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think+

opinion and editorial

Lines in the sand

by Paula Braitstein

Like the desert sands, the landscape of HIV in British Columbia is shifting, almost imperceptibly, depending on where you stand.

In BC, we now take for granted the fact that we have among the highest standards of HIV care in the world. Many people do not realize that this quality of care is due to the existence of the BC Centre for Excellence in HIV/AIDS (BCCfE), and that it is the BCCfE's Therapeutic Guidelines Committee—not BC PharmaCare—that determines who gets what HIV drugs. Once Health Canada approves a drug, the BCCfE has always had complete autonomy to decide whether and how to include the drug in the treatment guidelines. Especially with the advent of a new (and unfortunately not improved) layer of bureaucracy called the Common Drug Review (CDR), that autonomy has been particularly advantageous.

The CDR recently recommended that tenofovir (Viread)—currently prescribed to roughly 700 people in BC—no longer be covered by provincial formularies. Word on the street is that the BCCfE recently received a letter from BC PharmaCare stating that the Centre had overstepped its authority by providing a drug—namely, tenofovir—that the CDR did not recommend, further implying that the BCCfE may suffer financial repercussions as a result. That's the last thing the BCCfE needs, what with ever rising drug costs.

This particular case may or may not evolve into a larger problem. But it raises a bright red flag that threatens the

very independence of the BCCfE. Currently, availability of new antiretrovirals to patients is seamless, thanks to the BCCfE; as soon as Health Canada approves a drug, the BCCfE starts prescribing it. The CDR process means adding an extra year from the time that Health Canada approves a drug to the time that people can access the treatment. And that's if CDR recommends it.

When you look at this situation in the context of the direction that our regional and provincial health authorities are heading—for example, streamlining (read: assimilation of) services—I shudder to think of the consequences *if* the BCCfE takes a stand. +

Paula Braitstein was the senior policy advisor on health promotion.

After nine years at BCPWA Society, Paula Braitstein has moved on to new challenges fighting HIV in Africa and South America, working from a base in Switzerland.

Paula was our first Treatment Information Program coordinator in 1995; by the time she served her last day as our senior policy advisor on health promotion, she had become one of the most effective and respected HIV/AIDS treatment activists in Canada.

She is irreplaceable. But her legacy thrives in the victories she helped win, in the scores of HIV-positive treatment counsellors and activists she nurtured, and in the culture of empowerment within BCPWA she helped foster. Be well, Paula. Do good. And thank you for all that you did with us.

Ross Harvey is the executive director of the BCPWA Society.

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REALITY BITES



News from home & around the world

New BCPWA staff

BCPWA Society has several new staff members. Teresa Stancioff is the new volunteer coordinator. Teresa previously worked at the Lower Mainland Purpose Society where she headed the agency's HIV/AIDS program and implemented a client-based volunteer program. She also worked in HIV prevention in Mauritania, West Africa. Her volunteer experience includes AIDS Vancouver, Self-Help Resources Society, and BC Multicultural Health Services Society.

Paul Adomako recently became BCPWA Society's new director of prevention. Paul has worked in community-based health initiatives for several years. Last spring he was the project coordinator for Euphoria 2004 at AIDS Vancouver. He joined BCPWA in late 2004 as volunteer coordinator. With an emphasis on community building and empowerment, he is excited about the opportunities for collaboration and program development in the Positive Prevention Department.

Belated welcomes also go to Chris Hindle, events coordinator in the Fund Development Department, and Sabine Huss, treatment outreach coordinator in the Treatment Information and Advocacy Department.

Erythromycin warning

A study of medical records found that combining the antibiotic erythromycin with strong protease inhibitors of the liver enzyme CYP3A increased the risk of sudden death from cardiac causes—probably by abnormally raising the blood levels of erythromycin.

An article in the September 9, 2004 issue of *New England Journal of Medicine* reported that patients using the antibiotic erythromycin at the same time as drugs that

strongly inhibited cytochrome P-450 3A (CYP3A, an enzyme in the liver that helps remove many drugs from the body) had an increased risk of sudden death from cardiac (heart) causes. However, those who used amoxicillin, a different antibiotic, instead of erythromycin, did not have the problem. The authors concluded “concurrent use of erythromycin and strong inhibitors of CYP3A should be avoided.”

Source: AIDS Treatment News

New CD-ROM for HIV-positive women

The BCPWA Society has produced a new CD-ROM for HIV-positive women and healthcare providers, in partnership with the Positive Women's Network.

The CD-ROM, entitled “Retro Woman: Navigating Advanced Treatment Information for Women,” provides comprehensive advanced treatment information that is specific to HIV-positive women. It contains lecture slide series, one-page fact sheets, reference articles, and a glossary. To obtain a free copy of the “Retro Woman” CD-ROM, please e-mail retrowoman@bcpwa.org or call 604.893.2244.

Bristol-Myers Squibb and Gilead joint venture

Bristol-Myers Squibb and Gilead Sciences are collaborating to develop and commercialize the fixed-dose combination of Bristol-Myers Squibb's Sustiva (efavirenz) and Gilead's Truvada (emtricitabine and tenofovir disoproxil fumarate) in the US. If approved, the new product would be the first complete highly active antiretroviral therapy regimen for HIV available in a fixed-dose combination taken once daily. Fixed-dose combina-

tions contain multiple medicines formulated together and may help simplify HIV therapy for patients and providers.

The work necessary to co-formulate Sustiva and Truvada into a once-daily combination product has been ongoing throughout most of 2004 and will continue into 2005.

Guidelines issued by the US Department of Health and Human Services list the combination of emtricitabine, tenofovir disoproxil fumarate, and efavirenz as one of the preferred non-nucleoside reverse transcriptase inhibitor-based treatments for use in appropriate patients who have never taken anti-HIV medicines before.

Cheap antibiotic slashes death rate

All children with HIV in developing countries should take a low-cost antibiotic because it could nearly halve the death rate, researchers say.

Investigators at Britain's Medical Research Council tested co-trimoxazole, a combination of two drugs, on 534 children in Zambia under the age of 15 who were infected with HIV. Half the children were given the drug each day, while the other half took a sugar pill. The results were so favourable that researchers stopped the study early to allow the placebo group to start treatment.

Doctors usually frown on long-term use of antibiotics because the practice can spur the development of superbugs that are resistant to treatment. During the experiment, researchers found no signs of antibiotic resistance. The drug also had few side effects.

Co-trimoxazole costs less than 10 cents US per person a day.

Source: CBC News

REALITY BITES

News from home & around the world

New caucus in Victoria

There is a new organization on Vancouver Island for—and run by—people living with HIV/AIDS. The mission of the Vancouver Island PHA Caucus is the empowerment of PHAs committed to the improvement of quality of life through positive collective peer support.

The caucus is currently in the strategic planning phase, with 19 members and a founding committee of six core advocates meeting with AIDS service organizations and community supports, plus two coordinators mediating between the caucus and various other support. For more information or to join the caucus, contact v.i.caucus@telus.net.

Liberal discount medicine plan panned

The federal government's plan to get discount medicine to poor nations is flawed and may never succeed in sending a significant amount of drugs overseas, critics and aid groups warn. No drugs have been exported yet under the Jean Chrétien

Pledge to Africa Act, which was first tabled in Parliament more than one year ago. It passed in mid-May 2004 and the Liberals touted the measure in pre-election advertisements.

The law has still not come into force because Ottawa is still hammering out supporting regulations.

Relief groups fear that drugs won't start flowing even after the bill takes effect. They say that generic drug firms—which are supposed to play a key role in the process—have not embraced a proposal from Médecins sans frontières (Doctors Without Borders) to manufacture a handful of drugs the group wants to see copied and exported.

The law is supposed to eliminate legal hurdles for generic-drug companies to make cheap copies of patented medicine for export. This follows a 2003 World Trade Organization agreement that said countries may breach drug patents to help poor nations tackle health crises.

Source: *The Globe and Mail*

Crixivan warning for positive pregnant women

The Clinical Pharmacology section of the indinavir (Crixivan) label has been revised to include pharmacokinetic data from a study in HIV-infected pregnant women. Results from this study show substantially reduced indinavir concentrations in women at 30-32 weeks gestation compared to postpartum. Based on these data, the Precautions Section now states that indinavir is not recommended in HIV-infected pregnant patients.

Russian AIDS demonstrations

Russian AIDS advocates are speaking out about the problems faced by Russian PWAs. On December 1, World AIDS Day, they held a demonstration in Moscow and sent an open appeal to Russian President Vladimir Putin.

In autumn 2004, activists from the FrontAIDS movement carried out protest demonstrations in Kaliningrad and St. Petersburg, arguing that they could no longer stay silent about the fate of “young people who have been practically condemned to death because of the lack of antiretroviral drugs and necessary medical care.”

Kaliningrad was the first city in Russia to be hit hard by the HIV/AIDS epidemic. Of the 5,000 officially registered people living with HIV/AIDS in the Kaliningrad region, 845 have already died. St Petersburg has the second highest number of registered HIV infections, surpassed only by Moscow. UNAIDS estimates that between 800,000 and 1.4 million people in Russia are living with HIV/AIDS. ⊕



Santa and Santa's helper at the 2004 BCPWA Society Member's Christmas Dinner on December 15th at the Chateau Granville. The event was sold out. Everyone had a fabulous time and enjoyed the excellent food.

An honest day's work

The debate on sex work legislation

by Lucia Terra

There is much debate worldwide on the issue of sex work legislation. Governments, policy makers, and non-profit organizations seem unable to arrive at any agreement on the best course of action on issues as disparate as child prostitution, international trafficking, sex tourism, video pornography, cyber and phone sex. Different solutions must be considered for each situation. The regulatory options for adult sex workers span from strict prohibition, to different degrees of regulation, and, finally, to decriminalization.

Prohibition usually punishes disproportionately those people who are already in a vulnerable position. Often, legal prohibition or criminalization exists with a parallel *de facto* complete or partial tolerance of sex-related activities.

Regulation or legalization means that the law defines certain conditions under which sex work is permitted. Critics argue that regulatory laws often do not consider the human and labour rights of sex workers, making it difficult for them to comply with regulations.

Decriminalization means the removal of laws that criminalize adult commercial sex work. It is possible to decriminalize part of the sex industry while continuing to criminalize other parts. Sweden has taken this legal approach by prosecuting those who buy sexual services while decriminalizing the activities of sex workers. In some regions of Australia, brothels have been decriminalized, thereby allowing the industry to comply with occupational safety and health standards.

a certain extent. The Dutch government, for example, recognizes sex work as an economic activity and has promoted a legal quota of foreign sex workers in order to reduce the exploitation of immigrant women.

In view of the complexity and broad scope of activities and situations that the sex industry encompasses globally, the International Labour Organization (ILO) recognizes the variety of circumstances prevailing among sex workers and advocates for the elimination of abuses. For adults who choose sex work, the organization recommends improved working conditions and social protection. For those who have been recruited into the industry by force or deception, the group advocates their release, rehabilitation, and reintegration into society.

The ILO also argues that established standards and working conditions should be applied to the sex industry, including the right to refuse services to a client. In addition, measures such as maintaining records could be extremely useful in assessing health impacts within the sector. Overall, the ILO claims that attention should be focused on the economic and social factors that sustain the sex industry, rather than analyzing and managing the activities of sex workers themselves.

No matter which option one favours, any attempt to regulate prostitution—whether penalizing or allowing it—without first addressing issues of power structures and economic inequality between genders, groups, and countries, will be little more than a pretense of addressing the issue of the sex trade. ⊕

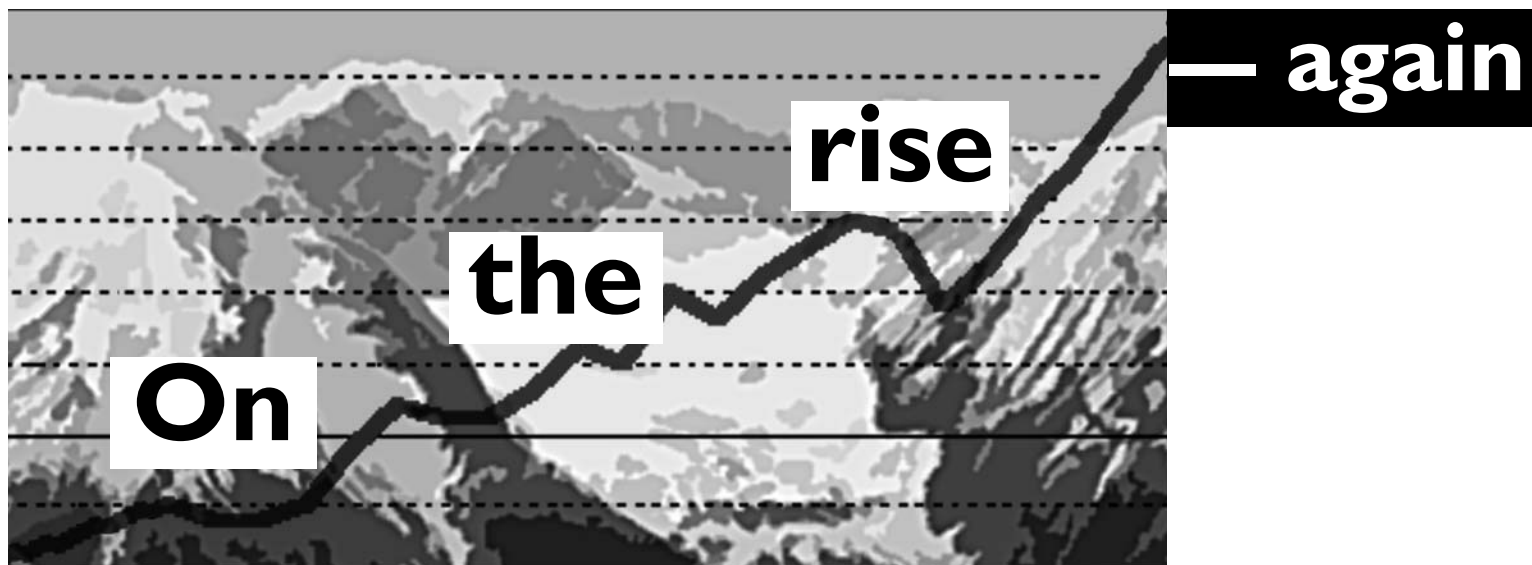
Many European countries have legalized or decriminalized sex work to a certain extent.

Decriminalization has also been associated with almost universal condom use and a reduction in the risk of sexually transmitted diseases and HIV infection. Under these circumstances, sex workers have better working conditions as well as the knowledge and materials to protect their health. According to research conducted by UNAIDS, organized sex workers in Calcutta's Mahila Songatchi group showed a rate of HIV infection of less than five percent compared to a more than 50 percent infection rate for unorganized sex trade workers in Bombay.

Many European countries have legalized or decriminalized sex work to



Lucia Terra is a Vancouver-based freelance writer.



North surpasses BC in new HIV cases for 2004

by Larissa Ardis

Less than one year after HIV rates were described by the Northern Health Authority (NHA) as lower in the northern regions of the province than in the rest of BC, its most recent data suggests this is no longer the case.

Unpublished data from the first half of 2004 show that the north recently reported 7.6 new cases per 100,000 people—exceeding BC as a whole, which identified 6.3 new cases per 100,000 for the same period. That statistic is up from 2003, when the region reported 6.9 cases per 100,000—for the entire year—while BC's overall rate was comparatively higher at 10.2 new HIV-positive cases per 100,000.

These recent statistics also show that newly reported cases in the north are continuing a steep climb already identified by 2002 and 2003 data. Twenty-three new HIV infections were reported in the region during the first half of 2004—exceeding the total of 21 new cases for all of 2003, which had already almost doubled from the 12 new cases reported in 2002. The vast majority of new cases have been diagnosed in Prince George.

“We have an epidemic,” says Catherine Baylis of Positive Living North, a Prince George agency that provides support to people who have or are at risk of contracting HIV.

The “front edge” of an epidemic

David Bowering, the chief medical officer with the NHA, uses the word “epidemic” cautiously, pointing out that the term has many accepted definitions that allude variously to the geographic spread, severity, speed, and unexpectedness of a disease outbreak. Bowering's preferred definition emphasizes the unanticipated aspect of disease outbreak—and in that sense, he claims, northern BC is not experiencing an epidemic.

“From my point of view, this is not unexpected,” he says, citing a well-documented high incidence in the north of sexually transmitted diseases (STDs), injection drug use, unprotected sex

(reflected in rates of teen pregnancies), and the sex trade. However, he suspects the new data do reveal the “classic front edge of an epidemic.” Bowering predicts they will mimic infection rate patterns in larger centres, and rise sharply for some years before levelling out.

