

inside

- [02] **THINK +**
Homophobia denies young people access to information about HIV prevention.
- [03] **REALITY BITES**
Bite-size HIV/AIDS news from BC and around the world.
- [05] **DEPRESSION**
The stigma and social isolation of depression, and digging your way out of it.
- [07] **CANADIAN STRATEGY FOR HIV/AIDS**
A report on the recent CSHA planning meeting among HIV experts.
- [08] **PROFILES OF OUR PAST**
A tribute to former BCPWA Society chair Lauro de Haan.
- [12] **BC WELFARE DISABILITY ALLOWANCE**
BC has changed its welfare laws and increased the penalties for breaking the laws.
- [14] **“LET’S TALK ABOUT IT”**
A new regular feature dedicated to promoting dialogue about prevention among PWAs.
- [40] **LAST BLAST**
How service with a smile—and a song—can lift the spirits.

features

- [09] **A RALLYING CALL TO ACTION**
Renowned Canadian activist Louise Binder offers some pearls of wisdom on the lessons she’s learned about the HIV/AIDS movement.
- [20] **HCV AND HIV CO-INFECTION**
We are only seeing the tip of the iceberg of the devastating effects of hepatitis C and HIV coinfection. Things are only going to get worse.
- [23] **THE HEALTH RISKS OF STREET DRUGS**
There’s a further down side to those party drugs: they can depress your immune system.

prevention

- [15] **BEHAVIOURAL APPROACHES**
We can’t create effective prevention programs based on the incomplete understandings of behavioural approaches.

treatment information

- [17] **COMPLEMENTARY THERAPIES**
• The long and winding road of research into complementary and alternative medicine.
• Homeopathy and HIV: A book review.
- [23] **ASK THE DOCTOR**
Dr. Natasha Press discusses what antiretrovirals you need if you’re HIV-positive.
- [24] **RESEARCH**
Is the placebo effect real or not? The research community is at odds.
- [26] **OPPORTUNISTIC INFECTIONS**
Though incidence rates have dropped, many PWAs still develop HIV-related dementia.
- [28] **STRAIGHT FROM THE SOURCE**
Young injection drug users may be more vulnerable to HIV and hepatitis C co-infection.
- [29] **LET’S GET CLINICAL**
Updates from the Canadian HIV Trials Network.
- [30] **NUTRITION**
• Understanding new dietary reference intake guidelines.
• Addressing food insecurity for PWAs in Vancouver’s Downtown Eastside.
- [34] **DECIPHERING YOUR DIAGNOSTICS**
Part 4 of the series: interpreting cholesterol and triglycerides tests.
- [36] **INFORMACION EN ESPAÑOL**
La sexualidad y el SIDA.



The British Columbia Persons With AIDS Society seeks to empower persons living with HIV disease and AIDS through mutual support and collective action. The Society has over 3,500 HIV+ members.

Living + editorial board

Wayne Campbell, Glen Hillson,
Joe NC Leung, Jeff Anderson

Managing editor Jeff Rotin

Design / production Britt Permien

Copyediting Darren Furey

Contributing writers

Denise Becker, Louise Binder,
Jim Boothroyd, Lawrence C.,
Pamela Fergusson, Diana Johansen,
Cari Miller, Mary Petty,
Dr. Natasha Press, Ron Rosenes,
Robyn Susse

Photography Britt Permien

Senior policy advisor on health promotion

Paula Braitstein

Director of communications and education

Naomi Brunemeyer

Director of treatment information and advocacy

Tarel Ouandt

Coordinator of treatment information

Zoran Stjepanovic

Prevention coordinator

Carl Bognar

Funding for *Living +* is provided by the British Columbia Ministry of Health and by subscription and donations

Living + Magazine

1107 Seymour St., 2nd Floor

Vancouver BC

V6B 5S8

TEL 604.893.2206

FAX 604.893.2251

EMAIL living@bcpwa.org

BCPWA ONLINE www.bcpwa.org

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think +

opinion and editorial

Homophobia and HIV prevention

by Carl Bognar

Homophobia is alive and well, and it's a problem for HIV prevention. Consider the Surrey School District's attempt to ban three books that portray children in families with same-sex parents. The school district claims it is protecting the rights of parents to shelter their children from objectionable lifestyles.

Homosexuality is a sexual orientation, not a lifestyle choice. Choosing between a red sports car and a scooter is a lifestyle decision. Virtually all gay men, lesbians, and bisexuals will tell you that the only choice they make about their sexual orientation is whether to express it or repress it.

Children in Surrey, like children everywhere in Canada, have parents who are lesbian, gay, or bisexual, and they deserve to see their home settings reflected in the curriculum they study. Preventing them from seeing their families represented in schoolbooks is as senseless as discriminating against children whose parents aren't married. Denying these children this basic right serves no constructive purpose: six year olds are hardly in a position to challenge or change the sexual orientation or living situation of their parents.

It's not just the children in same-sex parent households who suffer when school boards deny the existence of homosexuality. There are young people in every school in Surrey who will grow up to be homosexual. Sooner than we might imagine, those six year olds will grow up and start to have sex. The officially sanctioned silence about homosexuality places them in peril: where will gay,

lesbian, and bisexual students turn for help when they need it?

Research clearly demonstrates that young people who feel alienated from their schools and families start to engage in sexual activity at an earlier age than other young people. Not having your family welcomed at school is alienating. Knowing that you are gay or lesbian or bisexual and being aware of the controversy generated by the Surrey School District's intransigence on this issue is alienating for every gay, lesbian, or bisexual student in the district.

The epidemic of HIV is driven in part by stigma and discrimination, denial and silencing. Young people, straight or gay, need to be prepared for their first sexual encounter so that they can engage in behaviours that protect their health. If the existence of homosexuality is not acknowledged, young people are denied access to some of the basic facts of HIV prevention. Not having an important part of your human nature acknowledged leads to poor self-esteem and leaves young people vulnerable to confusion and exploitation.

Since the beginning of the HIV epidemic, 76 British Columbians between the ages of 15 and 19 have acquired HIV disease. Many other young people have acquired HIV as a result of their experience of silence about homosexuality. By any human and ethical standard, that is far more destructive than reading *Asha's Mums*, *Belinda's Bouquet*, or *One Dad, Two Dads, Brown Dad, Blue Dads*. ⊕

Carl Bognar is the prevention coordinator for the BCPWA Society.

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

REALITY BITES



AIDS activists receive medal

Twenty-five Canadian AIDS activists have been awarded the Commemorative Medal for the Golden Jubilee of Queen Elizabeth, in recognition of their years of hard work and dedication to the HIV/AIDS movement. In honour of the fiftieth anniversary of her reign as Queen of Canada, the medals were given to Canadians who have made a significant contribution to their fellow citizens, their community, or to Canada.

Recipients included three current and past board members of the BCPWA Society: chair Glen Hillson, Denise Becker, and Tom McAulay.

photo Britt Permien



BCPWA Society chair Glen Hillson was one of the recipients of the Golden Jubilee Commemorative Medals.

The other AIDS activists who received the medal were: Stephen Alexander, Paul C. Laybolt, Philip Lundrigan, Albert McNutt, Daniella Boulay-Coppens, Ralf Jürgens, Marc Lapierre, Louise Binder, Tracey Conway, Tony Di Pede, Dionne Falconer, Penelope Holeton, Shari Margoese, John McTavish, Ron Rosenes, Charles Roy (posthumous), Walter George Beswick

(posthumous), Kevin Midbo, Bob Mills, May O'Hanlon, Ken Clement, and Michael Yoder.

New entry inhibitor

GlaxoSmithKline and Ono have signed a worldwide agreement to collaborate on the development and commercialization of a cellular chemokine receptor (CCR5) antagonist discovered by Ono, designated as ONO-4128, currently in pre-clinical development for treatment of HIV infection, as well as associated back-up and follow-on compounds.

The CCR5 receptor is believed to be the predominant co-receptor used by HIV in the early and middle stages of infection. Blocking the CCR5 receptor with an antagonist may offer a novel mechanism for inhibiting HIV infection.

GlaxoSmithKline plans to initiate Phase I clinical studies in the USA in the first half of 2003.

BC transplant update

AIDS activists have chalked up another success. The BC Transplant Society has changed its policy of not performing transplants in HIV-positive people. It now has one of the most progressive policies in the world.

In a letter dated December 12, 2002, the Society stated: "The position of the BC Transplant Society Liver Transplant Program is that we are willing to...accept a CD4 count of 200 with an undetectable viral load. We will not insist that patients be on HAART medications for 12 months....However, we do expect them to be on HAART medications at the time of activation and while they are on the waiting list."

While this is good news, 30% of people on the waiting list die each year before a suitable organ becomes available. Becoming a candidate depends on a wide variety of non-HIV related factors, including his-

tory of drug and/or alcohol abuse, current social support, and mental health, as well as other health issues.

For more information, contact the BC Transplant Society at 604.877.2240.

Paula Braitstein

Bail denied for failing to disclose

A Florida man released from jail in November on \$1,000 bond, and on condition that he tell sex partners that he has HIV, was sent back to jail without bail for allegedly not disclosing his condition to a woman with whom he had unprotected sex. The woman discovered the man's serostatus when a friend showed her a newspaper article about his November arrest. The man has passed HIV to at least three other women, according to the Florida state attorney's office.

Source: AP

Canada's drug war a bust

A study by the British Columbia Centre for Excellence in HIV/AIDS (BCCfE), published in the *Canadian Medical Association Journal*, raises important questions about the effectiveness of Canada's war on drugs.

Evan Wood, a researcher at the BCCfE, said there is strong evidence that money would be better spent on treatment and programs to reduce the harm caused by drug abuse, rather than spending it on stopping criminal activity.

As part of a long-term study among injection drug users, the researchers monitored drug activity one year after one of the largest heroin seizures in Canadian history in the port of Vancouver. Police had evidence the heroin was destined for the Vancouver market.

"I was very surprised we did not see an effect," said Martin Schechter, head of the BCCfE. He said the findings add to a growing body of evidence that shows the North American approach to fighting

REALITY BITES



illegal drug use is not working.

Source: *The Globe and Mail*

Efavirenz side effects

A study at San Francisco General Hospital suggests there is a greater incidence rate of severe psychiatric illness resulting from HIV treatment with efavirenz than had previously been reported. Previous reports had stated that serious efavirenz side effects had less than a 2% incident rate. However, the authors of the study questioned the rate after seeing a number of HIV patients on the drug admitted to the psychiatry unit.

Researchers conducted a retrospective study of patients who had discontinued efavirenz from March 2000 to February 2002.

The study found that 18.3% of subjects on efavirenz reported vivid dreams, 14.7% complained of insomnia, 10% were lethargic or fatigued, 8.3% had headaches, and 7.3% had dizziness. The most common neuropsychiatric effect was depression, reported by 12%, while 9.2% reported anxiety, 2.8% reported suicidal depression, 1.8% reported hallucinations, and 1.8% reported agitation.

Source: *AIDS Alert*

Viral blips

It is not uncommon for HIV levels in patients to spike temporarily while they are taking highly active antiretroviral therapy (HAART), according to a recent U.S. study.

More than a quarter of the patients studied experienced brief viral elevations, but the high levels persisted for only 13 percent of patients. The study suggests that transient viral increases may not indicate that therapy is failing.

Dr. Peter Sklar conducted the research as part of the HIV Outpatient

Study by the Centers for Disease Control and Prevention. He said that a patient's incomplete adherence to the HAART regime might contribute to the viral blips. The 448 participants were on various types of antiviral therapy.

The study "supports current therapeutic approaches of 'careful monitoring' when transient increases in viral load are seen as opposed to a hasty decision to switch therapy," according to Dr. Diane Havlir, chief of the AIDS division at San Francisco General Hospital.

Source: *Gay.com*

Lesbian transmission of HIV

A rare case of female-to-female sexual transmission of HIV has been reported. Doctors suggest that the woman may have been infected through sharing sex toys after drug resistance tests found striking similarities between the genotypes of the woman and her female HIV-positive partner.

The 20-year-old Philadelphia woman had a negative HIV test result six months earlier, and had been in a monogamous lesbian relationship for the past two years. She denied having had any other sexual partners, had never injected drugs or received blood products, and had no tattoos or body piercings. The woman also had good oral health, which physicians took to mean that they could rule out oral transmission. However, the couple had occasionally uses sex toys vigorously enough to draw blood.

Source: *AIDS Map*

ALS and antiretrovirals

A Burlington, Ontario woman is the first person in the world to take highly active antiretroviral therapy (HAART) as a treatment for amyotrophic lateral sclerosis (ALS). The woman has been treated

for the last 18 months with HAART. She and her ALS physician, Dr. John Turnbull of McMaster University, report that her disease has slowed down and some symptoms have improved or gone away. Dr. Turnbull has begun a small clinical trial. Results of this trial will be available later this year.

ALS, also known as Lou Gehrig's disease, destroys the body while leaving the mind intact. It turns the body into a coffin. Ninety percent of ALS patients die within two to three years of being diagnosed.

Zimbabwe AIDS emergency extended

The Zimbabwe government has extended the declaration of emergency on the HIV/AIDS epidemic by a further five years. The extension will allow people continued access to generic drugs used in treating HIV/AIDS or any HIV/AIDS-related conditions.

Zimbabwe became the first country to declare a national emergency on HIV/AIDS last year when it made the declaration. The drugs are being given free of charge at about 35 centres throughout the country as part of the government's effort to reduce mother-to-child HIV transmission. Official statistics indicate that at least 2,000 people die of AIDS each week in Zimbabwe, and about 20 percent of the country's 12 million people are HIV-positive. ⊕

Source: *Africa News*

CORRECTION

The website for the Community-Based Research Centre is <www.hiv-cbr.net>. Incorrect information appeared in the January/February 2003 issue of *Living +*.

Reach out and touch someone

The stigma of depression can lead PWAs to further isolation

by Mary Petty and Neil



Depression among people living with HIV is as common a topic as antiretrovirals. “I can’t concentrate. I can’t seem to get out and do anything with anyone. I don’t feel like I fit in anymore. Am I depressed?”

We know that HIV-related stress contributes to depression, but we also know that the virus affects the mood-regulating aspects of the brain. Some people find that making social connections helps them move out of depression. Others want to explore anti-depressants but wonder, “Why should I take another pill? How do I find the right one? How do they work?”

Opinions about depression vary as greatly as each individual’s experience of it. Discussing the topic can be therapeutic in itself. Mary Petty’s contribution to this dialogue reflects her work on social/cultural aspects of depression; Neil’s reflects his extensive thinking and reading on psychological/biological aspects.

Mary: People living with HIV know all too well about the effects of stigma on their lives. The additional stigma associated with depression often prevents people from getting help.

