in large numbers of people. Certainly this is a promising development. However, as more people with HIV/AIDS use these drugs for longer periods, unexpected side effects may emerge. Therefore, while there is certainly an urgent need for

## **At this year's CROI conference, researchers became concerned that efavirenz may have the potential to cause lipoatrophy.**

these medicines, particularly among treatment-experienced people living with HIV/AIDS, some caution is needed since we don't know the long-term effects of these medications.

A good example of the complexity of assessing long-term side effects is the research into the loss of the fatty layer under the skin, called lipoatrophy. When this occurs, fat is lost in the face, arms, and legs, resulting in a disfiguring appearance. In the mid to late 1990s when this problem appeared in an increasing number of PWAs, researchers weren't sure why it occurred. Because PIs had been released during this period, it seemed natural to link their use to lipoatrophy.

However, several years of research revealed that exposure to certain medications called thymidine analogues—d4T (stavudine, Zerit) and AZT (zidovudine, Retrovir)—were the chief culprits behind the loss of fat. Recently, both British and American treatment guidelines have been amended so that the use of d4T, at least for initial therapy of HIV infection, is discouraged.

### **Concerns about efavirenz and lipoatrophy**

At this year's CROI conference, researchers became concerned that another medication, efavirenz (Sustiva, Stocrin) may have the potential to cause lipoatrophy. Several years ago, clinical trials found that efavirenz, when taken as part of combination therapy, had strong anti-HIV activity. Efavirenz was listed in several treatment guidelines as being as good a choice as a PI.

But researchers in France who were trying to understand fat loss in PWAs were meanwhile conducting test tube experiments on human fat cells with efavirenz. They found that this drug appears to affect the growth and development of fat cells. Also, over time, the concentration of efavirenz in fat cells becomes many times greater than it is in the blood. The accumulation of efavirenz in fat cells may cause these cells to malfunction and die.

At the 2007 CROI conference, two studies comparing the effects of efavirenz to PIs were presented. Both studies found that the use of efavirenz was linked to an increased risk for the development of fat wasting in people living with HIV/AIDS. This development has occurred several years after efavirenz was licensed and should stand as a cautionary note.

### **A new compound for lipohypertrophy**

Other abnormalities with fat can occur in people who use highly active antiretroviral therapy (HAART). One of them is a tendency to have fat accumulation in the belly—lipohypertrophy. In this condition, fat gets deposited deep in the belly, wrapped around vital organs. This type of fat, called visceral fat, is not easily removed.

So news that a new compound called TH9507 can help PWAs lose belly fat was encouraging. TH9507 is being developed by Theratechnologies, a Canadian company. The drug works by stimulating the brain to release growth hormone (GH). In HIV infection, levels of GH are less than normal. This hormone is important for maintaining muscles, as well as strength and decreasing fat. In a six-month placebo-controlled trial in PWAs, TH9507 helped to reduce belly fat. A downside is that the drug had to be injected under the skin daily. A second study is about to start recruiting participants across Canada.

All in all, this year's CROI conference featured many promising developments. But based on the history of HIV medications so far, you'd do well to add a bit of caution to your optimism whenever news about an emerging therapy appears. ☹

*Sean Hosein is the science and medicine editor at the Canadian AIDS Treatment Information Exchange in Toronto.*



# Dual crises

## **Research projects are tackling the interconnected relationship between HIV/AIDS and food security**

by Audrey Le

**A**t last year's XVI International AIDS Conference in Toronto, four important sessions focused specifically on the bi-directional relationship between food security and HIV/AIDS in various parts of Africa. The broad definition of food security is "the access and availability of food." It's a major issue in developing countries. Due to its correlation with the prevention and the treatment of HIV/AIDS, it's an area that needs more exposure and attention.

### **The RENEWAL Initiative**

The Regional Network on HIV/AIDS, Livelihoods and Food Security (RENEWAL) is a research network that addresses the interaction between HIV/AIDS and food security, nutrition, and livelihoods in sub-Saharan Africa. The RENEWAL Initiative set out to demonstrate "the ways in which extreme poverty and food insecurity place people at greater risk of being exposed to the virus." It's interesting to note the direct relationship between stigma and poverty and food insecurity. AIDS-related discrimination and stigma paralyzes households and communities and has negative impacts on food security and livelihoods.

