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

## British Columbia Persons With AIDS Society

The British Columbia Persons With AIDS Society seeks to empower persons living with HIV disease and AIDS through mutual support and collective action. The Society has almost 4000 HIV+ members.

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opinion and editorial

#### BC needs to get its act together

by Glen Bradford

Ur cover story for this issue of Living + deals with the challenges facing PWAs who live in rural BC. PWAs in the Interior, in northern BC, on Vancouver Island, and on First Nations reservations are under-served, with limited access to HIV care, antiretroviral drug treatments, and general health care. Compounding this issue is the fact that BC lacks a standard set of plain-language informational materials for people who are newly diagnosed with HIV, to guide them through their diagnosis and to help them adjust to their HIV status.

Numerous HIV/AIDS organizations provide information to recently diagnosed PWAs and their healthcare providers. However, these materials have typically been developed on an ad hoc basis. The result has been a patchwork of information, generated by various organizations to meet needs as they arise. This approach inevitably creates costly redundancies and inconsistent information. With each AIDS organization working from its own vision rather than from a comprehensive strategy, PWAs in smaller communities are among those most likely to fall through the cracks.

There is a vacuum in the area of leadership. BC lacks a provincial HIV/AIDS strategy and any formalized informationsharing mechanism. The provincial government has laid the responsibility for HIV health care at the feet of community-based organizations and health authorities, without committing sufficient financial resources to these efforts.

BC's needs are unique because of its geographic surroundings: mountains and water separate the regions, and the province

is divided into only six health authorities, each responsible for vast territories. In addition, BC has a high proportion of foreigntrained doctors who may be familiar with HIV/AIDS in their country of origin, but may not be aware of standards of care or support organizations in this province.

BC needs a comprehensive assessment of all treatment information materials which are presently distributed to newly diagnosed PWAs. The province also needs improvements in HIV/AIDS treatment education for healthcare professionals in rural communities, and the development of standardized materials that take into account the different population groups throughout BC. This must happen now. Otherwise, an increasing number of newly diagnosed people will continue to migrate to the larger cities for care and treatment, forcing them to abandon their social support systems and overburden an already overwhelmed urban healthcare system.

In this issue of the magazine, you'll notice a readership survey. The survey is also available on our Web site, <www.bcpwa.org>. The magazine and our Web site are two ways that the Society fulfills its mandate to empower PWAs with HIV information.

Membership engagement is a critical element of our efforts to eliminate HIV/AIDS health inequalities. However, the success of our efforts is contingent upon fostering communication between our organization, our members, and readers of *Living* +. Please take a moment to complete the survey and return it to us. It costs you nothing and it will help us to improve our communication tools.  $\oplus$  *Glen Bradford is the past chair of the BCPWA Society.* 

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#### New US border procedures

New US border crossing procedures may seriously affect HIV-positive persons. Apparently, US immigration authorities are now routinely asking persons seeking entry to the US if they are carrying any medications with them and, if so, which ones. It is not known why they have started posing this question.

The BCPWA Society has learned of one instance where US immigration officials at the border questioned a Vancouverite about his medications. He answered honestly, listing the HIV drugs he was carrying with him; the officials consequently determined he was HIVpositive and refused entry into the US.

Under US law, HIV-positive persons who are not American citizens are prohibited to travel to the US. (It is possible to apply for a waiver in specific instances, but it is an obscure and complicated process, and only rarely successful.)

If you are HIV-positive and travelling to the US, plan how you will answer any questions about your medications.

#### Viread not safe for co-infection

The US Food and Drug Administration (FDA) has announced that product labels for Viread (tenofovir) in the US will be updated to include a warning that the drug is not indicated for the treatment of chronic hepatitis B (HBV) infection, and the safety and efficacy of the drug have not been established for the treatment of HBV and HIV co-infection.

The FDA recommends that all HIV-positive individuals should be tested for hepatitis B before starting treatment with tenofovir. The product labelling also recommends that HIV and HBV co-infected patients who have been treated with tenofovir should have their hepatic function closely monitored for several months after discontinuing therapy with the drug, and where appropriate, receive anti-hepatitis B therapy.

#### Fat around kidneys predicts who gets lipodystrophy

An ultrasound measurement of fat thickness around the kidneys can accurately predict which HAART-naïve individuals will develop both the body shape disturbances and metabolic abnormalities associated with lipodystrophy syndrome, according to a small Spanish study published in *Clinical Infectious Diseases*. Investigators also found that the procedure could also accurately determine which individuals switching anti-HIV drugs because of body shape changes were most likely to see an improvement in their condition.

The investigators conclude that measuring peri-renal fat diameter is cheap, simple, and safe, and "its...advantages make it the first-choice procedure for the evaluation of this complication."

Source: www.aidsmap.com

#### Detectable CMV predicts new AIDS events

HIV-positive individuals with detectable cytomegalovirus (CMV) are more likely to experience new AIDS-defining illness and die, even in the era of highly active antiretroviral therapy (HAART), according to a UK study published in the *The Lancet*. The study's investigators, from London's Royal Free Hospital, recommend that HIV-positive individuals with detectable CMV receive either more intensive HAART or anti-CMV therapy.

In addition, they call for a randomized controlled trial to be designed to evaluate if pre-emptive therapy for CMV in HIV-positive patients receiving HAART is justified.

Source: www.aidsmap.com

#### Treatment failure not major cause of death

Researchers at the BC Centre for Excellence in HIV/AIDS have found that treatment failure due to drug resistance did not significantly contribute to the mortality of people with HIV in BC between 1997 and 2001. The study is the first to suggest that the exhaustion of treatment options due to drug resistance may not cause as much loss of life from HIV/AIDS as previously thought.

Researchers analyzed the post-HAART cause of death in all individuals who were enrolled in the province's free Drug Treatment Program between July 1997 and December 2001. They concluded that the results "strongly indicate that treatment failure due to antiretroviral resistance was not a major factor influencing mortality in this cohort... for most of the individuals studied, insufficient and/or intermittent exposure to antiretroviral agents, co-morbidities, and other factors likely played a larger role."

Source: www.aidsmap.com

#### Cancer risk among HIVpositive women

According to data from the Women's Interagency HIV Study, HIV-positive women have increased incidence rates for Kaposi sarcoma (KS) and non-Hodgkin lymphoma (NHL). Compared with the general population, lung cancer incidence was also significantly elevated among HIV-infected women, and it seems to be elevated among HIV-uninfected women although additional followup is needed for confirmation. The



standardized incidence ratios for KS and NHL decreased since the introduction of highly active antiretroviral therapy, but they remained significantly higher than the rates in the general population.

Source: www.natap.com

#### MSM beliefs about superinfection

Reinfection with a second strain of HIV after primary infection—also known as superinfection—has been confirmed in several case reports.

A study by the San Francisco Department of Public Health and the US Center for Disease Control and Prevention examined the attitudes of HIV-positive men who have sex with men (MSMs) regarding reinfection. It assessed whether concerns about the potential health effects of reinfection were associated with decreased unprotected anal sex with HIV-positive and unknown status partners.

Research results suggest that despite the lack of widespread clinical evidence that reinfection leads to adverse clinical outcomes, many MSMs are making their own risk reduction decisions about the potential consequences of reinfection. Many men are choosing to reduce unprotected behaviour with known HIV-positive partners, as well as partners who could be HIV-positive. Researchers also found that younger HIV-positive MSMs were more likely to engage in sero-concordant unprotected anal sex compared with older men. *Source: www.natap.com* 

#### oouree. www.matup.com

#### Sharps needle containers deemed unsafe

Peg-Intron is Schering-Plough's brand of injected pegylated interferon. Schering-Plough provides patients and clinics with Sharps containers for patients, family members, care providers, and clinic staff to deposit the used needles.

The Sharps containers are so thin that the needles poke through. The needles may contain enough hepatitis C and/or HIV that if a person was accidentally poked, they could potentially become reinfected or newly infected. There have been reports of accidental needlestick injuries occurring during the process of discarding used needles.



BCPWA Society's float in this year's Pride Parade in Vancouver. The theme of the float was a New Orleansstyle funeral procession, which celebrated lives and mourned losses.

#### Kaposi sarcoma cell origin discovered

Scientists at University College London have discovered that Kaposi sarcoma first develops in the inner cell lining of lymphatic vessels. The cell type in which the sarcoma develops has been a mystery for more than a century, but researchers say that genetic analysis shows that sarcoma cells are genetically similar to lymphatic endothelial cells. These findings could help scientists identify new ways to treat the condition.

Source: American Society of Clinical Oncology

#### Once-daily treatment not answer for adherence

Assuming that a regimen would be easier to adhere to just because it is once-daily could mean that other important factors affecting adherence are neglected, according to a recent study conducted in six US cities.

Investigators found that of seven HAART regimens currently in use, including both once-daily and twice-daily dosing, the one that patients perceived as the easiest to adhere to was a twice-daily regimen involving two pills a day, with no food restrictions, involving a single prescription and repeat prescription, one medicine bottle, and one payment.

The regimen which individuals said they would find hardest to adhere to also involved two daily doses, but with a total of thirteen pills, five of which needed to be taken with food. The regimen involved three prescriptions, three refills, three medicine bottles, and three payments.  $\oplus$ 

Source: www.aidsmap.com



# Network building then and now

by Glyn Townson

#### Then:

Issue #35, April 1990, Vancouver Persons with AIDS Society Newsletter

"The time has come, national network starting"

"A national Network of groups of persons living with HIV was established here in Vancouver at a meeting March 2-4. The process went quickly and fairly smoothly. There was consensus that we need a network and that the time is right, if not long overdue, for a unifying structure to strengthen the voice and address the needs of persons living with HIV.

Sponsored by the Canadian AIDS Society and the Vancouver Persons with AIDS Society, from a proposal developed here in Vancouver in consultation with the other groups involved, the meeting was a great success. For the first time, we were able to put a face to many of the groups we had heard of but not met. This was especially true of very young organizations which have been or are just being formed. One of the aims of the Network is to foster this especially in smaller centres across Canada. Another aim will be to accountably represent these groups on national committees/boards etc. that make decisions affecting persons living with HIV, and to speak on behalf of persons living with HIV in a unified voice. We set up the initial structure to work towards these goals, with a steering committee and four subcommittees. It was a very successful and positive step forward."

(Alex Kowalski)

Nou:

The importance of networking and coalition-building with other organizations has only increased over time. Since the BCPWA Society was founded nearly 19 years ago, it has endured several different municipal, provincial, and federal governments, each posing new challenges to our individual and collective well-being. We have had to fight hard for basic income support, housing, and access to treatment, legal rights, and new medications.

Since the above article was printed 14 years ago, BCPWA has changed names, from the Vancouver Persons with AIDS

Society to the Persons with AIDS Society of British Columbia, relocated from a small office on Hornby Street to the current location on Seymour Street, and grown into a provincial organization with over 4,000 members.

At present, the BCPWA Society actively participates in many different networks and coalitions on local, provincial, and national levels, representing the evolving needs and concerns of its membership. These groups include the Canadian AIDS Society (CAS), the HIV/AIDS Legal Network, the Pacific AIDS Network (PAN), Community AIDS Treatment and Information Exchange (CATIE), the Canadian Treatment Action Council (CTAC), Prisoner's HIV/AIDS Support Action Network (PASAN), and the Canadian Working Group on HIV and Rehabilitation (CWGHR).

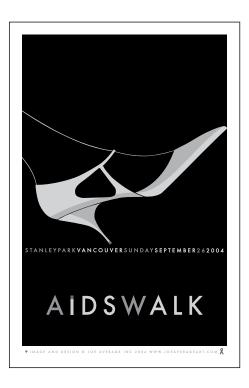
There is strength in numbers. Building stronger connections and alliances with other disability rights organizations enables us to increase the size of the pie rather than fight over the size of each slice.

Take an active role in the issues that interest you. Contact the office or visit the BCPWA Society's Web site at www.bcpwa.org for information on how you can become involved with current and ongoing activities. Links to the agencies listed above are available on the Society's Web site.

In July 2004, BCPWA's Collective Advocacy Committee was renamed the Community Representation and Engagement Committee. The committee is always looking for new volunteers who share their passion for advocating for the individual and collective rights of PWAs. Contact the information desk for dates and times of upcoming meetings.  $\oplus$ 



Glyn Townson is a board member with the BCPWA Society.



# AIDSWALK 04

Eleven community groups to benefit from AIDS WALK funds

**BC Persons With AIDS Society**'s mission is to enable persons living with HIV/AIDS to empower themselves through mutual support and collective action. AIDS WALK is the main source of revenue for the Complementary Health Fund, which provides financial assistance to PWAs to purchase vitamins, clean drinking water, and other services needed to stay healthy and live longer.

**A Loving Spoonful**'s guiding principle is that "no one living with AIDS should live with hunger." That's a bit easier to achieve thanks to their partnership with AIDS WALK. Volunteers and their canine companions enjoy a beautiful day in support of the fundamentals of health. All funds raised by walkers provide tasty, nutritious meals for clients.

**AIDS Vancouver** provides prevention and education initiatives for uninfected individuals who are vulnerable to HIV/AIDS. The organization also assists people with HIV who need help managing their affairs and developing long-term healthcare plans. WALK proceeds, allocated to the Case Management Financial Assistance Fund, provide support to meet critical short-term needs of PWAs.

Asian Society for the Intervention of AIDS provides culturally appropriate and language-specific support, outreach, advocacy, and education on HIV/AIDS and related issues. WALK proceeds support the volunteer-driven Positive Asians Dinner, supplement the PWA volunteer honorarium program, and contribute to emergency financial support to enhance the quality of life for Asian PWAs and their families.

**Friends For Life** provides complementary health services, free of charge, to people with life-threatening illnesses such as hepatitis C, AIDS, and cancer. WALK proceeds are used to provide massage/bodywork, workshops, individual counselling, support groups, meals served in a warm social environment, and care for individuals who are confined to their homes.

**Healing Our Spirit**'s mission is to prevent and reduce the spread of HIV/AIDS and to provide care, treatment, and support services to Aboriginal peoples infected with and affected by HIV/AIDS. WALK proceeds will assist Aboriginal PWAs with emergency funds, moving expenses, food vouchers, participation in the APHA retreat, and the annual Christmas Dinner.

**McLaren Housing Society of BC** provides safe, affordable housing to people with HIV/AIDS who are living on very low incomes. Currently, McLaren administers 62 apartment homes at Helmcken House, Mole Hill, and Seymour Place as well as 32 portable housing subsidies in downtown Vancouver. WALK funds go directly towards rent subsidies to help reduce the long wait list, which currently has over 200 names.

**Positive Women's Network** supports women living with HIV/AIDS to make informed choices. PWN provides safe access to support, advocacy, and education/prevention to women and their communities throughout BC. Because safe, affordable housing is a serious concern for women living with HIV/AIDS, WALK proceeds will fund portable housing subsidies for clients.

**Surrey HIV/AIDS Centre Society** has a number of programs that will benefit from the AIDS WALK, including The Djaeff Mahler Grocery (a high-protein supplementary food bank) and subsidized housing.

**Western Canadian Pediatric AIDS Society** is committed to helping children infected with or affected by HIV/AIDS by providing specialized recreational, social, educational, and support programs. WALK funds will go toward the Camp Moomba program, which builds a fun, enriching, and supportive community through a summer camp.