Neil: Yes, people often view their depression as a shameful personality flaw. I prefer to look at it as something that evolved in human behaviour for protective reasons. The fatigue and social withdrawal that accompany depression could, for example, have prevented injuries by keeping hunters away from a dangerous hunt

when they were not at their best. I think the stigma behind depression could be reduced if we see it “not as an aberration, but as something that has a biological rationale,” as one psychiatrist stated.

Mary: This stigma influences how we think about medications. Some people consider taking anti-depressants to be a sign of weakness. But it seems more helpful to consider the effectiveness, side effects, drug interactions, and so on. There seems to be a lot of new research on the brain and depression.

Neil: Studies have shown that our brains are constantly growing new connections between nerve cells as we learn and adapt. But depressed people’s brains lack certain nerve growth factors, and over time they become physically unable to grow the new connections that allow them to cope with changing circumstances. They literally get stuck in a rut of depressive thinking that they cannot escape through willpower alone. Anti-depressants correct neurotransmitter levels in the brain, but, more importantly, they actually let depressed people to begin “re-wiring” their brains to allow a more positive outlook on life. Seen this way, depression is not a moral weakness, but simply a physical ailment like a broken bone that needs medical treatment to heal.

Mary: It also seems that increasing one’s social connections—for example, support groups, seeing friends—helps stave off occasional or less persistent symptoms of depression. Throughout the

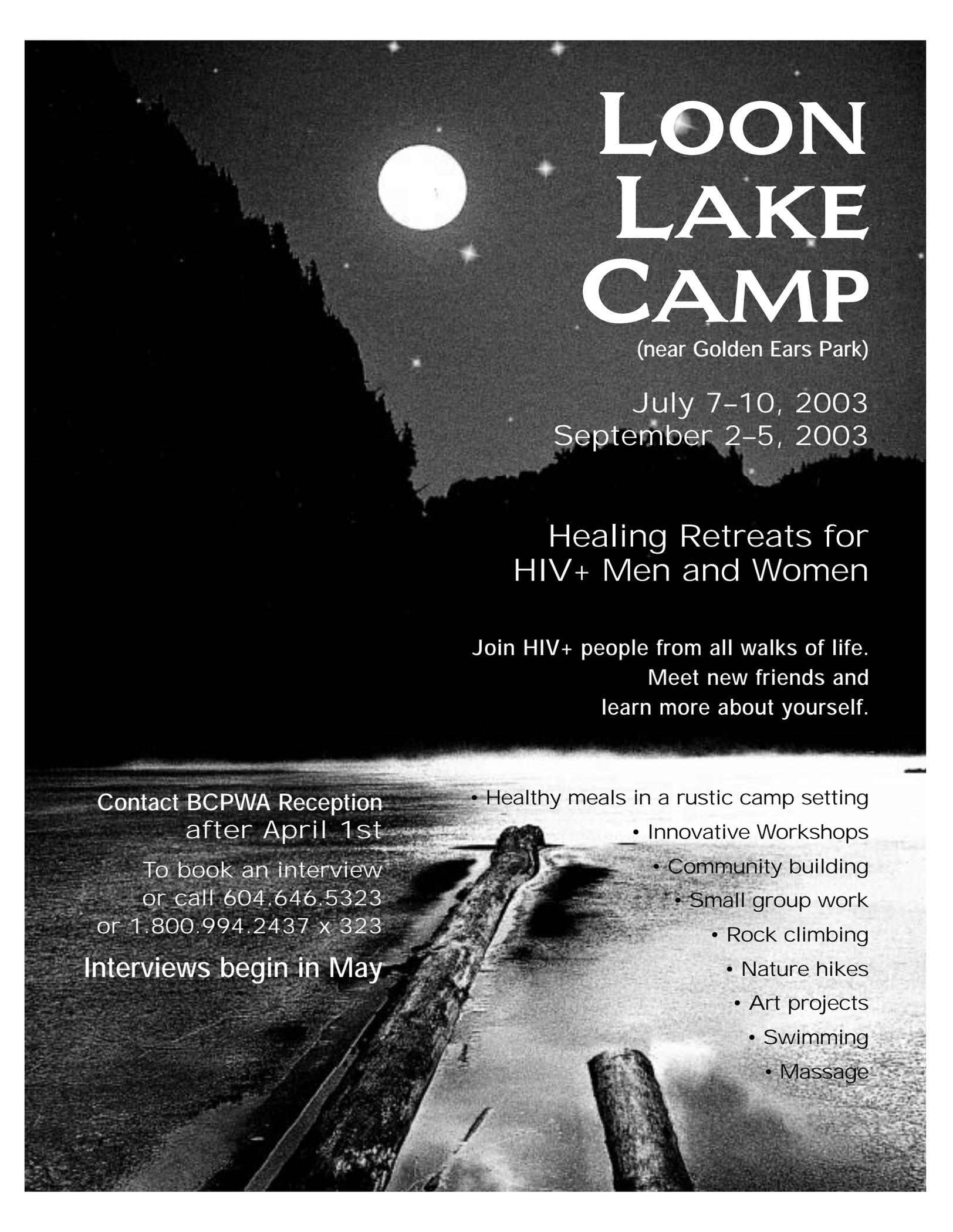
AIDS epidemic, I’ve seen unexpected benefits that individuals experience when they become activists or volunteer to help others.

Neil: This is so true, and not surprisingly, there are biological reasons for this effect as well. Recent studies have shown that cooperation, teamwork, and reciprocated altruism—people doing nice things for each other—flood the brain with dopamine and make us feel great. It’s clear that nature intended to reward us for these behaviours, for whatever reason. When you’re in the depths of a depression, you probably feel incapable of mustering the energy to do something nice for yourself, let alone for someone else. But I’ve found that even the smallest kindness I show another person, like a door held open or a smile in the elevator, immediately makes me feel a bit better.

Mary: Do you think the HIV/AIDS community takes depression seriously enough?

Neil: Frankly, no. Depression causes increased risk of all kinds of illnesses, yet it is still widely misunderstood, stigmatized, and poorly treated. People with HIV/AIDS should view depression as a serious threat to their physical health, just like pneumonia or shingles, and deal with it accordingly. ⊕

Neil has lived with AIDS for 12 years and views depression as a life-threatening opportunistic infection. Mary Petty is a social worker in the HIV Program at St. Paul’s Hospital in Vancouver.



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Feds finally consider PWA prevention

Report on planning meeting for Canadian Strategy on HIV/AIDS

by Carl Bognar

In early December, thirty experts in HIV/AIDS from across Canada were invited by Health Canada to develop a draft five-year strategic plan for the Canadian Strategy on HIV/AIDS (CSHA). These people were chosen to provide input into all aspects of the strategy in order to achieve an effective response to the epidemic over the next half-decade. These areas of the strategy include prevention, care, treatment and support, research, legal issues, epidemiology, community-based organizations, international issues, and intergovernmental relations. The participants also provided expertise in different populations, such as Aboriginals, gay men, people from endemic countries, prison populations, women, and youth.

At the meeting in Sainte-Adèle, Quebec, participants went through a series of strategic planning activities that resulted in the identification of draft issues, goals, and objectives to be addressed in the next five years. Strategic plans from various Canadian provinces and from other countries, including Switzerland and the United States, were presented as background documentation for consideration. Participants were encouraged to bring forward ideas that would answer the question "What do we need to do to optimize the Canadian response to HIV/AIDS over the next five years?"

Two innovations will be of particular interest to BCPWA members. The draft strategy includes, for the first time, some ideas about the importance of "positive prevention"—prevention

initiatives geared to HIV-positive individuals. As well, it seems probable that this plan will include support for the development of a national organization of people living with HIV.

Health Canada is currently developing a draft plan that will be reviewed at a national consultation to adjust the content, fill the gaps, and advise on methods of implementation.

For further information about BCPWA Society's involvement in the development of the five-year strategic plan for the CSHA, contact BCPWA Society board member Jeff Anderson at 604.893.2313. ⊕

Carl Bognar is the prevention coordinator for the BCPWA Society.



**BCPWA
Advocacy
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results!**

The BCPWA Society's Advocacy Program continues to work hard to secure funds and benefits for our members. The income secured for November and December 2002 is:

- ▼ **\$12,300.00** in debt forgiveness.
- ▼ **\$90,316.38** in housing, health benefits, dental and long-term disability benefits.
- ▼ **\$18,235.00** in Monthly Nutritional Supplement Benefits.
- ▼ **\$384,747.44** into members' hands for healthcare needs, from grandfathered Schedule C benefits.



Lauro de Haan and BCPWA Society employee Jackie Haywood in the early 90s.

Remembering our past

Former BCPWA chair believed in community involvement in HIV research

by Robyn Sussel

In the early 1990s, I was attending a World AIDS Day rally in Vancouver when I heard a voice I knew. The speaker looked familiar—dark, handsome—but I couldn't place him. I asked the woman next to me who he was. "Lauro de Haan," she said. "He's the new chair of BCPWA."

I didn't recognize the name, but by the end of his rousing and moving call to action, I knew that this man was a childhood friend I hadn't seen since grade 9. Back then I knew him as Kemmy Dean, and he was one of the brightest lights in our class, mature beyond his years and brutally funny.

Lauro's most enduring legacy may be his role in developing a plan to distribute protease inhibitors to the first candidates.

I got to know Lauro all over again at the Canadian HIV Trials Network. I knew he would add knowledge and reason to the deliberations of our newly formed Community Advisory Committee (CAC), which was given the responsibility of supplying a community perspective to scientists and policy-makers at the CTN. Nominated by the Canadian AIDS Society, Lauro was appointed as a member-at-large in the fall of 1992. Lauro remained an active and vital member of the CAC until his death three years later.

Lauro possessed unwavering logic. When committee members charged ahead with a new idea, he would suggest we investigate what existed already to prevent duplication of effort. Rather than just suggest we do the research, he was always the first to volunteer to do the task himself. These two qualities allowed the CAC to develop sound and well-researched recommendations and policies in its crucial early years. This reasoned approach also helped gain the trust of scientists and industry leaders who, at the time, were new to the concept of community input. This building of relationships later paved the way for CAC to be candid and forceful about community needs and to act as an equal partner in the research process.

Lauro's razor-sharp wit and droll sense of humour helped us see the light in the darkest tunnels. He was able to joke and laugh, even when he experienced profound personal and health problems that would leave most of us humourless.

However, his most enduring legacy may be his role in developing a plan to distribute the new class of drugs, protease inhibitors, to the first candidates. In his capacity as a CAC member, Lauro sat on an ad-hoc committee to advise Roche Canada on a compassionate release program for their new anti-HIV drug, Invirase (saquinavir).

Because worldwide demand for saquinavir outstripped the company's ability to manufacture it, a lottery system was employed in several countries to distribute the drug. The Canadian ad-hoc committee determined that a tiered system of access would be the most ethical approach to this difficult situation. At the time, no one knew who would benefit most from the drug. The committee suspected that people with very low CD4 counts and severe opportunistic infections would not benefit as greatly as people with slightly stronger immune status, although no data existed to support this guess.

Therefore, the group decided to allocate the drug to the sickest people first. Lauro advocated strongly for this position, despite the fact that his own CD4 count—the measure of the day—was only slightly higher than the cut-off point for the highest tier. So, despite knowing that this drug would likely prolong his own life, he strongly advocated for PWAs who were more ill than he to get the drug first. In hindsight, the courage and selflessness of this act speaks volumes about Lauro's character.

Lauro's poor health declined quickly over the following year. Though he was in a great deal of pain, he endured long flights and long meetings to remain a contributing member of the CTN's CAC until the spring of 1995. Lauro lost his fight against AIDS on July 29, 1995, at St. Paul's Hospital, surrounded by his family and friends. ⊕

Robyn Sussel was the head of communications and information at the Canadian HIV Trials Network from 1991 until 2000. She is now a communications consultant specializing in health and research.





The global feminist movement has been sharply criticized for years for its lack of response and mobilization around the AIDS pandemic. We in the HIV movement understand how women around the world often bear the brunt of the disease, including its risk factors and consequences. Unfortunately, despite this knowledge, the feminist movement has been slow to react.

In January, Louise Binder, co-chair of the Canadian Treatment Action Council and one of the world's leaders addressing women

and HIV, spoke at the International Gender Institute meeting in Halifax. In her inspiring speech, she asked: "What have we learned over the past twenty years about this epidemic and how to deal with it?" Her answer—what she referred to as her "top ten lessons learned"—is a rallying cry for everyone to get off their butts and continue advocating for the rights of Canadians living with HIV/AIDS. We have accomplished a great deal in the past 20 years, but much work remains to be done.

Lesson #1:**If you don't know where you are going, any road will get you there.**

Direction begins with leadership—political leadership to start. We did not get that automatically at any level of Canadian government. We mobilized within the community, and we found other important allies, including the healthcare sector, researchers, public health officials, the media, and other disease groups. Together we lobbied the politicians and bureaucrats, we demonstrated in the streets and in the halls of power, we held press conferences, we found natural leaders willing to speak out—and die—publicly to bring this issue to the public's attention. We succeeded in convincing the federal government and a number of provinces to put formal policies into place. These strategies outlined government commitments to addressing this epidemic and what they were willing to spend.

Lesson #2:**"If you think you are too small to make a difference, you have never been in bed with a mosquito." – Dalai Lama**

Unfortunately, marginalized groups do not feel they can make a difference. They often cannot mobilize to do so. In Canada, because the first wave of infections was among groups that by and large did feel part of the mainstream and therefore felt a sense of entitlement, they did mobilize and they forced politicians and other decision makers to take the leadership role they should play. If this epidemic were just starting today in Canada among the newer groups becoming infected, I think it is very questionable whether we would have achieved the important groundwork in advocating for the strategies and leadership needed to deal with this epidemic effectively. It is important to do capacity building in affected and infected communities and to nurture natural leaders in these groups. One group that has started to do exactly that in Canada is the drug-using community, through a user group in Vancouver called VANDU (Vancouver Area Network of Drug Users).

Lesson #3:**If you aren't part of the solution, you're part of the problem.**

We have learned that all of the relevant stakeholders—researchers, healthcare providers, AIDS service organizations, public health officials, politicians and bureaucrats at all levels of governments including those government agencies outside health that affect health determinants—must be part of the development, implementation, and evaluation of strategies. Most of all, we must ensure that people with HIV/AIDS and those at risk drive the agenda, are always part of the decision-making process, and are at the center of all that we do. As well, we must ensure that each of the populations at risk and infected are inte-

gral to the solutions for their specific population.

We did this—imperfectly, I admit—by creating both national and some provincial HIV/AIDS strategies with specific strategic areas of work. We also set up multi-stakeholder councils to monitor the work and to guide changes in direction as the epidemic moves into new populations. More recently, we convinced the federal government to endorse the UN General Assembly Declaration on HIV/AIDS (UNGASS), thereby establishing another clear set of objectives for us to meet.