One of the key points from this session was the need to avoid what they called AIDS exceptionalism: researchers and others need to use an HIV/AIDS lens to broaden their thinking from agriculture to livelihoods. The next few years of RENEWAL's work will focus on developing a policy response that emphasizes three pillars among community-based researchers: action research, local capacity building, and communication.

The presentation explored the themes of resilience and resistance, through examples from Zambia. In this context, resilience is defined as the extent to which households and communities maintain their well-being over time, despite distressful events. Resistance is defined as the ability to avoid HIV exposure at the individual and household levels while preventing high infection rates at the community level.

Factors affecting household resilience include the relative wealth ranking and socio-economic status of a household, the presence or absence of community support, and the presence or absence of illness or death. Factors affecting household and community resistance to HIV infection are: livelihood activities and rural-urban movements and the link to risky sexual behaviours, alcohol abuse and its association with extra-marital sex and lower condom usage, poverty and transactional sex (linked with lower socio-economic status), and disparities between women and men in resources and economic opportunities.

### **Breaking the vicious cycle**

A session entitled "Breaking the Vicious Cycle of Food Insecurity and HIV and AIDS" highlighted the experiences of programs that address food, nutrition, and income security in ways that help achieve the objectives of HIV prevention, positive living, access and adherence to treatment, and alleviation of social and economic impacts. The presentation demonstrated the interaction between the impacts of food and nutrition security at each of the stages of HIV/AIDS progression and alerted the need for linking food security programs to actions.

The session reiterated that food insecurity worsens the HIV/AIDS epidemic. The broad definition of food security fails to specify that the quality of food is more important than quantity. Adequate good quality food is necessary for proper treatment; PWAs on treatment have special caloric and protein needs.

The session drew attention to the fact that food security specialists have a very limited understanding of HIV/AIDS. In addition, public health and HIV/AIDS specialists have a limited knowledge and understanding of agriculture and food security.

## The connection between nutrition and treatment

A presentation entitled “Food and Nutrition in Care and Treatment Programs in Developing Countries” brought to light the problem that food and nutrition security has not been seen as a vital factor to antiretroviral therapy (ART) responses. The aim is to bring the same type of urgency to food security that ART received three years ago. The presenters noted that most people living in the research areas experienced very high levels of food insecurity and utilized their household money to fulfill their food security needs. On top of this, ART requires additional resources, which are not always available or attainable.

The AIDS Support Organization (TASO) in Uganda is an example of an advocacy effort to combine food with ART. TASO provides a basic food package for people who come for assistance as well as for their immediate family because it’s recognized that these people are most likely responsible for the family’s well-being. TASO’s efforts reaffirmed that without food, there is declining treatment adherence.

## How gender is connected to food security

A session called “HIV, Gender, and Development: The Poverty, Malnutrition, Food Security Cycle (from Evidence to Action)” talked about which households are most vulnerable to food insecurity. Countries emerging from armed conflicts are at risk of food shortages. As a result, HIV/AIDS is a very low priority item on the agenda of relief workers in these war-torn countries. In these countries, unemployment rates are extremely high and many large families are forced to survive on a single person’s wages.

The households that are most vulnerable to food insecurity are the ones that are affected by HIV/AIDS and headed by a woman. Child-headed homes are also particularly challenging, in that the children lack the resources, education, and experience to properly look after themselves. Communities try to assist them in obtaining food and education, however this is a difficult and inconsistent process. There is a great need for advocacy on behalf of these families.

Focusing on the interaction between HIV/AIDS and food is one aspect of the epidemic, but transforming this information into action is another. The effect of AIDS is determined by the existing political, economic, and social systems. Panelists offered four response requirements that need to be addressed simultaneously: strengthen the household and community, preserve and enhance livelihood options and strategies, protect vulnerable groups, and strengthen governance and capacity.

## Key themes from the food security sessions

- ▶ The recognition of a bi-directional relationship between food and nutrition security and HIV/AIDS.
- ▶ The critical need for access and availability of good quality food to diminish vulnerability and susceptibility, the need to improve prevention, treatment and care, and the need for positive living interventions.
- ▶ The need for a continuum of interventions to meet the needs of various groups.
- ▶ The importance of understanding HIV/AIDS as one of the many factors impacting food-insecure communities and the need to build on a multitude of partnerships to ensure sustainability and facilitate scaling-up strategies.

