inside ▷▷▷

features

treatment information ▷▷▷

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, Michael Connidis, Sam Friedman, Rob Gair, Derek Thaczuk, Glyn Townson

Managing editor Jeff Rotin

Design / production Britt Permien

Copyediting Alexandra Wilson

Contributing writers
Dave Boyack, Jennifer Chung, Dr. Marianne Harris, R. Paul Kerston, Thiha Maung Maung, Richard Pearshouse, Dani Shahvarani, Ashley Smith, Carley Taylor, David van den Broek, Shawn Wakley, Katolen Yardley

Photography Britt Permien

Acting director of communications & education
Julia Smith

Director of treatment information & advocacy
Adriaan de Vries

Treatment informationcCoordinator
Zoran Stjepanovic

Director of positive prevention
Elgin Lim

Subscriptions / distribution
Ryan Kyle, Joe LeBlanc, Martin Davies

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

British Columbia

EMAIL living@bcpwa.org
BCPWA ONLINE www.bcpwa.org

think ⊕

opinion & editorial . . .

Our Complementary Health Fund

by Glyn Townson

The Complementary Health Fund (CHF), which provides reimbursement to BCPWA members for the cost of products and services for HIV/AIDS-related symptoms not subsidized by other resources, was one of the very first services that BCPWA provided. As chair of BCPWA, I'm proud of the CHF. However, over the past few years the fund hasn't been used to its full capacity by our members who are eligible.

Back in 1988, it was costly and difficult for people living with HIV to maintain their health. Often BCPWA members were forced to leave good paying jobs and wound up on disability benefits and limited incomes. The CHF provided funds for alternate treatments, safe drinking water, and vitamins essential for members to live. Fortunately in BC, since the advent of antiretrovirals in the early 1990s (covered by the province through the BC Centre for Excellence in HIV) members' needs began to change.

Over many years, we have successfully advocated for enhanced benefits for our members from provincial government programs. However, even with available medications and treatments, there are many services that can greatly increase health and well-being that aren't covered by private or public insurance plans. For example, the CHF subsidizes Traditional Chinese Medicine, reiki, and acupuncture, which aren't covered by BC's Medical Services Plan.

The CHF is available to all BCPWA members who make less than $3,000 a month. If you collect a monthly nutritional supplement benefit (MNSB), you can't access the CHF for any items your MNSB covers, but you can still use the CHF to pay for items like a gym membership, or a massage, or reiki treatment. BCPWA members can attach eligible paid receipts from stores, community centres, gyms, and professional practitioners and be reimbursed for up to $55 per calendar month.

CHF is funded by our annual AIDS Walk for Life, a fundraising event that's been held every September for the last 22 years. The CHF program is administered and supported by volunteers. It's perhaps one of BCPWA's best examples of collective empowerment.

HIV medications continue to improve and we, as people living with HIV/AIDS, are living longer. New health challenges—such as heart disease, diabetes, and depression—can benefit from complementary and alternative modalities.

The CHF is just as important today as it was in 1988: A regularly scheduled gym routine can lower your blood pressure. Regular use of massage can reduce stress. And vitamins and supplements can help with fatigue.

I strongly encourage members who have not been using the CHF to utilize this unique service. CHF forms are available on BCPWA's website at www.bcpwa.org: look under "Empower Yourself" for "Support Groups and Services." If you're unsure if a particular product or service is covered or if you require further information, call a volunteer member of the CHF team at 604.893.2245. ⊕

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

REALITYBITES

News from home & around the world

Advocacy alert

Many BCPWA members have received a letter from the Ministry of Employment and Income Assistance reviewing reporting obligations. The Ministry wants people to report all changes to income, however the Act and Regulations state that you must report only income earned over $500 and changes to family unit. If you have concerns about reporting, please contact BCPWA's Advocacy Department at 604.893.2223.

Electronic record sharing may erect barriers to treatment

Almost two-thirds of HIV and sexual health clinic attendees questioned about electronic patient records (EPR) and record sharing don't want their physician informed of their visit, according to the results of a Scottish study recently published online in the journal, *Sexually Transmitted Infections*.

Investigators from the New Royal Infirmary in Edinburgh, Scotland sought to examine patient attitudes to the current trend towards the sharing of patient information across the National Health Service (NHS).

The study suggests that without substantial patient education, establishing EPR and wider record sharing may inadvertently erect barriers to HIV and STI testing and treatment, since one-in-four respondents said that they that they would be less likely to attend sexual health clinics if electronic sharing of their sexual health records occurred.

Source: www.aidsmap.com

Detox centre at InSite

The injection drug users of downtown Vancouver have a new ally in the fight to get clean. InSite, Vancouver's supervised injection facility, has opened a detox centre with 12 beds, private bathrooms, a nurse, and a counsellor. “People are being treated humanely,” says director Mark Townsend.

Prime Minister Stephen Harper opposes it, however, and the government will decide its fate in June 2008. Show your support at www.communityinsite.ca/support.html.

Source: www.poz.com

HIV infection and childhood vaccines

A new study conducted in Cameroon and the Central African Republic has found that HIV-negative and HIV-positive infants born to mothers infected with the virus had lower than normal levels of antibodies from childhood vaccines, *Science Daily* reports.

The study, coordinated by the Institut Pasteur in Paris, examined children ages 18 months to 36 months. Researchers found that HIV-positive children had particularly low levels of measles vaccine antibodies. HIV-negative children born to HIV-infected mothers also had lower than expected levels. The results suggest that children born to HIV-positive mothers may need adapted vaccine schedules.

Source: www.poz.com

Medical marijuana restrictions unfair, say lawyers

The federal government must loosen unfair restrictions that are preventing seriously ill Canadians from obtaining the medical marijuana they need to treat their debilitating illnesses, lawyers for the sick have argued in Federal Court in Toronto.

Licensed medical marijuana users are suing Health Canada over its rules regarding the growing of the drug and its distribution.

Health Canada has effectively established itself as the country's sole legal provider of medical marijuana, but is providing an expensive yet ineffective drug that doesn't meet the needs of many patients who use it to treat chronic pain, seizures and other ailments, Alan Young, an Osgoode Hall Law School professor said.

There are providers who want to supply various strains of the drug at a lower cost for medical use, but they're prohibited from doing so because government policy restricts them from supplying more than one patient, he added.

Source: The Canadian Press

HIV infection drastically enhanced by semen ingredient

A plentiful ingredient found in human semen drastically enhances the ability of the HIV virus to cause infection, according to a report in the December 14, 2007, issue of the journal *Cell*. The findings suggest a potential new target for preventing the spread of AIDS, the researchers said.

Collaborating research groups in Hannover and Ulm, Germany, show that naturally occurring fragments of so-called prostatic acidic phosphatase (PAP) isolated from human semen form tiny fibres known as amyloid fibrils. Those fibrils capture HIV particles and help them to penetrate target cells, thereby enhancing the infection rate by up to several orders of magnitude.

“We were not expecting to find an enhancer, and were even more surprised about the strength,” said Frank Kirchhoff

continued on next page

REALITYBITES

News from home & around the world

of the University Clinic of Ulm. “Most enhancers have maybe a two- or three-fold effect, but here the effect was more than 50-fold and, under certain conditions, more than 100,000-fold.”

Source: www.medicalnewstoday.com

Need for ARVs that restore immune function

New data on cancer rates among HIV-positive people underline the need for the development of antiretroviral drugs that restore immune function more effectively than currently available treatments, according to Mark Wainberg, director of McGill University’s AIDS Centre at the Jewish General Hospital in Montreal, in a recent *Washington Post* opinion piece.

As a result of increased life expectancy because of new antiretrovirals, clinicians and researchers are seeing higher rates of several life-threatening cancers among people who have been HIV-positive for long periods of time, Wainberg writes.

He adds that although the numbers are still relatively small overall, these cancers are occurring with far higher frequency among PWAs than among the general population. One reason for the increase is that HIV causes a decline in immunological function that can’t be completely repaired by antiretrovirals, according to Wainberg.

Source: www.kaisernetwork.org

Money for community programs in Ontario slashed

Federal funding for community AIDS programs in Ontario is being slashed as the Conservative government readjusts overall spending and redirects money to a Bill Gates AIDS vaccine initiative it announced earlier last year.

Money that helps prevent local organizations stem the spread of the virus and provide support to those infected is being reduced by 30 per cent across the province. Ontario was targeted because its funding cycle is different than that of other provinces, federal health officials explained, and much of the money for special projects had not been allocated as it had been elsewhere in the country.

When the money for the $139-million Canadian HIV Vaccine Initiative was announced last February, a federal news release boasted that “Canada’s new government and the Bill & Melinda Gates Foundation have committed major new funding.” In fact, approximately $26-million of the government’s portion had been redirected from other AIDS projects, including the community programs in Ontario.

Source: The Globe and Mail

One HIV subtype more deadly than others

Two studies led by researchers at the Johns Hopkins Bloomberg School of Public Health found that people infected with HIV in Thailand die from the disease significantly sooner than those with HIV living in other parts of the world. According to the researchers, the shorter survival time measured in the studies suggests that HIV subtype E, which is the most common HIV subtype in Thailand, may be more virulent than other subtypes of the virus.

The first study followed 228 men over a 14-year period starting in 1991. Researchers compared them to a group of similar HIV-positive men living in North America and Europe who were included in another study. The median time from HIV infection to death for the Thai men was 7.8 years compared to 11 years for HIV-positive men living in North America and Europe.

For the second study, researchers followed a small group of male blood donors and their wives from 1992 to 2007. The median survival rate from infection to death was 7.8 years for the men and 9.6 years for the women.

Source: www.sciencedaily.com

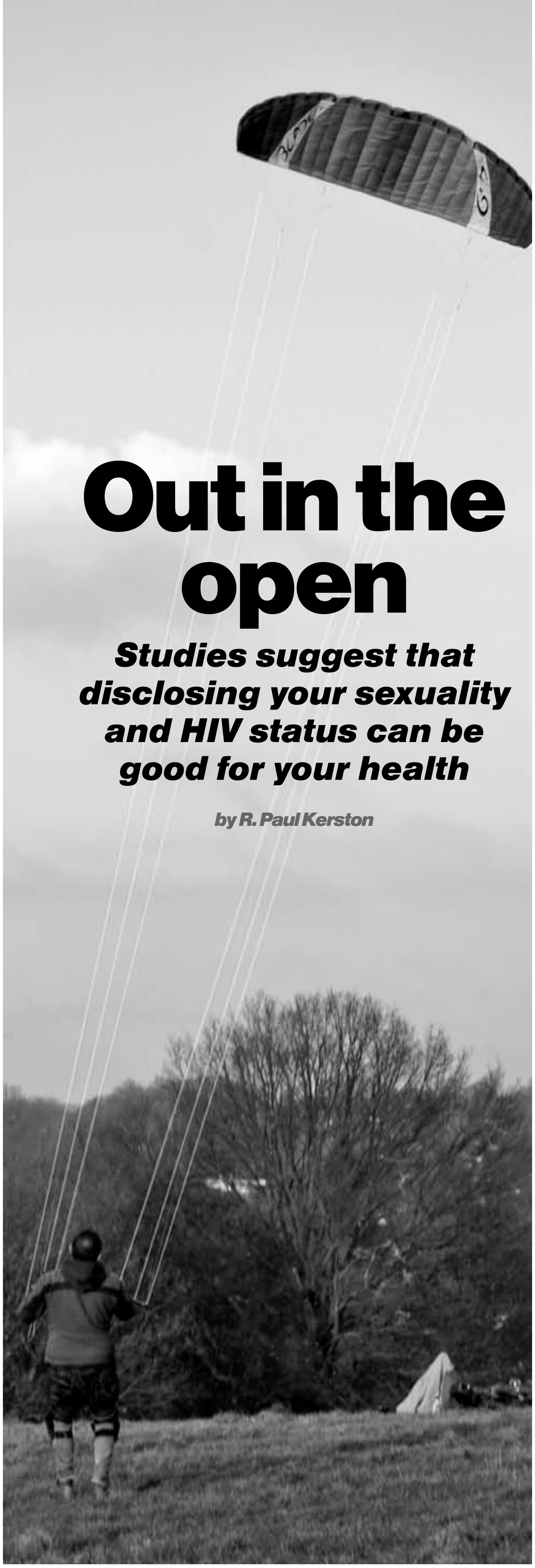
Increase in HIV/AIDS cases in China

The number of HIV/AIDS cases on mainland China increased by an average of 3,000 monthly between January 2006 and June 2007, according to the Chinese Center for Disease Control and Prevention.

By November, 2007, 32,235 new HIV/AIDS cases had been recorded for the year and about 3,000 people had died of AIDS-related causes since January 2007. About 38 percent of new HIV diagnoses were transmitted sexually, an increase of 30 percent from 2006. In addition, about 3 percent of new cases were transmitted among men who have sex with men.

The government estimates that 220,000 people nationwide were living with HIV/AIDS at the end of September; however, UNAIDS estimated that that number at about 650,000 people.

