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British Columbia Persons With AIDS Society

The British Columbia Persons With AIDS Society seeks to empower persons living with HIV disease and AIDS through mutual support and collective action. The Society has almost 4500 HIV+ members.

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BCPWA Society: 20 years strong

by Paul Lewand

2006 marks several anniversaries in the AIDS movement. In a broad context, it's been 25 years since the first cases of AIDS were documented and 20 years since the first AIDS drug was introduced. And ten years ago, protease inhibitors were released, significantly improving and extending the lives of PWAs.

In our own community, it's been five years since our victory with the BC government resulted in a Monthly Nutritional Supplement Benefit for PWAs to purchase essential healthcare goods and services. Ten years have passed since Vancouver hosted—and the BCPWA Society boycotted and organized strategic protests around—the XI International AIDS Conference. And it's been 20 years since the BCPWA Society was first established.

Our organization has a proud history. The Vancouver PWA Coalition, our original name, arose out of the passion and determination of a handful of AIDS movement pioneers who were determined to advocate for their health and rights. Their vision was for an organization created by and for people living with AIDS.

The Society originally drafted its mission statement in 1990, following the Coalition's first formal strategic planning process. At that time, it was agreed that the organization would exist to "enable persons living with AIDS and HIV disease to empower themselves through mutual support and collective action. From our personal struggles and challenges come our courage and strength." Several years ago, Arn Schilder, former chair of the Board stated: "that mission statement is one of the soundest, most useful mission statements ever. This is because it's still relevant and poetic as time goes by."

How very true.

From its very beginnings, BCPWA Society's empowerment philosophy and commitment to mutual support and collective action has been reflected in its operating structure at every level, from program planning to service delivery, and our governance has reflected the current and evolving needs of our members. Today, two decades later, the BCPWA Society has a voting membership of more than 4,400 HIV-positive British Columbians. Members live everywhere, from large urban centres to remote and rural communities. We represent all sexual orientations and gender identities. And our lives reflect diverse experiences and circumstances.

To commemorate our twentieth anniversary, the BCPWA Society has produced a short booklet documenting our history. These highlights—captured in words and photographs—represent two decades of a movement founded on personal empowerment, mutual support, and collective action. It's a brief record of our struggles and challenges as well as our courage and strength. A more comprehensive history document, developed through our archival records and interviews with many past and present members and staff, has been uploaded to our Web site.

This history is our legacy. We can all take pride in our roots. And through our continued involvement in the Society, we can continue to take pride in our future. ⊕

***Paul Lewand** is the chair of the BC Persons With AIDS Society.*

REALITYBITES

News from home & around the world

photo Malsah

New board at BCPWA

On August 26, 2006, members of the BCPWA Society elected 11 persons to its 2006-2007 Board of Directors: The Executive was elected at the first meeting of the new Board on September 13.
BCPWA Society Board 2006/2007 ***(from left to right, back)***:
Wayne Campbell (secretary), Neil Self, Keith Morris, Jim Harron, Ken Buchanan (treasurer), Paul Lewand (chair), Glyn Townson (vice chair), Malsah. ***(front)***: Damien Callicott, Mike Dilworth, Bernd Hoops

Giving a day's pay for AIDS

Toronto doctor Jane Philpott is asking Canadians to give a day's pay on December 1—World AIDS Day—to help fight the AIDS pandemic. The idea began in 2004 when Philpott challenged her colleagues at the Markham-Stouffville Hospital to give up a day's pay and donate it to the AIDS battle. That year they raised $33,000. Then in 2005, eight hospitals across the province got on board, donating close to $100,000 to the cause. Now, Philpott is hoping this year's campaign will go national.

All the funds raised will be used to support the work of Dignitas International and the Stephen Lewis Foundation, both Canadian organizations working at a community level to fight AIDS.

For more information on the Give a Day to World AIDS campaign, go to www.giveaday.ca.

Source: The Toronto Star

Side effects from PCP and TB drugs

Drugs used to treat pneumocystis carinii pneumonia (PCP) and tuberculosis are significantly more likely to cause adverse reactions in people with HIV than HIV-negative individuals, according to a review article published in the September edition of the ***Annals of Pharmacotherapy.*** The authors also found that HIV-positive individuals who were taking anticonvulsants were more likely to experience adverse events than HIV-negative patients who were taking this type of drug.

The investigators reviewed reports in medical literature, published between 1980 and 2005, of adverse reactions in HIV-positive patients taking three common classes of treatment that are regularly used in HIV-positive patients: sulfonamides for PCP; anticonvulsants for convulsions, pain caused by peripheral neuropathy, and bipolar depression; and antimycobacterials for tuberculosis. Their objective was to determine the incidence, symptoms, and possible causes of side effects.

Source: Aidsmap

Atripla coming to Canada

In September, Gilead Sciences and Bristol-Myers Squibb announced an agreement to commercialize Atripla (efavirenz 600 mg/ emtricitabine 200 mg/ tenofovir disoproxil fumarate 300 mg) in Canada, subject to the approval by Health Canada.

Atripla is the first once-daily single tablet regimen for HIV intended as a stand-alone therapy or in combination with other antiretrovirals. The product combines efavirenz (Sustiva), manufactured by Bristol-Myers Squibb, and emtricitabine/ tenofovir disoproxil fumarate (Truvada), manufactured by Gilead Sciences. The US Food and Drug Administration approved Atripla on July 12, 2006.

AIDS vaccine in clinical trials

A South Korean firm is committing $50 million to clinical tests of a vaccine developed by a research team headed by University of Western Ontario virology professor Dr. Yong Kang.

REALITYBITES

News from home & around the world

The commitment will be critical to gaining the US Food and Drug Administration (FDA) clearance to conduct the clinical trials needed before the new vaccine is cleared for use, said Dr. Kang. He expects FDA approval within a year.

"We expect that the initial tests will clear the way for this vaccine to be used therapeutically within three years to treat patients suffering from low-level HIV infection," Kang said.

Dr. Kang said he expected the full set of clinical trials, to be completed in six or seven years, will clear the vaccine for widespread use as an HIV/AIDS preventative. He was hopeful but cautious about the vaccine's chances of success.

Source: The Toronto Star

Drug combo may reduce PI-related disease

Researchers believe they may have found a way to decrease the risk of hardening of the arteries that accompanies the long-term use of protease inhibitors (PIs).

Researchers from the University of Kentucky found that when mice were given a nucleoside reverse transcriptase inhibitor (NRTI) and a PI in combination, it prevented hardening of the arteries often associated with long-term use of PIs alone. The mice received ritonavir (Norvir) in combination with d4T (Zerit) or didanosine (Videx).

The study also found that although PIs alone caused cholesterol to build up in mouse arteries, the increased cholesterol could not be detected in the blood. This means that when doctors test for cholesterol on human patients who are using PIs, their cholesterol levels may look normal even when they aren't, the investigators said.

Source: www.365Gay.com.

HIV in China spreading beyond high-risk groups

HIV in China has spread beyond high-risk groups such as injection drug users, commercial sex workers, and men who have sex with men, according to a senior health official with the Chinese government. The government estimates that there are 75,000 of whom have developed AIDS.

"We're now like Africa," said Hao Yang, deputy director of disease control for the Ministry of Health. "Last year, we found that 48 percent of those who were newly infected contracted the disease from sex, so it's not a disease that afflicts only high-risk groups."

To combat the spread of HIV, the Chinese government has made it mandatory for all entertainment venues to provide condoms, and methadone clinics have been established throughout the country. In addition, Chinese officials have been in talks with Abbott Laboratories and Gilead to negotiate a plan to provide second-line antiretroviral drugs for HIV-positive people who have built up resistance to first-line antiretrovirals.

Source: www.body.com. ⊕

BCPWA Society Treasurer Ken Buchanan (left) accepts a donation from Ms Gay Vancouver, Paige Turner, on behalf of the Rhinestone Phoenix Society. The monies raised from the group's annual fundraising event will purchase socks and underwear for BCPWA's free clothing store, Polli & Esther's Closet.


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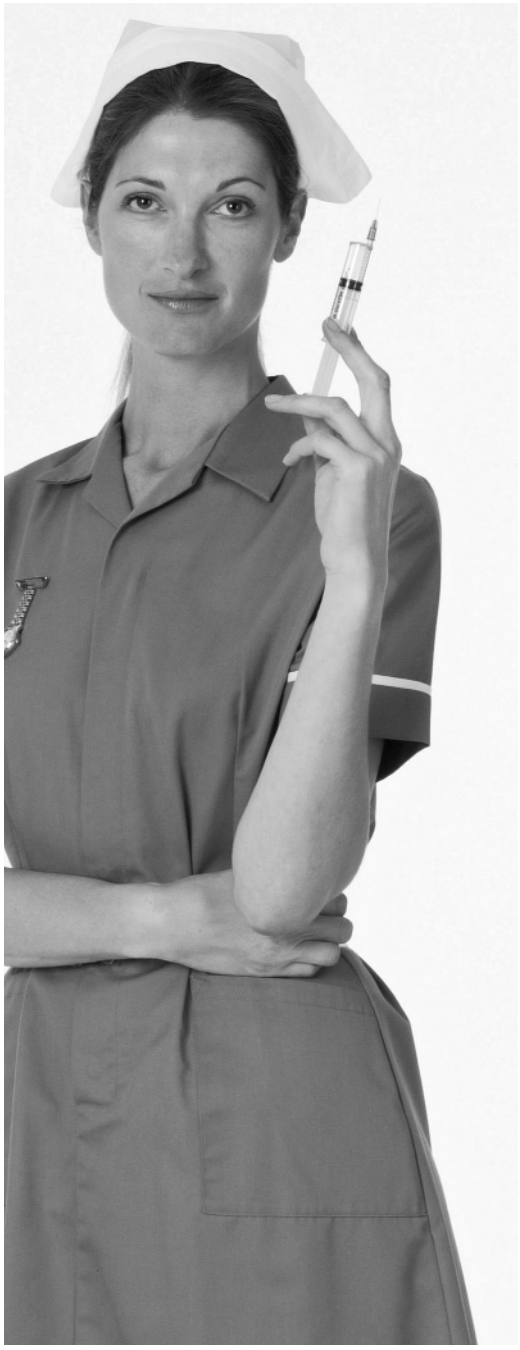
British Columbia Persons With AIDS Society

Short-term gain, long-term pain?

by Paula Braitstein



Most of you have probably heard about the World Health Organization's campaign to get three million people in lower-income countries onto antiretroviral therapy (ARV) by 2005—a strategy known as the "3 by 5" initiative. You're also probably aware that, unfortunately, this target was not met.

That said, in December 2003 only about 400,000 people in Africa, Asia, and Latin America were receiving ARVs, and by December 2005 an estimated 1.3 million people were on treatment. So, although the target was missed, the scale-up was impressive: almost one million more men, women, and children started treatment. Nothing to sneeze at, especially if you were one of them. Yet, these 1.3 million people represent only about 20 percent of those believed to be in urgent need of ARVs.

Traditionally, the major barrier to getting people onto treatment has been the cost of the drugs themselves. Between 2003 and 2005, the price of first-line treatment—usually AZT (Retrovir) or d4T (Zerit) plus 3TC (Epivir) and nevirapine (Viramune) or efavirenz (Sustiva) decreased by between 37 – 53 percent to $148 USD per person per year for the nevirapine-based regimens, and $549 USD per person per year for efavirenz-based combinations. Fabulous news, indeed.

Unfortunately, Abbott is up to its nasty old tricks by, among other things, not registering its new (and much improved) formulation of lopinavir/ritonavir (Kaletra) in most low-income countries, and by refusing to even sell it to Médecins Sans Frontières (check out their Campaign for Access to Essential Medicines at www.accessmed-msf.org/). So, the cost and accessibility of ARVs is still an issue.

Too few personnel to keep up with demand

In spite of continued issues around drug pricing, the bigger and, in many ways, more complex issue now is the limited healthcare infrastructure—including trained healthcare personnel—in place to get and keep people on treatment. While there is greater access to the drugs themselves, there are still many obstacles to getting the drugs to people.

In the article entitled "Identifying the missing links" in the July/August 2006 issue of ***living*** ⊕, I described some of the ART-LINC Collaboration's findings that the more recently people started treatment, the less likely they were to have any follow-up visits. This means that people start treatment and then disappear. Many of them probably die, but nobody really knows. Some clinics have active follow-up strategies in place, such as telephoning people or home visits, but even these centres are overwhelmed by the numbers of patients and simply can't keep up.

There simply aren't enough doctors and nurses working in African clinics, in part due to the HIV epidemic itself, and in part due to a major brain drain to the US or Great Britain, where nurses in particular are in high demand. The healthcare personnel who remain are seriously overworked and mostly underpaid. Patients usually have to wait

several hours before getting their few minutes of (usually interrupted) time with a doctor. There are backlogs in laboratory facilities, data entry, and follow-ups with patients who miss clinic visits.

Continued treatment is overlooked

The thorny issue here is whether clinics should continue to put people on treatment even if they don't have the capacity to really take care of them. Many of the people who have started or are starting treatment have been able to do so thanks to the US President's Emergency Plan for AIDS Relief (PEPFAR), which has gained some notoriety for only caring about how many men, women, and children start treatment every month. Congress gets regular reports saying that there were so many people who started treatment last month thanks to the generosity of the Bush Administration, but most of them could die the next day and it wouldn't be an issue. In the mean time, doctors and nurses are so busy starting people on treatment that they may take a while to notice how many people never come back for a follow-up visit.

The bigger and more complex issue now is the limited healthcare infrastructure—including trained healthcare personnel—in place to get and keep people on treatment.

The first principle of practicing medicine is "do more good than harm." Probably getting as many people started on treatment, regardless of the consequences or clinic capacity, will do more people more good than harm. But it doesn't do people much good to just start treatment—they need to stay on treatment and adhere to it over the long term for it to really have an effect.

Given that it will take years before clinics have developed sufficient infrastructure to accommodate the millions more people who already do or will require ARVs, this isn't a hypothetical issue. Nor is there a quick and easy solution; throwing money at the problem may help in the short term, but in the long term, there is no substitution for homegrown and well-developed healthcare infrastructure, and well-trained African healthcare personnel. Time is a luxury that most people in urgent need of ARVs simply don't have. ⊕

***Dr. Paula Braitstein** is an epidemiologist and former project manager of the ART-LINC (Antiretroviral Treatment in Lower Income Countries) Collaboration. She is currently savouring a life of leisure.*

THOUGHTS SPEAK VOLUMES

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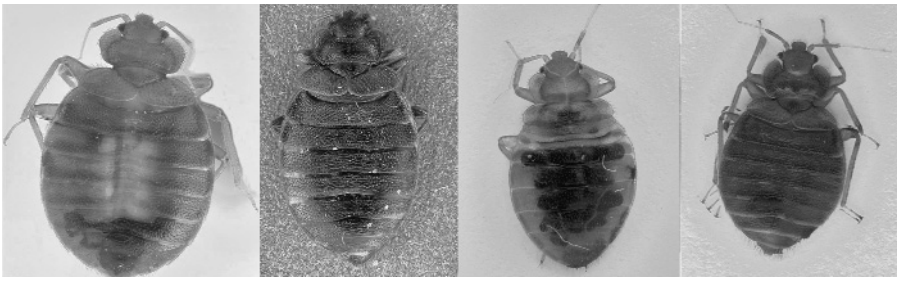
(Staffed: Weekdays 9AM – 5PM)



Bug off!

