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



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.

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think ⊕

opinion & editorial . . .

Join us at our AGM

by Glyn Townson

When a BCPWA member gets a fresh haircut from one of our volunteers or picks a new outfit from Polli and Esther's Closet, they can take pride in their appearance and feel better prepared to face the world. Those who visit our social lounge or join Average Joes for a fun night out can put aside any sense of shame or isolation, and gain confidence in the shared experience of living with HIV/AIDS. If a member is ready to re-enter the workforce, they can hone their skills and add value to their resume in a variety of BCPWA volunteer roles. Indeed, every issue of this magazine is designed to give our members greater knowledge so that they can best manage the challenges of "living positive."

Empowerment is at the heart of every service and program that BCPWA offers, and every public initiative we undertake on behalf of our members. Our mission is to empower persons living with HIV disease and AIDS through mutual support and collective action, and your responsibility as a member is to be actively involved to that end.

BCPWA's Annual General Meeting is an essential process in our business. Your participation is required to ensure continued success for our organization. Here, you will learn details of our revenues, expenditures, and activities in 2006/07, interact with and question our staff and, most importantly, cast your vote for new board members and resolutions. Decisions made at the AGM are integral to the future of BCPWA; I urge you to not miss this opportunity.

This year, we promise to make your attendance exceptionally worthwhile. The meeting will be held at 11:00AM on August 23 in the comfortable surroundings of Chateau Granville Hotel at 1100 Granville Street in downtown Vancouver. We'll provide a catered lunch to all attendees.

Let's work together to make 2008/09 a year of progress and enlightenment for our community. ⊕

Glyn Townson is the chair of BCPWA.





REALITYBITES

News from home & around the world



BCPWA's treatment information office now upstairs

The BCPWA treatment information office, formerly located in the library on the first floor of BCPWA's Seymour Street location, has moved upstairs. The Treatment Information Program will now be housed upstairs in the Treatment Information and Advocacy Department.

You can come and talk to volunteers or staff weekdays from 10:00AM to 4:00PM. In the mornings, you'll find treatment information volunteers upstairs in the multipurpose room (formerly the smoking room). Come and talk to us about your health, or bring any questions about the latest in treatments, complementary and alternative therapies, or access to physicians.

HIV drug linked to heart attack risk

A drug used in combination with other antiretrovirals to treat HIV infection has been linked with an increased risk of heart attack, according to the manufacturer.

GlaxoSmithKline, in conjunction with Health Canada, is advising patients taking abacavir-containing products—sold under the brand names Ziagen, Kivexa, and Trizivir—of concerns raised by a recent study in *The Lancet* about the possible elevated heart attack risk.

Patients should not stop taking any of the abacavir-containing medications without first consulting their doctors, the company said in a release. Patients should also discuss any serious, pre-existing cardiovascular disease with their physicians.

Health Canada is reviewing the new safety data and will advise Canadians if further measures are considered necessary.

Until then, patients taking abacavir-containing medicinal products should consult with their healthcare professionals before making any change to their medication.

Source: The Canadian Press

Activist prisoner wins human rights award

A federal prisoner and health activist is the recipient of the 2008 Canadian Award for Action on HIV/AIDS and Human Rights, the Canadian HIV/AIDS Legal Network and Human Rights Watch announced on June 16.

The award, which recognizes outstanding individuals and organizations that protect the rights and dignity of people living with or affected by HIV and AIDS, will be presented at a public reception and ceremony in Ottawa.

As a peer health counsellor, Peter Collins has been conducting HIV prevention education behind bars since the late 1980s. His efforts have also included providing support to prisoners living with HIV and hepatitis C, and advocating for better health care and HIV prevention services—including harm reduction measures—in prisons. Collins is currently serving his sentence at Bath Institution, a medium-security federal prison near Kingston, Ontario.

Source: newswire.ca

Advocates demand generic drugs for Mexico

Advocates from several nongovernmental organizations are calling on the Mexican government to declare a "national HIV/AIDS emergency" that will allow the country to import generic antiretroviral

drugs for people with HIV, according to the Apria Healthcare company's news site.

The organizations have formed a coalition to seek universal access to antiretroviral medications in Mexico. According to the coalition, AIDS treatment costs up to 30 times more in Mexico than in other countries with similar per capita incomes. They say that the allowance of cheaper, generic drugs would help to save the lives of nearly 180,000 Mexicans.

According to the article, there are 8,000 to 8,500 new cases of HIV reported each year in Mexico.

Source: www.poz.com

Lower-strength Kaletra approved

Abbott has received marketing authorization from Health Canada for the new lower-strength, tablet formulation of Kaletra. This new lower-strength Kaletra tablet for pediatric patients contains 100 mg of lopinavir and 25 mg of ritonavir.

The Kaletra formulation for pediatric patients is the first and only co-formulated protease inhibitor to date that can be used in children of appropriate age, weight, or body surface area.

Boehringer, Gilead freeze some antiretroviral prices in US

Pharmaceutical companies Boehringer Ingelheim and Gilead Sciences are freezing the prices of their antiretroviral drugs for select agencies in the US, the AIDS Healthcare Foundation (AHF) announced on June 3.

Gilead will freeze the prices on its antiretrovirals Viread, Truvada, and Emtriva for the US Public Health

continued on next page



REALITYBITES

News from home & around the world



Service, the Federal Supply Service, and state AIDS Drug Assistance Programs (ADAPs). The price freeze will be effective through Dec. 31, 2010.

Boehringer will freeze the price of its antiretroviral Aptivus for ADAPs through May 1, 2009, according to the AHF.

Source: Kaiser Daily HIV/AIDS Report

Experimental HIV drug hits snag

Development of Koronis Pharmaceuticals' KP-1461, an experimental antiretroviral (ARV), has been suspended after an analysis of existing data failed to show anti-HIV activity, according to a report by Project Inform.

Though KP-1461 is technically a nucleoside reverse transcriptase inhibitor (NRTI), its mechanism of action is quite different from other NRTIs. Whereas current NRTIs are incorporated into developing DNA to stop the chains of genetic material from becoming fully formed and infectious, the integration of KP-1461 into developing chains of viral DNA causes the virus to produce defective, harmless versions of itself.

The U.S. Food and Drug Administration had asked Koronis to do some additional lab studies to determine if HIV becomes resistant to KP-1461. Koronis subsequently found that the drug had no measurable effect on HIV, a stark contrast to earlier studies. Koronis then analyzed blood samples from people enrolled in its ongoing clinical trial and, to their surprise, again found no anti-HIV activity.

Source: www.aidsmeds.com.

Britain pledges 12 billion dollars to combat AIDS

Britain has pledged six billion pounds (11.8 billion dollars US) to improve health services and systems in developing countries in a bid to combat AIDS.

The seven-year commitment announced by International Development Secretary Douglas Alexander is in addition to one billion pounds already earmarked for the Global Fund to Fight AIDS, Tuberculosis and Malaria.

"If we are to achieve universal access, and to halt and reverse the spread of AIDS, the evidence demonstrates that we require a long-term approach, across a range of health systems and services," Alexander said in a written statement. He said the money "demonstrates (Britain's) determination to remain at the forefront of global efforts to achieve universal access."

The government will work with others to lower the cost of treatment, and increase the coverage of services for injecting drug users. It also aims to help support orphans and vulnerable children, particularly those affected by AIDS, and increase the availability of family planning information and condoms.

Source: AFP

Russia removes ban on gay blood donors

The Russian Ministry of Health announced on May 22 that it has removed the ban on blood donations from homosexuals, UK Gay News reports. The ban was put in place in September 2001, labelling gay men as a high-risk group for HIV infection.

Minister of Health and Social Development Tatyanna Golikova signed the decree to end the ban on April 16.

According to the article, activists from Russian LGBT human rights project GayRussia.ru have fought for removal of the ban since 2006, claiming that the ban contradicted the Russian Constitution and federal legislation.

"We conducted our campaign against the ban for two years and it brought the results," says activist Nikolai Alekseev. "Russian legislation finally got rid of the last direct discriminatory provision against homosexual people."

Source: www.poz.com ☉

Wanted for action

BCPWA's Advocacy Department is looking for people with HIV/AIDS who are currently being treated with antiretroviral therapies and, as a result of the therapy, have developed HIV-associated facial lipoatrophy.

The Advocacy Department is hoping to pursue financial coverage for facial lipoatrophy corrective action for BCPWA members through its provincial health plan coverage. If you want to be part of this project and are comfortable with the possibility of public exposure, please contact the Advocacy Department at 604.893.2223.

Nothing simplex about it

The importance of getting tested if you have symptoms of genital herpes

by **R. Paul Kerston**

Most folks don't know they have herpes, which is a sexually transmitted infection (STI). Knowing your herpes status and type is especially important if you're HIV-positive, because you have a higher risk of transmitting HIV to others. Soon the standard of care for newly-diagnosed HIV-positive persons may include baseline herpes testing and typing.

Genital herpes is caused by two viruses: herpes simplex type 1 (HSV-1) and type 2 (HSV-2). Previously, it was thought that HIV-1 caused sores and blisters on the mouth or face and HSV-2 caused the symptoms in the genital and/or rectal areas. Now it's understood that there's crossover for both types.

Herpes is incurable and once you're infected, you have the virus for life. It can be passed from a mother to her newborn, or by having sex with an infected person—even if they don't have visible sores. Herpes can be transmitted even if you use a condom, via skin-to-skin contact; thus, condoms reduce the risk but don't eliminate it. Herpes can be spread from the mouth to genitals if one partner has cold sores and engages in oral-genital sex.

Most people with herpes don't notice symptoms, which can include painful red dots or tiny blisters that break, leaving tender sores.

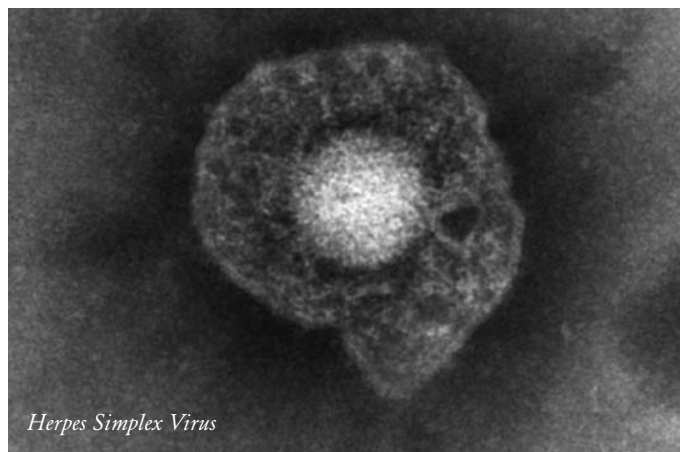
Most people with herpes don't notice symptoms, which can include painful red dots or tiny blisters that break, leaving tender sores. The sores can take two to four weeks to heal the first time they occur. Usually, another outbreak may appear weeks or even months after the first one, but it's almost always less severe and shorter than the first occurrence. Swollen glands, fever, and body aches may also develop, as well as itching, burning, tingling, and leg pain. Usually, symptoms begin to show between two and 30 days after infection, though they may not be visible for months or years. The number of outbreaks tends to decrease over time.

There are two diagnostic tests: a swab, which cultures from an active and suspected lesion; and testing for antibodies in blood serum, which until recently didn't distinguish by type. Soon there will likely be a polymerase chain reaction (PCR) test that detects herpes via genetic information.

Serum testing uses an immunoglobulin (IgG) test, which looks for antibodies. A positive result is confirmed via an EIA (or ELISA)

test, also used in HIV diagnoses. However, there still isn't enough access to the tests: STI clinics perform them, but doctor's offices generally won't order them, though your physician can arrange them in certain circumstances. You'll get diagnosis results—meaning you will know if you have antibodies to HSV in your blood—within a week and not long afterward for type (HSV-1 or HSV-2) of herpes virus.

Approximately 30 percent of swabs from genital lesions test positive for herpes. While the number of infected people in BC



Herpes Simplex Virus

isn't known, there's an increasing number of persons with a physician billing related to herpes—which may simply reflect that more people are aware of treatment options for herpes. Overall, the total number and rate of positive cultures for both types of herpes has been relatively stable in BC. Interestingly, many people test positive for herpes because they were exposed to the virus, orally, as a child.

More and more diagnoses are now type 2 rather than type 1, perhaps because people may be engaging in oral sex as a strategy to avoid riskier sex. US Centers for Disease Control statistics indicate that initial visits to physicians due to genital herpes have increased from near zero in 1966 to almost 400,000 in 2006.

Until now, treatment has focused on alleviating symptoms during outbreaks, called episodic treatment. Drugs include acyclovir (Zovirax), famcyclovir (Famvir), and valacyclovir (Valtrex). Now suppressive therapy uses the same medications but on a continuing basis and with different doses.