**Wings Housing Society** believes that every person living with HIV/AIDS deserves adequate, affordable housing. Wings provides 110 portable rent subsidies and operates a 31-unit apartment building for PWAs. WALK proceeds will be used for direct client emergency needs.

**YouthCO AIDS Society** is a youth-driven agency that works with youth ages 15-29 to address HIV, hepatitis C and related issues. It provides prevention education and support services, sexual health and harm reduction information, volunteer opportunities, and referrals. WALK proceeds will be allocated to their Support program, which provides support and information as well as coordinates discussion groups, social dinners, recreational activities, and retreats.

#### Participate in the AIDS WALK

#### Where the money goes

All proceeds from AIDS WALK 04 go to direct services for persons living with HIV and AIDS in your community! These services are provided through the BCPWA Society or one of our 11 Community Partner organizations.

Form a team
Walk on your own
Or walk with your dog!

#### Just 3 easy steps to get involved

Call 604.915.WALK or email us at walk@bcpwa.org

- Collect pledges
- **Walk the WALK**

## BCPWA Advocacy gets results!

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

- ▼ \$12,918.95 in debt forgiveness.
- ▼ \$54,782.98 in housing, health benefits, dental and long-term disability benefits.
- **\$31,000.00** in Monthly Nutritional Supplement Benefits.
- ▼ \$369,925.00 into members' hands for healthcare needs, from grandfathered Schedule C benefits.



AIDS conference notes inequalities in fighting the AIDS epidemic

expanding access

here is a crucial need to address the social, political, and economic inequalities of women and youth and empower them to protect themselves against HIV, according to experts at the XV International AIDS Conference in Bangkok, Thailand. Failing to do so will undermine the long-term effectiveness of any effort to fight the AIDS epidemic.

To succeed at preventing new infections among women and young people, "we must challenge the status quo and pursue creative and, at times, controversial prevention programs that speak to the realities of their lives," said Dr. Joep Lange, president of the International AIDS Society and conference organizing committee co-chair.

In the closing session, Mrs. Sonia Gandhi from the National Advisory Council, Government of India said, "the fight against AIDS is intrinsically connected with the efforts for achieving gender equality."

#### Women's lives at risk

In sub-Saharan Africa, women account for 60 percent of people living with HIV. Thirteen women are infected to every ten men. Existing HIV prevention strategies have failed to stop new infections among women and girls. For some women, their only risk factor is being married and being a faithful wife. According to some studies, married female adolescents are contracting HIV at a faster rate than sexually active unmarried teens.

Many women are vulnerable to HIV infection because they are unable to negotiate safer sex due to gender-based and societal power imbalances. In Africa and Asia, the worst affected countries, it is unrealistic for women to insist that their husbands use condoms, because they risk violence as a consequence of speaking out. Furthermore, at present there are no female-controlled HIV prevention methods such as microbicides.

Young girls and women must be educated to increase the knowledge, self-confidence, and independence they need to protect themselves from HIV/AIDS. Adolescent women get involved with older men, and because they are in love, poor, inexperienced, and lack appropriate AIDS education, they are at risk of HIV infection. Twenty-five percent of South African women are infected by the age of 22.

The conference highlighted the impact of AIDS on women and the importance of addressing social and economic factors that increase women's vulnerability to HIV infection. Reducing violence, to HIV education (including mother-tochild transmission), protecting women's rights, and ensuring equal access to prevention information and services are all essential to HIV prevention.

#### The need to engage youth

More than 50 percent of the 14,000 new infections that occur each day are among young people aged 15 to 24, and 2,000 are among children under the age of 15.

Young people are particularly vulnerable to HIV infection because of lack of access to HIV prevention information and health services, and because existing prevention initiatives fail to engage their interest. In many parts of the world, young people are educating themselves and their peers and demanding a leadership role in the services and programs that serve them.

Youth at the conference stressed that their involvement is critical to effective prevention programs. They want to be considered active participants in these efforts. "The key to prevention lies in giving us options, not ideologies," said a youth speaker with HIV. "We need to be accepted for our choices, not despite them—anything else will just fuel this epidemic."  $\oplus$ 

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



COVER STORY

The challenges of living with HIV in rural BC by Zoran Stjepanovic

ccording to statistics from 1989-2002, the Vancouver health region still accounts for the largest number of cumulative HIV-positive test results in the province at approximately 73 percent. Nevertheless, roughly 27 percent of new HIV diagnoses come from the interior and northern regions of BC, Vancouver Island, and the Fraser region.

continued on next page

iving in a rural community in British Columbia presents some unique challenges for people living with HIV/AIDS (PWAs). The BCPWA Society receives approximately 29 percent of its treatment inquiries from rural BC. Rural members often express frustration with finding a doctor. Some claim that their healthcare providers have never had an HIV-positive patient before, and others report that they never received preor post-test counselling with their HIV test. Perhaps the most common complaint expressed by PWAs living in rural areas is the issue of access to medical and social resources, which are concentrated in Vancouver. Living in the city provides more convenient access to HIV specialists and to the BC Centre for Excellence in HIV/AIDS.

For many rural PWAs, these problems are compounded by HIV-hepatitis C (HCV) co-infection. Approximately 3,350 British Columbians are infected with both HIV and HCV, which accounts for approximately 30 percent of the total estimated number of HIV/HCV co-infected people in Canada. Many aboriginal people, whose rates of HIV infection have increased from 13.3 percent to 15.9 percent between 2000 and 2002, are also co-infected with hepatitis C; a number of them live in rural communities where access to care and treatment remains limited.

#### Priorities for Action – all talk and no action

In September 2003, the provincial government released a report entitled *Priorities for Action in Managing the Epidemics* – *HIV/AIDS in British Columbia: 2003 – 2007*. The document offered an analysis of HIV/AIDS in BC and set broad objectives for the next five years, such as reducing the incidence of HIV infection by 50 percent and increasing the proportion of HIV-positive individuals who are linked to appropriate care, treatment, and support services by 25 percent.

Unfortunately, while *Priorities for Action* proposes to increase awareness of services in rural communities, it fails to address the issues of stigma and confidentiality frequently encountered by PWAs living in remote areas. Moreover, while this government plan invites stakeholders, community-based organizations (CBOs), and AIDS service organizations (ASOs) to achieve objectives as best as they can, it has not committed additional resources to these efforts.

Linking HIV-positive individuals to appropriate care, treatment, and support, without additional financial resources, becomes a serious challenge for rural CBOs and ASOs. It simply isn't possible to provide consistent and ongoing support services, in outlying areas within a broad geographic radius, without increased funding.

Similarly, while this government document acknowledges the importance of HCV screening for all HIV-positive individuals, it proposes neither an action plan nor funding resources to ensure that rural PWAs become educated about the importance of HCV screening. In addition, the document fails to address the reality that hepatitis C services and care are in very short supply within rural BC

#### Time to get creative

Many PWAs are finding creative ways to deal with the challenges of providing AIDS education, support, and treatment information in rural communities. Previous issues of *Living+* note the spirit of collaboration between people and community agencies in rural BC; crisis can foster cooperation, especially when resources are limited. Information is critical to selfempowerment—simply having the knowledge of available resources can be an important starting point.

#### Finding a doctor who accepts HIV-positive patients can also be a challenge for rural PWAs. For Mark, who lives in Nelson, that took a long time.

The *Priorities for Action* report emphasizes the importance of ASOs collaborating and involving PWAs to implement objectives. There have already been excellent examples of such cooperation, such as ASOs in the Interior and the North who are working with First Nations communities to provide support to aboriginal British Columbians in those areas.

William Porter, chair of ANKORS, says that the absence of an AIDS community in rural settings is extremely challenging, but when such a community does develop, the feeling of mutual support transcends what is usually found in urban centres. He recalls how he felt very welcomed by ANKORS staff and volunteers when he visited there for the first time.

Finding a doctor who accepts HIV-positive patients can also be a challenge for rural PWAs. For Mark, who lives in Nelson, this process took a long time and his doctor required a lot of education about HIV/AIDS. The financial and logistical challenges involved in travelling long distances to see an HIV specialist makes this option impractical for many. One creative way of addressing this problem would involve having a mobile HIV clinic, in which HIV specialists would visit rural communities on a rotating basis.

#### Home visits

There are a number of organizations in rural British Columbia that provide support to HIV-positive individuals. Some agencies will even arrange home visits.

Paul Lagace, the client services coordinator with the AIDS Society of Kamloops, visits anyone needing supportive counselling, advocacy, or information on physicians in their communities. His travels include a broad area covering Merritt, Lillooet, Williams Lake, and Clearwater. Lagace observes that the fear of being identified as HIV-positive remains a huge bar-

rier for PWAs in rural areas, since stigma and ignorance are still prevalent. Still, he says, there are some good doctors in small communities who are knowledgeable about HIV.

Lana Maree is the outreach service worker with ANKORS and her work covers a 600 km geographic radius, encompassing both the West and East Kootenays. She provides home visits and support to PWAs in the Kootenays. Currently, Maree is researching doctors in the Kootenay region who have knowledge of HIV and are accepting new HIV-positive patients.

The Internet also offers PWAs in rural communities a method of accessing information and communicating with one another. The Positive Women's Network, for example, operates Women and Virtual AIDS Education (WAVE), which provides support, advocacy, and education through a Web site. Users can remain anonymous and the site enables HIV-positive women in rural communities to connect with each other for mutual support and information sharing.

#### It simply isn't possible to provide consistent and ongoing support services, in outlying areas within a broad geographic radius, without increased funding.

Although living with HIV presents many challenges for people living in rural areas of BC, these difficulties are not insurmountable. Education workers from ASOs that serve rural communities are committed to increasing and expanding their efforts through awareness events, workshops, and displays to eradicate the stigma around HIV. They also stress that rural doctors and other healthcare providers need to be brought up to speed on HIV treatment options. In addition, healthcare workers and other professionals working with PWAs need to be sensitized to the importance of confidentiality in small communities.

Finally, rural ASOs provide a range of educational, advocacy, support and referral services. Other agencies have developed Internet resources, which allow PWAs living in rural areas to access information and communicate with one another. And, rural ASOs have generated a number of creative solutions to continue to meet the needs of PWAs in their communities. But their ability to implement these plans is restricted by limited provincial funding. The allocation of additional financial resources to rural ASOs, as well as provincial organizations serving rural communities, is clearly critical to effective ongoing outreach and

service delivery.  $\boldsymbol{\Theta}$ 



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

#### **Resources out there**

Each of the organizations listed below provide services for HIV-positive individuals in rural communities.

Contact information for each organization can be found on page 38 of this magazine. Chee Mamuk can be reached through the BC Centre for Disease Control in Vancouver. The telephone number is: 604.660.1673, email: cheemamuk@bccdc.ca.

AIDS Prince George is a community-based organization offering education, prevention and support services in the Prince George area.

AIDS Resource Centre – Okanagan and Region provides support groups, counselling, health maintenance programs, information, and referrals to appropriate health services in the Kelowna region.

AIDS Society of Kamloops offers peer-driven positive support groups, as well as client advocacy services. Other services include pre- and post-test counselling, physician information updates, and services directed to aboriginals.

AIDS Vancouver Island offers a positive wellness program consisting of counselling services, advocacy, information, and referrals to community resources and professionals.

**ANKORS** offices are based in Nelson and Cranbrook. Services cover the Kootenay region. ANKORS provides outreach, advocacy, and support services, as well as a resource library.

*Chee Mamuk* offers culturally appropriate, on-site, community-based HIV/AIDS and sexually transmitted disease education and training to aboriginal communities, organizations, and professionals within BC.

*Healing Our Spirit* provides services throughout BC for the aboriginal population. Services include family support and advocacy, peer support counselling, referrals to appropriate community health services, and cultural healing programs.

**Positive Women's Network** offers a range of education and support services to HIV-positive women throughout BC. The Women and AIDS Virtual Education (WAVE) initiative is an Internet-based support, advocacy, and educational resource.

The BCPWA Society offers support, prevention, and treatment information to HIV-positive members throughout BC, including mobile HIV Treatment and Care workshops conducted in rural communities in collaboration with the BC Centre for Excellence in HIV/AIDS.

# Talk to your doc

Glen Bradford talks with Dr. Fraser Norrie about the patient-doctor relationship

Dr. Fraser Norrie, a family resident doctor since 1989, works at Spectrum Health, Three Bridges Community Clinic, and is a teaching doctor at the Family Practice Residency Program of St. Paul's Hospital with the new graduates of the University of British Columbia.

**Glen Bradford**: How should someone find a new doctor that is HIV knowledgeable?

**Fraser Norrie**: Ask your friends or people you respect who have personal experiences or recommendations. The BCPWA Society and AIDS Vancouver keep a registry. Contact the HIV Infectious Disease Clinic on the 5th floor of St. Paul's Hospital.

GB: What questions should they ask?

**FN**: If you're not sure if your family doctor is HIV knowledgeable or comfortable with HIV and you have just found out you are HIV-positive, ask them if they have any other HIV-positive patients, or do they have any experience dealing with people who are HIV-positive, are they comfortable treating people with HIV and what their thoughts are. Do they recommend you stay with them or do they recommend someone who is more knowledgeable?

**GB**: One of the problems we are hearing about from rural communities is that the doctors are not familiar with HIV in any way and are reluctant to become more knowledgeable about the disease. Instead, they send them to a major urban centre. They don't want to deal with the stigma of having an HIV-positive person in their practice.

**FN**: I would suspect that a lot of that reaction comes from feeling that they don't have the experience or expertise. HIV has become such a specialized area and the medications are so complex that they just don't feel comfortable when there may be someone out there with more experience. The reality is that there is more experience in large urban centres. HIV can be managed by the family doctor, just like other illnesses, with referrals and consultations with specialists as need be. The College of Family Physicians is trying to support that model because we realize there are not enough HIV or sexually transmitted disease specialists to take care of everyone who is HIV-positive.

**GB**: How do you feel when I come in armed with treatment information on a half a dozen things that might be wrong with me?

**FN**: The whole idea of patient empowerment is that it is your right to take direction or take an interest in your own health. I think it's even more than a right—I think it's a responsibility. The patient is the number one advocate for his or her own health. I learned very early in my HIV work that I could learn an incredible amount from my patients. People will bring me articles. Doctors have to be open to that and have to take some of it with a grain of salt by looking at the source of the information. You still need the doctor to interpret the information to determine what's reasonable and what isn't.

You just have to be careful you don't bring in so much information that it overwhelms the visit. It's good to write down questions you want to ask, but prioritize them so that you're dealing with the most important issues up front. You don't want to run out of time and miss the opportunity to talk about the reason you came in.

**GB**: If a patient wants to keep a health journal, what would you recommend as important information in the journal?

**FN**: I like the idea of the health journal so you know what medications you've been on, what kind of specialists you've seen, and what kind of problems you've had with your medication. It's very difficult even for a very organized family doctor to keep everything straight. You don't have sole responsibility, but if you're organized and you know what medications you have been on in the past, what you have had problems with, or what specialists you have seen, that's very helpful to both of us. Again, it's a partnership. Even in a hospital setting such as emergency, you're not always thinking clearly and it's helpful to have that information handy.