Dr. Michael Rekart, executive director of the HIV/AIDS program at Vancouver's BC Centre for Disease Control, says three new developments may help explain the numbers. One is a new law, effective May 2003, which compels health professionals to locate and inform current and former sexual partners of people who have tested positive for HIV. Rekart says NHA healthcare professionals are “quite dogged” in fulfilling this new duty, which tends to identify more HIV-positive people than otherwise may have presented themselves for testing.

Another factor is a rise in injection drug use—now considered the most common means of transmission of the virus in northern BC, just as it is in Vancouver's Downtown Eastside. The correlation between increasing rates of HIV infection and injection drug use in the north applies especially in Prince George, where the vast majority of new cases have been diagnosed.

Another development is a research project associated with the BC Centre for Excellence in HIV/AIDS, now underway in Prince George. Modelled after a Vancouver study, the project offers a cash stipend to street-involved, injection drug using youth in return for their ongoing participation in research, which includes regular HIV testing. This cash incentive may be enticing more people to get tested, thereby producing more HIV-positive results.

“What might be happening is that we're uncovering an already existing epidemic,” says Dr. Bowering.

First Nations hit harder

Rapidly increasing infection rates aren't the only cause for concern. The data continue to show that BC's First Nations community, and aboriginal women in particular, are being hit

harder than any other identifiable group. Even considering First Nations' greater presence in northern BC, this population appears to be overrepresented in numbers of new cases. In 2003, First Nations people accounted for at least 57 percent of new diagnoses, and represented more than one-third of the 23 new cases in the first half of 2004.

Positive Living North's Catherine Baylis believes these figures will continue to grow. "The face of AIDS is changing, and here in the north that face is aboriginal," she says.

"We have an epidemic," says Catherine Baylis of Positive Living North, a Prince George agency.

Health professionals agree that HIV doesn't choose one race over another: it simply seizes opportunities for transmission through high-risk activities. Such activities, including participation in the sex trade and injection drug use, are frequently associated with the social and economic conditions of BC's most marginalized people. And people who believe their choices are limited are more likely to engage in high-risk behaviour.

"HIV spreads into aboriginal communities along the routes of poverty and oppression," Baylis says. "And poverty and oppression aren't letting up."

Although almost all of the new cases are diagnosed in Prince George, people shouldn't assume that more remote communities are exempt from infection. As the nexus of north-south and east-west travel routes, Prince George is a common stopover for many folks who are passing through *en route* to somewhere else. The Northern Health Authority's Dr. Bowering suspects that many people from small towns, who suspect they've been exposed to the virus, obtain HIV testing in Prince George out of well-founded concerns about pri-

vacy and the stigma associated with AIDS. Those who test positive may be more likely to settle in Prince George, to take advantage of the comparatively wider range of available health and social services.

Educating the healthcare providers

It's not yet clear if the NHA is adequately prepared to deal with the immediate and long-term challenges of an onslaught of new HIV diagnoses. At least five days of public health nursing time are required for each new case, not including additional time needed to notify former partners and collaborate with other healthcare providers to prepare treatment plans. Agencies that deal with HIV-positive clients are also questioning whether health service providers in northern BC are sufficiently educated about medical treatments and sensitive to social issues around the disease.

"One of our HIV-positive clients described an incident where she went to a hospital emergency room for treatment of [complications relating to] her condition," says Deb Schmitz of Positive Living North West in Smithers. "She was sent away quickly with a prescription, and told she couldn't be treated because there was no 'isolation room.' There is absolutely no need for HIV patients to be treated in isolation rooms!"

To Schmitz, who is helping the NHA draft an HIV strategy for the north, such reports belie shocking levels of misunderstanding among many rural healthcare providers about HIV and AIDS.

Bowering agrees that much work needs to be done in this area, but also says that he's not aware of any new health dollars specifically targeted for the treatment of new HIV cases. "As we come to terms with this, it's not just about making diagnoses. It's also about long-term care." ⊕



Larissa Ardis is an award-winning freelance journalist and communications consultant based in Smithers, BC.

Getting to the root causes

A Prince George initiative is hoping to address some of the root causes of why people make choices that put them at risk for HIV.

The Fire Pit is a new drop-in centre designed to reinforce positive aspects of First Nations experience and, indirectly, to promote awareness of how colonialization has affected it. According to Fire Pit coordinator Cathy Baylis, a member of the Annishnabe First Nation, that

awareness is a precursor to the emotional healing that will break intergenerational cycles of substance abuse and social disenfranchisement.

For Baylis, that awareness began by learning about one of the most destructive expressions of colonialism: First Nations children forced to attend government-sanctioned residential schools. "These schools rearranged and eroded our traditional ways of life, and our entire family structure, for generations," she says. Her father attended residential schools. "They left

a legacy of unresolved grief, trauma, and loss on many levels. People try to cope with that pain by turning to drugs, alcohol, and abuse."

The Fire Pit's location, in the basement of the Central Interior Native Health Society (CINHS), is no accident. Organizers hope the CINHS will become a primary healthcare delivery centre, where even the most at risk and marginalized people can easily access doctors, HIV support workers, drug and alcohol counsellors, and social workers.

How secure are income security programs?

by Glyn Townson

Last year, the Canadian Working Group on HIV and Rehabilitation (CWGHR) commissioned an environmental scan to determine how current practices and policies of the private insurance industry and Canada Pension Plan disability program (CPP-D) measure up for people living with HIV/AIDS. CWGHR hired a consulting firm to implement the income support research project in the spring of 2004. The aim of the project is to identify areas for further research related to the strengths, weaknesses, challenges, barriers, and gaps in current practices and policies.

The first phase of the project involves a literature review of articles and briefs specifically related to CPP-D and private disability insurance, as well as other relevant documents, to provide a broader view and analysis of Canadian income security programs.

Based on the findings from the literature review, individuals from specific stakeholder groups will be interviewed. The stakeholder groups include: PWAs who have had experiences with CPP-D and/or private insurance companies; policy and program staff from CPP-D and the private insurance industry; AIDS service organization advocates who assist people in accessing benefits; and healthcare providers who support PWAs in accessing benefits. The interview questions and methodology used for the interview process will be outlined in the final report.

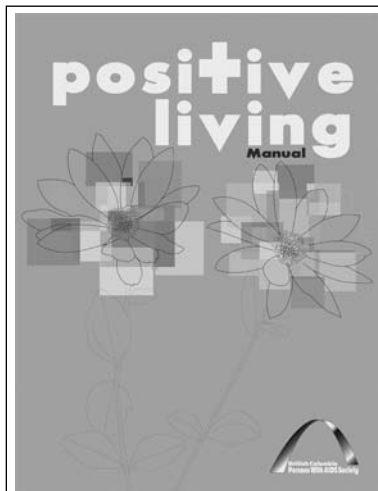
Results from this study will form the foundation for continuing research on income security issues encountered by PWAs.

Many of the existing income security programs have been based on an outdated assumption that most people with HIV/AIDS could expect to maintain their health for a limited time, after which their health would inevitably and rapidly decline. However, with the advent of new and improved treatments for people living with HIV, the disease profile has changed considerably and is currently viewed as a lifelong, episodic illness.

CWGHR's mandate focuses on two primary areas. The group aims to coordinate a national response to, facilitate and support the development of, and provide advice on rehabilitation issues in the context of HIV. Second, the organization raises and distributes funds for projects related to rehabilitation and HIV. CWGHR develops rehabilitation resources, new knowledge, and promotes awareness in a multi-sector collaboration with partners in the HIV/AIDS sector, rehabilitation professionals, and with other disability groups on issues of common concern. For more information on CWGHR, see page 6 of the November/December 2004 issue of *Living +*, or visit the CWGHR website at <www.backtolife.ca>. ⊕



Glyn Townson is vice-chair of the BCPWA Society, and the Society's board liaison to CWGHR. He sits on CWGHR's Income Support and Income Support Research committees.



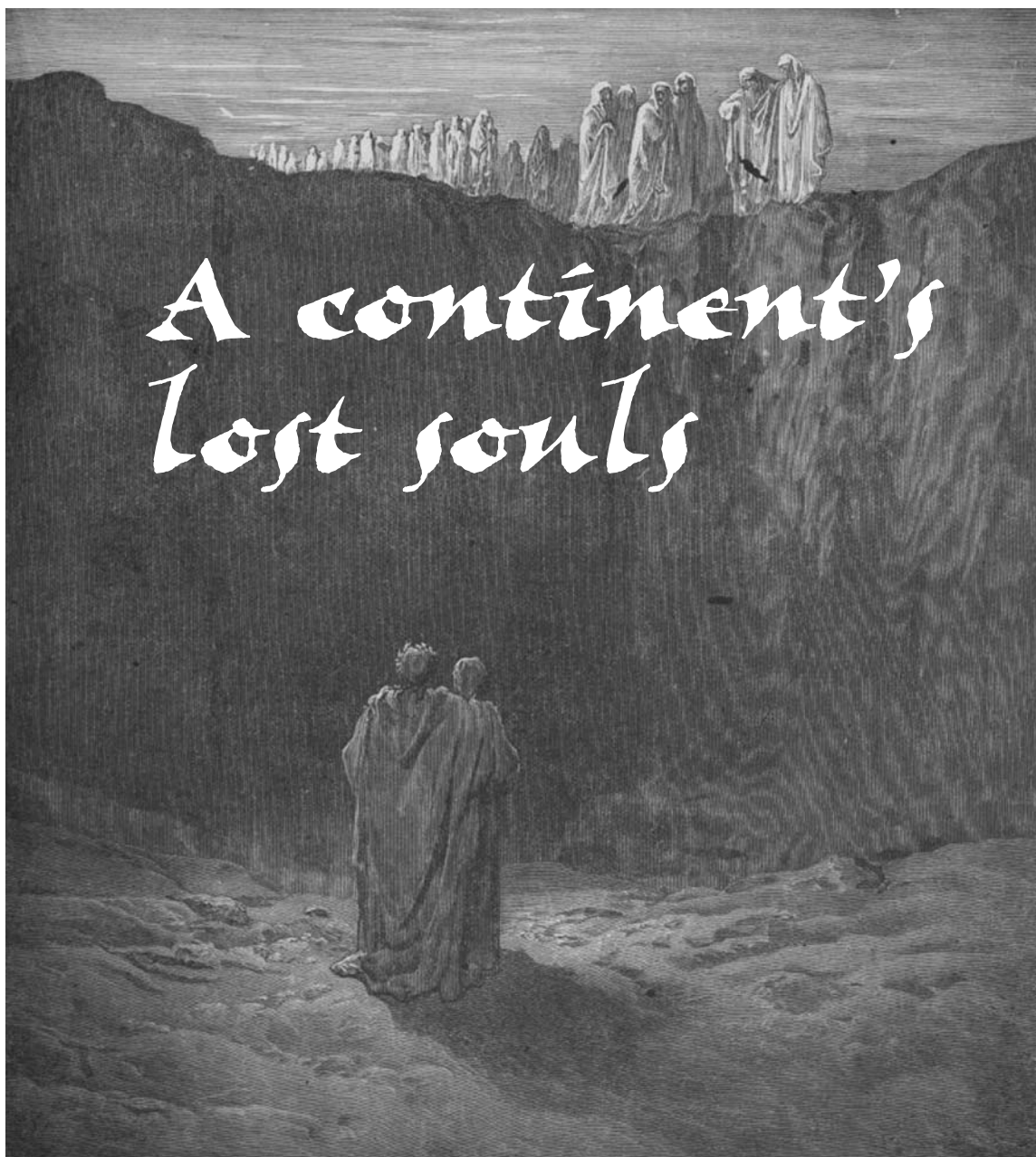
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A continent's Lost souls

Millions of children in Africa are orphaned due to AIDS

by Lucia Terra

Imagine what would happen if most working-age adults in your community suddenly disappeared and the only people left to run society were still in kindergarten and high school or already in nursing homes? Strange as it may sound, that is the future that many countries face,

especially in sub-Saharan Africa. In this region, a whole sector of the adult population is dying from AIDS, leaving millions of unprepared children and elderly people to fend for themselves. The resulting generational gap could turn this reality into a nightmare.

continued on next page

In some African countries, up to 40 percent of the adult population is infected with HIV or has already developed AIDS. Without the resources to purchase treatments that could prolong their lives, people are dying at a very early age—as young as 37 years old in countries such as Zambia and South Africa. AIDS has rapidly reversed decades of development, reducing mortality ages to the low levels of decades ago. The social, economic, and psychological impact on the survivors is overwhelming.

The situation is setting the stage for chaos. The loss of human resources and the resulting collapse at the social, economic, and political levels is almost guaranteed. In many countries, the pandemic has become a menace to an already struggling economy. The plummeting financial picture at the household and societal levels means exacerbated poverty and instability for the population. Political groups can exploit those left behind who have nothing else to lose. Discontent, frustration, and hopelessness among young destitute people mean that today's orphans can easily become the armies of tomorrow. Unattended, the consequences of the AIDS pandemic might set the ground for economic instability and violence.

Life as an AIDS orphan

International organizations estimate that 14 million children under the age of 15 have lost one or both parents to AIDS—11 million of these children in Africa alone. By 2010, an additional 25 million children in sub-Saharan Africa will likely be orphaned as a result of the disease, bringing the total number of orphans to over 40 million. In Botswana, Lesotho, and Swaziland, these figures translate into more than one orphan for every five children. In Zimbabwe, almost eighty percent of the country's more than one million children are already orphans due to AIDS.

Losing the adult working population and having to provide for remaining orphans would overwhelm even the best prepared country.

These children are sometimes referred to as “AIDS orphans.” In an effort to avoid further stigmatization and to represent the magnitude of the problem, international relief organizations use the term “orphans and highly vulnerable children” (OVC). According to World Vision, this terminology refers to children who are in precarious situations due to conditions created by HIV/AIDS in their immediate environment. This term includes pre-orphans—children whose parents are infected or dying and who face the prospect of an insecure future. OVC also includes children who have been abandoned by their families who are unable to cope with the effects of AIDS. In addition, the term refers to children living in households that have taken in orphans.

Children and youth in HIV/AIDS-affected families begin to suffer even before parents or caregivers die. As the family provider becomes ill and is unable to work, household income decreases. As the children take on the roles of caretakers and breadwinners, they inevitably neglect their studies or drop out of school. Short-term survival strategies, such as skipping meals or selling assets to pay for health care, increase the long-term vulnerability of the family. The children experience anger, frustration, fear, and uncertainty about the future.

In addition to enduring the death of one or both parents, many children subsequently encounter harsh treatment by the same people who are supposed to care for them. Due to ignorance and the stigma that still surrounds the disease, they may be denied access to schooling or proper health care. They are also likely to be subject to physical and emotional abuse, and are more vulnerable to coercion into child labour or the sex trade.

Orphans and other highly vulnerable children may also be infected with HIV themselves; however, due to a lack of resources, their status is typically unknown. Thus, since they have incomplete or inaccurate information about the disease, their own health is compromised.

When family is not enough

While some progress has been made in Africa with respect to AIDS and women, prevention strategies, and access to treatments, children affected by the AIDS pandemic have largely been ignored. But with the number of orphans reaching catastrophic proportions, the problem can't be ignored any longer.

So far, the *ad hoc* answer has been for relatives or neighbours in the community to adopt the orphans into their households. This network of extended families creates the burden of caring for additional children: in some regions of Africa, up to 90 percent of all orphaned children have been taken in by other family members. As the number of orphans continues to grow, an impossible strain is placed on those informal networks of support. Most of these families are living in disadvantaged communities and are already suffering from the effects of unemployment and structural inequalities. Some of these family members—uncles and aunts—are dying from AIDS themselves or are HIV-positive, and thus they are too weak to work and support an expanded family.

As the relatives responsible for the family become ill or die, orphaned children are left to fend for themselves, in what is often referred to as child-headed households. In these situations, an older sibling, sometimes as young as 10 or 11 years old, becomes the caretaker of the family's younger children, including infants.

The need for a concerted effort

Governments and international organizations have already identified the needs of OVCs and the provisions required to remedy their situation. Access to health services and medical treatment are paramount. As well, improvements to food security and nutri-

tion are crucial; this can be accomplished by teaching households about energy security and by training communities in food production and crop sharing. Providing adequate shelter for OVCs can be solved by addressing mobilization issues and by constructing facilities. Support and counselling groups are also needed to help children with their traumatic experiences and to safeguard them against all forms of abuse.

**An estimated 14 million children
under the age of 15 have lost
one or both parents to AIDS —
11 million of these children in Africa alone.**

OVCs also need unrestricted access to education and learning opportunities, particularly since schools have proven to be the most effective tool for curbing HIV infection. Education can empower young people, especially girls, by providing them with a strong foundation of knowledge, skills, and the confidence needed to protect themselves and their communities. Education can also break through barriers created by fear, stigma, and discrimination, and can encourage young people to seek counselling, testing, and treatment. Life skills training—the ability to handle real life situations and make informed decisions, especially about relationships, sex, and drugs—is particularly important for older children and for adolescents since transmission of HIV depends mostly on their personal decisions.