Source: www.kaisernetwork.org ⊕



Out in the open

Studies suggest that disclosing your sexuality and HIV status can be good for your health

by R. Paul Kerston

Some people wonder about the differences between being gay with HIV and being straight with HIV. Now there's proof that there may be an important difference between living both openly gay and openly HIV-positive—or not living openly.

Results from a Seattle study, published in *Psychosomatic Medicine*, showed that CD4 cell counts actually go up in individuals who disclose both sexual orientation as well as HIV-positive status compared to those who don't. While the researchers aren't advocating such disclosure, nor saying it's a strategy for improved health outcomes, the study seems to indicate a benefit to those who disclose—a benefit that argues against the stigma and other still all-too-common consequences of such actions.

Between 1994 and 2004, seven studies dealt with, among other issues, the subject of psychological inhibition—simply defined as not publicly expressing significant private experiences—and its relationship to such things as a faster decrease in CD4 cell counts, or worse. Researchers theorize that psychological inhibition puts stress on immune function.

In a related but different study result, James W. Pennebaker, of Southern Methodist University in Dallas, and his colleagues found that expressing thoughts and feelings about a significant event, over time, led to fewer doctor visits. However, in a study entitled "The role of disclosure in coping with HIV infection," published in *AIDS Care* in 1998, researchers showed that newly-diagnosed HIV-positive gay men were unlikely to disclose their serostatus at least until they came to terms with the news.

The latest information comes from 373 psychiatric patients who were evaluated in a study conducted at the University of Washington School of Medicine's Department of Psychiatry and Behavioral Sciences in Seattle over a four-year period. The study was published as "Disclosure of HIV Status and Sexual Orientation Independently Predicts Increased Absolute CD4 Cell Counts Over Time for Psychiatric Patients." The researchers took the hypothesis that disclosure of sexual orientation improved immune function and went a further step in exploring "whether concealment of HIV status has an effect on immune function" in similar fashion.

The objective of this 2007 study was to see if disclosure of HIV status within a psychiatric setting had the same effect of raising CD4 counts as gay people's self-outing. Investigators found that "consistent disclosure of both sexual orientation and HIV status independently"—and the word "independently" is key here—"predicted increased CD4 cell counts over time." The authors therefore conclude that "relieving potential psychological distress by disclosing sexual orientation and HIV status has a positive impact on CD4 cell counts over time, even among outpatients stressed by psychiatric illness and economic disadvantage."

These results have implications for the potential benefits of disclosure in Vancouver, given the parallels between Seattle, where the study was conducted, and Vancouver: a large gay community, pervasive homelessness, single-room occupancy hotel population, the many people receiving government economic assistance, and the many people who are unable to access necessary psychiatric healthcare in BC. The last words in this study are instructive: "Additional research is needed to understand whether and under what conditions disclosure should be part of HIV disease management."

Yeah, isn't that the truth. ⊕

__R. Paul Kerston__ is BCPWA's treatment outreach coordinator and community representation and engagement coordinator.

A helping hand

Paper examines legal issues related to assisted injection at supervised injection facilities

by Richard Pearshouse

The ban on assisted injection in supervised injection facilities may run afoul of the prohibition on discrimination and a person's right to life, liberty, and security of person. A recent paper by the Canadian HIV/AIDS Legal Network, called *A Helping Hand: Legal Issues Related to Assisted Injection at Supervised Injection Facilities*, looks at the ban through the lens of the *Canadian Charter of Rights and Freedoms*. The paper also considers potential forms of criminal and civil liability for those who might assist injections.

Supervised injection facilities (SIFs)—also called safe injection sites, supervised injection centres, and safe consumption centres—are legally sanctioned facilities that allow people to inject pre-obtained drugs with sterile equipment under the supervision of health professionals. These health facilities are a specialized health intervention within a wider network of services for people who use drugs.

According to the current legal framework and professional guidelines in Canada, SIF staff can't assist clients in administering their drugs, and clients can't help each other inject. While this policy doesn't represent a problem for many SIF clients, it does pose challenges for those people who have difficulty injecting themselves.

Recent studies show that the HIV prevalence rate for people who require assistance injecting illegal drugs is double that of those who don't, raising serious public health concerns. Women—who are frequently injected by their male partners or friends—are more than twice as likely as men to require assisted injection and twice as likely to report not knowing how to inject as the reason for requiring assistance.

The right to equal access

The prohibition on assisted injections may represent a barrier to equitable access for women, as well as for people with disabilities, who therefore can't benefit from SIFs.

In the context of the *Canadian Charter of Rights and Freedoms*, the prohibition of assisted injection at SIFs might be considered a violation of Section 7—the right to life, liberty, and especially security of the person. The ban could deter persons who require assistance injecting from gaining access to services that a SIF provides, such as medical supervision of injection, the use of clean syringes, and information on counselling and addiction treatment. Thus it could be argued that the ban creates an additional health risk for an already vulnerable group.

> **Recent studies show that the HIV prevalence rate for people who require assistance injecting illegal drugs is double that of those who don't, raising serious public health concerns.**

The prohibition might also be a violation of Section 15—the right to equality—in access to health care services. Case law suggests that when a treatment or service is offered by the government, Section 15 requires it be done in a way that is non-discriminatory. In other words, the government may have an obligation to take positive steps to ensure that disadvantaged groups benefit equally from services offered to the general public.

The murky question of liability

However, under criminal and civil law as it currently stands, if someone at a SIF did assist in an injection, he or she could be legally liable. But it's difficult to foresee all potential legal issues that might be associated with assisted injection at SIFs. The extent to which pre-existing jurisprudence can be applied to the practice of assisted injections at SIFs is also unclear.

There are potential areas of criminal and civil liability under Canadian law for health service providers and others who might provide assisted injections. Under the current law, it can be assumed that charges of possession and trafficking could be brought against SIF staff or clients if they assisted in injections.

Certain criminal law offences, which may at first glance appear to represent a problem—such as the offence of administering a noxious thing—may in fact not be applicable. But in a worst-case scenario, a person who receives assisted injection could die or be seriously injured from an overdose or other complication. It's unlikely that murder charges could be sustained in such cases; however, the situation would be much less clear in the case of manslaughter charges (in the case of an overdose death) or assault charges (in the case of serious harm).

The need for legal and policy reforms

It is clear that law and policy reforms may be necessary to reconcile the legal situation with human rights principles. Assisted injections at SIFs could be enabled under a modification of the current legal framework, explicitly providing for assisted injections in certain circumstances. Section 56 of the *Controlled Drugs and Substances Act* (CDSA) gives the federal Minister of Health broad authority to exempt people from the applications of the CDSA where he or she considers that "the exemption is necessary for a medical or scientific purpose or is otherwise in the public interest." This would evidently need to be complemented by necessary changes to the existing guidelines governing SIFs to set out the parameters governing assisted injections.

However, such an exemption would not remove other forms of liability, such as under the Criminal Code. Therefore, it may be beneficial to have a policy of non-prosecution for offences arising in the context of assisted injection. A non-prosecution policy could be adopted by provincial ministries or attorneys general in the jurisdictions in which the SIFs operate.

The law, particularly the criminal law in its current formulation, poses some challenges. Yet Canada's legal obligations to respect, protect, and fulfill the human right to the highest attainable standard of health for all persons—with a particular attention to the needs of the most vulnerable—also demands action, and may provide solutions, if the willingness can be found to take up the challenges. ⊕

Read up

You can read *A Helping Hand: Legal Issues Related to Assisted Injection at Supervised Injection Facilities* and other publications related to drug policy and harm reduction at www.aidslaw.ca/drugpolicy.

Richard Pearshouse *is the director of research and policy at the Canadian HIV/AIDS Legal Network.*

FIGHTING WORDS

Falling through the cracks

The need for treatment access for BC's non-status immigrants and refugees with AIDS

by Sam Friedman

Equitable and secure access to health care, treatment, and support services for all people with HIV/AIDS is an achievement at the heart of the AIDS movement. As the decades roll by and the demographics of AIDS in Canada rapidly changes, maintaining this high standard of universal excellence is proving to be difficult. Among the newest and most vulnerable faces of AIDS in British Columbia today are immigrants, refugees, and other non-status people.

In 2005 alone, 668 immigrant and refugee applicants tested HIV-positive through Citizenship and Immigration Canada. That equates to 15.7 percent of the total HIV-positive tests reported in Canada that year. (More recent statistics are not yet available.)

That disturbing statistic represents one of the fastest-growing rates of new HIV infections; and sadly, immigrants and refugees experience some of the harshest HIV-related stigma, sexism, homophobia, and racism documented anecdotally. That's on top of the losses and traumas many of them suffered in migrating to Canada.

This demographic faces numerous barriers: difficulties navigating the complex bureaucracy and legalities of the immigration system (for example, not understanding their rights); a low proficiency in reading, writing, or understanding either official language; and the fear and anxiety from cultural, legal, and human rights misunderstandings. As well, due to their non-status designation, they're restricted to the Interim Federal Health Programs' limited scope of basic and emergency services. In some cases it might only cover essential health services and the lowest-cost alternatives for prescription medications, which might not be enough to build a suitable drug regimen. As a result, far too many of these souls are—out of frustration and desperation—disappearing into an invisible life of silence, poverty, and ill health.

Why do these barriers still exist? The BC provincial AIDS community is known for fighting the good fight, for standing up for our rights and needs as a community. So how do we, the AIDS community, account for the fact that we haven't resolved these long-standing deficiencies in the system?

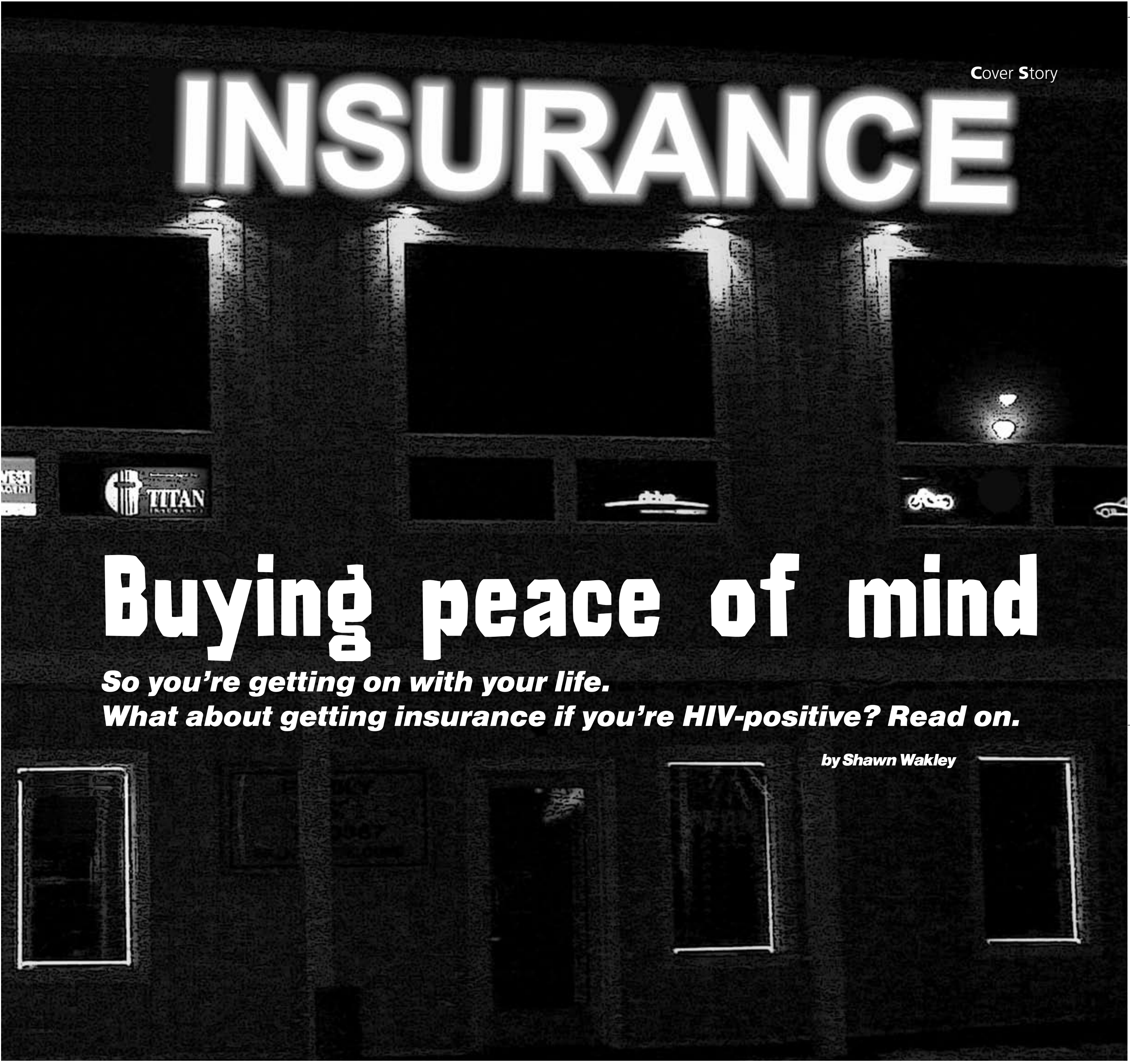
Advocates of the BC AIDS community and those of us living with AIDS should be working to prevent more of these people from falling through the cracks. We need to find the means to ensure they have access to HIV therapies through a compassionate access program, with translation services and access to resources and information, so our newest community members know we support and welcome them.