Lesson #4:**Never rest on your laurels.**

We have learned this in the prevention area. Earlier in the epidemic, we did a fine job of reducing the transmission rates in gay men by excellent targeted prevention messages and campaigns through community mobilization, not government programs. Then we got somewhat complacent because we thought we had solved that problem.

We learned that we must sustain the good work we have done or it will slip away as young people come along and as the older group finds it harder and harder to follow those messages without ongoing support.

Lesson #5:**One size does not fit all.**

We learned this in the prevention area as well. The messages, and the way they were delivered that worked for the gay community, were not reaching the other populations at risk. Thus, these populations were being infected in large numbers. Women had no idea they were at risk, aboriginal people thought HIV was a white man's disease, intravenous drug users weren't being taught harm reduction practices, and pregnant women weren't being offered testing. No wonder the numbers were growing so fast in all of these populations.

This is true in the care and support areas as well. Thus AIDS service organizations have sprung up to deal with the discreet needs of particular populations. One example is Voices of Positive Women, a provincial organization started by two HIV-positive women with thirty founding members. It now has over 550 members, and it is run solely by and for HIV-positive women.

This is also the case in the research area. Women have recognized for a long time the need for a protection method, which, unlike condoms, is solely within the control and knowledge of the woman herself. We have recognized that the traditional subordinate role of women socio-economically and the resultant violence against women are co-factors for HIV.

Finally, and recently, research decision makers are listening. Microbicide research is moving forward. The same is true for research about the particular impact of antivirals on women, given our distinct metabolism. In the area of social justice, human

rights policy work is needed for each of the marginalized groups. In Canada, excellent work is being done in that area by the HIV/AIDS Legal Network, a national non-governmental organization that develops policy papers in such areas as intravenous drug users, prisoners, and immigrants. For women, one issue in Canada has been the debate about the human rights implications of mandatory testing for pregnant women.

Lesson #6:

Contrary to popular opinion, knowledge is not always power.

We have learned that knowing that you are HIV-positive only confers power where there are treatment strategies in place to let people improve their life and health. Before we had access to antiretroviral treatments, there was little incentive for people to be tested. Denial was easier than knowledge of certain death. With this denial came continued unsafe sex practices and sharing of needles and other unsafe practices. The availability of treatments made a tremendous difference to prevention work. As well, we have learned that the public health driven prevention strategy of partner notification does not stop this epidemic.

Lesson #7:

Even though it may look like a duck and quack like duck, it may not be a duck.

Things are not always what they seem. On the surface, HIV may look like a health issue. Thus, you might conclude that the solutions to this epidemic lie within the health sphere. We have learned that nothing could be further from the truth. HIV is a socio-economic issue, a human rights issue, a social justice issue, a gender bias issue, and a racial and religious issue. It is influenced by the determinants of health, including poverty, homelessness, education, employment, and race. Unless the decision makers in these areas are engaged, we will never solve the root causes that allow the spread of this disease. In Canada, we have recognized this but have done very little to address it.

Lesson #8:

It's a small world after all.

Canada is starting to recognize that what happens to the rest of the world is indeed linked to what happens to us. The advocacy to convince the government to sign on to the UNGASS agreement is an important step in that direction. The advocacy to spend more in foreign aid in general and specifically in relation to HIV activities has been very important. We are still woefully stingy in contributing to the Global Fund. We must continue to speak out in favour of increasing our commitment there.

Lesson #9:

Follow the money.

This epidemic is fuelled by international trade agreements and other international policies, driven by multinational companies and interests. Because we cannot possibly be everywhere or know everything relevant to this issue, it is crucial that we develop partnerships and alliances with antiglobalization, health, and environmental groups. We can educate them about our issues so that they can integrate our needs into their work. In turn, we can use information they provide us in the development of our policies and positions. The whole is always greater than the sum of its parts. We must continue high level lobbying with our governments in the international arena. This certainly worked in convincing the Canadian government to endorse UNGASS.

There are some big gaps in our approach to HIV/AIDS policy and strategies in Canada. The first involves collaboration and coordination. There is not enough collaboration across government departments on issues that impact health, such as housing, welfare, justice, and health. In fact, these departments do not recognize the impact of their work on health and HIV. Levels of government do not coordinate their work to ensure that we get the best value for our money with the far too scarce resources—human and financial—that we have. This applies to other relevant stakeholders' collaborations.

Secondly, with great regret I must report that HIV is not on the broader women's health agenda. I have concluded that the major factors at work here are denial and discrimination: the conspiracy of silence. Indeed, of even greater concern is that we are not any longer on the public's list of important issues, let alone important health issues.

Lesson #10:

"Never for the sake of peace of quiet deny your experience and knowledge." –

Dag Hammarskjöld, UN Secretary-General 1953-1961

We must continue to work together to create a social justice framework for all people. We must remember the example of the mosquito when we feel discouraged and powerless. My own personal mantra in doing this work is "if one of us is not safe, none of us is safe." ⊕



Louise Binder is chair of the Canadian Treatment Action Council, co-chair of the Ministerial Council on HIV/AIDS to the federal Minister of Health, and chair of Voices of Positive Women.

Penalizing the poor

What you should know about recent changes to welfare laws

by the BCPWA Collective Advocacy Standing Committee

The BC monthly welfare disability allowance rates are not keeping up with the cost of living. The rates are far below Statistics Canada's low-income cut-off lines, more commonly called the poverty line. While the income needed to live at the poverty line continues to increase, the new welfare laws are keeping the rates for disabled people frozen. Disabled persons live on up to 50% less income than the poverty line. (See Table 1.)

Not only do low welfare rates increase the difficulties in meeting living costs, other attacks on income security for disabled persons have made the situation even more perilous. The welfare-earning exemptions have been capped at \$300/month. The additional 25% above \$300 earned monthly has been taken away, thus limiting disabled persons' abilities to work towards partial or full independence or to meet their high medical costs. As well, many healthcare goods and services are no longer covered by welfare or Pharmacare, forcing disabled persons to go without necessities of life in order to pay for their medical needs or to simply not meet those needs at all.

Overall, the increase in the PST, the new restrictions on the federal Disability Tax Credit, and provincial cuts (or impending cuts) to many community services threaten the tenuous stability of many disabled people.

Know the rules and the penalties

Welfare laws have changed, and penalties for breaking those laws have increased. Because the laws are new, it is unknown

how much attention the government will place on enforcing the new provisions. However, it's important to know the rules so that you can make good decisions and protect your welfare income.

You can be barred from receiving welfare if you give false or misleading information to the government or if you fail to report changes in your financial and personal situation to the government.

Under the new law, the penalty for the first offence is a twelve-month ban. A second offence will get you barred from welfare for 24 months, and your third offence will get you barred for life.

Giving false or misleading information

Here are some examples of what *could* be false or misleading information.

- You and your partner live together but you both apply for welfare as singles.
- You and your partner live together, and you apply for welfare while your partner works or has another source of income.
- Not fully declaring all valuable assets such as artwork, vehicles over \$5000, etc.
- Making unsubstantiated claims about your health problems and health needs.
- Claiming your child lives with you full-time when your child lives with someone else more than 50% of the time.
- Giving away your assets—such as a car, art, property, or RRSP—for below market value before you apply for welfare.
- Not disclosing all your bank accounts.

Reporting changes to your personal or financial situation

These are the types of changes to your personal or financial situation that you *may* need to report.

- Leaving the province for more than thirty days in one year.
- Living rent-free while continuing to collect shelter allowance.
- Moving in with your lover.
- Selling your assets.
- Earning less than \$300 a month but not reporting it to welfare.
- Working part-time.
- Sharing your apartment with a friend and receiving money from your friend to cover rent.
- Winnings from the lottery or bingo.
- Receiving inheritance money or valuable gifts.
- Receiving CPP retroactive payments, ICBC insurance claims, EI, or WCB payments.
- Receiving student loans for costs of living.

Other reasons for ineligibility

You can be found ineligible for welfare or have your monthly disability allowance reduced if you

- sell your property or possessions for under market value any time two years before you apply for welfare or while you are on welfare; or
- didn't accept a job you could perform or other income that could support you any time two years before you apply for welfare or while you are on welfare.

Employment plans

In the future—we don't know how near or far—all persons receiving a disability allowance will be required to enter into an employment plan with the Ministry of Human Resources. While the Ministry may exempt persons who are too disabled to comply with any employment plan, many disabled persons will not be exempt. According to the government, such plans will assess an individual's employability and provide supports to enhance that individual's self-sufficiency. The degree of an individual's disability will impact the plan. An employment plan's goal can range from fulfilling volunteer commitments, following through on skills training, and finding part-time or full-time work.

You can be bumped off welfare or have your disability allowance reduced if you do not follow *some* of your employment plan obligations. If you have any concerns about meeting your employment plan, talk with your worker and an advocate immediately. ⊕

Table 1: Disabled persons living below poverty line

Family size	Welfare disability rate/month	Poverty line	Percentage below poverty line
Single disabled person	\$786.42	\$1611.00	49%
Single disabled person + full nutritional benefit	\$1011.42		37%
Single parent, one child	\$1075.08	\$2013.00	47%
Single parent, one child + full nutritional benefit for adult	\$1300.08		36%
Couple, both disabled	\$1150.56	\$2013.00	43%
Couple, both disabled + full nutritional benefit for both adults	\$1600.56		20%

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Let's talk about it!

This is your page to express your opinions on "positive prevention".

"Positive prevention" means the participation of HIV-positive people in prevention issues that concern us. In order to develop a Canadian vision for positive prevention, we at the BCPWA Society are eager to hear from our readers. "Let's talk about it" is a new regular feature in Living + dedicated to promoting dialogue.

We welcome your comments on prevention articles published in this magazine or in other publications. We also want to generate discussion about prevention issues. Alternatively, send us your questions or suggestions for future prevention articles.

Please keep all essays and letters under 400 words, and send them to:

CARL BOGNAR,
PREVENTION COORDINATOR
BCPWA
1107 SEYMOUR ST., 2ND FLOOR
VANCOUVER BC V6B 5S8
prevention@bcpwa.org
FAX: 604.893.2251

We received *this letter from an AIDS service organization. The writer declined to be identified, but we still feel this is an important topic to discuss. This is an excerpt from the letter:*

"We have concerns over the message your article ("Sex and Sensibility", Issue 22, Jan/Feb 2003), may be sending to our client population. Although it is certainly up to the individuals involved to decide for themselves, we believe you may be sending mixed and/or dangerous messages. You say that "Condoms are probably a good idea if your HIV isn't being treated or if your viral load is detectable." This seems to be saying that it is okay if you are being treated or the viral load is undetectable. This is a potential recipe for disaster. What about the sharing of different strains of HIV, and what about HCV infection?

"At our organization, we promote condom use at all times, and believe in erring on the side of safety. Certainly we have gaps in knowledge, but that should make us even more vigilant in promoting the safest sex possible: consistent use of condoms. Even if the risk is minimal, would you bet your life on it?"

Our response:

We agree that it's important to keep in mind the potential dangers of unprotected sex between HIV-positive people, especially dangers related to hepatitis C and sexually-transmitted infections, and the fact that these may be more difficult to treat if you're HIV-positive. At the same time, we do know that some HIV-positive people are choosing to engage in sexual activities only with other PWAs, as a way of minimizing risk while avoiding the need to use condoms for the rest of their lives. Given our current understanding of how the virus works, this may well be a reasonable decision between HIV-positive partners, especially those in a stable relationship.

There are many complex issues related to drug resistance, and as yet, there is no clear scientific consensus about whether transmission of drug-resistant virus has an impact on long-term health. Evidence to this effect may emerge in the future, and we may well find it necessary to modify our thinking about this issue. ⊕

Carl Bognar,
prevention coordinator



Tunnel vision

Behavioural approaches to prevention come up short

by Carl Bogner

Behavioural approaches characterized the initial public health responses to preventing the spread of HIV, and they continue to characterize much of the prevention work still being done around the world. There are a number of variations on behavioural approaches (for example, see Peterson and DiClemente, 2000, for a summary), but these approaches tend to make a number of assumptions that place serious limitations on our thinking about HIV prevention. These assumptions can lead to an inadequate understanding of the circumstances in which HIV is transmitted. Effective prevention programs cannot be built on incomplete understandings.

Knowledge is not enough

Behavioural approaches to prevention have their limitations. They usually assume that risk behaviours can be eliminated merely by providing individuals with appropriate knowledge. As long as the epidemic persists, there will be a continuing need for education about HIV transmission, particularly for young people and for people coming to Canada from other countries where they may not have been exposed to the basic facts of HIV prevention. Research findings make it clear, though, that as far as adults are concerned, much of this work has already been done. The majority of people are well aware of the basic facts of HIV transmission.

However, some areas of confusion remain, particularly in relation to more complex questions such as the importance of viral load and transmissibility and the relative perils or safety of oral sex. These remaining areas of public confusion are largely a reflection of ongoing debates in the scientific litera-

ture and among public health professionals. These debates, unfortunately, are not likely to be resolved any time soon.

Knowledge alone is not enough to prevent the spread of HIV. Behavioural approaches make the assumption that decision-making about risk-taking behaviours is entirely rational. However, it is obvious that sexual activities and drug use may well be the two areas of life that are least amenable to reason. By nature, they are driven by passion. Emotional responses in these situations are important aspects of our humanness.

If we limit our thinking about HIV transmission to understanding a few simple behaviours, we run the risk of treating the people who are the targets of our research as pathological. A researcher working from this perspective could well ask: Why are they still engaging in unsafe behaviours when they should know better?

Recognizing cultural contexts

Behavioural approaches also place responsibility for HIV prevention entirely on the individual. By so doing, we ignore the larger social and cultural contexts in which risk behaviours are located. Cultural contexts are critical to understanding why people engage in risk behaviours and how we might help people to reduce or eliminate those risks.

For example, injection drug use takes place in more than one subculture. Consider the differences between women who inject drugs to ease the pain of working in the survival sex trade and young men who inject steroids to maximize the impact of their weight training at the gym.

This type of conceptualization led epidemiologists to create the category "men who have sex with men" (MSM). While this designation allows scientists to count males who have acquired

HIV through same-sex sexual activities, it combines men who identify with gay culture with those who have sex with other men but who do not identify themselves as gay. Acknowledging the existence of gay culture provides us with a wealth of opportunities to capitalize on the strengths of gay culture in turning the tide on the HIV epidemic.

Understanding vulnerability

Behavioural models of prevention tend to ignore differences between individuals and differences within individuals over time. In behavioural research, individuals are treated as equivalent, interchangeable, and unchanging. By ignoring possibly important differences between individuals that are related to personality or culture of origin, we lose the benefit of understanding HIV vulnerability in relation to important events in people's lives, such as finding or losing a partner or having a partner who seroconverts.