A bedbug infestation in the Lower Mainland is wreaking havoc on people's lives

by Taz Fletcher

If you feel like bedbugs are everywhere, that's because they are. Bedbug-related reports to the BC Ministry of Health have increased a whopping 600 percent from 2003 to 2005, and by mid-summer of this year, the BCPWA Society's Advocacy Department was dealing with at least one bedbug complaint a day. As people with HIV are already dealing with the day-to-day stresses of medications, their side effects, poverty, and lack of decent housing, having to face a bedbug infestation can cause additional anxiety.

The bedbug is a small, reddish-brown oval-shaped insect with a flattened body, usually about the size of a ladybug. Their main source of sustenance is the blood of humans and they usually feed in the early hours of morning when you're sleeping. Once you have a bedbug infestation, they're notoriously hard to get rid of. It can take months—and multiple sprayings—to properly resolve the problem.

The psychological impact of living with bedbugs may be more detrimental than any physical threat.

Bedbug bites produce inflamed spots similar to a mosquito bite. Allergic reactions can take up to nine days to appear and are identifiable as large wheals, often one centimetre in diameter, and usually cause itching and inflammation.

Some people who have experienced numerous bites develop a sensitivity syndrome marked by nervousness, agitation, and insomnia. This can be especially difficult for people with addiction issues. "One aspect of crystal [methamphetamine] psychosis is the belief of having bugs under one's skin," says Dr. Fraser Norrie, a physician at Three Bridges Community Health Centre. "Actual bedbug bites are likely to validate this belief, increasing the risk of self injury."

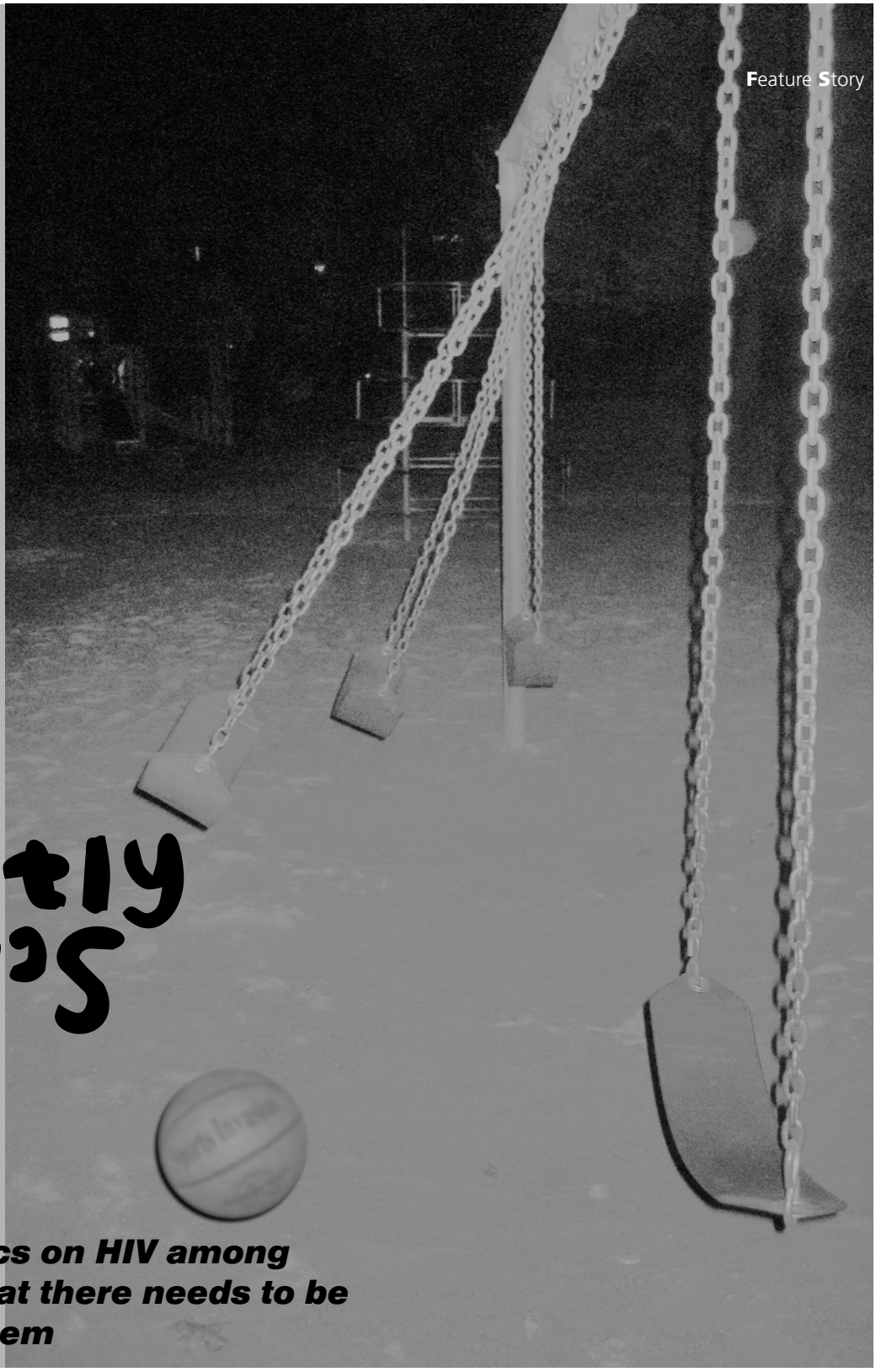
As widespread as the problem is, the general medical opinion is that bedbugs don't transmit disease. Therefore, the Vancouver Health Department doesn't consider them a health problem. There are no studies investigating the effect of bedbug bites on people with compromised immune systems. Vancouver City Council has asked the provincial government to provide financial support to research into this and other bedbug-related concerns.

The psychological impact of living with bedbugs may be more detrimental than any physical threat they may pose. Infestations occur across the economic spectrum, from five-star hotels to low-income housing, but that doesn't make it any easier for people to reach out for help. "People are embarrassed to discuss this problem with us because of the social stigma attached," says BCPWA Society advocate Suzan K. She's concerned not only with the recent increase in bedbug complaints, but also with the emotional toll it takes on people. "Many feel dirty, ashamed, or at fault, but the reality is that bedbugs are a problem experienced by all socio-economic groups in the Lower Mainland and very often has nothing to do with cleanliness and the lack of self-care."

Waking up with bites all over your body can create such strong anxiety that many people have trouble sleeping. Some resort to sleeping in their cars in order to avoid them. As well, the process of dealing with an infestation may include the additional stress of moving and possible disposal of furniture, clothing, and personal keepsakes. For people on limited incomes, the financial burden of having to wash all their clothes and bedsheets may impact their ability to afford food and nutritional supplements. The anxiety can also make it difficult for some to follow their daily drug regimens.

The BCPWA Society's Advocacy Department can help members who are dealing with bedbug problems by working with welfare workers to get a new bed or to receive emergency crisis grants to offset the extra cost of laundry. For more information, please contact an advocate at 604.893.2223 or read our online Bedbug Advocacy ***ActionKit*** at www.bcpwa.org. You'll find the link on the home page under "Featured Publications." ⊕

Taz Fletcher *is a volunteer with the Advocacy Department at the BCPWA Society.*



Not exactly child's play

Sobering statistics on HIV among children show that there needs to be more focus on them

by Audrey Le

In spite of the large population of children around the world who are HIV-positive, HIV/AIDS is too commonly viewed as a disease that affects adults. This assumption is pervasive in Canada as well as many other developed countries. Yet, worldwide the highest rate of new HIV infections is among young people. Approximately one-sixth of the 5.8 million new infections in the past year were among children under the age of 15. Even more alarming: nearly half of those new infections were among youth between the ages of 15 and 24. The fact is, HIV does occur in children and youth, and it affects them much differently than adults.

continued on next page

Most children are infected at birth

Most children with HIV are infected around or during the time of birth. Perinatal transmission accounts for over three-quarters of AIDS cases among children. The remainder of this population was infected through blood products or transfusions. Mother-to-child transmission (MTCT) of HIV resulting from a lack of intervention by medical professionals is believed to occur at a rate of 15 – 30 percent. Of those children who are infected through MTCT, 30 percent are infected during pregnancy, 70 percent during labour and delivery, and 14 percent during breastfeeding.

Although perinatal HIV transmission rates in Canada are declining for babies who are exposed to the virus during pregnancy, not all women are being screened for HIV. If Canada tested all pregnant Canadian women for HIV, 36 infections a year could be prevented. If this screening process were adopted universally, worldwide rates of perinatal HIV infection could decline drastically.

Youth may become infected during adolescence due to a number of reasons: the interaction of behavioural, biological, and socioeconomic factors can increase their vulnerability to HIV infection. Studies have shown that many youth are misguided or uninformed about the risks associated with unprotected sex. Some believe that oral sex is completely safe, while others simply don't believe that HIV is prevalent among Canadian youth.

Poverty and lack of access to health care, education, and prevention tools are also associated with increased vulnerability to HIV. HIV-positive youth without access to adequate care are less likely to build a relationship with their healthcare providers and in turn, may not seek or receive proper, continual care.

Drug use also places youth at risk. Some youth may experiment with intravenous drugs without using sterile needles.

The mode of diagnosis is different

Children are often diagnosed at the time that their mothers are diagnosed. The median age of diagnosis among Canadian children is 12 months old, although children have been diagnosed as late as 13 years old. Late diagnosis may occur because many healthcare providers don't think of HIV as a possibility in their young patients.

Children who are exposed to HIV around the time of their birth must be diagnosed differently than adults. That's because standard antibody tests for HIV can't be done until 18 months of age. Instead, a polymerase chain reaction (PCR) test is used to detect viral nucleic acid. Children are given a clean bill of health if: they have two negative tests (performed after one month of age and around four months of age), have lost their maternal antibodies, and have signs of clinical wellness. On the flip side, they are diagnosed as HIV-positive if two separate HIV PCR or viral culture tests are positive.

HIV-positive children may have a variety of symptoms. Nervous system symptoms include:

- developmental delay or regression
- small head or poor head growth
- spasticity
- gait disturbances
- difficulties in school
- behavioural changes.

Other possible symptoms of HIV in children include:

- slow growth
- recurrent infections such as pneumonia, which can be particularly problematic because it may be resistant to treatment.
- reactive airway conditions such as asthma, with no family history of these problems
- an inexplicably large heart at birth
- low blood cell counts
- unexplained large liver or spleen
- enlarged lymph nodes and glands.

Accelerated rates of infection

HIV infections in children accelerate at a faster rate than in adults. Ten to 30 percent of children are rapid progressors and may become symptomatic as early as several months after infection. Unfortunately, these children die more rapidly. Intermediate progressors are the ones who develop symptoms during toddler years; this occurs in 70 – 85 percent of HIV infected children. Long-term progressors who show symptoms much later in their childhood or adolescence account for less than five percent of infected children.

The numbers tell the story

2.3 million
Number of children under the age of 15 years living with HIV/AIDS at the end of 2005

700,000
Number of those 2.3 million children who were newly infected

570,000
Number of estimated deaths from AIDS-related illnesses among children under 15 years old in 2005

14 seconds
How frequently a person between the ages of 15 & 24 is infected with HIV

26.9 %
Percentage of positive HIV test results in Canada as of June 30, 2002 that were among 20 – 29 year olds

1.5 %
Percentage of positive HIV test results in Canada as of June 30, 2002 that occurred among 15 – 19 year olds; however, this low percentage may be due to under testing of this age group.

Statistics from the World Health Organization (WHO) and the State of the World Population 2003 Report *by the United Nations Population Fund.*

Children with HIV generally have a higher viral load than adults do. For children, the peak in viral load occurs in the first two to three months and remains high for a year before declining slowly over the next several years. The reason for this lies in the fact that their immune system is still immature and therefore has difficulty controlling the virus. Viral replication is also harder to suppress by medications. The central nervous system is an area that needs careful examination for children with HIV. Encephalopathy, a disease of the brain, is common and often affects language development. Because the incidence of HIV in children with ongoing cranial development is fairly low, further research needs to be completed to examine the effects of antiretrovirals on the developing brain.

Another consideration about HIV in childhood is how the hormonal effect of puberty affects HIV progression and the way antiretrovirals work. However, these differences between age and HIV progression and treatment fade as the age of the person increases. The progress of infection in adolescents and older children closely resembles the progression in adults.

Managing HIV among children takes a team approach

The management of HIV in children and youth requires a team approach. The team includes nurses, social workers, nutritionists, physicians, and pharmacy professionals. In Canada, HIV-infected children are often cared for in specialized programs. A network of support is important because there is usually more than one infected person in their family.

The social aspect of children living with HIV is one of most challenging issues. Many of their families live in poverty; many of them are from marginalized groups. Disclosure and confidentiality also pose many difficulties. Children themselves may be unaware of their diagnosis.

Very little is known about the changes that may occur in drug-body interactions during puberty, since body fat distribution changes significantly during this period of development.

Treatment can also be a challenge, and daily HIV treatment regimens can strongly affect children's quality of life. HIV-positive children may be too young to administer their own medication, and thus need caregivers to help them. Multiple family members may also be responsible for different aspects of their treatment, and because of the nature of a child's life, activities such as socializing with friends and attending school activities may cause disruptions in their medication schedules.

Adolescence poses particular problems with treatment

When HIV-positive youth reach adolescence, they face other treatment challenges. One of the most significant problems is adherence, due to possible sporadic and poor eating habits. Teens may also experience feelings of denial and fear about their HIV status, which in turn affects their adherence to their medications. In addition, teens tend to mistrust the medical system.

However, adolescents who were infected during childhood or are long-term survivors of perinatal infections are unique in that they are just emerging as a distinct group.

Ten to 30 percent of children are rapid progressors and may become symptomatic as early as several months after infection.

Very little is known about the changes that may occur in drug-body interactions during puberty, since body fat distribution changes significantly during this period of development. Generally speaking, though, treatment regimens depend on the youth's development. Adolescents in pre- or early puberty stages need to take doses according to pediatric guidelines set by weight and height. Post-puberty adolescents can follow adult antiretroviral guidelines.

Many of these older youths are very experienced at taking antiretrovirals, and thus far it appears that their medications are working. However, being "experienced" in this context can also mean that they sometimes experience resistance to certain drugs.