**GB**: What steps could a patient take if they want a more empowered relationship with their doctor, but this has not historically been the way they interact?

**FN**: When you're talking about empowerment, you need to have someone you can talk to, who you can ask questions about your disease, and who is open to telling you if they don't know the answers. You want someone who's prepared to work with you to find the answers. The model of patient empowerment is becoming more dynamic.

There's going to be personality styles that affect the interaction. If you're not happy with your doctor, you need to tell them that. Tell them you want to be involved in decision-making, that you don't want it to be a one-way dogmatic interaction. The flip side of this is that some people prefer the more traditional model; they don't want to make decisions about medications.

**GB**: In the old days, I would have just bailed on a doctor I wasn't happy with. But with you, I'm trying to hang in there and say when I'm not happy. I'm trying to stay in the relationship and work it through.

**FN**: If you look at it that way, it's kind of an investment. You're spending a lot of time and energy getting to know your doctor and vice versa, and training them to treat you the way you like to be treated. They're also training you about the way they run their practice. Starting over is frustrating for everybody, but especially for the patient.

If you aren't comfortable yourself or the doctor is rushed because they're behind schedule, then write them a letter. I would really recommend the letter. That way, the next time you go in you can talk about that. Or, if you want to bring up issues face to face, you may want to make a specific appointment about your concerns; that's completely appropriate and it will show the doctor that this is important to you. Also, you won't get sidetracked from the health issues you're both trying to deal with, while underneath you're pissed off about something else.

**GB**: Is it appropriate to bring an advocate in with you? **FN**: Yes, you always have the right to bring someone in with you who's a friend; they don't have to be related to you. But I would be careful calling them an advocate because it puts

#### It's kind of an investment. You're spending a lot of time and energy getting to know your doctor and vice versa, and training them to treat you the way you like to be treated.

your support person in an adversarial position. Have them there as a friend so that the doctor doesn't get his or her back up. So often, patients have to fight with their insurance company, or their income provider; but you don't want to be in that position with your doctor.

**GB**: I have noticed that if you don't have the answer to a health issue, you will say so and seek help. I like this honesty. How does this approach impact other patients?

**FN**: I think that the old school approach, where the doctor was viewed as having to have all the answers, just isn't the reality. And I learned that a long time ago. It's important if you don't have the answers to say so. You don't want to bullshit because it ends up making everyone look bad and uncomfortable.

The flip side is don't expect the doctor to have all the answers. If they don't have the answer right away, don't take that as a sign that they aren't a good doctor. It's impossible to know everything about HIV, especially with all the different medications, side effects, changes, and interactions.

**GB**: I think the next step we're going to see in the future of health care and empowerment is more of an integrated health-care model, where the patient is at the center and they have a GP, an HIV specialist, with occasionally a naturopath, a physiotherapist, a case manager, and/or some form of therapist. It will be more of a team approach with the patient in the center, managing the team. No one can be all that we need.

**FN**: I agree with you completely. I see my role as being one person in the cog of health care. Family doctors can help coordinate the team and navigate through the heathcare system.

**GB**: Do you have anything you want people to know?

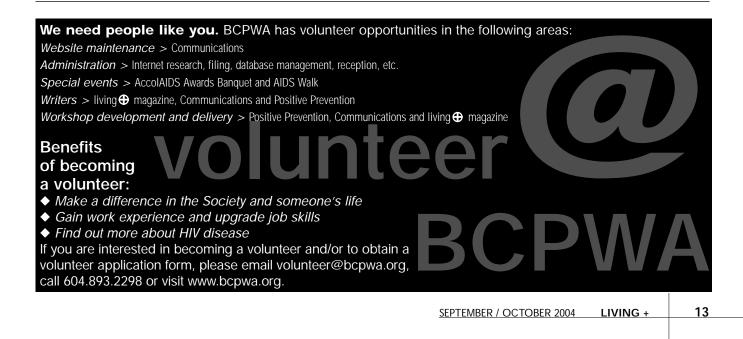
**FN**: Look at your health care as a partnership involving shared responsibilities—it should be a dialogue. Be respectful of each other as people. If you want to call your doctor by their first name, you should ask them because some doctors won't feel that's okay.

Remember, we have bad days too. HIV medicine is very interesting, but it's also very emotional. People are still dying of HIV, and because of the relationship we develop with our patients, we can get very close to people and it does affect us. If somebody had a bad reaction to medication, we're going to feel badly about that. Remember that doctors are people with insecurities just like everyone else.

**GB**: Thank you for taking the time to share your thoughts, Fraser.  $\oplus$ 



Glen Bradford is the past chair of the BCPWA Society.



# FIGHTING WORDS

# The evolution of **AIDS** advocacy

by Jeff Anderson

IDS has challenged the health, medical, and social network like no other issue in modern times. People with HIV experience greater continual need than perhaps any other group of people living with disease or illness. While the advocacy movement has had some great successes, PWAs continue to face tremendous hurdles to find dignity within their communities as their lifespan extends.

Social and governmental systems were wholly unprepared for the AIDS epidemic when it emerged in the early 1980s. Advocacy efforts, which organized early on in response to this health crisis, effectively pressured the medical system to consult with PWAs on drug trials and on hospital and health committees to a degree unheard of prior to the epidemic. Over the years, disability groups and governments have responded to the needs of PWAs. And the stigma of AIDS has decreased somewhat.

However, as we enter the third decade of the epidemic, the AIDS movement is under pressure to win continued advances in the areas of health and social justice and is under increased criticism for diminishing successes.

In the 1980s, advocacy first took the form of support groups to help PWAs search for medical answers and adjust to what was essentially, at that time, an imminent death. When families and communities refused to acknowledge HIV, AIDS organizations emerged to target collective needs.

It took public demonstrations and civil disobedience in the US before the Reagan administration would even acknowledge the existence of AIDS. New York's AIDS social action group, ACT UP, spawned chapters around the world, including Vancouver, at a time when civil disobedience seemed to be the only way to speed government and medical responses to emergency needs. We caught the attention of unresponsive officials through loud whistles and by chaining ourselves to the offices of government, health facilities, and pharmaceutical corporations. "Silence = Death" became the rallying cry.

The AIDS quilts were perhaps the first visible advocacy tools, calling attention to lost lives while simultaneously honouring the memories of PWAs. Following that, the red ribbon became synonymous with HIV/AIDS; when celebrities began wearing them to awards ceremonies, we knew that AIDS had become a recognized social movement. People uninfected with HIV began wearing the ribbons. The tactic was so successful that other health causes began to use the ribbon motif for their respective causes.

Successful advocacy often requires a catchphrase for demonstrations and placards. When combined with effective public protest and institutional pressure, they can have great success. Indeed, the "Patents = Death" slogan, which was created to highlight the right of countries to produce medicine necessary for survival of their citizens, has been partly responsible for recent international trade agreements and for Canada's pending legislation to produce generic drugs for poorer countries.

Advocacy successes in British Columbia range from universal HIV drug access and increased provincial disability benefits through the monthly nutritional supplement, Schedule C, to improved conditions for prisoners and addiction-challenged PWAs. Few can forget front-page pictures of Premier Van der Zalm's car, splattered with red paint to represent blood. Such actions throughout the past two decades have helped gain quicker access to benefits and medicine.

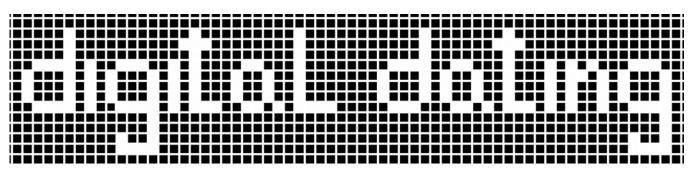
PWAs continue to live in poverty, face stigmas, and experience increasing needs for affordable housing and social supports. Given that governments resist even the word "advocacy", our work is as difficult and as essential as ever. Whether we are still up to the job will depend on our success in alleviating devastating poverty and poor living conditions—and helping PWAs gain

greater inclusion into their communities.  $\oplus$ 



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

# prevention



Taking precautions when using Internet and phoneline dating services

by Melissa Davis

friend Brian swears by phone sex services. "Dating for the electronic age—quick and dirty," he says. "The first-time sex is never a disappointment, and I don't have to spend the night."

Telephone and Internet dating have become increasingly popular amongst the single set in recent years. And the trend doesn't seem to be restricted to any particular demographic although women do seem to gravitate more towards Internet dating, while men use both the Web and the telephone. Various companies target their services to either male or female users and also on the basis of sexual orientation. Service users can create individual "profiles" detailing everything from their age and HIV status, to hobbies and fetishes.

The broad appeal of telephone and on-line dating makes sense. On the one hand, it provides shy people with viable alternatives to the bar scene, blind dates, and other highly social venues where people traditionally meet. On the other hand, it offers bolder types a novel approach to cruising. The appeal also exists in the fact that these services provide something for everyone—anonymous sex, casual dating, and even the opportunity to explore and cultivate a serious, intimate relationship.

All this, and so much more, from the privacy of your own home! Safe, convenient, easy. Sign me up!

#### Quick and easy

That's what Jamie, a single, HIV-positive, gay man in his late forties thought. He used Web-based dating services, directed at men who have sex with men, for about a year. "The draw was easy," he said. "Quick. Anonymous."

Jamie was looking exclusively for anonymous sex and found the Internet services very accessible and a fast, easy way to meet other guys in Vancouver. "Initially, it was quite addictive, especially after some successful hook ups. I could see how people get obsessed with it—that 'high' of casual, anonymous sex," he said.

However, Jamie also cautions new users about these services; his advice is applicable to both Web and phoneline dating. "Don't try to make the service something that is isn't." Although the purpose of casual phone and on-line cruising is to meet for sex, there is a high degree of no-shows for sex dates. It goes without saying that some people simply don't present as well in person as they do on-line or over the telephone. "I limited my expectations," Jamie said. "I wasn't looking for romance—and, in that sense, I knew I wouldn't be disappointed if things didn't work out."

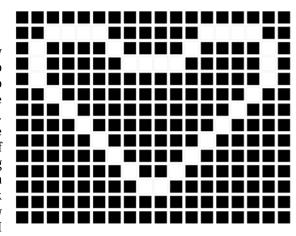
HIV-positive people who use the Internet and phoneline dating services for anonymous sex, casual dating, or to explore

# Some PWAs feel more comfortable disclosing their HIV status in an on-line communication rather than during a personal meeting.

relationship possibilities, encounter some unique issues. Many PWAs appreciate the uninhibited quality and freedom from disclosure that is possible when masturbating during phone and on-line sex. Disclosure issues often arise for PWAs who meet for sex and want to communicate their status and negotiate safe play practices. As well, chatting on-line or via e-mail for an extended time, without a personal meeting, can create a certain quality of depth, intimacy, and trust. For this reason, some PWAs feel more comfortable disclosing their HIV status in an on-line communication rather than during a personal meeting: words can be carefully chosen, nervousness can be concealed, and the recipient has private time to consider the information and how they wish to respond.

#### A great leveler

Andrew is a forty-five year old gay male who lives in Seattle. He also describes himself as someone "who happens to be HIV-positive"—one of many aspects of his identity. Andrew began exploring on-line dating services initially out of curiosity, but with the underlying hope of meeting someone with whom he could connect. "I think that using the Internet is *the* new way of meeting people," he says. "I



am in my mid-forties and don't go out drinking or socializing in the gay scene here in Seattle, which effectively limits my options of meeting someone."

While Andrew claims that Web-based dating can be somewhat impersonal, he also views it as "a great leveler"—a communication tool to discern whether or not you have compatible interests or chemistry with people you meet on-line. "I think the Internet enables two people to get to know each other's attitudes, feelings, outlooks, and what they are looking for in the other person."

Andrew approaches disclosure as he always has: "I decided years ago that 'honesty is the best policy'. While it is a gamble that the other guy may walk away after finding out I am HIVpositive, living with integrity, for me, means disclosing before we get sexually involved."

Andrew and Jamie's objectives were very different, but somehow they connected on-line. While Jamie stated clearly at the outset that he was not looking for a relationship, he couldn't deny that their e-mail exchange had created some "spark". Both of them agree that the outcome has been wonderful. "Sometimes I'm still amazed that we met at all," says Andrew. "But day after day my interest about Jamie grew and, after we really started to get to know each other, we decided to meet." Although they have been maintaining a long-distance relationship between Vancouver and Seattle over the past year, Andrew is planning to immigrate to Canada within the year.

So, what do we make of newfangled dating rituals in the electronic age? Telephone and on-line sex can be fun, thrilling, and safe. Hooking up for sex in person can also be fun, but remaining cautious and mindful of personal safety is important. Taking the time to get to know someone on-line can be a good experience, provided you keep your expectations reasonable. As Andrew says: "Don't get your hopes up that technology is going to find your knight in shining armour. The Internet and the telephone are just tools, which bring people together. It's the people that make things work, not a telephone dial or a keyboard."

#### Tips for using phone dating lines and Internet dating sites

#### When creating a voicemail or on-line profile:

▼ State clearly and briefly who you are and what you are seeking.

▼ Be cautious about how much information you reveal: too much might compromise your privacy, too little might create suspicion. Honesty is the best way to avoid disappointment.

When talking on the phone or chatting on-line:

- ▼ Determine whether you can trust a person before disclosing your home or work telephone number or e-mail address. Use a phoneline dating service to keep your own telephone number private, and/or set up a separate, free e-mail account to use for dating.
- ▼ You can report problem callers to the phoneline dating company's customer service department. They can block the caller's number from system access. Similarly, if you receive any e-mails that cause concern, don't hesitate to block the sender's e-mail address and/or create a new e-mail address and profile for yourself.
- ▼ It's easy to be very open from behind a computer screen, but keep in mind that there are dishonest people on-line. Be cautious about the risks involved in disclosing very personal information and sending photographs through the Internet.

#### Hooking up for a date or sex:

- ▼ Consider meeting, for the first time, in a busy public place such as a coffee shop, restaurant, bar, or with friends. Don't rely on your date for transportation. This will give you the flexibility to leave when you want. Later, if you feel confident that your date is trustworthy, you can always go somewhere more private.
- ▼ Tell someone about the date: who you are meeting, the time, and the location. Leave a note or voicemail, send an e-mail, or ask someone to phone your cell phone at a certain time to make sure you are okay.
- ▼ Use common sense and basic rules of personal safety. If you feel uncomfortable, trust your intuition and leave.
- ▼ If you plan to meet a stranger for sex, take condoms with you.
- ▼ Don't feel pressured to do anything you don't want to.
- ▼ If your safety is threatened or you are harmed in any way, the incident can be reported to the police. ⊕



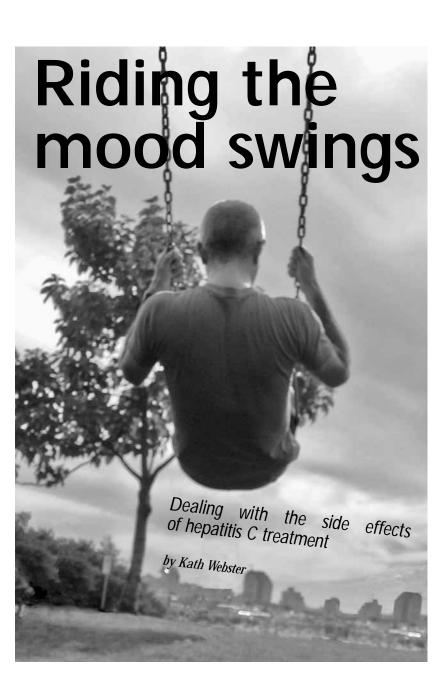
Melissa Davis is a Vancouver-based freelance writer and editor.