There has been a tendency to look for pathological differences between people who become HIV-infected and those who do not. Research tends to focus on risk factors, such as low self-esteem, drug and alcohol use, and the effects of physical and psychological abuse during childhood, to ascertain what makes people as individuals vulnerable to HIV. While studies have clearly demonstrated that all of these factors do indeed contribute to vulnerability to HIV, not everyone who has HIV has been abused and not everyone who has been abused has HIV. This line of thinking may, in fact, be counterproductive, in that it gives "normal" (read: non-abused, non-addicted) HIV-negative people a false sense of security. In reality, under the right circumstances, everyone is vulnerable to HIV. Pathologizing runs the risk of distancing non-abused, non-addicted HIV-negative people from understanding their own vulnerabilities.

The importance of interaction

Placing responsibility for prevention on the individual underestimates the importance of social interaction in HIV transmission. Behavioural approaches tend to ignore the interaction between two individuals that is necessary for HIV transmission to take place. To make HIV prevention more effective, we need to develop a deeper understanding of how these factors interact when two or more people are involved. To each encounter where HIV might be transmitted, each partner—whether the relationship is casual, regular, or permanent—brings a myriad of individual factors, including his or her personality, needs, desires, long-term goals, self-esteem, negotiation skills, and sexual history. HIV transmission requires the participation of two individuals, so effective prevention requires an understanding of the way that all of these personal factors interact.

By ignoring the social interactions that are required for HIV transmission to take place, behavioural approaches imply that "it's every man for himself." The early 1990s public health message "use a condom every time" is a prime example of an HIV prevention message designed to appeal, inadvertently, only to the individual. Many people are now critical of such messages because they appear to ignore the realities of everyday life.

HIV transmission happens as a result of social interaction, so understanding the nature and content of that social interaction is crucial to prevention. For example, some prevention research shows that young people—both heterosexual and homosexual—tend to stop using condoms at an early point in a new relationship because condoms interfere with naturally growing patterns of trust and intimacy. In this context, condoms are viewed as an impediment to a stable relationship. Discussion, negotiation, understanding, and trust are required in these instances. Additionally, using a condom every time is not an option for people in relationships where there are power differentials.

Situational differences

Behavioural models tend to assume that people behave in the same way in all environments. Effective prevention needs to be based on an understanding of the interactions between individuals, and an understanding of the situations and environments in which these interactions take place. There is evidence that HIV-positive gay men weigh the level of disclosure of HIV status required by the nature of the situation. They may rarely offer disclosure in an outdoor cruising area, while it may be expected in a new relationship. Thus, gay men may seek out various types of environments—bars, baths, parks, and telephone lines—depending on a mix of their mood, their longer-term goals, and their willingness and capacity to disclose.

Broader models of HIV prevention are emerging, particularly in Europe and Australia. These newer models are based on different and more comprehensive assumptions about how and why HIV transmission happens. These approaches require us to examine the meanings and contexts of risk behaviours, rather than just the risk behaviours themselves. This does not mean that the behavioural research that has been done so far is wrong, only that it is woefully incomplete and, therefore, may not provide the solid foundation needed for HIV prevention. We will present some ideas about how to develop new prevention approaches in future issues of *Living +*. ⊕



Carl Bognar is the prevention coordinator for the BCPWA Society.

Behavioural approaches treat individuals as interchangeable and unchanging, ignoring important differences due to personality or culture of origin.

treatment information

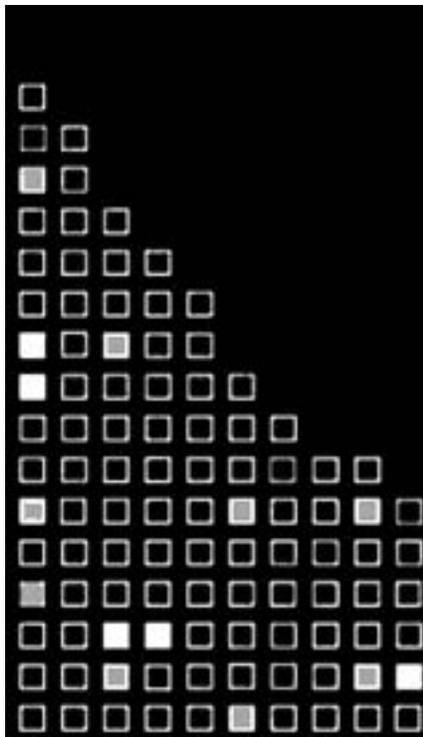
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In accordance with our mandate to provide support activities and facilities for members for the purpose of self-help and self-care, the BCPWA Society operates a Treatment Information Program to make available to members up-to-date research and information 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 judgement 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, nor 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.

A language of its own

by Ron Rosenes



We live in an era of evidence-based medicine. For biomedicine, the gold standard of evidence usually means a double-blinded, placebo-controlled, randomized trial. That's how researchers determine the ability of an investigational drug to reduce viral load over a

given period of time, for example. Compounds or substances are compared with a placebo in settings where neither the patient nor the doctor knows who is getting what and every attempt is made to screen out any factors which might confound or confuse the result.

Researchers in the field of complementary and alternative medicine (CAM) face a different set of challenges when it comes to building the evidence for therapies that are based on complex whole systems of treatment. Traditional Chinese Medicine (TCM) is an example of one such whole system. Part of that system is the administration of herbal remedies, which could be researched for their safety and efficacy like other compounds. That is, if you could standardize them and isolate their active ingredients. That in itself adds a layer of complexity to the study of herbs compared to pharmaceutical compounds. But TCM treatment may also involve acupuncture, which is dependent on the skill of the practitioner.

A "whole systems" approach
PWAs often create their own "whole systems" of self-care, and they struggle to make choices about treatment from a menu of products and practices offered by

continued on next page

a myriad of healthcare providers. How do we make informed decisions about what works and what doesn't? Can research studies be designed to prove the effectiveness of CAM?

A group of leading CAM researchers and practitioners from Canada, the US, and the UK met in Vancouver in the fall of 2002 to advance the agenda for whole systems research. The group included naturopaths, western doctors, TCM doctors, homeopaths, chiropractors, biostatisticians, bioethicists, folks from the Natural Health Products Directorate, and one lone consumer advocate. The advocate's task was to keep the discussion focused on the needs of people (such as PWAs) who live in the real world and create their own whole or holistic systems of healthcare on a daily basis. The discussions were fascinating and pointed to the need for researchers of complementary medicine to develop a rigorous new language that can provide evidence of CAM's effectiveness and ultimately change the way healthcare is delivered.

Assessing holistic outcomes

Randomized clinical trials (RCTs) are an important part of the equation, but they must be constructed in ways that take into account the holistic nature of complementary medicine. In other words, they must find ways of assessing quality of life that are acceptable both to patients and the broader medical community. The goal of conventional medicine has been the diagnosis and treatment of illness based on the concept of the pathogen or germ. The term "reductionist" is often used to describe this approach because it reduces the cause to an identifiable culprit. CAM also seeks to relieve symptoms and promote wellness, but it tends to involve the individual in a self-healing process

that examines mind, body, and spirit. Increasingly, a holistic view of health includes the environment, both psychological and social, in which the individual lives.

Rigorous research methods must therefore take into consideration these philosophical points of view. For example, some complementary medicine embraces the interconnectedness of everything, including the relation-

Randomized clinical trials must be constructed in ways that take into account the holistic nature of complementary medicine.

ship between the individual and the practitioner. Some practitioners may work to uncover the underlying disharmonies—such as anger, diet, and genetic predisposition—that may be the cause of illness. This approach to medicine introduces an element of spirituality to the process of self-healing and makes the practitioner a stakeholder in the outcome. The challenge, then, is to marry the philosophical concerns of all stakeholders with the highest standards of methodological rigor in order to produce evidence that satisfies all parties.

Studying long-term outcomes

HIV poses specific challenges to outcomes-based research. It is now just a few years since the advent of powerful antiretroviral drugs that enabled us to view HIV as a complex chronic condition that may have a relapsing and remitting pattern. Many of us have integrated CAM interventions into our treatment with the aim of long-term healing as opposed to a cure.

Many PWAs see CAM as a way to forestall the time when they may decide to use pharmaceuticals. Health changes tend to be gradual and subtle. Therefore research must be funded to allow for the long-term study of outcomes.

Most importantly, outcomes need to be viewed differently from surrogate markers such as the simple quantification of CD4 cells or reduction in viral load, or from end points such as death. The researchers at the Vancouver meeting did not lack suggestions on ways to design research protocols that respect and value individual experience, capture the patient-provider relationship, and answer questions based on individual expectations. By combining qualitative and quantitative methods, we can get a clearer picture of why and for whom certain treatments work, and not just what works.

But don't expect satisfactory answers to treatment questions until the research community comes to agreement on the components needed for high quality research and is able to engage the support of government and industry. The Vancouver meeting proved to be a good step along what appears to be a long road toward a definition of a new language for CAM research. ⊕



Ron Rosenes is a board member of the Canadian Treatment Action Council.

Homeopathy and HIV

by Zoran Stjepanovic



A *IDS and Complementary & Alternative Medicine: Current Science and Practice* is a recently published book that examines the current use of CAM in treating AIDS. In this issue, I'll review the chapter on homeopathy.

According to the author of this chapter, Leanna J. Standish, homeopathy began in Germany in 1810. It remains a controversial area of alternative medicine, with some critics arguing that it is irrational. However, it is considered standard practice in parts of Europe and India. The physician for the British Royal Family has traditionally been a homeopath.

Standish defines homeopathy as a system of medical practice that treats a disease with minute concentrations of medicines that, if administered at higher doses to a healthy person, would produce symptoms of that disease. If a high concentration of a substance causes a medical problem, the homeopathic law of similars predicts that the same substance will effectively treat that problem when prescribed in very small concentrations. The flu shot, for example, contains just a bit of the flu virus, which stimulates the immune system to react and create antibodies for that particular strain of flu.

Homeopathic diagnosis involves a comprehensive interview about symptoms and practices. This interview can often last for an hour or more. Homeopathic medicines are then prescribed on the basis of a person's unique pattern of symptoms.

Homeopathy can also be used to treat people living with HIV/AIDS. The Bastyr University AIDS Research Center's study of 1666 HIV-positive men and women indicated that approximately 9% of HIV-infected individuals who used complementary and alternative medicine were treated by a homeopath.

Homeopathy is particularly common among the growing HIV population in India. Homeopathic physicians there sometimes treat HIV/AIDS with homeopathically prepared HIV concentrated in the buffy coat (lymphocyte fraction of whole blood) of centrifuged blood samples.

Standish also cites a 1999 study that examined the effect of individualized homeopathy for PWAs in India. One hundred

HIV-positive individuals between the ages of 17 and 50, of which 71% were male, were randomized to receive either a single homeopathic treatment or a placebo. The group receiving the homeopathic treatment showed statistically significant increases in CD4 counts after six months. Unfortunately, Standish does not provide enough data from this study, such as the participants' CD4 counts before and after the study and the list of side effects they may have experienced. In addition, it is not clear whether these participants were taking any other treatments besides homeopathic medicines. Research is starting to emerge on the effects of homeopathy on HIV-positive individuals, but research methods and experiences need to be more transparent.

Standish points out that the administration of homeopathic nosodes is an area of homeopathic medicine that deserves more investigation. Nosodes are dilutions of antigenic material taken from diseased tissues that can be administered orally. Many homeopathic medicines are nosodes, such as medorrhinum, syphilinum, and tuberculinum, which are made from gonorrheal, syphilitic, and tubercular-infected tissues. Standish writes that many naturopaths prescribe homeopathically prepared viral nosodes for the treatment of HIV co-infections such as hepatitis, human papilloma virus (HPV), Epstein-Barr virus, and cytomegalovirus (CMV).

This chapter provides a good introduction to homeopathy and how it works. The discussion of homeopathy provides some evidence from clinical studies, but the section on HIV and homeopathy is too brief. More research is needed in this area. When considering homeopathy, it is important to find a homeopath that has experience in treating HIV/AIDS. ⊕



Zoran Stjepanovic is the treatment information coordinator with the BC Persons With AIDS Society.

Tip of the iceberg



We've only just begun to see the grave impact of hepatitis C co-infection

by Paula Braitstein

We've known for several years now that the hepatitis C virus (HCV) was going to be bad news for people living with HIV/AIDS. However, until recently, we didn't quite fully comprehend just how bad the situation is. Hepatitis C co-infection is a huge problem, and it is only going to get bigger.

Have you noticed all those people who look like they are probably living on and/or off the streets, but they have big bellies? You think they're well fed so you decide not to give them spare change. In fact, most of them have ascites, a condition that develops when cirrhosis or scarring of the liver occurs. Because the liver isn't processing anything properly, all the fluid that is consumed through eating and drinking doesn't get processed either. This

fluid accumulates in the belly—and later in the legs, genitals, face, and other areas of the body—until the person looks like he or she is nine months pregnant. It's painful and extremely uncomfortable.

A trip to the HIV ward on the 10th floor of St. Paul's Hospital in downtown Vancouver underscores the problem. In nearly every bed, there are people whose bodies are wasted everywhere but their abdomens. Lactulose, a syrup that induces frequent bowel movements in the hopes of excreting ammonia and other toxins which will otherwise accumulate in the brain and cause brain dysfunction, is doled out to patients like candy. At nearly every door, trays stand full of equipment for paracenteses, a procedure to drain fluid from the abdomen using a large needle.

The leading cause of death

Last year, the BC Centre for Excellence in HIV/AIDS (BCCfE) checked their data to see if hepatitis C was a leading cause of death among people on antiretrovirals. It was not. This year, they had another look at the same question and discovered otherwise—and that's after taking into account viral loads and CD4 counts when people start therapy. Of the 1516 individuals who started naïve (that is, for the first time) on triple-combination antiretroviral therapy, 235 of them—16 percent—had antibodies to hepatitis C. However, only 552 of the total group of 1516 had ever been tested for hepatitis C. Thus, when you examine the prevalence of hepatitis C from this perspective, 43% of the 552 people tested were HCV-positive.

Considering how important and dangerous hepatitis C is, it is surprising that more people aren't getting tested, especially since two years ago, the BCCfE wrote a strongly worded letter to BC physicians recommending that all HIV-positive patients, regardless of their risk factors, be tested. If they test antibody-negative but are having liver problems, they should get a PCR test to see if there is actual HCV present, even if the immune system isn't working well enough to create antibodies to the virus. The BCCfE found (in unpublished data) that women and people who had physicians with limited HIV experience were more likely to not be tested.

The reason that the BCCfE didn't discover that HCV was a leading cause of death in HIV-positive people until recently is probably because of the timing of when most people actually became infected. Although a large proportion of people with hepatitis C are not injection drug users (in this instance meaning anyone who has used injection drugs even once in their lifetime), an equally large proportion of people are. The epidemic of HIV and hepatitis C among IDUs in Vancouver spiraled out of control in 1996 or 1997. While HCV can take twenty to thirty years to develop in people who have HCV only, people with both HIV and hepatitis C can expect their hepatitis C disease to progress in seven to ten years. Thus, for people infected in 1996, the brunt of the disease is only beginning to be felt now.