We know what needs to be done. The question, then, is how to best implement these plans. Any wide-ranging plans will take time to implement. So, on a short-term basis, the crisis must be addressed by providing immediate support to families and communities that are already trying to care for the orphans. Small non-profit societies, community-based groups, grassroots organizations, and individuals will continue to deal with the most pressing needs. These relief groups have the flexibility to address the particular needs of each region, and they can quickly adapt their outreach initiatives based on emerging needs, reaching the orphans directly and promptly.

Thus far, non-profit organizations have tackled the next level of response after extended families. Since many of these organizations were already managing orphanages and foster care, they only need to modify their services slightly to support the families that are taking care of orphans.

Keeping orphans in their community

Keeping orphans in their home communities is generally accepted as the best approach. Children who remain within their communities are able to maintain their own culture, identity, and previous relationships; siblings can stay together and avoid further trauma caused by displacement. In these situations, organizations provide families with extra resources such

as financial support and counselling services. This assistance helps families cope with the added stress and responsibility of caring for more children. In addition, offering the orphaned children free basic education as well as safe and viable options for earning an income makes them feel like less of a burden to their host families.

When arrangements such as these are simply not viable, foster care, adoption, or institutionalization should be considered as last resort options. While far from ideal, supportive housing facilities provide safe environments to orphans who might otherwise be abandoned or end up on the streets, where they risk further abuse and exploitation. Locally based or foreign-supported, these houses/orphanages face increasing demands in terms of space, operational costs, and adult guidance. In the town of KwaZulu Natal in South Africa, for example, 10 infants are abandoned each month.

Losing the adult working population and having to provide for remaining orphans would overwhelm even the best prepared country. For countries already struggling with economic and social difficulties before the AIDS pandemic, the situation is reaching disastrous proportions. Their ability to cope is increasingly contingent on support from the international community.

Addressing the problems created by AIDS is central to the achievement of almost every other developmental goal. And the course of the pandemic in sub-Saharan Africa and throughout the world will greatly depend on whether we can protect the children and young people from its impact. ⊕



Lucía Terra is a Vancouver-based freelance writer.

What can I do?

For more information on how to donate money, sponsor a child, pressure authorities to take action in response to the AIDS crisis in Africa, or to volunteer, visit the following Web sites:

www.acceskenya.org

www.doctorswithoutborders.org

www.rwandahope.com

www.sos-childrensvillages.org

www.stephenlewisfoundation.org

www.unicef.ca

www.worldvision.org

www.vsocan.org

A helping hand and an open heart

Canadians pitch in with more than money for African orphans

by Lucia Terra

Watching this year's winner of the CBC Wilderness Award, Judy Jackson's documentary on the AIDS orphans crisis in Africa, one's first reaction might be: "What can I do?" While the typical answer is to donate money and food, some Canadians have found other ways to contribute.

Love and care, for example, are in high demand, as Pam Havery and Joanne McAlpine can attest. Feeling that it was important to give their time to these orphans, they left their work and home in Ontario to commit to six months of pre-school teaching, homework and playtime supervising, feeding marathons, and endless bedtime storytelling. They are presently working in an orphanage in South Africa. The children live in houses with adult caregivers, attend nearby schools, receive three meals and two snacks each day, and get basic health care. Havery and McAlpine note that the work at the orphanage can be overwhelming. Try preparing food for 120 people every day!

But their experience is often draining for other reasons. Many of the children are very ill; they are often in and out of the hospital, suffering from opportunistic infections and diseases until their organs begin to fail. Havery and McAlpine watched some of them die. The orphanage has four graves for children who died last year. "It was a very sobering experience to see the graves, and a reminder to us just how sick some of the kids are," says Havery. "Not that we forget, but the kids are so happy and full of energy, that unless you see all the meds they take, it's easy to not think about their illnesses sometimes."

The orphanage experience can also be empowering. The rewards usually come at bedtime, when the children shower them with hugs and exclamations of "*I lob you berry much.*" According to Havery, those hugs make it all worthwhile.

Though she might not receive this same type of immediate feedback from the orphans she helps, documentary filmmaker Judy Jackson is also committed to making a change. A long-time social justice and human rights activist, she has produced two documentaries on AIDS in Africa. In her most recent film, she follows Stephen Lewis, current United Nations special envoy for HIV/AIDS in Africa, during his visits to the continent.

During these trips, Jackson witnessed wonderful training programs in Zambia and Uganda. Centres provide one-year training programs in sewing, woodwork, hairdressing, and office administration, for adolescent girls who have dropped

out of school. School is often abandoned in order to care for a dying relative—a decision which ultimately puts their future in jeopardy. Providing these girls with a means of sustenance empowers them with greater control over their lives.

Jackson also visited hospices for orphans in Kenya and South Africa. When hospices were able to provide antiretroviral drugs, they saw the children "rise from the dead." Mothers receiving treatment also recovered enough to return to work. One mother, concerned about her children's future, expressed how she just wants to "stay alive long enough to get my kids through school." Many agree that keeping the parents alive could be enough to improve the orphan crisis.



Cast of Snow White and the Seven Dwarves at an African orphanage.

Back in Canada, Jackson is a mentor for a program run by schoolchildren on Salt Spring Island, BC; these youth are organizing a support program for children in Africa by fundraising and writing them letters. "For kids who have lost everything back in Africa, knowing that other kids care, has a lot of value," says Jackson. After her second film, *The Value of Life*, aired on television, the Stephen Lewis Foundation received over \$120,000 in donations. "Proof that Canadians are responding," she says. Responding indeed—in more ways than one. ⊕

Lucía Terra is a Vancouver-based freelance writer.

Privacy coalition challenges US access to databases

by Ross Harvey

As most HIV-positive Canadians know, it is illegal under American law for people with HIV or AIDS to enter the United States unless they have a special permit. This doesn't really bother most HIV-positive British Columbians because, really, how would US border guards know?

Answer: because the BC government allowed those US border guards to access that information.

Post-9/11 US anti-terrorism laws allow the FBI to obtain secret court orders to seize any information they want from any American company. The BC government signed deals with several American companies to take over various databanks, including those for BC Medical Services Plan (BCMSP) and PharmaCare. Thus, it is entirely possible that your medical records—including records pertaining to your HIV status—could wind up first in the hands of the FBI, and next in the hands of US border authorities.

Obviously, this possibility is of great concern to the BCPWA Society and the thousands of HIV-positive British Columbians it

serves. So, last spring the Society coordinated a coalition of interest groups, including the BC Freedom of Information and Privacy Association, the BC Civil Liberties Association, the BC Health Coalition, and the BC Seniors Network to create the Right to Privacy Campaign <www.righttoprivacycampaign.com> aimed at fighting this alarming development.

The Right to Privacy Campaign was key in securing a review by the province's privacy commissioner on the deal between BCMSP/PharmaCare and the American corporation MAXIMUS. That review led directly to the introduction of new major privacy protections into BC law.

The privacy commissioner has determined that more investigation needs to be done. So, the Right to Privacy Campaign will continue its work, with the BCPWA Society maintaining its leadership role. Visit the Society's website <www.bcpwa.org> for information about the new campaign and what you can do to help. ☺

Ross Harvey is the executive director of the BCPWA Society.

BC increases disability assistance rates

On November 6, 2004, the BC government announced an increase to disability assistance rates from \$786/month to \$856/month for a single person. If more than one adult in the family is receiving "Persons With Disability" (PWD) assistance, each adult will receive the increase. The \$70 increase, per person, is to help people with disabilities meet the costs of daily living.

For individuals whose only source of disability assistance has been the Canada Pension Plan (CPP), this announcement may positively affect their entitlement to welfare benefits. If you receive more than \$786 per month (but less than \$856) from CPP, you should be eligible for PWD status and financial assistance from the province. With PWD, the province will top up your monthly financial assistance to \$856 and you will be able to access healthcare supports and other needs provided by welfare.

If you only receive CPP disability assistance and your total monthly income, before taxes, is less than \$856, contact the BCPWA Society Advocacy Program at 604.893.2223. The advocates will discuss your next steps with you. ☺

TABLE 1. NEW DISABILITY ASSISTANCE RATES

Case type	Current maximum	New maximum
Single	\$786	\$856
Couples (with one PWD)	\$1151	\$1221
Couples (both PWD)	\$1329	\$1469
Two parent families (one PWD, two children)	\$1281	\$1351
Two parent families (two PWDs, two children)	\$1459	\$1599
One parent families (two children)	\$1165	\$1235



St. Paul's Hospital services whittling away

by Glyn Townson

Two years ago, Vancouver Coastal Health prohibited hospitals from running deficits in their operating budgets. With an annual deficit of about \$200,000, St. Paul's Hospital in Vancouver was required to cut services to patients and chose to close three palliative care beds—two respite beds and the only symptom management care bed in their palliative care ward.

This decision has had a severe effect on people living with HIV/AIDS who, over the years, have come to depend upon these services. When patients needed more medical attention than their partners or caregivers could provide, respite care offered a hospital setting with well-trained staff and services available around the clock for short-term planned visits.

Respite care allowed patients to schedule one-week stays at St. Paul's, alleviating the fear of extended periods of hospitalization. The respite bed also provided a practical way to schedule multiple

appointments in one location, rather than several separate appointments, which involve travel costs and other inconveniences. A short-term respite stay was also useful when dealing with such situations as medication problems and changes, serious or uncontrollable fevers, dietary problems, and caregiver burnout.

Since the elimination of respite care at St. Paul's, this type of service is now provided through home care support. However, because home care is income-based, some individuals face hefty user fees and have limited services available to them. By contrast, costs for hospices and hospital palliative care are completely covered by our provincial medical plan.

Before the cuts to service, St. Paul's Hospital had one of the best models for comprehensive care. The cut is a step backward. The continuum of support has now been broken, with fewer choices available for specialized care.

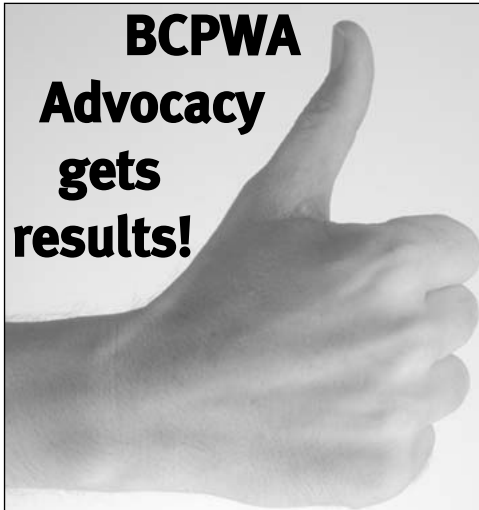
Unfortunately, the cuts don't stop there.

The social worker at St. Paul's will soon be leaving the Emergency Department and the HIV Psychiatry Department is scheduled to shut down. Youth Services and the Dusk to Dawn program may also be at risk.

Respite care can save the provincial health system money by reducing further strain on both emergency and acute care services that are already stretched to the limit. It also prevents partner and caregiver burnout, providing brief periods of reprieve and additional support, while simultaneously allowing patients the dignity and hope they deserve.

Contact your local MLA and government officials and let them know that the cuts have gone too far and cut way too deep. You can find more information on how the community is dealing with these cuts at www.members.shaw.ca/youcanhelp/index.htm. ⊕

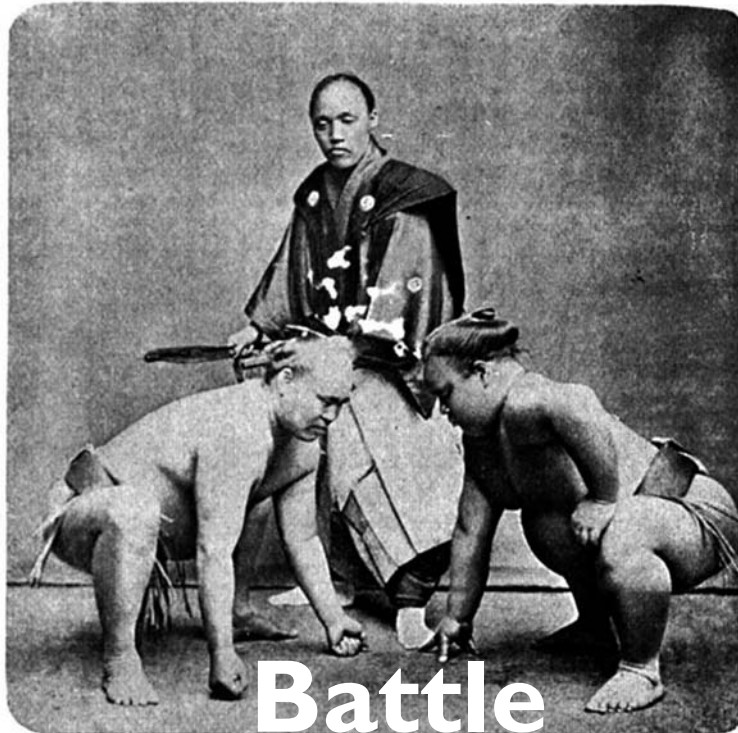
Glyn Townson is vice-chair of the BCPWA Society.



**BCPWA
Advocacy
gets
results!**

The BCPWA Society's Advocacy Program continues to work hard to secure funds and benefits for HIV+ individuals. The income secured for August and September 2004 is:

- ▼ **\$28,538.92** in debt forgiveness.
- ▼ **\$123,868.23** in housing, health benefits, dental and long-term disability benefits.
- ▼ **\$32,260** in Monthly Nutritional Supplement Benefits.
- ▼ **\$368,072.00** into members' hands for healthcare needs, from grandfathered Schedule C benefits.



Battle of the prevention strategies

by Jeff Anderson

ABC versus CNN might sound like a battle of US media giants, but in fact these are acronyms for the increasingly sharp divisions of philosophy determining international AIDS funding.

ABC stands for Abstinence, Being faithful, and careful Condom use, which promotes a traditional Judeo-Christian or western lifestyle. ABC promotes the safest behaviours by everyone. CNN refers to Condoms, Needles, and Negotiations, which seeks to lessen harmful effects by accepting the actions people typically engage in and making them safer. CNN adopts new approaches to the actions that place people at risk of HIV infection.

Both ABC and CNN are effective strategies to prevent HIV under different circumstances. Education and support is an essential first step to promoting behaviour change, but the education provided is often determined by which approach is funded by governments. Both approaches are useless, however, if individuals do not adopt them. Should governments fund prevention education that focuses on promoting preferred behaviours or on helping people to adopt self-determined behaviour that is safer? Therein lies the future of prevention programming—and billions of dollars in HIV funding.

The ABC approach

Abstaining from the exchange of sexual fluids and avoiding blood-contaminated needles under the skin are key strategies to prevent HIV infection. The US government and the Catholic church are the two biggest advocates of the abstinence approach. However, this method is not effective in regions where Christian churches have little sway, such as the Masai, where wives are considered communal property. Abstinence is also an unrealistic option for injection drug users, whose desire for drugs outweighs other imperatives.

Being faithful—to one uninfected sexual partner—is preferred by the US government and many religious groups. Clearly, fidelity is an ineffective prevention strategy for people who enjoy non-monogamy, or where one partner explores sex outside of the primary partnership. In a recent on-line article posted on PWhA-NET, South African PWA advocates David Patient and Neil Orr wrote: “statistics show that [an African] woman who gets married doubles her risk of infection the day she gets married, because she loses the cultural and religious right to protection (i.e. condoms).” In response to African cultural norms, health workers use sex education to improve sexual relationships between partners as a strategy to prevent men from seeking other partners for sex. Thus the “B”, for some, means Better sex.

If condoms never failed, their use would always prevent infection. As they say, “there’s the rub.” When a condom slips or breaks, HIV can be transmitted. “Condom use is high—and effective—in youth and sex worker sectors, but not elsewhere, at least in the developing world,” Patient and Orr report. “The reason is simple: people want children when they get married or commit to each other in the long term. This aspect of committed relationship is deeply entrenched, and reinforced culturally and via religious institutions.”

Condoms are the least preferred strategy among ABC proponents. The Catholic church has great influence among the world’s largest HIV population, Africa, and clearly opposes condoms. The US government also prefers abstinence and being faithful over condom use; in fact, as the largest source of international AIDS funding, the government reinforces its ideology by requiring all international programs receiving US sponsorship support to promote its position regarding condom failure. Many HIV experts strongly disagree with these tactics. In the fall issue of the American Bar Association’s *Human Rights Magazine*, Canadian HIV/AIDS Legal Network executive director Joanne Csete argues that the US government “exaggerates failure rates of condoms and instructs parents that telling their children about condoms may be putting those children in danger.”