## Taking action

Among organizations dealing with these issues, Grassroots Organizations Operating Together in Sisterhood (GROOTS) is a community-based organization of women who are helping women and children living with HIV. Their work focuses on educating women and children about poverty issues, in order to empower them with the knowledge to intervene when the law tries to take their property away.

The Swaziland Positive Living (SWAPOL) organization was founded in 2001 by five HIV-positive women. Their work involves spreading the knowledge that nutrition is important to the efficacy of medical treatment. They conduct activities related to food production, vegetable growing, seedling production, and neighbourhood care points where orphans and vulnerable children can obtain food and have exposure to informal education and play.

These four AIDS conference sessions made a great effort to shed light on the interlinking challenges of the dual crises of HIV/AIDS and food security. Food security issues need to be integrated with prevention and treatment of HIV/AIDS programs in a comprehensive way to address the AIDS epidemic. ☺



*Audrey Le is a researcher and writer for BCPWA .*



# Average JOES

Numbers Cabaret,  
1042 Davie Street

Wednesdays 8:30PM - 11:00 ISH

For more info

phone: 604.893.2200 or 604.893.2258

[www.bcpwa.org](http://www.bcpwa.org) > click on Support groups  
and services



Weekly Gathering  
of Poz Gay Men

Food, Fun & Games  
Seasonal Events & Excursions  
Draws & Prizes

# Volunteering at BCPWA

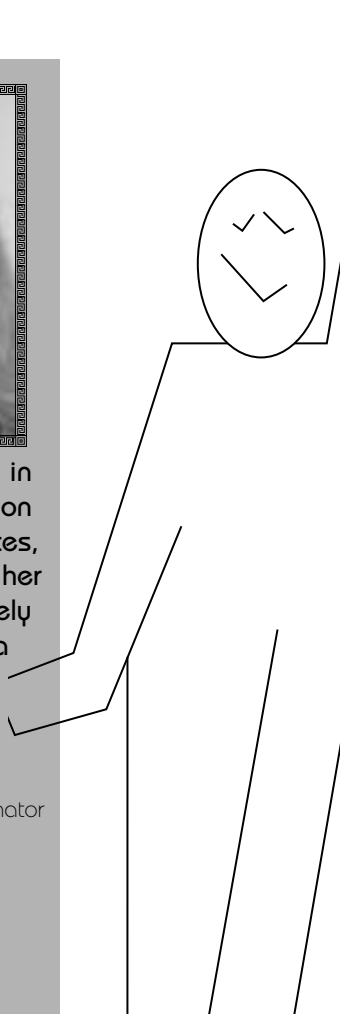
Profile of a volunteer:

## Joey Ufnal



"It's great to have Joey in the Treatment Information Program. She participates, asks questions, shares her experiences, and genuinely cares for others. She's a great example of an empowered volunteer."

**Zoran Stjepanovic,**  
treatment information coordinator



### Volunteer history

I started at BCPWA in the coffee lounge serving coffee and other refreshments, then I was inspired by people that I was able to talk to and I became involved in the Treatment Information Program as a counsellor.

**Started at BCPWA**  
2003

### Why pick BCPWA?

To become better informed about HIV/AIDS.

### Why have you stayed?

I feel BCPWA is an incredible organization that has helped many people struggling with the many perils of everyday living.

### Strongest point about volunteering

I feel it empowers people. The BCPWA mission statement says it all.

### Favorite memory

My favorite memory of BCPWA is ongoing. The staff and my fellow volunteers have made an incredible impact on my life. I've never seen such dedication and strength in a group of people.

### Future vision of BCPWA?

I have great hopes for more funding, a better understanding by those around us, and an end to the stigma related to this devastating virus.

## Polli & Esther's Closet

Your peer-run, second time around store!

Bring your membership card  
and pay us a visit at  
1107 Seymour Street, 2nd Floor

Open Tuesday, Wednesdays & Thursdays,  
11AM to 2PM for your shopping convenience

Great selection!



# where to find help

If you're looking for help or information on HIV/AIDS, the following list is a starting point.