A devastating effect on HIV

It is still not clearly understood why hepatitis C has such a devastating effect on HIV. However, scientists believe that having an altered immune status has an effect on the body's ability to cope with HCV. It may be that with fewer CD4 cells, a greater number of HCV quasi-species or strains can develop, and that the more types of HCV you have, the worse your disease will be. It may be that HIV can somehow kill

liver cells directly, or perhaps it interrupts the immune system's way of preventing liver disease.

Does HCV viral load play a role? Although no relationship appears to exist between HCV viral load and disease progression in people who are mono-infected with HCV (in sharp contrast to HIV disease, where there is a direct and causal relationship between HIV viral load and disease progression), people who are co-infected tend to have higher HCV viral loads than people who are mono-infected.

The other major problem in terms of the interaction between HIV and hepatitis C is related to CD4 counts. People with higher CD4 counts are more likely to respond to HCV treatment and less likely to have rapidly progressing liver disease. Unfortunately, people with low CD4 counts almost uniformly respond poorly to HCV treatment and tend to progress quickly in their liver disease. Immune restoration can also sometimes be a double-edged sword in HCV. People with lower CD4 counts who start antiretroviral therapy may also be kick-starting HCV disease when they do. This scenario is similar to when people with low CD4 counts start antiretrovirals and suddenly develop mycobacterium avium complex (MAC, an opportunistic infection), since it is the immune system's reaction to the disease that causes the symptoms rather than the disease itself. All of this is debated in the literature, and there are no firm answers.

Go to a doctor for testing

Should you be worried? Well, that depends. Have you ever had a tattoo? Have you ever snorted cocaine? Ever shot drugs? Had sex? Had acupuncture? Shared a toothbrush? If the answer to any one of these questions is yes, then you should be concerned. Here's what you should do:

- Get tested. And don't take "no" for an answer. Many doctors still fallaciously believe that only drug addicts are at risk. However, hepatitis C is spread by blood, and it is hundreds of times more infectious than HIV. All it takes is a minute amount of blood to spread. A little rough sex, an old tattoo, a line or two of coke could all easily allow HCV to spread.
- Don't assume you're healthy, even if your lab work suggests you are. There are more questions than answers with hepatitis C. For example, your liver function tests (LFTs), and particularly your AST/ALT, may be normal. If they're elevated, then you know there's something going on—it could be HCV, it could be antiretroviral toxicity, or any number of other of things.
- Even if your LFTs are not elevated, that doesn't mean there isn't a problem. Many people have very advanced liver disease, yet their LFTs are normal or close to normal. You

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may have elevated bilirubin. Your doctor might tell you that it's not a clinically relevant reading because all it causes is a little jaundice, or yellowing of skin and eyes. However, jaundice isn't normal, and you need to find out what's going on. If your antibody test was negative, demand a PCR test which tests for the virus itself.

- Pay attention to your body. Feeling excessively tired, losing your appetite, or experiencing changes in your taste or sleeping patterns are all symptoms of liver disease. If you have any of these symptoms, get a referral to a hepatologist—a liver specialist.

Do what you can to support your liver. Avoid alcohol as much as possible. Reduce your salt intake. Consult an HIV-specialist dietitian and/or pharmacist to discuss changes to your diet or supplementing. Don't start supplementing with too many herbs or minerals—you can do more harm than good.

- Get vaccinated for hepatitis A and hepatitis B. Some evidence suggests that hepatitis A combined with hepatitis C can be deadly, quickly. And you don't want hepatitis B. It, too, can cause long-term liver damage, and it is preventable. If you do have hepatitis C, consider treating it early.

To treat or not to treat

One of the biggest questions in the management of HCV disease is whether and when to treat it. Treatments for HCV include combining alfa-interferon and ribavirin, usually taken together in a combination called Rebetron. Both of these drugs are very toxic, especially the ribavirin, and cause quite debilitating and sometimes irreversible side effects such as anemia, loss of salivary production, taste perversion, and depression. They are difficult drugs to take, and they are expensive. The government is usually only willing to pay for a six-month course, even though we know that people with HIV in particular need to take them for at least one year to have any substantial impact.

Perhaps most importantly, Rebetron only “works”—meaning a sustained virologic response where the HCV becomes undetectable and stays that way for at least six months—in about 40% of people who are HCV mono-infected and in only about 20% of people who have both HIV and HCV. This difference may be related to HIV, but it may also be related to the HCV genotype.

Contributing factors to successful treatment

HCV has four major genotypes: 1 (including 1a and 1b), 2, 3, and 4. Genotypes 1 and 4 are the worst—they cause faster disease and lead to poorer treatment responses. Unfortunately, they are also the most common genotypes in people living with HIV. Even the new pegylated interferon

doesn't work as well in people with genotypes 1 and 4. Response rates for people with genotypes 2 or 3 taking pegylated interferon are close to 70%. In people with genotypes 1 or 4, they are closer to 50%.

Successful treatment depends on many factors, including genotype. Other success factors include being under 50, premenopausal female (men and post-menopausal women tend to do more poorly), and HCV viral load. Oddly, although HCV viral load doesn't appear to be related to disease progression, it is related to treatment outcomes.

Considering how important and dangerous hepatitis C is, it's surprising that more people aren't getting tested.

Unfortunately, the treatment of HCV in people living with HIV/AIDS has not been adequately studied. However, it is known that the higher the CD4 count, the more likely you are to have a sustained viral response. In other words, treating early is better. Treating your HCV before treating your HIV is probably a good idea, although very little data exist to prove this.

This brief overview touched on some of the major challenges of the rapidly emerging problem of co-infection. The issues are complex and multi-factorial. Hepatitis C is quite different in people who have only have hepatitis C versus people who have both hepatitis C and HIV. So much so, that the definition of HCV as a co-infection rather than as an opportunistic infection will need to be re-evaluated in the near future. ⊕

For more information, contact the BCPWA Society Treatment Information Program at 604-893-2243 or email tip@bcpwa.org. In addition, the US-based National AIDS Treatment Advocacy Project (NATAP) has an excellent website for co-infection resources: < www.natap.org >.



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



Q. Which vaccinations do I need?

by *Natasha Press, MD*

A. After initial diagnosis with HIV infection, doctors will usually recommend vaccinations that help prevent HIV-positive individuals from developing certain infections. Recommended vaccines may include Pneumovax, influenza, hepatitis B, and hepatitis A.

The Pneumovax vaccine protects against a bacterium called *Streptococcus pneumoniae* or pneumococcus. This bacterium is a common cause of pneumonia, but it can also cause blood infection and meningitis. Patients respond better to the vaccine if they have a high CD4 count (over 200), so they should be vaccinated as soon as possible after diagnosis. It's not yet known whether patients who had received Pneumovax when they had a low CD4 count would benefit from being re-vaccinated after starting highly active antiretroviral therapy (HAART) and having achieved a CD4 count above 200. Usually, it is recommended that patients be re-vaccinated after five years.

The influenza vaccine is given annually in the fall. The vaccine changes slightly every year depending on which strain of the flu is going around. The vaccine not only prevents the flu, it also prevents pneumonia and the worsening of heart and lung problems.

The hepatitis B vaccine is recommended for people who are not already infected with hepatitis B or who do not

have natural immunity to it. The vaccine for this liver infection is a series of three shots over a six-month period. When infected with hepatitis B, most adults recover and develop natural immunity, which protects them from being infected again. However, some infected people will develop liver disease. After many years, liver disease can cause poor liver function, yellowing of the skin, retention of fluid, and sometimes liver cancer. Hepatitis B usually spreads the same way HIV does, through blood, sex, and shared needles.

The hepatitis A vaccine is indicated for individuals who don't have natural immunity to hepatitis A and who are at higher risk for catching hepatitis A or for developing severe liver disease if they do get it. People who should get a hepatitis A vaccination include patients actively injecting drugs, men who have sex with men, and people with other liver disease, such as hepatitis C. Like hepatitis B, hepatitis A virus affects the liver, but, unlike hepatitis B, it does not cause ongoing liver disease. All people infected with hepatitis A become immune when they recover. However, having hepatitis A can lead to severe liver disease and possibly death.

Some vaccines are not advisable for HIV-positive individuals, including vaccines that contain live virus. In immunocompromised patients, vaccines

containing live virus can actually cause the disease. For example, the chickenpox vaccine can cause a rash and fever similar to chickenpox if given to someone who is immunocompromised.

All vaccinations have side effects. These side effects may include some redness and pain at the site of the vaccination. Some people may also develop fever and tiredness for a few days. Some people cannot receive certain vaccines because of allergies to some of the components.

HIV viral load may increase after a vaccination. This increase may occur two to four weeks after receiving a vaccination, but the viral load will then go back down. Therefore, patients should not have their viral load measured for a couple of weeks after receiving a vaccine. ⊕

Natasha Press, MD, is an infectious diseases and HIV physician at St. Paul's Hospital. She's involved with HIV research with the Canadian HIV Trials Network.





All in the mind

Scientists debate the validity of the placebo effect

by Paula Braitstein

When conducting research, scientists have a number of tools to attempt to control for real or potential confounding factors or unsuspected systematic differences in the way participants are treated in addition to the intended treatment conditions. These tools include the use of a control group;

- ▼ blinding (not disclosing to either the patient or the doctor or both (double-blinding) which treatment the patient receives);
- ▼ randomization of assigning study participants to one treatment or another;
- ▼ stratification (separating in either design or analysis a particular group of people); and
- ▼ matching in either design or analysis (each study participant is matched to others based on certain characteristics, such as age or gender).

In the control group method, scientists use a placebo for a comparative assessment of the effect of an intervention relative to a group that does not receive the intervention, all other factors being equal. Placebos are inert substances (such as saline or sugar) intended to have no benefit other than the perception of being offered treatment. Although placebos are intended to have no clinical benefit, since the 1950s research has shown both objective and subjective changes in outcomes in a broad spectrum of clinical conditions, including asthma, hypertension, and chronic pain.

Nevertheless, many doctors and researchers believe that this placebo effect is clinically meaningless and that placebos are

powerless. When people say that an effect is a result of a placebo, they commonly mean that the effect essentially doesn't exist, or that it's "all in the head." It is often said of complementary and alternative medicines that their effects are often no more powerful than placebo. It is not surprising to think that a placebo would have no effect, considering that the substance chosen for a placebo is chosen explicitly because it is inert or inactive. Yet, placebos have been documented to have an effect, even to the extent of causing side effects known as the nocebo phenomenon.

Hence, the controversy. Is the placebo effect essentially a product of the imagination and, therefore, not real, or is it an illustration of the concept of mind-body interaction?

Placebo effect critics suggest that the substantial effects seen by researchers can be explained through bias arising from lack of a properly controlled study, misconceived theoretical formulations, or chance.

How the placebo effect is defined is an indication of the lack of understanding and consensus about what the placebo effect is. It has been defined variously as an intervention without any specific effect on a given disease but with a possible unspecific effect; an effect for which no empirically supported theory for the mechanism of action exists; and an effect not unique to a given treatment.

According to a recent publication, no commonly accepted definition of the placebo effect has been established. There is, however, a widely acknowledged effect due principally to the psychological effect of the patient-provider interaction, and the placebo effect is

considered the effect of all the psychological processes involved in the meeting between a doctor and a patient. This effect has been quantified, including through systematic reviews of literature, to get the combined big picture of the effect of an exposure or a drug. Most clinicians would agree that the doctor-patient relationship is an important component of the therapeutic strategy.

Although some evidence supports the concept of the placebo effect as a therapeutic strategy, many practitioners resist further investigation of the subject.

Because the placebo effect, defined here as a measurable clinical benefit, has so often been observed in studies, the study of placebos and the placebo effect has become a branch of inquiry within epidemiology. A systematized review analyzed 114 randomized trials with both a placebo group and a no-treatment group and found no significant pooled effects of placebo interventions in trials with binary or objective outcomes. An apparent minor effect was seen in trials with patient-reported outcomes when measured on continuous scales, especially pain.

Another systematic review examining placebos in the context of analgesics found that nearly all studies examined showed antagonistic or synergistic effects of naloxone or progulumide on placebo-induced analgesia. The authors were able to conclude that endogenous opiates (opiate substances produced by our own bodies) were implicated in the response, suggesting an important biologic mechanism for how placebos in the field of analgesia can work.

In many ways, the placebo effect can be contextualized within the framework of mind-body medicine. Within this framework, it is believed that the mind (thoughts, emotions) affects physical

health. A large body of literature has documented the influence of mental health (including stress, depression, optimism, loneliness, and isolation) on physical health. One of the more commonly accepted theories of biologic mechanisms for these associations is the hyperactivation of the hypothalamic-pituitary-adrenocortical system—the flight or fight response. Recent studies indicate that by changing mental activity, measurable changes in the central nervous system can be detected.

The placebo response has also been described as a post-therapeutic response because any effects seen are not, in fact, inherent to the placebo but occur in the patient after taking the placebo. The sources of this response can be categorized into four distinct possibilities:

- ▼ the natural biologic healing that occurs in the natural course of a disease;
- ▼ the patient's psychological state, which can affect beliefs about the cause of the disease and/or the effect of the therapy;
- ▼ the expectation of benefit that can alter the way both patients and providers react in the therapeutic situation; and
- ▼ the "iatrotherapeutic" effect produced by the providers' professional behaviour.

Debates about the validity or utility of the placebo effect have been constrained by the resistance of many allopathic practitioners to further investigate the subject despite some evidence to suggest that placebo effect is a potentially useful therapeutic strategy. If one of the primary goals of clinical research is to improve patient care, then it would be appropriate to determine the personal behaviours and characteristics of both patients and providers that produce the favourable components of the post-therapeutic response.

In an article in a 1985 issue of *Lancet*, J. Blau sums up the debate nicely: "The doctor who fails to have a placebo effect on his patients should become a pathologist." ⊕

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



Join the tip team!

HIV positive people needed to provide volunteer Peer Treatment Information Counselling.

BCPWA'S Treatment Program needs HIV+ people who:

- *want to take an active role in learning about HIV and treatment*
- *will provide treatment information and support for individuals*
- *want to make a difference —Empower!*
- *are outgoing and friendly*
- *are able to commit to one shift a week for 3 hours*

Training starts in October.

**If interested please contact Zoran (BCPWA)
604.893.2239 or email Zorans@bcpwa.org**



Even with HAART, dementia is still a threat

by Zoran Stjepanovic

Cohort studies have shown decreases in incidence rates of HIV-associated dementia following the introduction of highly active antiretroviral therapy (HAART), but these decreases do not mean that dementia is no longer a concern. Even with HAART, 30% of people with HIV will eventually develop cognitive impairment and about 15% will develop dementia. These findings demonstrate that AIDS Dementia Complex (ADC) continues to be an issue.