The CNN approach

In the CNN approach, C again stands for condoms. Emerging epidemics in Asia are fuelled largely by the sex trade and, to a lesser extent, among men who have sex with men; therefore, many people view condoms as an effective prevention option. Studies report a 97 percent success rate of HIV prevention when condoms are used properly. Despite failures, condoms still represent a “best under the circumstances” approach, especially until a viable microbicide is developed. The additional benefit of preventing other STD infections means healthier populations and less favourable conditions for HIV.

As for the needle component of the CNN approach, after years of controversy, the widespread benefits of providing clean needles to injection drug users are finally recognized. Ensuring that users do not share needles prevents the transmission of HIV, hepatitis C, and other diseases. Safe injection sites have been successful overall. European, Australian, and Canadian sites in Vancouver report reduced infection rates, a decline in overdose-related deaths, and an increased number of users accessing health services.

In New York City, former drug-destroyed neighbourhoods are gentrifying into desirable areas. Drug users, originally driven into dangerous neighbourhoods, developed programs such as CitiWide Harm Reduction in the Bronx. In an ironic twist, the improved conditions in these areas has attracted new neighbours who then want the programs shut down, claiming they attract the wrong element to “their” community.

In terms of negotiation, the 2004 World AIDS Day thematic focus on women and girls reflects the cross-cultural reality that women have less power to affect the circumstances surrounding sex. HIV transmission from men to women is many times higher than from women to men; consequently, when women are

victims of sexual violence, they also increase their risk of HIV infection. Teaching the ethics and practice of negotiating sex to both men and women increases the likelihood of condom use and the future use of microbicides. Nevertheless, in order for this strategy to work, there needs to be an interpersonal and cultural shift in gender-based power dynamics.

The clash of religious, personal, and culture mores

Religious, personal, and cultural mores are foremost in the tussle between ABC and CNN. Last year’s \$100 million US President’s Emergency Plan For AIDS Relief (PEPFAR) to abstinence-based international aid, coupled with USAID’s requirement that partners agree to US imposed guidelines, signify the Bush administration’s influence on HIV work in the developing world.

At the 2004 International AIDS Conference, USAID required that all working partners—even workshop presenters—promise not to “promote or advocate the legalization ... of prostitution [and] must have a policy explicitly opposing ... prostitution and sex trafficking.” Under these circumstances, and with a further stipulation that any information on condom use include failure rates, the Canadian HIV/AIDS Legal Network felt it could not sign a UNAIDS funding agreement for the Bangkok conference. The Network argued that it is a human rights organization that supports the rights of sex workers. “We believe that a rights-based approach is required to protect and promote sex workers’ right to health.” The Network claimed “we would not be able to do our work credibly if we signed the contract.” Vancouver researcher Dr. Mark Tyndall later noted that “in African countries [the US approach] is taking a step backwards and will not be helping very many people.”

ABC proponents see themselves advocating proven methods to prevent HIV by saying “no” to risky behaviour. CNN advocates try to prevent infection through harm reduction in the real world. BC infection rates are revealing: they are essentially unchanged since 1996, despite additional prevention tools such as better HIV programs, improved medical interventions, and one of the world’s most responsive health and social environments. At a recent community briefing on Bangkok 2004, Dr. Tyndall remarked, “the chance of HIV infection is about 2.5 percent in the Downtown Eastside (DTES) of Vancouver, twice as high as the worst areas of New York City.” He added the likelihood of death by HIV in the DTES is 60 percent higher than in the rest of BC.

While education is having a positive effect, it would appear that it has not fully changed people’s behaviours, and might never do so. The HIV/AIDS community in BC, especially in Vancouver, has chosen to officially encourage both abstinence-based and harm reduction-based strategies. With so much at stake, this pragmatic view of a continuum of prevention may be the best strategy to prevent infection of HIV—locally and around the world. ⊕

Jeff Anderson is a long-time activist and volunteer, including past treasurer of the BCPWA Society from 1997 – 2002.



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



It's that time of year when I feel the need to review my nutritional supplementation program. It's expensive, it comes out of my disability pocket, and I eat pretty well, so why do I need it? Welcome to my annual moment of doubt, when I wonder aloud why I continue to take so much *stuff* on top of my medications. Then, I open the newspaper and read that high doses of vitamin E might be associated with a higher risk of death. That's not good.

While sifting through my collection of clippings, an article entitled "Can a Vitamin a Day Keep AIDS Away?" caught my eye. The article refers to findings from a study recently published in the *New England Journal of Medicine*, a reputable, peer-reviewed paper with serious academic credentials. The study shows that

pregnant and postpartum women in Tanzania who received a daily multivitamin had slower disease progression and better surrogate markers (CD4 and viral load) than women who were given a placebo. [The study is also discussed in "The Buzz on Multivitamins" in the November/December 2004 issue of *Living+.*] Already I'm feeling sorry for the women on placebo and wondering how an ethical review of this study was conducted, but that's another article.

The Tanzanian study

The important thing is the role that multivitamins can play in treating HIV disease, especially in the developing world where so many people need antiretroviral medications but don't have access to them.

continued on next page

Dr. Wafai Fawzi, a Harvard University researcher who led the study, randomized a group of 1,078 pregnant and HIV-positive Tanzanian women into one of four groups: daily multivite containing vitamins B, C, and E; vitamin A alone; vitamin A plus multivite; or placebo alone. The study was “double blind,” meaning neither doctors nor patients knew who was receiving vitamins and who was receiving a placebo. The groups had similar baseline characteristics, that is, similar ranges of CD4 counts, viral load, and general health when measured at the outset of the study. The study also followed up on participants for a period of up to six years.

**I have convinced myself once again
that supplementation offers more benefit
than harm, even for those of us
who feel we eat properly.**

Compared with those receiving placebo, women taking multivitamins showed a lower risk of progression to serious AIDS defining illness and death. Beneficial effects from the vitamin regimen were apparent within 12 to 24 months and lasted, in some cases, beyond four years, regardless of the participant’s nutritional status or CD4 cell count at the outset. Compared to the placebo group, there were fewer oral and gastrointestinal symptoms reported, CD4 counts increased on average 48 cells/mm, and viral loads were significantly lower ($-0.18\log$, copies/mL). Vitamin A, however, was not shown to be protective against disease progression; in fact, this vitamin appeared to reduce the benefit when added to a multivitamin compared to the placebo.

This well-designed trial adds to the growing body of research about the potential benefits of nutritional supplementation in people with HIV, although much more investigation is needed to determine the benefits in HIV-infected men and among people with varying degrees of nutritional deficiency.

As a result, I have convinced myself once again that supplementation offers more benefit than harm, even for those of us who feel we eat properly. If you’re like me and have trouble maintaining body weight, there is a valid concern that we may not be getting all the nutrients we need from food alone, especially if HIV has damaged the digestive system, making it even harder to absorb those nutrients. Then there’s the stress of HIV on the immune system, which needs all the help it can get.

Deciding on how much to take

But how much supplementation is enough? And what about the recent information suggesting that high doses of vitamin E can be deadly? A team of US researchers re-analyzed data

from 19 clinical trials involving more than 135,000 patients in North America, Europe, and China. They compared death rates between people who were given vitamin E with those receiving a placebo and found a significant increase in risk associated with daily doses above 400 International Units (IU). Given the increased risk of cardiovascular disease among people living with HIV, it seems prudent to cut back on vitamin E. As a result, I no longer take more than 200 or 300 IU per day. It’s a good idea to check your bottles and add up the total from all sources.

When it comes to the basics, like vitamin C, I find I have cut back over the years to about 1,000mg per day. Vitamin C is water soluble and regularly excreted by the body. The only time I take more is when I feel a cold coming on; then I increase the dose to 1,000mg every hour to a maximum of eight to ten pills a day. Diarrhea may result from higher doses, so cut back if that happens.

Vitamin A can build up in the body with successive doses and is known to cause health problems at high levels. Too much vitamin A (over 25,000 IU per day), for instance, can cause headaches, hair loss, and liver damage, or abnormal fetal development in pregnant women. There is also some evidence to suggest that high or toxic levels of vitamin A can contribute to osteoporosis, another risk factor of concern to PWAs.

Large doses of vitamin D (50,000 IU per day, 125 times the US recommended daily allowance) can increase calcium absorption from the intestinal tract, and possibly also increase calcium resorption from the bones, leading to elevated levels of calcium in the blood. These effects can lead to abnormal calcium deposition in soft tissues, such as the heart and lungs, impairing function. If you can, check with a nutritionist or naturopath to determine the most appropriate ratio of calcium, magnesium, and vitamin D for you to take.

Also, exercise caution when taking iron supplements. Women typically need more iron than men. However, daily doses higher than 100mg could interfere with absorption of zinc, a mineral that speeds wound healing and helps regulate the immune system. I am a carnivore who takes a multivite without iron.

My vitamin philosophy has changed over the years to a “less is more” approach. Note to self: take the time to cook and eat a healthy meal. ☺

Ron Rosenes is vice-chair of the Sherbourne Health Centre in Toronto, a member of the boards of the Canadian Treatment Action Council and AIDS ACTION NOW! and an honorary director of the AIDS Committee of Toronto.



New treatment guidelines

by Rob Gair

New treatment guidelines for adult HIV infection were published in the *Journal of the American Medical Association* in July 2004. A 16-member panel of international HIV experts developed these recommendations. All members of the panel came from countries with adequate access to antiretroviral medications. The US International AIDS Society provided funding for the work, with no additional contributions provided by government or private industry.

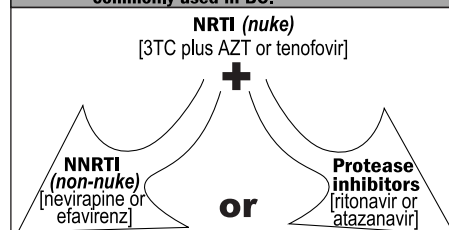
The objective of the new guidelines was to update treatment advice for physicians, including when to start HIV therapy, what drugs to use, when to change drugs, and what to switch to when therapy fails. In September 2004, Dr. Julio Montaner from the BC Centre for Excellence in HIV/AIDS presented these new guidelines to physicians and healthcare providers at St. Paul's Hospital in Vancouver.

The decision to start antiretrovirals for people who have not previously taken HIV drugs is based on symptoms and CD4 cell counts. Viral load is not considered a factor at this stage. Most people do not develop serious HIV symptoms as long as their CD4 cell counts remain above 200 (with a CD4/CD8 ratio above 14). Therefore, people in good health do not usually start HIV therapy until these blood counts fall below this threshold. However, patients with symptoms of HIV disease

should start antiretrovirals as soon as possible, regardless of their CD4 cell counts.

The choice of drug regimen is based on data from numerous studies examining antiretroviral effectiveness and tolerability. People who have never taken HIV medications are generally placed on a three-drug combination regimen that includes two "nukes" (nucleoside reverse transcriptase inhibitors, or NRTI) plus either a "non-nuke" (non-nucleoside reverse transcriptase inhibitor, or NNRTI) or a protease inhibitor (PI). Figure 1 outlines antiretroviral regimens.

Figure 1. Examples of first-line antiretroviral regimens commonly used in BC.



In terms of specific drugs, nevirapine is preferred over efavirenz except in people co-infected with hepatitis C. Pregnant women should not take efavirenz. People with syncytium-inducing virus (a more aggressive form of HIV) should begin treatment with a regimen that contains a protease inhibitor. Some PIs need to be administered in combination with ritonavir to "boost" the drugs' activity. See Table 1 for a list of currently available antiretrovirals.

Changes to initial antiretroviral regimens commonly occur within the first two years, usually because of side effects, inconvenience, or drug failure. PIs may cause elevated lipids. Efavirenz is commonly associated with impaired concentration or nightmares, while nevirapine is linked to rashes and liver toxicity.

In addition, inconvenient drug schedules can lead to missed doses, which commonly triggers drug resistance and treatment failure. The goal with drug therapy is to achieve adequate CD4 cell counts along with a fully suppressed viral load (less than 50 copies/mL of blood or "undetectable" levels). The occasional viral load blip above 50 does not predict drug failure, but sustained elevations indicate possible viral resistance.

A new regimen containing at least three active drugs should bring viral replication under control. Your options may be limited and you may require help from an HIV specialist. Newer drugs such as T-20 (Fuzeon) are reserved specifically for people with advanced treatment failure and multiple drug resistance. ⊕



Rob Gair is the pharmacist at the BC Drug and Poison Information Centre.

Table 1. Currently available antiretrovirals

NRTIs	NNRTIs	Protease inhibitors	Fusion inhibitors
zidovudine (AZT) 3TC d4T ddI tenofovir (Viread) abacavir (Ziagen)	nevirapine (Viramune) efavirenz (Sustiva) delavirdine (Rescriptor)	lopinavir/ritonavir (Kaletra) atazanavir (Reyataz) ritonavir (Norvir) saquinavir (Fortovase) saquinavir mesylate (Invirase) nelfinavir (Viracept) indinavir (Crixivan)	enfuvirtide (Fuzeon, T-20)

The TOP 10

Things you should know if you're newly diagnosed with HIV

by Kath Webster

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It's been nine years since my HIV diagnosis, so I no longer fit into the "newly diagnosed" category. But, like many HIV-positive folks, my memories of the hours, days, and months following my diagnosis are crystal clear. If I had to do it all over again, there are a few things I would want to know to help guide me. I spoke to several HIV-positive people to find out what their concerns were immediately after diagnosis and how they dealt with them. After all, other PWAs are one of our best resources for getting support and learning about how to live well with HIV.

Your life will never be the same after an HIV diagnosis; but

due to great advances in treatment and a better understanding of how to care for ourselves, the outlook is promising.

I After the shock, getting your head around it

Finding out that you're HIV-positive can really knock the wind out of you. You may react with shock, fear, guilt, anger, or depression. You have suddenly entered the unknown world of HIV, which can be terrifying and overwhelming. Anxiety attacks are not uncommon—after all, your life has irrevocably changed and you are facing your mortality, perhaps for the first time. Some people are diagnosed late—meaning, long after

they were infected—and might already be sick, which can make the impact of the situation even more challenging. Allow yourself to go through the myriad of emotions that an HIV-positive diagnosis can trigger. This process will take time, but eventually you will get your head around it.

Although there is no cure for HIV, a positive diagnosis is no longer a death sentence. There are people who have survived with HIV for well over 20 years. People continue to work, have relationships, have children and have long-term goals and dreams. After the initial shock fades, you will be able to look ahead and feel hopeful again. There's no changing the diagnosis, but you do have control over the way you react to it.

Consult with your doctor if you need to treat depression, anxiety, or insomnia. Your local AIDS service organization (ASO) may also be able to provide counselling as well as peer or group support (see item 3 below).

2 Navigating the medical maze, finding a good match

Finding a good doctor and other healthcare professionals is one of the keys to managing HIV. It's crucial to have a doctor whom you can trust. Some people view the doctor/patient relationship as a partnership. They want to be included in decision making about treatment options, such as starting or switching medications. Ultimately, you make the final decisions about your health, but the doctor can be an essential resource person. Feeling this sense of control is important and may help you be more committed to your healthcare plan. A key characteristic identified among long-term survivors is that they take an active role in their own healthcare decisions.

Finding a good doctor and other healthcare professionals is one of the keys to managing HIV. It's crucial to have a doctor whom you can trust.

Other people prefer a more traditional doctor/patient relationship, where the doctor is the leader and the patient is the follower. In either case, some of the qualities you should look for in a doctor are knowledge and experience with HIV, bedside manner (do you feel comfortable with him/her?), attention to detail, thoroughness, respect, and responsiveness to questions from patients. It may be helpful to bring a friend along to your appointments, especially in the period immediately following your diagnosis, when the amount of information can be overwhelming. Bring a list of questions to ask. Some people keep a health journal documenting blood work results, medications, symptoms, and side effects.

For help in finding a doctor or other healthcare professionals, contact your local ASO. Another valuable resource is other people with HIV who can provide informal recommendations based on their experiences.

3 Good help is not so hard to find

Getting emotional support is essential when diagnosed with HIV. However, this may be complicated if you are not ready to disclose your HIV status to family and friends. A counsellor or psychologist can help you work through difficult emotions that surface after a diagnosis.

Alternatively, many people find it easier to talk confidentially to someone at an AIDS organization, either in person or anonymously, over the telephone. Often, an HIV-positive person will be available to provide peer counselling. Many phoneline support services offer toll-free telephone numbers, which helps to address some of the added challenges encountered by PWAs living in rural communities. Internet support groups and chat rooms for people living with HIV are also good ways to connect anonymously with others. It's important to reach out in whatever way works for you.

Remember, you are not alone. Isolating yourself can lead to depression. The BCPWA Society organizes retreats each year. Membership is open to all HIV-positive residents of BC. The retreat program is a great way to meet other HIV-positive people within a supportive and relaxing atmosphere.