> **Far too many of these souls are—out of frustration and desperation—disappearing into an invisible life of silence, poverty, and ill health.**

For too long, it's been accepted that non-status immigrant PWAs' lack of citizenship status was responsible for restricting their access to HIV treatment and services. That rationale is negative and blameful, and only serves to hold us back. It most certainly has no place in the positive, outcome-driven solution that's needed to address this issue.

The solution requires communication and commitment by community organizations, clinicians, healthcare organizations, pharmaceutical companies, government, and new citizen representatives. ⊕

***Sam Friedman** is the BC representative for the Canadian Treatment Action Council, a community-based research investigator, an International AIDS Society abstract reviewer, and a community writer.*



Buying peace of mind

***So you're getting on with your life.
What about getting insurance if you're HIV-positive? Read on.***

by Shawn Wakley

Insurance. Most of us release a yawn of boredom at the mere mention of the subject. How can such an important facet of our everyday lives be so arduous? For starters, most people misunderstand insurance, and very few are comfortable talking about their own mortality. Nevertheless, it's a crucial topic of discussion—the need for financial protection is real and growing.

And what about people living with HIV/AIDS? Today, PWAs can no longer be neglected or excluded. With the many advances in treatment and knowledge, PWAs are living long and healthy lives, giving them the opportunity to fulfill conventional Canadian dreams, like buying a home and starting a family. How is the present Canadian financial industry responding to the fact that people with HIV/AIDS are no longer doomed? How are the financial interests of PWAs being protected?

continued on next page

Consider the stories of two people living with HIV. The first, Meg, is a 27-year-old straight African-Canadian woman living in Yaletown; she works as a lab technician and makes about $55,000 a year. The second person, Tom, is a 42-year-old gay male who lives in East Vancouver and works at a small deli making about $9 an hour. At first, it may appear that we're comparing apples and oranges, but since they're both HIV-positive, they face the same stigmas, medical concerns, and—in terms of insurance—the same hurdles.

You can refuse certain mortgage insurances

Since learning of their infection, both Meg and Tom have moved on with their everyday lives; Tom found love and got married. Meg fell in love with a beautiful condo in Kitsilano.

With Meg's new purchase came a huge debt and a mortgage payment that would be hard to honour if she wasn't working. When she applied for the funds from her bank, she was faced with decision of taking credit life insurance and disability insurance to protect her payments should she die or become ill. Both of these lines of coverage required that she answer a question about HIV status.

> **When Meg applied for a mortgage, she was faced with decision of taking credit life insurance and disability insurance. Both required that she answer a question about HIV status.**

At this point, Meg realized she could lie about her status, but she would risk being denied the payments at claim time, and even run the risk of criminal proceedings, if the insurance company wanted to charge her with misrepresentation. Being of good morals, Meg politely declined the insurance. It is important to know that Meg couldn't be refused her mortgage funds if she declines to take the coverage. This would be called "tied selling" and it's an illegal practice in the financial industry. The bank may require Meg to apply for insurance through Canadian Mortgage and Housing Corporation (CMHC), but this is insurance to protect the bank should she default on her payments and it's not tied to her health.

Life insurance for when you're gone

One of the principles behind life insurance is financial protection for those you leave behind. Contrary to popular belief, it isn't about people becoming rich from your death, but to ensure that their lifestyles continue, your final expenses can be covered, and any large debts can be resolved.

In Meg's case, this isn't a present concern, since she was lucky enough to have bought a Term20 life insurance policy—a policy that terminates after 20 years of coverage. When she found out she was HIV-positive, she exercised the right to convert her Term20 policy into a whole-life policy (remains in force until the day she dies, provided that premiums are paid) without having to disclose her HIV status or undergo any medical examination.

While Meg isn't eligible to buy any more individual life insurance, she won't lose the coverage she had prior to her infection. Additionally, Meg has life insurance provided through her employer's group benefits program. This insurance requires no medical evidence or questions as long as she stays below the maximum allowable without the testing.

Tom, on the other hand, wasn't able to afford insurance before he became infected, and he now has a need for it with his recent marriage to his partner, Mark. Unfortunately, because of his HIV status there's no conventional life insurance product available to him in Canada. However, there are some solutions. There is a "final expense" product available to PWAs in Canada, which will at least provide funds for funeral costs. Once purchased, this amount of coverage grows over time, so if you live a long life, the amount can grow enough to help build education funds or pay off large portions of mortgages.

The importance of disability insurance

For both Meg and Tom, disability insurance is one of the most valuable lines of coverage that they can have to help protect their financial interests. Disability insurance helps protect your weekly and monthly income should you temporarily become ill. Due to the episodic nature of HIV, there's a strong likelihood you might not be able to work for a while—and on more than one occasion. That said, people with HIV/AIDS aren't considered "insurable risks" by insurance companies.

Meg already has short-term disability and long-term disability insurance through her employer's group benefits. Because this is a part of a group program, no medical questions are asked to get the coverage, provided the amount of coverage is below the evidence limits stipulated in the contract. Luckily for Meg, if she left her company, she may have the option to take the coverage with her.

Tom isn't so fortunate. His employer is very small and can't afford the group benefits plan, and Tom won't qualify for private disability coverage due to his HIV status. However, he does have other financial options. A detailed discussion with his financial planner and his partner will help him create a savings plan to build a financial cushion should he fall ill and not be able to work. Alternatively, Tom does have coverage through governmental programs such as Employment Insurance Disability (EID) and Canada Pension Plan Disability (CPPD), which he can apply for if he becomes ill.

The barriers of returning to work

Both Meg and Tom will likely face some sort of illness—either an HIV/AIDS-related illness or side effects from treatment—that will limit their ability to work for a period of time. In both cases, returning to work can be quite difficult physically, mentally, and emotionally.

Many medical conditions today are treatable to a point where people are able to return to work on a gradual basis and make a full recovery over a short period of time. The problem, as it relates to insurance, is that many plans don't allow you to return gradually to your job and will cut off your benefits as soon as you return in any capacity. This creates financial strain due to the limited amount of income being earned and doesn't provide security or incentive to return to work.

> **From a business perspective, there isn't a huge economic incentive for the insurance industry to build products for PWAs.**

Take Tom's situation. He works for a small employer who has a small staff and really can't afford to hire someone else if Tom becomes ill and has to take time off work. Because illness and side effects of medication can repeatedly take Tom away from employment, either partially or entirely for periods of time, his employer may begin to feel the strain—and may have to consider terminating his employment.

This is a common concern for many PWAs. While many employment laws are in place to protect employees from situations like this, it's still a regular occurrence.

Tom may also be concerned about the loss of his EID and CPPD coverage because he hasn't been able to stay at work long enough to make the required contributions to these programs. Luckily, the federal government is working on reviewing these programs to make them more accessible to people with episodic illness and increase the incentive to return to work without fear of future repercussions.

Insurance for when you get the travel bug

Both Meg and Tom may need travel medical coverage at some point in their lives: Meg for a well-deserved vacation from work, and Tom for his honeymoon. Traditionally, PWAs would have been declined coverage because HIV/AIDS would be a pre-existing condition and make them uninsurable. However, today many travel insurance policies still exclude pre-existing conditions, but those conditions are only considered a problem if they weren't "stable" for the 90 days prior to the effective date of your coverage.

For Meg and Tom, this may be a problem if their reported CD4 counts dipped into the lower threshold where doctors would typically consider medication, or if they had started new medications or dosages within that time period. In this case, if either Meg or Tom became ill during a trip and the illness was in some way related to HIV/AIDS, then a claim may not be payable. The best way for Tom and Meg to buy travel insurance is to find a travel agent they know and trust and discuss any concerns they may have.

When it comes to insurance solutions for PWAs in Canada, there aren't any conventional answers at present. This isn't so surprising when you consider that far less than one percent of the Canadian population has reported living with HIV/AIDS and of that number, a large percentage earns less than $20,000 per year. So from a business perspective, there isn't a huge economic incentive for the insurance industry to build products for PWAs, given that most wouldn't be able to afford the high premiums.

Still, you can protect your financial interests through more traditional methods—like savings accounts, RRSPs, and other savings vehicles. You must also very carefully consider what debts you're able to take on and maintain during periods of illness when your income may be limited or non-existent.

Despite the treatment advancements, our expanding knowledge, and the increased survival rate of PWAs, the financial industry has been slow to respond to insurance needs, and there's no lobbyist voice to address the change. If we hope to diminish discrimination and increase opportunity, the responsibility falls on the shoulders of those dealing with the HIV/AIDS, like Meg and Tom, to demonstrate a need and demand a solution. ⊕

Shawn Wakley *is a volunteer with BCPWA's Advocacy group, specializing in insurance matters.*

The Burma stories

A new series in which we hear the personal accounts of PWAs in Southeast Asia

by Thiha Maung Maung

Thiha Maung Maung was a private doctor in Burma (now Myanmar), treating people living with HIV/AIDS. When he was exiled in early 2004, he fled to Thailand, where he continued to work as a doctor and trainer for PWAs. He is now a permanent resident in Canada. When he worked with PWAs in Burma as well as with illegal migrant workers in Thailand, he recorded their life experiences. In the next several issues of living⊕*, we will publish some of those stories.*

"I am a Burmese woman living with HIV. I grew up with my cousins, as my parents got divorced when I was very young. In my definition of a family, the husband and wife should be happy and stay together.

In 1999, one of my friends learned she had AIDS. Her husband had died of the same disease. I didn't know what AIDS was, but when I looked her failing body, her whole body was covered in lesions and her muscles had completely wasted away. It was like someone had put clothing on a skeleton. Her image was haunting.

A few weeks later, she passed away.

In 2001, I met the man of my dreams and fell in love with him. I thought, "I am going to have a happy family life." After we were married in 2003, we moved home to stay with my mother and stepfather. His love for me was incredible. He worked many jobs to support me, though he could never find regular work in our depressed village. Yet, my stepfather would always argue with my husband and berate him. We didn't like this but there was nowhere else for us to live.

In the final stages of my pregnancy, my husband and stepfather had a terrible disagreement that could not be resolved. In frustration, my husband decided to move to a new village to look for work, and to relocate our family. He left that same night.

I cried endlessly but there was nothing I could do to change our situation. A month later, my son was born. He was very small and looked just like his father. But, within two months, our son became very ill. I did all I could to care for him but before his twelfth week, he succumbed to disease.

Then, I began to have many fevers. In my feverish dreams, my husband would come to me. In January 2005, I was admitted to a clinic on the Thai-Burma border for free medical care. A health counsellor gave me information on HIV infection and gave me a blood test.

The results were positive for HIV.

Now, my pain had doubled. My body ached from infections and my mind ached from worry. HIV medications were too expensive to buy.

Two weeks later, my husband returned. When I first saw him, I didn't know whether to be overjoyed or heartbroken. I had waited and dreamed of this moment for such a long time and it had finally arrived, tainted by a horrible cloak of sadness.

He said he still loved and trusted me. He promised to keep working and to spend every penny he earned on finding a cure for HIV. He still believed we could return to his village once I was healthy again and continue being a happy family.

But I know what it means to be HIV-positive without getting HIV medications.

My husband stays with me and does everything in his power to relieve my pain. He feeds me and holds me and takes away my sadness. This has been the best time of my life and I never want it to end.

I am only 23 years old and my health has become so frail I can no longer walk. This evening, when I went to shower, my husband helped me to the bathroom. Inside, there was a long mirror the length of my whole body. When I looked into it, I saw a lady looking back at me.

Her whole body is covered in lesions and her muscles have completely wasted away. It is like someone has put clothing on a skeleton. Her image still haunts me." ⊕

***Thiha Maung Maung** is a volunteer with BCPWA's Treatment Information and Advocacy Department.*

LOON LAKE CAMP

June 23–26, 2008
September 2–5, 2008

HEALING RETREATS FOR HIV+ PEOPLE

MEET NEW FRIENDS.
LEARN MORE ABOUT YOURSELF.

To book an interview call 604.893.2200 or 1.800.994.2437 x 200

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

Cut off for registration:
Friday, May 30, 2008

British Columbia
Persons With AIDS Society

Report card on ma

Counselling before and after HIV testing remains a weakness in the system

by Neil Self

HIV became a reportable communicable disease in BC in 2003. Since then, the data collected by BC Centre for Disease Control (BCCDC) has been mostly positive. Despite fears, there was no decrease in the number of people being tested and there were no major breaches of confidentiality. However, there are still some issues about HIV testing, pre- and post-test counselling, and partner notification.