Very little research has been conducted on HIV infection in children and youth. Ultimately greater emphasis needs to be placed on health and drug education geared towards youth. In turn, HIV-infected children and youth as well as their families can and should gain access to specialized programs and support groups. Although Canada isn't at the forefront of the ongoing HIV crisis in the world, we can most certainly set the standard and act as a model for the world to follow.⊕

***Audrey Le** is a researcher/writer for the BCPWA Society.*

SOME RESOURCES FOR CHILDREN & YOUTH WITH HIV

CAMP MOOMBA
A specialized summer camp program in BC for kids age 6 - 17 who are impacted by HIV/AIDS.
www.campmoomba.com

CAMP OASIS CANADA
Canada's first national summer camp (in Muskoka, north of Toronto) just for children, either infected or affected by HIV/AIDS, offers facilities,programs and medical support, plus input and ongoing guidance.
www.campoasis.com

KIDS HELP PHONE
Counsellors answer calls and online questions from across Canada, no matter what the problem or concern. Provides immediate and caring support, information and, if necessary, referral to a local community or social service agency.
1-800-668-6868
www.kidshelphone.ca

LET'S TALK
Based in Toronto. Provides a safe space for people to speak about HIV/AIDS—to ask questions and share stories.
www.kidstalkaids.org

HUMMINGBIRD KIDS SOCIETY
Run by volunteers, Hummingbird connects families and children to support, services, and opportunities. Deals directly with the kids and their families.
www.hummingbirdkids.com

OAK TREE CLINIC
Provides specialized HIV care for infected women, pregnant women, partners, children and youth residing in BC, and support services for affected families. The clinic accepts referrals from physicians, other healthcare professionals, community agencies, and support workers. Self-referral is also possible.
www.bcwomens.ca/Services/HealthServices/OakTreeClinic

PLANETAHEAD
Condomania is an interactive website for teens by teens, providing convenient and confidential answers. Made up of teen website committee members, youth peer educators, and program staff who care about young people & their sexual health.
www.planetahead.ca

THE TERESA GROUP
Provides practical assistance & emotional support through trained volunteers. Working in association with the HIV/AIDS Comprehensive Care Team at the Toronto Hospital for Sick Children and other community agencies.
www.teresagroup.ca

YOUTHQUEST!
Operates drop-in, youth support, and community development services and programs for queer positive youth in suburban and small-town communities across BC.
www.youthquest.bc.ca

YOUTHCO AIDS SOCIETY
A non-profit organization building capacity with youth between the ages of 15-29 throughout BC to reduce vulnerability to HIV, AIDS and hepatitis C through peer support, peer education, and shared leadership.
www.youthco.org

WWW.LIVEPOSITIVE.CA
A web site for youth, developed by Positive Youth Outreach, the Hospital for Sick Children, Canadian AIDS Treatment Information Exchange (CATIE), and TeenNet at the University of Toronto, in collaboration with youth and youth-serving agencies across Canada.

Are you HIV-positive?

www.bcpwa.org

British Columbia
Persons With AIDS Society

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

604.893.2200

On your guard

Forced HIV testing for prisoners in federal correctional facilities won't solve anything

by Terry Howard

The Office of Public Safety and Emergency Preparedness Canada is considering drafting legislation that would permit forced testing of prisoners for HIV and other blood-borne pathogens, in the event of occupational exposure to blood and bodily fluids within federal correctional institutions.

The Union of Canadian Correctional Officers (UCCO) submitted a proposal to federal Minister of Public Safety Stockwell Day. The proposal makes no sense, due to the flawed rationales upon which it is based, and the failure of such legislation to offer real health and safety protection for workers exposed to blood-borne pathogens in the course of their work.

The proposal runs counter to Canadian law, which holds that everyone has a right to keep their personal health information confidential baring exceptional circumstances.

When a correctional officer is exposed to body fluids, immediate access to post-exposure prophylaxis (PEP) is available through the closest hospital emergency ward. It is neither helpful nor accurate to obtain the inmate's serostatus at that time, as PEP must be administered four to 72 hours after exposure. An inmate who contracted HIV within the six months prior to the incident may conceivably test negative for HIV antibodies at the time of the occupational exposure, thus giving the correctional officer a false sense of security.

The false negative results may also prevent the officer from critical follow-up testing. This would be counterproductive to the proposed legislation and would not protect anyone involved in an occupational exposure incident.

Facts obtained from a Freedom of Information request show that from 2000 to 2005, there was not a single reported incident of a prison guard being stabbed with a needle or syringe. Under Correctional Service of Canada (CSC) policy, correctional staff are obliged to report all incidents involving serious bodily injury and assaults causing major injury. There is, therefore, no evidence to support the need for such legislation.

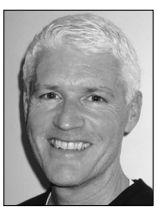
What's more, the proposal runs counter to Canadian law, which holds that everyone has a right to keep their personal health information confidential barring exceptional circumstances. People don't lose this right just because they're in prison. Forced medical testing of prisoners won't make the working conditions of prison guards any safer.

The CSC has detailed policy and protocols to address occupational exposures to blood and other bodily fluids (Commissioner's Directive Protocol 821-1, ***Managing Exposure to Blood and/or Bodily Fluids***, 24 March 2004). This directive clearly outlines the safe procedure for staff to follow in the event of exposure.

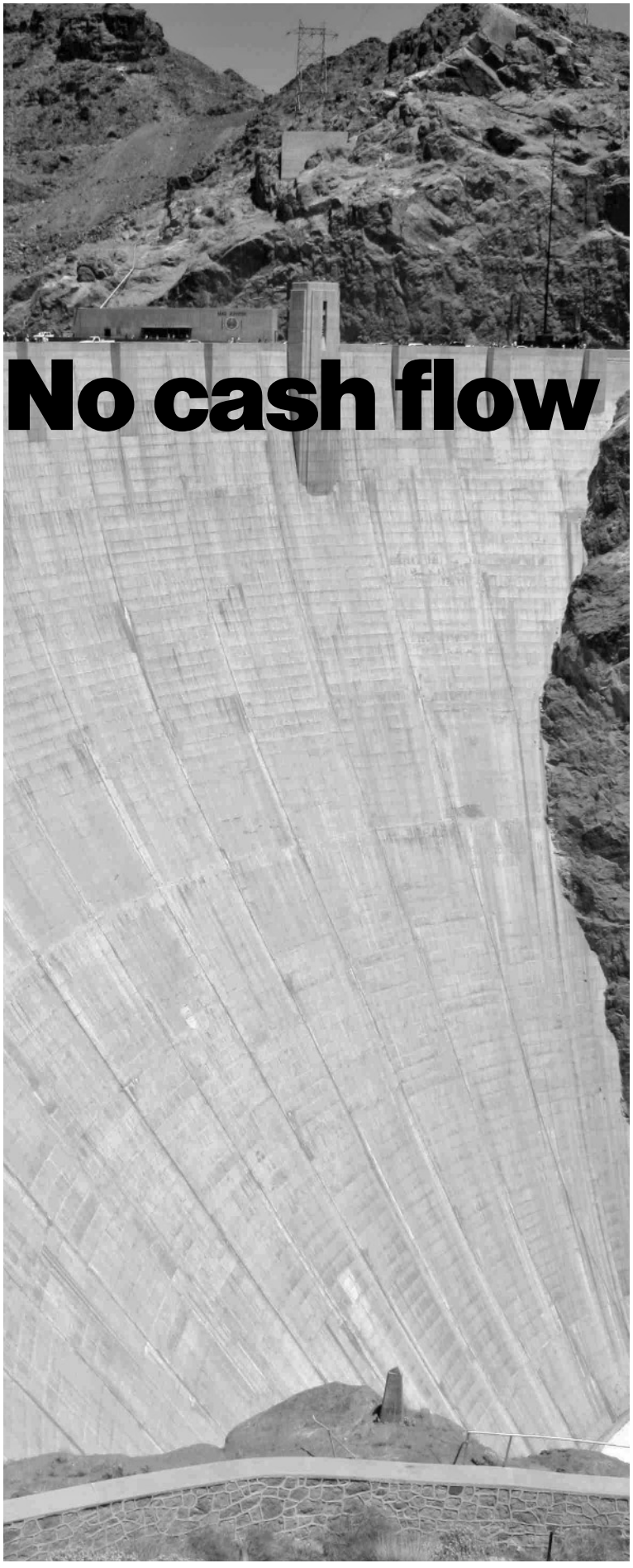
In response to a letter of concern written by BCPWA Society chair Paul Lewand, Minister Day wrote, "CSC authorities assure me that no decision has been made to introduce mandatory testing for HIV. The issue is still under discussion and, if and when a decision is made to introduce such testing, all comments received will be taken into consideration."

The only true way to ensure the safety of CSC staff and inmates is through the implementation of practices that would reduce the likelihood of exposure in the first place. Programs such as the Safer Tattooing Practices Pilot Study and needle exchanges in prisons are the best options for reducing the spread of infectious diseases and ensuring public safety for all persons at risk of exposure to blood-borne pathogens.

The BCPWA Society Prison Outreach Program, Canadian AIDS Society, and the Canadian HIV/AIDS Legal Network all continue to monitor the situation closely to balance the consideration of the human rights of inmates equally with concerns for public safety. ⊕



***Terry Howard** is the coordinator of the Prison Outreach Program at the BCPWA Society.*



No cash flow

The recent allocation of new public health funding didn't seem to make it to many AIDS organizations

by Ross Harvey

The first installments of the famous $60 million in new public health funding, which BC Health Minister George Abbott announced in November 2005, have now been distributed. According to Abbott, at least part of that new money was earmarked for community-based AIDS organizations (see "Show us the money" in the July/August 2006 issue of ***living*** ⊕).

But guess what? Of the regional health authorities that responded to a request for information about their use of the funds, only two out of four are investing any of their share of that $60 million in AIDS organizations. The others are directing all of their shares of the money to other areas.

(Fans of the BC Health Ministry will recall Abbott's 2005 speech in the BC Legislature when he said that "HIV/AIDS organizations play an important role in helping us to deal with this challenge, and we have added an additional $60 million to our budget for the public health area over the next three years for health authorities to work with AIDS organizations to assist us in trying to meet the very ambitious goals that have been set out.... The $60 million is for public health, not just for AIDS, but AIDS is an important part of it.")

Responding to a letter from BCPWA Society chair Paul Lewand requesting more information, Abbott wrote a May 16, 2006 letter revealing a total of just under $8 million in new funding had been distributed to BC's six health authorities for the 2006/07 fiscal year. (The letter also noted that the total amount of these new "public health" dollars going to health authorities over three years would be $48 million, $12 million short of the originally announced $60 million. No explanation given.)

Abbott's letter noted each health authority was getting at least some new public health money, but the amounts range from a low of $431,000 (Northern Health Authority) to a high of $2,305,000 (Vancouver Coastal Health Authority).

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The amounts for the others are: Fraser Health, $1,874,000; Interior Health, $1,199,000; Provincial Health Services, $622,000; and, Vancouver Island Health, $1,568,000.

In his letter, Abbott studiously avoided the question of how much, if any, of this new funding will actually go to AIDS organizations. Instead, he wrote, "Health authorities are responsible for allocating the funding they receive to specific programs across the continuum of care, in accordance with the health needs of their population."

So, the BCPWA Society wrote in July to the heads of all six health authorities asking each in turn where they put their additional allocation, and how much, if any of it, they have passed through to community-based AIDS organizations working in their area.

As of this writing, we had received responses from four of the six. A quick summary:

- Fraser Health's executive vice-president for Health Promotion and Community Programs, Betty Ann Busse, wrote: "In anticipation of new funding in fiscal 2005/06, Fraser Health allocated $200,000 new funding to Surrey HIV/AIDS Society ...." She also noted than an additional $150,000 would be directed in 2006/07 to public health nursing within the Fraser Health bureaucracy to develop an HIV/AIDS case management system.
- Interior Health's senior medical health officer, Paul Hasselback, wrote, "... existing Interior Health contracts with AIDS organizations were unaffected, and no new contracts were awarded as a result of receiving (the $1,199,000)."
- Provincial Health Services Authority's [PHSA] president and CEO, Lynda Cranston, wrote that their share "has been allocated to support West Nile Virus, Environmental Health, and Lab Surveillance and the funds have been directed to the PHSA Laboratories and BCCDC [BC Centre for Disease Control] in support of these initiatives."
- Vancouver Island Health's president and CEO, Howard Waldner, wrote "in fiscal year 2005/06 we used the new public health funds to make a one-time contribution to (AIDS Vancouver Island, Vancouver Island Persons Living with HIV/AIDS, Victoria AIDS Respite Care Society, and one other unidentified organization) totaling $350,000 (to reduce) a structural deficit incurred by the four HIV/AIDS organizations ... due to changing service needs and staffing requirements."

No word yet from Northern Health or Vancouver Coastal Health. ⊕

__Ross Harvey__ is the executive director of the BCPWA Society.

Tell 'em what you think!

You can contact the respective health authority heads to pursue these matters further:

Fraser Health:
Keith Anderson,
1.877.935.5669

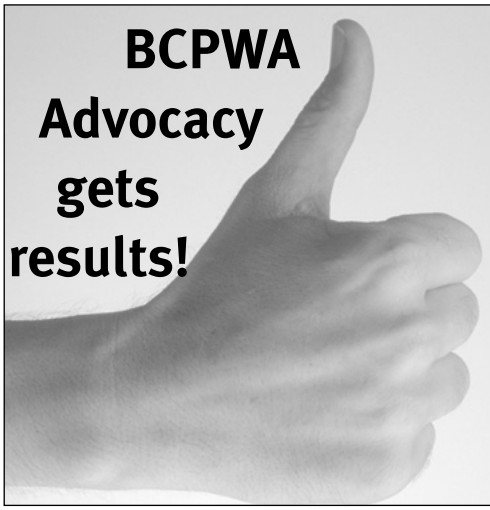
Interior Health:
Murray Ramsden,
250.862.4200

Northern Health:
Malcolm Maxwell,
250.565.2649

Provincial Health Services:
Lynda Cranston,
604.675.7400

Vancouver Island Health:
Howard Waldner,
250.370.8699 or 1.877.370.8699

Vancouver Coastal Health:
Ida Goodreau,
604.875.4252 or 1.866.884.0888.



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 June and July 2006 is:

- **$84,216** in debt forgiveness.
- **$44,099** in housing, health benefits, dental and long-term disability benefits.
- **$25,485** monthly nutritional supplement benefits
- **$2,250** in ongoing monthly nutritional supplement benefit for children

treatment. information

TREATMENT INFORMATION PROGRAM MANDATE & DISCLAIMER

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

The Treatment Information Program endeavours to provide all research and information to members without judgment or prejudice. The program does not recommend, advocate, or endorse the use of any particular treatment or therapy provided as information. The Board, staff, and volunteers of the BCPWA Society do not accept the risk of, or the responsibliity 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.