4 To tell or not to tell

Disclosing your HIV status can be challenging. Whether it's sexual partners, co-workers, or parents, there's no easy way to tell someone that you're HIV-positive. Deciding who, when, and whether or not to tell is a very personal decision. There's no great rush to tell anyone, unless you need to notify sexual partners who may have also been exposed.

Before disclosing, think it over carefully. Know why you want to tell someone and if you have any expectations when you disclose your status to them. You can prepare for their questions by informing yourself more about HIV. Get additional support from a counsellor or someone you trust.

For some, the stress of keeping a secret might outweigh the stress of telling. Many HIV-positive individuals who have disclosed their status to others discover that people are generally very supportive, and there is a huge sense of relief in sharing the information with others.

5 The ABCs of HIV

Knowledge is power and it will make a difference in your fight against HIV. If you understand some of the basics about the virus and how it operates, you will be better equipped to make decisions and take charge of your health. But take your time. The vast amount of information and new research can be overwhelming.

continued on next page

Some of the information may be conflicting and confusing. Pace yourself, and learn a little at a time. If you are facing a difficult treatment decision, take the time you need to investigate all the facts so you feel comfortable with your decision.

Unless you received a late diagnosis and are encountering health problems, you probably won't need to start HIV medication for several years. Your focus, instead, will be on learning about HIV and ways to stay healthy. Treatment information is available from your doctor or your local ASO. The Internet also has many informative Web sites. Two good places to start are the "Just Diagnosed" section of the The Body at <www.thebody.com/learning.html> or Project Inform's "Day One: After You've Tested Positive" <www.projinf.org/fs/day1.html> section.

Suggestions for your first medical appointment:

- ▼ Get baseline blood work done (CD4, viral load, lipids, liver, etc.)
- ▼ Make sure your vaccinations are up-to-date
- ▼ Treat any other infections or health problems

6 Your body – your temple

You've heard it all before: eat properly, get enough sleep, and exercise regularly! But now that you're HIV-positive, this advice is even more important. Your immune system is vulnerable and you need all your defenses. For some people, HIV is like a wake-up call for them to take better care of themselves. Doing this doesn't mean you have to eliminate all your guilty pleasures immediately. It just means that in order to stay as healthy as you can, you may need to make a few changes.

Inform yourself by consulting with other PWAs and healthcare professionals. Talk to a dietician or naturopath to evaluate your nutritional needs and to get information on vitamins and supplements. Talk to your doctor if you are having any trouble sleeping. If you need help managing an addiction, talk to a counsellor or another healthcare provider. Your local ASO can also help with referrals to a variety of healthcare professionals. For more information on self care, I highly recommend Lark Lands' article "The Ten Commandments of Living Long and Well with HIV" at <www.larrylands.com/lark>.

7 Suddenly seeking services

Services for people with HIV vary among communities. Get connected with your local AIDS service organization and find out about your eligibility for such services as income assistance, housing subsidies, funding for purified drinking water and vitamins, access to food banks, body work, and healing retreats. At the BCPWA Society, membership provides access to many of these services.

8 Don't stress, it's only yoga

Many studies have shown that stress can have a direct negative impact on the immune system. According to psychologist Dr. Jeffrey Leiphart, who works with PWAs at the San Diego Center for Social Services and who has written extensively on this

topic, high stress levels can "erode the immune function and hasten the onset of AIDS." In other words, long-term stress may cause HIV to progress more quickly.

It's impossible to eliminate stress completely from our lives; in fact, living with HIV is a source of stress in itself. Since a certain amount of stress is a given, the important thing is to learn how to manage it. There are many ways to decrease stress: deep breathing, yoga, tai chi, aerobic exercise, deep relaxation, massage, meditation, laughing, and having fun—to name just a few. The key is to make stress reduction a priority.

9 Is there sex after HIV?

An HIV diagnosis is by no means the end of your sex life. Sex is an important part of our overall well-being. Being HIV-positive presents added challenges, but many people both in and out of relationships have active and fulfilling sex lives. You do, however, need to educate yourself and your partner(s) about safer sex.

Contrary to what some people believe, safer sex is also recommended between HIV-positive partners. The *Sex Positive Guide* recently produced by the BCPWA Society suggests that "HIV-positive people may want to avoid the risk of getting re-infected with HIV. It may be possible for someone with a drug-resistant strain of HIV to give it to another person, which could limit treatment options." Preventing other sexually transmitted diseases (STDs) is also important because open sores are a source of easy transmission of HIV. In addition, STDs put additional strain on the immune system. For more information, contact the Positive Prevention program at the BCPWA Society or, for services directed specifically to women, contact the Positive Women's Network.

10 The mind-body connection

Having a positive and hopeful outlook is another important characteristic of many long-term survivors. Decide that you will take charge of your life and health, and rise above this virus. The power of the mind to boost the body toward healing is amazing. Have a strong will to live and never give up!

An HIV diagnosis is a turning point in your life. Effective treatment, information, support, self care, and a positive attitude will go a long way in helping you stay healthy. Hopefully, you will discover new ways to heal, be in the moment, and live this adventure known as life. ☺

For a list of HIV/AIDS resources, please refer to page 38 of this magazine. You can also reach the BCPWA Society's Treatment Information Program by calling 604.893.2243 or toll-free at 1.800.994.2437.



Kath Webster is a researcher and treatment information counsellor for the Treatment Information Program at the BCPWA Society.



is for bodily fluids

An update on hepatitis B

by R. Paul Kerston

Hepatitis is a disease which causes inflammation of the liver. There are several types of hepatitis, primarily types A, B, and C. An estimated 95 percent of people living with HIV have been exposed to hepatitis B (HBV).

People can contract hepatitis B without becoming aware. HBV is typically spread through direct contact with bodily fluids between infected and non-infected individuals; it can also be transmitted between mother and newborn infants. In most cases following exposure, the immune system deals with the hepatitis B virus and the disease resolves itself without treatment. Once resolved, antibodies can be detected through blood tests, but the virus poses no further risk of transmission. People are effectively immunized against further infection, just as if they had been vaccinated.

Other people may experience fever and flu-like symptoms, including tiredness, loss of appetite, nausea, and pain in the abdomen following infection. Additional symptoms of HBV include dark urine, clay-coloured bowel movements, and yellowing of the skin and eyes.

Roughly six to ten percent of people infected with hepatitis B will develop an ongoing (chronic) form of the disease, which means the virus remains active and can be transmitted to others. In most people, chronic infection is essentially harmless, and few people exhibit signif-

icant or severe symptoms. However, in a limited number of cases, HBV can produce bouts of illness.

Vaccinations against hepatitis B have been available since 1982. The vaccine requires a series of three injections, the last one within six months of the initial inoculation. Immunization is considered roughly 90 percent effective, but protection is achieved only following the third injection. The vaccine is safe for HIV-positive people, although it may not be as effective for them, particularly on a long-term basis.

For people with symptomatic hepatitis B, the goal of treatment is to achieve long-lasting suppression of the virus and to prevent the onset of liver disease. Treatments for chronic HBV infection include interferon (alpha 2b), lamivudine (3TC)—a nucleoside analogue (NRTI) drug used in HIV therapy—and adefovir (Hepsera). Hepsera is still not approved in Canada. The treatment selected usually depends upon the results of specific blood tests and the state of infection.

Interferon alpha (by injection) and lamivudine (oral) can be administered alone or together; however, they are often most effective as a combination therapy. Lamivudine can require a long or indefinite period of treatment, which can result in a higher risk of resistance over time. Nevertheless, there are fewer side effects associated with this drug's use as compared with interferon.

Adefovir (oral) also requires a prolonged treatment period, but the drug may not be as effective as lamivudine; moreover, a small number of cases of renal toxicity have been reported with adefovir. Still, adefovir is effective in the treatment of lamivudine-resistant HBV.

In the US, recent treatments include pegylated interferon, which appears to be more effective than alpha interferon. Three newer NRTIs presently under investigation include emtricitabine (FTC), tenofovir, and entecavir. The latter drug only has study results for a six month period. Emtricitabine appears to provide good viral suppression at one year. Tenofovir appears to be an excellent treatment option, demonstrating HBV suppression among HIV-positive persons, and is an effective treatment alternative for lamivudine-resistance; however, no data is available beyond six months.

Combinations of nucleoside analogues (similar to highly active antiretroviral therapies) are also under investigation. Consult with your doctor to determine which option is the best course of treatment for you. ⊕



R. Paul Kerston is a researcher with the BCPWA Society's Treatment Information Program.

Show me where it hurts

The pain of dealing with chronic pain

by Derek Thaczuk

Dr. Zachary Smith, the famous campy villain of *Lost in Space*, made sure everyone for light years around knew about his pain. Who hasn't heard that tragic interstellar whine: "Oh... the pain... the pain of it all!"

Here on Earth, the medical community is acknowledging that, unlike Dr. Smith, chronic pain all too often goes unrecognized and untreated. The *Southern Medical Journal* has stated, "Despite its prevalence, chronic pain remains one of the most poorly understood and untreated conditions in primary care." Pain in HIV disease has been called "the best-kept secret in AIDS." One recent study found that a whopping 69 percent of PWAs interviewed suffered from constant pain that "moderately or severely" interfered with their daily living. Other studies have shown that pain is under-treated in as many as 85 percent of PWAs.

Figures like these seem hard to believe. How could matters come to such a painful pass? Unfortunately, reasons abound. The underlying cause of pain may be difficult to diagnose—and therefore, to treat. Treatments themselves may cause pain that is hard to distinguish from the pain due to disease. The most effective treatments, narcotics, are also the most problematic. Ultimately, pain is subjective and difficult to substantiate.

Those last two points form a fifth: patients and doctors can sometimes be at odds over what constitutes "adequate treatment."

Difficulties in diagnosis

Pain is your body's way of saying something's wrong. It's a built-in bodily alarm system, and it's there for a reason (for example, don't cook your tongue with boiling hot coffee). Tragically, though, for people with chronic medical problems, pain can be like an alarm bell that you can't shut off. The nerve signals keep pouring into the brain, producing ongoing—and useless—pain.

The best way to deal with pain is to fix the cause, except that the cause may be hard to find. And ironically, while many AIDS-related conditions can be painful, so can the measures needed to treat them. For example, HIV itself can cause the nerve damage of neuropathy, but many antiretrovirals can also be the culprit. The usual suspects for drug-induced neuropathy are the d-drugs: d4T (Zerit), ddI (Videx) and the rarely prescribed ddC (Hivid). However, other AIDS medications can sometimes pack a sting as well. Painful myopathy (muscle pain), headaches, and joint pain also crop up frequently in people with HIV.

The point is, make sure you've looked 'til you've found the right

cause. Simply masking pain with painkillers may cause the underlying damage to continue. It's crucial to make sure that diagnoses are correct—the underlying problem may be serious. A PWA went from one physiotherapist to another before a doctor finally diagnosed the lymphoma that was causing pressure on his nerves.

After the "show me where it hurts" step, the next question is, how much? Gauging the degree or severity of pain is a peculiar problem. Many other medical problems can be definitively diagnosed and measured with microscopes and lab tests, but pain is notoriously subjective. Nobody feels your pain but you. Even in this world of high-tech MRI scanners, imaging, and diagnostic devices, the only way someone can measure your pain is to ask you. This can be frustrating if you're not sure they believe your answer. Plus, pain can be hard to describe. As American writer Naomi Wolf says: "Pain is real when you get other people to believe in it. If no one believes in it but you, your pain is madness or hysteria."

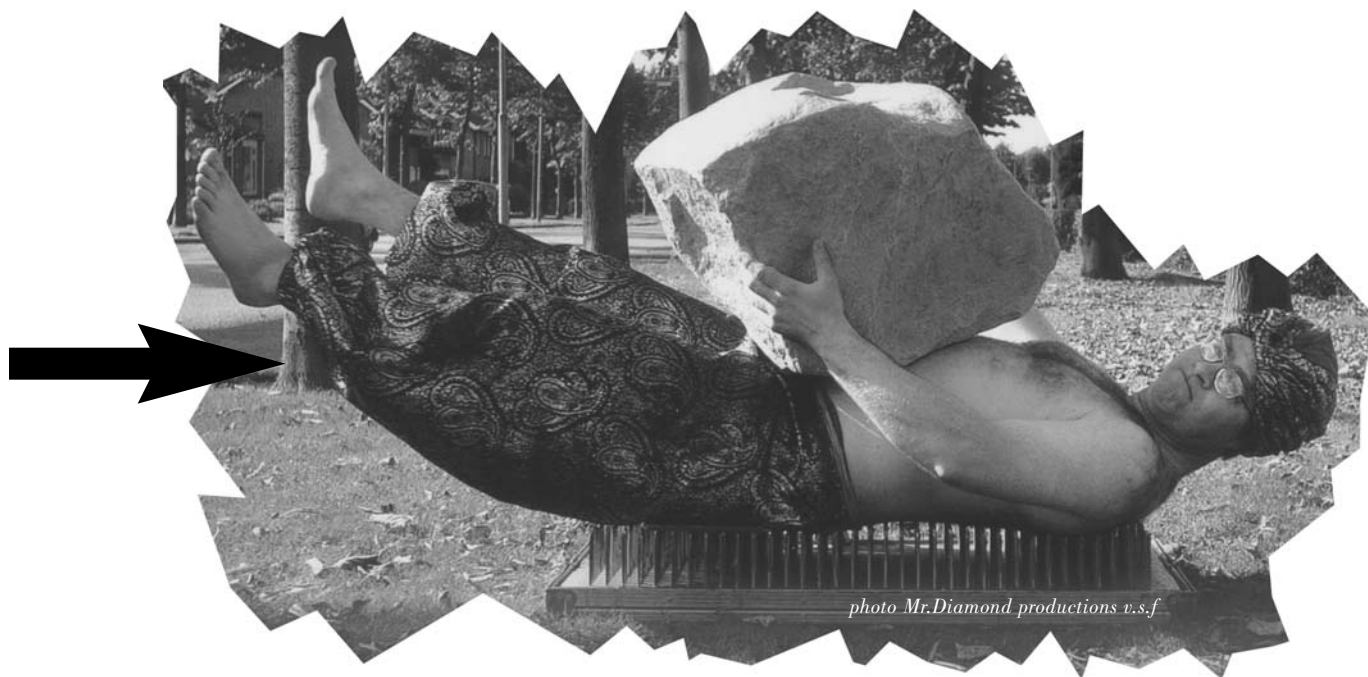
Treating pain

Medications that dampen or deaden pain are called analgesics, or painkillers. Different types are aimed at different intensities of pain. The most effective painkillers are opiates, or narcotics, which also happen to be highly addictive, often physically dangerous, and controlled by law. Therefore, the medical standards for treating chronic pain follow the World Health Organization's "analgesic ladder" or "stepped-care strategy," which starts small, and hauls out the bigger guns only as necessary.

When you open wide and say "ouch," your doctor is obligated to try non-narcotic medications first: acetaminophen (Tylenol) and the so-called nonsteroidal anti-inflammatory drugs (NSAIDs) such as aspirin, naproxen (Aleve; Anaprox), and ibuprofen (Advil; Motrin). Adjuvant or "helper" drugs may also play a role; for example, antidepressants such as amitriptyline (Elavil; Endep) are often prescribed for neuropathic pain.

If this kid stuff doesn't cut it, step two consists of mild-to-moderate opiates—codeine, hydrocodone (Vicodin and others), and oxycodone (Percocet, Percodan, and others)—alone or in combination with the step one drugs.

Truly severe pain requires the strongest opiates: hydromorphone (Dilaudid), fentanyl patches (Duragesic), and meperidine (Demerol). The various strengths or steps also depend on dosage and combination, and a doctor's judgment will depend on the individual situation. As long as you feel your pain is being controlled and the



doctor doesn't feel that he or she is being pushed to over-prescribe, everyone should be happy—so to speak. But when your doctor's notion of what's best is at odds with your own, problems can arise.

Why on earth would a doctor *not* want to help ease a patient's pain? It's not that they don't, according to Sally Simpson, a registered nurse who has 15 years experience in HIV/AIDS care; the issue is more about trust. "Doctors want to support their patients," she says. "They want a therapeutic relationship that gets the patient what they need. But the reality is that narcotic misuse does happen, which puts pressure on the physicians."

That pressure can cost them their jobs. If doctors are found to have prescribed narcotics too freely or inappropriately, they can lose the right to prescribe narcotics, or their job, or even their medical licence.

Doctors' fear of overprescribing

So, doctors have reason to watch their step. Unfortunately, this can sometimes lead to excessive reluctance to prescribe pain medication.