If you're HIV-positive and have symptoms of herpes, get tested and know your type, plus consider suppressive therapy. And talk with your partners about it. ☺

R. Paul Kerston is BCPWA's treatment outreach coordinator & community representation and engagement (CRE) coordinator.



Scotiabank

AIDS WALK FOR LIFE

The Walk will do us good

Where the money goes

In addition to BCPWA's Complementary Health Fund, funds raised from this year's Scotiabank AIDS WALK for LIFE will benefit other AIDS and community service organizations to help them provide direct services for PWAs. This is a partial list of our community partners at press time.

A Loving Spoonful is a volunteer-driven, non-partisan organization that provides free, nutritious daily meals to people living with HIV/AIDS in the Greater Vancouver area. A Loving Spoonful believes that by meeting this fundamental need, it improves the health and well being of its clients, enabling them to focus on life's other demands. Proceeds from the WALK will ensure a supply of fresh fruit is available to accompany the weekly delivery.

Camp Moomba is about belonging. Established in 1997, this specialized summer camp program is for children between 6 to 17 who are impacted by HIV/AIDS. It's the only camp in Canada specifically dedicated to this cause. Many of the children who attend Camp Moomba face similar issues in their lives. By coming together each year, they're able to find the type of support that can only come from understanding. Funds from the WALK will go towards Camp Moomba 2009.

National Congress of Black Women Foundation is a national charity that promotes and facilitates activities that foster advancement, recognition, health, and education of black women and their families through community-based services. In BC, the Foundation's UMOJA Resource Centre serves as a conduit to access HIV/AIDS health-related services. Money from the WALK will go to supporting prevention and education initiatives, community workshops, development of culturally specific resources and programs, counselling services, and the resource library.

Positive Living Fraser Valley Society's mandate is to support people living with and affected by HIV/AIDS, and to communicate and collaborate with others for the purposes of HIV/AIDS education, stigma reduction, and service development. Funds raised at the WALK will go to support future services, including support group, nutrition resources, and a support worker.

Positive Women's Network is a partnership of women living with and affected by HIV/AIDS. PWN provides safe access to support and education/prevention for women in communities throughout BC, supports women in making informed choices about HIV and health, and provides leadership and advocacy around women's HIV/AIDS health and social issues. Proceeds from the WALK will go towards the PWN Housing Subsidy Program.

Red Road HIV/AIDS Network is one of three provincially based Aboriginal organizations. The purpose of Red Road is to reduce or prevent the spread of HIV/AIDS, improve the health and wellness of Aboriginal people living with HIV/AIDS, increase awareness of HIV/AIDS, and establish a network which supports the development and delivery of culturally appropriate, innovative, coordinated, accessible, inclusive, and accountable HIV/AIDS programs and services.

Surrey HIV/AIDS Centre Society assists the community and those living with HIV/AIDS in overcoming vulnerability, challenges, and stigma through education, advocacy, research, ongoing support, and empowerment. WALK funds will go toward such client services as supplies for weekly support group meetings, group recreational activities, additional food for the Djaeff Mahler Grocery food bank, and bus passes.

YouthCO AIDS Society is a non-profit organization building capacity with youth between the ages of 15 and 29 throughout BC to reduce vulnerability to HIV, AIDS, and hepatitis C through peer support, peer education, and shared leadership. Money from the WALK will go to YouthCo's breakfast program, member dinners, member activities, and outreach supplies. ☎

Note: For an updated list of the 2008 Scotiabank AIDS WALK for LIFE community partners, visit our website at www.bcpwa.org or contact Kat Biondi, BCPWA's manager of appeals, at 604.893.2282.

Join us for the Scotiabank AIDS WALK for LIFE!

WHEN:

Sunday morning —
September 21, 2008

WHERE:

Stanley Park —
Vancouver

Two easy ways to register!

ON-LINE: Go to www.bcpwa.org
and click on the Scotiabank
AIDS WALK for LIFE logo.

BY PHONE: Call us at **604.915.WALK**

BCPWA Advocacy gets results!



The BCPWA Society's Advocacy Program continues to work hard to secure funds and benefits for our members.

The income secured for April 2008 and May 2008 is:

- **\$ 0** in debt forgiveness.
- **\$7,512** in housing, health benefits, dental and long-term disability benefits.
- **\$775** in monthly nutritional supplement benefits.
- **\$2,250** in ongoing monthly nutritional supplement benefit for children

FIGHTING WORDS



Big brother is coming

by Ross Harvey

Residents of the Northern Health Authority (NHA) will be the guinea pigs in an initial rollout of parts of the provincial Government's eHealth system.

EHealth is the new computerized system for storing and sharing virtually all our personal health information, except information kept by individual general practitioners in their offices. (That information, called the Electronic Medical Record, will be incorporated into eHealth a little later in a slightly different way.) So all our prescriptions records, diagnostic imaging records (such as x-rays and CT-scans), lab results (including blood work) and so on will be kept in health information banks, which will be accessible by any healthcare provider—and others, including social workers, emergency response workers, and so on—with the necessary access permission.

It's an enormous project, costing considerably more than \$100 million (see *living*⊕, September/October 2006, "Not-so private records," and March/April 2007, "Opening the floodgates"). And it's coming to all communities within the NHA region—including Prince George, Smithers, Williams Lake, Prince Rupert, Masset, Quesnel, Terrace, and Dawson Creek—as early as November.

BCPWA and other disability and privacy groups have been working on eHealth with representatives of various government and healthcare interests for almost two years. We've been trying to ensure policies are in place to protect individuals' rights to control who gets to see their private, confidential health information. We haven't had a lot of success. And it looks like people in the NHA region won't even enjoy the limited privacy and confidentiality protections that were initially promised.

Instead, the best they can hope for is a modified keyword system. Under this system, already in place with PharmaNet (the old prescription drugs record-keeping

system), a patient comes up with a password for his or her records. Only healthcare practitioners to whom a patient supplies his/her password can retrieve those records. The problem is that it's an all or nothing system. If you supply a pharmacist with your keyword, he/she will have access to all your health information on the eHealth system, not just to your pharmaceutical records. The same would apply to lab technicians and any other authorized person.

For HIV-positive people trying to keep their serostatus confidential in their home communities, the problems with the eHealth system are obvious.

For HIV-positive people trying to keep their serostatus confidential in their home communities, the problems with this system are obvious. The potential for unauthorized people to find out about their serostatus is enormous—especially in smaller centres where there may be only one pharmacy, for example. This can lead to cruel and destructive discrimination if their HIV-positive status becomes public knowledge.

Although it's being tested in the Northern Health—and only with prescriptions and lab work—eHealth will soon roll out to the entire province. The law creating the system was rammed through the BC legislature in late May. BCPWA

and its partner organizations managed to secure some small changes to that law as it was originally presented, but we'll have to continue to press hard for changes in the system if we want to ensure individuals can exercise effective control over their personal health information.

Even then, a much larger threat to personal privacy is looming. Starting with the provincial ministries of Children and Family Development and of Employment and Income Assistance (welfare), the government intends to implement an integrated case management system of sharable personal electronic records. It will work like the eHealth system, but will span almost all departments that keep information about individuals and will include the entire eHealth system. Work to make this Big Brother system a reality began late last year.

For updates as eHealth and the battle for personal privacy unfold, visit the BCPWA website at www.bcpwa.org. ☉



Ross Harvey is BCPWA's executive director.

How to protect your privacy

If you live in the Northern Health Authority region, here's what to do if you get a prescription filled or some form of lab work done

- ▶ Inform the pharmacist or lab technician upfront that you absolutely do not give your consent to have your prescription or lab work placed within the eHealth system, in either the eDrug (for prescriptions) or PLIS (for lab work) health information banks.
- ▶ If the person doesn't accept your denial of consent, inform him/her that you require the prescription or lab work to be keyword protected, and give them your password—or, if this is the first time you use your keyword, have the person create a password of your choosing—to keyword protect your prescription or lab work records.
- ▶ Ask the person to place a note on your file showing that you haven't consented to the collection of the information and forwarding it to the eHealth system, and that you protest its storage and distribution within the eHealth system.

The **COMPLIMENTARY TICKETS PROGRAM** offers donated tickets to live theatre, movies, sports events, ballet, circus, ice shows, special events for children and families, opera, and many more unique entertainment events at no cost to BCPWA members.



**Enjoy
a free
evening out!**

Getting out of the house gives BCPWA members an opportunity to take a family member, partner, caregiver, or child to a stimulating cultural event at some very special venues, such as the Orpheum Theatre, GM Place, Chan Centre, or a circus tent.

For more information, or to find out how you can sign up for the program, call 604.893.2285 or email comptix@bcpwa.org.


Don't be left on the sidelines when you can enjoy an evening out on us!

Feature Story



Untested, undiagnosed, and untreated, part 2

The final installment of our feature story on how different population groups require targeted strategies

If prospects are so much better, why is HIV diagnosis getting worse? That's the question we posed in the May/June 2008 issue of *living* , in the first part of this feature story.

It's estimated that one-quarter of all HIV-positive Canadians may be unaware they're infected. Studies indicate that more people than ever don't find out they're positive until late in the course of their infection. That has serious implications, not only in terms of people's own health—a late diagnosis can mean greater immune damage, lower CD4 counts, and a higher risk

of life-threatening opportunistic infections—but also in terms of transmission of the HIV virus.

We're examining some of the populations where people still find themselves untested and untreated, and looking at the hurdles and the strategies being used to promote testing, ensure timely diagnosis, and encourage treatment. In the last issue, we looked at five distinct communities: women, prisoners, rural communities, men who have sex with men, and youth. In this issue, we look at Aboriginal peoples, South Asians, immigrants and refugees, and East Asians.



Aboriginal peoples

by *Dr. Gina Ogilvie*

In BC, although Aboriginal peoples comprise less than five percent of the overall population, 13 percent of new cases of HIV occur among Aboriginal people. This disparity is the result of historical discrimination and disenfranchisement, coupled with decreased access to services and care in the province.

Broad-based creative strategies for prevention, education, testing, and treatment and policies are needed to decrease the incidence of HIV and AIDS in this population. HIV education needs to be presented in a culturally sensitive manner, grounded in an empowerment model, and should be mindful of the context and history of the lives of Aboriginal peoples; moreover, the education needs to be available both on and off reserves and in community settings. Plus there's an urgent need for both peer- and community-based support, to decrease stigmatization.

Successful strategies range from on-reserve educational workshops grounded in community development principles to the use of new media, including the Internet and web-based technologies for youth. Innovative projects such as Around the Kitchen Table aim to empower Aboriginal women, with an emphasis on those living in remote communities, to combat the spread of HIV/AIDS by reinstating women's traditional roles and joining them in a community network of support and education. This project provides train the trainer sessions as well as online and DVD instruction, so Aboriginal communities can run their own Around the Kitchen Table sessions, using their own traditions and local resources.

On another front, Chee Mamuk's Star in Your Own Stories project has created two multimedia sexual health campaigns targeting youth, using short films written and produced by Aboriginal youth themselves to highlight positive messages that underscore responsibility, educated choices, and self-respect.

Effective harm reduction approaches in communities is a key issue. Data has shown that Aboriginal people are at significant risk for HIV acquisition from injection drug use. However, access to clean drug equipment in rural areas can be challenging. Continued efforts to increase understanding and awareness of the effectiveness of harm reduction programs are needed.

Testing for HIV and other sexually transmitted infections should be more broadly available to Aboriginal peoples throughout the province, particularly in remote regions, to increase awareness of HIV status. Health practitioners need to deliver these clinical services in a confidential, respectful, and culturally sensitive manner. Use of innovative technologies designed to increase access to testing, such as point-of-care HIV testing, should only be offered after community consultation. The community also needs to be ready, with supports in place, for potential HIV-positive people. Treatment needs to be available widely across the province, to ensure that HIV-positive Aboriginal people can receive exemplary care in their own communities, close to home.

At a policy level, an initiative called Renewing Our Response has identified strategic priorities for Aboriginal communities in BC based on renewing the response to the BC Aboriginal HIV strategy. These priorities include more provincial coordination of services, an Aboriginal persons living with HIV forum, capacity building in Aboriginal HIV research, a harm reduction/risk reduction project, and a community-based HIV/AIDS awareness campaign.

Dr. Gina Ogilvie is an assistant professor at the University of British Columbia and associate director of the Division of STI/HIV Prevention and Control at the BC Centre for Disease Control.



South Asians

by *Parm Poonia*

The term South Asian includes individuals who come from diverse South Asian identities based on geography, religion, language, culture, and ancestral roots. The largest population of South Asians in the Lower Mainland identify as Punjabi Sikh.