The quality of the counselling has raised questions, in part because it's entirely dependant on the person delivering it. In many cases, a family doctor with a good doctor-patient relationship provides counselling with compassion and skill. In other cases, the doctors—especially in clinics, emergency rooms, and drop-in medical centres—may not have the requisite skill, time, or relationship with the patient. This is an increasing concern given the difficulty of finding a family doctor in BC. The BCCDC should therefore be applauded for dedicating public health nurses to assist in this process. The nurses are specifically trained to provide this health service and can spend much more time with patients—an average of 6.7 hours per person.

Another concern with the counselling involves the frame of mind of the newly diagnosed person. Many are in a state of shock and they don't absorb valuable information. The BCCDC reports that less than half of newly tested people recall being told that HIV was reportable or that there was a non-nominal (anonymous) option.

To address this situation, there needs to be improved relationships between patients and healthcare providers, as well as appropriate follow-up and referrals. BCPWA has therefore developed a pocket-sized resource for newly diagnosed people, to ensure they have all the information the need when they leave the counselling session—regardless of how much detail they were able to retain.

Point of care (POC) testing adds a completely new level of problems to counselling. Unfortunately, there are more questions than answers here. Currently these rapid-result POC HIV tests are available throughout BC; we've been assured that they will adhere to standard counselling procedures. Further research and vigilant monitoring will be required before we can evaluate the effects of this new technology.

While there hasn't been a decrease in the number of people being tested for HIV since HIV reporting begin in BC, there are still populations that aren't getting tested. Even the best counselling procedures and resources may not be enough to overcome the physical and psychological barriers that continue to block access to testing for many people. The stigma associated with HIV hasn't decreased, despite considerable medical advances. The continuing stigma of having HIV combined with even the slightest apprehension about making HIV reportable will continue to be a challenge for public health in BC.

Hard-to-reach populations, such as the homeless and sex trade workers, access health services less frequently and may not connect with the 9-to-5 world of the healthcare system. Fortunately, public health nurses and some doctors are willing to work outside the 9-to-5 system. Allowing patients to be tested and counselled outside their area of residence is also a step in the right direction, particularly for Aboriginal and people living in rural areas who are concerned with privacy in their small communities.

HIV testing in BC, isn't perfect, but we've come a long way and we appear to be heading in the right direction. ⊕

A future article will be devoted to partner notification.

***Neil Self** is an individual advocate at BCPWA.*

andatory reporting

Prevention issues need to remain in the forefront

by David van den Broek

In 2003, BC became the last Canadian province or territory to make HIV a reportable communicable disease. Even so, it was a contentious topic of debate for more than two years prior to that. Mandatory reporting has significantly altered how patients, health practitioners, and public health agencies deal, treat, and assess HIV/AIDS.

During public consultations that started in February 2002, the outcry against mandatory reporting was nearly unanimous. Community stakeholders continue to cite numerous rationales against it, including issues of confidentiality and increased discrimination, which could make people reluctant to come forward and get tested—a chief concern from the standpoint of preventability. These issues are a particular concern for at-risk communities such as Aboriginal people, people in abusive relationships, and street youth.

Mandatory reporting has benefits and drawbacks

While mandatory reporting is a controversial practice, it does have benefits, both for individuals and the public. From a public health standpoint, mandatory reporting allows for consistent and comprehensive surveillance of HIV.

The Provincial Health Officers' 2006 report, *Evaluation of the Impact of Making HIV a Reportable Infection in British Columbia*, notes that antiretroviral treatment has increased the length of time people remain HIV-positive before progressing to full-blown AIDS. That means HIV-positive individuals are living much longer without developing AIDS. In order to provide care to those already infected and develop strategies to prevent future infections, it's important to have as complete an understanding as possible of the transmission and development characteristics of HIV—an understanding which is improved by mandatory reporting.

However, mandatory reporting has significant drawbacks. The report highlights areas of concern with respect to health practitioners. During pre-test counselling, 25 to 30 percent of physicians didn't inform their patients that HIV is now reportable or that non-nominal testing is an option. Similarly, some physicians don't recommend Partner Counselling and Referral Services when a test comes back positive. The report suggests that this may be because doctors are concerned that doing so would place increased demands upon limited resources. This failure to recommend partner counselling is an alarming finding, particularly from a prevention perspective, which needs to be addressed.

During pre-test counselling, 25 to 30 percent of physicians didn't inform their patients that HIV is now reportable or that non-nominal testing is an option.

Another area of concern is the four official critical incident cases, thus far, on breaches in confidentiality and threats of violence after HIV reporting. While these four cases may be anomalies, their very existence at all is disconcerting. If the community as a whole doesn't have confidence in HIV reporting, mandatory reporting will discourage people from getting tested. The Provincial Health Officers' report stresses the importance of continuing to learn from these cases so that

continued on next page

strategies can be designed and employed to prevent similar incidents from occurring in the future.

Non-nominal testing has its drawbacks, too

There are also issues with non-nominal (anonymous) testing. While at first glance non-nominal testing appears to address concerns about confidentiality and discrimination, that's only in terms of the testing itself. Even if people choose the non-nominal option when getting tested, if they test positive they'll need to disclose their identity to access HIV medical care. Still, from the viewpoint of prevention, non-nominal testing allows individuals to know their HIV status with anonymity and to choose safer sex practices; from there, individuals can decide whether or not to pursue treatment options.

In the end, when comparing the periods before and after mandatory HIV reporting, the 2006 report found no significant difference in trends of HIV testing and rates of HIV infection, either overall or by gender. These findings are similar to other provinces' studies, though data is limited. The report notes that there has been a positive impact in consistent case management for newly-diagnosed cases.

The report also offers recommendations that, while continuing to affirm the practice of HIV reporting, address areas of concern—including ongoing problems of non-nominal testing, informed consent, pre- and post-test counselling, partner notification (particularly in cases of domestic violence), and stressing confidentiality among health care professionals.

Like it or not, HIV reporting is here to stay. The challenge is to ensure that issues of prevention remain in the forefront and to mitigate and resolve any mandatory reporting problems that do occur. Health practitioners, public health agencies, and the HIV community need to work together to protect and help people in need. ⊕

David van den Broek *is a volunteer writer for BCPWA.*

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 responsiblity 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.

Research project aims to STOP HIV/AIDS in BC

by Glyn Townson

The BC Centre for Excellence in HIV/AIDS (BCCfE) has put forward a research proposal called "Seek and Treat for Optimal Prevention of HIV/AIDS" (STOP HIV/AIDS). The aim is to further the research, presented by Dr. Julio Montaner at the AIDS 2006 conference in Toronto, into expanding access to highly active antiretroviral therapy to curb the growth of the HIV epidemic.

Evidence of the life-saving properties of the available highly active antiretroviral therapy (HAART) regimens continues to grow. It's widely acknowledged that HAART reduces AIDS-related morbidity and mortality. Recently, there has also been substantial evidence suggesting that HAART may play a critical role in preventing HIV transmission by reducing HIV load in plasma, a key predictor of HIV transmission. The key evidence includes: a 90 percent reduction of perinatally-acquired HIV infection (mother-to-child transmission); decreased HIV transmission rates among sero-discordant heterosexual couples when the index partner is on HAART; and an approximately 50 percent reduction in new HIV infections in the province of BC, and Taiwan, following the implementation of HAART programs in 1996 - 1999.

continued on next page

There are still too many people who are eligible for treatment under the current medical guidelines yet aren't accessing these life-prolonging therapies. Of the 12,300 HIV-positive individuals in BC—with the majority living in the Metro Vancouver area—approximately 4,000 are currently enrolled in HAART. Another 2,000 PWAs meet the guidelines but aren't accessing therapy. In particular, for those living with HIV in the Vancouver's Downtown Eastside (DTES), where HIV prevalence is as high as 30 percent among the most vulnerable groups, access to primary and specialized care continues to be woefully inadequate.

> **The proposal identifies the importance of providing therapy to those who need it, rather than waiting for them to seek it. Although St. Paul's Hospital is only two kilometres from the DTES, the two remain worlds apart, economically and socially.**

This research proposal finally identifies the importance of providing therapy to those who need it, rather than waiting for them to seek it. Although St. Paul's Hospital in downtown Vancouver is only two kilometres from the DTES, the two remain worlds apart, economically and socially. The research includes the development of a new HIV/AIDS clinical research unit in the DTES, as well as the expansion of research facilities at the St. Paul's campus to provide the infrastructure necessary to support these plans.

The research will determine the added preventive of expanded use of HAART; the proposed expansion will occur among people who are medically eligible based on current guidelines, but aren't currently accessing therapy. The main target populations will be hard-to-reach individuals, injection drug users, minorities, individuals with co-morbidities such as mental illness and hepatitis C, sex trade workers, incarcerated individuals, and First Nations people. It will also provide unique insights into the efficacy and safety of modern compact HAART regimens in these populations, with additional emphasis on adherence, resistance, and cost effectiveness.

Some of the specific research themes will include:

- Enhanced case findings and linkages to care. BCCfE research has found that only 13 to 18 percent of First Nations PWAs who are clinically eligible for treatment are accessing HAART, and only 40 percent of eligible intravenous drug users (IDUs) have ever accessed HAART. Only 50 percent of all PWAs in BC who died in 2003 had ever been on HAART.
- Expanded uptake of HAART and incidence monitoring. The BCCfE proposes to expand the access of HAART from the current 4,000 to at least 6,000 clinically-eligible PWAs. Based on an assumed incidence of 2 percent per year, the BCCfE predicts a 10 percent decline in incidence following the treatment of an additional 2,000 people.
- Monitoring drug adherence, resistance, and adverse events. Incomplete adherence is one of the biggest challenges in HIV medicine, with studies reporting long-term adherence from 50 to 80 percent among treated individuals. The proposed research would allow the BCCfE to develop, implement, and measure the impact of incentive strategies on addictions treatment and adherence, determine the impact of single-dose combination therapies, and determine the impact of directly-observed therapy programs. It will also enable them to evaluate the impact of depression and hepatitis C infection on HAART outcomes.
- Population impact, resource utilization, and cost-effectiveness. This will be achieved by investigating factors that influence population health, such as: income and social status; social support networks; education; employment; working conditions; biological and genetic make-up; personal health practices; coping skills; healthy child development; health services availability; gender; and culture.

Knowledge translation and capacity building will be translated directly into policy through links with the Ministries of Health in BC and Canada. Results will be disseminated to scientific bodies, the healthcare system, AIDS service organizations, public audiences, and international conferences. Results will also be used to develop expanded training programs for physicians, nurses, and pharmacists, including distance education for healthcare professionals in rural and remote areas.

The proposed research findings will serve as the basis to evaluate and model the potential effect of further expansion of HAART. The movement towards bringing therapies and services to the most vulnerable populations is certainly timely if the province of BC ever hopes to achieve a true reduction in new HIV infections. ⊕

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

Ten years later: How are we doing?

NEW Research Project, LISA, aims to learn about the personal experiences of individuals managing HIV and HAART

Vancouver's introduction to HAART during the 1996 International AIDS Conference has turned HIV into a manageable, chronic disease for thousands of British Columbians. The unique position that BC holds of having a centralized Drug Treatment Program through the BC Centre for Excellence in HIV/AIDS enables high quality population-based research to be conducted. The distribution of HIV medications has been centralized through the Drug Treatment Program since 1992, allowing the Centre to conduct research that is inclusive of all HIV positive British Columbians on medications.

The CIHR recently approved a 3-year grant for a project that is being conducted through the Drug Treatment Program at the Centre.

Over ten years after the introduction of HAART in BC, this new research project, entitled **L**ongitudinal **I**nvestigations into **S**econdary and **A**ncillary Health Services, or **LISA**, will investigate how people are coping with HAART. The study will examine a broad range of topics for people living with HIV such as: neighbourhood satisfaction, quality of life, employment opportunities, food security, women's health, and physician relations.

This project will provide an opportunity for people living with HIV to voice the challenges and successes they face in their daily lives. Eligible participants are those who are HIV positive and started antiretroviral therapy after 1996.

For more information about the LISA project, or to be involved, contact the study coordinator, Eirikka Brandson, at the BC Centre for Excellence (604 682 2344)

British Columbia
Centre *for* Excellence
in HIV/AIDS

All in good time

Determining when to start antiretroviral therapy involves multiple factors

by Michael Connidis

Since the advent of highly active antiretroviral therapy (HAART), people who start treatment and adhere to their regimen rarely progress to AIDS. HIV is no longer a death sentence; it's become a manageable chronic infection. However, if left untreated, HIV disease will develop into AIDS within 10 to 12 years. And in about 10 percent of people, the disease progresses much more rapidly, developing into AIDS within two to three years. Death typically occurs within three years of an AIDS diagnosis, although about five percent of people who are infected with HIV can be symptom free well beyond 12 years.