## **A Loving Spoonful**

Suite 100 – 1300 Richards St,  
Vancouver, BC V6B 3G6  
604.682.6325  
e clients@alovingspoonful.org  
www.alovingspoonful.org

## **AIDS Memorial Vancouver**

205 – 636 West Broadway,  
Vancouver BC V5Z 1G2  
604.216.7031 or 1.866.626.3700  
e info@aidsmemorial.ca www.aidsmemorial.ca

## **AIDS Society of Kamloops**

P.O. Box 1064, 437 Lansdowne St,  
Kamloops, BC V2C 6H2  
t 250.372.7585 or 1.800.661.7541  
e ask@telus.net

## **AIDS Vancouver**

1107 Seymour St, Vancouver BC V6B 5S8  
t 604.893.2201 e av@aidsvancouver.org  
www.aidsvancouver.bc.ca

## **AIDS Vancouver Island (Victoria)**

1601 Blanshard St, Victoria, BC V8W 2J5  
t 250.384.2366  
e info@avi.org www.avi.org

## **AIDS Vancouver Island (Cowichan Valley)**

t 250.701.3667

## **North Island AIDS (Campbell River) Society**

t 250.830.0787

## **North Island AIDS (Port Hardy) Society**

t 250.902.2238

## **AIDS Vancouver Island (Nanaimo)**

t 250.753.2437

## **North Island AIDS (Courtenay) Society**

t 250.338.7400 or 1.877.311.7400

## **ANKORS (Nelson)**

101 Baker St, Nelson, BC V1L 4H1  
t 250.505.5506 or 1.800.421.AIDS  
f 250.505.5507 e info@ankors.bc.ca  
http://kics.bc.ca/~ankors/

## **ANKORS (Cranbrook)**

205 – 14th Ave N, Cranbrook,  
BC V1C 3W3  
250.426.3383 or 1.800.421.AIDS  
f 250.426.3221 e gary@ankors.bc.ca  
http://kics.bc.ca/~ankors/

## **Asian Society for the Intervention of AIDS (ASIA)**

210 – 119 West Pender St,  
Vancouver, BC V6B 1S5  
t 604.669.5567 f 604.669.7756  
e asia@asia.bc.ca www.asia.bc.ca

## **BC Persons With AIDS Society**

1107 Seymour St, Vancouver BC V6B 5S8  
604.893.2200 or 1.800.994.2437  
e info@bcpwa.org www.bcpwa.org

## **Dr Peter Centre**

1100 Comox St,  
Vancouver, BC V6E 1K5  
t 604.608.1874 f 604.608.4259  
e info@drpetercentre.ca  
www.drpetercentre.ca

## **Friends for Life Society**

1459 Barclay St, Vancouver, BC V6G 1J6  
t 604.682.5992 f 604.682.3592  
e info@friendsforlife.ca  
www.friendsforlife.ca

## **Healing Our Spirit**

3144 Dollarton Highway,  
North Vancouver, BC V7H 1B3  
t 604.879.8884 or 1.866.745.8884  
e info@healingourspirit.org  
www.healingourspirit.org

## **Living Positive Resource Centre Okanagan**

101–266 Lawrence Ave.,  
Kelowna, BC V1Y 6L3  
t 250.862.2437 or 1.800.616.2437  
e lprc@lprc.ca  
www.livingpositive.ca

## **McLaren Housing Society**

200 – 649 Helmcken St,  
Vancouver, BC V6B 5R1  
t 604.669.4090 f 604.669.4092  
e mclarenhousing@telus.net  
www.mclarenhousing.com

## **Okanagan Aboriginal AIDS Society**

101 – 266 Lawrence Ave.,  
Kelowna, BC V1Y 6L3  
t 250.862.2481 or 1.800.616.2437  
e oaas@arcok.com www.oaas.ca

## **Outreach Prince Rupert**

300 3rd Ave. West  
Prince Rupert, BC V8J 1L4  
t 250.627.8823  
f 250.624.7591  
e aidspr@rapidnet.net

## **Pacific AIDS Network c/o AIDS Vancouver Island (Victoria)**

1601 Blanchard St.,  
Victoria V8W 2J5  
t 250.881.5663 f 250.920.4221  
e erikages@pan.ca www.pan.ca

## **Positive Living North**

1–1563 2nd Ave,  
Prince George, BC V2L 3B8  
t 250.562.1172 f 250.562.3317  
e info@positivelivingnorth.ca  
www.positivelivingnorth.ca

## **Positive Living North West**

Box 4368 Smithers, BC V0J 2N0  
3862 F Broadway, Smithers BC  
t 250.877.0042 or 1.886.877.0042  
e plnw@bulkley.net