For South Asians, there is still a lack of open, non-judgmental, and factual communication regarding HIV/AIDS. Many believe that HIV won't happen to them or anyone they know. Low HIV testing rates are perpetuated by socio-cultural beliefs and practices, such as a fear that if you talk about something bad it will happen, or that a lack of religious faith leads to infection. There are also myths regarding HIV trans-

mission—for example, that HIV is a “white person's” or homosexual illness, or that women don't get HIV unless they're promiscuous.

There are a number of challenges in raising HIV awareness among South Asians. Firstly, male responsibility is often not acknowledged and as a result, they are less involved in receiving messaging and intervention. As well, South Asian males who have sex with males are very closeted about their own sexuality and aren't proactive around HIV risk or testing due to fear of cultural and community stigma, rejection, and potential disownment from friends or family. Women in relationships with

Feature Story

men are often unaware they are at risk because they are unaware of their partner's engagement in risky behaviour.

Keeping face, or not bringing shame to oneself or one's family, is a strong cultural value and practice. Being tested for HIV or accessing treatment can be seen as a proactive and preventative health measure but it can also be perceived with suspicion and mistrust. As a result, secretcies, masked identities, and risky behaviours flourish.

Thus, testing rates remain low for this community. Most South Asians aren't aware of confidential HIV testing and therefore don't get an HIV test. Furthermore, many South Asian doctors aren't providing HIV testing as a potential health concern or a routine checkup.

South Asians aren't native to Canada, therefore issues of immigration, adjustment, and acculturation need to be addressed when providing HIV programs and services. Many new immigrants are better informed about HIV/AIDS than their long-term counterparts.

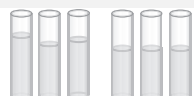
Strategies for working with South Asian communities need to include disseminating basic HIV education; addressing socio-cultural complexities in program planning and delivery; identifying effective routes for messaging, such as ethnic radio talk

shows; addressing cultural and language needs; and increasing the number of South Asians working in the HIV community.

Also, there's a need to build self-empowerment regarding prevention, treatment, and care. For example, education must address issues of sexual health and self-esteem before being able to talk about HIV and safer sex, especially among South Asian youth. Similarly, HIV prevention messaging needs to be positioned not as a sexual health issue but a health issue.

More and more South Asians are testing positive for HIV every day. It's unfortunate that testing tends to happen under required circumstances, such as immigration, prenatal testing, and insurance qualifications versus personal choice. Even more unfortunate is that HIV-positive South Asians are usually symptomatic by the time they access testing, support, or service. Initiatives such as Step 1 and Transmit Knowledge Not HIV have been instrumental in beginning to address HIV for local South Asian communities, but there is more work to be done.

***Parm Poonia** is a community developer; her leadership has been in the areas of HIV/AIDS prevention, healthcare impacts for immigrant/refugee populations, and best practices for the voluntary management sector.*



Immigrants and refugees

by *Daphne Spencer, Cathy Wall, Publi Chakraborty, Devon Haag, and Dr. Mark Gilbert*

Persons from countries where HIV is endemic are over-represented in Canada's HIV epidemic, accounting for 16 percent of all new infections nationally in 2005. In 2002, testing for HIV infection was added to the immigration medical exam required by Customs and Immigrations Canada (CIC) for all immigrants and refugees. Positive HIV test results are identified through routine surveillance (if tested within BC) or through direct reporting from CIC to public health authorities. Between 2005 and 2007, 25 to 48 immigrants and refugees with HIV were identified annually in BC—34 percent of them coming from HIV-endemic countries. Approximately half were newly diagnosed with HIV at the time of testing, with the remainder having previously tested positive.

Dealing with a new or existing HIV diagnosis and accessing HIV-related services becomes one of many issues that immigrants and refugees must face, and they may perceive it as a low priority compared to finding employment and housing, and adjusting to a new culture.

Minimizing barriers to access of appropriate HIV-related services is a high priority for this population. Barriers include HIV-related stigma and concerns about reactions of family or community members if seen accessing HIV-specific services.

There can also be a sense of isolation and lack of social support, and accompanying mental health issues such as depression and post-traumatic stress disorder. Another issue is language barriers and reliance on family or community members for translation, which may affect confidentiality.

New immigrants also may lack an understanding of the Canadian health care system, including medical services plan coverage, and how to access clinical, diagnostic, and pharmacy services. In that vein, they may not be aware that highly active antiretroviral therapy is free and available, and significantly improves health outcomes. And they may not have access to centralized HIV-specific services outside of their home communities, particularly if they hold multiple jobs with few resources for travel.

Providing culturally appropriate and accessible services to these clients is challenging and requires the cooperation of community-based organizations, immigrant support workers, HIV care and treatment providers, public health agencies, and social services. This is often time-intensive, especially because in this population, HIV may have an impact on entire families and all members may need support in accessing testing and care. A major focus of existing services is to provide support

for navigating the healthcare system—such as assisting with accessing specialist care, and providing referral information—and providing clients with information about HIV.

Better assessment of the needs of this population in BC and of the current availability of services is required. Programs that provide local cultural- and language-appropriate care, treatment, and support services will likely have the greatest impact. There could potentially be improved access to services if multidisciplinary case management approaches are expanded, HIV strategies are integrated into employment and support programs for immigrants and refugees, and increased resources are targeted to this population. Implementing these strategies may help us to fully welcome these new arrivals to British Columbia.

Daphne Spencer is the HIV nursing team leader, and is a member of the Surveillance Team with **Dr. Mark Gilbert** and **Devon Haag** in the Division of STI/HIV Prevention and Control at the BC Centre for Disease Control. They have recently been joined by **Cathy Wall**, a former public health nurse from Fraser Health who currently is the clinical research nurse in STI/HIV Prevention and Control. **Bubli Chakraborty** is a former street nurse and currently is the acting manager of the PHSA HIV/AIDS Program.



East Asians

by Shimpei Chihara

In many East Asian cultures, there's a strong stigma attached to sex, so it's considered taboo to talk about anything related to sexual health. Sexual matters are not considered an appropriate topic of conversation even among friends. This taboo becomes a major obstacle when it comes to HIV outreach and education within the East Asian communities in Vancouver.

Silence and ignorance within East Asian communities can result in a lack of knowledge about HIV/AIDS, create misinformation about safer sex, and develop a prejudiced view of people with HIV/AIDS. For instance, some believe that HIV/AIDS is a “non-Asian” thing and therefore there's no threat to East Asian communities.

Due to such cultural myths and lack of knowledge, many East Asians believe that HIV testing isn't important, even if they know testing is available. Furthermore, the stigma attached to sex and HIV/AIDS makes it very difficult for even those people who have concerns about their HIV status to get tested due to a fear of being found out and consequently isolated and discriminated in their own community. And because people know each other well within the community, some East Asians find it difficult to ask their physician about HIV/AIDS and HIV testing when the physician is a community member.

At the same time, there isn't much language specific and culturally appropriate HIV/AIDS information and/or testing services readily available for East Asians. Consequently, many East Asians, especially those who don't speak English well—if at all—may face a greater risk to their sexual health.

In order to prevent HIV epidemics within East Asian communities, it's crucial to break the cultural norms of not talking about sex and sexual health. To achieve this goal, language specific

and culturally appropriate HIV prevention outreach within and outside of East Asian communities is a significant step.

For example, outreach programs targeting sex workers and sexually active men who have sex with men (MSM) among East Asians can be an effective strategy. Visiting massage parlours and bathhouses or organizing social networks of Asian MSM can also open up some opportunities for vulnerable people to access health services or at least learn more about health issues. Social workers with some Asian language skills can provide language specific HIV/AIDS info along with referrals to doctors or health clinics. However, the services being provided at present are quite limited.

The Asian Society for the Intervention of AIDS (ASIA) in Vancouver currently has a number of initiatives to encourage HIV testing. It has multilingual resources about HIV and testing that it distributes around Vancouver and at events. It also gives presentations in ESL classes, to encourage HIV testing. And the Outreach and Research in Community Health Initiatives and Development (ORCHID) Project—which provides culture and language specific HIV and sexually transmitted infection (STI) education and support services to indoor sex establishments, where there are many Asian women—also encourages testing through its partnership with the BC Centre for Disease Control, by providing onsite self swabs and HIV testing. ASIA will also launch a language-specific hotline this summer that will include information about testing services. ☉

Shimpei Chihara is a social worker who coordinates an MSM program at ASIA. He is currently organizing VariAsia, a social support group for Asian gay men, bisexuals, and MSM.

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A Russian revolution

HIV in Russia is spiralling out of control—and the government isn't responding fast enough

by *Sergey Kovynev*

Russia has one of the fastest growing HIV/AIDS epidemics in the world. According to an UNAIDS report published in 2006, 350,000 HIV infections have been officially documented in Russia since the epidemic began, though the actual number of Russians living with HIV is estimated to have been as high as 1.6 million at the end of 2005 (within an overall population of just over 140 million). The World Bank notes that if the situation stays unchanged by 2010, the epidemic will cost the country 4 percent of its economic growth.

According to Russian authorities, there were 358,000 registered HIV-positive people living in Russia by November. The number of reported diagnosed cases of AIDS was only 1,963, and 1,388 people had died of HIV/AIDS related causes.

The changing face of the epidemic

Russia's HIV/AIDS epidemic is changing. While using non-sterile needles remains the predominant risk factor, the epidemic is hitting all population groups, not just high-risk groups. According to Alik Khachatryan, UNAIDS's representative in Moscow, everybody is vulnerable, especially given that the disease is spreading more rapidly in Russia than in most countries.

An example of this trend is Elena, a 24-year-old Russian woman. She learned about her HIV infection when she was pregnant, following a routine check-up. Her husband then got tested but he was HIV-negative, which left her wondering how she got infected, given that she didn't have a drug addiction, nor was she sexually promiscuous. At first she tried to convince the doctors they were wrong, but numerous blood tests all confirmed that she was HIV-positive. She and her husband subsequently divorced.

Despite such cases, Russian officials do not recognize the transformation of the epidemic. "Several years ago, we certainly had quite high rates of HIV infection growth—in

2001, for instance, we registered 87,000 new cases—but now the growth has slowed down to around 30,000 new cases a year," says Ministry of Health representative Larisa Dementieva. She therefore believes it's too early to talk about an HIV pandemic in Russia.

The government offers grossly insufficient support



Vadim Pokrovski

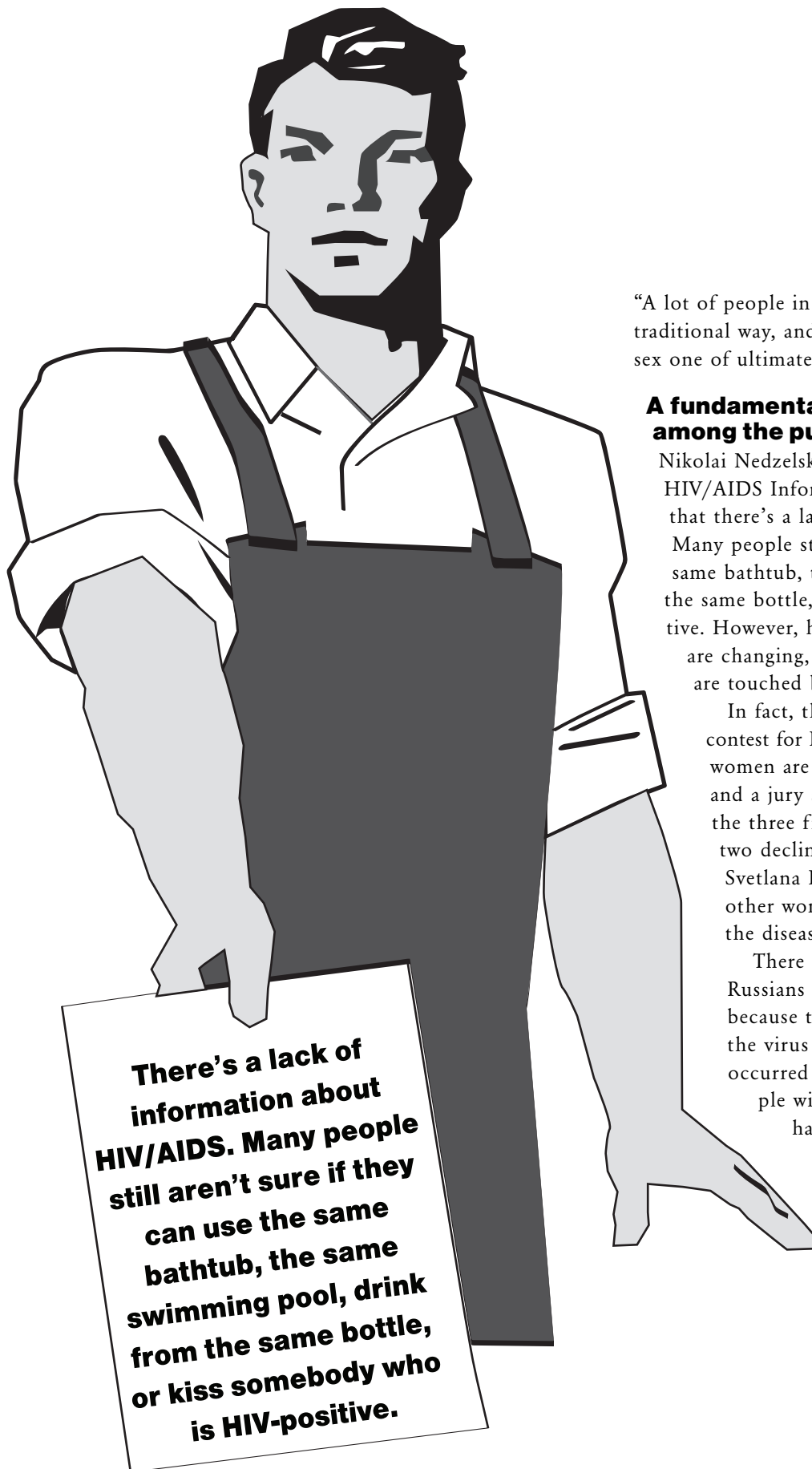
Not everyone shares her optimistic point of view. One of the leaders in the HIV/AIDS field in Russia, Vadim Pokrovski, head of the Federal Centre for AIDS, told BBC Russian Service that the worst was yet to come. The Russian state only pays for enough HIV treatment for a few thousand people a year. "Soon those 350,000 people who are officially recog-

nized as HIV-infected will rely on the state for their AIDS treatment," he says.