# treatment information

#### TREATMENT INFORMATION PROGRAM MANDATE & DISCLAIMER

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

The Treatment Information Program endeavors to provide all research and information to members without 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 responsibliity for, damages, costs, or consequences of any kind which may arise or result from the use of information disseminated through this program. Persons using the information provided do so by their own decisions and hold the Society's Board, staff, and volunteers harmless. Accepting information from this program is deemed to be accepting the terms of this disclaimer.



pproximately 30 percent of HIVpositive people in Canada are coinfected with hepatitis C. The current treatment for hepatitis C is pegylated interferon (Pegetron) combined with ribavirin, which is injected once a week for either 24 or 48 weeks. Interferon is very effective and 40 percent of people (higher for people not co-infected with HIV) can reach an undetectable viral load after treatment.

continued on next page

However, like all drugs, interferon has side effects. Along with flu-like symptoms, it can cause severe mood swings, depression, irritability, and anxiety. Up to 33 percent of people who take interferon reported such cognitive side effects.

Three Vancouver men who are co-infected with HIV/HCV describe their experiences with interferon:

#### **Joe** – recently completed 24 weeks of treatment

"I was told that hep C treatment would be prolonged and sometimes severe. Initially, Pegetron really affected my mental state which, in turn, affected those around me. I had extremely raw nerves and my ability to control my feelings was almost nonexistent. I was unpredictable and never knew when I would have an outburst of any emotion ranging from the blues to crying. My emotions were just below the surface and my psych drugs needed to be adjusted. Thank god for my psychiatrist.

Eventually, the side effects dissipated somewhat and it was just three or four days of the week that were difficult. I learned to cope with the emotional roller coaster. I would phone friends or the clinic social worker for moral support or just to vent. Sometimes I would isolate myself to avoid outbursts. I was unable to commit to anything that took an ounce of energy because I had very little energy during the whole treatment period.

#### "You have to commit to this treatment through thick and thin, but always remember the benefits of the treatment."

I think the most important thing is to be aware of the possible side effects of Pegetron, and how it can affect your daily life. I think anyone taking this treatment should have a psychiatrist involved on his or her support team.

You have to commit to this treatment through thick and thin, but always remember the benefits of the treatment. That's the big thing: remember the benefits!"

#### **Bob** – has completed 41 out of 48 weeks treatment

"Pegetron put me on an emotional roller coaster ride of depression, anxiety, panic attacks, and suicidal thoughts. I experience Pegetron rage, as I call it, which is a cycle of irritability and mood swings. This emotional roller coaster peaked when I developed anemia and had to cut my meds in half.

I deal with the emotional side effects by getting as much support as I can. On the top of the list for me is psychiatric care. Not everyone needs this, but I personally would not have just completed week 41 without it. Next, would be my support group and the buddy system—there's nothing like sharing an experience with a friend who also happens to be strapped in the front seat of the roller coaster.

After 41 weeks of Pegetron, meditation is something I practice when I have no energy for anything else. Reflexology, massage, and journalling have also helped me regain emotional balance during tough times.

My recommendation to anyone embarking on this journey

would be to have a consultation with a social worker and consider him or her as part of your treatment team. The goal of medical treatment is to clear the virus from my body. My personal goal is to learn and grow spiritually and emotionally along the way. I have come far enough to realize these goals are really one. And if one comes at the expense of the other, the latter goal is my choice.

I know there are people who manage to work full-time while undergoing the treatment and I think that's amazing. It can be a rough ride. Accept support from the medical team: they are on your side. Remember, you're not alone."

#### Gordon - completed 24 weeks of treatment

"The physical effects of Pegetron (a flu-like feeling for a day or two following the weekly injection) seemed more dominant than the emotional effects, but there is a strong interplay between the two. Feeling physically crummy creates a mental downer. There were many days that I considered write-offs. I had no energy and even getting out of bed was a chore. While I often felt rather down and listless, I don't recall ever getting to the stage where the world seemed really bleak. Going into this, I knew there would be side effects, but the treatment period was fixed at 24 weeks. I had to look beyond that and remember that my poor old liver is essential for processing the antiretrovirals I take.

A very good piece of advice I received was to be watchful of my mental state and ask close friends to tell me if they noticed a disturbing variance from my usual behaviour. I asked three people to be on the lookout. They also provided emotional support.

Aside from the general lassitude, the thing I noticed in myself was grumpy impatience. I had a much lower tolerance for listening to inane arguments at small dinner gatherings. I got snappish at a few friends. Given the combination of low energy and reduced capacity for social interactions, the best course was to limit how often I went out and with whom.

Another aspect of the treatment that affected me physically and emotionally was sex drive. For the first four months of treatment, sex was about the furthest thing from my mind. Eventually there were little signs that there might be some life left in the old rogue yet, but so far the desire is mild and not acted upon.

When my head got into grumpy overdrive about my state of being, I focused on the fact that this was a relatively short-term treatment that held one key to long-term survival with HIV.

When feeling physically down and emotionally sapped, it's easy and far too tempting to withdraw completely. You can find yourself sucked into a vortex of constant concern about your own state of being. That self-concern can be protective, but it's important to give oneself a figurative kick in the butt and work at being

involved in the larger world. I think my old Scots grandmother would have put it along these lines: 'Don't stew in your own juices.'  $\oplus$ 

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





# new frontiers

There is hope for a successful salvage therapy by *R. Paul Kerston* 

ne of the biggest challenges facing PWAs and their healthcare practitioners is determining what drugs to use when the current regimen no longer works. Salvage therapy is a last resort treatment option, when previous regimens have failed and the virus has become resistant to the three major drug classes: protease inhibitors (PIs), nucleoside reverse transcriptase inhibitors (NRTIs), and non-nucleoside reverse transcriptase inhibitors (NNRTIs).

When considering salvage therapy, the first priority is to determine the reason for the drug failures. This may involve resistance testing (genotyping) and/or drug-level monitoring to assess whether adequate levels of drugs are present in the bloodstream for a sufficient period of time. Drug toxicities and tolerability may also be studied to see if side effects and reactions are causing difficulties. After considering a person's adherence to the prescribed regimen, doctors may prescribe a new program. The person's drug history is important when making decisions about switching and starting any treatment plan.

The goal of salvage therapy is the same as any regimen, to decrease the virus to undetectable levels (currently defined as less than 50 copies of virus per milliliter of blood). Even a goal of less than 1,000 copies may be beneficial.

Resistance to drugs in one class often means resistance to other, if not all, drugs in the same class. However, resistance may only be partial, and some drugs may continue working, particularly when prescribed in combination with other drugs. This is called recycling. Pill burden, having to take a large number of pills each day, must also be considered in regimens that include a number of new drugs plus recycled drugs.

Structured treatment interruptions are not advisable before salvage therapy, as there appears to be no real benefit. In fact, it may be harmful.

Recent salvage therapies include tenofovir (a relative of NRTIs), atazanavir, T-20, and tipranavir. Creatinine and phos-

phate levels should be monitored for kidney toxicity. Atazanavir, a PI, seems to work even when the virus becomes resistant to other PIs. For salvage therapy, 300mg of atazanavir with 100mg ritonavir is prescribed once daily. Some other drugs, including tenofovir and efavirenz, can lower atazanavir levels in the blood; therefore, ritonavir boosting is advised when those drugs are given together.

T-20, a fusion inhibitor, is now available in BC. Though the virus quickly develops resistance to this drug, there may still be a benefit when T-20 is taken with other new or recycled drugs. A study of treatment-experienced persons using T-20 in conjunction with three to five other drugs showed that this combination worked better than the background regimen alone (without T-20) at approximately the one-year mark.

Researchers are studying tipranavir, a PI, for first-line regimens and salvage therapies, especially when resistance to other PIs exists. It must be used with ritonavir. Results appear good at the roughly half-year mark. However, there are issues of tolerability, including nausea, diarrhea, and vomiting. This agent should be available through expanded access in the near future.

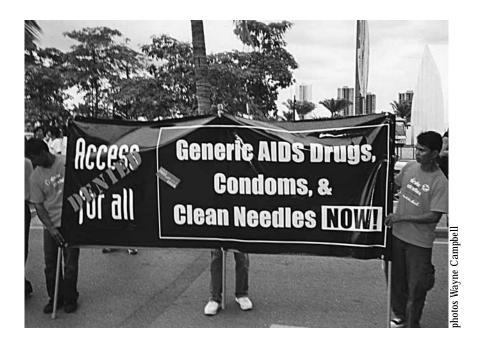
There is hope for a successful salvage therapy. A considerable amount of research is underway. Among the promising drugs under investigation are two NRTIs, SPD754 and D-D4FC, an NNRTI called TMC125, and TMC114, a PI. According to a presentation by Canadian researchers Julio Montaner and Marianne Harris about the 11th Conference on Retroviruses and Opportunistic Infections, research appears to be moving to a new conclusion: that the answer is not in new agents within existing drug classes or in agents from new drug classes that are saved for salvage therapy. Rather, new

drugs will be more effective if they are included earlier, when an effective background regimen is still available.  $\oplus$ 



R. Paul Kerston is a researcher with the Treatment Information Program at the BCPWA Society. Feature story





# Access for all, once and for all

Report on the XV International AIDS Conference in Bangkok, Thailand

#### by Enrico Mandarino

he XV International AIDS Conference in Bangkok, Thailand brought together an unprecedented 19,000 medical professionals, researchers, policy makers, activists, world leaders, educators, people living with HIV/AIDS, care volunteers and even international pop and movie stars to promote awareness and discuss the current realities, challenges, and hopes for a future without AIDS. There were hundreds of debates, activities, major speeches, and protests, and over 9,000 abstracts.

I had the honour of meeting UN Secretary-General Kofi Annan and Nelson Mandela at a special reception. They, too, were searching for a ray of hope as they tried to rally the world's attention, resources, and will to meet the growing challenges of HIV/AIDS.

While this conference included little new medical information or major treatment breakthroughs, the political and social components of this meeting took on a new heights with amplified calls for a united global response to AIDS. Activists campaigned daily to address a number of policy issues, often disrupting conference sessions to deliver their messages.

#### A global problem

The AIDS epidemic is not just a problem for developing countries. It is a global problem with worldwide implications, and it needs the full cooperation of both rich and poor countries. In the opening address of the conference, UN Secretary-General Annan warned that the international community is not doing enough to fight AIDS and meet the targets set by world leaders three years ago. "AIDS is far more than a health crisis," he said. "It is a threat to development itself."

There are countries where AIDS has taken such a toll on lives that only a few workers between the ages of 20 and 40 remain. Agriculture, education, and mentoring are void of a generation of productive people. Industrial growth and expansion have stalled. We cannot underestimate the global ripple effect of this epidemic.

This year's conference aimed to advance knowledge of HIV/AIDS in all its medical, social, scientific, community and political aspects; the hope was that this approach would lead to firm commitments to deal with the global HIV/AIDS epidemic.

The theme of the conference was "access for all." However, donor countries have failed to deliver on promises of financial aid for prevention and treatment. Only seven percent of the five to six million people who need HIV treatment in low- and middleincome countries had access to treatments by the end of 2003. And only one out of five at-risk and affected people worldwide currently have access to prevention, diagnostic, and therapeutic strategies.

UNAIDS executive director Dr. Peter Piot said that these figures illustrate the world's failure to provide prevention and treatment to the people who need it. Until recently, AIDS was largely a problem for sub-Saharan Africa, but now the epidemic is entering into a globalization phase. Today, one out of every four new infections occurs in Asia.

#### A call for action and a global response

The conference's "access for all" theme underscored the urgent need for HIV- related science, prevention, treatment, and resources for people worldwide. Community and scientific experts said that concrete commitments and accountability are essential to the global success in the battle against AIDS. Prevention, treatment resources, and political commitment remain key issues to curbing the spread of the virus and ending the stigma.

In some ways, the conference was a "global check" to make sure that promises made in Barcelona will not be broken. It has been two years since the Barcelona conference and antiretroviral drug access is still desperately stalled. Global campaigns to treat three million people by 2005 have so far failed to reach their goals, with only an estimated 400,000 AIDS patients currently receiving antiretroviral drug.

UN Secretary-General Annan said that leaders must no longer hide behind a veil of apathy. "Leadership means respecting and upholding the human rights of all who are vulnerable to HIV/AIDS—whether [they are] sex workers, drug users, or men who have sex with men."

Dr. Piot, representing UNAIDS, said that leadership is key in responding to the epidemic. "From harm reduction for drug users to condoms being advertised on TV, these issues need strong leadership."

A great deal of the conference focussed on prevention. It seemed as if we were going back in time, with discussions on whether to focus primarily on scientifically-proven condom use—as Thailand has done—or on moral and ideology-driven polices such as abstinence and faithfulness, as in the US. This seemed to be a huge setback to our efforts because we have always talked about harm reduction. Unfortunately, the new technologies for prevention, microbicides and vaccines, which are the key to ending the epidemic, are still years away.

#### Prevention and the ABC approach

Abstaining from sexual activity, being faithful/mutual monogamy, and using condoms are three key behaviours that can prevent or reduce the likelihood of sexual transmission of AIDS virus. Collectively they are referred to as the "ABC" approach: A for Abstinence, B for Being Faithful, and C for Correct and Consistent Condom Use during casual sexual activity and other high-risk situations.

The ABC approach drew much criticism when Uganda President Yoweri Museveni insisted that condoms were less effective for HIV prevention than campaigns to promote abstinence and loving relationships.

In Africa, many new infections occur amongst monogamous

#### It has been two years since the Barcelona conference and antiretroviral drug access is still desperately stalled.

married women who are already being faithful; abstinence is simply not an option for them. By contrast, in Asia the emerging epidemic is largely driven by prostitution, so condoms must come first in any prevention effort.

Many researchers feel that the ABC approach is simplistic and could be counter-productive if young people do not obtain information on effective condom use. Studies show that when used properly, condoms are 97 percent effective in preventing the transmission of HIV through sexual contact.

In some countries where infection rates are rising among injecting drug users, young people, and homosexuals, many are advocating for the CNN approach: Condoms, Needles, and Negotiation.

Moralizing plays a big part to how we respond to this epidemic. People will continue to become infected with a completely preventable disease because we will not distribute scientifically proven prevention resources. Moral, ideological, religious, and financial reasons are often invoked as excuses not to employ proven prevention strategies, such as providing condoms for young people or clean needles for drug users.

#### The progress of microbicides

Microbicides are gels or creams that, in theory, could reduce HIV transmission when applied vaginally. Microbicides would kill HIV in semen, block the attachment of the virus to its target cell, or prevent HIV from multiplying if the virus enters the cell. For women who are unable to control their partners' use of condoms or negotiate other safer sex practices, microbicides would give them the ability to protect themselves against HIV infection. Microbicides could similarly help protect men who have sex with men.