## **Positive Women's Network**

614 – 1033 Davie St, Vancouver, BC V6E 1M7  
t 604.692.3000 or 1.866.692.3001  
e pwn@pwn.bc.ca www.pwn.bc.ca

## **Purpose Society HIV/AIDS program**

40 Begbie Street  
New Westminster, BC V3M 3L9  
t 604.526.2522 f 604.526.6546

## **Red Road HIV/AIDS Network Society**

804 – 100 Park Royal South,  
W. Vancouver, BC V7T 1A2  
t 604.913.3332 or 1.800.336.9726  
e info@red-road.org www.red-road.org

## **Vancouver Native Health Society**

441 East Hastings St, Vancouver, BC V6G 1B4  
t 604.254.9949  
e vnhs@shaw.ca

## **Victoria AIDS Resource & Community Service Society**

1284 F Gladstone Ave, Victoria, BC V8T 1G6  
t 250.388.6620 f 250.388.7011  
e varcs@islandnet.com  
www.varcs.org/varcs./varcs.nsf

## **Victoria Persons With AIDS Society**

#330-1105 Pandora St., Victoria BC V8V 3P9  
t 250.382.7927 f 250.382.3232  
e support@vpwas.com www.vpwas.com

## **Wings Housing Society**

12 – 1041 Comox St, Vancouver, BC V6E 1K1  
t 604.899.5405 f 604.899.5410  
e info@wingshousing.bc.ca  
www.wingshousing.bc.ca

## **YouthCO AIDS Society**

205 – 1104 Hornby St.,  
Vancouver BC V6Z 1V8  
t 604.688.1441 1.877.968.8426  
e information@youthco.org  
www.youthco.org

**For more comprehensive  
listings of HIV/AIDS  
organizations and services  
please visit [www.bcpwa.org](http://www.bcpwa.org).**

## Upcoming BCPWA Society Board Meetings:

Date	Time	Location	Reports to be presented
May 9, 2007	4:30	Board Room	Written Executive Director Report / Standing Committees
May 23, 2007	4:30	Board Room	Financial Statements - April / Director of TIAD
June 6, 2007	4:30	Board Room	Written Executive Director Report / Executive Committee
June 20, 2007	4:30	Board Room	Standing Committees / Financial Statements — May / Director of Communications
July 4, 2007	4:30	Board Room	Written Executive Director Report / Director of Support
July 18, 2007	4:30	Board Room	Executive Committee / Director of Development

BCPWA Society is located at 1107 Seymour St., 2nd Floor, Vancouver.

For more information, contact: **Alexandra Regier, office manager** Direct: 604.893.2292 Email: alexr@bcpwa.org

## BCPWA Standing Committees and Subcommittees

If you are a member of the BC Persons With AIDS Society, you can get involved and help make crucial decisions by joining a committee. To become a voting member on a committee, please attend three consecutive meetings. For more information on meeting dates and times, please see the contact information on the right column for the respective committee that you are interested in.

### Board & Volunteer Development

Contact: Adriaan de Vries  
 ☎ 604.893.2298 ✉ adriaand@bcpwa.org

### Community Representation & Engagement

Contact: Marc Seguin  
 ☎ 604.646.5309 ✉ marcs@bcpwa.org

### Education & Communications

Contact: Melissa Davis  
 ☎ 604.893.2209 ✉ melissad@bcpwa.org

### IT Committee

Contact: Marie Cambon  
 ☎ 604.893.2280 ✉ mariec@bcpwa.org

### living+ Magazine

Contact: Jeff Rotin  
 ☎ 604.893.2206 ✉ jeffr@bcpwa.org

### Prevention

Contact: Elgin Lim  
 ☎ 604.893.2225 ✉ elginl@bcpwa.org

### Support Services

Contact: Jackie Haywood  
 ☎ 604.893.2259 ✉ jackieh@bcpwa.org

### Treatment Information & Advocacy

Contact: Jane Talbot  
 ☎ 604.893.2284 ✉ janet@bcpwa.org

### Yes! I want to receive living+ magazine

Name \_\_\_\_\_

Address \_\_\_\_\_ City \_\_\_\_\_

Province/State \_\_\_\_\_ Country \_\_\_\_\_ Postal/Zip Code \_\_\_\_\_

Phone \_\_\_\_\_ E-mail \_\_\_\_\_

I have enclosed my cheque of \$\_\_\_\_\_ for living+

- \$25 within Canada     \$50 (Canadian \$) International  
 please send \_\_\_\_\_ subscription(s)
- BC ASOs & Healthcare providers by donation: Minimum \$6 per annual subscription  
 please send \_\_\_\_\_ subscription(s)
- Please send BCPWA Membership form (membership includes free subscription)
- Enclosed is my donation of \$\_\_\_\_\_ for living+