Saving face

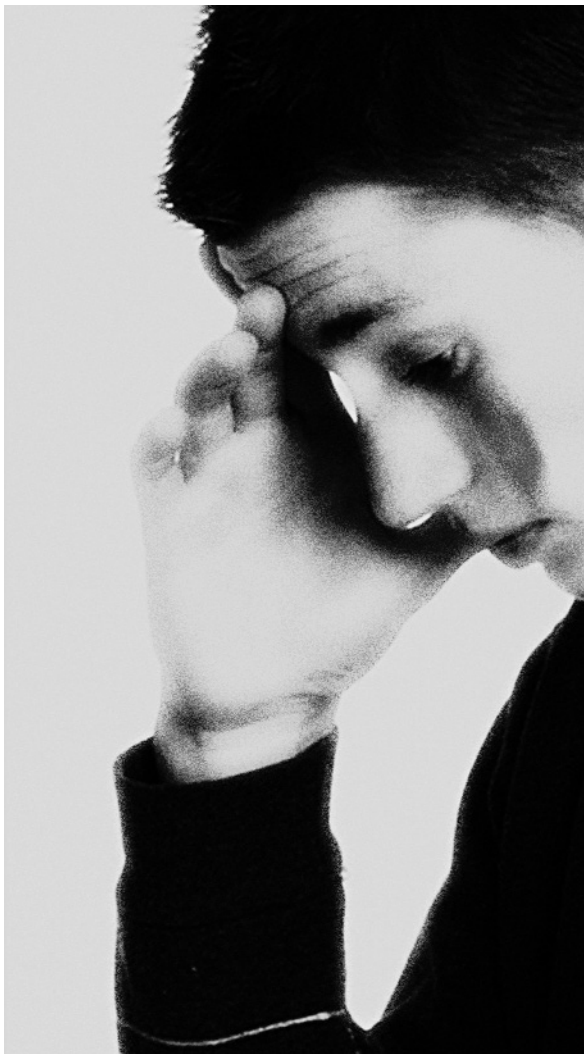
Making the case for treating facial wasting

by Ron Rosenes

If you suffer from facial wasting, you'll be interested in two studies presented at the Canadian Association of HIV Research (CAHR) conference in Quebec City in May.

Facial lipoatrophy (FLA), or fat loss in the cheeks and temples, is the most visible sign of lipodystrophy. Lipodystrophy syndrome refers to the body shape changes that occur in some people who have been on certain HIV antiretrovirals for several years. Other symptoms include thickening of visceral fat in the abdomen, gynecomasty or thickening of the breasts in men and women, thinning of the arms and legs, and a "buffalo hump" behind the neck. In Ontario and some other provinces, patients with buffalo hump may have the fat removed in a procedure covered under the public healthcare system. This is not the case yet for procedures that can reverse facial wasting.

Things, however, are about to change. Now that two new products, Bio-Alcamid and Sculptra, have been approved for sale in Canada, there are options for treating this disfiguring condition.



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Switching regimens may be an option

It may be possible to avoid or lessen the degree of severity of FLA by avoiding some drugs like stavudine (d4T, Zerit) and zidovudine (AZT, Retrovir). Doctors have begun starting or switching their patients to regimens that are less likely to lead to lipodystrophy. However, there is no guarantee that the metabolic abnormalities—including elevated lipids (fats in the blood) and insulin resistance, which can also lead to type II diabetes—can be avoided and thus prevent the occurrence of unwanted body shape changes.

While the research results for Bio-Alcamid are positive, the challenge now is to get the public healthcare system to cover the costs of this necessary reconstructive procedure.

Can switching drugs help? One study presented at CAHR and funded by Gilead Sciences did show some improvement in fat loss and lipid abnormalities in patients who switched from stavudine to tenofovir (Viread) in combination with lamivudine (3TC, Epivir) and efavirenz (Sustiva).

Patients from selected sites in Argentina, Brazil, and the Dominican Republic were put on a tenofovir-containing regimen. The data showed significant improvement in limb fat 48 weeks after switching. Switching resulted in significant decreases in blood triglycerides and LDL ("bad") cholesterol through week 48. There were no changes observed in spine bone mass density (BMD) but there were small decreases in hip BMD.

These results suggest less fat wasting in the limbs but don't necessarily translate to the face. It does make sense, however, to monitor your lipids and discuss with your doctor which medications have the least likelihood of elevating the fats in your blood.

Bio-Alcamid improves quality of life

In the second study, researchers from the Maple Leaf Clinic in Toronto, led by Dr. Mona Loutfy, reported on a study of immediate versus delayed Bio-Alcamid injections for the reconstruction of facial lipoatrophy in HIV-positive patients. Bio-Alcamid is a polymer in sterile water that, once injected, becomes encapsulated in the body's own collagen and is permanent but removable. The objective of the study was to assess the safety, efficacy, and impact on quality of life of two randomized groups of men who received treatment with Bio-Alcamid, either immediately or 12 weeks later.

All patients completed 12 weeks of follow-up. Physicians gave both groups a median rating of grade 2 FLA before treatment. As expected, the side effects—including swelling, redness, bruising, and pain—were transient. These side effects were considered mild and resolved within one to two weeks. At week 12, the group that received Bio-Alcamid had no noticeable FLA. At 24 weeks, both groups had no noticeable FLA.

Patient self-assessment revealed much higher quality of life scores for the immediate group versus the delayed who had not yet received treatment. While this may seem obvious, it does demonstrate the comparative ratings of satisfaction before and after treatment by physicians as well as patients' own assessments.

Getting the treatments on formularies

While the research results for Bio-Alcamid are positive, the challenge now is to get the public healthcare system to cover the costs of this necessary reconstructive procedure for people who don't have private insurance or the means to pay out of their own pocket. The procedure must be deemed necessary in the same way as reconstructive breast surgery for women who have undergone mastectomies following breast cancer.

Activists around the country have begun to take this issue to the provincial Ministries of Health, starting in Quebec, Ontario, and British Columbia. We are working together to build on the early work accomplished by the Lipo-Action Group in Quebec, whose public demonstrations have done so much to draw attention to lipoatrophy. We have taken the Lipo-Action Group's briefing documents and added the clinical data from the researchers at Maple Leaf Clinic, as well as a series of compelling testimonials from people who have received treatment in these first clinical trials.

In Ontario, we met with Ministry of Health policy officials who gave us advice on how to get a billing code for the procedure, as well as the required formulary listing to cover the cost of the filler regardless of which one is used.

In the meantime, the manufacturers and distributors of Bio-Alcamid and Sculptra are either offering, or preparing to offer, patient assistance programs. Eventually, we should expect that access to reconstructive facial fillers will become available to all who need it. As is so often the case in our public health system, the only question is: which province will be the first to cover the procedure and set the precedent for the others to follow? ⊕

***Ron Rosenes** is a board member of AIDS Action Now!, co-chairs the Community Network Advisory Committee of the Ontario HIV Treatment Network, and was a founding board member of AIDS2006 Toronto Local Host, which was a co-organizer of the XVI International AIDS Conference.*

A roller coaster ride

The psychological impact of multiple drug failures

by Wayne Campbell

My lover says I should write a book about my adventures with HIV medications. If I did, I'd call it ***My Secret Life as a Guinea Pig***. Seventeen drug regimens, sixteen failures; and a story to go with each of them.

One of my early treatment adventures involved a strange chemical reaction when the pill I was prescribed was mixed with water. A single oral dose felt like swallowing a handful of thumbtacks. I took these pills six times a day, for two years.

A more recent regimen attacked my gross motor control along with my HIV. True, my viral load was almost undetectable, but the constant flailing of my arms and legs was more than a nuisance, especially when my poor lover suffered the consequences of my bedtime thrashing, and when I sent my nightstand lamp crashing to the floor. I called it quits after three weeks.

Sometimes the drugs don't do what they're supposed to do. At other times, they work for a time—the CD4s rise and the viral load drops—and then, for whatever reason, they're no longer effective. I've learned to ride the HIV emotional roller coaster: vacillating from elated to defeated, depending on my blood work, side effects, and drug interactions. I've also learned what it's like to live in the drug pipeline, keeping up-to-date on treatment research and constantly pressuring my doctor to investigate whatever looks promising.

I know I'm not alone. But it's complicated to talk about the psychological impact of multiple drug failures for long-term PWA survivors. Depression is common. And no wonder: it's exhausting to bounce between extremes of hope and despair with each new regimen.

The experience of survivors' guilt also takes an emotional toll. I've lived through this epidemic since the beginning, and remember attending two or more funerals a week, losing friends and lovers. Those memories don't fade. It's one thing to grieve; it's another thing to grieve multiple losses. And it's entirely something else to grieve those losses while living with the very same illness.

It hasn't been the smoothest ride, but eventually I've come to a place of accepting that I'm here for a reason. Still, managing the emotions is a work in progress. Here are a few tips:

Become a scientist. Well, not exactly. But learn everything you can about the disease, current treatments, and research. BCPWA Society's Treatment Information Program is a great place to start. With a solid knowledge base, you can investigate and interpret the latest research, treatments, and clinical trials.

Get a doctor you trust. That includes HIV specialists and general practitioners. A good doctor will not only monitor the effectiveness of your HIV medications, he or she should also help manage side effects and the psychological issues associated with HIV. A good doctor will also be open to investigating new drugs and clinical trials that you learn about through your own research.

Ask for and accept support. Self-sufficiency is one thing; self-isolation is another. Support exists on many levels. Reach out to trusted friends and family. Join a peer support group. Get a referral to a counsellor, social worker, psychologist, or psychiatrist that specializes in HIV-related issues. Maybe you need to manage depression with medication for a while. Do whatever it takes—you're worth it.

Stay connected. It might sound simple, but it helps to have a regular routine in your life: work (paid or volunteer), activism, socializing, recreation, entertainment. Sure, keeping busy can be a distraction of sorts, but you may also find that every day, you are making a contribution—to your workplace, to the advancement of a cause you believe in, and to the lives of others.

Remember: whatever emotional roller coaster HIV takes you on, you're still here. And that's a good thing. ⊕

***Wayne Campbell** is the secretary of the board of the BCPWA Society.*

Who can you trust?

Professional misconduct is nothing new, but has the corporatization of science pushed it over the line?

by Derek Thaczuk

Dr. Ranjit Kumar Chandra's study was just the kind of thing we love to see published: a nutritional supplement tested in people over 65 had dramatically improved memory problems and other impairments in brain function. It seemed perfect: a non-toxic vitamin and mineral combination—a natural alternative to drugs—that proved promising for people with Alzheimer's disease. Plus, the study design met the "gold standard" for research methodology: a randomized, blinded, placebo-controlled trial. Dr. Chandra, a professor at the Memorial University of Newfoundland, had also published papers showing that nutritional supplements could improve immune function in the elderly. Perhaps this research could lead to similar promise for people with HIV/AIDS.

The only problem? It wasn't true. The study results were, at best, fudged—or quite likely, completely made up.

So the odd bad apple ends up in the basket, a scandalous new story now and then to shake our heads and cluck over. But, of course, stories like Dr. Chandra's leave far broader questions rippling in their wake—like the 200 papers that cited his findings before they were discredited. Where was the safety net that should have caught this in the first place? Does the filthy bottom line besmirch everything? And when do a few bad apples become a pervasive rot, and who ***can*** you trust any more?

Pretty much nobody, say the pessimists.

The forensics of fraud

On the surface, there certainly appeared to be no reason to believe Dr. Chandra couldn't be trusted. He was a renowned expert in nutrition and immunology and a member of the Order of Canada. The soon-to-be infamous clinical study of this supplement was conducted through Memorial University and published (with Dr. Chandra cited as sole researcher) in the journal ***Nutrition***, in September 2001. The results attracted attention from the mainstream media, including the ***New York Times***.

However, Dr. Chandra himself developed and patented the supplement in question, Javaan 50. The sales rights of the product were licensed to the Javaan Corporation, a company founded by Dr. Chandra's daughter.

It soon came to light that Dr. Chandra had already submitted essentially the same paper to the more prestigious ***British Medical Journal (BMJ)*** in October 2000. The ***BMJ*** found serious problems with the paper during peer review, and had chosen not to publish it. The reviewers doubted, for starters, that a single person could have conducted a study of this scope. Moreover, they raised substantial questions about the actual study data. Statistical anomalies led the ***BMJ's*** statistical reviewer to conclude that the data "had all the hallmarks of being entirely invented." Three other independent scientists, who recalculated Chandra's results, said they "could make no sense of them."

Several of the problems—such as the absurd claim that Javaan 50 enabled participants to remember number strings up to 50 digits long—turned out to be simple typos or misunderstandings, which were corrected and the criticisms withdrawn. However, remaining concerns were still serious enough to permanently scuttle the study's validity. "The statistics were not just implausible," said psychologist Dr. Seth Roberts, "they were impossible."

The statistical implausibilities pile up

In an editorial and letter in ***Nutrition*** in November 2003, the journal not only retracted and apologized for the published study; it raised doubts about some of Chandra's previous work, including a precursor to the Javaan trial published in ***The Lancet*** back in 1992. (***The Lancet*** followed up by publishing a letter in June 2003, which described similar statistical implausibilities in the 1992 study.)

Dr. Chandra steadfastly maintained his innocence, stating: "I stand by my research. I am confident the conclusions of our study will be confirmed." He claimed that he had adequately addressed all the criticisms leveled at his work. Unfortunately, in order to fully vindicate him, a full analysis of the raw data files would be required—files which had, in the meantime, mysteriously vanished from his offices. Dr. Chandra blamed their disappearance on theft by parties unnamed (shades of conspiracy, à la ***The Constant Gardener***).

Dr. Chandra also claimed that he had never personally received money from sales of Javaan 50, and repeatedly challenged his critics to divulge their own financial conflicts of interest. In other words, the dirty hand of corruption was at work, alright, but on the other side of the fence.

When the dust settled, the Javaan studies were considered discredited, and Dr. Chandra himself eventually resigned from Memorial University and moved to India, where he ceased to cooperate with investigations. Dr. Richard Smith, former editor of ***BMJ***, has stated that "it would be wise for the world to disregard these two studies unless Professor Chandra can prove their validity."

The dim view: when money talks, science walks

While professional misconduct is nothing new, many have argued that the increasing corporatization of medicine has pushed it over the line. Journalist Shannon Brownlee's article "Doctors Without Borders," published in 2004 in ***The Washington Monthly*** is frankly subtitled "Why you can't trust medical journals anymore." The pharmaceutical industry and its pervasive financial clout may not exactly be news, but it's sobering to see the figures.

One systematic review confirmed that, out of 1,140 published papers, those sponsored by industry were significantly more likely to reflect favourably on the sponsor, compared to studies funded by government or non-profit. Another survey of clinical researchers found that nearly 20 percent had, at some point, delayed publication of study results to allow for patent applications, to protect their scientific lead, or to slow the dissemination of results that might hurt their sponsor's sales. This was often done without overt pressure from the company.