While delaying treatment too long can have dire consequences, at what stage of HIV disease does initiating HAART provide the greatest benefit? There are multiple factors to evaluate before starting HAART. The timing must be individualized and take into account people's health, the stage of their HIV disease, their preparedness to start an exacting regimen, and the risks of drug toxicity.

Before starting treatment, it's imperative that each person has a thorough physical and psychosocial assessment. Once the person starts therapy, the assessment provides a baseline profile that can be used to monitor and evaluate all aspects of treatment, including potential toxicity of the drugs, how well the virus is suppressed, and how well the immune system has recovered. Screening for co-infections—such as hepatitis C, tuberculosis, and syphilis—as well as vaccinating for influenza, pneumococcal pneumonia, and hepatitis A and B, are also recommended where indicated. Treatment-naïve patients should be tested for drug resistance.

The old "hit hard, hit early" approach

Determining the best time to start HAART and choosing the best combination of antiretrovirals are equally important, and require an expert opinion, since HIV-related treatment issues are complex.

The early treatment maxim used to be, "hit hard, hit early." The hit hard approach used optimal combinations of available antiretrovirals for maximum impact on the virus. Combinations of at least three antiretrovirals, a triple cocktail mixed from the expanding arsenal of drugs, were found to be the most potent HAART and delivered a solid knock down—although not knock out—punch to HIV. The drugs weren't powerful enough to extirpate the virus from the body. Reservoirs of HIV were found in cells, tissues, and organs, seemingly untouched by antiretrovirals.

Not only was HIV still present in the body, but people on HAART experienced a range of health problems, in some cases life-threatening reactions attributed to the drugs. The drawbacks of available therapies became apparent. The "hit early" maxim came under fire. Doctors started advising a "hit hard, but wait until it's time" approach.

An advantage to waiting to start HAART is that the benefits of HAART haven't been without cost to the individual, although most have been willing to pay the price. Multiple adverse side effects of the drugs can have a negative impact on your quality of life. Further, strict adherence to a treatment regimen is critical, but that can be difficult, especially when you're dealing with unpleasant side effects. And since resistant strains of the virus can develop and limit treatment options if the drug regimen isn't sufficiently potent and/or adherence is poor, it makes sense to wait to start a challenging regimen.

What the BCCfE guidelines say

We now have a much better understanding of HIV disease, as well as reliable indicators of disease progression. The clinical symptoms and indicators of disease are both considered when determining the start point for treatment.

According to the BC Centre for Excellence guidelines, all adults in BC who are HIV-infected and have clinical symptoms must be offered HAART. There are two categories of clinical symptoms: Category C symptoms are the opportunistic infections and body wasting associated with AIDS. Category B symptoms are those attributed to HIV infection and/or that indicate a defect in the body's immune response or complications managing a condition due to HIV. In some cases, a high viral load of 50,000 to 100,000 may also factor in the decision.

> **To date, no reliable markers have been isolated that would indicate irreversible damage to the immune system, and hence when it's best to start treatment.**

While current guidelines are useful, they don't identify or target optimal conditions for starting HAART. To date, no reliable markers have been isolated that would indicate irreversible damage to the immune system, and hence when it's best to start treatment. However, some studies indicate irreversible damage starts soon after infection and continues throughout all stages of HIV disease.

What happens to the immune system

During the first weeks of the acute phase of HIV infection, the CD4 cells populating the gut lining are rapidly depleted. Even with optimal viral suppression and a rebound in plasma CD4 counts following HAART, the gut lining remains depleted of CD4 cells. Losing these sentinels from the gut leaves the body exposed and vulnerable to infection; it's as if the gut lining is leaking, allowing bacteria to migrate into the body. Indeed, elevated levels of lipopolysaccharides (LPS)—fragments of bacterial cell walls—are detectable in the blood of people with HIV. In cases of more advanced HIV disease, even higher levels of LPS are found in the blood. It appears that the gut lining becomes increasingly porous to bacteria over the course of HIV disease.

The chronic stimulus by the virus and the increasing systemic exposure to bacteria pushes the immune system into perpetual overdrive. Immune cells activated by HIV become prime sites for HIV reproduction, releasing more HIV, which then activate more immune cells. Activated immune cells also secrete inflammatory cytokines, which signal massive cell death and cause scaring in the lymphatic tissue. This is called immune activation, a complex process whereby the immune system essentially attacks and damages itself, slowly depleting its capacity to function. This could be one of the reasons the immune system doesn't rebound as well if treatment is started after the CD4 count drops below 200 cells/mm3.

continued on next page

Your CD4 count when you start HAART

The CD4 count has become the primary indicator of when a person should start HAART:

- People with CD4 counts that stay at or below 200 cells/mm3 should be offered treatment, whether they have symptoms or not.
- People with CD4 counts between 200 and 350 cells/mm3 and who have no symptoms may or may not be offered treatment, depending upon their individual clinical and laboratory profile, as well as their stated preference. They'll be offered treatment if their CD4 percentage continues at or below 15 percent, their viral load remains high, and/or there's a rapid decline in their CD4 count.
- People who are recently infected and are in the primary acute stage of HIV infection aren't being offered HAART at this time, nor is treatment being recommended for those people without symptoms who have a CD4 count greater than 350 cells/mm3.

So, if there's ongoing damage to the immune system, why not treat HIV infections right away? After all, we usually treat infections right away with effective antibiotics or antivirals. Early treatment of HIV is possible, but it isn't practical or ethical at this time. There are ongoing concerns about the toxicity of antiretrovirals. Most of the drugs have been in use for less than 10 years and the long-term side effects of HAART remain to be seen.

Treating those PWAs who are most in need

In any discussion regarding when to start antiretroviral therapy, it's our moral imperative to give priority to treating those most in need of medical help. Treating HIV disease is far more effective, in terms of outcome and cost, than treating AIDS. Yet, over one-third of the people who die from AIDS in British Columbia have never received the antiretroviral therapy that could have saved their lives. Despite efforts to reach and treat those who are most in need, too many people don't seek even basic health care, let alone treatment for HIV.

There are barriers to people receiving care and treatment. Many HIV-positive people don't seek medical care until they're sick with advanced AIDS. Other people, who may already be infected or who are at risk of infection, don't know their HIV status. The most vulnerable and disadvantaged people—who are unable to negotiate the healthcare system or self-manage their treatment—need additional support if HAART is to be effective. To do this requires substantial resources in addition to those already invested in the battle against HIV in BC.

Paradoxically, if we started everyone who tested positive for HIV on HAART sooner rather than later, we could leave even more people behind by diverting already insufficient resources. The concern remains: will people experience permanent damage to their immune systems that could have been prevented?

As the saga of HIV/AIDS plays out, advances will continue to be made. We have good reason to be optimistic about the future. Our expanding knowledge of the immune system and HIV disease bodes well for new and improved therapies—and possibly even vaccines. Full suppression of HIV is now achievable on HAART, effectively halting the progression of HIV to AIDS. People with a viral load of less than 50 mm3, although still infected with HIV, are far less infectious. The continuing development of powerful drug combinations that are well tolerated and easy to adhere to are promising not only in terms of HIV treatment, but also in terms of preventing HIV transmission.

Will treatment and prevention strategies one day merge and both be promoted in a "get tested, get treated" message? I wonder. One thing is clear: we've come a long way since 1983 when HIV was identified as the cause of AIDS. ⊕

__Michael Connidis__ is a BCPWA member and a member of the living ⊕ *editorial board.*

Drink to your health

Researchers explore green tea's potential in fighting HIV

by Dave Boyack

A simple leaf that is dried and steamed has been used as a medicine for nearly 4,000 years. The Chinese have been brewing the leaves of the *Camellia sinesis* plant as green tea. It's been part of their health regimens for eons, and only recently has the West become more interested in the medicinal effects of this Asian plant.

In the West, we've known for many years that green tea has antioxidant qualities. Antioxidants help prevent cellular damage which can lead to many diseases.

Test tube studies have demonstrated green tea's health-giving properties. Ingredients in the tea have shown to have anti-fungal, anti-tumor and anti-viral effects. Recent studies reveal that green tea can reduce HIV replication, but this is in test tube studies only.

One ingredient of green tea is called Epigallocatechin gallate (EGCG). Researchers have found EGCG to be 100 times more powerful than vitamin C and 25 times more effective than vitamin E. Scientists believe that EGCG is the main ingredient that provides green tea's widely reported health benefits. Many previous studies have suggested green tea can protect against cancer, aging, heart disease, Alzheimer's disease, and other diseases.

> **Test tube studies have demonstrated green tea's health-giving properties. Ingredients in the tea have shown to have anti-fungal, anti-tumor and anti-viral effects.**

It's not surprising, then, that scientists have delved into green tea's potential effects on HIV. Researchers from the University of Genoa in Italy claimed in a 2001 report that their study was the first to demonstrate EGCG-inhibited HIV infection and replication in test tube studies. They said further studies were needed to examine the mechanism into how EGCG inhibits HIV replication. They also foresaw the potential low cost of producing green tea extracts or EGCG, which could be used in conjunction with current HIV therapies.

In 1993, scientists in Japan reported that they found EGCG stopped HIV from binding to healthy immune cells. If HIV can be blocked from binding to the CD4 cells, then HIV infection might be avoided. The Japanese scientists concluded from their study that much more research is needed to determine if EGCG could be used in new anti-HIV drugs. They also noted that simply drinking green tea would not protect a person against HIV infection.

However, a more recent test tube study earlier this year in Sheffield, England also found that EGCG may reduce the HIV virus's ability to bind to CD4 cells by as much as 40 percent within just one hour of drinking 2-3 cups of green tea. The investigators noted that much more research needs to be done in order to determine if green tea protects against HIV disease or disease progression.

Professor Mike Williamson, from the Department of Molecular Biology and Biotechnology at the University of Sheffield, and his colleagues from Baylor College of Medicine in Texas, cautioned that green tea shouldn't be used a sole prophylactic against HIV. They concluded that green tea "may be useful in combination with other retroviral therapies."

"It is not a cure, and nor is it a safe way to avoid infection," said Professor Williamson. "However, we suggest that it should be used in combination with conventional medicines to improve quality of life for those infected. Future research is also currently underway in order to determine how much effect can be expected from different amounts of tea."

Keith Alcorn, an editor with the Aidsmap website, cautions that these results are from test tube studies and that research with animals is needed before conclusive evidence shows drinking green tea has any potential benefits. He noted that many substances in test tube studies have been shown to prevent HIV infection but in real life they have little or no effect.

Lisa Power, from the Terrence Higgins Trust, concurs. "Anything that boosts your immune system is beneficial for people with HIV," she says, "but green tea can't be a substitute for proper medication and prevention techniques." ⊕

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

Cold snap

Supporting your immune system through a cold or flu

by Katolen Yardley

Even though we're in the middle of the winter season, it's never too late to enhance your immune system to prevent a cold or flu from setting in. Colds occur most commonly in the winter as viruses thrive in cold weather.

You could look at a cold as a positive state: a time for transition, your body's opportunity to cleanse and detoxify, throw off the old, and make room for the new. When your body temperature rises at the onset of a viral infection, it's your immune system's way of fighting off foreign agents, gathering its immune system troops to fight off infection; the subsequent sweating is your skin's way of aiding elimination through the skin. The key is to support and enhance your immune system's ability to throw off the infections.

Think about it: if a cold is a time for your body to cleanse and expel wastes, it makes sense to support your body's natural inclinations and activities and encourage the natural cleansing processes. You can support the cleansing process through additional rest, and by increasing fluids, herbs, and supplements to enhance the immune system function.

It's easier than you think

There are many simple ways you can support your immune system function:

- Give yourself extra time to rest so your body can replenish its defenses.
- Wash your hands for at least 20 seconds—and wash them frequently. Viruses can live for several hours on hard surfaces, and are easily transferred by touching your hands to your face or lips.
- Take a bath with epsom salts. Use 2 - 4 cups of salts in a hot bath. It's ideal for aching muscles, to increase your body temperature, and stimulate your immune system defenses.
- Add essential oils of eucalyptus, rosemary, and peppermint to a bath, or inhale them through a steam inhalation—doing so can help keep your sinuses clear.

Look at a cold as a positive state: a time for transition, your body's opportunity to cleanse and detoxify, throw off the old, and make room for the new.

Some food and supplement suggestions to help immune function during a cold or flu:

- Increase your intake of hot liquids to prevent dehydration.
- Add fresh garlic to food. Roasted garlic is not only delicious but its multipurpose immune benefits protect against respiratory infections, contain antiviral, antibacterial, and antifungal properties, can be used to loosen phlegm, for sinuses congestion, and to help prevent a cold and flu.
- Avoid sugar (also found in fruit juice). Sugar reduces your white blood cell function, and interferes with the function of your immune system.
- Take vitamin C with bioflavinoids hourly. As sugar depletes the white blood cell function, vitamin C can help to enhance its function.
- Eat ginger and green onions, chopped and prepared as a tea. The volatile oils are useful to clear up respiratory congestion and congested sinuses.