Most AIDS-related illnesses are caused by other infections, such as bacteria, fungi, and viruses. ADC is one of the only illnesses that can be caused directly by HIV. Some studies show that HIV can enter the brain within a couple of days after the virus first enters the body. HIV then damages the nerve cells in the brain, although researchers don't totally understand how this happens. AIDS-related dementia can happen at any CD4 cell count, but it is more likely to occur when the CD4 cell count falls below 200.

The symptoms

The symptoms of early dementia include difficulty remembering, trouble learning new things, confusion, depression, and changes in behaviour. Once dementia takes hold, the symptoms become more severe. Speech, balance, and vision difficulties are signs that dementia is progressing. Loss of

bladder control, problems walking, and mania are also signs of dementia. Any of these symptoms can have many different causes, so it is important to discuss any changes in mood, concentration, or behaviour with a healthcare provider to find out what might be going on.

HIV-related dementia progresses in four key stages. Stage 1 is mild—signs and symptoms of intellectual and motor impairment may occur, but a person is able to perform activities of daily living. In stage 2, a person cannot work or maintain the more demanding aspects of daily life but is able to perform some basic activities of self-care and may require a cane for walking. Stage 3 becomes more severe. The person cannot follow news or personal events, cannot sustain conversations, and needs assistance with walking. In the end stage (stage 4), an individual will experience very limited intellectual and social comprehension, is nearly mute, is paraplegic, and has no control over bladder or bowel movements.

Diagnosis and treatment of ADC

ADC can have similar symptoms to other opportunistic infections, such as toxoplasmosis, progressive multifocal leukoencephalopathy (PML), and lymphoma. Several different tests are necessary to determine the actual causes of symptoms. The most common tests include X-rays, CT scans,

and MRIs. These tests provide doctors with images of the brain and spinal column.

A spinal tap may also be used. In this procedure, a needle is inserted into the spinal column to drain a small amount of cerebrospinal fluid, the liquid that surrounds the brain and spinal column. This fluid is then examined for organisms that might cause symptoms. Studies have shown that elevated cerebrospinal fluid levels of HIV ribonucleic acid (RNA) are associated with subsequent progression to neurological impairment.

Some current research seems to suggest that HIV RNA levels in cerebrospinal fluid can predict the risk of neurological impairment in the HIV-positive population. In one study conducted in San Diego, individuals with HIV RNA levels of 200 copies/mL in their cerebrospinal fluid had a 26% likelihood of neurological impairment, whereas individuals with lower levels had only a 6% likelihood of neurological impairment. This difference shows the importance of checking cerebrospinal fluid.

AIDS dementia complex is one of the only illnesses that can be caused directly by HIV.

Antiretrovirals interfere with the reproductive cycle of HIV in order to achieve the goal of an undetectable viral load. They can also be used as treatments for ADC. Some drugs are more effective than others. Nucleoside reverse transcriptase inhibitors such as AZT, d4t, 3TC, and abacavir may help slow HIV damage in the brain. Non-nucleoside reverse transcriptase inhibitors such as nevirapine (Viramune) and efavirenz (Sustiva) may also be effective. So too amprenavir, a protease inhibitor.

Healthy tips for living with dementia

Even though anti-HIV medications may be helpful to people with ADC, they do not completely reverse the symptoms. Various coping strategies play an important role in making life easier.

- ▼ **Educate yourself.** Learn all you can about dementia, such as the signs and symptoms, as well as how it progresses. The treatment information office at the BCPWA Society has information. Talk with your doctor about your progress and discuss treatment options.
- ▼ **Find support.** Support groups for PWAs exist throughout the Lower Mainland. Ask for assistance when needed. It helps to talk with people in your support network about your fears and concerns.
- ▼ **Keep active.** Individuals with dementia may withdraw from certain activities, whether it's spending time with friends, spending time outdoors, or participating in favourite hobbies. Some individuals with ADC may experience social anxiety. Still, it is important for individuals to continue with daily activities. Having a sense of purpose contributes to empowerment and well-being.

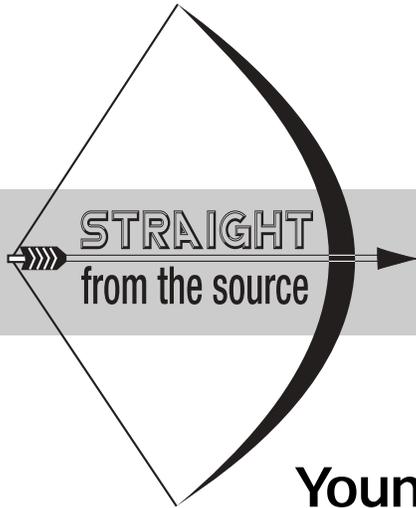
- ▼ **Write important reminders to yourself.** Write notes to yourself and place them where you're most likely to see them, places that are hard to miss, such as the bathroom mirror or by the coffee machine. To cope with memory problems, it helps to have an uncluttered household. Items such as keys, calendars, and letters can be found more quickly if kept in their usual places.
- ▼ **Keep a diary.** Write the things you wish to remember.
- ▼ **Install gas detectors and smoke alarms.** They can alert you when you forget to turn off the oven or snuff out candles.
- ▼ **Keep important things together.** It's best to keep items such as money, keys, and eyeglasses in one central place. Electronic tags can be attached to these items to help locate them.

Tips for caregivers

Living with dementia is a challenge for PWAs. It can also be a painful and difficult time for their caregivers, who may find the task demanding and frustrating. Here are some tips for caregivers supporting individuals with dementia.

- ▼ **Help them to help themselves.** People living with dementia do not need to be waited on hand and foot. Allowing them to do things, such as household chores, by themselves will foster a sense of empowerment.
- ▼ **Be patient.** You must give people the time and space they need. Do not take over.
- ▼ **Improve communication skills.** Take the time needed for communication. Speak slowly and allow for a response. Individuals can sometimes have difficulty focusing when other things are happening. For example, turn down the television or turn it off completely during conversations. Eliminate distracting noises or activities. Because people living with dementia experience speech and communication problems, it helps to use short words and short simple sentences. Ask only one question at a time. Individuals who have difficulty understanding language often retain their ability to understand body language, so be mindful of the messages you send with your body.
- ▼ **Make bathrooms and kitchens safer.** These rooms can present challenges for individuals with vision or coordination difficulties. It's advisable to keep things in cupboards, especially glass. Grab bars or seats for toilets will make them easier to use.
- ▼ **Find support for yourself.** Talk to a friend or someone on a care team about your experiences. Caregivers must also get assistance when they need it.
- ▼ **Don't take things personally.** Troubling behaviour is not always intentional. It can result from dementia.
- ▼ **Take time out to care for yourself.** There will be times when you need a break. Perhaps someone else can be the caregiver for a few hours. Self-care is important and prevents burnout. ⊕

Zoran Stjepanovic is the treatment information coordinator for the BCPWA Society.



what's new in research

Young injection drug users and co-infection

by Cari Miller

In 1996 and 1997, Vancouver experienced an explosive outbreak of HIV infection among injection drug users (IDUs). Since the outbreak, policy debates have focused on whether Vancouver's needle exchange contributed to the epidemic rather than addressing the need for other prevention modalities. Arguably, this failure to implement further prevention strategies has contributed to the continued spread of viral disease among Vancouver's IDUs. Vancouver youth who use injection drugs have not been spared; they may be bearing the brunt of inaction by government and policy-makers who continue to debate the usefulness of scientifically proven harm-reducing drug policies.

Young injection drug users may be more vulnerable to HIV and hepatitis C (HCV) than older injectors. Less experience injecting means many youth need to rely on others to inject them. That means someone else may be controlling the types of drugs youth use, when they use them, and whether they use a clean needle.

Youth, especially girls, may be introduced to injection drugs by sexually exploitative men who get them addicted and then put them to work in the sex trade to "pay for their addiction." These youth may face the threat of violence by the men controlling them.

Many youth who use injection drugs were sexually abused as children, a factor that often reduces their ability to negotiate safer sex or take care of themselves in other ways. Many continue to be sexually abused by pimps and through the sex trade. They may also be in sexual partnerships with older men who may not be willing to use condoms, and others may not have the skills to insist on condom use.

Other factors contributing to youth vulnerability include an increased likelihood of not having a stable and safe place to live and being unaware of safe drug use practices. Some may have warrants out for their arrest, thus limiting their access to services such as needle exchanges.

When the BC Centre for Excellence looked at the youth participating in the Vancouver Injection Drug Users Study

(VIDUS), we found that less than half were infected with hepatitis C (HCV) and about 10% were infected with HIV when they first enrolled in the project. Although these findings were much lower than among older injectors when they first enrolled in the study, young people became HIV and HCV positive at much higher rates than the older people. The majority of these youth became HIV and HCV positive within the first two years of injecting. With infection rates like these, youth and new users clearly need services targeted towards them.

Recently, VIDUS researchers looked at the number of VIDUS youth aged 29 and under living with HIV and HCV co-infection. We found that about 50 (10%) were co-infected with HIV and HCV when they first enrolled and a further 73 became co-infected during the study period. The average age of youth who seroconverted was 22 years, and they had only been injecting for two years. In total, a staggering 25% of VIDUS youth are now HIV and HCV co-infected. Co-infection was concentrated among young females and aboriginal people. Youth who borrowed needles and injected cocaine daily were at higher risk for seroconversion.

We know co-infection leads to more rapid HCV progression, and deaths of co-infected individuals from liver failure are increasing. Women and aboriginal people, particularly those who use injection drugs, are less likely to access antiretroviral therapies. Specific issues related to treating this young population may include concerns such as pregnancy, access to antiretroviral therapy, and prevention of liver failure. We must act now to ensure that the rate of infection in this population does not continue to increase and that those who need and want treatment have access to it. ⊕



Cari Miller is a research student in the first year of an interdisciplinary PhD program at the BC Centre for Excellence in HIV/AIDS.



Popular lipid-lowering trial comes to BC

by Jim Boothroyd

Two clinical sites in Vancouver will soon begin recruiting participants for a popular clinical trial that assesses a new approach to reducing the risk of heart disease and other cardiovascular illnesses in people on stable antiretroviral therapy.

The trial, "Fenofibrate & L-Carnitine for Elevated Triglycerides" (CTN 157), assesses two approaches in managing hypertriglyceridemia, or elevated levels of triglycerides (lipids) in the blood, which is a side effect of antiretroviral therapy.

People with elevated triglyceride levels are at greater risk of heart disease and other cardiovascular illnesses.

Among other requirements, participants must be on a stable antiretroviral regimen and have fasting serum triglyceride levels between 5 mmol/L and 29 mmol/L. They will be allocated randomly to receive either fenofibrate alone or fenofibrate plus L-carnitine. The study will last three months and has an enrolment target of 124 participants nationally, of which two Vancouver sites will contribute about 20 participants.

Participants will receive nutritional advice from a dietitian to reduce the risk of diet being a contributing factor in increasing triglyceride levels. A substudy will also assess the effect of the two approaches on fasting blood levels of cholesterol, C-peptide (a residue in the formation of insulin) and insulin.

The Vancouver sites are the Downtown Infectious Diseases Clinic, led by principal investigator Dr. Brian Conway,

and Providence-St.Paul's Hospital, led by principal investigator Dr. Julio Montaner.

The CTN trial, which was designed by Dr. Emil Toma of Hôpital-Dieu in Montreal, is enrolling swiftly at sites across Canada. L-carnitine is a naturally occurring and relatively non-toxic and inexpensive agent. The most common side effect is a temporary increase in body odour.

HIV Research Needs You!

That's the title of a new poster presenting Canada's most comprehensive list of HIV clinical trials now enrolling. The bright poster is published quarterly and lists trials sponsored by pharmaceutical companies as well as publicly funded trials conducted by the CTN and other networks. To get a copy, contact your local AIDS organization or clinic, or call the CTN toll-free at 1.800.661.4664. ☎



Jim Boothroyd is communications manager at the Canadian HIV Trials Network.

CTN trials enrolling in BC:

CTN 110 — ESPRIT: Subcutaneous Interleukin-2
BC site: Cool Aid Community Health Centre, Victoria

CTN 161 — SPRINT: Simplified Protease Inhibitor Trial
BC sites: Cool Aid Community Health Centre, Victoria;
St. Paul's Hospital and Viron, Vancouver

CTN 164 — STI (Structured Treatment Interruption) Trial
BC sites: Downtown Infectious Disease Clinic (IDC),
Vancouver, and Cool Aid Community Health Centre, Victoria

CTN 167 — OPTIMA: Options with Antiretrovirals
BC sites: Viron, 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 175 — Nevirapine to Lower Cholesterol
(SCHMALTZ) Trial
BC site: St. Paul's Hospital, Vancouver

CTN 177 — Nucleoside Sparing Trial
BC site: St. Paul's Hospital, Vancouver

For more information about CTN trials, please visit the CTN website: www.hivnet.ubc.ca/ctn.html or call 1.800.661.4664.



Are you getting enough?

*Nutrition, that is.
How to make sense
of new dietary guidelines*

by Diana Johansen

It's hard to make sense of dietary guidelines for people living with HIV. Years ago, the basic recommendation was to eat high calorie and high protein foods. All nutrition strategies were aimed at preventing weight loss. Times have changed. For some individuals, high calorie-high protein diets are still required, but more and more people have to cope with fat redistribution, being overweight, and the risk of developing heart disease. It can be quite confusing because sometimes competing nutrition priorities make it difficult to choose the appropriate diet.

Recommended dietary intakes

Build a solid nutrition foundation by meeting the nutrition recommendations that govern the recommended dietary intakes for healthy populations. Up to a few years ago, the recommended dietary allowance (RDA) was the benchmark to assess nutritional adequacy. The RDA for nutrients was set to meet the nutritional needs of 97% of the healthy population.

More recently, recommendations were updated with the development of dietary reference intakes (DRI), new recommen-

dations that try to address issues such as preventing chronic disease and over-nutrition. The expert panels that developed these guidelines also defined safe upper tolerable limits, so individuals can avoid harm from consuming too much of any single nutrient. DRIs are designed to meet the needs of healthy people who have no disease or condition that might affect their nutritional requirements.

Although HIV/AIDS clearly impacts nutritional needs, DRI recommendations meet the minimum intakes required for health and should be the starting point in considering nutrition plans for HIV-infected individuals. See Table 1 for examples of the recommended intake (AI) and the upper safe limit (UL).

Calories

In Table 2, the new recommendations for calorie intake are tied to weight, height, and activity level. Calories should come from a variety of foods containing carbohydrates, fats, and protein. The new guidelines call for getting 45–65% of calories as carbohydrates (such as grains, fruits, and vegetables), 20–35% from fats (added and hidden fats), and 10–35% from protein (such as meats,

dairy, and beans). The wide ranges allow individuals to arrange their diets to meet their specific health needs. They also promote greater flexibility in choosing foods because the bottom line is the amount of calories consumed, not necessarily the source. People with HIV generally need the higher range for protein and somewhere in the middle range for fat and carbohydrates.