Dr. Marcia Angell, former editor-in-chief of the ***New England Journal of Medicine***, bluntly says, "Results can be jiggered. You can design studies to come out the way you want them to. You can control what data you look at, control the analysis, and then shade your interpretation of the results." In fact, Dr. Angell believes the definition of research misconduct used by the US Office of Science and Technology Policy—"fabrication, falsification, or plagiarism (FFP) in proposing, performing, or reviewing research, or in reporting research results"—is far too narrow, and that what she calls "jiggering" and "shading" is likely far more pervasive and problematic.

A recent commentary in ***The Lancet*** similarly acknowledged the "slippery slope between honest errors and intentional fraud," describing a spectrum that ranges from simple slip-ups, through bias and undeclared conflicts, up to the terrible trinity of fabrication, falsification, and plagiarism.

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The tip of the iceberg

This point is borne out by a study published in ***Nature*** in June 2005, in which three Minneapolis health researchers anonymously surveyed US scientists in many fields of work about their research practices. Among the 3,247 surveys collected, the most reprehensible behaviours formed a sort of tip of the iceberg, very seldom admitted outright (falsifying data outright, 0.3 percent; failing to disclose direct financial conflicts, 0.3 percent; stealing ideas without credit, 1.4 percent).

However, fully 15.5 percent of the respondents admitted to "changing the design, methodology or results of a study in response to pressure from a funding source"–a number which increased to 20.6 percent among scientists later in their careers. What's more, 13.5 percent of respondents conceded to using "inadequate or inappropriate" study designs. And 12.5 percent reported overlooking flawed data or questionable interpretations in other scientists' work.

Given the seriousness of such conduct and the consequences of reprisal, the researchers suggest that their "estimates of misbehaviour are conservative." Moreover, they suggest that the problem is in fact systemic, not just an aberrant bad-apple scenario. "Efforts [at deterring research misconduct] are typically confined to 'fixing' the behaviour of individuals," the investigators conclude in the article. "Little attention has so far been paid to the role of the broader research environment in compromising scientific integrity. It is now time for the scientific community to consider... what changes are likely to be most fruitful in ensuring integrity in science."

Slipping through the cracks

"Little attention" has been paid? "Time to consider" how to ensure integrity? What kind of checks and balances do we have, anyway? Rather a lot, as it turns out: peer review, regulatory bodies, institutional conflict-of-interest policies–but by Murphy's implacable law, if a system can fail, it always will. Unfortunately, cases like Dr. Chandra's can also become serious games of hot potato, which nobody wants to get stuck holding.

In July 2005, an article in ***BMJ*** by its former editor, Dr. Richard Smith, tackled the question directly: "Who has the responsibility for investigating previous work and, if necessary, punishing the researcher and correcting the scientific record?" Surely, the journals that published the work would bear the brunt of the responsibility? Not so, wrote Dr. Smith: "Journals are privileged whistleblowers" he insists–respected authorities, often in the position to first spot dubious research–but the "fact that an author has published a study in a journal does not give the journal the legal legitimacy to investigate even that particular study... The journal clearly... has a duty to notify its readers [but] must depend on others, usually employers, to hold an investigation and ... reach a conclusion on the status of the work."

Employers, then–such as hospitals and universities–are certainly legally entitled to address misconduct issues, and have the direct power to sanction the offenders. Increasingly, Dr. Smith pointed out, these institutions have "declared, transparent, and legally sanctioned processes for dealing with accusations." But until recently, many did not, and "globally it is still probably the case that many, even most, do not." Also, employers themselves face a conflict of interest. To "expose one of your employees as fraudulent is unpleasant and does harm to ... the institution," Dr. Smith wrote. "Often the miscreant will be a friend, a respected colleague." Whiffs of misconduct swept under the rug, or quietly dealt with out of the spotlight, must surely drift through many a prestigious hall.

Stories like Dr. Chandra's leave far broader questions rippling in their wake—like the 200 papers that cited his findings before they were discredited.

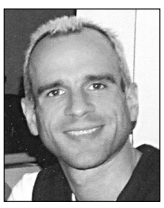
Dr. Chandra's considerably more public departure from Memorial University left an equally public stain on his name, but also left the institution with no real leverage over a former employee. As to examining some 200 of his former research papers, the University admitted that "that's a formidable undertaking and would require a forensic statistician."

Where the buck stops

In Dr. Smith's opinion, ideally an international body should be established to take the lead on investigating research misconduct and questionable published research. In the meantime, the responsibility lies within the existing infrastructure: journals and their editors, scientific peer reviewers, research funders, professional societies, and the whole interconnected mass of the academic, medical, and professional communities.

The saving grace may lie in the highly competitive world of medical science itself. Scientists are human beings with multiple agendas: furthering the science, healing the sick, for sure, but also making themselves look good. Professionals may be quick to stick together, and defend their profession as a whole, but are probably even quicker to critique colleagues.

So, somewhere in that pseudo-chaotic welter of individual doctors being dubious of each other, with or without a "final authority" to which to appeal, a safety net emerges. We'd all be screwed if the pessimistic view was true–that you just can't trust anybody–but at the end of the day it can't be quite that dire. ⊕



Derek Thaczuk *has worked in information and support services within the HIV community for over a decade and is now a freelance writer and editor.*

The global picture

The pandemic rages on, but there are signs of progress

by Derek Thaczuk

After the splash of Sunday night's opening ceremonies, the first full day of the International AIDS Conference got down to stark realities. Monday morning's plenary session, "Taking Stock: Current Challenges in the Global Response," presented the most recent figures on HIV infection rates and perspectives on HIV transmission and disease progression. In the following symposium, "Priorities in Ending the Epidemic," the two Bills—Clinton and Gates—addressed the policy, monetary, and development issues necessary to adequately tackle the epidemic. The politics and logistics of scaling up current efforts to meet the enormity of the global challenge were themes that ran throughout the conference.

Even without considering the attendant political, human rights, and social issues, HIV/AIDS now ranks as the largest health crisis in the history of the world in sheer numbers alone. Since it was first recognized in 1981, HIV has infected 65 million people and killed more than 25 million. An estimated 38.6 million people worldwide are currently living with HIV—more than the entire population of Canada. An estimated 4.1 million became infected in 2005, and nearly three million men, women, and children lost their lives.

The overall global HIV ***incidence*** rate—the annual number of new HIV infections as a percentage of the population—doesn't seem to be on the increase. Worldwide incidence is believed to have peaked in the late 1990s, and appears to have stabilized. Consequently, overall global HIV ***prevalence***—the actual percentage of the population living with HIV—has leveled off, at least according to estimates.

Global averages are misleading

However, the epidemic differs so widely between different parts of the world that it is almost meaningless to talk about global averages. The great majority of people with HIV/AIDS—approximately 25 million—live in sub-Saharan Africa (the countries lying south of the Sahara Desert, roughly south of the Arabian peninsula). Southern and Eastern African countries are hardest hit: in Botswana, Lesotho, and South Africa, infection rates approach or exceed 20 percent of the population. Despite these appalling figures, there are regions of Africa where HIV prevalence rates are falling off, or at least are not continuing to rise. Kenya and Zimbabwe, for example, are actually seeing declines in overall HIV prevalence.

Poor and developing countries elsewhere in the world continue to bear the brunt of the epidemic, and several new areas are emerging as new "hot spots" of increasing HIV infection, particularly Central Asia and Eastern Europe. In Eastern Europe, 220,000 people were newly infected in 2005, bringing the total to around 1.5 million. Numbers of new infections in this region have increased 20-fold in less than a decade. Russia, Ukraine, Belarus, and Estonia are beginning to show HIV rates of over 20 percent among their injection drug user (IDU) populations.

> **"Ending AIDS will not be the success of one great scientist, one great community worker, or one great leader; it will be an accomplishment of the whole human family working together for one another." — Melinda Gates**

Despite the fact that epidemiology is largely a science of numbers, scientists at the conference constantly took pains to remind us that they were talking about human beings, in all their diversity. Presenters repeatedly stressed that HIV/AIDS, far from being simply "an epidemic," is a complex phenomenon involving viral, biological, social, behavioural, economic, and political factors.

We were also reminded that, just as many different populations are affected by HIV here in North America, the same is true in every region of the world. Women, men, and children are affected in every country. HIV can be sexually spread from man to man in areas where the epidemic is primarily heterosexual—all the more so in areas where homosexuality is enormously stigmatized. While it is crucial to understand the predominant ways in which HIV is being spread in individual areas, no group of people should become invisible.

Some progress in prevention and treatment

Despite the scale of the epidemic, there has been significant progress in terms of increased prevention initiatives and

continued on next page

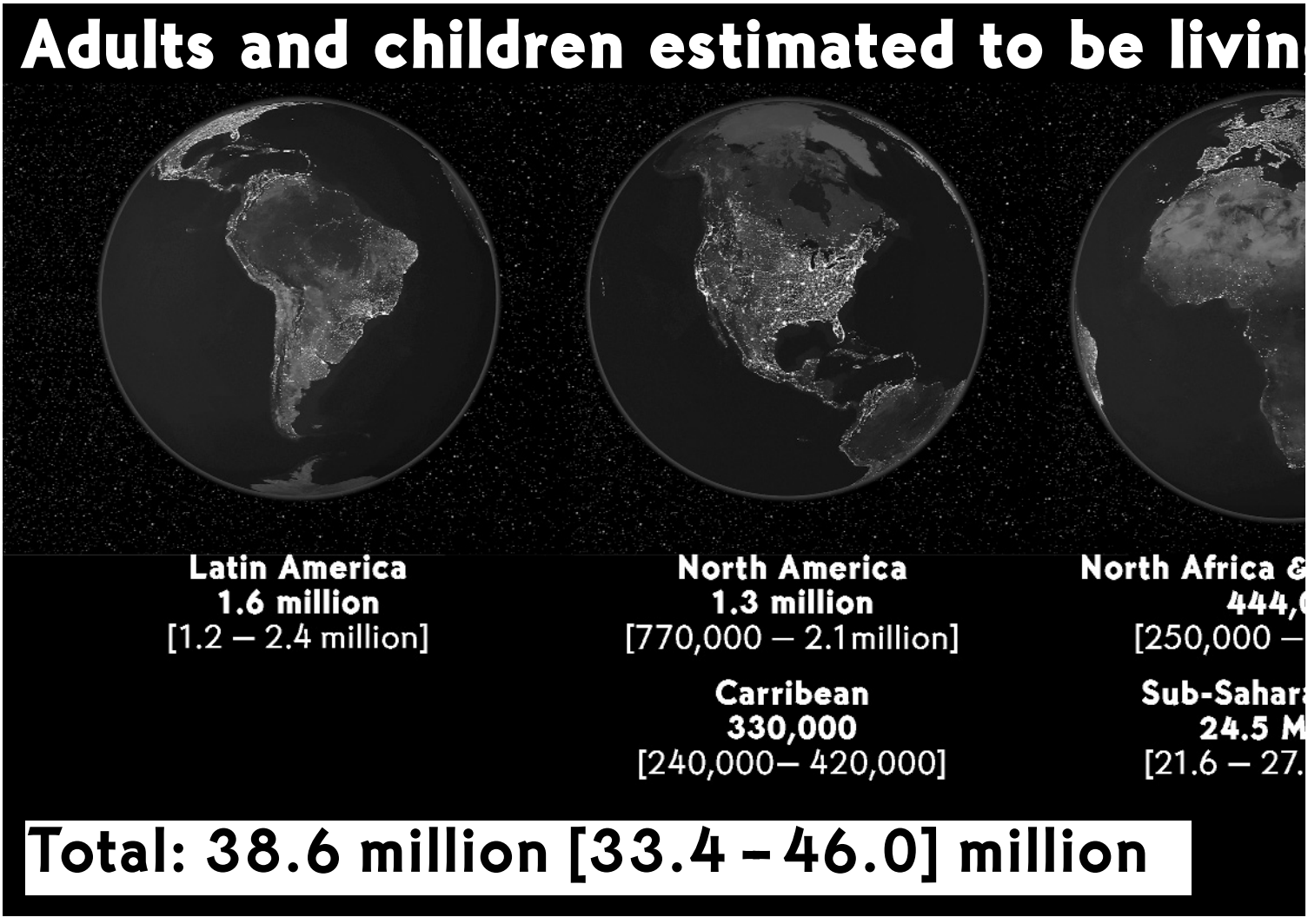
treatment rollout. Most significantly-affected countries have established at least a solid foundation on which to continue to build an effective response. Still, the magnitude of response varies enormously between countries and regions.

The "3 by 5" initiative, launched by the Joint United Nations Programme on HIV/AIDS (UNAIDS) and the World Health Organization in 2003, was a global plan to provide antiretroviral treatment to three million people in low- and middle-income countries by 2005. While the goals of "3 by 5" have not been reached, there have been dramatic expansions in treatment access in many developing countries. In 2001, only 240,000 people in the developing world were accessing antiretrovirals. In 2005, the number was 1.3 million. Also, the number of people using HIV testing and counselling services has quadrupled in the past five years (in over 70 countries surveyed), from roughly four million people in 2001 to 16.5 million in 2005.

The Global Fund to Fight AIDS, Tuberculosis and Malaria has allocated $4.7 billion USD towards fighting these diseases since the program's inception in 2001. At the end of 2005, a reported 384,000 people were receiving antiretroviral treatment supported by the Global Fund, mostly in Africa and Asia. Over the next five years, the Fund plans to put 1.8 million people on therapy and reach 62 million with counselling and prevention efforts.

The Bill and Melinda Gates Foundation has contributed over $6.6 billion to global health spending, nearly $2 billion of which has been dedicated to HIV, tuberculosis, and reproductive health. Much of this spending has been invested in vaccine research. The Gates Foundation has recently declared "stopping AIDS" to be its top priority, and announced a $500 million contribution to the Global Fund just before the International AIDS Conference. Microbicide research is another high priority for the Gates Foundation; co-chairs Bill and Melinda spoke strongly on the need to "put the power to prevent HIV in the hands of women." They also called for increased global access to prevention and treatment, and greater advocacy to break the stigma of AIDS.

The President's Emergency Plan for AIDS Relief, also known as PEPFAR, is a five-year, $15 billion USD global initiative to combat HIV/AIDS. The expenditures were



approved in 2003, with a strong emphasis on the provision of treatment and care. Fifty-five percent of the fund is slated for treatment, with just over 40 percent to be spent on antiretroviral drug distribution between 2006 through 2008.