\* Annual subscription includes 6 issues

Cheque payable to BCPWA



# living+

1107 Seymour Street  
 2nd Floor  
 Vancouver BC  
 Canada V6B 5S8

For more information visit  
[www.bcpwa.org](http://www.bcpwa.org)  
 e-mail to [living@bcpwa.org](mailto:living@bcpwa.org)  
 or call 604.893.2206



# For the love of chocolate

## *A story with a sweet beginning and an even sweeter ending*

by Denise Becker

**T**here's a secret connection between chocolate and CD4 machines. I was amazed to discover just how curiously one can lead to another.

Since childhood, I have had a secret bad habit: chocolate. The truth is, I just can't get enough of it. When I go chocolate, I go big—whole bars at a time. No popcorn for me at movies! No, it's M&Ms, and they're gone before the coming attractions are finished. It's really quite pathetic.

I was driving my truck the other day when I mysteriously took a right turn and parked in front of Chocolaterie Bernard Callebaut. Dazed, I went inside and before I could say, "Holy Cow, I'm in this place again," the manager was offering me samples of some naughty little delicacies. Imagine the movie *Chocolat*: the rolling eyes, the closing eyelids, the slow motion chewing. Délicieux!

I opened my eyes just long enough to catch sight of a piggy bank on the counter with "AIDS WALK" written on it and realized these guys were one of the biggest donors in Kelowna. So, while reaching for another truffle, I talked with the owner about our common acquaintance, Daryle Roberts, the executive director of Kelowna Living Positive Resource Centre. I realized I hadn't had a good chat with Daryle for about two years.

When I got home, the phone rang. Unbelievably, it was Daryle. He had been thinking about me as a guest speaker at Trinity Baptist Evangelical Church, the biggest church in Kelowna, to talk about what it's like to live with HIV/AIDS. The coincidence was just too weird, so—despite my apprehensions about standing in front of a potentially hostile group of people—I agreed to give the talk, but only if I could meet the pastors first. If they were going to hear my life story, I wanted to hear their opinions first.

The next day I met with Pastor Greg. He listened intently to what I had to say. He told me his wife was a nurse who had practiced in California. Then he said: "Denise, I have to tell you that I think the way the church has treated gay people is not just a sin but an abominable sin." My jaw dropped.

I had to let it sink in for a minute. I wanted to hug him. I knew this speaking engagement would work.

The first service on Saturday night was low key, mainly for young people. It was a good way to start and I even recognized a hymn, which made me feel more comfortable. I glanced at a couple sitting behind me with a giggling baby, and they returned my smile. I then went on stage and explained how I found out about my HIV diagnosis when my baby got sick and tested positive for AIDS; Katie died at nine months old. The couple looked shocked, their eyes welling up with tears. Then they left the service.

After I spoke, Pastor Tim came on the stage. He asked a little girl who was about 10 years old what she had made for dinner, what she did for a living, and how she was going to balance the budget in the house. The little girl looked bewildered and replied, "I don't know!" The congregation laughed. But Tim was illustrating what an orphan in Africa deals with every day.

There were two more services on Sunday. One woman approached me after one of the services and said she had never told anyone that her husband died of AIDS. It was so gratifying to have her share her story openly.

All in all I spoke to 2,200 churchgoers. Pastor Tim taught the congregation how Jesus would have treated people if He were alive today; he told them that the church was determined to provide two CD4 machines to the Congo and Nigeria. It would cost more than \$20,000.

They raised the money in just 15 days. I felt like crying when I heard the news. I was thrilled to see how my trip to the chocolate shop was by some higher design, serving some greater purpose. It made me realize just what can happen when you get in touch with Mr. Big—both the chocolate and heavenly varieties! ☺

*Denise Becker is a board member of the Canadian HIV/AIDS Legal Network and the founder of the Hummingbird Kids Society. She lives in Kelowna.*