Carbohydrates

The new guidelines recommend a minimum of 130 grams of carbohydrates daily to produce enough glucose for the brain to function well. The guidelines also suggest that added sugar should make up less than 25% of calories consumed. Added sugars come from candy, pop, sweetened cereals, fruit drinks, other sweets, and sugar added to foods. This recommendation was derived from evidence that people who eat a lot of sugar tend to have lower intakes of essential nutrients.

Fats

The panel did not make a clear recommendation for total fat intake because fat is a major source of calories and people have different needs. Dietary fat is also required to help fat-

Table 1: Vitamin and mineral requirements

	Calcium (mg)		Vitamin D (µg)		Magnesium (mg)		(mg)		Vitamin A (mg)		Selenium (µg)		Zinc (mg)		Vitamin C (mg)		Folate (mg)		Vitamin E (mg)	
	AI	UL	AI	UL	AI	UL	AI	UL	AI	UL	AI	UL	AI	UL	AI	UL	AI	UL	AI	UL
Male	1000	2500	5	25	420	420	1.3	100	3000	10000	55	400	11	40	90	2000	400	1000	15	1000
Female	1000	2500	5	25	350	420	1.3	100	2330	10000	55	400	8	40	75	2000	400	1000	15	1000

soluble nutrients get absorbed into the body. Therefore, the panel recommended that people eat as little as possible of the “bad” fats, such as saturated fats from meat and dairy and trans fatty acids (hydrogenated oils), because these fats are known to increase the risk of heart disease by raising blood cholesterol levels.

The so-called “good” fats, mono- and polyunsaturated fatty acids, provide the essential fats alpha-linolenic acid and linoleic acid. These fats are essential because the body cannot make them. These “good” fats can be found in foods such as vegetable oils, fish, nuts, and flax. The recommended intakes for alpha-linolenic acid is 1.6 grams for men and 1.1 grams for women, and for linoleic acid, 17 grams for men and 12 grams for women. Most people get at least 50 grams of fat a day. If most of it comes from “good” fats, it is easy to meet these requirements.

Protein

Protein recommendations did not significantly change in this review. The old recommendations were that healthy people needed 0.86 grams per kilogram of body weight per day. The new DRI sets the daily requirement for a healthy adult at 0.8 grams per kilogram of body weight. A person weighing 70kg, for example, would require 56 grams of protein per day. Individuals with HIV are generally recommended to get at least 1.0 gram per kilogram and even more in some situations.

Fibre

For the first time, recommendations were made for a target fibre intake. The guideline is based on studies that show increased risk of heart disease when a person’s diet is low in fibre. Evidence suggests that fibre may also protect the colon from cancer and help with weight control. For adults up to 50 years of age, the recommended fibre consumption is 38 grams for men and 25 grams for women. For people over 50 years old, the recommendation is 30 grams for men and 21 grams for women. Foods high in dietary fibre include whole grains, bran cereals, vegetables, and fruits. Anyone

Table 2: Calorie requirements

	Sedentary Calories required	Active Calories required
5 feet, 1 inch (98–132lb)		
men	1919-2167	2104-2290
women	1688-1834	2104-2290
5 feet, 5 inches (up to 150lb)		
men	2068-2349	2490-2842
women	1816-1982	2267-2477
5 feet, 9 inches (125–169lb)		
men	2222-2538	2638-3078
women	1948-2134	2434-2670
6 feet, 1 inch (139–188lb)		
men	2382-2736	2883-3325
women	2083-2290	2605-2869

with chronic diarrhea should exercise caution when increasing fibre intake.

Exercise

The new guidelines have also taken a strong stance on physical activity. The old guidelines merely said people should be more active. However, many health problems are influenced by activity levels as well as dietary factors. The new guidelines recommend a total of 60 minutes per day of activity. The time of 60 minutes was derived from studies of the activity levels of people who maintained their weight. The time spent on activities is added up throughout the day including low intensity activities of daily living, such as walking and housework, as well as more vigorous exercise such as swimming or cycling.

The bottom line

Try to have balance in your diet. Enjoy eating a variety of foods that provide the nutrients you need for health. Get enough calories to maintain a healthy weight. Restrict as few foods as possible. Be as active as you can. A dietitian can fine-tune your diet to help you meet your unique needs. ⊕



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

Food for thought

HIV and food security in Vancouver's Downtown Eastside

by Pamela Fergusson

Hastings Street in Vancouver's Downtown Eastside is a busy street on a Monday morning. A stream of traffic rolls downhill, funneling commuters, one by one, from the suburbs to their downtown offices. The street is opening up for the day. Workers with ID badges and swipe cards walk past security and into their offices, getting ready for another week.

Already the sidewalks are dotted with line-ups. A little crowd has gathered outside of Positive Outlook at the Vancouver Native Health Society. People are waiting to see a nurse, waiting for breakfast, and waiting to get out of the rain. "Cheque day" is still nine days away and everyone is hungry.

Positive Outlook, a members-only club for people living with HIV, has started serving breakfast because most of its clients depend on Positive Outlook as their main source of food, and they know lunch is not enough. Of all the issues that the Downtown Eastside (DTES) community faces each day, food security may be the most universal.

Ensuring all have access to food

The 1996 World Food Summit proclaimed that "Food security exists when all people, at all times, have physical and economic access to sufficient, safe, and nutritious food to meet their dietary needs and food preferences for an active and healthy life." Most people do not think of food security as a Canadian issue, but people in neighbourhoods all over Canada are food insecure. In 1976, Canada signed the United Nations Covenant on Social, Economic, and Cultural Rights, which includes the fundamental right of everyone to be free from hunger. The Canadian government has since developed a Food Security Bureau and an Action Plan on Food Security.

The domestic policy section of this Action Plan elaborates on commitments Canada made with global partners at the World Food Summit in 1996. The second commitment, Access to Food, states that "We will implement policies aimed at eradicating poverty and inequality and improving physical and economic access by all, at all times, to sufficient, nutritionally adequate and safe food and its effective utilization."

The Action Plan also states, "The question of access also revolves around issues of poverty and social justice. It is the poorest and most vulnerable members of society—the people

with no voice—who are the most likely to be food insecure and the most powerless to change their circumstances...efforts to improve their situations must be sustainable. 'Band-aid' measures, whether they are food banks or emergency food aid, only provide temporary relief. Enduring solutions involve empowering the food-insecure to help themselves."

HIV/AIDS is only one factor

The Food and Agricultural Organization's (FAO) Committee on World Food Security has noted the relationship between HIV/AIDS and food security. In a 2001 paper entitled "Impact of HIV/AIDS on Food Security," the FAO states that "all dimensions of food security—availability, stability, access, and use of food—are affected where the prevalence of HIV/AIDS is high."

For most PWAs in the DTES, getting three healthy meals every day is an impossible challenge requiring strength, resourcefulness, and ingenuity.

True enough for many of the HIV-positive people living in Vancouver's DTES, where disease is only one of the reasons why their food security is at risk. The DTES is Canada's poorest and most vulnerable neighbourhood. It is a community with Canada's highest concentration of HIV/AIDS, injection drug use, and poverty.

Good nutrition is an essential part of good health. For most of us, eating well is a goal we cannot always reach for various reasons. Busy schedules, lack of knowledge about healthy food, high cost of fresh food, illness, lack of cooking skills, and poor access to fresh-food groceries in our neighbourhoods can all contribute to an inadequate diet. Most of the residents of the DTES face all of these barriers and more every day. For these people, getting three healthy meals every day is an almost impossible challenge, requiring strength, resourcefulness, and ingenuity.



Barriers to nutritional health

In 1999, AIDS Vancouver published a study on HIV-positive injection drug users entitled "Building Nutritional Health." They found three main factors impacted the nutritional health of study participants:

- ▼ life issues and eating patterns;
- ▼ access to food; and
- ▼ food quantity and quality.

Life issues and eating patterns include the impact of illness and drug use on food security. AIDS can have a dramatic effect on nutritional status. AIDS may cause malnutrition because of poor absorption and increased nutrient requirements. AIDS and AIDS-related medications often cause nausea, fatigue, and suppressed appetite. People who are also living with addiction will face other barriers. "You smoke for a couple days, then it's, 'Oh yeah, I forgot to eat,'" said one study participant. Another participant told of being on the way to get food with \$50, meeting friends on the street, and spending the money on drugs instead.

Barriers to food security

Access to food is a difficult issue. Many people are unable to stand in meal line-ups. "You get long line-ups, and I have neuropathy," said a participant, "so an hour and a half in the line-up is really cruel when you've got full-blown AIDS." Others who decide to cook for themselves often have to contend with inadequate facilities. Another participant noted, "If you live in one room, and you're tripping around your suitcase and the cockroaches and whatnot to get to your toaster oven or your little hotplate or whatever... actually you become quite an artist to be able to cook at all."

In the DTES Food Provider and Client Survey, conducted by the Vancouver/Richmond Health Authority in 1998, clients identified the top five barriers to food security.

1. Not enough money.
2. Food available is unappealing (poor variety, not food of choice).
3. Can't afford bus fare for transportation to purchase food at large store.
4. Can't store or cook food at home because of cockroaches and mice.
5. Can't travel to food or stand in food lines because of disability.

Food quantity and quality is a frequent topic of discussion in the DTES. Recently, the Food Providers Coalition obtained funding from the Vancouver Health Authority to hire a dietitian to provide education for food providers and clients about healthy eating. One consumer of DTES food services reported, "I'm lacking in fruits and vegetables. I'll try to get those, but it's harder to get vegetables than anything else...it's easy to get starch and sugar and stuff like that." Food providers are aware of this situation, but are not always able to afford healthier choices because of budget constraints. Fifty-five percent of food providers in the DTES rely on donated food and operate on monthly food budgets of \$500 or less. Thirty-one percent have no food purchase budget.

Another barrier to improving food quality is the perception that the DTES community is only interested in sugar and pastries and does not want healthy food. Research has shown this perception to be false. A recent study by the Food Providers Coalition found that most client concerns relate to having too much refined or processed foods in their diets and not enough fibre, whole, fresh, vitamin- or mineral-rich foods, or complex carbohydrates and protein. Those with health concerns requiring a particular diet found it next to impossible to access the diet they need.

Food programs in the DTES

The food security issue in the HIV-positive community of Vancouver's DTES is complex. Many agencies are working to support the community. Two of the most active are Positive Outlook and A Loving Spoonful. Positive Outlook (441 East Hastings) is a drop-in program providing care and meals for their members. It currently has over 1600 clients. Anyone who is HIV-positive is welcome.

A Loving Spoonful delivers frozen meals to people living with AIDS who are at high nutritional risk. A Loving Spoonful also has a hot meal program at the Portland Hotel Café. For more information, contact Lukas, Meal Program Coordinator at 604-682-6325. A comprehensive list of free and low-cost meals in the DTES is available at the Carnegie Centre.

In 1996, Canada joined 186 other nations to endorse the World Food Summit's goal to eradicate hunger and to reduce the number of undernourished people by half by no later than 2015. The need for emergency food aid from food banks and food provider agencies, described as 'band-aid measures' by the Canadian Food Security Bureau, seems to be increasing. Canadians, in a country with a food surplus, should be leaders in the world in reducing and even eliminating food insecurity. However, driving down East Hastings on a Monday morning, you can see we have a lot of work to do. ⊕



Pamela Fergusson is a community nutritionist who works at the Vancouver Native Health Society and sits on the board at A Loving Spoonful.

Deciphering your diagnostics, part 4

Interpreting cholesterol and triglycerides tests

by Lawrence C.

Heart disease is the number one killer in Canada. It is also emerging as a major health concern for PWAs on highly active antiretroviral therapy (HAART). The heart is a strong muscular pump a little larger than a fist. It is part of the body's circulatory system, which includes other organs, such as the lungs, and a network of blood vessels, arteries, veins, and capillaries.

Since 1998, reports have emerged about relatively healthy people with HIV/AIDS developing heart disease or suffering from heart attacks. We know that such factors as a diet high in saturated fat, smoking, heavy alcohol consumption, recreational drug use (particularly cocaine and amphetamines), and a lack of exercise can lead to the development of heart disease, whether you have HIV or not. Additional risk factors include age, gender, lifestyle, and heredity. Blood fat problems such as high cholesterol and high triglyceride levels may also increase the risk. And if that's not enough, now some HIV drugs have been linked to changes in the body's metabolism, which could also increase the risk of heart disease.

PIs and NNRTIs

Protease inhibitors (PI) seem to interfere with the body's ability to break down blood fats. Giorgio Barbarini, MD, of University La Sapienza in Rome studied 1,200 HIV-positive persons. Half of

them received regimens containing a PI and other half took a PI-sparing combination. After three years, 23 new-onset cardiovascular events—12 heart attacks and 11 cases of angina—occurred in the PI arm, compared with two cases in the PI-sparing arm. The factors most highly associated with heart disease were elevated cholesterol and triglyceride levels.

Other studies have shown that HAART regimes that include non-nucleoside reverse transcriptase inhibitors (NNRTIs) also increase blood fats but to a lesser degree. While this side effect may seem alarming, bear in mind that many traditional risk factors besides HAART contribute to a person's risk of heart disease, and all things need to be considered when choosing your HIV medications.

It is highly advisable for PWAs to do everything they can to lower their risk for heart disease by

- ▼ quitting smoking;
- ▼ losing weight;
- ▼ keeping blood pressure and stress under control;
- ▼ exercising appropriately;
- ▼ eating healthy diets (refer to Canada's Food Guide to Healthy Eating);
- ▼ cutting back on saturated fat intake;
- ▼ monitoring regular blood work that measures cholesterol and triglyceride levels; and
- ▼ making informed anti-HIV drug therapy choices

Cholesterol and triglycerides

Cholesterol and triglycerides are fatty substances in the blood and are sometimes referred to as blood lipids. Cholesterol, which is made in the liver from saturated fats in food, is a waxy substance that is found throughout the body. It is essential for the production of sex hormones and the repair of cell membranes. To move around the body, cholesterol joins up with special proteins to form lipoproteins, which are carried in the blood.

There are two kinds of lipoproteins, low-density lipoproteins (LDL), which carry cholesterol from the liver to the cells and high-density lipoproteins (HDL), which return excess cholesterol to the liver. HDL or "good" cholesterol clears cholesterol from the arteries to the liver, where it is removed from the body. LDL or "bad" cholesterol is associated with hardening of the arteries, which can lead to angina, heart attack, and stroke.

Triglycerides are one of the basic building blocks from which fats are formed. They are composed of one glycerol molecule and three fatty acid molecules. See Table 1 for cholesterol and triglyceride levels.