In a Medscape "Ask the Experts" on-line column on how much pain medication to give patients, physician assistant Blaine Carmichael says that the most common cause of patients' escalating pain complaints is disease progression, not tolerance to pain medications. Pseudo-addiction is caused when inadequate analgesic medication is prescribed; patients will stop wanting more drugs once they receive adequate medication dosages. In cases of true addiction, the drug-seeking behaviour continues to escalate.

"The difference between tolerance, physical dependence, and addiction is frequently misunderstood," Carmichael says. "The belief that the use of opioids for pain relief causes addiction is a common clinical misconception that is a significant barrier to good pain management."

Carmichael describes an all too familiar scenario where patients receive inadequate pain management. They then develop feelings of anger and isolation, which can cause them to act out. Clinicians may get frustrated by their inability to

control the patient's complaint of pain, followed by fears of inducing tolerance and dependence. "Over time, clinicians may seek to avoid contact with the patient as a means of reducing the source of conflict," he says. "Both cycles continually interact until a crisis based on mistrust results."

To avoid this downward spiral, it's best not to let it begin. Nurse Sally Simpson says you need to establish a trusting relationship. "The doctor is going to have a perception of what patients require, and patients are going to have their own perceptions." There can be a disconnect between those two, she says, so it requires planning and understanding from both the doctor and patient.

This need for planning is never more apparent than when a patient sees a doctor for the first time. "The best practical advice is, do not go to a new physician on day zero when you've just run out of pain medication," Simpson says. "Leave some room for the doc to do the work that they need to do—to explore your history with your previous doc, find out what has worked for you, transfer records, whatever. If you can provide any medical evidence or any other healthcare workers to vouch for you, so much the better. But try to plan ahead." ⊕

RESOURCES:

- ▼ Canadian Pain Society <www.canadianpainsociety.ca>
- ▼ International Association for the Study of Pain <www.iasp-pain.org>
- ▼ <www.pain.org>
- ▼ "Pain, Killer Pain" POZ magazine, June 2002

After eight years with the Toronto PWA Foundation, Derek Thacuk is launching a solo career as a medical and science writer. He can be reached at <www.readablewriting.ca>.





When the immune system runs amok

Understanding autoimmune diseases

by Michael Connidis

We coexist with an abundance of other life forms. Inside and out, our bodies are home to many other organisms. Too small to see with the naked eye, they are called microbes. Some microbes are necessary to our continued health, while others need to be kept in check before they cause disease. We are also constantly assailed by foreign matter in both the air we breathe and what we put into our bodies. We need some of these foreign materials to sustain ourselves; others can be harmful.

To protect us from this onslaught, our bodies have several lines of defense. The first barriers are the external and internal membranes of our bodies, such as our skin and the linings of our digestive and respiratory systems. Secretions coating these membranes trap foreign particles and contain enzymes that kill microbes before they penetrate our bodies. When any of these membranes are damaged, or when the secretions that cover them are depleted, our bodies are vulnerable to infection.

When microbes and harmful foreign matter infiltrate the membranes of our body, our immune system defends us. Cells and biomolecules circulating in our blood and lymph fluids—concentrated in tissues of the thymus gland, spleen, lymph nodes, and bone marrow—continually watch for invaders. The immune system is able to distinguish between self (the body it is protecting) and non-self (anything foreign and potentially harmful) because of the distinct surface structures of cells that the immune system recognizes.

Three types of immune disorders

As microbes or foreign materials enter our body, they are recognized as alien due to their different surface structures. The immune system launches a highly coordinated attack to eliminate these aliens. If the immune system repeatedly fails to defend the body, this is likely a sign that a person has an immune disorder. There are three forms of immune disorders: allergies, immunodeficiencies, and autoimmune disorders.

Some people's immune systems respond unnecessarily and excessively to essentially harmless foreign materials identified as "non-self". They may react to certain foods or to substances that have no potential for causing disease, such as pollen. This constitutes an allergic reaction, which presents as a mild chronic nuisance for some during hay fever season, or a severe and life-threatening crisis for others during an anaphylactic reaction.

The immune system can also underperform and ineffectively defend our bodies, a condition referred to as immunodeficiency. This response can be age related. As children, our immune systems have not fully developed and we are more susceptible to infections, which will ultimately build and strengthen our immune systems. However, as we age, so does the immune system, and its capacity to protect us diminishes along with our physical vigour.

There are many other causes of immunodeficiency. People may suffer from immunodeficiency when they take immunosuppressing drugs to prevent rejection of transplanted organs,

or when their immune system is damaged due to chemotherapy. The human immunodeficiency virus (HIV) attacks specific cells of the immune system, progressively destroying it; antiretroviral therapy slows this relentless process.

The wide range of autoimmune disorders

The third form of immune disorder occurs in a wide variety of ailments collectively called autoimmune disorders. Here, the immune system attacks specific cells, tissues, or organs in the body, or even multiple tissues and organs. Any and all tissues and organs can be affected by autoimmune disorders.

The signs and symptoms of autoimmune disorders vary depending upon the particular disease or illness and the parts of the body involved. While fever is the most common symptom, inflammation and tissue damage resulting from autoimmune disorders may cause mild to severe responses, including chronic pain, joint deformity, weakness, fatigue, skin irritation, skin disfiguring, respiratory problems, jaundice, delirium, and death.

People living with HIV/AIDS may be at a greater risk for developing autoimmune disorders.

The long list of autoimmune disorders includes rheumatoid arthritis (RA), multiple sclerosis (MS), amyotrophic lateral sclerosis (ALS), Huntington's chorea, Crohn's disease, fibromyalgia, chronic fatigue syndrome, type 1 diabetes, and psoriasis. Some lesser-known autoimmune disorders are lupus, Gulf War illness, Sjogren's syndrome, and vitiligo. Some of these illnesses are rather benign, while others are progressively degenerative and debilitating; some others are fatal.

The cause of autoimmune disorders remains elusive. Some appear to be inherited, as in Huntington's chorea, which runs in families through a dominant gene sequence located on the fourth chromosome. In other cases, heredity may contribute to a person's susceptibility to developing a disorder, as with psoriasis and vitiligo. Extreme psychological, emotional, or physical trauma may also cause changes in the immune response that result in an autoimmune disorder. Some diseases are more common in women, indicating that hormonal levels may be a factor.

Cells that control the immune response may behave in abnormal ways and begin to produce antibodies to cells in the body. This occurs when a foreign substance that enters the body is similar to a natural substance in the body. When the immune system identifies and attacks the foreign substance, it also destroys the natural substance. Chemicals, radiation, and sunlight stimulate this type of response by altering normal tissues. Chronic infection with particular strains of mycoplasmas and other microbes such as Chlamydia, has been closely correlated with autoimmune diseases.

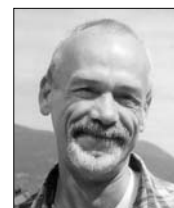
Causes for concern among PWAs

People living with HIV/AIDS may be at a greater risk for developing autoimmune disorders. If research continues to support theories relating chronic infections as causative agents or co-factors, then immunodeficiency could increase the risk of certain autoimmune disorders. Some PWAs have symptoms similar to diseases like lupus, RA, psoriasis, and Sjogren's syndrome. However, there is limited data on the relative incidence of autoimmune diseases among PWAs and the general population. Interestingly, reports of a decrease in symptoms of RA and Crohn's disease among some HIV-positive individuals suggest a weakened immune system suppressing the autoimmune response.

New and enhanced scientific technologies that have advanced research in HIV/AIDS are also being applied to the field of autoimmune disorders. One technology, polymerase chain reaction (PCR), amplifies small amounts of DNA, enabling researchers to identify previously undetectable microbes, such as species of mycoplasmas. A significantly higher incidence of these mycoplasmas was observed in people with some autoimmune diseases. These same species have also been found in blood samples of people with HIV/AIDS. Some mycoplasma species have been implicated as co-factors in HIV infection and disease progression. These theories and supporting research remain controversial; further research is needed.

People living with chronic diseases such as autoimmune disorders and/or HIV/AIDS suffer from nutritional and vitamin deficiencies. Typically, they have depleted levels of vitamins B, C, and E, as well as minerals such as zinc. This deficiency is often due to poor absorption caused by the disease itself and/or the side effects of medications. Taking higher supplementary doses of these vitamins and minerals is recommended. When antibiotics are used to treat symptoms or other infections, an imbalance or depletion of intestinal bacteria often occurs, which allows undesirable and potentially harmful species to flourish. Dietary supplementation with Lactobacillus acidophilus is advised. Other complementary and alternative medicines can also help to maintain the balance of beneficial microbes in our bodies and support the immune system.

Living with chronic illness is a huge challenge. Take care of yourself by eating well, supplementing your diet in a balanced and informed way, maintaining an adequate level of activity, sleeping well, and minimizing stress. Play safe to avoid other common infections that could further compromise your health and complicate your illness. Most important, seek out and embrace the love and support of those who care about you and your good health. ☺



Michael Connidis is a member of the BCPWA Society and a volunteer researcher and writer for Living+ magazine.

Eat right, gain right

Nutrition issues in regaining lost weight

by Kristen Yarker

While millions of North Americans may dream of losing weight, for PWAs weight loss is often unintentional and scary. Nutrition obviously plays a key role in regaining lost weight, but, nutrition is not the sole performer.

First, you need to determine the reason for the weight loss. Is the cause associated with an opportunistic infection, a medication side effect such as diarrhea or loss of appetite, or a symptom of disease progression? Once you identify and treat the underlying cause, you can focus on regaining weight. I recommend seeing a dietitian, if possible, as he or she can work with you to design a plan that is suited to your unique medical needs.

Weight gain is not just about piling on the carbohydrates or making Krispy Kreme your new home. The trick is to regain healthy weight without triggering other health problems such as high cholesterol and high blood sugar.

In addition to energy or calories, you also need protein, vitamins, minerals, and many other nutrients found in food when

you gain weight. The body needs energy and building blocks such as protein and fat to rebuild itself. Vitamins and minerals are often involved in this rebuilding process—they function like construction workers facilitating the necessary tasks—but a handful of vitamin pills will never supply this workforce the way that food can. That said, a multivitamin is generally recommended. A dietitian can identify whether or not you require any additional vitamins or minerals.

Healthy eating is the key to ensuring that you have all the nutrition you need to rebuild the body. A balanced diet requires eating from the four food groups: vegetables and fruit; protein foods; starch foods; and calcium foods. Throw low fat and diet foods out the window. Eat foods from the four groups with hearty helpings of oil, butter, or non-hydrogenated margarine.

Eating regular meals and snacking throughout the day will help you get the extra calories needed to rebuild the body.. Think of snacks not as a time for junk food, but as an opportunity for healthy eat-

ing. Plan meals and snacks that include items from three or four of the food groups (see Table 1 for ideas). Take advantage of opportunities for passive eating, such as watching TV or running errands.





Physical activity can play a role in rebuilding muscles. However, I make this recommendation with great caution. Speak to your doctor before you start any exercise activity. Your doctor is in the best position to make individualized recommendations about exercise, based on your current strength and weakness, and in consideration of the cause of the weight loss.

Healthy weight gain takes time. You will feel frustration at times. Think of it as a fantastic opportunity to work on the virtues of perseverance and patience. ⊕

Kristen Yarker, BSc, MSc, RDN, is a nutritionist/dietitian working with the ADAPT (Aboriginal Diabetes Awareness, Prevention, and Teaching) Program at Vancouver Native Health Society.



Table 1. Snacking on the four food groups

	Vegetables and Fruit	✦ Eat veggies with dip or fruit with full-fat yogurt.
	Starch	✦ Choose whole grains: whole wheat bread or rye and crackers such as Ryvita or Wasa.
	Protein	✦ Nuts, cheese, peanut or other nut butters, soybeans, nuts, and hardboiled eggs are great for snacking. ✦ Make dips like hummus from beans and lentils. ✦ Pack meat or fish sandwiches. Keep them refrigerated for food safety. ✦ Protein powders, Ensure and Boost-type drinks, and protein bars are handy but not magical. See Issue 28 (Jan/Feb 2004) of <i>Living +</i> for alternative ideas.
	Calcium foods	✦ Full-fat yogurt, milkshakes, fruit smoothies, plain or chocolate soy or dairy milk are good snacks. Remember to keep them refrigerated for food safety.

Ask the dietitian

If you have a diet or nutrition question, email it to dietitian@bcpwa.org or mail it to *Living +*, BCPWA Society, 1107 Seymour Street, 2nd Floor, Vancouver, BC V6B 5S8.

Weighing in on supplements

by Jennifer Hrushkin

Question:

I work as a prison nurse and clients often ask me about supplements. Some HIV-positive clients receive nutritional supplements such as Ensure and Boost. Many clients believe they are underweight and undernourished, when in fact they often exceed a healthy body mass index (BMI). Are these persons doing themselves a disservice by supplementing excessively with additional sources of protein supplements and meal replacement drinks? Are there guidelines for the use of nutritional supplements for PWAs? J.S.

Answer:

When deciding if supplements are appropriate, remember that no two people are the same, even if diagnosed with the same condition. Calorie and protein needs vary depending on exercise level, age, body weight, muscle mass, and health condition. In general, PWAs have higher calorie, protein, and micronutrient needs than someone without HIV. Visit the Therapeutic Guidelines section of the BC Centre for Excellence website at www.cfenet.ubc.ca/guide/open.html for more information about nutritional guidelines. Bear in mind these are only guidelines, and nutritional needs vary from person to person.

Calorie/protein needs tend to vary depending on the goal. People require fewer calories to maintain weight than they do to gain weight. Ideally, the goal is to maintain muscle mass, or increase it if

there is muscle mass deficiency, so that the individual has a healthy weight with a BMI of 20 to 25. When a person gains weight, they require adequate protein and exercise to ensure that they are gaining muscle and not just fat.

If a person's weight is above their healthy range but the excess weight consists mainly of muscle, this is not a health concern. Muscle is more metabolically active than fat, so this individual will have higher calorie/protein need than someone whose excess weight is comprised mainly of fat.

If a person's excess weight is caused by fat, particularly around the abdomen, there is a higher risk of diabetes and heart disease. In this situation, if the person is maintaining or gaining weight, there is no need for supplements which could lead to continued weight gain and higher health risk. Combined with highly active antiretroviral therapy (HAART), weight gain introduces the added risk of dyslipidemia (disorders of lipoprotein metabolism) and high glucose levels. Diets containing far more protein than necessary can be detrimental to bone and kidney health.

It is also important to assess eating habits. Do PWAs in prison receive more calories and protein than their HIV-negative counterparts do? Can an inmate maintain a healthy body weight with food alone? If huge volumes of food are required to maintain or gain weight and

the person is not physically able to eat very much, supplements can be effective by condensing calories into a smaller volume. If an individual has a poor appetite, supplements can be very helpful. However, if a person's nutritional needs are met by eating regular food (without experiencing nausea, vomiting, diarrhea, or a sore mouth), there is no need to supplement with meal replacements.

Do prisoners receive vitamin or mineral supplements? If they meet their protein needs through regular food and they receive adequate vitamins and minerals, there would be no need for supplements unless there was some other specific need, as mentioned above.

Overall, nutrition plays a very important role in the health of people with HIV/AIDS. Inadequate intake can lead to malnutrition, which can decrease immune function. PWAs should get regular assessments from a dietitian. HIV-positive inmates should discuss nutritional issues and supplements with the dietitian at the facility. ⊕

Jennifer Hrushkin, RD, is a member of the Vancouver Dietitians in AIDS Care and is a dietitian in Ward 10C and the Infectious Diseases Clinic at St. Paul's Hospital in Vancouver.



The price ain't right

Summary of Legal Network discussion paper on drug pricing in Canada

by Richard Elliott

*In July 2004, the Canadian HIV/AIDS Legal Network published a report, *Controlling Drug Costs for People Living with HIV/AIDS: Federal Regulation of Pharmaceutical Prices in Canada*. The following is an abbreviated version of the Executive Summary.*

Controlling Drug Costs for People Living with HIV/AIDS is the second paper in a series developed by the Canadian HIV/AIDS Legal Network on legal and ethical issues related to HIV/AIDS care, treatment, and support. The issue of drug pricing, identified as a priority by a project advisory committee, supports existing advocacy efforts by other AIDS organizations in Canada. The question of pharmaceutical prices is also receiving considerable international attention. The cost of medicines is an obvious concern to people living with HIV/AIDS. An analysis of federal policy on drug price controls, with recommendations for improving or reforming policy where appropriate, can help protect the interests of PWAs and Canadians generally, in accessing affordable health care.

There are many factors that affect Canadian drug prices—whether someone is paying for medicines or enjoying full or partial coverage through public and/or private insurance plans. These factors include the behaviour of drug manufacturers, patients, and prescribers, as well as the actions of drug wholesalers, retailers, and pharmacists. Similarly, the laws, regulations, and policies implemented by the federal and provincial governments and various regulatory bodies, as well as measures implemented by private insurance companies to control drug claims, all have an impact. The paper focuses on the specific question of how federal legislation regulates the prices charged by manufacturers for their medicines.