In 2002, the International Partnership for Microbicides was established to help accelerate the development of safe, effective, and accessible microbicides for women in developing countries...

There are currently six microbicides entering clinical trials. Determining efficacy during this testing phase is critical to the enrolment of more than 20,000 women over the next three years. continued on next page



#### "AIDS is far more than a health crisis. It is a threat to development itself." – UN Secretary-General Kofi Annan

If the current products in large-scale trials are effective, there could be a microbicide on the market within five years. However, if the trials are not considered successful, it could take up to ten more years to develop an effective microbicide. The biggest stumbling block for microbicide research is that there are not enough resources allocated to this new technology.

#### The ever-elusive vaccines

Vaccines are often referred to as the Holy Grail to ending this epidemic. However, an International AIDS Vaccine Initiative (IAVI) report claims that an effective vaccine is still years away and the process might require doubling of funds.

There are at least 30 possible vaccines involving the same approach to vaccination against HIV, now in the early stages of clinical trials in 19 countries. Only one has entered into Phase III trials in Thailand, and will involve 16,000 participants. If the current approach is not considered successful, IAVI says that researchers might have to go back to the drawing board.

IAVI president and CEO Seth Berkley said that less than one percent of the total spending in all HIV/AIDS product development is going toward vaccine research. He called for US \$1.3 billion annually for vaccine development. "The single biggest obstacle is that vaccine development is not a top scientific, political, and economic priority," he said. "Only a vaccine can end the epidemic."

#### Increased resources needed

By 2005, an estimated US \$12 billion will be needed annually to effectively fight HIV/AIDS in developing countries. The 2004 UNAIDS Report on the global AIDS epidemic stated that current annual global spending totals less than half of that amount. Experts estimate that by 2007, the resources needed to mount a comprehensive battle against AIDS will reach US \$20 billion.

Bangkok will be remembered as a call to stop all the rhetoric. Conference participants demanded accountability from heads of states, agencies, and individuals who are obstructing progress or failing to effectively address the gaps and inequities in HIV/AIDS treatment access and prevention.

In the closing ceremonies, almost every speaker stressed the vision of the conference and that their hopes for the next conference in Toronto in 2006 were for "promises made, not promises broken."

"Some of the greatest challenges we face today are of our own making: the obstruction of bureaucracy, the injustice of stigma, the rivalry, lack of coherence, and the failure of political leadership," Dr. Piot said.

We must choose between the future and the past, between reason and ignorance, between true compassion and mere ideologies. The XVI International AIDS Conference in Toronto will be the true test to see if we have taken a giant stride forward for the good of all humanity.  $\oplus$ 

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



#### The current statistics

- ▼ Today, between 35 to 42 million people worldwide are living with HIV/AIDS, according to the World Health Organization (WHO).
- ▼ 25 million infections are in sub-Saharan Africa.
- ▼ AIDS has already claimed the lives of 20 million people.
- ▼ The fastest-growing AIDS epidemic is in Asia, where an estimated 7.4 million people are infected with HIV.
- ▼ In 2003, a record five million people became infected with HIV, and three million died.
- ▼ Of the estimated 14,000 new HIV infections that occur each day worldwide, about 7,000 are among young people aged 15 to 24; 2,000 are among children under the age of 15.
- ▼ 75 percent of new infections are among women and girls.
- Women now account for half of the world's population living with HIV.

LIVING + SEPTEMBER / OCTOBER 2004



# A cornucopia of facts

Everything you wanted to know about psychoactive substances but were afraid to ask

by Lawrence C.

or those curious individuals who are interested in learning more about psychoactive substances, Erowid.org, or the Vaults of Erowid, contains a cornucopia of information about plants, chemicals, and other related topics. Rather than a traditional medical database brimming with scientific babble, it is an on-line comprehensive compendium of mind-altering substances—everything from 2C-I, 2C-B, and 5-MeO-AMT, to methamphetamine, kava-kava, peyote, and nutmeg.

The interwoven Web pages contain a wealth of information collected from experienced professionals, including doctors, researchers, teachers, sociologists, pharmacists, and lawyers, as well as from users of these drugs. The Web site contains over 20,000 documents, incorporating thousands of charts, graphs, photographic images, research summaries, abstracts, editorialized papers, and "experience reports." The site also contains information about the chemical and biological effects of psychoactive substances on people and the legality of these potentially harmful substances. These substances, in higher or lower dosages, are traditionally used in medical treatments, spiritual healing, and for recreational purposes.

For each psychoactive drug listed on the Web site, there is a corresponding "vault" of information. Each vault offers colourful buttons leading to basic information that any novice would need to know.

Delving even deeper into the maze of the Web site, readers will find a variety of cultivation and preparatory techniques for these substances, user and abuser personal experiences, and a variety of cross-referenced writings and articles.

With an average of 25,000 hits per day, Erowid.org, founded in 1995, has demonstrated its popularity among students and professionals alike. Some information on the Web site is based on reliable science; however, to a large degree, the information is highly anecdotal. The founders of the

The website contains thousands of charts, graphs, photographic images, research summaries, abstracts, editorialized papers, and "experience reports."

site, self-named Earth and Fire Erowid, do not hold PhDs in any field. However, they have collected a range of information from other sources and professionals that may or may not be contained in a traditional scientific medical database.

Recently, *LA Weekly* reported on a young man who checked himself into an emergency ward complaining about paranoia and irrational thoughts. Hospital staff discovered that he had taken 2C-I. Unfamiliar with this illegal recreational drug, the staff searched their databases and found no information. Fortunately, a well-informed third-year medical student had heard about Erowid.org and searched the

database. To the surprise of many welltrained and educated medical professionals, the Erowid.org vaults contained detailed information on 2C-1, including its chemical structure and a link to a recent scientific review. Armed with this information, the emergency professionals were able to use their medical expertise to respond with an appropriate treatment that would completely resolve the symptoms.

In spite of this apparent success story, readers should exercise caution regarding the contents of the vaults. The *LA Weekly* also reports that though the site's founders post many pieces themselves, Erowid is essentially a collection of other people's documents, many of which contradict one another. "They do not attempt to vet every wild and wacky claim," the article claims, "though they strive to maintain an overall tone of caution, pragmatism, and healthy skepticism. Warnings of known dangers are prominently posted, but moralizing is abandoned in favor of fact and reasonable conjecture."

Overall, Erowid.org is a well organized Web site with an abundance of apparently well researched and anecdotal information. It is easy to navigate and the multitude of graphics helps to maintain reader interest. Happy surfing!  $\oplus$ 

Lawrence is a member of the BCPWA Society.

# Beyond the dark mirror

A personal account of overcoming depression

by Derek Thaczuk

**I ? …** lucky to be one of the "success stories" of HIV: still here, and doing pretty well, even though the odds have been against me. In 1997, my CD4 counts had plummeted to 32, and my viral load was over 200,000. I thought I was resistant to every available drug, and really didn't hold much hope for the future. Yet here I am six years later: viral load undetectable, CD4 counts over 300, living large and mostly well.

If only I could keep some meat on my bones. I'm not exactly a piece of beefcake to begin with—165 pounds on a lanky 6'1" frame at the best of times. Since I've been HIV-positive (ten years that I've known about, probably more like 18), my weight has bounced up and down a lot, but I've come to consider 160 pounds my "redline"—the point below which I start to worry. To stay above that line, a host of things must be going well: mood, appetite, workouts, plus time and planning. It's a lot of work, and it doesn't take much to throw the whole thing off the rails.

#### The downward slide

It was November 2002. I weighed about 155 pounds and it began to scare me. My life was reasonably organized and I was even going for regular workouts at the gym. My doctor even shot me a few months of anabolic steroids to help me build myself into a nice, beefy studpuppy, or a reasonable 40-year-old facsimile.

Then I got sick. Not HIV-related, just some flu-type thing, probably some version of the Norwalk virus, I initially thought: fever, the shits like you wouldn't believe, exhaustion. No sooner did I recover when I was hit by a second bout, then a third. After that I lost count. I finally figured out that the weekly steroid shots were the cause.

At some point around the longest, coldest night of the year, when the sleigh bells are ringing and children are singing and everything's merry and gay, it finally got to me. This drawn and skeletal face stared back at me from the mirror. The bathroom scale had moved ten pounds in the wrong direction. At 145 pounds, I could pull my pants off without even unzipping them.

That's when I thought: why bother? What's the point of trying when it's one step forward, ten steps back? When the stuff that's supposed to beef me up makes me thinner? When the drugs to cheer me up turn my dick limp and useless? When the drugs that stop the virus give me the runs? When one thing always screws up something else, and the whole damn treadmill drags you backward if you stop for even one solitary second?

That's when I found myself looking into that dark mirror: Depression.

#### A surprisingly common condition

Depression is a mental disorder caused by shortages of chemicals called neurotransmitters, which carry signals between nerve cells (neurons) within the brain. It is quite a common condition, affecting up to one-quarter of the population at least once during a person's life. It is more common among people with immune system disorders such as HIV infection.

#### So AIDS is depressing. This is news?

Actually, yes. I was surprised to learn that, when you compare people living with various life-threatening illnesses, depression occurs even more frequently when the diseases involve the immune system. Two different things are happening at once: the mental and emotional stress of dealing with the illness, plus a biochemical component which simply makes the immune-compromised brain more susceptible to depression.

This biochemical aspect of depression is a tough sell. The concept is easy enough to grasp, but to apply it to yourself? It's easier to distance yourself from a physical ailment. I may *have* a disease; I don't feel that I am that disease. I *am* me; I have a cold. Or pneumonia. Or even HIV.

But mental illness is different. Suddenly, it's harder to say, "I have this condition known as depression." Instead, there's something wrong with *me*. I'm weak. I'm feeling sorry for myself. I should be stronger, more of a man. Instead, I'm this self-pitying loser—all of which sinks you even lower, until you hate yourself for feeling sorry for yourself. And so it spirals downward.

Like a car needs gas and oil and transmission fluid, our brains need chemicals: serotonin, norepinephrine, dopamine. Depression drains these compounds from our brains.

Never mind the chemistry. Human beings need strength and hope and energy to get through every single day of living with this damn disease, trying to believe in some kind of future. That diabolical beast called depression robs us of the strength to do that, takes away our ability to cope, leaves us feeling vulnerable.

When those chemicals in my brain get depleted, when that hard-won strength fails, the dam breaks. All those worries and fears, all that negativity and bitterness and ugliness and desolation and despair that I struggle so hard to hold back—it all comes flooding in like an icy-black, bitter sea, crashing in waves, dragging me toward the bottom. For a while I go under, breathing in—revelling in—the darkness and the cold.

But if you stay there you will drown.

And at some point I decided that I simply did not want to drown.

#### Faking it 'till it's real

I realize that a lot of people have problems that dwarf my own. Skinny? Big deal. I have a nice place to live, good friends, a good life. But perspective doesn't help anyone deal with depression. It's not rational. It can make it worse by leading you into the self-criticism trap: "How pathetic I am to feel so pathetic."

It's that dark mirror, that thing inside my head that makes what felt good yesterday feel pointless, hollow, and empty today.

It's unbearable to remain that way. So we do what we can to find the way out.

Some people choose the permanent way out when the torment is so great that they simply can't face it. When they've clung to the window ledge of the burning building for long enough, and the flames simply become too painful, they may finally let go of the ledge.

I thank God I've never been driven to that extreme. My way out begins by simply acknowledging the problem, and by recognizing that it *can* be dealt with. After that, it depends on a couple of things: antidepressants, for one. I fought against taking them for the longest time. My psychiatrist, God bless her, respected my wishes. Like so many of us, I take enough damn pills already, and I didn't want to add more. I refused to buy into anything that smacked of a knee-jerk "throw-a-pill-at-it" solution. Plus, I clung to all that pseudo-macho shit about toughing it out.

At some point I decided that, since I didn't know how long I would live, I'd be damned if I was going to waste one more week of my precious life lying on the couch feeling miserable.

#### At some point I decided that I'd be damned if I was going to waste one more week of my precious life lying on the couch feeling miserable.

#### If it takes another pill, then down the hatch.

The next challenge was finding an antidepressant that would be effective without screwing up anything else too badly. So far, I've been through Prozac, Zoloft, and Paxil (which left me completely limp-dicked for a month and a half—that certainly didn't help matters). But Effexor seems to be doing the trick, and the machinery is back in working order.

Antidepressants take time to work. In the meantime, I've come to rely on what I call "faking it 'till it's real." Never mind whether I feel like doing anything: do it anyway. Get out of bed. Feed the cat. Get out of the house. Walk around the block. Go shopping. Go out with friends. Go through the motions of a normal life, no matter how hollow and meaningless it all seems. If I just keep putting one foot in front of the other, I will eventually discover that I'm actually walking, that some glimmer of the pleasure from these everyday things has returned. Then I know it can only get better from there.

One chooses one's battles, and I've chosen not to give a damn about the number on the bathroom scale. I'll show up for Pride Day alive, thank you very much, and leave the perfect pecs and sculpted abs to those who have the time to worry about them.

I happen to be blessed with an incredible circle of friends and family. I have also chosen a career in which I help other people with HIV, and go home every day feeling like I matter. These things have been invaluable to me during those bleak spells.

At times, when I see the headlines of war, injustice, or a new album from that insufferable Madonna, I can't help but see the human race as a monumental plague upon our planet. Yet, the way we are capable of looking after each other moves me profoundly. It has brought tears to my eyes. It has kept me going when I thought I couldn't. Whenever one of my friends is falling into that cold

black water, someone else is there with a hand to help them out. And that has meant more to me than I could possibly say.  $\oplus$ 

Derek Thaczuk is the treatment information coordinator at the Toronto People With AIDS Foundation and a freelance writer and health coordinator.



SEPTEMBER / OCTOBER 2004 LIVING +

# A is for apple

Back to school nutrition for youth with HIV



by Sarah Fielden

AS many young people begrudgingly pull on their knapsacks to return to school, nutrition for HIV-positive youth is a timely topic to explore.

Youth is a period of rapid growth and transition, physically, emotionally, and cognitively. Young people define themselves during adolescence and the early years of adulthood. They move from school to work and/or to university. Many transition from home into new living situations. These transitions can upset established routines of meals and food production at home. And somewhere amongst all of the chaos, youth living with HIV must learn to take care of their unique nutritional needs.

Environmental factors can play a big role in a youth's ability to meet his or her own nutritional needs. Some youth with HIV are extremely marginalized, living on the streets and/or coping with addictions. In these cases, holistic support, including access to safe and nutritious foods, is essential for optimal health. Housing, stability, finances, and life skills are some of the factors that will determine a youth's ability to purchase, prepare, and consume nutritious food. For in-school youth, some schools do not offer many nutritious options. Therefore, youth need to be armed with the knowledge to make the best choices and empowered to ask for healthier alternatives.

In many ways, HIV-positive youth do not differ significantly from other youth in terms

of nutritional concerns. Like other young people, youth with HIV may be influenced by concerns about body image and may be affected by eating disorders, and they may skip meals or opt for convenience foods that are high in fat and low in nutrients. For HIV-positive youth, these problems may be compounded by the side effects of medications that can lead to a lack of appetite, lipodystrophy, and high triglyceride levels. Adolescence is also the time when people develop their peak bone mass, so bone strengthening exercises and calcium-rich foods are especially important.