Cause for Concern

The Canadian AIDS Treatment Information Exchange (CATIE) suggests it is

time to be concerned if your total cholesterol is greater than 250mg/dL on repeated measures or if you have an unfavourable cholesterol/HDL ratio (which is variable, depending on age and sex; age above 40 and being male are greater risks).

Factors that would add to the concern include

- ▼ high triglyceride levels
- ▼ family history of cholesterol problems or heart disease
- ▼ diabetes
- ▼ smoking
- ▼ high blood pressure
- ▼ being overweight

Similar to HIV viral load, lipid levels are subject to variation, both from day to day and throughout the day. A single test will rarely provide enough information to guide decisions about intervention. Normally, a series of measurements are required to give a clear picture.

The battle for a healthy heart is a tough one. PWAs need to recognize traditional and other risks that contribute to heart disease and build successful strategies to combat it. A major part of this strategy is knowledge and management of the risks. So, be vigilant, and talk to your doctor about your HIV medications and the possible risks of heart disease. ⊕

Lawrence C. is a member of the BCPWA Society.

Table 1:Cholesterol and Triglycerides levels
(The US National Cholesterol Education Program)

Total cholesterol	
Less than 200 mg/dL.....	desirable
200-239 mg/dL.....	borderline high
240 mg/dL or greater.....	high
LDL cholesterol	
Less than 100 mg/dL.....	optimal
100-129 mg/dL.....	near or above optimal
130-159 mg/dL.....	borderline high
160-189 mg/dL.....	high
190 mg/dL or greater.....	very high
HDL cholesterol	
Less than 40 mg/dL.....	low
40-60 mg/dL.....	normal (acceptable)
60 mg/dL or greater.....	high (desirable)
Triglycerides	
Less than 150 mg/dL.....	normal
150-199 mg/dL.....	borderline high
200-499 mg/dL.....	high
500 mg/dL or greater.....	very high

BIA (Bioelectric Impedance Analysis) is a way of measuring body composition, and has been accepted by HIV nutrition experts as a good way to get information about what's going on with your body.

Body weight and body cell mass are linked to survival. A 10% loss in body cell mass is associated with severe adverse outcomes. Scale weight is not an adequate means of monitoring your health status.

BIA is a simple, non-invasive test. Michele Blanchet, RDN, of Gilwest Clinic, will discuss the results with you.

When: Tuesday, March 18 & Tuesday, March 25

Time: 2:00 – 5:00 pm.

Where: Treatment and Advocacy area, 1107 Seymour Street, Vancouver

How: Call ahead to book an appointment at 604.893.2243, or drop by the Treatment Information Program office.

For more accurate results, please:

- don't drink any alcohol for 12 hours before the test
- don't exercise vigorously on the day of the test

BIA is back!!!



La sexualidad y el SIDA

por Sergio Plata



Desde la aparición del VIH-SIDA la sexualidad pasó del juicio privado al juicio público, aun así nuestra conciencia acerca de la diversidad sexual y el derecho al placer es ínfimo respecto a las prácticas sexuales que van más allá de la reproducción y el coito.

Según Leo Barsani existen ciertas prácticas sexuales estigmatizadas, alguna de ellas es el rechazo histórico al sexo oral, a la imagen de macho penetrado, símbolo de inferioridad y sometimiento. La pregunta es. El recto es una tumba o el lugar donde se lleva a cabo una santa inquisición contra las prácticas antinaturales? Existiendo incompatibilidad entre la pasividad sexual y la autoridad cívica: ser penetrado es abdicar al poder. A partir de esto, es posible concebir como funciona la descalificación moral del homosexual, mitologizado como ser eminentemente pasivo susceptible de recibir todo tipo de castigos por la infracción máxima al principio de autoridad. El padecimiento del SIDA es según esta concepción la consecuencia lógica de una sanción histórica.

En la actualidad el enfoque más claro que ha dado el sistema de salud pública respecto a la epidemia del VIH-SIDA ha sido bajo el término epidemiológico de 'riesgo' y desde esta perspectiva *la sexualidad se convierte en riesgo*, provocando un discurso de miedo a la muerte, miedo al cuerpo y miedo al placer, creyendo que el riesgo de una infección del VIH-SIDA existe únicamente a partir del comportamiento sexual del individuo.

Uno de los retos principales de la sociedad debe ser el de la educación sexual y sus derechos de manera individual, libre y compartida y es dentro del contexto social donde realmente se podrá hablar sobre la sexualidad y el derecho al placer, entendiendo éste como impulsos eróticos inherentes al ser humano.

La sociedad debe ofrecer espacios de educación de información y crear una verdadera disposición política de los

gobiernos para que todos los grupos sociales puedan acceder a los servicios de salud.

Si bien el problema del VIH-SIDA es social, también lo es político, económico y cultural y la sociedad es parte importante del problema, porque finalmente es la sociedad la que marca comportamientos sexuales. Mas allá de las ideas dominantes debemos conocer las necesidades tan amplias como concretas de la diversidad del comportamiento sexual: aprendiendo y entendiendo, tolerando y respetando, educando e informando, es así como iremos construyendo una verdadera democracia sexual.

La educación sexual y el derecho al placer en tiempos de SIDA es tarea de todos porque en la cotidianidad de la vida la sexualidad tiene una realidad y ésta no debe ser de riesgo y miedo, sino de amor, compromiso y conocimiento. Para Jonathan Mann esto nos lleva hasta el umbral del *empoderamiento*, el cual es un concepto muy importante para nosotros. Este *empoderamiento* reposa sobre dos bases: una es la del conocimiento, es decir, la comprensión de la importancia que tienen para la salud los determinantes sociales, las formas en que los derechos humanos pueden ayudarnos a analizar y a responder a las carencias sociales que son la base de la vulnerabilidad a una enfermedad prevenible a la discapacidad y a la muerte prematura. Sin

embargo, también es muy importante la Segunda base: la creencia, la fe y la confianza en que el mundo puede cambiar 2. ⊕



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 Hame a la línea directa: 604.893.2243 email: treatment@bcpwa.org

Volunteering at BCPWA

Profile of a volunteer:



"Joan provides our members with comfort, a relaxing massage, and a good joke or two during a hectic time in their lives. She has been a welcome sight at BCPWA for many years and hopefully for many more to come."

Mike Verburt
Coordinator, Member Services

Joan Hunter

Volunteer History

I am in my seventy-fifth year of volunteering for many charities. I taught seniors exercises until I was seventy. I started with the Red Cross at age eight and have a medal for sixty years of volunteering with them. People with HIV/AIDS have been the nicest and the most grateful.

Started at BCPWA?

I don't count days or hours, just needs—and I felt needed! I think I have done massage at BCPWA for around five years. I also worked in the office answering phones with May McQueen.

Why pick BCPWA?

I could help more people in one day, mostly young men whom I could love in place of my lost son.

Why have you stayed?

Could I find people more deserving, in need, and appreciative?

Rating BCPWA

There is so much caring and dedication, so much real interest in people—the staff aren't just working at jobs.

Strongest point of BCPWA

Acceptance of each and every person. No condemnation!

Favourite memory

Instant acceptance and welcome. Talk about open arms!

Future vision for BCPWA

That some day, people will recognize that everyone has a right to be different and will enjoy what they can contribute.

**Gain
and share your
skills for a
valuable cause**

IF YOU HAVE

- administration skills that include word-processing, or
- law and advocacy skills, or
- research and writing skills, and
- the ability to work independently and in a group,

WE CAN FIND A MATCH FOR YOU IN OUR NUMEROUS DEPARTMENTS AND PROGRAMS!

for further information and an application form **contact:**
volunteer coordination at 893.2298
adriaanv@bcpwa.org
or Human Resources at 1107 Seymour Street

visit our web-site at www.bcpwa.org for further information on volunteer positions

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
info@bcpwa.org
www.bcpwa.org

A Loving Spoonful Location

Suite 100 – 1300 Richards St,
Vancouver, BC V6B 3G6
604.682.6325
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
info@aidsmemorial.ca
www.aidsmemorial.ca

AIDS Prince George

1– 1563 2nd Ave,
Prince George, BC V2L 3B8
250.562.1172
ogodwin@bcgroup.net

AIDS Prince Rupert

Box 848 Prince Rupert, BC V8J 3Y1
250.627.8823
aidspr@rapidnet.net

AIDS Resource Centre – Okanagan and Region

202 – 1626 Richter Ave,
Kelowna, BC V1Y 2M3
250.862.2437 or 1.800.616.2437
arc@arcok.com
www.arcok.com

AIDS Society of Kamloops

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

AIDS Vancouver

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

AIDS Vancouver Island (Nanaimo)

201 – 55 Victoria Rd, Nanaimo, BC V9R 5N9

AIDS Vancouver Island (Victoria)

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

ANKORS (Nelson)

101 Baker St, Nelson, BC V1L 4H1
250.505.5506 or 1.800.421.AIDS
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
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
604.669.5567
asia@asia.bc.ca
www.asia.bc.ca

Dr Peter Centre

2nd Floor, 1056 Comox St,
Vancouver, BC V5E 4A7
604.608.1874
info@drpeter.org
www.drpeter.org

Friends for Life Society

1459 Barclay St, Vancouver, BC V6G 1J6
604.682.5992
ffl@radiant.net
www.friendsforlife.ca

Healing Our Spirit

Suite 100 – 2425 Quebec St,
Vancouver, BC V5T 4L6
604.879.8884 or 1.800.336.9726
info@healingourspirit.org
healingourspirit.org

McLaren Housing Society

200 – 649 Helmcken St,
Vancouver, BC V6B 5R1
604.669.4090
mclarenhousing@telus.net

North Island AIDS Coalition (Campbell River)

684B Island Hwy,
Campbell River, BC V9W 2C3
250.830.0787 or 1.877.650.8787

North Island AIDS Coalition (Courtney)

355 6th St, Courtney, BC V9N 1M2
250.338.7400 or 1.877.311.7400

North Island AIDS Coalition (Port Hardy)

8635 Granville St, Ground Floor,
Port Hardy, BC V0N 2P0
250.902.2238
niac@island.net
www.island.net/~niac

Okanagan Aboriginal AIDS Society

202 – 1626 Richter Street,
Kelowna, BC V1Y 2M3
250.862.2481 or 1.800.616.2437
oas@arcok.com
www.oas.ca

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

250.881.5663
erikages@pan.ca
www.pan.ca

Positive Women's Network

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

Red Road HIV/AIDS Network Society

Suite 100 – 2425 Quebec St,
Vancouver, BC V5T 4L6
604.879.8884 or 1.800.336.9726
info@red-road.org
www.red-road.org

Vancouver Native Health Society

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

Victoria AIDS Respite Care Society

2002 Fernwood Rd, Victoria, BC V8T 2Y9
250.388.6620
varcs@islandnet.com
www.islandnet.com/~varcs/

Victoria Persons With AIDS Society

541 Herald St., Victoria BC V8W 1S5
250.382.7927
support@vpwas.com
www.vpwas.com

Wings Housing Society

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

YouthCO AIDS Society

203 – 319 Pender Street,
Vancouver BC V6B 1T4
604.688.1441
info@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 Positively Happening section of the BCPWA Society website at www.bcpwa.org.

Upcoming BCPWA Society Board Meetings

Date	Time	Location	Reports to be presented
March 5, 2003	1:00	Training Room	Written Executive Director Report / January & February Financial Statements / Director of Support Services
March 19, 2003	1:00	Training Room	Executive Committee
April 2, 2003	1:00	Training Room	Standing Committee / Written Executive Director Report
April 16, 2003	1:00	Training Room	Director of Fund Development
April 30, 2003	1:00	Training Room	Quarterly Department PHSA Report / Written Executive Director Report / Executive Committee / Financial Statements—March
May 14, 2003	1:00	Training Room	Standing Committee

The BCPWA Society is located at 1107 Seymour St., Vancouver.

For more information, contact:

Alexandra Regier, Office Manager

Direct: 604-893-2292

Email: alexr@bcpwa.org

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- I am a PWA and can not afford the full subscription price
- Enclosed is my donation of \$_____ for *living+*
- Please send me more information about Planned Giving
- I want to become a member of BCPWA

Cheque payable to BCPWA



www.bcpwa.org

living+

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

It ain't over till the fat lady sings



by Denise Becker

It's been a very tough, cheerless winter. But, in the midst of it all, a little starburst in my black night reminds me of the Robert Frost quote: "Happiness makes up in height what it lacks in length."

It all started when my mother and father, both in their eighties, became very sick. My mother had a stroke and was told she needed assisted living. Then a very good friend of mine was hospitalized. My husband Lloyd's best friend died of a heart attack on Christmas Day. Lloyd caught the flu on Boxing Day. The stress from all this did a number on my HIV and, before long, my blood counts dipped lower and lower.

A young man in surgical greens approached me. "I'm David, the vet's assistant, and I've been sent to sing to you."

Throughout everything, the family seemed to be ignoring our dog, Molly. So, Molly decided to get in on the act and started limping around the house. Here was yet another problem. I made an appointment at the animal clinic. When we arrived, a receptionist advised me that I might have a long wait because the veterinarian was performing an emergency operation. Being no stranger to waiting in doctors' offices, I smiled and picked up *Dogs Canada* from the magazine table. Thirty minutes later, the receptionist appeared again and offered to buy me a free latte. I gratefully accepted and she ran across the road to the nearest coffee shop.

Finally, after an hour, a young man in surgical green shirt and pants approached me. "I'm David, the vet's assistant, and I've been sent to sing to you."

I looked at him and wondered if I was dreaming.

"What would you like to hear?" he asked.

Still confused, I stammered, "Well, how about John Denver?"

He looked blank.

Obviously not, I thought.

"I don't care what you sing," I

said, "just don't scare the dog.

She's already petrified." I looked down at Molly, who was a pathetic, shaking disgrace to all Dobermans worldwide.

Nervously at first, then more boldly, David started to sing an aria from an Italian opera. The words came sweetly and gently, and I was transported to an olive grove on the slopes of a Mediterranean shore. "Arrete! Arrete!" he sang. The receptionist smiled at me as I sat in perfect serenity.

It was beautiful. In a moment, this young man had made my problems dissolve, and I felt at peace. It was a simple act that made me feel like someone cared.

It also made me think of Pat White. I have waited many times at the downtown Vancouver office of Dr. Julio Montaner. Pat is Dr. Montaner's assistant, and he gives loving attention to patients with HIV every day.

I am sure that you have your own "opera singer." You may even be reading this magazine right now in your doctor's waiting room. How many times do we take the doctor's assistant for granted? They give us welcoming smiles, shoulders to cry on, and lend us a hand in our most needful times. Their job is to support the doctor, but very often they support the patients.

Now, I was thinking: the next time I'm at Dr. Montaner's office, would it be too much to ask Pat to do a rendition of "Knees Up, Mother Brown" or "Roll Out the Barrel"? ⊕



Denise Becker is a board member of the BCPWA Society and founder and former chair of the Hummingbird Kids Society.