The paper:

- ▼ highlights the impact of policy on pharmaceutical pricing, given increasing costs and spending on medicines as part of overall healthcare expenses in Canada.
- ▼ identifies recent and important developments that inform current debates in Canada over regulating drug prices.
- ▼ outlines current federal law and policy on the regulation of pharmaceutical manufacturers' prices.

- ▼ makes recommendations for federal regulation reform of pharmaceutical prices in Canada.

The paper presents a number of recommendations regarding Canada's policy approach to regulating the price of medicines in Canada. The recommendations are as follows:

Remedies for excessive pricing

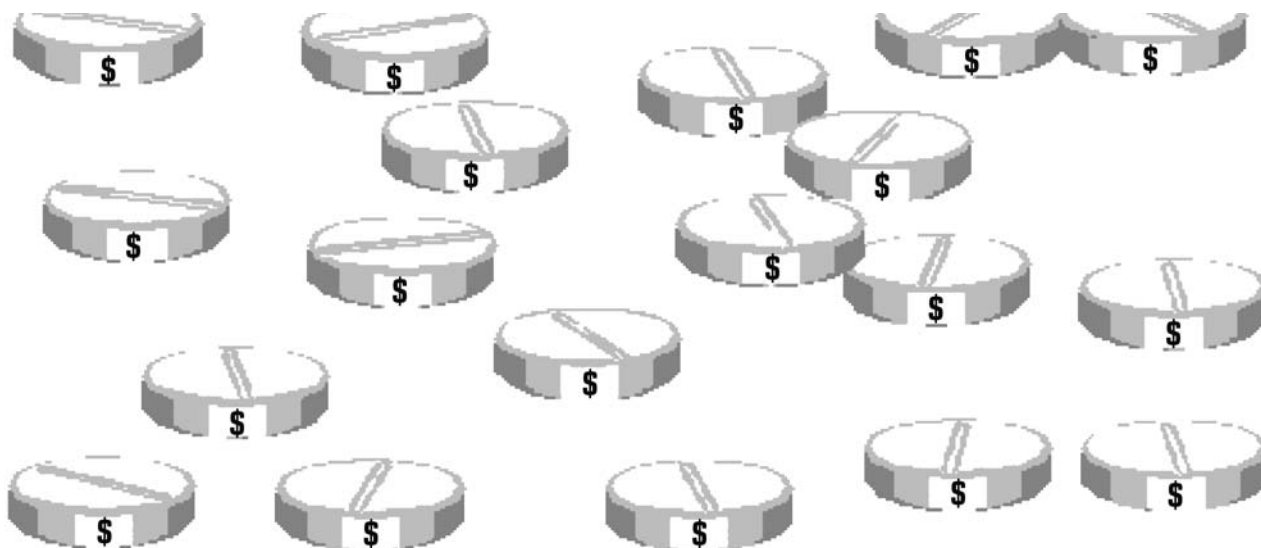
Parliament should:

- ▼ consider methods for compensating private or individual purchasers of medicines for prices determined to be excessive by the Patented Medicine Prices Review Board (PMPRB).
- ▼ amend the Patent Act (section 83) authorizing the PMPRB or, the Commissioner of Patents to issue a compulsory licence as a remedy for excessive pricing by manufacturers of patented medicines.

Price guidelines

The Patented Medicine Prices Review Board should:

- ▼ apply its revised definition of the "value" of drugs to the pricing of Category 2 new drug products (breakthrough drugs).
- ▼ revise its Excessive Price Guidelines to limit the introductory price in Canada for Category 3 new drug products (those that offer moderate, little, or no therapeutic advantage over existing medicines) based on a specified formula relating to the cost of drugs in similar countries and/or the cost in Canada for drugs in the same therapeutic class. An additional price differentiation might be based on distinguishing between new drugs offering "little or no therapeutic advantage" and those offering "moderate" therapeutic advantage.
- ▼ review the appropriateness of using a retail price increase index to limit manufacturers' prices on patented medicines.
- ▼ explore, with the federal Departments of Health and Industry, options to amend the Patent Act, the Patented Medicines Regulations, and the Excessive Price Guidelines, so a closer correlation exists between Canadian price levels for patented medicines and Canadian expenditures by patentees on pharmaceutical research and development (R&D).
- ▼ review, in consultation with the public and consumers, the group of countries currently used for international pharma-



ceutical price comparisons. The review should also identify other potentially suitable countries. Based on the conclusions, the PMPRB should then consider recommending to the minister of health and the federal cabinet that the Patented Medicines Regulations be amended to include a revised list of countries used for international price comparisons.

- ▼ revise its Excessive Price Guidelines so that prices of patented medicines realistically reflect the cost of development and manufacture, as well as allow a “reasonable” profit margin.
- ▼ amend the Patent Act and/or the Patented Medicines Regulations to allow provisional pricing for newly released patented medicines; the price would be periodically reviewed to take into account new evidence of its therapeutic merits and its merits compared to similar or equivalent medicines.
- ▼ be given the authority to conduct periodic reviews of drug prices and adjust the maximum “non-excessive” price of a medicine upward or downward based on new evidence of a product’s therapeutic merit.

Jurisdiction to regulate medicine prices

Parliament should amend the Patent Act to:

- ▼ define and clarify the term “medicine” in order to prevent excessive pricing by manufacturers of any invention pertaining to a medicine.
- ▼ give the PMPRB the authority to regulate the prices of patented medical devices.
- ▼ give the PMPRB the authority to regulate the prices of medicines during the period of time when a patent is pending.

Other recommendations:

- ▼ Parliament should enact a national legislative scheme to regulate prices of generic medicines to prevent excessive pricing, complementing current guidelines related to patented medicines. The federal and provincial governments should collaborate in designing this plan to ensure that the program is consistently implemented and to draw upon lessons learned from provincial policies and price control measures pertaining to medicines.
- ▼ The PMPRB should have continued authority to regulate the prices of patented non-prescription medicines.

Spending on pharmaceutical R&D

Parliament should amend the Patent Act to:

- ▼ require manufacturers of non-patented medicines to report annually, to the PMPRB, all revenues from the direct or indirect sales of medicine in Canada, and all expenditures in Canada on R&D relating to medicine.
- ▼ create legally binding requirements for R&D spending in Canada by pharmaceutical patentees; offending patentees would be subject to an annual levy calculated on a formula which applies the ratio of R&D to sales. In addition, sales of all patented medicines should be subject to a levy, and revenues collected would be dedicated to funding research into “neglected diseases,” particularly those prevalent in developing countries.

Patentees’ reporting obligations

Federal government amendments to the Patented Medicines Regulations should require patentees to report annually to the PMPRB on the types of promotional activities carried out as well as related expenditures.

A draft of the paper was sent to several people from government, industry, and the community to provide comments. The final paper will be sent to selected individuals and organizations working in the areas of HIV/AIDS and pharmaceutical policy in Canada, as well as to appropriate government policy makers, the PMPRB, consumer organizations, pharmaceutical industry associations, and other interested parties. These groups will also be asked for their comments and their views on how best to implement the recommendations.

Easy-to read information sheets, summarizing the federal regulation of pharmaceutical prices in Canada and the contents of the paper, will be prepared and circulated, making the report more accessible to a wider audience. ⊕

Copies of the paper can be obtained from the Canadian HIV/AIDS Legal Network at www.aidslaw.ca or through the Canadian HIV/AIDS Information Centre (tel: 613.725.3434, fax: 613.725.1205, email: aidssida@cpha.ca).

Richard Elliott is the director of legal policy and research for the Canadian HIV/AIDS Legal Network.



Bangkok bites

Abstracts on entry inhibitors presented at the XV International AIDS Conference

by Enrico Mandarino

Entry inhibitors work by preventing HIV from entering healthy CD4 cells in the body. They attach to proteins on the surface of CD4 cells or proteins on the surface of HIV.

In order for HIV to bind to CD4 cells, the proteins on HIV's outer coat must bind to the proteins on the surface of CD4 cells. Entry inhibitors prevent this from happening. Some entry inhibitors target certain proteins (gp120 or gp41) on HIV's surface. Other entry inhibitors target the CD4 protein or specific receptors (CCR5 or CXCR4) on a CD4 cell's surface. If entry inhibitors are successful in blocking these proteins, HIV is unable to bind to the surface of CD4 cells and gain entry into the cells.

Oral fusion inhibitor

Only one entry inhibitor has been approved, T-20 (Fuzeon). This drug targets the gp41 protein on HIV's surface to prevent the virus from binding to the CD4 cell. Researchers identified small molecules that bind to gp-41 proteins and inhibit membrane fusion, just as T-20 does. The disadvantages of this drug are that it is costly to produce and must be injected. These compounds will hopefully lead to the development of other fusion inhibitors which can be taken orally and which are less expensive to manufacture than T-20.

Co-receptor inhibitors

Three abstracts were presented on UK-427,857, a CCR5 antagonist which blocks this specific co-receptor on the CD4 cell. Phase III studies involving hundreds of treatment naïve and experienced patients are about to start. Recent data shows that a once-daily dose of this compound produces a 10 to 100 fold fall in HIV blood levels after 10 days. UK-427,857 can be taken with or without food.

A novel CCR5 antagonist, 873140, exhibits potent anti-HIV activity in laboratory settings. It has a prolonged receptor occupancy and good oral bioavailability.

Among CD4 antagonists, NSC 13778 is a new class of small molecule HIV entry inhibitors that target the gp120 binding domain of the CD4 cells. The National Cancer Institute found a small molecule that competes with the HIV gp120 for CD4 cell binding. Presumably, it blocks the interaction of gp120 and the CD4 receptor.

Maturation inhibitors

PA-457 is the first in a new class of antiretrovirals that inhibit HIV replication by disrupting virus maturation. Specifically, PA-457 disrupts the conversion of the Gag Capsid (CA) precursor protein p25 to mature CA protein, p24. PA-457's mechanism of action is distinct from that of protease inhibitors in that it targets the Gag precursor protein rather than the viral protease enzyme that is responsible for Gag processing.

Phase I study data suggest that PA-457 will not exhibit significant drug interactions when used in combination with other HIV drugs. PA-457 exhibits good oral bioavailability and a long half-life in rats and marmosets, and moderate oral bioavailability in mice and dogs.

New targets

In a symposium on identifying new targets for novel HIV therapies, identification of new targets for inhibition of HIV replication were discussed.

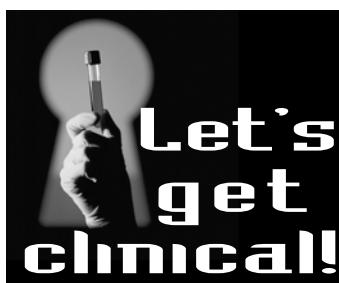
There are five HIV-1 accessory proteins (tat, rev, nef, vif, and vpr) that could be targeted to inhibit HIV replication. These targets are more difficult to inhibit with small molecules, since as their function involves protein – protein interactions or protein – nucleic acid interaction. Currently, T-20 targets a non-enzymatic protein – protein interaction.

There are 37 known host proteins involved in HIV-1 replication and there are likely many more that have not yet been discovered. Molecules that bind to CCR5 or CXCR4 and inhibit HIV-1 binding are good examples of feasible host targets.

Endogenous inhibitors of retroviral replication such as TRIM5-alpha (REF-1) and APOBEC 3G may also give us clues how we can develop new inhibitor of HIV replication. ⊕



Enrico Mandarino is secretary of the board of the Canadian AIDS Society and a board member of the Canadian Treatment Action Council. He was also a member of the Scientific Committee Track A: Basic Science for the XV International AIDS Conference.



Rescue therapy trial deemed safe and relevant

by Jim Boothroyd

A major clinical trial that compares methods of treating people with advanced HIV disease, who are no longer benefitting from conventional antiretroviral therapy, has been declared safe and of continued clinical relevance by an independent, international data safety monitoring board.

The board's verdict was announced at meetings in Washington, DC in October, after a closed interim analysis of results from the trial known as Options with Antiretrovirals (OPTIMA or CTN 167).

OPTIMA was designed and developed by Dr. William Cameron, an Ottawa-based infectious diseases specialist. The international study is funded by the Canadian Institutes of Health Research, the Medical Research Council in the UK, and the Veterans Administration in the US. It began enrolling in June 2001 and aims to enroll 504 participants in the three countries.

The randomized, controlled trial compares the effect of different management strategies on survival, time to AIDS or other serious health problems, virologic and immunologic response, quality-of-life measures, and other health outcomes during an average of two years of follow-up.

Participants are allocated randomly to one of four treatment groups: mega-antiretroviral therapy (five or more anti-HIV drugs) or standard-ART (up to four anti-HIV drugs), with or without a three-month antiretroviral drug-free period (structured treatment interruption) before re-treatment.

Among other criteria, eligible participants must have experienced failure with at least two different multi-drug regimens containing drugs in each of three classes that the patient can tolerate.

There has been controversy about interrupting anti-HIV treatment in this setting—even temporarily—since clinical opinion is divided. The few clinical trials that have been conducted on treatment interruptions before so-called salvage, or rescue, therapy have generated mixed results.

Some studies suggest that interrupting therapy can improve a patient's subsequent response to treatment; other research shows that, in the absence of good preventative treatments for PCP or thrush, these infections may increase in severity. However, these studies have differed significantly. Previous studies have recruited people at various stages of HIV, and have looked at people with different drug resistance profiles. In addition, the studies have offered treatment interruptions of different durations as well as re-treatments of various intensities.

Many questions remain. The OPTIMA study, which is already the largest trial of this type, is large enough to address these questions.

See list of sites below. ⊕



Jim Boothroyd 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 (IDC) and St. Paul's Hospital, Vancouver

CTN 167 — OPTIMA: Options with Antiretrovirals
BC sites: Viron Health, Downtown IDC, and St. Paul's Hospital, Vancouver, and Cool Aid Community Health Centre, Victoria

CTN 169 — DAVE: d4T or Abacavir plus Vitamin Enhancement
BC site: St. Paul's Hospital, Vancouver

CTN 178 — Rosiglitazone maleate (Avandia)
BC site: St. Paul's Hospital, Vancouver

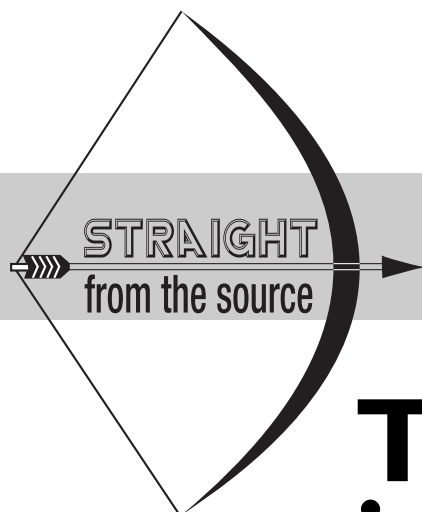
CTN 183 — Continuous versus Intermittent Treatment
BC site: St. Paul's Hospital, Vancouver

CTN 189 — 3TC or No 3TC for HIV with 3TC Resistance
BC site: St. Paul's Hospital, Vancouver, and Cool Aid Community Health Centre, Victoria

CTN 190 — Strategies for Management of Antiretroviral Therapy (SMART) BC site: Downtown IDC, Vancouver

CTN P 201 — Interactions between TMC-125 and Lopinavir/Ritonavir and Saquinavir
BC site: St. Paul's Hospital.

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.



what's new in research

The art of ART in co-infection

Special considerations for antiretroviral therapy among people with HIV and hepatitis C

by Paula Braitstein

The following article is a summary of Paula Braitstein's PhD literature review. The full article will appear in a forthcoming issue of the international journal, AIDS.

Hepatitis C virus (HCV) is present, on average, in 25 to 30 percent of people living with HIV. However, in some groups—such as people who acquired HIV through injection drug use or via contaminated blood products—nearly all people who are HIV-positive will also be HCV-positive, because the virus is so infectious.

There are many questions about the use of antiretroviral therapy (ART) in people who are co-infected with HIV and HCV. When should they start ART? How will they respond—will they have more toxicity and more treatment interruptions? Since hepatitis C does its damage through the immune system (similar to HIV), what effect do immune suppression and immune reconstitution have on the progression of HCV disease? Here are some of the key findings from my literature review:

Response to ART

There is general agreement that HCV has little or no effect on the HIV virologic response to ART, meaning it makes no difference in the ability to achieve or maintain an undetectable viral load. However, there is no clear answer about immune response. Some studies show that HCV prevents people from having a full immune response to ART, while others show no effect. BC data indicates that people with HCV will have a poorer CD4 response to treatment. Why different studies have reached different conclusions isn't clear, although varying results may be due to inconsistencies in how immune response is defined.