A "new sense of optimism"

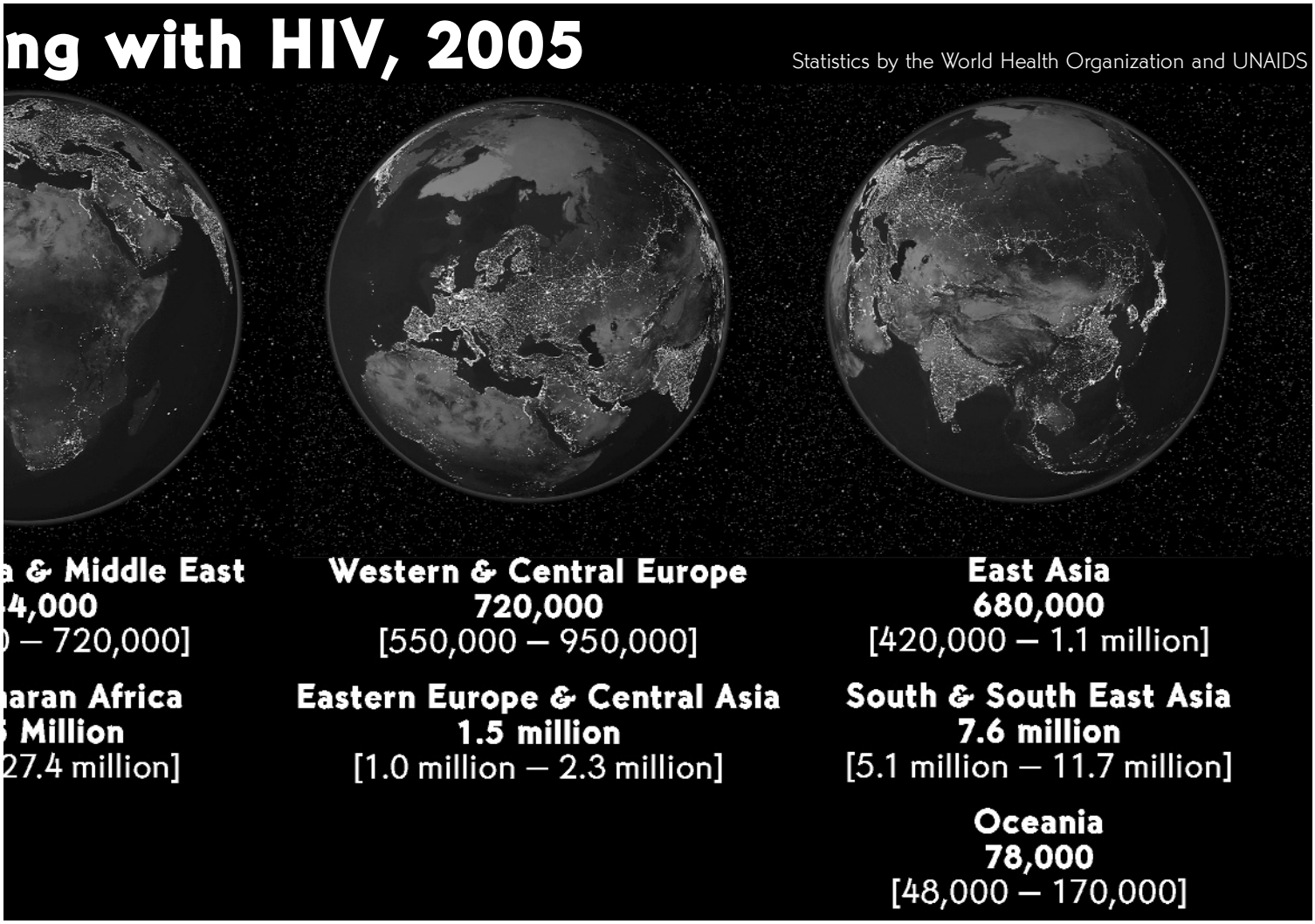
Bill Gates dramatically described the effects of these programs in his keynote address. He expressed a "new sense of optimism" in Africa because "the world is doing far more than ever before to fight AIDS" through the Global Fund, which is active in 131 countries. The Fund, he explained, provides HIV drugs to more than half a million people, access to testing and counselling to nearly six million people, and basic care to more than half a million orphans.

"The Global Fund is one of the best and kindest things people have ever done for one another," he said. "It is a fantastic vehicle for scaling up the treatments and preventive tools we have today—to make sure they reach the people who need them." That's why, he went on to say, his foundation was donating a $500 million grant to the Global Fund.

The prominence of figures like Bill Clinton and Bill and Melinda Gates did not go uncriticized by participants, who argued that wealth and fame should not be the measures of status. Perhaps the best perspective on this issue came from Melinda Gates herself:

"It is hard to overstate the historic scale of our goal. In the history of human accomplishment, ending AIDS will fill a category all its own. It will stand as a work of scientific genius. It will be a testament to diplomatic brilliance. It will represent enormous generosity of spirit and compassion. But above all—and unlike so many other great works—ending AIDS will not be the success of one great scientist, one great community worker, or one great leader; it will be an accomplishment of the whole human family working together for one another. Thank you, once again, for dedicating your lives to ending AIDS. We're so honoured to be part of your work." ⊕

***Derek Thaczuk** has worked in information and support services within the HIV community for over a decade and is now a freelance writer and editor.*



AIDS 2006
Time to Deliver • Passons aux actes

What's new with HIV medications

by Zoran Stjepanovic

Researchers at the International AIDS Conference presented encouraging developments in several new classes of drugs and some interesting studies on existing classes of drugs. Some highlights:

Integrase inhibitors showing promise

Four classes of drugs are currently in use: protease inhibitors, nucleoside reverse transcriptase inhibitors (NRTIs), non-nucleoside reverse transcriptase inhibitors (NNRTIs), and entry inhibitors. Integrase inhibitors are a new class of drugs under development. They work to prevent the genetic code of HIV from being integrated into the genetic code of the infected cells.

One such drug, MK-0518, is showing promise. The trial presented at the conference studied 197 treatment-naïve individuals with HIV viral loads greater than 5,000 copies/ml and CD4 cell counts greater than 100. All participants received tenofovir (Viread) and lamivudine (3TC, Epivir). The study compared MK-0518 (at four different twice-daily dosing levels) to efavirenz (Sustiva) for 24 weeks. MK-0518 had strong antiretroviral activity, with 85 – 95 percent of patients achieving HIV viral loads under 50 copies/ml of blood after 24 weeks. This drug was generally well tolerated and it achieved viral suppression faster than efavirenz. The 400mg twice-daily dose will be investigated in a 96-week trial and in Phase III studies.

New entry inhibitors in clinical trials

Entry inhibitors work to prevent HIV from entering CD4 cells. There is currently only one entry inhibitor on the market, T-20 (enfuvirtide; Fuzeon). Vicriviroc is an experimental entry inhibitor under study. Researchers presented results from a study comparing vicriviroc (at 5mg, 10mg, and 15mg doses once a day) to a placebo, in addition to a current HIV regimen. There were 118 individuals in this study, with an average viral load of 36,380 and average CD4 count of 146.

After two weeks, participants taking either 10mg or 15mg of vicriviroc saw decreases in their viral load, while those on a placebo experienced slight increases in their viral loads. At 24 weeks, the percentage of participants with viral loads below 50 was seven percent in the placebo group, 40 percent in the 10mg vicriviroc group, and 27 percent in the 15mg vicriviroc group. (The 5mg vicriviroc dose was not as effective, and was discontinued.) Also at 24 weeks, CD4 cell counts decreased by six cells in the placebo group compared to 142 CD4 cell count increases in the vicriviroc groups. There were five reports of cancers in participants taking vicriviroc, and investigators are exploring this.

Another trial of 82 participants examined an entry inhibitor called TNX-355. All participants had experienced drug failure in all three classes of drugs—protease inhibitors, NRTIs, and NNRTIs, and had viral loads of at least 10,000. This study compared two doses of TNX-355—10mg and 15mg per kilogram of body weight—to a placebo.

People in the TNX-355 groups saw greater decreases in their viral load than those in the placebo group; however, few people reached an undetectable viral load after 48 weeks. At the 15mg of TNX-355/kg dosage, seven percent had viral loads below 400 and four percent had viral loads below 50 copies. Among people in the 10mg/kg group, four percent achieved viral loads below 400 and no participants had viral loads below 50 copies. No patients in the placebo group had viral loads below 400 copies.

Three independent studies of Kaletra monotherapy all showed that this unorthodox treatment might be an option for some individuals.

Interestingly, the overall drop in viral load was higher in the 10mg/kg TNX-355 group than in the 15mg/kg group. Further development of TNX-355 has slowed because the US Food and Drug Administration (FDA) has requested additional early-stage phase II studies to determine correct dosing of TNX-355. There will likely be more studies of this experimental drug.

The possibility of Kaletra monotherapy?

Current treatment guidelines recommend that antiretroviral drug combinations contain at least three drugs; monotherapy (the use of a single antiretroviral agent) has long been regarded as unsuitable. However, three independent studies of lopinavir/ritonavir (Kaletra) monotherapy all showed that this unorthodox treatment might be an option for some individuals. The ethical considerations of how such trials were approved in the first place were not discussed.

The conference stats:

photo Glyn Townson

- ▲ 6 days
- ▲ 24,000 delegates
- ▲ 2,500 media reps
- ▲ 100 countries participated
- ▲ 2,000 delegates received full or partial scholarships to attend
- ▲ 13,000 abstracts submitted
- ▲ 1,100 expert abstract reviewers
- ▲ 4,500 abstracts presented
- ▲ 1,014 printed pages of abstracts
- ▲ 400 sessions, meetings, and workshops
- ▲ 143 exhibitors
- ▲ 142 listed satellites and mini-satellites (commercial and non-commercial)

One study compared Kaletra as monotherapy to Kaletra plus AZT and 3TC (Combivir). The 126 patients enrolled in this study were starting HIV treatment for the first time. Viral loads averaged between 20,000 and 30,000; CD4 cell counts were 257 in the Kaletra monotherapy group, and 234 in the Kaletra/Combivir group. At 48 weeks, 98 percent of the Kaletra/Combivir group reached viral loads below 50, and 84 percent of the Kaletra monotherapy group also had viral loads below 50. CD4 cell counts increased by 150 cells in both groups.

Similarly, the other two studies also showed that Kaletra monotherapy was a well-tolerated regimen that effectively controlled viral load in a surprising proportion of participants. None of the researchers went so far as to suggest that such monotherapy should be considered yet a standard treatment alternative. Many questions have yet to be answered, such as which individuals are most likely to succeed on monotherapy, and under which circumstances Kaletra monotherapy might be justified as a real treatment option.

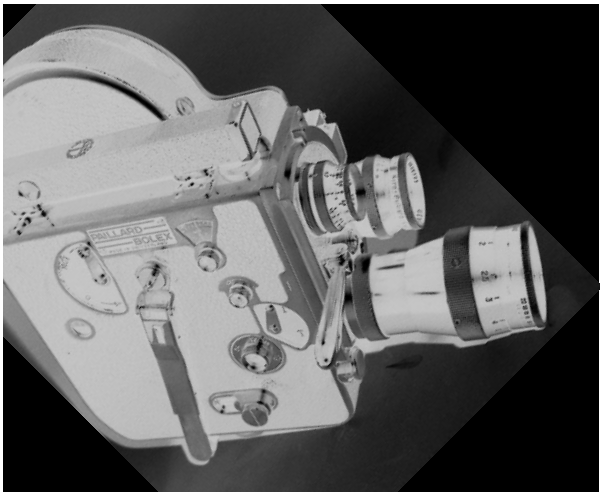
What's more effective, Sustiva or Kaletra?

Current North American treatment guidelines recommend either Sustiva or Kaletra, in combination with two NRTIs, as preferred treatment options for individuals beginning treatment. Now, a study reported at the conference has looked at which of these two drugs is the more effective. There were 757 treatment-naïve individuals in this head-to-head comparison of Kaletra and Sustiva. Three different drug regimens were compared: Kaletra plus two NRTIs, Sustiva plus two NRTIs, and Kaletra plus Sustiva without any NRTIs.

The study showed that each of the three drug regimens was effective. The key difference was in virologic failure after initial treatment success. Those in the Kaletra/NRTI arm of the study had a shorter time to virologic failure—that is, viral rebound happened faster in those whose viral loads had previously become undetectable. At 96 weeks, 89 percent of participants had a viral load of less than 50 copies in the Sustiva/NRTI group, 83 percent had a viral load of less than 50 copies in the Kaletra/Sustiva group, and 77 percent had a viral load of less than 50 copies in the Kaletra/NRTI group.

However, there were more gains in CD4 cell count in the Kaletra/NRTI group. While there is still more data to analyze from this study, early results show that Sustiva plus two NRTIs appears to be more effective than Kaletra plus two NRTIs. Interestingly, the "nuke-sparing" option of Kaletra plus Sustiva—an approach that hasn't been widely studied—compared favourably as well. ⊕

Zoran Stjepanovic *is the coordinator of the Treatment Information Program of the BCPWA Society.*



The clinical picture

by Zoran Stjepanovic

Several sessions at the International AIDS Conference focused on HIV/hepatitis C co-infection (HIV/HCV). In Eastern Europe, more than half of HIV infections are transmitted from injection drug use, and as many as 80 – 95 percent of injection drug users (IDUs) are co-infected with HIV/HCV. One researcher from Russia presented data on the treatment of acute hepatitis C in HIV-infected injection drug users. It was a small study involving 12 former and current IDUs diagnosed with HIV and HCV. The majority of participants had HCV genotype 2 or 3 (which are considered easier to treat than genotype 1). All were treated with pegylated interferon and ribavirin (also tribavirin; Virazole). At 24 weeks, 94 percent of the participants achieved sustained virologic response. This is almost three times better than in co-infected individuals treated during the chronic phase of HCV.

Are we really living "longer, better"?

Since most clinical trials focus on the success of specific treatments, it isn't always easy to see the big picture of how well PWAs are doing overall. One conference session, "Are We Living Longer, Better Lives? Trends in Morbidity and Mortality," looked at causes of death among HIV-positive individuals in the era of highly active antiretroviral therapy (HAART). A researcher from New York presented information on how substance abuse was contributing to deaths among people with AIDS from 1999 to 2003. Researchers focused on two groups: men who have sex with men (MSM) and IDUs.

The investigators discovered that IDUs accounted for 30 percent of PWAs among their sample, and 43 percent of deaths resulted from injection drug use. In New York, deaths have declined in all transmission groups, however the death rate for IDUs was two to three times higher than for MSM. The most frequent cause of death in IDUs was drug abuse, including overdose (21.5 percent in IDUs versus 4.1 percent in MSM). Liver disease contributed to 16.4 percent of deaths in IDUs compared to 7.6 percent in MSM. Hepatitis C contributed to 60.3 percent of liver disease deaths. The researchers concluded that deaths could be reduced substantially through substance abuse treatment, hepatitis C treatments, and promotion of harm reduction strategies such as needle exchange programs.

The other presentation in this session looked at trends in mortality and causes of death among HIV-infected individuals in the UK. Researchers analyzed surveillance data on HIV-positive individuals who died in the UK between 1993 and 2004, the majority of this time occurring in the era of HAART. Researchers compared deaths before and after the advent of HAART. They found increases in the proportion of deaths due to pneumocystis carinii pneumonia (PCP) (six percent before HAART versus 11 percent after HAART), non-Hodgkin's lymphoma (five percent versus nine percent), cardiovascular complications (five percent versus eight percent) and liver disease (three percent versus seven percent). The majority of AIDS-related deaths in the HAART era were late diagnoses.