Comparing Russia to Brazil—both countries have a similar population size and economic situations—Pokrovski points out that Russia allocates a paltry \$4 million US a year for the fight against HIV/AIDS, whereas Brazil's annual budget is \$800 million US. In 2006, the Russian state paid for the treatment of 15,000 people with HIV. That figure was supposed to double in 2007. But this is clearly insufficient given the scale of the problem.

Funding isn't the only obstacle. Raising awareness is also an issue. "When we talk AIDS, we talk sex. In Russia it means to teach people the basics," said Victoria Kasikova, who works for the AIDS Foundation East West in Moscow, in an interview with the BBC Russian Service.

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“A lot of people in Russia still practice sex in a very traditional way, and it makes the issue of protected sex one of ultimate importance.”

A fundamental lack of knowledge among the public

Nikolai Nedzelsky, the director of Moscow's HIV/AIDS Information Centre, also acknowledges that there's a lack of information about HIV/AIDS. Many people still aren't sure if they can use the same bathtub, the same swimming pool, drink from the same bottle, or kiss somebody who is HIV-positive. However, he feels that attitudes towards AIDS are changing, since more and more people's lives are touched by the disease.

In fact, there's even been a web-based beauty contest for Russian women with HIV. HIV-positive women are encouraged to send in their pictures and a jury selects a winner. Interestingly, among the three finalists of the first contest in 2005, two declined to reveal their names. The winner, Svetlana Izambaeva, says she understands the other women, due to the continuing stigma of the disease.

There are still cases where HIV-positive Russians have been forced to quit their jobs because their co-workers have feared catching the virus from them. Some of those cases occurred in hospitals, which means even people with medical educations sometimes have little knowledge about HIV/AIDS.

Russians still have a lot to learn about HIV/AIDS. As Nedzelsky puts it, we must learn to live in a world where people are dying because of AIDS. ⊕

Sergey Kovynev is a volunteer with BCPWA's Treatment Information Program.



TREATMENT INFORMATION PROGRAM MANDATE & DISCLAIMER

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

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

treatment. information



Canadian Association for HIV Research

Report on the 2008 CAHR conference

by **R. Paul Kerston and Zoran Stjepanovic**

The Canadian Association for HIV Research (CAHR) held its annual conference on HIV/AIDS Research in Montreal on April 24 to 27. There were over 900 registrations from clinicians, researchers, and community organizations attending a four-track program: basic science, clinical science, epidemiology and public health, and the social sciences. The theme of this year's conference was prevention.

There was considerable material about recently released Swiss guidelines concerning zero infectivity in HIV-positive persons who received highly active antiretroviral therapy (HAART) and were monitored by a physician to "undetectable" levels for the prior six months, with no sexually transmitted infections. Presentations showed that there isn't a perfect correlation between plasma viral load and viral load in seminal fluid. Due to

this, the virus may not be detectable in blood and might still be transmissible.

A much anticipated debate took place between Dr. Mark Tyndall, from the BC Centre for Excellence in HIV/AIDS in Vancouver, and Dr. Mark Wainberg of the McGill University AIDS Centre in Montreal. Dr. Tyndall argued in favour of HAART as prevention, whereas Dr. Wainberg argued against it. Some of the exchanges were humorous, which some people felt trivialized the subject. That said, Dr. Wainberg's presentation garnered the bigger vote.

PWAs and heart attacks

GlaxoSmithKline's presentation by company researcher Dr. Jaime Hernandez, MD, reported that the risk of myocardial infarction (heart attack) is more attributable to traditional factors—such as gender, age, weight, and smoking—than to antiretroviral therapy, but that possible increased risk may be more attributed to protease inhibitors than nucleoside reverse transcriptase inhibitors.

Marek Smieja, from McMaster University, demonstrated that HIV presents a 40 to 100 percent increase in risk of cardiovascular disease (CVD) events compared to the general population due to higher amounts of atherosclerosis in HIV-positive persons. Lower amounts of both high- and low-density lipoproteins (HDL and LDL, good and bad cholesterol, respectively) were seen in HIV-positive people, generally, as were lower body mass indices and weight but higher blood pressures and insulin resistance. Smoking emerged as the main risk factor for CVD events among HIV-positive people, followed by lipid imbalances. He indicated that high triglycerides were less problematic than high LDL and total cholesterol counts for determining CVD risk.

Smieja stressed that risk assessments should include a patient's full medical history, waist circumference (not exceeding 96 and 102 cm for females and males, respectively) plus a full cholesterol panel and an APO-A test. Baseline assessments using the standard Framingham guidelines, plus five or more years on HAART and smoking were primary determinants of CVD risk. These findings were further confirmed in the D:A:D study; Julian Falutz of the McGill University Health Centre presented some of the results of this study.

Statin use for controlling cholesterol was considered good, especially in people with more than five years on HAART, who have double the CVD risk.

Other highlights from the conference

Which combination is more effective, Kivexa or Truvada? To find out the answer to this question, researchers at Clinique médicale l'Actuel in Montreal compared the virologic response to Truvada and Kivexa at 24 weeks in a community-based setting in Montreal. This was a retrospective study, which

included 68 individuals receiving Kivexa or Truvada as part of their first-line regimen. The other drug added to their regimen included either a boosted protease inhibitor or a non-nucleoside reverse transcriptase inhibitor. Virologic response was defined as the number of individuals with viral loads below 50 copies. The study found that the rate of viral suppression (viral load below 50) was higher in individuals treated with Kivexa (82.5 percent) versus Truvada (47.1 percent).

A much anticipated debate took place between Dr. Mark Tyndall and Dr. Mark Wainberg: Tyndall argued in favour of HAART as prevention, whereas Wainberg argued against it.

In another study, researchers at BC Women's Hospital in Vancouver looked at whether there were gender differences in tolerability of Truvada and found that there were more frequent Truvada-related side effects among women, especially nausea, vomiting, and rash. Seventy-one individuals participated in this study, with 57 women and 14 men. Truvada-related side effects were found in 18 out of the 57 women in this study and 1 out of 14 men, so further studies are needed to identify risk factors. This study also highlights the need to know more about how some drugs affect women differently than men.

Finally, investigators from the University of Toronto and the Ontario HIV Treatment Network looked at effect of gender on viral load suppression among HIV-positive individuals starting their first antiretroviral regimen. There were 253 individuals in this study, with 60 percent men and 40 percent women. Preliminary data showed that women responded more rapidly to antiretroviral therapy, possibly because they started their initial drug regimens with lower viral loads and higher CD4 counts. This is another area warranting more research. ☉

R. Paul Kerston (l) is BCPWA's treatment outreach coordinator & community representation and engagement (CRE) coordinator.

Zoran Stjepanovic is BCPWA's treatment information coordinator.





License to pill

Proposed new legislation will regulate drugs throughout their lifecycle

by Ruth Pritchard

Bill C-51, which entails amendments to the federal Food and Drugs Act, has excited considerable attention and comment since its introduction in the House of Commons in April. In this article, Ruth Pritchard of the Canadian Treatment Action Council (CTAC)—a national organization of HIV-positive people and their organizations (including BCPWA) dedicated to ensuring access to therapies and treatments for people living with HIV/AIDS by working with the public, private, and not-for-profit sectors—offers CTAC's appraisal of the Bill.

The current laws that regulate drug approval and monitoring in Canada are about to undergo major changes—and it's high time. Our present laws are antiquated compared to other countries and today's realities. The laws are from the 1950s and can't possibly address the changing landscape of diseases and new drug therapies that HIV/AIDS and co-infected communities now have.

On April 8, 2008, Prime Minister Stephen Harper and Health Minister Tony Clement announced that the federal government would be moving forward with the introduction of the new regulations to amend to the *Food and Drugs Act*. Updating the regulatory system is part of Health Canada's Blueprint for Renewal, a comprehensive initiative started by the Liberals. Part of the initiative involves changes to the drug approval system, which will have an impact on people living with HIV/AIDS and those who are co-infected with HIV and hepatitis C.

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Feature Story

How progressive licensing will work

The new, proposed drug approval system is referred to as the Progressive Licensing Framework. This framework will ensure that a life-cycle management approach is applied to a drug throughout its time on the market, pre- and post-approval. Progressive licensing refers to how drugs are approved, and life-cycle management refers to the way a drug is regulated once it's on the market.

Progressive licensing is the way in which a drug will move through the drug regulatory system at Health Canada and ultimately how, and on what basis, the drug will be approved for sale. First, a manufacturer will meet with Health Canada in a pre-submission meeting. At this juncture, the manufacturer and Health Canada will look at the existing and planned clinical data—in Canada and in other countries—of a new drug. They'll look at what's currently known about the drug at its particular stage of clinical development. The result of the meeting will be a signed agreement between Health Canada and the manufacturer, so that they're both on the same page.

These pre-submission meetings are similar to what currently happens in the US between manufacturers and the Food and Drug Administration.

The current system has shortcomings

The current licensing system doesn't allow for ongoing enforcement of a drug as part of the approval process. Essentially, once a drug is approved, there's very little Health Canada can do to regulate its use in the marketplace. However, under progressive licensing, binding conditions can be placed on a drug, including more post-approval surveillance such as confirmatory phase IV studies, or real world outcome data collection. Consumers of medicines and prescribing healthcare providers will therefore have a better understanding of what a drug is doing, for example to people who weren't part of the population included in initial clinical trials.

There's been a great deal of media coverage by groups opposed to the Progressive Licensing Framework. Much of the negative press appears to come from those who don't understand the current regulatory system. Critics use terms such as "lowering the bar" to suggest that the new system won't provide the same quality of scientific review that it does presently. This simply isn't true.

Critics of progressive licensing have assumed that drugs will be approved with a less rigorous review. This isn't the case: only people living with life-threatening diseases who have few treatment options will have an accelerated access to new drugs, as is currently the case. Many naysayers don't seem to realize that Canada has always had a process to provide for accelerated review of drugs where there is serious threat to people's health or life, or for diseases with

limited treatments available. The majority of antiretroviral drugs have come on the Canadian market in this way.

Otherwise, new drugs will still be reviewed with the same scientific rigour as is currently the practice at Health Canada. What critics fail to recognize is that progressive licensing will provide much more post-approval information throughout the drug's lifecycle—information Health Canada currently does not collect.

Monitoring a drug via life-cycle management

This post-approval information will be gleaned through life-cycle management, the process to monitor the safety and efficacy of a drug throughout its use among the general public. The longer a new drug is on the market, the more information we learn about it. Life-cycle management isn't new. Most European countries use it to monitor drugs. By adopting this in Canada, we're merely catching up with many other parts of the world.

The life-cycle management approach is based on the assumption that no drug is without some safety concerns. Therefore, there's a need to evaluate the benefits of a drug against its potential harm, and how to manage any risks. Many of the potential conditions imposed on a drug's approval will provide the necessary information for a robust post-approval follow up.

**Under progressive
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For example, a confirmatory study could be required within a population that may use the drug widely in Canada but wasn't part of clinical trials. Also, a side effect might emerge that needs to be followed in greater detail. Likewise, Aboriginal populations are rarely part of the large, global clinical trials, yet we know that they're predisposed to certain diseases, such as diabetes and cardiovascular disease. A life-cycle management approach may make it feasible to have more risk/benefit post-approval data specific to Aboriginal people living with HIV/AIDS and who may be co-infected.