Try some herbal options

Herbs can also be used to treat your cold or flu. Diaphoretic herbs are herbs that stimulate perspiration. One example is boneset (*Eupatorium perfoliatum*), which raises your body temperature, increases your body's ability to fight infection, and aids the elimination of toxins through the skin.

Among other herbs, osha (*Ligusticum porteri*) is a native American root that is chewed for its potent antiviral and antibacterial properties to prevent respiratory and bronchial ailments. Wild indigo (*Baptisia tinctoria*) is a powerful herbal antiseptic used for symptoms of a fever with gastrointestinal symptoms, enlarged lymph nodes, sore throat, and mouth ulcers. And mullein (*Verbascum thapsus*) aids a hollow cough, and it's a soothing demulcent herb and antispasmodic for a deep, raspy cough.

Antibiotics aren't the answer

In the past, mainstream medicine has often prescribed antibiotics during a cold or flu. However, recently researchers have uncovered that antibiotics only work for bacterial infections and aren't effective for upper respiratory tract infections caused by viruses. In fact, overuse of antibiotics can kill off the good bacteria in your body—bacteria that helps to keep foreign agents at bay—thus hindering your body's ability to fight infection. Overuse of antibiotics can also increase the likelihood of superbugs—antibiotic-resistant infections.

As well, a flu shot may not be the best option for everyone, especially for those who are immune compromised. The BC Centre for Disease Control states anyone who has had a history of Guillain-Barre Syndrome or has an egg allergy should avoid the flu vaccine. Also, the informed consent form for the flu vaccines states that the vaccine should be avoided by anyone currently experiencing a cold, flu, or respiratory infection; anyone who has as a reaction to latex or rubber; is on blood thinners; and by anyone who has had a serious reaction from medication or a bee sting. The vaccine contains several preservatives such as formaldehyde and thiomersal, a mercury derivative. Be informed before getting the vaccine to ensure it's the right choice for you.

The bottom line is, take care of your body so it can take care of your cold or flu. ⊕

__Katolen Yardley__, MNIMH,
is a medical herbalist
is private practice at Alchemy &
Elixir Health Group in
Vancouver and Coquitlam.

Not exactly a vacation

Tips for making your hospital stay a more pleasant one

by Carley Taylor

When you're sick, just about the last place you want to be is in a hospital; it's not exactly the most comforting or restful place. And when you have HIV/AIDS, there's a strong possibility that at some point you might have to go there. It's a good idea to be prepared; your hospital stay will be a lot less stressful and more comfortable if you are.

One of the best things you can do if you have a chronic condition like HIV/AIDS is to become familiar with what your future healthcare needs may be. Discuss with your doctor not only what to expect but also the range of treatment options that are available to you if your condition should worsen. Not only will you have a more accurate picture of what can happen, you'll be better prepared to make decisions when the time comes, and you will be able to discuss these needs with your family or friends.

Also discuss with your doctor the task of overseeing your medical care should it become necessary for more than one expert to become involved. This doesn't happen automatically, so make sure beforehand that your doctor agrees to take on this role, if that's what you want.

Advocating for your rights

Also try to arrange in advance for an additional source of support, such as a friend or relative, who can act on your behalf during your hospital stay. This is helpful because sometimes you might be too ill or medicated to make decisions on your own or to understand or remember what you've been told. If possible, discuss your wishes—around such things as treatment options—with your advocate in advance.

Choose someone you trust and who is knowledgeable about HIV. When you're admitted to the hospital, you can have his or her name placed on your medical chart with permission to have access to all information about your health. You can also request that this person be consulted about all decisions affecting your care. Preparing a medical power of attorney beforehand is a good idea.

> **Try to arrange in advance for an additional source of support, such as a friend or relative, who can act on your behalf during your hospital stay.**

When it comes to preparing for a hospital stay, perhaps nothing is more important than realizing you do have rights as a patient. One of the most important is the right to receive an explanation of any treatment being prescribed, why you're receiving it, and what the risks are.

Be your own advocate and ask questions. Make sure you understand the purpose of a treatment or medication. Your elected health advocate can ask these questions on your behalf. Also remember that you have the right to refuse any treatment—including tests.

Knowing what to expect

Food in hospitals can be less then great. Getting loved ones to bring in your favourite comfort foods and nutritious foods can help make your stay more enjoyable. You can also work with the hospital dietitian if you have specific dietary requirements.

Hospitals are pretty good about letting your visitors come outside of regular visiting hours, but in order not to get overwhelmed you might want to select a time when no one can visit, so you get the rest you need. If you're feeling tired or unwell, it's okay to ask visitors to leave—they'll understand.

When you're up for it, you should try to get out of your room. Walk the halls, go to the hospital lobby, and if you're able, take trips outside for a few hours or overnight.

Nurses are an important part of your recovery and can make your stay a better experience. So if you have serious problems with your nursing care, ask to speak to the nursing supervisor, the director of nursing, a social worker, a chaplain, or a hospital ombudsman.

As important as preparing for your hospital stay is being prepared for your return home. Often, you'll be sent home before you're fully recuperated, so you'll need to be prepared for home care. This includes nursing care, childcare, food, medications, and people to check in on you. The hospital social worker can help you prepare for your convalescence at home.

Things to bring to the hospital

Ideally, you should bring a folder containing important information such as a list of all the medications, vitamins, and herbs you're currently taking. Make sure to include information about any allergies and adverse reactions to medications. Also important is a list of telephone numbers of family and friends. If you have a written power of attorney or living will, bring those with you too.

You can bring your medications, vitamins, and herbs, but be sure to let a nurse or doctor know what you're taking.

To make your stay more comfortable, bring some or all of the following:

- **Money** for newspapers, vending machines, and other incidental purchases. But don't bring too much, because theft can occur in hospitals. For this reason, it's also a good idea to leave your jewelry at home.
- **Comfy clothing** such as pajamas or lounging clothes. You may also want to bring a cardigan-style sweater to keep you warm and a pair of slippers to walk around in the hospital.
- Your own **pillow** if you can't bear to part with it.
- **Eyeglasses**, if needed. Usually it's best to leave contact lenses at home.
- **Writing paper and pen**, for making notes or recording questions you want to ask your doctor.
- **A prepaid phone card** for calls from your room telephone.
- **Toiletries**. You can bring your toothbrush, toothpaste, lotion, deodorant, soap, shampoo, a comb or hairbrush, and other toiletries, but avoid perfumes and any highly-scented products.
- **A headband, hat, or scarf** if you aren't able to wash your hair for a while.
- Entertainment such as **books or magazines** to help pass the time. Some hospitals have DVD players, so ask ahead if you can bring DVDs with you.
- **Photos or small personal items**. Many people enjoy having a couple of small, framed photos or mementos from home to personalize their hospital space.

Finally, check the hospital's policy about electronic items before you pack your laptop, portable DVD player, MP-3 or CD player, radio, or cellphone. In particular, cellphone use is forbidden in many hospitals, since it can interfere with electronic patient monitoring equipment.

Make sure your hospital doctor calls your primary physician about your condition before you're released, because your primary physician will be responsible for your follow-up care. ⊕

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

Killing me softly

Taking a supplement when you're a PWA isn't a straightforward decision

by Dani Shahvarani

There's so much confusion around multivitamins: are they good for you or bad for you? One of the most frequent questions people ask me is whether they should start taking a multivitamin and if it's safe to take large doses of vitamins or minerals on a regular basis. Other people are convinced the 20 supplements they take each day are keeping them healthy. The discussion on whether or not to take them is a difficult one—so much of it has to do with personal beliefs, and the sense of control over one's health that taking supplements provides. However, it's also important to consider that natural is not always synonymous with safe, and excesses in vitamins and minerals (also known as micronutrients) can lead to toxicities.

Micronutrients fall under the category of complementary and alternative medicine (CAM), which includes such non-prescriptive therapies as meditation, yoga, massage, marijuana use, dietary supplements, and herbal supplements. According to a study by the BC Centre for Excellence for HIV/AIDS, 80 percent of PWAs surveyed use vitamin or mineral supplements, mainly to reduce the side effects of antiretroviral medications (ARVs) and to boost their immune system. So the potential problems associated with excess supplementation can't be overlooked.

Although Health Canada regulates the practice of CAM and has some safety standards for CAM products on the market—products have to be proven safe for consumption—these products don't undergo the same rigorous investigation as prescription drugs because they're classified as food products rather than medications. Little is known about the short- and long-term effects of CAM products on the body, and even less is known about their effect when coupled with ARV and other HIV-related medical therapies.

The power of advertising

Because CAM products like supplements aren't regulated as stringently as prescription drugs, it can be difficult to know exactly what you're getting. Even to the most discerning skeptic, marketing strategies that evoke hope, healing, and a guaranteed promise can be enticing.

On average, PWAs who use CAM will spend between $50 to $200 per month on supplements and therapies. Yet many CAM marketing claims—especially for micronutrients and herbal products—are based on little or no scientific evidence, with inadequate regulation of what is printed on the bottle. A label on the bottle might state that the product will reduce your symptoms by 90 percent, which sounds pretty effective. But if you research further, you realize that of 10 people they asked, nine reported a reduction in their symptoms. That's hardly a reliable or scientific sample. Also, what isn't clear is how bad their symptoms were to begin with.

> **There's scientific evidence that oversupplementation of iron, zinc, selenium, vitamin E, vitamin A, folic acid, and vitamin C can lead to toxicities.**

Even if the claims are true, they may not address the particular needs of PWAs, who are often on specialized medical therapies, and who require special considerations in their nutritional and health needs. It may be as a result of the interactions between CAM and HIV-related therapies that CAM users who are on ARVs are more likely to report adverse side effects.

The risks of taking too much

The legitimacy of marketing claims isn't the only problem with micronutrients. There's scientific evidence that over supplementation of iron, zinc, selenium, vitamin E, vitamin A, folic acid , and vitamin C can lead to toxicities. Many micronutrients metabolize very slowly, so they sit in body tissues and accumulate. This is especially a concern when people take individual micronutrients for prophylaxis—that is, as a preventive measure—without having their mineral levels checked first.

This is a particular issue for people with HIV, because they are often deficient in micronutrients mentioned above. That means they're also likely to take these supplements, and therefore at greater risk of developing toxicities if they take too much. While there's ample scientific research to show PWAs need higher levels of micronutrients, each individual will differ in terms of his or her additional needs.

This doesn't mean that taking a multivitamin, other vitamin, or mineral supplements automatically places you at risk for toxicity. If your healthcare professional has identified that you have nutritional deficiencies, it's vital that you add the required supplements to your diet in order to prevent health complications associated with prolonged deficiency.

Refer to the guidelines and speak to a professional

That said, there are guidelines for how much of a particular supplement people can take without exceeding maximum limits. These are called the Dietary Reference Intakes and are available for most nutrients. While these guidelines are a good reference for average daily needs and upper limits of micronutrients, they are an approximation based on information from healthy individuals, and may or may not be geared toward individuals who have multiple health problems. The best idea is to consult with your healthcare professional.

The bottom line: the goal of CAM is to minimize medication side effects and help improve your overall health. To help achieve this, speak with your health care professional who can diagnose whether you have nutrient deficiencies.

In addition, a dietitian can review your current food intake and suggest how to increase micronutrients in your diet first, before starting a pill regimen. A few dietary additions may be all you need to correct your deficiency. If you do need a supplement, healthcare providers can give you the proper dosage recommendations. If your physician assesses that you need a supplement, prescriptions for vitamins and minerals are often covered—for example B12, vitamin D, calcium, and iron—so it can be a cost-saving measure to consult with your doctor first.

It's definitely a challenge to read between the lines when so much press surrounds the use of CAM in PWAs. What is reported in the media as beneficial one day can be detrimental the next. Ultimately, your health is in your hands, and the informed decisions are yours. No bottle of pills can change that. ⊕

__Dani Shahvarani__ is a registered dietitian who has worked in HIV care for two years, and is currently undertaking a Master's degree in HIV and nutrition.

How much should you take?

Learn more about Dietary Reference Intakes for nutrients—estimated average requirements, recommended dietary allowances, adequate intakes, and tolerable upper limits—by visiting the Health Canada website at **www.hc-sc.gc.ca/fn-an/nutrition/reference/index_e.html.**

Fat free?

Phase III results indicate that TH9507 may help PWAs wishing to reduce belly fat

by Zoran Stjepanovic

In the September/October 2005 issue of *living* ⊕ we reported on a new compound, TH9507, which showed early promise in reducing abdominal fat in phase II trial results. The findings from Phase III trials were presented in February 2007 at the Conference on Retroviruses and Opportunistic Infections in Los Angeles—and the results continue to be encouraging.