Unlike many youth of today who eat leftover hot wings off the kitchen counter for breakfast or eat mystery meat at the back of the refrigerator for dinner, HIVpositive youth have unique nutritional needs that make these rights of passage into adulthood particularly hazardous. Food safety is crucial for people with HIV to avoid bacterial infections. Precautions such as storing food at the right temperature, cleaning hands and kitchen surfaces, and keeping raw meats separate from other foods, help to keep an HIV-positive youth healthy.

Malnutrition is a common problem for people with HIV, and youth are no exception. Proper nutrition can help keep a young person's immune system strong and can help prevent nutritional deficiencies. Eating regular and balanced meals, although perhaps mundane, will contribute to better overall quality of life. Nutritional tips for HIV-positive youth:

- ▼ Avoid skipping meals. This slows your metabolism and robs you of precious energy.
- Eat meals and snacks that are rich in nutrients and protein, such as smoothies.
- ▼ Take a daily multivitamin to maintain your nutrient stores.
- Try meals that are easy to prepare or are frozen, such as bean burritos or lasagna.
- ▼ Learn about how to prepare and store food hygienically, to keep it safe for consumption.
- Try a cooking class or experiment with a good cookbook. Being able to cook is an asset at any age.
- ▼ Find some physical activities that you enjoy, and do them regularly. Try a sports team or find a friend who wants to join you skiing, walking, running, biking, etc.
- Try weight-bearing exercises such as walking and weight training to strengthen your bones.
- ▼ Talk to a dietitian about strategies to help you find the best way to meet your nutritional needs. ⊕

Sarah Fielden is a PhD student at the University of British Columbia and a member of Vancouver Dietitians in AIDS Care.



# A?k the dietitian

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

## Some tasty advice

by Karen Giesbrecht

## Foods I used to like don't taste right anymore. What can I do to make food taste better?

Your illness and medications may have affected your sense of taste. Here are some suggestions for selecting and preparing foods that appeal to you.

- ▼ To remove an unpleasant, lingering taste in your mouth, try sugar-free gum, mints, or sour candies. It may also help to rinse your mouth with tea, salted water, ginger ale, or water with baking soda.
- Check with your doctor to see if taste changes could be related to your medications. Do not stop taking your medications unless directed by your doctor.
- Chew your food well and move it around in your mouth to stimulate your taste buds and release flavours.
- ▼ A strong, bitter flavour such as coffee can temporarily decrease sensitivity to food, so wait until after you eat to enjoy the brew.
- Maintain good oral hygiene, brush your teeth often, and visit your dentist to see if you have any dental problems.
- Try using plastic utensils if you have a bitter or metallic taste in your mouth when you eat.
- ▼ Vary the colours, temperatures, and textures of your meal.

- ▼ Foods that look and smell good often taste better.
- If your mouth or throat is sore, avoid irritating spices, tart foods, and hot foods or drinks.

If food lacks flavour, simple additions can spice it up:

- ▼ For extra crunch, add bacon bits, chopped green onions, nuts and seeds, or crushed crackers. Add cereal to yoghurt, pudding, or ice cream.
- ▼ Experiment with fresh or dried herbs such as oregano, basil, chives, parsley, cilantro, rosemary, garlic, and ginger.
- ▼ Use salsa, barbecue sauce, salad dressings, ketchup, mustard, teriyaki or soy sauce to create a zesty flavour.
- ▼ Add a tangy taste with vinegar, wine, lemon, lime or orange juice.
- ▼ Top a sweet dish with brown sugar, maple syrup, or honey.
- ▼ Eat foods at peak freshness for the fullest flavour.

If food tastes too sweet, tone it down by:

Adding yoghurt, buttermilk, fresh fruit, instant coffee powder, or extra milk to milkshakes or nutritional drinks.

- Choosing foods such as cheese, chips, cottage cheese, crackers, fruit, nuts, or peanut butter instead of sweet snacks.
- ▼ Using butter or margarine on cooked cereal, toast, and pancakes, instead of syrup or jam.
- Drinking beverages such as fruit juice, milk, lemonade, or ginger ale.
- ▼ Adding a little salt or lemon juice.

If food tastes too salty, moderate it by:

- ▼ Avoiding seasonings and processed foods containing sodium.
- ▼ Trying bland, mild foods.
- ▼ Adding a little sugar.

If meat doesn't taste right:

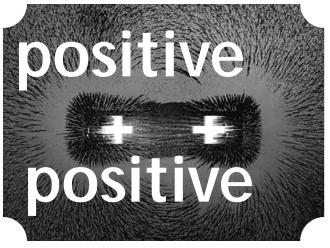
- ▼ Try alternative sources of protein such as eggs, cheese, cottage cheese, nuts, beans, or peas.
- ▼ Make sure the meat hasn't gone bad. Don't eat spoiled meats.

If these measures do not help, or if you are losing weight, ask your doctor or a registered dietitian for further advice  $\oplus$ 

Karen Giesbrecht is a member of Vancouver Dietitians in AIDS Care.

SEPTEMBER / OCTOBER 2004 LIVING +

# When posi attracts



PWAs are choosing sexual partners based on HIV status

by Michael Connidis

igh-risk sexual encounters between men who have sex with men (MSM) are on the rise, according to recent surveys and studies. A higher incidence of unprotected anal intercourse parallels an increase in new HIV infections. How closely these factors parallel one another is debatable, but the connection is clear: you risk HIV infection when you don't protect yourself during intercourse. Risk management is a critical factor in sexual encounters with others.

When engaging in passionate play, protection from infection with HIV may no longer be a risk management issue for HIV-positive people. While managing your own safety, the potential for infecting another person with HIV remains a serious concern for many. In addition, there are still all the other sexually transmitted infections that may seem more or less life-threatening than HIV. The new, albeit indeterminate, risk factor of HIV superinfection further compounds these risks.

When it comes to HIV prevention strategies, two dominant programs have advocated from very different ends of the socio-political spectrum: ABC (abstinence, being faithful, and condoms) or CNN (condoms, needles, and negotiating skills). There is also a third, somewhat underground, HIV prevention strategy that some MSM are practicing, primarily in urban centres. People with HIV are selecting other HIV-positive people exclusively as sexual partners, thus eliminating the risk of infecting another person. This strategy for preventing HIV transmission is called serosorting sexual partners (SSP).

As an HIV prevention program, what would SSP advocate? Given the current legal onus imposed on PWAs to disclose their status to their sexual partners, the primary issue is ensuring that you and your partner know your respective serostatus. One survey found that roughly one in four MSM who tested positive for HIV had stated they thought they were negative or did not know their serostatus. How do we

Discerning who is and who isn't HIV-positive need not be surreptitious. Avoid the pitfall of making assumptions when sorting out someone's serostatus.

know who is HIV-positive and who isn't?

Knowledge is power and puts you in the best position to manage the risks of an active, healthy sex life. In urban centres, especially in communities such as Vancouver's West End, there are more opportunities to connect with other HIV-positive people in our daily lives. We access the same medical services, see the same doctors, and belong to the same organizations. For those of us who live with the body-altering effects of HIV and the medications we take, there are also familiar physical features that identify us as being HIV-positive. However, discerning who is and who isn't HIV-positive need not be surreptitious. Avoid the pitfall of making assumptions when sorting out someone's serostatus. Communication is essential to SSP. Whether you are cruising on the phone lines, through Internet services, in bars, baths, or parks, to successfully follow SSP you must be open, declare clearly that you are HIV-positive, and seek the same information from prospective play partners.

Whether we live in urban centres, the suburbs, or the rural hinterlands, SSP and any other form of negotiating safer sex requires knowledge, honesty, and acceptance. We must strive to be knowledgeable about the relative risks and possible consequences of our actions and choices. We must continue to struggle to be honest with our sexual partners and ourselves, and to disclose our HIV-positive status in spite of possible rejection and loss. Above all, we must accept ourselves as being healthy in our desire to be passionate, intimate, and sexual, living positively with HIV.  $\oplus$  For some interesting data, check out:

- ▼ <www.mens-survey.ca>
- ▼ <www.think-again.ca>
- ▼ "Kiss & Tell", POZ magazine, July 2004 <www.poz.com>

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





Guarding against community-acquired pneumonia by Sam Friedman

ommunity-acquired pneumonia (CAP) refers to dozens of bacterial, fungal, and viral infections that can progress to severe pneumonia. Exposure to and transmission of these infections occurs in any public, social, or work environment.

A single CAP pathogen or "bug" that causes infection, be it bacterial, viral, or fungal. CAP is never caused by two or more pathogens and no co-pathogens are involved.

Among HIV-positive people, 85 percent of cases of pneumonia are caused by Streptococcus pneumoniae, Haemophilus influenzae, and Moraxella catarrhalis. The remaining 15 percent are generally acquired in hospital settings and are mostly caused by Mycoplasma pneumoniae, Chlamydia pneumoniae, and Legionella species. Mycobacterium tuberculosis, anaerobic aspiration pneumonia, and Pneumocystis carinii pneumonia (PCP) are not normally considered CAP pathogens.

Symptoms of CAP can surface slowly or suddenly and include shakes, chills, high fever, chest pain, coughs that produce a rust-coloured or greenish mucous, sweats, rapid breathing, fast pulse rate, and bluish lips and nail colour due to insufficient blood oxygen. If any of these symptoms present during a severe infection, immediate medical attention is required to properly identify the cause and initiate treatment.

The most accurate tools to identify CAP pathogens are tests by Sputum Gram stain and blood cultures.

The probability of developing CAP increases dramatically when multiple risk factors are present. HIV-related risks include a compromised immune system, unknown HIV status, lack of HIV knowledge, missed HIV therapy doses, and hospitalization for a persistent or drug-resistant infection. Social factors also increase risk, including poverty, lack of housing, poor nutrition and supplementation, stress, reduced sleep and exercise, and lack of access to health care. Using illicit drugs, sharing drug paraphernalia, cigarette smoking, and environmental toxins also increase the risk of developing CAP.

Transmission or reactivation generally occurs in three ways. First, during our lives we are exposed to and acquire antibodies to many organisms, including CAP pathogens—which cover our skin and live in the mouth, throat, and gut. Although the immune systems of most HIV-positive individuals keep these pathogens in check, being severely immuno-compromised often leads to reactivation of CAP, causing infection that requires hospitalization.

Second, when a CAP-infected person coughs or sneezes, they spread microscopic droplets into a radius of several feet. If an immunocompromised person within this radius directly inhales these particles, there is a major risk of transmission or reactivation.

Transmission or reacquisition is also possible, but extremely rare, by touching an object exposed to an infected person's cough or sneeze and then touching your eyes or mouth.

CAP treatments include both oral and intravenous antibiotic and antimicrobial agents. Penicillin or doxycycline remain the standard, effective, cost-saving treatments for regular, persistent, and resistant bacterial CAP infections. Other treatments used with equal success and varying side effects include levofloxacin, ciprofloxacin, vancomycin, methicillin, ceftriaxone, linezolid, respiratory quinolone, cefepime, and meropenem. Several of these treatments are new and may require special authority approvals to be covered under PharmaCare; otherwise, some of the drugs may require full or partial payment.

Complementary therapies for CAP include garlic, cayenne and chili pepper. Symptom relief is possible with natural preparations of lobelia and sanguinaria.

Ultimately, your best defense against community-acquired pneumonia is to wash your hands often and avoid the risk factors. It is also important to quickly identify any serious infection and initiate the correct treatment as early as possible.  $\oplus$ 

Sam Friedman is a member of the BCPWA Society. He has advanced HIV disease.

### Herbal remedies for peripheral neuropathy

by Katolen Yardley

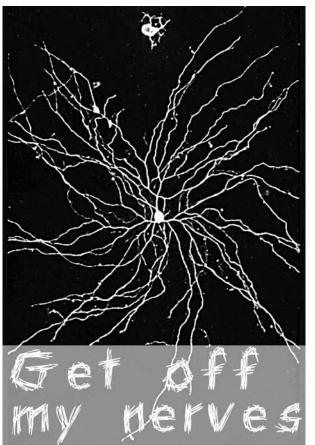
Peripheral neuropathy is a disorder of the peripheral nerves that initially affects the feet and hands, and then progresses up the limbs. Symptoms can include redness, swelling, pain, numbness, and a "pins and needles" tingling sensation.

There are numerous causes of

peripheral neuropathy: heredity, diabetes, hypothyroid, arthritis, HIV, cancer, alcohol and heavy metals such as lead, mercury, and arsenic. Medications can also cause the condition, including ddI, and d4T. Nutritional deficiencies seem to worsen the symptoms. Viral infections can directly attack the nervous system or can indirectly stimulate the immune system's formation of antibodies, leading to destruction of the myelin sheath, the membrane surrounding the nerves. To some extent, the nervous system can regenerate itself after damage has occurred. Remyelination can occur from stem cells that have the ability to differentiate into myelin-making cells, and from healthy cells that can still produce myelin.

A number of supplements can help alleviate symptoms of peripheral neuropathy. Vitamin D is an immune system regulator and powerful antioxidant used to prevent destruction of the myelin sheath. B vitamins are essential for brain function and a healthy nervous system. Vitamin B6 reduces the formation of prostaglandin 2, which contributes to inflammation in the body. Vitamin B12 plays a role in the formation and maintenance of the myelin membrane; a deficiency of this vitamin interferes with the myelin's ability to repair itself and, over the long-term, can contribute to its destruction. Vitamin C complex is also an excellent addition to a supplement regimen since it is water soluble, and therefore is not stored as a reserve in the body.

Among herbs, nerve tonics such as skullcap (Scutellaria lateriflora), cramp bark (Viburnum opulus) and oat seed (Avena sativa) can be used to treat muscle weakness, nerve damage, and numbness. St. John's Wort (Hypericum perforatum) can either be mas-



saged topically or taken internally for its antiviral and nervous system tonic properties.

Fish oil, a source of essential fatty acids, can also be used to treat peripheral neuropathy. Up to 75 percent of the myelin is composed of fat. However, it is important that

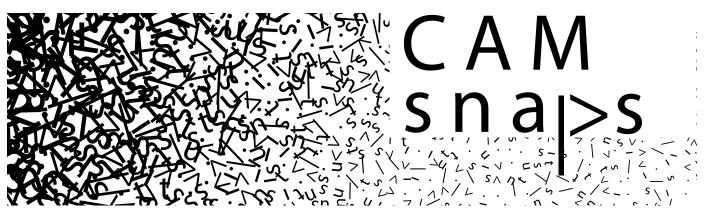
the body receives the proper amount of good fats (thin light oils). Look for fish oil that is high in docahexaenoic acid (DHA); one of the thinnest oils in the body, DHA lines the nervous system and is used for rapid message relay. Avoid deep fried foods, animal and trans fats, hydrogenated oils and saturated fats—these are the heavy fats that compete with thinner oils for placement in the myelin sheath and effectively slow down message relay.