CTAC is raising some issues with the legislation

On the whole, CTAC has publicly supported progressive licensing because people with life-threatening illnesses will still have access to new and much needed drugs in a timely fashion, there will be more checks put in place before a drug comes to market, and there will be greater surveillance placed upon a drug once it's on the market and used by more people.

Life-cycle management isn't new. Most European countries use it to monitor drugs. By adopting this in Canada, we're merely catching up with many other parts of the world.

However CTAC is concerned about some areas of the proposed legislation, and is raising those issues Health Canada. Firstly, the proposed wording of the Act dealing with a manufacturer's ability to advertise a product is too vague, allowing for too wide an interpretation of what direct to consumer advertising can include; CTAC is arguing that Health Canada needs to be more precise in clearly prohibiting it.

Also, there are two sections in the proposed Act that would give the Minister of Health discretionary powers to share personal medical information, which becomes known to the regulator during a clinical trial. The current wording would allow the Minister to share such information with other governments or agencies if there is an apparent safety risk, for example if a person is known to have tuberculosis or a blood-borne disease. In either circumstance, the Minister would have authority to provide personal medical information to a province, agency, or other country.

CTAC's position is that present public health legislation and procedures are more than adequate to deal with either situation. *The Privacy Act* and the *Charter of Human Rights* also apply in these situations. The Minister doesn't need this power in the Act.

How it applies to natural health products

There has been a great deal of media attention focused on progressive licensing being applied to natural health products. Manufacturers are opposed to this as they feel the process is too onerous and expensive. CTAC strongly supports the proposed legislation dealing with natural health products. CTAC has taken the position that if a manufacturer makes

claims about the efficacy of a natural health product for a certain disease, it should be regulated by progressive licensing. If a manufacturer claims a product can cure a condition, it should have to provide clinical evidence and there should be adequate post-approval surveillance.

CTAC has long advocated for a robust post-approval surveillance system and that by adopting a life-cycle management approach to our drug regulatory process, Canadians living with HIV/AIDS and those co-infected with HIV and hepatitis C will be better served by the drugs we rely on.

Historically, our community has had to wait longer than HIV-positive people in most other western countries for new antiretroviral agents. Likewise, as a community we have lived with side effects and toxicities that have largely gone under-reported at best; we are encouraged that the proposed new system will continue to ensure an effective review process as well as provide a active post-approval system.

We know that the drugs we rely on to stay alive have risks associated with them, but we benefit from these drugs. To have a system that measures and captures the benefits and risks is good for those people who depend on drugs to stay alive. ⊕

Further reading on all the issues

- ▷ For more information on the Blueprint for Renewal, visit www.hc-sc.gc.ca/ahc-asc/branch-dirgen/hpfb-dgpsa/blueprint-plan/index_e.html.
- ▷ For more information on progressive licensing, visit www.hc-sc.gc.ca/dhp-mpps/homologation-licensing/index_e.html.
- ▷ To read the proposed changes to the proposed legislation in Bill C-51, visit www2.parl.gc.ca/HousePublications/Publication.aspx?DocId=3398126
- ▷ To read about CTAC's position on the post-approval surveillance system, visit www.ctac.ca/en/resources/PASS

Ruth Pritchard is the senior policy advisor at the Canadian Treatment Action Council. She has worked in the healthcare/HIV field for 20 years, including at the Canadian AIDS Society, as well as in the pharmaceutical and medical device industries.



Inquiring minds

BCPWA survey explored where PWAs are getting their HIV/AIDS information

by Philip Dawson

Where do people find their information on HIV/AIDS? BCPWA's Treatment Information Program (TIP) recently conducted a survey to uncover the answer.

Much has changed in the almost 30 years since the first case of HIV/AIDS was reported. The fast pace of change, especially in recent years, is becoming overwhelming: more medications are available, there's the hope of a vaccine on the horizon, and HIV/AIDS has become a chronic manageable disease rather than a death sentence. Access to the Internet has also dramatically changed how people find information; a hotline is no longer the only community source.

BCPWA conducted the survey among 69 participants at the Positive Gathering in February. The Gathering offered an ideal setting where individuals attended HIV/AIDS workshops. There were nine simple questions in the survey, ranging from basic knowledge of HIV/AIDS to alternative therapies.

The survey revealed some commonalities, as well as regional differences in available treatment options and knowledge of treatment services.

The survey revealed that medical professionals are the most reliable and main source for information regarding HIV/AIDS. Two-thirds of respondents also felt that information from someone with HIV/AIDS was reliable. As well, many respondents are going online to medical websites, on their own, in search of medical information.

As expected, many people also access information from HIV/AIDS organizations. People are aware of the TIP counsellors and the role they perform; however, a low percentage of respondents indicated that at present they didn't need the services. People outside the Greater Vancouver area feel isolated, with less access to counselling services. Some of these people from regional areas indicated that, even with BCPWA's online and telephone support, they didn't have access to services.

Print material from BC and Canadian sources continues to be a useful source of information. Most respondents were also aware of Canadian AIDS Treatment Information Exchange (CATIE) as an information source.

Very few respondents were acquiring HIV/AIDS information through complementary therapy practitioners or alternative therapy websites. This suggests either a lack of knowledge of alternative therapies or little desire for this type of therapy.

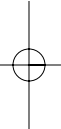
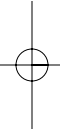
The survey also revealed that PWAs have health concerns about side effects, new treatment options, new drugs, lipodystrophy, and



opportunistic infections. Aging with HIV/AIDS also emerged as a common issue, as increasing numbers are aging and living HIV/AIDS. Highly active antiretroviral therapy (HAART) has changed the life expectancy of PWAs, and as a result people are seeking information on aging.

Based on the results of the survey, BCPWA will implement changes to how it provides treatment information and peer counselling. ☺

Philip Dawson is a BCPWA board member.



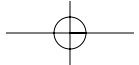
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Honest to doc

Talking to your primary physician about your complementary therapies

by *Alix Mathias*



If you're using complementary and alternative medicine (CAM) and haven't told your doctor, you're not alone. Not by a long shot.

Seventy percent of us use some form of CAM—which includes everything from herbal supplements and acupuncture to yoga and meditation—as well as vitamins and mind/body medicine (including prayer). In fact, the majority of Canadians incorporate several different types of CAM into their wellness routine. Twenty percent of us regularly visit an alternative medicine practitioner such as a chiropractor, naturopath, or herbalist. Yet less than half of us ever tell our doctors we're using these alternative modalities.

What is it that we're hiding from our doctors and why are we so afraid to tell them the whole story? Most patients report that they simply forgot or that their doctor didn't ask so they assumed it wasn't important. A smaller percentage report that they withheld the information due to fear of a negative reaction from their doctor.

Not wanting to disagree with your doctor

If you're less than assertive with your doctor, you're pretty normal; you don't want the person who might be standing between you and your well-being to be pissed off at you. And in our polite Canadian culture, "agreeing to disagree" is difficult at the best of times.

During my first spring in Vancouver, I developed a constant runny nose and watery eyes. I had a brand new interest in alternative therapies and a strong case of naïveté. I went to my doctor and my visit lasted all of 45 seconds. She declared I had allergies and handed me a prescription for antihistamines.

Holding the script in my hand, I nervously blurted out, "I'm not really into taking chemicals."

She looked down her nose at me like a ninth grade science teacher and dismissed me with "everything is chemical." Although she didn't add, "you idiot," it hung in the air nonetheless. Many years passed before I found the courage to talk about alternative therapies with a doctor again.

Omitting details could lead to interactions

If you don't have a similar story, you've likely heard one. These accounts run the gamut of nasty outcomes—from feeling unsupported to outright name-calling and being refused further treatment. While these reactions from doctors likely don't happen that often, hearing it just once causes most of us to think twice about fully disclosing our herbal remedies, shamanic healings, and spinal adjustments to our doctors.

So, in an effort to protect your doctor-patient relationship—or out of sheer forgetfulness—you don't tell your doctor the truth, the whole truth, and nothing but the truth. Why does it matter? What's the worst that could happen?

Well, the worst that could happen is a negative interaction between different forms of treatment: a lack of healing, amplified side effects, or a serious harmful reaction.

Many typically beneficial supplements such as vitamin E, garlic, and ginkgo biloba shouldn't be used prior to surgery because they either interfere with the body's clotting ability or don't mix well with anesthesia. Milk thistle, herbal cleanses, and laxatives may flush your prescription medications through your system so quickly they lose their effectiveness. Research has revealed that even a seemingly innocuous therapy, Hemi-sync relaxation tapes, increased post-surgical bleeding by nearly 50 percent because the body relaxed so deeply that the blood vessels remained open longer than usual.

Inform your doc and be informed yourself

Does telling your doctor about your CAM use guarantee you protection from harmful outcomes? No. It does, however, increase the odds that you'll be alerted to a danger. If you inform your pharmacist, doctors, and your CAM practitioners and you do your own research, the odds increase dramatically.

Your doctor may suggest that you avoid all alternative therapies "to be on the safe side." The truth is there is no safe side when it comes to medical intervention—conventional or

otherwise. All therapies include an element of risk and the best we can do is become informed and empowered risk-takers.

The fact that alternative therapies are powerful is good news to celebrate, not fear. If used wisely, they'll most likely support your use of conventional treatments by decreasing side effects, boosting your immune system, and maximizing your body's ability to respond. CAM therapies will also be there if you ever find yourself at the end of what conventional medicine has to offer.

So, here's what you should do:

- ▶ Before your next visit to your doctor, make a list of everything you take and do to increase your well-being.
- ▶ Give the list to your doctor, pharmacist, and everyone else involved in your care.
- ▶ Be prepared to educate your doctor on the CAM you use.
- ▶ Bring along some articles from trusted sources and courageously share your experiences.
- ▶ Keep the list up-to-date.

Who knows, next time you see your doctor it might be at your favourite yoga class! ☺

Alix Mathias recently completed four years as the wellness services manager at Friends For Life in Vancouver. She now lives in the Okanagan and is learning about wellness, country-style.



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

HIV+ Women Volunteers Needed > knowledge of HIV, medications, tests, health treatment issues.

Interested in obtaining speaking and/or workshop development skills?

Second Hairstylist > Volunteer hairstylist needed to provide professional haircutting and styling at our own in-house salon

Lounge Host > Serve coffee, tea, juices and pastries to members

Polli & Esther's Closet Assistant > Help in a free clothing store that provides clothing and small household items to members

Special events > AccolAIDS Awards Gala and AIDS WALK for LIFE

Writers > *living* ☺ magazine, Communications

Benefits of becoming a volunteer:

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

If you are interested in becoming a volunteer and/or to obtain a volunteer application form, please email volunteer@bcpwa.org, call 604.893.2298 or visit www.bcpwa.org.

volunteer
@ BCPWA



Should you be a guinea pig?

Making a well-informed decision about participating in an HIV clinical trial

by Thiha Maung Maung

The benefit of clinical trials is indisputable. Take penicillin, for example. In 1929, a young Scottish research scientist, Alexander Fleming, discovered this efficacious life-saving drug. With controlled experimentation, researchers found that penicillin cured mice with bacterial infections. Then they tested it on a few human subjects and saw amazing results. The rest is history.

The life-saving antiretroviral drugs that we have today wouldn't exist without clinical trials on humans, and the lives of people living with HIV/AIDS have been vastly improved as a result. But should you enroll in a clinical trial? That's a personal decision, and shouldn't be made lightly. It helps to understand the process, as well as the risks and benefits of participating.

The four phases of clinical trials

Every new drug starts in a laboratory, where scientists confirm the chemical effect on tissue samples or a virus. Next, they have to test those new chemicals in living animals, normally mice. Such tests show whether a potential drug has toxic side effects and how safe it is at different doses.

If the results of early laboratory and animal studies look good, it becomes mandatory to test the new medication in humans. Clinical trials are the most effective way for scientists

to assess whether the benefits of a particular treatment outweigh its risks.

Clinical trials can be divided into four main stages: Phase I, Phase II, Phase III, and Phase IV trials. Phase I trials assess whether the new drug is safe or not in humans, so it's the riskiest. It normally takes a few weeks and tests on a few participants.

Phase II trials assess whether the new treatment really works, and test on about 100 participants. Phase III trials investigate the long-term results of new drugs and last about two to three years. They may involve several hundred participants and are the safest phase of clinical trials.

Some researchers continue to study a drug's effects after it has been approved. This is called post-marketing or Phase IV trials.

Clinical trials contribute new knowledge about diseases and treatments. Some trials compare a new drug with a placebo, which looks, smells, and tastes like the active drug but has no active agent in it. Most trials compare one treatment with another. All these trials are a key part of the process of finding out which drug or treatment options are better, which don't work, and why.

The pros and cons of participating

Participating in a clinical trial can give you access to medications that haven't been approved. You may have already tried every available anti-HIV medication. If your viral load is high and your T-cell count is low, a clinical trial can help you gain access to an experimental medication that may keep your HIV infection from getting worse and improve your health.