The use of highly active antiretroviral therapy (HAART) has led to body shape changes, with excess fat around the belly and a "buffalo hump" behind the neck. These side effects have proven difficult to treat. Fat accumulation is also associated with the development of a metabolic syndrome of high lipid levels (blood fat), insulin resistance, and diabetes, all of which increase the chances of cardiovascular disease. It can also be very stigmatizing for individuals with HIV who are noticing body shape changes. Some reports indicate that up to one-third of people on antiretroviral therapy may be dealing with visceral fat accumulation.

The use of recombinant growth hormone has had some success in reducing fat around the abdominal organs—also referred to as visceral adipose tissue, or VAT. Unfortunately, there has been evidence that most of the fat around the belly returns even with the use of recombinant growth hormone. To make matters worse, with recombinant growth hormone you can also lose fat from your face, limbs, and buttocks, which are all symptoms of lipodstrophy.

A new compound, TH9507 is a peptide that helps to stimulate the body's own production of growth hormone. So, instead of using recombinant growth hormone, this compound stimulates production of your own naturally occurring growth hormone. Results are showing that it may have beneficial effects for people wishing to reduce belly fat.

In the recent Phase III study, 412 participants were randomized to receive either 2 mg of TH9507 or a placebo. In order to be eligible for this study, participants had to have a CD4 cell count of more than 100, abdominal fat accumulation while taking antiretrovirals, large waist circumference, and a high waist-to-hip ratio. Eighty-four percent of the participants were male, and the mean age was 48 years. Researchers were looking to see if participants taking TH9507 would have decreased abdominal fat compared to the placebo group, which didn't receive the compound.

After 26 weeks, they found a 15 percent reduction in abdominal fat in the group receiving TH9507, while those in the placebo group actually saw a 5 percent increase in abdominal fat. They also found that waist circumference decreased 3 centimeters on average in the treatment group—or one pant size.

Researchers found a 15 percent reduction in abdominal fat in the group receiving TH9507, while the placebo group actually saw a 5 percent increase.

People receiving TH9507 also saw improved lipid profiles, and no increases in fasting glucose. TH9507 didn't appear to either raise or lower CD4 cell counts. Some of the side effects reported included headaches and joint pain in more than 10 percent of participants in both groups. Those taking TH9507 showed slightly more swelling, muscle aches, and allergic rash compared to the placebo group. Although this treatment is not a lipid lowering drug, it was noted to have a lipid lowering effect.

The drug manufacturer, Theratechnologies, is conducting more studies on TH9507 and a second phase III trial is now taking place in Europe. If further results confirm the compound's benefits, we can expect to see the company seeking a license to use TH9507 as treatment for HIV-associated belly fat. The evidence so far appears promising, however time will tell whether this compound will be effective in reducing belly fat. ⊕

***Zoran Stjepanovic** is BCPWA's treatment information coordinator.*

Second chance

The results of phase III trials on etravirine are encouraging

by Ashley Smith

Further studies of etravirine continue to show its promise as a second-line drug. Etravirine, also known as TCM 125, is a new experimental non-nucleoside reverse transcriptase inhibitor (NNRTI). This class of drugs, which includes efavirenz (Sustiva) and nevirapine (Viramune), binds to the viral enzyme, reverse transcriptase, thereby rendering it inactive and inhibiting the trasncription of the viral RNA into the viral DNA.

Like its counterparts, etravirine—which is manufactured by Tibotec—is used in conjunction with drugs from other classes, such as protease inhibitors and nucleoside reverse transcriptase inhibitors (NRTI) to prevent viral replication by disrupting the life cycle of the virus.

> **Etravirine's unique chemical structure allows for flexibility, which allows it to bind to reverse transcriptase even when the enzyme has several mutations.**

What's most interesting and exciting about etravirine is its mutation tolerance. Many drugs used to treat HIV become ineffective due to viral genetic mutations. Efavirenz and nevirapine can tolerate relatively few mutations before the efficacy of the drug is compromised. By contrast, etravirine escapes this fate due to its unique chemical structure that allows for flexibility, which allows it to bind to reverse transcriptase even when the enzyme has several mutations. Etravirine has shown promise as a good second-line drug once the virus has become resistant to efavirenz.

Etravirine is currently undergoing clinical trials. In a phase II trial, 16 patients were given etravirine and then compared to a placebo group. The etravirine group showed an average of a 100-fold decrease in viral load and some patients fell below 400 copies/ml of blood. The virus showed no mutations in this seven-day course of monotherapy with the drug. Etravirine has also been shown to decrease viral loads in patients that have failed efavirenz or nevirapine. There was an average of just under a 10-fold change in viral load in these patients, regardless of dosage. The more mutations the virus has, the less effective etravirine was in decreasing viral load.

Not all the clinical trials have been so positive. A phase II clinical trial had to be stopped when the etravirine group of the study was doing worse than the control group, which was taking a protease inhibitor.

Still, etravirine has relatively few side effects when tested in trials. As with efavirenz and nevirapine, rashes were common; however, they appear to resolve a few days after treatment is started. There has been no research into the effects on a fetus or what the transmission rate was with mothers who are breastfeeding, so etravirine isn't recommended for pregnant woman or woman who are breastfeeding.

On September 20, 2007, the US Food and Drug Administration granted priority review to etravirine. That will allow for a timely analysis of the drug and its side effects, since it meets the requirement of medical urgency for its availability and usage. The expected approval date is January 2008. ⊕

__Ashley Smith__ is a respiratory therapist at Vancouver General Hospital and a fourth-year cellular biology major at the University of British Columbia.

Are you HIV-positive?

www.bcpwa.org

living⊕ Magazine
Fundraising Events
Treatment Information
Support Services
Volunteer Opportunities
Advocacy Services
Positive Prevention
Prison Outreach

British Columbia
Persons With AIDS Society

604.893.2200

Getting to the HAART of the matter

by Jennifer Chung

Heart disease is striking more HIV-positive people—and at a younger age. Dr. Greg Bondy, associate director of the Heart Centre at St. Paul's Hospital in Vancouver and a researcher at the BC Centre for Excellence in HIV/AIDS, plans to do something about it. Bondy is leading a new study investigating how the cholesterol-lowering drug rosuvastatin (Crestor) interacts with highly active antiretroviral therapy (HAART). The trial, CTN 218, will also determine whether the drug successfully prevents hardening of the arteries.

"We have made great strides in HIV treatments and simplifying drug regimes, but we have to start tackling some of the other health issues that are affecting people with HIV," says Bondy, who specializes in endocrinology. "This trial is one of first ways we can identify an approach to prevent hardening of the arteries."

While it isn't completely understood why people with HIV are at a higher risk for cardiovascular disease, a number of factors can be pointed to as the most likely causes. Researchers have found that antiretroviral drugs cause cholesterol levels to rise, and they believe that HIV disease itself may put individuals at an increased risk. In addition, a high prevalence of smoking among this specific population is of particular concern.

Bondy says findings generated from this study could potentially provide a definitive and effective strategy to prevent heart disease in HIV-positive people as well as information for HIV treatment guidelines.

He and his team are seeking participants with at least one risk factor for heart disease, such as hyperlipidemia (the presence of excess fat or lipids in the blood) and hypertension (abnormally high blood pressure). Participants will receive either 10 mg rosuvastatin or a placebo on a monthly basis. Rosuvastatin belongs to a class of medications known as statins. Statins travel directly to the liver, where 80 per cent of the cholesterol in the blood is made. Once there, they shut down the enzymes that produce cholesterol.

According to Bondy, what makes this study unique is its use of carotid ultrasound, an imaging technique that can detect any hardening of the arteries at the start and end of the trial. By looking directly at the arteries, Bondy and his research team will be able to determine whether a participant should receive rosuvastatin or placebo.

"We have a world-class study that is not only important for HIV disease, it could also have broader implications in the general population, particularly those with metabolic disorders," says Bondy.

CTN 218 is a two-year, randomized, double-blinded study that will recruit 250 participants at sites in BC, Ontario, and Quebec. The study is expected to begin enrolling participants by early 2008. ⊕

***Jennifer Chung** is the information and communications coordinator at the Canadian HIV Trials Network in Vancouver.*

Trials enrolling in BC

CTN 194 — Peg-Interferon and Citalopram in Co-infection (PICCO)
BC sites: Downtown Infectious Diseases Clinic (DIDC), 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

CTN 221 — NGX-4010 for the Treatment of Painful HIV-Associated Neuropathy
BC sites: DIDC, Vancouver

CTN 222 — Canadian Co-infection Cohort
BC sites: DIDC, Vancouver

To find out more about these and other trials, check out the **Canadian HIV Trials database** at www.hivnet.ubc.ca or call 1.800.661.4664.

Raltegravir continues to show promise

by Dr. Marianne Harris

Raltegravir, formerly known as MK-0518, is an HIV integrase inhibitor. This type of drug blocks HIV from inserting its genetic material into the DNA in the host cell nucleus, a step called integration. While other investigational integrase inhibitors are being studied, raltegravir is the first agent in this class to be approved by Health Canada. It's already available in the US under the brand name Isentress.

Being from a new class, this drug will still be active against viruses that have developed resistance to other available antiretroviral drugs, including nucleoside reverse transcriptase inhibitors (NRTIs), non-nucleoside reverse transcriptase inhibitors (NNRTIs), protease inhibitors (PIs), and the fusion inhibitor T-20.

Raltegravir is taken orally as one 400mg tablet twice daily, with or without food. In two large international studies called BENCHMRK 1 and 2, this dose of raltegravir was shown to be highly effective in reducing the viral load and increasing the CD4 cell count in people infected with HIV that is resistant to the three standard antiretroviral classes: NRTIs, NNRTIs, and PIs. There are no apparent drug interactions between raltegravir and other antiretrovirals, so dose adjustments—of raltegravir or other drugs taken at the same time—aren't needed. The drug also seems quite safe and well-tolerated, with no more side effects or laboratory abnormalities seen in people taking raltegravir than those taking placebo in the BENCHMRK studies. Raltegravir doesn't appear to cause elevations in liver enzymes or in cholesterol and triglycerides.

Until recently, T-20 (enfuvirtide, Fuzeon) has been a successful cornerstone of therapy for people with multi-drug-resistant HIV. Although it's an effective antiviral agent, T-20 is difficult to take, especially over the long term, because the twice-daily injections cause unpleasant reactions in the area the injection is given.

In BC, 29 people have switched from T-20 to raltegravir since July 2007, through Health Canada's Special Access Program. They had been taking T-20 for between seven months and six years before switching. All had viral loads below 50 copies/mL on their T-20-containing regimen, for an average of two years. All individuals were also taking NRTIs and PIs, and some were also taking an NNRTI. No other changes were made to their regimen.

It appears that replacing T20 with raltegravir within a successful regimen is safe and maintains control of the HIV viral load, at least over the short term. So far, all 29 people have kept their viral load below 50 copies/mL. They've had good tolerance to the new regimen and any injection-related problems have resolved. Three people developed new medical conditions but they don't appear to be related to raltegravir. No new laboratory test abnormalities have been seen so far. Needless to say, everyone is happy to be taking a pill and no longer have to give themselves injections twice a day.

Once raltegravir becomes available in Canada by prescription, it will be available to more people, either to replace T-20 or other drugs causing side effects, or as part of a new regimen for those who have undergone previous treatments. At least initially, its use will likely be restricted to people with drug-resistant HIV. However, studies are ongoing to look at raltegravir as a component of first-line HIV therapy. If the drug continues to be safe and effective, in the future it may have a role across many different stages of HIV disease. ⊕

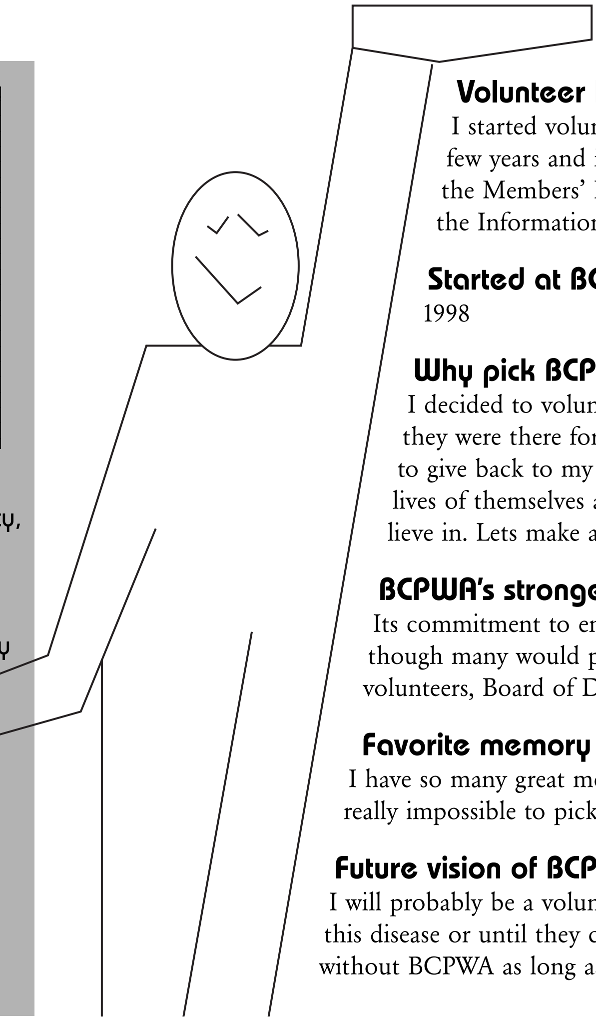
***Dr. Marianne Harris** is a family doctor with the AIDS Research Program at St. Paul's Hospital in Vancouver.*

Volunteering at BCPWA

Profile of a volunteer: Oliv Howe

As competent as she is tall, as committed as she is saucy, Oliv brings a no-nonsense attitude with wit and caring to the unique Complimentary Ticket Program.