Eat a diet high in fruit, vegetables, and fresh fish. Avoid high intake of meat, caffeine, sugar, and artificial sweeteners, such as aspartame. Aspartame, contained in NutraSweet and Equal, has been linked to degenerative nervous system conditions. When ingested, it breaks down into formaldehyde, a known carcinogen, and other toxic chemicals. Regular use can lead to headaches, numbness, slurred speech, dizziness, memory loss, muscle spasms, and joint pain. Continued use of Aspartame can aggravate neurological conditions, including chronic fatigue, multiple sclerosis, and Parkinson's disease.

Although vitamins, supplements, and diet can help alleviate some of the symptoms associated with peripheral neuropathy, it is best to treat chronic conditions in a clinic environment where a practitioner takes into account the whole body and designs a program specific to an individual's needs.  $\oplus$ 

Katolen Yardley, MNIMH, is a medical herbalist in private practice at Gaia Garden Herbal Dispensary in Vancouver and the Tri City Natural Health Clinic in Coquitlam.





by Tom Mountford

#### Shyness study

New research demonstrates an important mind-body relationship in HIV disease progression and suggests a new treatment mechanism. Socially inhibited HIV-positive individuals had a viral load setpoint eight times higher than others did. Their antiretroviral (ART) response was about one-eighth of the viral load reduction of other study participants. Elevated activity of the autonomic nervous system explained most of the difference; shy individuals have a higher baseline stress level; and they control excess stress by limiting social interaction.

Other studies show that norepinephrine, which the body releases in response to stress, changes the function of cells in several ways that result in faster HIV replication. Research also shows that naturally occurring differences in autonomic nervous system activity can be associated with up to a 100fold difference in HIV viral load.

These findings suggest benefits of a treatment plan that includes ART and complementary therapy to address high baseline stress levels. Shyness or being socially inhibited may require treatment or therapy separate from that used for depression, to slow HIV progression and reduce viral load.

#### Magnesium facts

Magnesium is an important mineral for nearly every function and tissue in the body. It plays a critical role in many acute and chronic diseases. Recent national studies in the US found that as many as three-quarters of Americans do not consume enough unprocessed foods to avoid the adverse effects associated with chronic magnesium deficiency.

Experts believe that insufficient magnesium may be a primary factor in the relationship between heart disease and cardiac risk factors such as high blood pressure, obesity, diabetes, and stress. Magnesium deficiency may also play a role in the reported increase in heart attacks and strokes among menopausal women undergoing hormone replacement therapy; magnesium counters the possible blood clots caused by estrogen. Stroke patients and resuscitated victims of cardiac arrest have recovered better when given magnesium immediately after the incident.

Magnesium therapy has also proved beneficial in treating

bronchial asthma and migraine headaches. Intravenous treatment with the mineral is used in emergency rooms for acute asthma attacks and is more effective at preventing migraines than costly prescription drugs. Research also shows that people with diabetes need less medication to control their blood sugar and blood fats when treated for six months with oral magnesium.

Symptoms of magnesium deficiency include weakness, confusion, personality and/or mood changes (including depression), muscle tremors, anorexia, nausea, lack of coordination, and gastrointestinal disorders.

Foods that are relatively rich in magnesium include: wholegrain breads and cereals such as 100 percent bran, oats, Cheerios, and Wheaties; legumes such as tofu, soybeans, and lima beans; a variety of vegetables including spinach, corn, and broccoli; nuts, such as almonds, cashews, peanuts, walnuts, and pecans; such fruits as dates, raisins, and bananas; and seafood.

Consume magnesium-rich foods in equal doses throughout the day. For maximum absorption, the supplement, magnesium citrate has greater solubility and bioavailability than magnesium oxide.

It is critical to achieve a balance between calcium and magnesium in order to optimize the effectiveness of both minerals. The goal should be a 2 to 1 ratio of calcium to magnesium.

Magnesium is a laxative—it may help counter any constipation brought on by calcium supplements—so it is best to start slowly and gradually increase the dose. If loose stools are a problem, another option is to take magnesium separate from calcium, with a meal that contains protein to enhance absorption. Magnesium can also function as a sleep aid; a dose at bedtime can assist in getting to sleep.

For those with kidney impairment, toxicity is an important issue, since the kidneys act as an escape route for excess magnesium. Symptoms of toxicity include drowsiness, weakness, and lethargy.  $\oplus$ 



Tom Mountford is a volunteer with the Treatment Information Program at the BCPWA Society.



#### How food intake affects drug absorption

by Rob Gair

A ntiretrovirals are life savers for people living with HIV, although long-term use is difficult to manage. Most people can handle annoyances such as pill burden, proper storage of medications, and timing of doses. But the side effects can be debilitating.

Compounding these complications is the food factor. Eating regular balanced meals to maintain health is one concern, but the use of food to optimize drug levels in the body presents a myriad of issues—especially since antiretroviral users take a number of different medications, some of which have conflicting food requirements. Juggling food intake with drug schedules is often challenging, particularly at work, in social gatherings, or while travelling. Thankfully, food consumption with antiretrovirals is easier than it used to be.

Once a pill is swallowed, it passes into the stomach where it dissolves into molecules. These molecules pass into the small intestine where they are absorbed into the bloodstream. Food affects the absorption of drugs through a variety of mechanisms: it increases acid levels in the stomach, which may enhance or hinder the dissolution of some drugs; it may increase or decrease transit time through the gut; or it may inhibit or enhance drug-metabolizing or drug-transporting enzymes.

Shortly after the drug is absorbed, the concentration in the blood reaches its maximum ( $C_{max}$ ); the minimum concentration ( $C_{min}$ ) is usually reached just before the next scheduled dose. The goal in HIV therapy is to ensure that the  $C_{max}$  is high enough to inhibit viral replication and that the  $C_{min}$  never falls low enough to allow replication. The prescribed dosage and the timing of doses are

designed to maintain this balance. Food recommendations are usually arranged to enhance drug absorption. Food does not affect absorption of drugs given by injection, such as T-20. Table 1 summarizes current food requirements for people taking antiretrovirals.

#### Different antiretrovirals, different interactions

Nucleoside transcriptase inhibitors (NRTIs), or nukes, are the oldest group of antiretrovirals. Drugs such as d4T, 3TC, AZT, and abacavir can be taken with or without food. The drug ddI is usually taken on an empty stomach because it is easily destroyed by stomach acid.

A notable exception occurs when enteric-coated ddI is taken with tenofovir. These drugs interact and inhibit degradation of ddI in the body, causing elevated levels and prolonged action. Taking food with this combination actually decreases ddI absorption compared to having no food, though the tenofovir interaction seems to more than make up for it. Since taking all medications together with food makes things easier for people, this is generally recommended. An added benefit is that ddI can be given at lower doses using the tenofovir combination, thus causing fewer side effects.

Non-nucleoside reverse transcriptase inhibitors (NNRTIs), or non-nukes, are the most flexible group of antiretrovirals since most are well absorbed either with or without food. Food actually increases the absorption of efavirenz. High-fat meals increase absorption of efavirenz even further, which may increase certain side effects, such as the dozy feeling that often occurs shortly after taking the medication. Therefore, the manufacturer recommends once-daily administration on an empty stomach at bedtime. However, some patients suffer nightmares if they take a large dose before bed, so a number of clinicians are recommending splitting the dose and taking it twice daily with or without food.

Protease inhibitors (PIs) need stomach acid in order to dissolve, therefore food is generally recommended for proper absorption. Most PIs are better absorbed with high-fat meals, except indinavir, which is best absorbed on an empty stomach. These days, boosting indinavir with ritonavir compensates for different absorption characteristics, thus reducing the need for some of the more finicky food recommendations. In other words, you may not need to monitor fat intake but food is still required.

Amprenavir, another PI, is better absorbed in the presence of vitamin E, so capsules are filled with liquid vitamin E. People taking this drug are advised not to take additional vitamin E supplements because more than enough is provided in the amprenavir capsules to meet daily requirements.

	Drug	Empty Stomach*	With or after meals	With or without food	Comments
	abacavir	1.9		X	
NNRTIS NRTIS	ddl (enteric coated)	x			May take with food if taking with tenofovir
	зтС			X	
	d4T			x	
	AZT			x	
	tenofovir (Viread)			x	
	delavirdine (Rescriptor)			x	With acidic drink (orange or cranberry juice) if taking acid-lowering drugs
	efavirenz (Sustiva)			X	
	nevirapine (Viramune)			х	
Protease Inhibitors	amprenavir (Agenerase)			x	No vitamin E supplements
	atazanavir (Reyataz)		х		Avoid antacids, especially at the same time as dose
	indinavir (Crixivan)		х		Only with ritonavir boosting
	lopinavir/ritonavir (Kaletra)		x		
	nelfinavir (Viracept)		Х		
	ritonavir (Norvir)		X		
			Х		
	saquinavir mesylate (Invirase)		X		

#### Grapefruit affects drug absorption

Grapefruit is known to inhibit the metabolism of certain drugs within the lining of the gut wall. The usual result is a higher level of absorption of the drug into the bloodstream, possibly causing increased side effects or fluctuating levels if you don't eat grapefruit every day. Drugs most likely affected are NNR-TIs and PIs, though we do not know the clinical significance for most medications. The effect lasts all day following consumption of the grapefruit, so taking drugs at a later time in the day does not prevent the interaction.

#### Thankfully, food consumption with antiretrovirals is easier than it used to be.

Grapefruit juice and Seville oranges (marmalade) can also cause the same phenomenon. Given the unpredictability of this interaction on drug levels, people taking antiretrovirals should avoid these fruits altogether. Other types of oranges and citrus fruits do not appear to cause these interactions.

Among other foods, alcohol and caffeine may increase dehydration and the possibility of kidney stones in people taking indinavir. Garlic decreases saquinavir levels. Some studies show that St. John's wort decreases indinavir levels, either by reducing absorption or increasing liver metabolism; St. John's wort should be avoided altogether, since this interaction may also affect other PIs or NNRTIS.

#### **Determining food quantities**

Dietary requirements can be different for each person. There are several resources to help tailor individual dietary needs: *The Canada Food Guide* provides detailed information on healthy eating. The Immunodeficiency Clinic at St. Paul's Hospital in

Vancouver offers dietary counselling, and patients of Spectrum Health in Vancouver can access a dietitian through the appointment desk. A referral from your physician is not required.

High-fat meals commonly used to study absorption of protease inhibitors usually contain more than 50 grams of fat. This translates into a burger and fries or a similar meal, a large muffin, or a large bag of potato chips. Regular intake of high-fat meals is not recommended because of other health risks; moderation is the key. Regardless of the fat content, meals should be balanced with the appropriate number of calories and with an assortment of items from all of the food groups.

The dynamics between food and antiretrovirals is complex. It requires vigilance to maintain some of the recommended food schedules and it is difficult to remain consistent. Drug combinations that boost levels of some of the more finicky antiretrovirals help to reduce the need for rigorous monitoring of food intake. Nevertheless, careful attention to some of the issues around food, in combination with a balanced diet, will help to ensure drug longevity and a healthy lifestyle.  $\bigoplus$ 

Special thanks to IDC pharmacists Junine Toy and Daphne Chow for their assistance in the preparation of this manuscript.

Canada Food Guide: <www.hc-sc.gc.ca/hpfb-dgpsa /onppbppn/ index\_ e.html>

Immunodeficiency Clinic, St. Paul's Hospital: 604.806.8060. Ask to book an appointment with the dietitian.

Spectrum Health: 604.681.1080



Rob Gair is the pharmacist at the BC Drug & Poison Information Centre. STRAIGHT from the source

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what's new in research

## Supervised treatment interruptions

by Adrienne Toulson

he development of highly active antiretroviral therapy (HAART) has greatly enhanced the management of HIV, resulting in improved quality of life and longer survival for people living with HIV/AIDS. Despite the benefits, the effectiveness and continued use of HAART for many individuals tend to be limited due to pill fatigue, multiple side effects, and the development of drug resistance.

Some people experiencing these difficulties may stop treatment with or without their doctor's advice. For others, their doctor may recommend a supervised treatment interruption (STI) if it is believed that HAART is not immediately necessary. STI may lessen the total time a patient takes HAART, thereby reducing drug toxicity, avoiding the development of drug resistance, and decreasing the costs to the healthcare system.

The clinical impact of STI, including its effects on viral load and CD4 cell count, was recently evaluated in the St. Paul's Hospital Immunodeficiency Clinic in Vancouver. Current treatment guidelines recommend initiating HAART therapy when the CD4 is less than 200 cells/mm3, with any viral load. In this study, HAART was interrupted in people whose CD4 had never fallen below 200. Participants had monthly CD4 monitoring and were advised to resume therapy once their CD4 levels reached near or below 200 cells/mm3.

The research studied various factors which predicted whether an individual was likely to reach this CD4 threshold and consequently restart HAART sooner. Thirty percent of those who had an STI had returned to treatment by the end of the study. For those who returned to treatment, the average length of the STI was 15 months. To date, the others remain off treatment from nine to 25 months, with CD4 cell counts over 200.

The patients who returned to treatment had lower CD4 cell counts in the past (usually below 250), as well as lower CD4 counts and a higher viral load at the start of STI, compared to those who remained off treatment on the STI. At three to six months after restarting therapy, most participants reached an undetectable viral load.

Before you start an STI, your doctor should fully assess your past medical history as well as past and present lab tests. While it is believed that interrupting HAART results in a decrease in CD4 cell counts and viral load rebound, these levels are likely to return to baseline after therapy is resumed. The study found that STI, if closely supervised, may be a viable alternative to continued therapy for people whose CD4 cell counts have never been below 200. The study further suggests that STI may be appropriate for people with adequate CD4 cell counts and viral load responses to antiretroviral therapy and who are medically stable. It also suggests that many people with HIV can remain stable for over one year without HAART.

#### Patients who returned to treatment had lower CD4 cell counts in the past as well as a higher viral load at the start of STI.

As seen at the St. Paul's Hospital Immunodeficiency Clinic, many people with HIV who are given the option of interrupting treatment may feel frightened at the very thought of it. For many of them, HAART has become an integral part of daily life and they may be concerned about the consequences of stopping treatment. However, once treatment is discontinued, many people welcome the break. They are relieved of the constant pressures of adherence and of the side effects caused by treatment. Research suggests that STI with regular lab moni-

toring may be a reasonable option for some.  $\oplus$ 



Adrienne Toulson is a research assistant for the BC Centre for Excellence in HIV/AIDS in Vancouver.





### Trial results—and how to get them

#### by Jim Boothroyd

Participants in clinical trials sometimes complain about the difficulties trying to get results from the studies in which they participate. Their doctors and nurses don't tell them the results. Or they tell them long after the trial has ended. Or the results are communicated in language that is hard to understand. This seems unfair, particularly as participants often put themselves at risk and *rightly* feel some ownership of the knowledge generated by studies done on them.

Most doctors and nurses who conduct clinical trials acknowledge this sense of ownership. Many try hard to inform trial volunteers of the results in a timely and understandable manner. They are, however, duty-bound *not* to report results until the study is complete and the findings have been carefully examined. It can be months or even years after a participant leaves a study before principal investigators present the outcomes. When they do—usually at a scientific conference or in a professional journal—it can be very challenging to track down participants and convey the study results, to each of them, in plain language.

The Community Advisory Committee of the Canadian HIV Trials Network (CTN) recognizes these challenges, but requires that volunteers be told in advance how and when they will be informed of the study results.