You may also get better clinical care. As a regular patient, it isn't always easy to get as much one-on-one time as you want with your doctors. When you get involved in a clinical trial, you'll have a close relationship with the research team, including doctors and nurses. You may have more healthcare professionals involved in your care and a great resource for questions about HIV. At the same time, you'll receive supervision and care from your family doctor.

Joining a clinical trial contributes to the development of new medications and strategies to treat HIV and HIV-related infections. This means you're helping other people living with HIV.

However, there are safety concerns with drugs undergoing clinical trials. The medication may cause bad side effects or have a poor effect on HIV. Phase I trials are riskiest, because there is no safety information available. That said, if you're resistant to all available anti-HIV treatments and have no treatment options, you might be willing to participate in a Phase I study. But if you've never taken HIV medications and have many treatment options available to you, you might choose a lower-risk Phase II or Phase III study.

You may have to stop taking your current anti-HIV medications to participate in a trial. This could cause your HIV infection to progress more rapidly.

Making an informed choice

Before deciding whether you want to enroll in a clinical trial, learn all you can about the drug and the research: the advantages and disadvantages, as well as your rights and responsibilities. The research team will discuss with you the trial's purpose, procedures, risks, benefits, and your rights as a participant. This process is called informed consent. The purpose is to protect you and other participants by providing access to information that can help you make an informed choice.

Also discuss the trial with your doctor, your friends, and your family. Every clinical trial has a protocol, or action plan, for conducting the trial. The plan describes what will be done in the study, how it will be conducted, and why each part of the study is necessary. Each study has its own rules about who can participate. Some studies need volunteers with a certain disease. Some need healthy people. Others want just men or just women.

Clinical trial doctors and nurses will examine whether you meet the strict entry requirements called inclusion and exclusion criteria during the screening visit. Inclusion criteria ensure that relatively similar people take part in a trial, for example, only those with CD4 count between 100 and 300. Exclusion

criteria protect people who might be harmed by the study drug. Pregnant women are rarely allowed to enter drug trials in case the drug harms the fetus.

If you're eligible for a particular clinical trial and you decide to commit to that trial's procedures—which will include regular clinic visits and laboratory tests—you'll need to sign a consent form. You'll be given a copy of the form for your records.

What to expect once you're enrolled

Once you've enrolled, you're responsible for following the rules of the trial. You must show up for all appointments. If you can't follow the trial schedule, talk to the trial staff, and they'll reschedule your appointments. Participants who don't follow the trial rules will be withdrawn.

You can leave a trial at any time, for any reason.

As a trial participant, your health will be monitored mainly by the trial research team. However, you should also see and consult your own family doctor while you're in the trial. If your family doctor is one of the trial's clinical investigators, he/she will ask you to review the trial protocol and informed consent with another doctor. That ensures a doctor's interest in enrolling volunteers for the trial doesn't conflict with his/her obligation to provide the best possible patient care.

Near the end of a trial, you'll have to think about how to handle your HIV treatment after the trial ends. If you're receiving an experimental medication as part of the trial, you may continue to receive that medication, especially if it's about to become available by prescription.

You'll be asked to participate in an exit interview with trial research team. Even after the trial ends, keep in touch with investigators and report any symptoms or side effects.

Making a decision to enroll in a trial isn't easy. There is some degree of uncertainty involved in testing a new drug therapy. Before making a decision, discuss the advantages and disadvantages with your doctor and the people close to you. Your participation could help scientists develop a cure for HIV, or at least better treatment for HIV. ☺

For more information about participating

If you want to know about specific clinical trials, contact BCPWA's Treatment Information and Advocacy Department.

For the current listing of clinical trials, try the Canadian HIV Trials Network website at www.hivnet.ubc.ca. Also read page 35 of this issue.

Thiha Maung Maung is a volunteer with BCPWA's Treatment Information and Advocacy Department and a graduate student at the Faculty of Health Sciences at Simon Fraser University.

Nutrition

Their big fat diet



Study looks at whether eating traditional foods in Aboriginal community can treat diabetes *by Dani Shahvarani*

Our food has morphed from the produce of the land to a commodity, with choices shifting from fresh ingredients to cardboard meals. Fast food has become a primary choice in the marketplace. Everyone is affected and cultural practices are deconstructed. Nowhere is this more apparent than among Aboriginal people, who have seen a dramatic rise in obesity, diabetes, and heart disease in the past 60 years.

Aboriginal people are five times more susceptible to these conditions than those from other cultures, yet before this cultural shift in eating habits, diabetes was unknown in Aboriginal communities. However, the Aboriginal diet has transitioned from the traditional low carbohydrate diet—consisting of seafood, fish, game meats, berries, and animal fats—to highly processed foods with refined carbohydrates and sugar.

Dr. Jay Wortman, a Métis physician working in Aboriginal health, conducted a research study in 2006 in Alert Bay, a small community off the coast of Vancouver Island. Dr. Wortman proposed that a diet high in fat and protein and low in carbohydrates would lead to significant weight reduction and minimize diabetes complications.

He based his theory on his own experience. When Dr. Wortman was diagnosed with Type 2 diabetes, he began a low carbohydrate diet. Soon after, his sugar and blood pressure had normalized and he began to feel much better. Subsequently, he hypothesized that Aboriginal communities would also benefit from a more traditional diet, to which their bodies are more adapted.

(Dr. Wortman views this diet as a therapeutic one, requiring close monitoring by a physician. He also stresses that this diet is not meant to replace the Canada Food Guide or Aboriginal Food Guide.)

The Alert Bay community, comprised of Namgis First Nation and non-Aboriginals, was eager to participate. The Namgis also felt disconnection from their traditional way of life and hoped that restoring their traditional food habits would strengthen cultural identity.

For one year, 60 to 70 participants eliminated sugar and starches—such as bread, potatoes, rice, pasta, and corn—from their diet. But they included high amounts of such fats as cream, bacon, and butter to mimic the high fat they traditionally followed. They were permitted to include unlimited amounts of meats, seafood and fish, eggs, and some vegetables. A major source of monounsaturated fat, called oolichan grease, which is very similar in characteristics to olive oil, was also included as part of the traditional Aboriginal diet.

Participants lost over half a ton of weight, reduced their cholesterol levels, and improved their diabetes control

CBC Newsworld chronicled the study in a documentary titled *My Big Fat Diet*.

While the final results of the study aren't available yet, participants lost over half a ton of weight, reduced their cholesterol levels, and improved their diabetes control. Other beneficial results included improved family relationships, self-esteem, and nutrition knowledge when shopping for and preparing meals. Many of the participants plan to continue the diet and are encouraging other Aboriginal communities to participate. ☺

Dani Shahvarani is a registered dietitian who has worked in HIV care at St. Paul's Hospital in Vancouver, and is now undertaking her Master of Science in Public Health at the University of British Columbia.



Welcome MAT

Antiretroviral adherence program is a success story in the Downtown Eastside

by **Kath Webster**

It's well documented that adherence—taking HIV medications as prescribed, on time, and without missing doses—is the key to successful, effective antiretroviral therapy (ARV). You need at least 95 percent adherence to achieve optimal control of HIV. People who adhere to their HIV medications do better clinically and are less likely to develop resistance to ARVs.

The Maximally Assisted Therapy Program (MAT) is a Vancouver Coastal Health multi-disciplinary ARV adherence support program. Started as a pilot project by the BC Centre for Excellence in HIV/AIDS in 1999, it now operates out of the Downtown Community Health Clinic in Vancouver's Downtown Eastside. The clinic buzzes with activity seven days a week, 365 days a year. On average, 55 participants show up for breakfast, a wide array of support and, most importantly, to receive their daily or weekly doses of HIV medication. Another 30 clients come in either weekly or monthly.



The goal of the MAT Program is to provide social and health support for people with multiple barriers in order to assist them in maintaining high adherence to their HIV

treatments. That can be a challenge, because many of them have multiple diagnoses: along with HIV, many are co-infected with hepatitis C, have mental health issues, and the vast majority is actively addicted to street drugs. Many participants are homeless and live in extreme poverty with very chaotic lifestyles. Potential participants need to be referred and reviewed by the team to ensure they meet eligibility criteria. Those with the most barriers receive top priority.

The MAT Program offers a multi-disciplinary approach to help participants. The program is staffed daily by two nurses, two community liaison workers, a pharmacist, and a program coordinator. Participants can get their blood work drawn on site, and meet with a pharmacist or nurse for side effect management and other health care issues. Community liaison workers play a key advocacy role in helping participants with housing and income assistance issues, referrals to other agencies, as well as mental health and addiction counselling needs. They accompany participants to medical, housing, and other appointments.

Participants who receive daily observed therapy and don't attend the drop-in by 2:00 pm are put on the outreach list. A nurse and community liaison worker then go to the person's home or, if necessary, to the streets, parks, or other hangouts to locate and give the participant his/her ARVs and other support as needed.

The adherence rate of MAT participants is an impressive 92.6 percent, and statistics from February 2007 show that 96 percent of participants have viral loads of less than 500.

MAT has been extremely successful, indicating that social support makes a tremendous difference in achieving high rates of ARV adherence. The staff are highly committed and strive to create a genuine community of caring. This includes celebrating special events such as birthdays and holidays. Staff members say that participants who feel a sense of belonging and caring are further committed to attending the program.

Vancouver Coastal Health estimates that half the people eligible for HIV treatment in Vancouver don't receive it, due to such barriers as poverty, mental health issues, and homelessness. Based on the success of the MAT Program, it would seem that creating more programs based on this model would be a step in the right direction towards addressing the gap in HIV care in the Downtown Eastside. ⊕

Kath Webster is a volunteer with BCPWA's Treatment Information Program.



Bridging the language gap

Newly-diagnosed guide is translated into different languages

by Glen Bradford

Imagine you're living in BC but don't speak English very well, and you've just discovered you're HIV-positive. In addition to dealing with the diagnosis, you have to contend with language barriers. That's why BCPWA has translated a guide for people newly diagnosed with HIV into different languages.

Non-English speaking people in BC who are living with HIV must overcome major hurdles when accessing health care. To start, there's a lack of language-appropriate information on HIV and a lack of available HIV services with free language interpreters. People are often unaware of the available services, and if they are informed, may have difficulty asking for services or understanding the services and information provided due to language barriers. On top of that, cultural misunderstandings between patients and healthcare professionals can lead to a failure to comply with HIV medication regimens.

Though doctors, nurses, and hospitals have free access to interpreters and translated health information through BC Language Services, some are resistant to use the service. It can take up to two days to arrange an interpreter in non-emergency situations. Community-based HIV agencies must pay to access the service.

So where do non-English speaking, HIV-positive people access HIV information? And how do community-based agencies get HIV information and services to non-English speaking HIV-positive people? In response, BCPWA embarked on a project to rewrite and translate the pocket guide "Information for People

Diagnosed with HIV" into simplified Chinese, Punjabi, French, and Spanish.

At the same time, BCPWA sought out organizations that could deliver HIV services to people speaking these languages. Regional barriers between Vancouver Coastal Health Region and Fraser Health Region were difficult to overcome. Although there are a number of agencies in the Fraser Health Region that provide HIV support programs, none are able to provide complex advocacy and treatment information—people must go to Vancouver for those services. And while the Fraser Health Authority has many settlement/multicultural agencies, few are able to handle the health-specific needs of someone with HIV; most of them focus on employment education, language training, and family development. Those that are health-focused were unwilling to escort an HIV-positive person into Vancouver for interpreter services.

Few Vancouver-based language and HIV organizations are funded provincially to support cross-regional health care; as a result, non-English, HIV-positive people from the Fraser Health region will have to come to Vancouver to first contact a multicultural organization.

BCPWA therefore formed partnerships with several multicultural organizations that were HIV-friendly and provided free or low-cost interpreter services, and developed protocols for the organizations to provide interpreter



services for people’s HIV treatment, advocacy, and support needs. Those multicultural agencies are Immigrant Services Society of British Columbia, Settlement Orientation Services, La Boussole, The Asian Society for the Intervention of AIDS (ASIA), and the British Columbia Multicultural Health Services Society, all Vancouver-based.

As well, BCPWA formed partnerships with three ethnocultural health clinics: Bridge Health Clinic in Vancouver, New Canadian Clinic in Burnaby, and New Canadian Clinic in Surrey.

Phase two of this project will involve translating the guide into Arabic, Korean, and Vietnamese.

As well, a priority recommendation from the first phase was to identify communities that have both HIV and interpreter services near each other to work together to provide interpretation in the Interior, North, and on Vancouver Island. Larger, comprehensive HIV organizations across the province may be working informally with multicultural health and interpreter agencies in their own regions.