There has also been some research on the effect of HCV on treatment interruptions and switching due to liver-related side

effects. In general, HCV-positive people have more liver-related side effects, and are more likely to have toxicity-related treatment discontinuations. Quite a few studies reveal that injection drug users (IDUs) will be less likely to adhere to antiretroviral treatment; unfortunately, none of the studies examine the effect of HCV on adherence to ART. Given the fact that all those IDUs are co-infected with HIV and HCV, these studies need to take a second look at various possible explanations for this group's difficulty with treatment adherence.

Side effects and toxicity

HIV drugs are associated with a variety of negative side effects, including metabolic changes and mitochondrial toxicity. Both of these metabolic and mitochondrial issues stem from the liver and liver function, and are often deemed liver toxicity. So, it's no surprise that HCV is also strongly associated with metabolic diseases and mitochondrial toxicity. For example, the small amounts of data available suggest that people co-infected with HIV and HCV are at double the risk of developing diabetes. See Figure 1 for an illustration of how HCV infection and ART toxicity may overlap. In addition, there is fairly strong consensus that co-infected people are two to three times more likely to develop elevated liver enzymes; these people may also be more likely to experience the symptoms associated with elevated liver enzymes, including malaise, nausea, vomiting, fever, and jaundice.

Interestingly, a number of studies consistently show that people who are HIV and HCV co-infected may have more favourable cholesterol, HDL, LDL, and triglycerides profiles. It's not clear why this is the case, but it may be the result of impaired synthesis of cholesterol in the liver.

Certain drug combinations are not recommended for people with HIV and HCV. Where possible, nevirapine and ritonavir

should not be considered as a treatment option for co-infected people. Low-dose ritonavir has not been well studied, and existing data are conflicting, so it should be avoided as well. It's already known that ddI and ribavirin (a treatment for HCV) should definitely not be taken together. Any drugs that cause mitochondrial toxicity (AZT, ddI, d4T) should also be avoided, if possible.

Immune function and liver disease

The relationship between immune function and liver disease is very complicated, and not well described in the literature. With or without antiretrovirals, a low CD4 cell count is strongly associated with the progression of liver disease. Two studies show that even a CD4 count below 500 cells/mm³ is associated with faster liver fibrosis, even in people without HIV. There is virtually no debate in the literature on the effect of immune suppression and liver disease progression: HCV progresses at about two to three times faster in people with HIV. Hepatitis C is considered an opportunistic infection in the US.

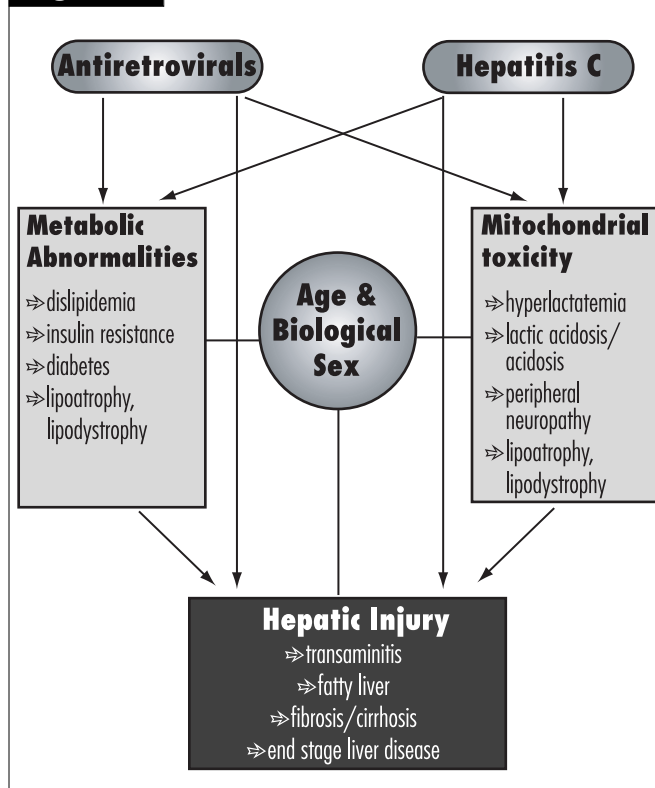
A few studies have shown that antiretrovirals have a positive effect on liver disease. Unfortunately, these studies haven't been very well executed, so the findings are difficult to confirm. However, it makes a lot of sense that preventing immune suppression will be good news for the liver. This opinion is partially explained by the fact that the hepatitis C virus is not believed to cause disease directly: it stimulates an immune response whereby, for example, the immune system destroys virally infected cells.

Liver fibrosis/cirrhosis, or liver scarring, is a wound healing response to ongoing liver injury. People with HIV have higher HCV viral loads than HIV-negative people, and these levels go up even further when antiretroviral therapy is initiated. This increase in HCV viral loads may be because of the dual immune dysregulation from infection with both HIV and HCV.

The issue of immune restoration is particularly interesting. There have been a few case reports of HIV co-infected people spontaneously clearing HCV upon starting ART. It has been suggested that this immune response might be most likely to occur when individuals are relatively young. However, numerous case reports and case series indicate that immune reconstitution actually kick-started HCV-related fibrosis progression. These reports are primarily among individuals with low CD4 cell counts (less than 200 cells/mm³) at the time of initiating ART.

Given how HCV may do its damage, it is believed that redeveloping a functioning system can actually cause disease. There are other examples in HIV—for example, *Mycobacterium avium* complex (MAC)—of this kind of immune reconstitution and restoration syndrome. The ideal solution is probably to prevent immune suppression and prevent conditions that require making the immune system recover.

Figure 1.



Some recommendations in the full article include:

Before starting antiretrovirals:

- ▼ If possible, treat HCV even before signs or symptoms of HCV disease progression appear
- ▼ Genotype the HCV (associated with severe elevations in liver enzymes and the development of fatty liver)

When to start:

- ▼ Consider initiating ART at higher CD4 cell count levels

When starting:

- ▼ Avoid using ddI and d4T
- ▼ Closely monitor for signs or symptoms of lactic acidosis, particularly if you are female and/or older
- ▼ Avoid using AZT and ribavirin, or ddI and ribavirin together
- ▼ Avoid using nevirapine and full dose ritonavir
- ▼ Consider a baseline liver biopsy

After starting:

- ▼ Rely on a variety of markers to assess HCV disease progression
- ▼ Closely monitor for fatty liver, especially genotype 3
- ▼ Closely monitor for insulin resistance and diabetes
- ▼ Eat well and exercise ⊕



Paula Braitstein was the senior policy advisor on health promotion for the BCPWA Society.

VIH y su corazón

por José Gutiérrez

El conservar un corazón fuerte y sano es muy importante; muchas de las cosas que hacemos cotidianamente pueden afectarlo negativa o positivamente. Si bien el riesgo de enfermedad cardíaca es ligeramente mayor en las personas con VIH (Virus de Inmunodeficiencia Humana) que en personas sin VIH, la relación causa-efecto que existe entre los medicamentos anti-VIH y las enfermedades cardíacas está aún bajo discusión. Hasta el momento ha sido difícil determinar cuánto contribuyen los medicamentos anti-VIH al desarrollo de enfermedades cardiovasculares.

Los investigadores han identificado varios factores que incrementarían los riesgos de desarrollar una enfermedad cardíaca o ataque al corazón. Algunos factores, como la edad y el sexo, no pueden ser modificados, mientras que otros, como el hábito de fumar y la dieta, sí son modificables. Cuanto más factores de riesgo uno tenga, mayor es la posibilidad de padecer una enfermedad cardíaca o un ataque al corazón. En lo que respecta a los medicamentos anti-VIH, cuanto más tiempo los haya estado uno tomando, mayor es el riesgo de desarrollar enfermedades cardiovasculares.

Actualmente existe más preocupación sobre la calidad de vida de la gente que vive con VIH y sobre los efectos colaterales a largo plazo. El énfasis, en muchos casos, está puesto en disminuir aquellos factores de riesgo que son modificables. Algunos de los factores de riesgo que es posible modificar son: colesterol sanguíneo elevado, alta presión arterial, diabetes, hábito de fumar tabaco, estrés, inactividad física, consumo de alcohol, consumo de drogas recreacionales, sobrepeso y obesidad.

Colesterol sanguíneo elevado

Un nivel de colesterol elevado incrementa las probabilidades de desarrollar enfermedades cardíacas. El consumo de alimentos con alto contenido de grasa contribuye al aumento del colesterol y al aumento del peso corporal. El nivel de colesterol también se ve afectado por la edad, sexo y herencia (factores genéticos). Los médicos recomiendan realizar exámenes para medir los niveles de colesterol y conocer así la cantidad de grasa que la persona tiene en la sangre. Si su colesterol es superior a lo

normal, su médico intentará bajarlo, dependiendo de otras condiciones que uno padezca. La dieta es siempre el primer paso para disminuir el colesterol. Dietas ricas en frutas, vegetales y fibras pueden disminuir el riesgo de desarrollar enfermedades cardíacas. La actividad física también ayuda a disminuir los niveles de colesterol.

Alta presión arterial

Tener alta presión arterial incrementa la carga y el trabajo del corazón, causando que el corazón se engrose y sea más rígido. Esto puede conducir a un proceso conocido como falla cardíaca congestiva. También aumenta el riesgo de infarto, ataque al corazón y falla renal. Cuando usted tiene alta presión, está con serio sobrepeso, fuma, y además padece de altos niveles de colesterol o diabetes, el riesgo de ataque al corazón o infarto se multiplica.

Diabetes

La diabetes incrementa seriamente el riesgo de desarrollar enfermedades cardiovasculares, aún cuando la diabetes está controlada. Si su diabetes no está controlada, el riesgo es aún mayor. Alrededor de tres cuartos de las personas que tienen diabetes, morirá, eventualmente, de alguna forma de enfermedad cardíaca o vascular. Si usted tiene diabetes, es extremadamente importante que trabaje con su médico y un nutricionista para manejar la enfermedad y controlar cualquier otro factor de riesgo que pueda tener. Algunos medicamentos anti-VIH denominados inhibidores de la proteasa pueden causar resistencia a la insulina o empeorarla. Para mayor información sobre diabetes consulte a su médico. ⊕

BCPWA Treatment Information Program (TIP)

Ofrece información sobre tratamientos del VIH/SIDA.

Todos los miércoles 1:00PM a 5:00PM.

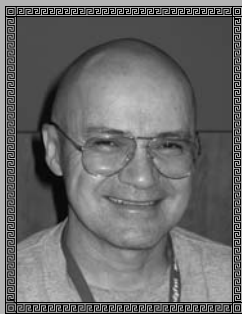
1107 Seymour Street, 2nd Floor, Vancouver, BC V6G 5S8

Llame a la línea directa: 604.893.2243

email: treatment@bcpwa.org

Volunteering at BCPWA

Profile of a volunteer:



What better way to be greeted on a cold winter day than by such a great smile and a sincere desire to help.

Jackie Haywood,
Director of Support Services

Don Poslowsky, Sr.

Volunteer history

I started volunteering in 1998 with the Community Awareness Group, then Alcoholics Anonymous in 2000, and finally a senior's group in 2001.

Started at BCPWA?

June 2004.

Why pick BCPWA?

I had attended the Prison Outreach Program in Agassiz, BC, and helped out with their AIDS Walk.

Why have you stayed?

The staff and volunteers are a special breed of people that are a pleasure to be around.

Rating BCPWA

I think BCPWA is a top notch place to volunteer. The people and the cause are both noble and that is why I enjoy this work.

Strongest point

That it feels right and fulfilling to help others as I have been helped by others.

Favourite memory

Helping out with the AIDS Walk in Agassiz. Although the Christmas Dinner for support volunteers was a close second!

Future vision of BCPWA

To become more involved with the Prison Outreach Program and to help in any way I can to ease or eradicate the challenging impacts of HIV/AIDS.



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 writer's 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.

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

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 Prince George

1–1563 2nd Ave,
Prince George, BC V2L 3B8
t 250.562.1172 f 250.562.3317
e ogodwin@bcgroup.net www.AIDSPG.ca

Living Positive Resource Centre Okanagan

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

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

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

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 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 groups, societies, programs and institutions in British Columbia serving people touched by HIV disease and AIDS, please visit the Resources section of the BCPWA Society website at www.bcpwa.org.

			Upcoming BCPWA Society Board Meetings:
Date	Time	Location	Reports to be presented
January 19, 2005	1:00 PM	Board Room	Written Executive Director Report — Standing Committees Director of Treatment Information & Advocacy
February 02, 2005	1:00 PM	Board Room	Quarterly Department Reports — Financial Statements / December Director of Prevention
February 16, 2005	1:00 PM	Board Room	Written Executive Director Report — Executive Committee
March 02, 2005	1:00 PM	Board Room	Standing Committees — Financial Statements / January Director of Support Services
March 16, 2005	1:00 PM	Board Room	Written Executive Director Report
The 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 to the right for the respective committee that you are interested in.

Board & Volunteer Development

Contact: Paul Adomako
t 604.646.5377 e paula@bcpwa.org

Community Representation & Engagement

Contact: Adriaan de Vries
t 604.893.2298 e adriaand@bcpwa.org

Education & Communications

Contact: Lisa Gallo
t 604.893.2209 e lisag@bcpwa.org

Positive Gathering

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

IT Committee

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

Living + Magazine Subcommittee

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

Prevention

Contact: Paul Adomako
t 604.893.2225 e paula@bcpwa.org

Support Services

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

Treatment Information & Advocacy

Contact: Tarel Quandt
t 604.893.2284 e tarelq@bcpwa.org

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☐ I am a PWA in BC and can not afford the full subscription price
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living+

1107 Seymour Street, 2nd Floor
Vancouver, BC
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Disharmony and misunderstanding

Waiting impatiently for the dawning of the Age of Aquarius

by Denise Becker

I always felt ripped off as a kid. You see, my birthday falls at the beginning of February. After the chaos of Christmas shopping, holiday entertaining, Boxing Day sales, and New Year's Eve parties, people have pretty much had it with gift giving and going out for dinner by February 8th, and they're saving their energy for Valentine's Day one week later.

I finally stopped feeling cheated around 1968, when the musical "Hair" opened on Broadway. That's when I became a somebody: an Aquarian. I was over the moon. The Fifth Dimension had written a song about my star sign. I walked around humming it, whistling it, singing it. I was so proud of my new-found identity that I goaded people into asking me about my star sign.

"So, what's your sign?" I'd casually ask some poor, unsuspecting soul.

"Sagittarius."

"Oh," I'd say with a hint of pity, "Mine's Aquarius. You know: harmony and understanding. You've probably heard the song."

If, perchance, someone replied that they were also Aquarians, we'd give each other a knowing nod. It was heaven.

I developed an interest in astrology. I consulted books, which described Aquarians as animal lovers, romantic, humanitarian, shy, sensitive, gentle, and patient; my sign was also described as enthusiastic and lively, with a tendency to be exhibitionist. It was amazing—it seemed to describe me perfectly. Other books noted that Aquarians often dream about being surrounded by water, which could account for all of my night sweats. It all made perfect sense.

I even began to read Tarot cards: the Star card in the Tarot deck is the sign of Aquarius. We are fortune tellers.

Then, recently, I ran into a Gemini who doused my shooting star. When I proudly announced my star sign, he asked with a wry smile: "So, when is 'the dawning of the Age of Aquarius'?"

Didn't it start with the new millennium and hasn't there been very little harmony and understanding since then?" Panic-stricken, and feeling like I was falling into a big, black hole, I searched the Internet to revisit the words of the song:

Harmony and understanding
Sympathy and trust abounding
No more falsehoods or derisions
Golden living dreams of visions
Mystic crystal revelation
And the mind's true liberation

By Jupiter, he was right! Where was the sympathy and trust abounding? These qualities certainly didn't seem to exist much in my AIDS world. Indeed, since the beginning of the millenium, there had been a heck of a lot of war, conflict, and disease abounding instead. Could it all be some horrible sham? Had the wool been pulled over my eyes? Was I just a little too eager to be a *somebody*?

It turns out that the "moon is [not] in the seventh house and Jupiter [is not] aligned with Mars"—not yet, anyway. According to stargazers and scholars, the Age of Aquarius hasn't begun. (Kepler predicts the year 2080, Robert Hand says 2060, and Robert Bauval and Adrian Gilbert claim 2070).

What a relief to learn that all of the divisiveness has been caused because we are still in the Age of Pisces. It figures! My brother was a Piscean and he was terribly disruptive when I was young.

So take heart, those of you who are depressed from recent events. It is a passing age and help is on the way in the next 50 years or so: "Aquaariiuiuuus! Aquaariiuiuuus!" ☺

Denise Becker is a former board member of the BCPWA Society. She lives in Kelowna.