The researchers also found that, between 1993 and 2004, the proportion of deaths in MSM declined significantly, from 70 percent to 46 percent; in the same period, the proportion of deaths among black African heterosexuals increased from seven percent to 21 percent. During the HAART era, black African heterosexuals died at a younger age and more frequently of AIDS-related causes compared to MSM. The most common causes of death among black African heterosexuals were pneumonia, PCP, tuberculosis, and cardiovascular disease. The most common causes of death among MSM included pneumonia, PCP, cardiovascular disease, non-Hodgkin's lymphoma, and liver disease. The researchers pointed out that early diagnosis and treatment could prevent some AIDS-related deaths among black African heterosexuals. ⊕

***Zoran Stjepanovic** is the coordinator of the Treatment Information Program at the BCPWA Society.*

Youth issues continue to fall under the radar screen

by Glyn Townson

Mainstream media coverage at AIDS2006 focused on high-profile issues; however, there were many abstracts, posters, and sessions that addressed sensitive issues that didn't get media attention. A case in point: the impact of HIV/AIDS on young people, as illustrated by the dramatic rise in the number of children and adolescents orphaned by the disease. There are now over 15 million children orphaned by AIDS, mostly in sub-Saharan Africa. If the current trend continues, 18 million children are likely to become orphaned due to HIV/AIDS by 2010.

A session at the conference talked about providing children in the sex trade with age-appropriate information on prevention methods for HIV and sexually transmitted illnesses.

Orphaned children and adolescents need supports to acquire the social experiences and values to become stable, productive citizens who fully participate in society. But, as things currently stand, most of them lack extended families and medical and community care. They bear responsibilities beyond their ability and experience. And they are at risk of exploitation by falling into high-risk labour situations, including commercial sex work, to support themselves.

The sexual exploitation and trafficking of children, child pornography, and forced marriages all heighten the risk of HIV infection, particularly among girls—though boys are also at risk. An estimated 1.2 million children are trafficked every year, and two million children are believed to be exploited through prostitution or pornography.

An interesting session at the AIDS conference talked about providing children in the sex trade with age-appropriate information on prevention methods for HIV and sexually transmitted illnesses. The children were being taught how to negotiate lower-risk activities from their often older, predatory customers, including negotiating the use of condoms. Younger sex workers are particularly vulnerable because of their inexperience in negotiating safe sex. Clients can react violently, or simply move on to someone willing to have sex without a condom.

(Here in Canada, we can learn from these early prevention interventions and start to develop appropriate messaging for our youth. Currently, education on HIV and sexually transmitted diseases is often delayed until adolescence.)

Restrictive monetary policies by the International Monetary Fund limit the amount of social spending a country can do if it receives loans and support from them. The result has been the creation of user fee structures for most public services, such as school, medical services, and access to clean water. School is often out of reach, as there is no money to pay for school fees or uniforms. Likewise, access to proper medical care and stable food supplies are difficult to obtain.

Although expanded access to antiretroviral medication is a reality in many countries, without a holistic approach to provide other basic living necessities like education, food, and shelter, HIV-positive orphans have little chance of survival.

Global funding for these programs, while on the increase, is still well below the minimum requirements to effectively deal with these issues. Lobbying efforts must be strengthened to promote science-based harm reduction models that are cost effective. We must address child poverty by forcing our governments to provide adequate funding for foreign aid. Support and cooperation from key gatekeepers—such as governments and service providers—is critical if we hope to reverse this growing problem. ⊕

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

British Columbia Persons With AIDS Society

NEW HOURS AT BCPWA

A major change at BCPWA: more flexible hours to accommodate *YOUR SCHEDULE.*

The Board of Directors and Staff of BCPWA are responding to numerous requests from the membership:

The office will be open on Tuesday and Thursday evenings until 9:00PM, starting October 2, 2006.

A series of workshops, info sessions and trainings will be scheduled on Tuesday evenings.

Thursday evenings will be open for drop-ins to meet treatment counselors or advocates.

This will be a year-long pilot project to determine the need for these extended hours.

THE BCPWA LOUNGE WILL NOT BE OPEN FOR DROP-IN DURING THESE EXTENDED HOURS.

To provide feedback on our new hours and to suggest future programming ideas, contact Mike V. at 604.893.2253 or email newhours@bcpwa.org

Eat up and keep it up

A proper diet can make the difference between being a dud or a stud in bed

by Ágnes P. Kalmár

What's on your plate has a lot to do with your performance in bed. While we all know there are medical treatments for impotence, you may not realize that diet and other lifestyle factors play a major role with impotence and can help address the problem.

Impotence is the inability to get or keep an erection long enough to have sexual intercourse. It becomes more common as you get older, but it is ***not*** a normal part of aging. At age 40, about five percent of men suffer from impotence, and that number increases to 15 – 25 percent by age 65. But it can strike at any age.

More than 90 percent of all cases can be traced back to a physical cause. Anything that damages the blood vessels to the penis and therefore reduces blood flow will contribute to erectile dysfunction. Causes include poorly managed diabetes, cardiovascular disease, high blood triglycerides and cholesterol, smoking, spinal cord injuries, prescription drugs, low testosterone, and Parkinson's disease. A smaller percentage of cases are psychological in origin.

A long-term study of more than 1,800 men who were healthy at the outset found that age, obesity, high cholesterol and high triglycerides in mid-life predicted not only heart disease risk but erectile dysfunction decades later. Another research study involving over 2,000 men found that those who had experienced a heart attack were three and a half times more likely to have erectile dysfunction than those who had not had heart attacks.

Erectile dysfunction affects 34 – 45 percent of men with diabetes, so good blood sugar control is very important.

Lifestyle changes can help prevent or reverse erectile dysfunction. Try to:

- get plenty of exercise
- get plenty of sleep
- reduce your stress levels
- quit or cut down on smoking
- avoid drinking alcohol before having sex
- lose a few pounds if you are overweight, and,
- if you have high blood pressure, talk to your doctor about getting it well controlled.

Eating a healthy diet can also help. Here's what should be on your plate:

- Fruit and vegetables: between 5 – 10 half-cup servings a day

- Protein, such as lean meats, beans, lentils, eggs, and fish, with most of your meals
- Dairy: 3 – 4 servings of low-fat dairy daily for the calcium and vitamin D
- Whole grains, instead of sweets and refined grains
- Omega-3 fatty acids, from such foods as fatty fish (salmon, herring, mackerel, sardines), flax seed, and walnuts

Stay away from trans fats and avoid products made with hydrogenated vegetable fats. Eat everything in moderation; a healthy diet and quitting bad habits will pay off. One study showed that 30 percent of obese men with impotence regain their sexual activity after two years of exercising regularly and losing weight.

Finally, if you are experiencing erectile dysfunction, talk to your doctor. ⊕

***Ágnes P. Kalmár** is a registered dietitian at the BC Children's and Women's Health Centre in Vancouver.*

A grand old age

Seniors were a topic of discussion at the recent Association of Nutrition Services Agencies conference

by Diana Johansen

The Association of Nutrition Services Agencies (ANSA) conference is a gathering of dietitians working in HIV/AIDS and organizations that provide food programs to people living with HIV. ANSA used to stand for AIDS Nutrition Services Agencies but they changed the name because many member organizations now diversify beyond HIV; providing meal programs for seniors has become a common area of expansion. Therefore, the 13th annual Association of Nutrition Services Agencies conference, held in San Francisco in August 2006, covered seniors' issues.

The physiology of aging

Mary Louise Zernicke, a dietitian working at the Alameda County Area Agency on Aging, gave an interesting presentation entitled "Nutrition for Older Adults." The first bit of surprising–and even dismaying–information was that "older" means over 60 years, making this presentation relevant to HIV/AIDS, since many people living with HIV are approaching and even past 60 years old. I was also struck by the similar nutrition issues that older people and people living with HIV face. Many younger adults with HIV experience the same barriers and issues that decrease nutritional well-being. The key nutrients and risk factors for weight issues and for other chronic diseases are also similar.

The normal physiology of aging follows a fairly predictable course. Between 40 – 60 years, a person can lose up to 22 percent of muscle mass (kind of makes you want to renew that gym membership!). All of the body organs and systems show signs of wear and tear, and the heart, lungs, arteries, brain, bones, and bladder don't work as well. Sight and hearing decline, loss of balance may occur, and body weight and body fat distribution changes. In the brain, the connecting neurons get shorter, which causes a bigger gap for neurotransmitters (brain chemicals that signal brain activities) to travel across; the result is slower thought processes.

According to US data, the most common chronic diseases that affect the 70-plus age group are arthritis, high blood pressure, and loss of bone mass, followed by heart disease and cancers. The physiological changes that affect nutrition are slowing of metabolism, decreased taste acuity, decreased thirst

sensation, decreased stomach acidity, decreased kidney function, and thinning skin. One of the most common problems is dehydration. Old people don't feel as thirsty and the bladder doesn't work as well so there is a tendency to cut back on fluid intake to reduce accidents.

Dietary surveys in the US reported that only 31 percent of seniors get enough vitamins and minerals from food, but that 72 percent take vitamin supplements. Many older adults in their sixties and seventies are overweight, but the prevalence in people over 75 drops significantly. In fact, there tends to be more of a problem with being underweight in the very elderly. Other issues affecting the nutritional status of older adults include dental problems, decreased cognition (thinking ability), lower income, decreased ability to shop for food or cook, depression, and food-drug interactions.

Key nutrients for older adults

It's important to get enough protein to help muscle, bone, enzymes, and hormones. Zernike recommends 1 – 1.2 grams per kilogram of body weight, which is similar to recommendations for people living with HIV.

Older people and people living with HIV face similar nutrition issues. Many younger adults with HIV experience the same barriers and issues that decrease nutritional well-being.

Calcium is a key mineral for everyone to maintain bone health, yet most people don't get enough of it. In the general population of older adults, the prevalence of osteopenia is as high at 50 percent in women over 50 and osteoporosis as high as 25 percent. In fact, the risk of dying from osteoporosis is equal to the risk of dying of breast cancer. For people with HIV, the prevalence of osteopenia is about the same but it happens at a much earlier age. Calcium requirements from food and supplements are 1000 – 1500mg per day. (See "What's bred in the bone," ***living*** ⊕ July/August 2002, for more information on osteoporosis and HIV.)

Vitamin D is also emerging as a crucial vitamin for older adults because it functions as a regulator of cell differentiation (that is, how cells become specialized), the endocrine system, and immunity. Vitamin D is also important for muscle strength and calcium balance. It's difficult, however, to get enough of this nutrient from food, and sunshine is unreliable in Western Canada, so you'll need a supplement. Most calcium supplements and multivitamins have some vitamin D. The basic requirements are 400 – 600 IU per day, but the latest evidence suggests that we need up to 1000 IU a day. (See "The sunshine vitamin," ***living*** ⊕, March/April 2006, for more information.)

Vitamin B12 is another nutrient that is commonly low in older adults. Even though you require a very small amount, it has a critical role as a co-factor for numerous pathways in human metabolism. It can become low because there isn't enough stomach acidity or it isn't absorbed in the intestine. Some medications, including antacids and metformin, increase the likelihood of problems. Vitamin B12 is found in animal foods like meats and dairy products as well as fortified milks.

A micronutrient study among PWAs

Dr. Jon Kaiser also gave an interesting presentation at the ANSA conference on a micronutrient study he conducted with HIV-positive patients in his medical practice. Dr. Kaiser promotes using natural and standard medical practices together in an integrated approach to health care. He promotes diet and micronutrient therapy, hormone therapy, regular exercise, stress reductions, antiviral therapy, and the elimination of intestinal parasites—which he claims are present in 50 percent of HIV-positive persons. His immune enhancement diet is high in protein, vegetables, and whole grains, and low in processed carbohydrates and fat.

Dr. Kaiser's company, Integrative Health Consulting, recently conducted a study of a custom-designed micronutrient supplement. The formulation is unusual in that it has much higher amounts of vitamins and minerals than the usual multi-vitamin. It also contains alpha lipoic acid, acetyl-L-carnitine, and N-acetyl cysteine (NAC). Forty participants were on stable antiretroviral drugs. The study was a double-blinded placebo controlled trial where half of the participants received the vitamin and the other half received a placebo.

At the end of three months, the group that got the vitamins had a CD4 increase of 64 cells and the placebo group did not. Although the results of the study look promising, it was quite a small study and all the participants were on antiretroviral therapy. When Dr. Kaiser presented these results at the International AIDS Conference, other experts in the audience cautioned that it's difficult to separate the effects of the vitamin from that of the antiretrovirals. The vitamin supplement is sold as KPAX in the US; it costs $120.00 USD per month and you have to take eight pills twice a day for the full dose.

Mary Louise Zernicke's and Dr. Kaiser's presentations at the ANSA conference both reinforced the belief that it's prudent for people living with HIV to continue taking a daily multivitamin-mineral supplement. Anything else should be based on your individual needs. ⊕

***Diana Johansen**, RD, is the dietitian at Oak Tree Clinic in Vancouver. She specializes in HIV.*

TMC125 and TMC114 continue to show promising results

by Dr. Marianne Harris

TMC125 and TMC114 are two new antiretrovirals manufactured by Tibotec, a Belgian drug company. Until recently, neither drug was approved by Health Canada, meaning they weren't available by regular prescription in this country; they could only be obtained through experimental programs. (See "Fighting for life" in the March/April 2006 issue of ***living*** ⊕.) This process, called an Expanded Access Program (EAP), is already in place in BC for TMC114. Health Canada approved TMC114 in August, and the drug will be available by prescription once agreements are reached in each province. An EAP for TMC125 is expected some time in the next several months.

TMC125, also known as etravirine, is a non-nucleoside reverse transcriptase inhibitor (NNRTI) that is resistant to the standard NNRTIs such as nevirapine (Viramune) and efavirenz (Sustiva). TMC114, also known as darunavir, is a new protease inhibitor (PI) that is resistant to standard PIs, including lopinavir/ritonavir (Kaletra) and atazanavir (Reyataz). Like most PIs, TMC114 needs to be taken with a small dose of ritonavir (Norvir, or ABT-538) in order to achieve high enough levels in the blood to be active.

Because HIV is able to develop resistance to single new drugs very quickly, it's important that people get at least two active drugs in their treatment regimen, thus slowing down the virus' ability to become resistant. However, some HIV-positive people who have received many combination treatments over a long period may be resistant to virtually all available approved antiretroviral drugs. For them, using two new drugs like TMC125 and TMC114 together may be a good alternative, especially if they have a third new drug they haven't taken before, such as enfuvirtide (Fuzeon, or T-20). The problem is that we don't have a lot of information on the use of TMC125 and TMC114 together—how well they work and whether the combination is safe.