In the short term, to address some of the immediate needs of HIV-positive, non-English speaking people in these other regions, a language-specific resources pullout guide was created to tuck into the back pocket of the pocket guide. The pullout guide provides a list of HIV/AIDS health service agencies, as well as instructions on how to find a

health nurse at a local health unit or how to contact BC NurseLine. The NurseLine will answer any medical questions, and refer people to their local Health Unit. Translation services are available in over 130 languages.

The pathway that an HIV-positive, non-English speaking person will take to access community-based HIV services is complicated. Hopefully some of these initiatives will help simplify that process. ⊕

Glen Bradford is a volunteer with BCPWA's Prevention Department.

Help get our translated guides out

If you’re an HIV public health nurse, multicultural-specific community health/STI testing clinic, or HIV or multicultural organization interested in promoting and distributing BCPWA’s translated pocket guide, “Information for People Diagnosed with HIV,” contact BCPWA’s director of prevention at 604.893.2225 or email prevention@bcpwa.org.



Breaking down barriers

A BC study explores why injection drug users aren't being treated for hepatitis C

by Ashley Smith

Injection drug users make up approximately 75 percent of hepatitis C (HCV) cases, and approximately 65 to 95 percent of them will become infected at some point in their life. Yet a Vancouver study showed that only about one percent of infected people with substance abuse problems are being treated for hepatitis C. Why is the most affected population not being treated for this deadly disease? A recent study tried to answer that question.

Until recently, injection drug use has been on a list of exclusion criteria for the treatment of chronic HCV infection. It was argued that injection drug users (IDUs) are less likely to comply with therapy, are more susceptible to side effects, and their lifestyle could lead to high reinfection rates after the virus had been cleared from their blood. In studies conducted in 2003 and 2004, researchers felt that the decision to treat the IDUs with HCV should be made on a case-by-case basis.

A 2006 study conducted at two community health care centres in BC—Cool AID Community Health Centre in Victoria

and Pender Community Health Centre in Vancouver—looked at the barriers to treating marginalized, inner-city HCV-positive people. A group of about 200 participants were given a questionnaire that allowed investigators to draw some conclusions.

Co-infection further complicates matters

Those who had received treatment for HCV differed from those who hadn't in two statistically significant ways. Among the group that had received treatment, significantly fewer had tested positive for HIV. As well, few of them had injected drugs within the previous 30 days.

Researchers believe the reasons for the lack of HCV treatment in IDU patients may be multifactorial. The study cited that physicians may be reluctant or biased against this population, therefore hindering the treatment availability, due to the belief that these patients will have adherence problems or an increased chance of reinfection. Investigators also hypothesized

that IDUs may be less eager to seek medical advice due to the entrenchment in their addiction.

Furthermore, participants who were HIV/HCV co-infected were less likely to have received HCV treatment. HIV/HCV co-infection expedites tissue changes in the liver, leading to a much more rapid descent to liver failure or liver cancer, therefore underscoring the importance of treatment. Yet other studies have revealed that only 40 percent of co-infected people have been referred by their physician for HCV treatment. The researchers suggest that strategies for evaluation by a physician and treatment referral need to improve.

**The study cited that
physicians may be
reluctant or biased against
intravenous drug users,
due to the belief that
they will have adherence
problems or an increased
chance of reinfection.**

An unwillingness to seek treatment

Finally, the study looked at factors involved in an HCV-positive person's willingness to seek treatment. Investigators compared the characteristics of individuals who said that they'd be willing to try HCV treatment to those who were opposed to the treatment. HIV/HCV co-infection and current heroin use decreased people's willingness to try treatment. Poor perceived health also increased people's willingness. Previous studies have shown that IDUs have a greater interest in HCV treatment if they're informed of the potential life-threatening conditions as the disease progresses.

Investigators felt that co-infected people may not be as willing to try HCV treatment for a number of reasons, including wanting to concentrate on their HIV treatment regime, previous negative experience with HIV treatment, or an unwillingness to treat another chronic condition that is asymptomatic at the time.

Overall, of the individuals who hadn't yet had treatment, 77 percent said they'd be willing to start therapy.

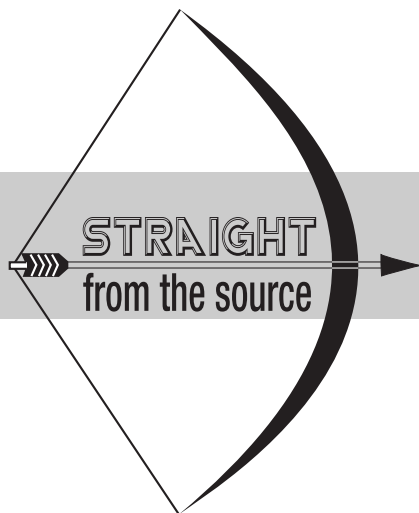
Both healthcare practitioners—especially non-specialists—and people with HCV need to be educated to address the bias associated with HIV treatment for IDUs, and ultimately to help marginalized individuals get treatment. People must be informed not only of the dangerous conditions that can be caused by HCV, but also the available treatment. Peer media-

tion is an effective way to convey this crucial information. HCV treatment can also be coupled with methadone programs, to treat the addiction and HCV at the same time. ⊕

Ashley Smith is a treatment information volunteer with BCPWA's Treatment Information Program.

Some facts about hepatitis C

- ▷ The hepatitis C virus (HCV) is a blood-borne virus and is more virulent than HIV and therefore can be transferred more easily. Like HIV, hepatitis can be transferred through sexual intercourse and by sharing contaminated needles. Once in the bloodstream, the virus binds to, and gains entry to, the liver cells and makes several thousand copies of itself. It then leaves the liver cell through a process called "budding." Budding tires the liver cell, causing it to die, leading to chronic inflammation and eventually cirrhosis of the liver or liver cancer.
- ▷ Similar to HIV, HCV can mutate easily. By the time the immune system has an effective response to the infection, the virus has mutated and the immunological defense is no longer sufficient to fight off the infection.
- ▷ Initially hepatitis C was treated with interferon monotherapy. Interferon is an immunological protein that is naturally occurring and used by our immune system to fight viruses, however it had a poor success rate: only 10 to 20 percent of patients were virus free after six months. Recently, hepatitis C has been treated with a combination of pegylated interferon and ribavirin, which interferes with the virus's ability to replicate. This combination therapy has achieved sustained viral resistance in 50 to 85 percent of people.
- ▷ People start combination therapy if they have high blood alanine aminotransferase (ALT) levels, as well as moderate to severe liver damage, which is diagnosed through a liver biopsy. They'll receive combination treatment for 24 weeks through an injection just underneath the skin. If there's no change in viral loads after 24 weeks, the therapy is stopped and the person is deemed a non-responder.
- ▷ The genetic composition of the virus dictates the response to the therapy. HCV genotype 1 is less affected by the combination therapy, where genotype 2 or 3 responds well to the treatment.



what's new in research

Reduced bone density in HIV

by Dr. Marianne Harris

Reduced bone mineral density—either moderate (osteopenia) or severe (osteoporosis)—is common among older, post-menopausal women. Now, HIV-positive men in their forties or younger are increasingly experiencing these conditions, putting them at risk for bone fractures after little or no trauma.

In the general population, risk factors for reduced bone density include older age, a family history of osteoporosis, low body weight, inadequate calcium in the diet, excessive intake of caffeine or alcohol, smoking, lack of weight-bearing exercise, and certain medications such as corticosteroids and anticonvulsants. These factors play a role in bone loss in HIV; however, it remains unclear how HIV-specific factors—such as HIV infection itself and antiretroviral medications—contribute to the development of reduced bone density. This was the subject of a study by Dr. Silvia Guillemi and colleagues at the BC Centre for Excellence in HIV/AIDS (BCCfE), presented at the CROI conference in Boston in February 2008.

The investigators studied 285 adults (32 women and 253 men) with HIV. Participants answered questions about their medical history and lifestyle, and had a panel of blood and urine tests. They also had a DEXA scan to measure their bone mineral density (BMD).

Surprisingly, two-thirds of the participants had lower-than-normal BMD: 54 percent had osteopenia and 13 percent had osteoporosis. Reduced BMD was more common among people who were white or who had a low body mass index (BMI) or a lower current CD4 cell count. Among men, low BMD was also more common in those with higher alcohol intake, lower levels of physical activity, and higher HIV viral load. The researchers didn't find any specific laboratory test abnormalities that appeared more often in participants with osteoporosis or osteopenia.

The investigators obtained the participants' antiretroviral history through the BCCfE Drug Treatment Program database. Reduced BMD wasn't associated with longer total time on antiretrovirals or protease inhibitors, as suggested in other studies. However, people who had received tenofovir (Viread) for more

than six months were twice as likely to have reduced BMD compared to people who had never taken the drug or who had taken it for less than six months. This is of interest, since studies in animals have suggested that tenofovir can affect bone density, but this has never been shown in clinical trials.

The study results aren't conclusive, and a number of other factors may explain the findings. Further studies are required, including measuring BMD by DEXA scans over time in HIV-positive people on various antiretroviral regimens, to determine whether an association really exists between tenofovir exposure and reduced BMD.

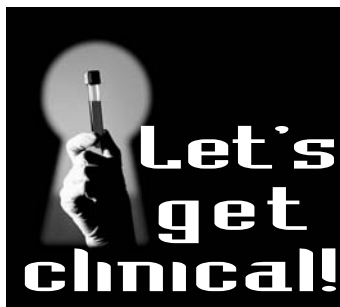
Dr. Guillemi's group concluded that their results supported the recommendations that HIV-positive individuals should be closely monitored for bone density abnormalities. Further studies are planned.

Since HIV infection itself, particularly more active disease with higher viral load and lower CD4 cell count, is associated with reduced bone density, on balance antiretroviral therapy is better for your bones than untreated HIV infection. Not enough is known about the effects of specific antiretroviral drugs to suggest that certain regimens, or changes in your current regimen, would be beneficial.

If you're HIV-positive, you should take preventive measures to lessen the chances of developing osteoporosis. These measures include optimizing your dietary intake of calcium and vitamin D (mainly in milk and dairy products, plus supplements if necessary), maintaining a normal body weight, avoiding alcohol and cigarettes, and regular weight-bearing exercise such as walking, running, and lifting weights. ☺



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



Updates from the Canadian HIV Trials Network



Tackling depression in co-infection

by Jennifer Chung

Depression is an all too common side effect for people undergoing HIV and hepatitis C virus (HCV) therapy. Consequently, those affected often stop taking their medication or interrupt important cycles of dosing. But what if the prevention of depression could improve adherence to therapy? According to James Kreppner, who has been living with HIV and HCV for more than 20 years, a new study gives community members an opportunity to help researchers find the answer.

“Not only can this study shed light on how best to treat HIV/HCV therapy-related depression, but participants will have the advantage of receiving medical and psychiatric support on a regular basis for their treatment during the study,” says Kreppner.

Kreppner, a founding member of the Canadian HIV Trials Network’s (CTN) Community Advisory Committee—which must give its stamp of approval in order for a study to go ahead—is referring to CTN 194. Led by Dr. Marina Klein of the Montreal Chest Institute, the study adds the antidepressant citalopram to the standard HIV/HCV therapy of pegylated interferon.

Because mental health is one of the focuses of this study, participants will also receive psychiatric care support through telemedicine, where they’ll communicate with a psychiatric nurse via videoconference.

Enrolment is targeting people co-infected with HIV and HCV who are about to begin HCV treatment for the first time. Researchers are evaluating the use of citalopram before starting and during treatment for HCV.

“I think it’s important for people in the co-infected community to participate in this study for a couple of reasons,” says

Kreppner. “The study could be beneficial to you because it will help to establish whether an antidepressant should be used as a preventative measure before you start pegylated interferon/ribavirin, which we know causes depression in a lot of cases. Also, you’ll be helping your friends and colleagues because data from this study will help co-infected people get better treatment.”

Nearly 80 participants at sites across the country will be randomly assigned to receive either citalopram or a placebo in this double-blinded trial. After receiving citalopram or a placebo for three weeks, they’ll receive Pegatron/ribavirin for 24 to 48 weeks depending on their HCV genotype. The study will compare adherence to HCV treatment and symptoms of depression between participants who receive citalopram and those who receive a placebo.

“If a co-infected person is going to seek HCV treatment, they’re going to have to face the risk of depression in any case,” says Kreppner. “So the only real question is: is it better to do it under a closely monitored study or is it better to do it on your own separately, just as conventional treatment? I would strongly suggest you’re better off doing it under a strictly monitored study.”