Jackie Haywood,
Director of Support Services



Volunteer history

I started volunteering for Theatre Positive, had a break of a few years and in November 2003 started volunteering in the Members' Lounge. Then in February 2005 I started on the Information Desk and Member Services Desk.

Started at BCPWA

1998

Why pick BCPWA?

I decided to volunteer at BCPWA because when I was sick they were there for me, and for a lot of others as well. I wanted to give back to my community. People working to improve the lives of themselves and their community is a cause I firmly believe in. Lets make a difference!

BCPWA's strongest point

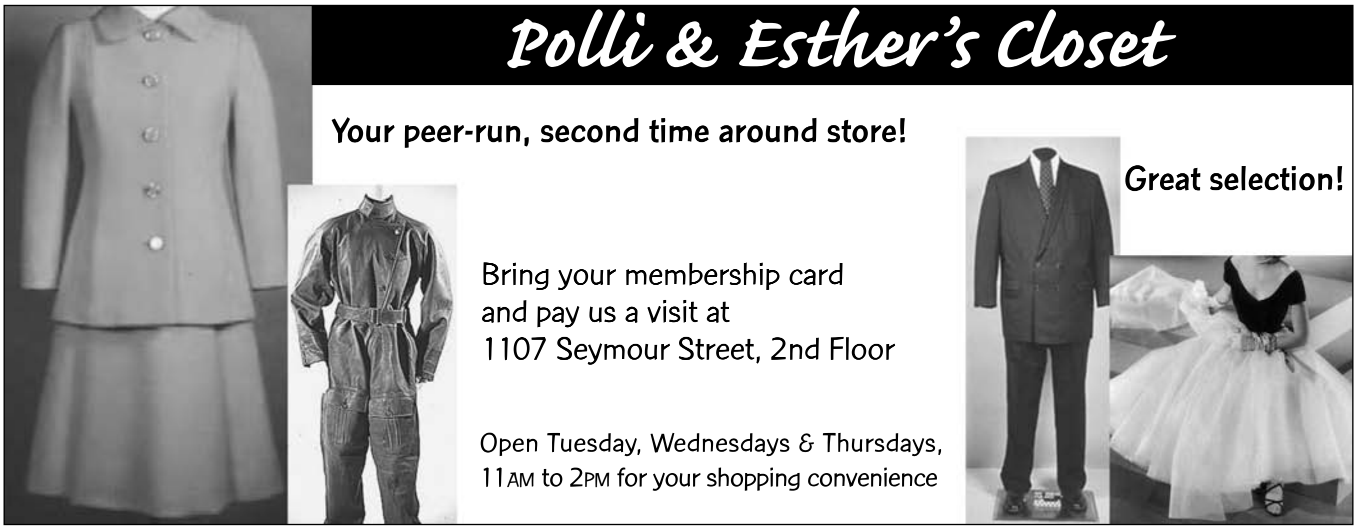
Its commitment to empowering people living with HIV/AIDS, though many would probably say its strongest point is its people, volunteers, Board of Directors, and staff.

Favorite memory

I have so many great memories of volunteering at BCPWA that it's really impossible to pick just one.

Future vision of BCPWA?

I will probably be a volunteer at BCPWA until they find a cure for this disease or until they carry me out feet first. I can't foresee a future without BCPWA as long as there is HIV/AIDS.



SIMPLY POSITIVE

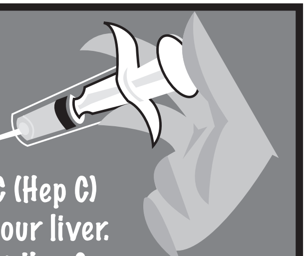
An easy-to-read page on HIV treatment & care.

At BCPWA we want to ensure that HIV related information is accessible to everyone, regardless of reading ability. So the easy-to-read page aims to explain HIV as simply as the ABCs.

British Columbia
Persons With AIDS Society

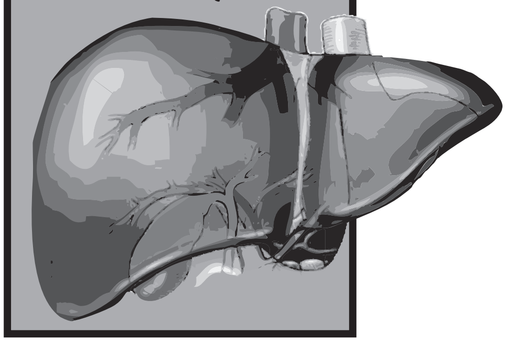
Hep C & HIV

HIV damages your immune system.



Hepatitis C (Hep C) damages your liver. You can get Hep C from blood and body liquids, especially through sharing needles and unsafe sex.

Your liver processes HIV meds. It also processes food and separates poisons to be removed from the body.



If you have HIV, Hep C is easier to get. There is no vaccine for Hep C.

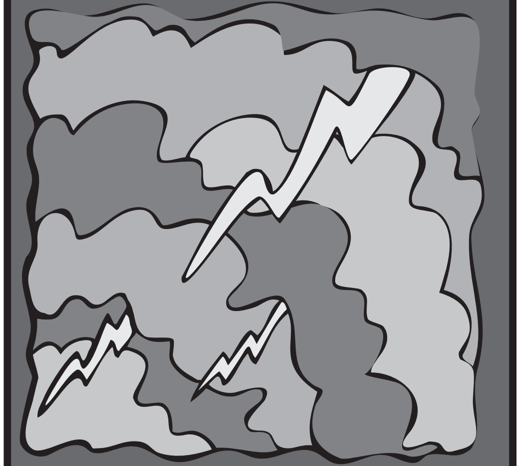
Don't be confused: Hep C does not have a vaccine, however there are vaccines for Hep A and Hep B.

You could have Hep C for 20 years and not know it. You might have Hep C if you feel sick or tired, throw up, have diarrhea or stomach pains, or have yellow skin or eyes. A doctor should examine you.

Hep C sometimes goes away on its own but usually it needs treatment, which can last 6-12 months, but sometimes longer.

Drinking alcohol can do more damage to your liver and cause you more problems.

Hep C treatment can make you feel sad or mad, or give you pain and other illnesses, like the flu. Don't avoid treatment. Report your feelings because many of these can be treated.



HIV complicates Hep C treatments, making Hep C harder to fight. Doctors decide what's right for each person. Some HIV drugs do not work with Hep C drugs.

Have a blood test to check for Hep C because knowing sooner can mean doing better on treatment.

Go to your doctor to find out if you have Hep C and see what treatments might be helpful.

TREATMENT INFORMATION PROGRAM

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

t 604.893.2243
t 604.893.2239
e treatment@bcpwa.org
1.800.994.2437
f 604.893.2251
www.bcpwa.org

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 or 1.800.665.2437
e info@avi.org ***www***.avi.org
AIDS Vancouver Island
(Cowichan Valley Mobile Needle Exchange)
t 250.701.3667
AIDS Vancouver Island (Campbell River)
t 250.830.0787 or 1.877.650.8787
AIDS Vancouver Island (Port Hardy)
t 250.949.0432
AIDS Vancouver Island (Nanaimo)
t 250.753.2437
AIDS Vancouver Island (Courtenay)
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 info@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 info@oaas.ca ***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 BCPWA's website at www.bcpwa.org and click on "Links and Services" under the "Empower Yourself" drop-down menu.

Upcoming BCPWA Society Board Meetings:

Date	Time	Location	Reports to be presented
January 16, 2008	1:00	Board Room	Executive Committee / Financial Statements — November Director of TIAD
January 30, 2008	1:00	Board Room	Written Executive Director Report / Standing Committees Director of Prevention
February 13, 2008	1:00	Board Room	Financial Statements — December / Director of Communications
February 27, 2008	1:00	Board Room	Written Executive Director Report / Executive Committee
March 12, 2008	1:00	Board Room	Standing Committees / Financial Statements — January Quarterly Department Reports — 3rd Quarter
March 26, 2008	1:00	Board Room	Written Executive Director Report / Director of Support

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: Marc Seguin
t 604.893.2298 e marcs@bcpwa.org

Community Representation & Engagement
Contact: Paul Kerston
t 604.646.5309 e paulk@bcpwa.org

Education & Communications
Contact: Julia Smith
t 604.893.2209 e julias@bcpwa.org

IT Committee
Contact: Ruth Marzetti
t 604.646.5328 e ruthm@bcpwa.org

***living*⊕ Magazine**
Contact: Jeff Rotin
t 604.893.2206 e jeffr@bcpwa.org

Positive Gathering Committee
Contact: Stephen Macdonald
t 604.893.2290 e stephenm@bcpwa.org

Prevention
Contact: Elgin Lim
t 604.893.2225 e elginl@bcpwa.org

Support Services
Contact: Jackie Haywood
t 604.893.2259 e jackieh@bcpwa.org

Treatment Information & Advocacy
Contact: Adriaan de Vries
t 604.893.2284 e adriaand@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*

www.bcpwa.org

living⊕

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

For more information visit
www.bcpwa.org
e-mail to living@bcpwa.org
or call 604.893.2206

The wizards of AIDS

Forget about a heart, a brain, or courage—this PWA needed the gift of a good drug cocktail

by Michael Connidis

It was 1996, twelve years after I'd tested positive and I was sinking fast. My CD4 count had dropped to below 60 and my viral load was in the hundreds of thousands and rising. I could imagine the billions of HIV particles coursing through my veins, destroying as many immune cells each day. It was strange; I could actually feel myself going under, unable to keep treading water for much longer. I wasn't giving up though, I was just very aware of the battle that was going on in my body, a battle I was losing.

Just when the sand was about to run out in my hourglass and the wicked witch of HIV was going to do me in, protease inhibitors came to the rescue.

The treatment wizards at St. Paul's Hospital saw me and in no time I was heading home with my dual therapy cocktail in a brown paper bag. Within six weeks my viral load was undetectable and my CD4 count was climbing for the first time in years. Yes, there was that nasty shock of immune reconstitution syndrome, with those painful swellings that appeared on my neck due to some weird strain of mycobacterium. A couple of surgeries and some antibiotics had me sorted out in no time. I began to feel myself rising back up into the world of the living. The cocktail was my lifeline and I was hanging on!

There were changes to my cocktail as researchers explored what antiretrovirals could do, good and bad, while keeping PWAs alive. In 1998 my drug regimen was spiked with some blue pills, turning it into a triple cocktail with more staying power. A few years later, after my body fat had melted away—leaving my arms and legs stripped, and veins bulging—I tried some of the so-called "better" drugs that had become available. All the while, the virus stayed suppressed and my immune system continued to recover. Things were going along nicely; I was alive and enjoying a decent quality of life.

Then, while attending a presentation at BCPWA for Treatment Information Program (TIP) volunteers, I heard some unsettling news about those blue pills in my cocktail. It was hot off the press: Health Canada was pulling nelfinavir because it contained a potentially carcinogenic and teratogenic contaminant.

I felt my lifeline weakening. My anxiety started to grow. Immediately after the presentation, I was off to see the wizards at St. Paul's, thankfully just a few blocks away. The nurse I spoke to was impressed that I had already heard about the problem less than 24 hours after the hospital had been notified. TIP volunteers really are well informed!

> **Just when the sand was about to run out in my hourglass and the wicked witch of HIV was going to do me in, protease inhibitors came to the rescue.**

One of the wizards explained the situation, which reassured me, and set me up with an appointment with the grand wizard the following week. He was sure that I was the only person in the country taking my particular cocktail. The toxic, archaic drug regimen I had taken for years was history and I soon started my updated, once-a-day boosted cocktail.

So far, so good on the new cocktail. My body is still adjusting to the different drugs, but the side effects are manageable. I'm not yet used to taking my cocktail just once a day, but I'm sure it won't take me long to adapt.

I feel incredibly lucky and grateful that I have access to and receive such a high level of care. It confirms for me that trading the house, the pets, and the garden in White Rock for a slice in the sky in downtown Vancouver, to be as close as possible to the resources and services I would need, was the right thing to do. Best of all, my lifeline feels strong and the hold I have on it is as firm as ever. ⊕

***Michael Connidis** is a BCPWA member and a member of the* living ⊕ *editorial board.*