Informed consent forms for all CTN studies must therefore

#### Trials enrolling in BC

- CTN 147 Early Versus Delayed Pneumococcal Vaccination BC sites: St. Paul's Hospital and Downtown Infectious Disease Clinic (IDC), Vancouver
- CTN 157 Fenofibrate & L-Carnitine for Elevated Triglycerides BC sites: St. Paul's Hospital and Downtown IDC, Vancouver
- CTN 164 STI (Structured Treatment Interruption) BC sites: Downtown 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

state this information clearly, though informed consents for other clinical trials often do not.

If you're having trouble obtaining information about the outcome of a study, try the following:

Ask the doctor in charge of the study to give the results in plain language—his or her telephone number should be printed on the informed consent form that you signed before entering the study.

Ask the nurse in charge of the clinic where the trial was conducted to provide this information.

Check the results posted on the Web site of the CTN or call our information manager, Sophie Geeraerts, at 1.800.661.4664 for help.

Call the Canadian AIDS Treatment Information Exchange (CATIE) at 1.800.263.1638.

If you really like to dig, search the abstracts listed on the Web sites of major HIV scientific conferences, or do a search of PubMed Central, the US National Library of

Medicine's free digital archive of biomedical and life sciences journal literature.  $\oplus$ 



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

- CTN 171— CellCept (Mycophenolate Among Patients with HIV Receiving Abacavir) BC site: St. Paul's Hospital, Vancouver
- CTN 178 Rosiglitazone Maleate (Avandia) BC site: St. Paul's Hospital, Vancouver
- CTN 183 Continuous versus Intermittent Treatment BC site: St. Paul's Hospital, Vancouver
- CTN 189 3TC or No 3TC for HIV with 3TC resistance BC site: St. Paul's Hospital, Vancouver
- CTN 190 Strategies for Management of Antiretroviral Therapy (SMART) *BC site*: Downtown IDC, Vancouver

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

SEPTEMBER / OCTOBER 2004 LIVING +

#### **INFORMACIÓN EN ESPAÑOL**

## La reinfección del VIH

por Juan Gutierrez

reinfección de VIH es un gran problema y lamentablemente cada vez se reciben más y más reportes de casos comprobados. Cuando una persona con VIH es infectada por segunda vez con otra variante del VIH, esto se conoce como reinfección o superinfección.

Geográficamente hablando hay 3 grupos de VIH: VIH1, VIH2 y VIH3. Estos a su vez están divididos en subtipos diferentes, y cada subtipo tiene diferentes formas recombinantes. Por ejemplo, el grupo VIH1, que es el responsable de la mayoría de las infecciones en el mundo, tiene 8 subtipos diferentes (A, B, C, D, F, G, H, J). El subtipo A es responsable de casi todos los casos en Estados Unidos, Canadá, algunos países de Sudamérica, Europa Occidental y Australia. Este subtipo tiene 4 formas de combinación de virus: AE, AG, AGI, AB. Las combinaciones del virus VIH1 se presentan cuando una persona se infecta con dos subtipos diferentes. Una persona con VIH puede entonces estar infectada con diferentes variantes del virus que coexisten simultáneamente, siendo una de ellas predominante sobre las demás.

Hay muchas explicaciones de cómo esto puede ocurrir. La persona puede haberse infectado con dos virus diferentes al mismo momento de la infección primaria. O la persona se infectó inicialmente con una sola variante del VIH, pero al tomar medicamentos antirretrovirales se generaron mutaciones de resistencia y se desarrollaron nuevas variantes del virus. En un tercer caso, una persona puede haberse infectado inicialmente con una variante del VIH y posteriormente infectarse con un segundo subtipo o variante del virus (superinfección).

Hay al menos cuatro reportes de casos bien documentados de superinfecciones con VIH. En dos de los casos la infección ocurrió con un virus de un subtipo diferente. En los otros dos casos la segunda superinfección ocurrió con un virus del mismo subtipo. En todos los casos se observó un dramático aumento de la carga viral del VIH acompañado de una disminución acelerada del recuento de células CD4.

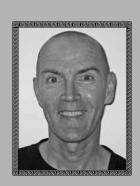
La superinfección por el VIH tiene varias repercusiones clínicas. En primer lugar se ha observado en animales que el deterioro inmunológico se acelera, lo que implica un promedio de vida más corto. Las observaciones clínicas en casos humanos muestran la misma tendencia. En segundo lugar la respuesta a medicamentos antirretrovirales puede verse gravemente afectada. Si una persona que ha logrado un buen control del virus con medicamentos se infecta con otras variantes del virus que sean resistentes a esos medicamentos, el control logrado seguramente se perderá y hará que el tratamiento falle. En tercer lugar es muy difícil diseñar una vacuna que brinde protección contra todos los grupos, subtipos y variantes del VIH. Sabiendo que la respuesta inmunológica contra el VIH que el cuerpo desarrolla es específica hacia un solo subtipo de virus, la superinfección con VIH representa un problema bastante serio.

Es muy probable que la superinfección con variantes del VIH ocurra más comúnmente de lo que suponemos. Esto reafirma la necesidad de practicar sexo con protección, aún entre personas infectadas con el VIH. Por otra parte es necesario estudiar mejor los mecanismos de la respuesta inmunológica contra el VIH, para así poder entender mejor este fenómeno llamado superinfección.  $\oplus$ 

**BCPWA Treatment Information Program (TIP)** Ofrece información sobre tratamientos del VIH/SIDA. Todos los miercoles 1:00PM a 5:00PM. 1107 Seymour Street, 2nd Floor, Vancouver, BC V6G 5S8 Llame a la línea directa: 604.893.2243 email: treatment@bcpwa.org

# Volunteering at BCPWA

#### Profile of a volunteer:



Gordon has been volunteering with the Treatment Information Program for over a decade. He continues to educate, support and inspire us all!

Zoran Stjepanovic, Coordinator of Treatment Information

#### **Gordon Waselnuk**

Volunteer history

I started volunteering with BCPWA in 1991.

#### Why pick BCPWA?

They had gone out of their way to help a close friend who was dying. I was his caregiver and they asked me if I would be interested in volunteering.

#### Why have you stayed?

Initially, I needed a place to channel my anger and grief over the loss of friends and lovers. I stayed because the work I am doing is very interesting, challenging, and a wonderful skills builder. It has taught me to become a more compassionate, understanding, and caring person.

#### **Rating BCPWA**

I volunteer with a few other organizations, and I highly rate BCPWA for its professionalism and for caring for its volunteers and staff.

#### **Favourite memory**

My fondest memories are the faces and names of courageous men and women I have met over the years who fought for dignity, respect, and equality for themselves and others. Many of them are no longer here, but their legacy lives on.

#### **Future vision of BCPWA**

I hope one day that we close the doors as AIDS becomes a distant memory.



#### **Onterested** in writing?

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

Volunteers should possess the following skill sets: — Ability to analyze and distill information

- Excellent research and writing skills
- Ability to work independently

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

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

# where to find help or information on HIV/AIDS, the following list is a starting point.

#### **BC Persons With AIDS Society**

1107 Seymour St, Vancouver BC V6B 5S8 604.893.2200 or 1.800.994.2437 e info@bcpwa.org www.bcpwa.org

#### A Loving Spoonful Location

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

#### **AIDS Memorial Vancouver**

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

#### AIDS Prince George

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

#### Living Positive Resource Centre Okanagan

101–266 Lawrence Ave., Kelowna, BC V1Y 6L3 t 250.862.2437 or 1,800.616.2437 e Iprc@Iprc.ca; www.livingpositive.ca

#### 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 t 250.753.2437 f 250.753.4595

#### **AIDS Vancouver Island (Victoria)**

1601 Blanshard St, Victoria, BC V8W 2J5 250.384.2366 info@avi.org; www.avi.org

#### **ANKORS (Nelson)**

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

#### **ANKORS (Cranbrook)**

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

#### AIDS Vancouver Island (Cowichan Valley)

1 Kenneth Place, Duncan, BC V9L 2Y9 t 250.701.3667 f 748.3509

#### Asian Society for the Intervention of AIDS (ASIA)

210 – 119 West Pender St, Vancouver, BC V6B 1S5 t 604.669.5567 f 604.669.7756 e asia@asia.bc.ca; www.asia.bc.ca

#### **Dr Peter Centre**

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

#### Friends for Life Society

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

#### **Healing Our Spirit**

3144 Dollarton Highway, North Vancouver, BC V7H 1B3 t 604.879.8884 or 1.800.336.9726 e info@healingourspirit.org www.healingourspirit.org

#### **McLaren Housing Society**

200 – 649 Helmcken St, Vancouver, BC V6B 5R1 t 604.669.4090 f 604.669.4092 e mclarenhousing@telus.net WWW.MCLARENHOUSING.com

#### North Island AIDS

(Campbell River) Society 684B Island Hwy, Campbell River, BC V9W 2C3 t 250.286.9757 or 1.877.650.8787 f 250.830.0784

#### North Island AIDS (Courtenay) Society 355 6th St, Courtenay, BC V9N 1M2 250.338.7400 or 1.877.311.7400

#### North Island AIDS (Port Hardy) Society

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

#### **Okanagan Aboriginal AIDS Society**

101 – 266 Lawrence Ave., Kelowna, BC V1Y 6L3 250.862.2481 or 1.800.616.2437 oaas@arcok.com; www.oaas.ca

#### **Outreach Prince Rupert**

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

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

1601 Blanchard St., Victoria V8W 2J5 t 250.881.5663 f 250.920.4221 erikages@pan.ca; www.pan.ca

#### **Positive Living North West**

Box 4368 Smithers, BC VOJ 2N0 3862 F Broadway, Smithers BC 250.877.0042 or 1.886.877.0042 plnw@bulkley.net

#### **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**

804 – 100 Park Royal South, W.Vancouver, BC V7T 1A2 604.913.3332 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 Resource &

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

#### Victoria Persons With AIDS Society

#330-1105 Pandora St.,Victoria BC V8V 3P9 t 250.382.7927 f 250.382.3232 support@vpwas.com; www.vpwas.com

#### Wings Housing Society

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

#### YouthCO AIDS Society

205 – 1104 Hornby St. , Vancouver BC V6Z 1V8 604.688.1441 1.877.968.8426 information@youthco.org; www.youthco.org

#### For more comprehensive

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

Upcoming BCPWA Society Board Meetings:								
Date	Time	Location		Reports to be presented				
September 15, 2004	1:00	Board Room Standing Committee		Standing Committee				
September 29, 2004	1:00	Board Room Written Executive Director Report — Financial Statements / A Director of Prevention		Written Executive Director Report — Financial Statements / August Director of Prevention				
The BCPWA Society is located at 1107 Seymour St., 2nd Floor, Vancouver.         For more information, contact:Alexandra Regier,Office Manager         Direct: 604.893.2292         Email:alexr@bcpwa.org								

#### **BCPWA Standing Committees and** Subcommittees

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

Board & Volunteer	Development				
Contact: Adriaan de Vries					
<b>t</b> 604.893.2298	e adriaand@bcpwa.org				
Community Representation &					
Engagement					
Contact: Lisa Gallo					
t 604.893.2209	e lisag@bcpwa.org				
Education & Communications					
Contact: Lisa Gallo					
t 604.893.2209	e lisag@bcpwa.org				
Fund Developme	nt				
Contact: Alasdair Hooper					
<b>t</b> 604.893.2264	e alasdairh@bcpwa.org				
IT Committee					
Contact: Ruth Marzetti					
<b>t</b> 604.646.5328	e ruthm@bcpwa.org				

#### Living + Magazine Subcommittee

Contact: Jeff Rotin t 604.893.2206 Prevention Contact: Peter Hall t 604.893.2225

t 604.893.2259

e jeffr@bcpwa.org

e peterh@bcpwa.org

#### **Support Services** Contact: Jackie Haywood

e jackieh@bcpwa.org

Treatment Information & Advocacy Contact: Tarel Quandt t 604.893.2284

e tarelg@bcpwa.org

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O I am a PWA in BC and can not afford the full subscription price

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## Disobedience school

A little bit of mischief goes a long way

by Denise Becker

"If all the beasts were gone, man would die from a great loneliness of spirit. For whatever happens to the beasts, soon happens to man. All things are connected." – Seattle Chief of the Dwamish, Suquamish, and allied tribes

think there is very little in life that can make one more miserable than the death of a beloved pet. Earlier this year, my 12-year-old Doberman, Molly, died of cancer. I felt like life was just one disaster after another. While having HIV can make us appreciate the good things in life more than most people, I think we also feel the tragedies more keenly, too.

My friends encouraged me to "take the cure" and buy another dog. I resisted for a while but eventually decided to follow their advice and soon after adopted a Doberman puppy. I called her Jasmine, or Jazz for short.

It quickly became apparent that Jazz was probably the worst behaved dog I had ever encountered. I had owned two Dobermans before her and they were smart, calm, and eager to please. This one, however, was incredibly naughty. I was at a total loss as to how to train her. I was a disgrace to my heritage. Didn't every Englishwoman have Barbara Woodhouse in her genes? For God's sake, our Queen has Corgis!

Obviously, I needed a refresher course. Out of desperation, I went to the local bookstore. There, I found every title imaginable: *The Monks of New Skete Train Their Dogs, Don't Shoot the Dog: The New Art of Teaching and Training, How to Speak Dog, The Tao of Bow Wow*, and—yes folks, this one is really out there—*Dog Training, Fly Fishing* and *Sharing Christ in the 21st Century.* 

Confused, I returned home, flipped through the newspaper and, quicker than you can say "snaussages", I phoned and registered for dog training classes.

To make a good impression on the opening night, I practiced with Jazz at home, teaching her to "sit" and "stay." It was cheating a little but, after all, they might expect something more from someone with an English accent and from a dog with such a stellar reputation. I didn't want to disappoint.

There were roughly twenty dogs milling around in the field



when we arrived on a cold and windy Tuesday evening. Jazz gladly set to work chasing furry tails; she was totally fascinated with them since she had only ever seen stumpy wagging ones. The trainer gathered us and explained the "sit" technique. I looked around, with a bit of Mr. Bean-ish smugness.

#### I was a disgrace to my heritage. Didn't every Englishwoman have Barbara Woodhouse in her genes?

"Okay, class, have your dog heel and then bring it to a sit," the instructor said. I walked ahead and issued a firm "sit!" command. I looked around and noticed people pointing and laughing. Jazz had become a huge ball of Jello. It was like having a 20-pound sack of potatoes on the end of a lead: the more I tried to get her to sit up, the more she became dead weight. Then, ever so slowly, she began to roll onto her spine, curving it like a rocking chair rail. We all broke down in laughter what a character this dog was!

The next week we learned the "down, stay!" command. Jazz dutifully lay down—then crawled across the field on her belly. At that point, I began to secretly take pride in her ingenuity. This dog was not easily tamed and, doggone it, she had spirit! We soon earned the reputation as the class clowns and everyone looked forward to her next stunt.

At the end of eight weeks, I had made many new friends. Jazz and I received our Beginner's Certificate, which I proudly displayed on the dining room table—until, that is, I found it torn to shreds in the front room, the culprit hiding around the corner with a twinkle in her eye.  $\oplus$ 

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