To learn more about this study, visit www.hivnet.ubc.ca. ☺



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

Trials enrolling in BC

CTN 233— Pharmacokinetics of antiretroviral therapy (ARV) in HIV-positive women
BC sites: Children’s and Women’s Hospital, Vancouver; St. Paul’s Hospital, Vancouver; Downtown Infectious Diseases Clinic (DIDC), Vancouver

CTN 222— Canadian Co-infection Cohort
BC sites: DIDC, Vancouver; St. Paul’s Hospital, Vancouver

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

CTN 194— Peg-Interferon and Citalopram in Co-infection (PICCO)
BC sites: St. Paul’s Hospital, Vancouver; DIDC, Vancouver

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

SIMPLY POSITIVE

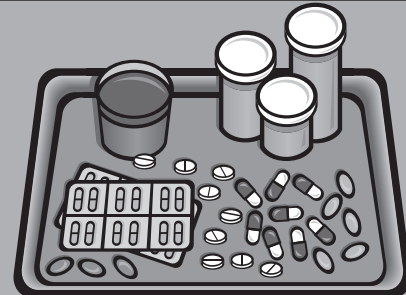
An easy-to-read page on HIV treatment & care.

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.



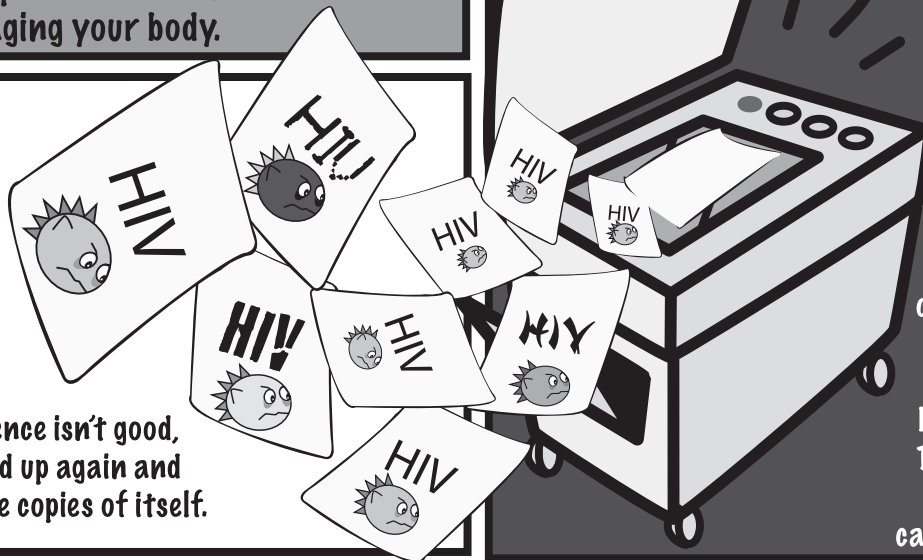
HIV Drug Adherence and Resistance

Adherence is about taking your HIV drugs the right way at the right times every day.



When you have good adherence you have enough HIV drugs in your body to slow down the virus.

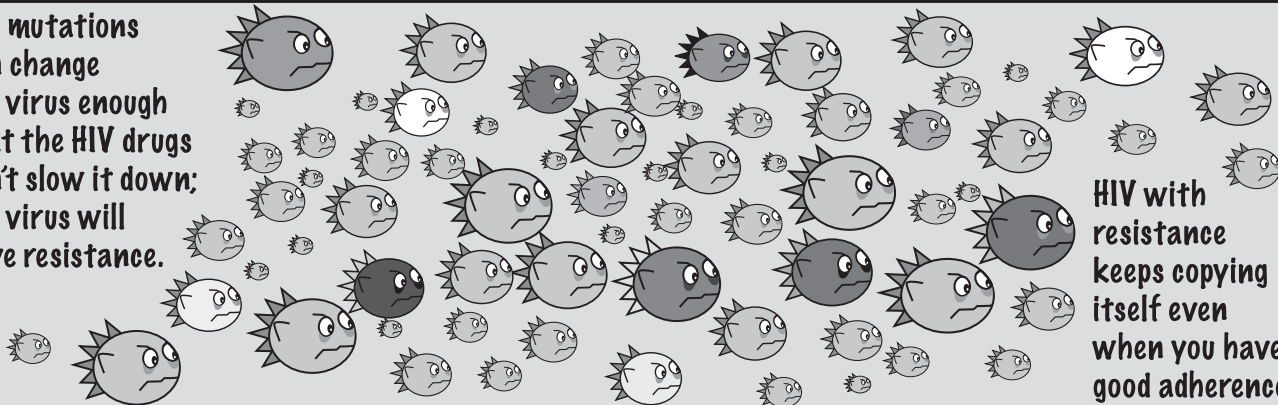
When the HIV drugs slow down the virus it can't make copies of itself and can't keep damaging your body.



When your adherence isn't good, the virus can speed up again and start making more copies of itself.

HIV does a sloppy job of copying itself and some copies are a bit different. The different copies are called mutations.

HIV mutations can change the virus enough that the HIV drugs can't slow it down; the virus will have resistance.

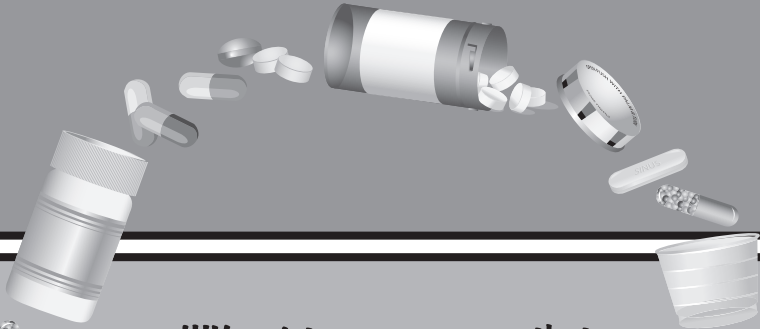


HIV with resistance keeps copying itself even when you have good adherence.

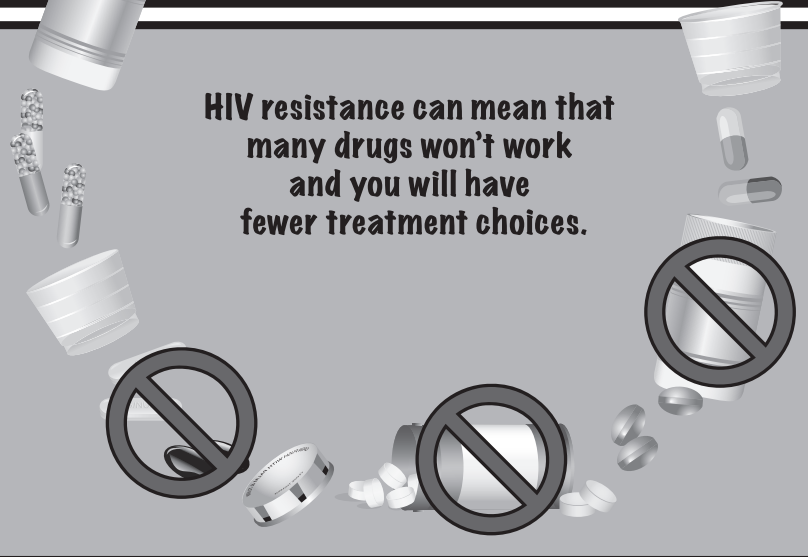
When your HIV develops resistance it will damage your body and be harder to slow down again.



You will have to take a different mix of drugs when your HIV starts to have resistance.



HIV resistance can mean that many drugs won't work and you will have fewer treatment choices.



If you are having problems taking your HIV drugs, talk with your doctor or pharmacist before making any changes.



Good adherence protects you from HIV resistance so you can stay healthy and live longer.



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 1.866.877.0042
e plnw@bulkeley.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 f 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
July 16, 2008	1:00	Board Room	Written Executive Director Report / Standing Committees Financial Statements — April
July 30, 2008	1:00	Board Room	Financial Statements — May / Director of Support
August 13, 2008	1:00	Board Room	Written Executive Director Report / Executive Committee Director of Development
August 27, 2008	1:00	Board Room	Standing Committees / Financial Statements — June
September 10, 2008	1:00	Board Room	Written Executive Director Report / Quarterly Department Reports /1st Quarter Director of TIAD

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

☎ 604.893.2298 ✉ marcs@bcpwa.org

Community Representation & Engagement

Contact: Paul Kerston

☎ 604.646.5309 ✉ paulk@bcpwa.org

Education & Communications

Contact: Adam Reibin

☎ 604.893.2209 ✉ adamr@bcpwa.org

IT Committee

Contact: Ruth Marzetti

☎ 604.646.5328 ✉ ruthm@bcpwa.org

living⊕ Magazine

Contact: Jeff Rotin

☎ 604.893.2206 ✉ jeffr@bcpwa.org

Positive Gathering Committee

Contact: Stephen Macdonald

☎ 604.893.2290 ✉ stephenm@bcpwa.org

Prevention

Contact: Elgin Lim

☎ 604.893.2225 ✉ elginl@bcpwa.org

Support Services

Contact: Jackie Haywood

☎ 604.893.2259 ✉ jackieh@bcpwa.org

Treatment Information & Advocacy

Contact: Adriaan de Vries

☎ 604.893.2284 ✉ 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



living⊕

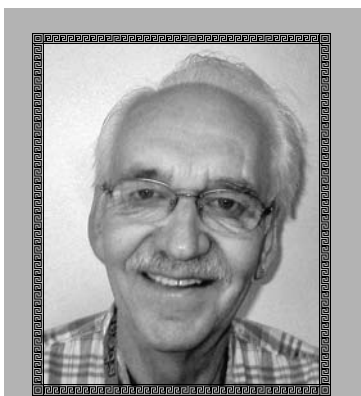
1107 Seymour Street
2nd Floor
Vancouver BC
Canada V6B 5S8

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

Volunteering at BCPWA

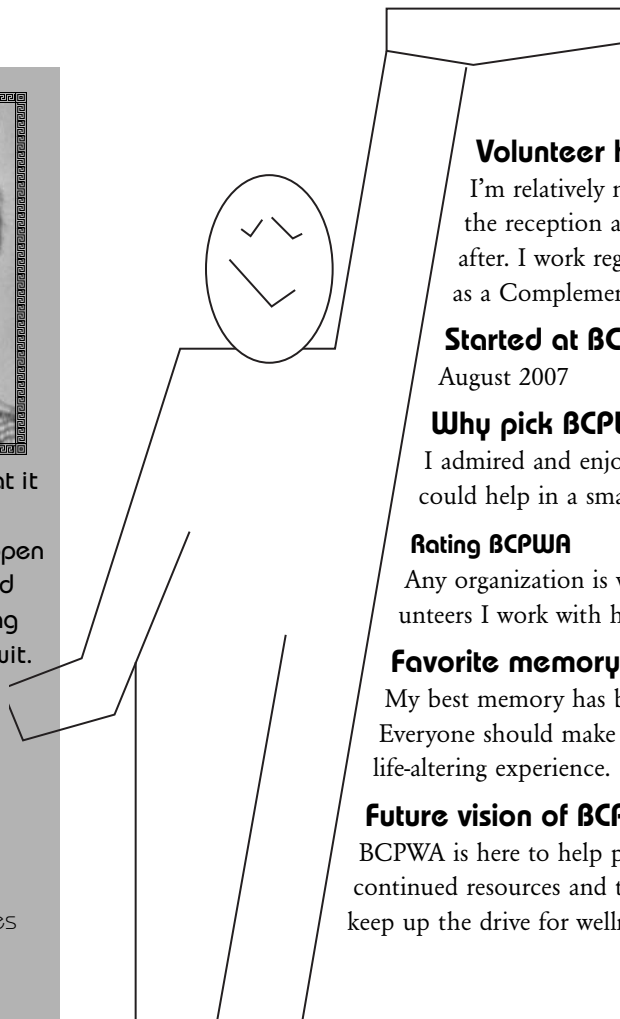
Profile of a volunteer:

Glenn Clark



"Glenn demonstrates what it takes to be a consistent, reliable volunteer. He is open to learning new things and accepts tasks with a strong sense of duty and sharp wit. From the CHF team to Average Joes to heading up the reception team, Glenn is a smart and compassionate leader."

Jackie Haywood,
Director of Support Services



Volunteer history

I'm relatively new, starting as a member services assistant in the reception area, then became team leader shortly thereafter. I work regularly two to three days a week, and one day as a Complementary Health Fund assistant.

Started at BCPWA

August 2007

Why pick BCPWA?

I admired and enjoyed what BCPWA was doing and thought I could help in a small way to serve and help this community.

Rating BCPWA

Any organization is what we make it, and with the quality of volunteers I work with here, it makes it all worthwhile.

Favorite memory

My best memory has been attending the Loon Lake Retreat. Everyone should make an effort to attend—it really is a life-altering experience.

Future vision of BCPWA?

BCPWA is here to help people in their daily lives, and with the continued resources and the dedicated staff and volunteers, we will keep up the drive for wellness for people living with HIV/AIDS.



Polli & Esther's Closet

Your peer-run, second time around store!

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

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



Great selection!