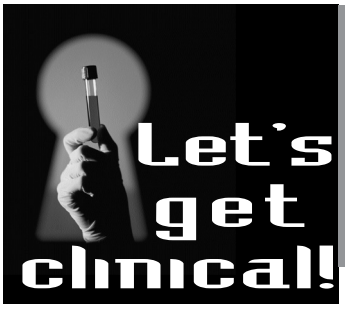
A group of doctors at Chelsea and Westminster Hospital in London, England gave TMC125 and TMC114, along with nucleoside reverse transcriptase inhibitors (NRTIs) with or without enfuvirtide, to 11 HIV-positive adults whose virus was resistant to NRTIs, NNRTIs, and PIs. The results, presented at the Conference on Retroviruses and Opportunistic Infections in Denver in February 2006, were encouraging: all combinations demonstrated good decreases in viral load, increases in CD4 cell counts, and no safety problems. The investigators also checked the levels of TMC125 and TMC114 in the blood and found that they were sufficient, meaning that neither drug was lowering or raising the levels of the other.

Five HIV-positive men in Vancouver started the same combination of drugs in January 2006 under the supervision of Dr. Julio Montaner. Again, all had long-term HIV infection and, over years of treatment, had developed resistance to most approved antiretroviral drugs. Four of the men also received some NRTIs along with TMC125 and TMC114. Three of them also took enfuvirtide in their combination.

So far, all the men are doing well, with no serious side effects. Four of them have reached a viral load below 50; for some of them, this is the first time they have reached that threshold in many years. Most have also had impressive gains in CD4 cell count, including one who went from 100 to 260 six months after starting the new drugs. They have also gained weight, one person gaining as much as 10 kilograms. These results were presented at the International AIDS Conference held in Toronto this summer.

These early results are promising, but clearly we need a lot more information before these drugs become standard treatment for people with drug-resistant HIV. We need to see how people respond over a longer time than six months and whether any unexpected side effects develop. Large international studies are currently ongoing that should help to answer these questions. ⊕

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



Study takes aim at co-infection side effects

by Julie Schneiderman

Anxiety and depression can be devastating side effects for people undergoing treatment for both HIV and hepatitis C (HCV). But this might not be the case for much longer. The innovative research of Canadian HIV Trials Network (CTN) investigator Dr. Marina Klein of the Montreal Chest Institute, is transforming treatments for co-infection.

The Peg-Interferon and Citalopram in Co-Infection study (PICCO, CTN 194) will test whether the prevention of depression can improve adherence to HCV treatment. Currently, the most common course of treatment for those co-infected with HIV and HCV is with a Pegatron/Ribavirin combination for their HCV. However, this mix of therapies has been shown to negatively affect the mental health of patients, thereby reducing the effectiveness of their HCV treatment.

Dr. Klein's PICCO study attempts to tackle anxiety and depression head on, by introducing an antidepressant called citalopram into the mix of standard treatment. Enrolment for this national clinical trial will target people co-infected with HIV and HCV who are about to begin HCV treatment for the first time. Researchers will evaluate the use of citalopram before starting and during treatment for HCV.

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 will then 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 citaolopram and those who receive a placebo.

Unique to the PICCO study is the use of telemedicine for evaluating the mental health of participants from across the country: participants will complete questionnaires and participate in video conferencing with a psychiatric nurse.

PICCO is expected to begin enrolling participants before the end of 2006 at St. Paul's Hospital and the Downtown Infectious Diseases Clinic in Vancouver. Researchers are eager to see this trial go ahead in BC, since the province claims one of the highest rates of co-infection in the country. "The population we study and care for could really benefit from this kind of study," says Dr. Marianne Harris, Pacific Regional Director of the CTN and clinical researcher at the BC Centre for Excellence in HIV/AIDS in Vancouver. "New approaches for treating hepatitis C that take mental health into account could greatly improve the overall health status of our co-infected patients."

To learn the latest about the PICCO study and other new trials, visit www.hivnet.ubc.ca. ⊕

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

Trials enrolling in BC

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

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

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

British Columbia Persons With AIDS Society

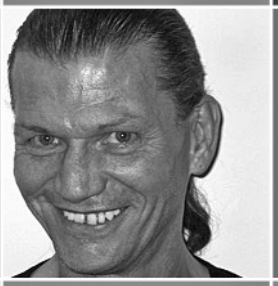
BCPWA Society needs you...

As a BCPWA volunteer your time and experience go a long way.

You'll make a difference!

Why volunteer?

- To make a positive change
- Gain work experience and references
- Learn new skills and upgrade job skills
- Keep informed about HIV issues
- Lead a program
- Influence policies
- Meet new people and be part of a talented team
- Access in-house services
- Earn lunch vouchers



For more information contact us at:

www.bcpwa.org t 604.893.2298 e volunteer@bcpwa.org

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t 604.893.2298

e volunteer@bcpwa.org

Volunteering at BCPWA

Profile of a volunteer: Rob Gair

Somehow, whenever a *living*⊕ deadline looms and we need an extra article or proofreader's eyes, Rob appears, offering those four save-the-day words: "how can I help?"

Melissa Davis,
Acting director
of communications
and education

Volunteer history
A writer for *living*⊕ magazine, a stint on the Prevention Committee, and the BCPWA representative on the Drug Advisory Committee at the BC Centre for Excellence in HIV/AIDS.

Start at BCPWA
2001

Why pick BCPWA?
I was interested in writing articles for *living*⊕ magazine.

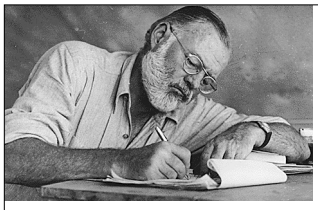
Why have you stayed?
Volunteering at BCPWA is rewarding. As a health professional living with HIV, I have a unique perspective and I'm happy to share this with others.

Rating BCPWA
Eight out of 10. People at BCPWA work very hard to provide services to the HIV community with very limited resources.

Strongest point about volunteering
Just connecting with people who are committed to doing good things for our community.

Favourite memory
Having the opportunity to go to the International AIDS Conference in Toronto. It was an amazing experience.

Future vision of BCPWA
I would like to see gay men better connected with the organization—especially those who have recently seroconverted or those who are at high risk for seroconversion.



Interested in writing?

We need articles on HIV-related prevention, advocacy and treatment. Volunteer for *living* ⊕ magazine...

Volunteers should possess the following skill sets:
— Ability to analyze and distill information
— Excellent research and writing skills
— Ability to work independently

Here's what one of our writers had to say: "I find the whole process challenging and rewarding, not to mention the 'feel good' feeling after finishing a piece. "Volunteering for *living*⊕ provides the flexibility to work from home.

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

where to find **help**

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

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

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

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

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

AIDS Vancouver Island (Victoria)
1601 Blanshard St, Victoria, BC V8W 2J5
t 250.384.2366
e info@avi.org ***www***.avi.org
AIDS Vancouver Island (Cowichan Valley)
t 250.701.3667
North Island AIDS (Campbell River) Society
t 250.830.0787
North Island AIDS (Port Hardy) Society
t 250.902.2238
AIDS Vancouver Island (Nanaimo)
t 250.753.2437
North Island AIDS (Courtenay) Society
t 250.338.7400 or 1.877.311.7400

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

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

Asian Society for the Intervention of AIDS (ASIA)
210 – 119 West Pender St,
Vancouver, BC V6B 1S5
t 604.669.5567 ***f*** 604.669.7756
e asia@asia.bc.ca www.asia.bc.ca

BC Persons With AIDS Society
1107 Seymour St, Vancouver BC V6B 5S8
604.893.2200 or 1.800.994.2437
e info@bcpwa.org ***www***.bcpwa.org

Dr Peter Centre
1100 Comox St,
Vancouver, BC V6E 1K5
t 604.608.1874 ***f*** 604.608.4259
e info@drpeter.org ***www***.drpeter.org

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

Healing Our Spirit
3144 Dollarton Highway,
North Vancouver, BC V7H 1B3
t 604.879.8884 or 1 866.745.8884
e info@healingourspirit.org
www.healingourspirit.org

Living Positive Resource Centre Okanagan
101–266 Lawrence Ave.,
Kelowna, BC V1Y 6L3
t 250.862.2437 or 1.800.616.2437
e lprc@lprc.c
www.livingpositive.ca

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

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

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

Pacific AIDS Network
c/o AIDS Vancouver Island (Victoria)
1601 Blanchard St.,
Victoria V8W 2J5
t 250.881.5663 ***f*** 250.920.4221
e erikages@pan.ca ***www***.pan.ca

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

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

Positive Women's Network
614 – 1033 Davie St, Vancouver, BC V6E 1M7
t 604.692.3000 or 1.866.692.3001
e pwn@pwn.bc.ca ***www***.pwn.bc.ca

Purpose Society HIV/AIDS program
40 Begbie Street
New Westminster, BC V3M 3L9
t 604.526.2522 ***f*** 604.526.6546

Red Road HIV/AIDS Network Society
804 – 100 Park Royal South,
W. Vancouver, BC V7T 1A2
t 604.913.3332 or 1.800.336.9726
e info@red-road.org ***www***.red-road.org

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

Victoria AIDS Resource & Community Service Society
1284 F Gladstone Ave, Victoria, BC V8T 1G6
t 250.388.6620 ***f*** 250.388.7011
e varcs@islandnet.com
www.varcs.org/varcs./varcs.nsf

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

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

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

For more comprehensive listings of HIV/AIDS organizations and services please visit www.bcpwa.org.

Upcoming BCPWA Society Board Meetings:

Date	Time	Location	Reports to be presented
November 8, 2006	4:30	Board Room	Executive Committee / Director of Support
November 22, 2006	4:30	Board Room	Written Executive Director Report / Standing Committees Financial Statements — October / Director of Development
December 6, 2006	4:30	Board Room	Director of Prevention
December 20, 2006	4:30	Board Room	Written Executive Director Report / Executive Committee
January 3, 2007	4:30	Board Room	Standing Committees / Financial Statements - November
January 17, 2007	4:30	Board Room	Written Executive Director Report

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

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

BCPWA Standing Committees and Subcommittees

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

Board & Volunteer Development
Contact: Adriaan de Vries
t 604.893.2298 e adriaand@bcpwa.org

Community Representation & Engagement
Contact: Ross Harvey
t 604.893.2252 e rossh@bcpwa.org

Education & Communications
Contact: Melissa Davis
t 604.893.2209 e melissad@bcpwa.org

IT Committee
Contact: Marie Cambon
t 604.893.2280 e mariec@bcpwa.org

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

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

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

Treatment Information & Advocacy
Contact: Jane Talbot
t 604.893.2284 e janet@bcpwa.org

Yes! I want to receive living⊕ magazine

Name _____

Address _____ City _____

Province/State _____ Country_____ Postal/Zip Code_____

Phone _____ E-mail _____

I have enclosed my cheque of $_____ for *living⊕*

❍ $25 within Canada ❍ $50 (Canadian $) International
please send _____ subscription(s)

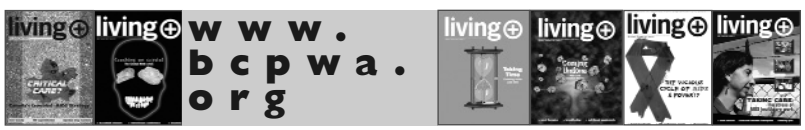
❍ BC ASOs & Healthcare providers by donation: Minimum $6 per annual subscription
please send _____ subscription(s)

❍ Please send BCPWA Membership form (membership includes free subscription)

❍ Enclosed is my donation of $_____ for ***living⊕***

** Annual subscription includes 6 issues*

Cheque payable to BCPWA

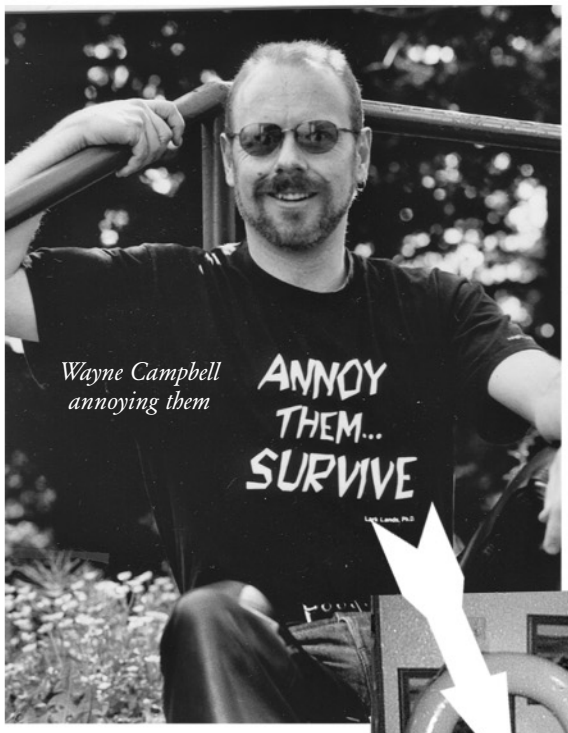


living⊕

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

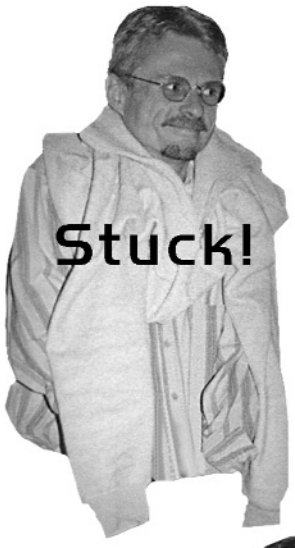
For more information visit
www.bcpwa.org
e-mail to living@bcpwa.org
or call 604.893.2206

Pop!



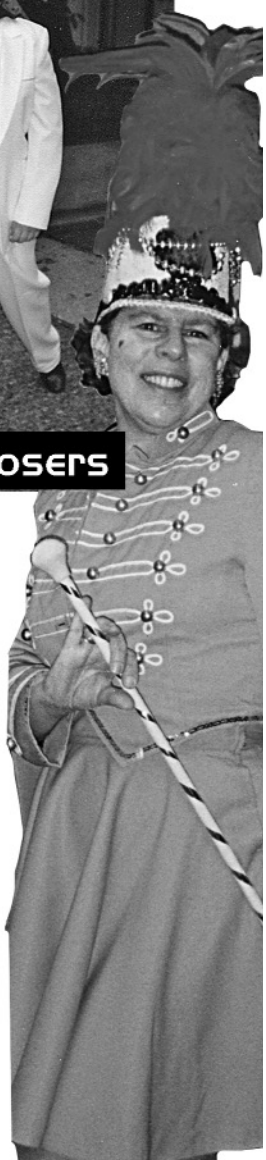
Wayne Campbell annoying them

Posers



Stuck!

Ross Harvey surviving



Hello!

20 years of BCPWA

photos by John Kozachenko & Britt Permien

Glen Hillson sticking it to them