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

Living + editorial board

Jeff Anderson, Wayne Campbell, Joel NC Leung

Managing editor Jeff Rotin

Design / production Britt Permien

Copyediting Darren Furey

Contributing writers

Denise Becker, Dr. Carl Bognar, Jim Boothroyd, Dr. Jack Forbes, Sam Friedman, Dr. Peter Granger, Eileen Kabaroff, R. Paul Kerston, James Kreppner, Carole Lunny, Malsah, Mary Petty, Sergio Plata, Wallace Robinson, Ron Rosenes, Melanie Rusch

Photography John Kozachenko
Britt Permien

Senior policy advisor on health promotion

Paula Braitstein

Director of communications and education

Lisa Gallo

Director of treatment information and advocacy

Tarel Quandt

Coordinator of treatment information

Zoran Stjepanovic

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Living+ Magazine
1107 Seymour St., 2nd Floor
Vancouver BC
V6B 5S8

TEL 604.893.2206

FAX 604.893.2251

EMAIL living@bcpwa.org

BCPWA ONLINE www.bcpwa.org

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think +

opinion and editorial

The winds of change

by *Malsah*

On June 12, the BCPWA Society suffered a great loss in the passing of its chair, Glen Hillson. Glen was an extraordinary leader and played an integral role in creating the success and stability that the BCPWA Society enjoys today. He brought great tenacity, determination, commitment, and compassion to his work. These are the hallmarks by which he lived his life.

In November, with his health in serious decline, Glen expressed his desire that I assume the role and responsibilities of acting chair. He invested his trust and respect in me by nominating me for vice-chair at our inaugural board meeting following the 2002 Annual General Meeting. On June 25, I was elected as Glen's successor, in keeping with his wishes.

This change in BCPWA Society's leadership brings hope within the HIV/AIDS movement and community in BC. An attitudinal shift began to emerge during the Canadian AIDS Society (CAS) Forum and AGM in Montreal in June. Members of the CAS Pacific Caucus asserted that the BCPWA Society and many of its board members have had a reputation for arrogance in their relationships with other organizations for well over a decade. They complained that the BCPWA Society does not do enough to support other organizations in addressing the demands and challenges of HIV/AIDS. They felt that the BCPWA

Society could be more consultative and cooperative and could share its knowledge and experience.

Many also expressed their optimism that new leadership would bring renewal. I can only speculate that this optimism arises from a feeling that my strengths are in building community relationships and fostering cooperation.

I have always been committed to the greater community and have given unwavering support for the work done in rural communities. I have always felt that the BCPWA Society could better inform people of its activities and undertake a public relations campaign and a membership drive to build its links with all BC communities. If we are not able to adequately empower persons living with HIV/AIDS across this province, then we should invest resources in assisting other community-based organizations to do that work, especially in rural communities. It's not about who gets the credit; it's about empowering and supporting PWAs across BC.

I hope to be a builder of bridges. I seek harmony and cohesiveness within the greater community. I will be a dedicated leader, striving relentlessly to achieve these goals with sincerity, compassion, and determination. ⊕



Malsah is the chair of the BCPWA Society.

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

REALITY BITES



News from home & around the world

PWAs recoup dietary allowance

This past spring, the B.C. Ministry of Human Resources discontinued a monthly dietary allowance to persons living with HIV/AIDS receiving Schedule C health benefits. The BCPWA Society was able to lobby the government to overturn this decision. As a result, 85 BCPWA Society members were awarded back their dietary allowance.

Stakeholders withdraw from CSC consultations

In November 2002, a group of twelve community-based AIDS organizations and service providers announced their decision to withdraw from participation in consultation processes and committees of the Correctional Service of Canada (CSC).

The group took the decision because of a “lack of CSC commitment to engage in a serious process of community consultation and collaboration that could lead to substantive improvements in HIV and hepatitis C services for prisoners.” They expressed frustration at the CSC’s lack of action to implement new, much-needed HIV and HCV services, and to improve existing programs and services based upon the groups’ feedback.

The group decided to increase its own efforts to improve access to care, treatment, and support for prisoners living with HIV and/or HCV, as well as access to HIV and HCV prevention measures in prisons. The group has requested a meeting with the Solicitor General and the Health Minister.

Source: *Canadian HIV/AIDS Policy & Law Review*

Glen Hillson tribute

The City of Vancouver has recognized Glen Hillson’s contribution to community and AIDS activism. At a City Council meeting, Mayor Larry Campbell read a proclamation recognizing July 8, 2003 as Glen Edward Hillson Day.

Glen Hillson was the BCPWA Society’s chair from 1998 until his passing on June 12, 2003 from complications due to AIDS and co-infection with hepatitis C virus.

Tenofovir-lamivudine-abacavir warning

The European Medicines Evaluation Agency has told physicians not to start HIV-infected patients on tenofovir in combination with abacavir and lamivudine after a study found that nearly half of patients on this regimen failed to respond.

In a statement on its website, the EMEA added that patients already taking this combination should be “frequently monitored with a sensitive viral load test and considered for modification of therapy at the first sign of viral load increase.”

It also advised patients receiving, or about to receive the three drugs to immediately inform their doctor.

The advice follows reports of a high rate of early virologic non-response observed in a GlaxoSmith Kline-sponsored study of therapy-naïve adults receiving the combination on a once-daily basis.

The precise nature of any interaction leading to non-response in this study is still not known.

Source: *Reuters Health*

CPP reinstatement

Human Resources Development Canada announced it will introduce automatic reinstatement of Canada Pension Plan (CPP) disability benefits if beneficiaries fail at return-to-work attempts.

Automatic reinstatement will allow Canada Pension Plan disability clients who leave benefits to work to be reinstated if they are unable to continue working because of their disability. It will be available to clients for two years from the date their Canada Pension Plan disability benefits are discontinued.

Hepatitis induced by kava

A German study published in the *Journal of Hepatitis* reported the potentially severe hepatotoxicity of kava.

Using a clinical diagnostic scale established for adverse hepatic drug reactions, researchers analyzed 29 novel cases of hepatitis along with kava ingestion that occurred between 1990 and 2002 in addition to seven previously published case reports. They found hepatic necrosis or cholestatic hepatitis with both alcoholic and acetonic kava extracts. The majority of the 29 patients and the additional seven published reports were women.

Nine patients developed fulminant liver failure, of which eight patients underwent liver transplantation. Three patients died, two following unsuccessful liver transplantation. In all other patients, a complete recovery was noticed after the withdrawal of kava.

FDA approves Reyataz

The U.S Food and Drug Administration (FDA) announced the approval of Reyataz (atazanavir sulfate), a protease inhibitor (PI) to be used in combination with other

REALITY BITES

News from home & around the world

antiretroviral agents for the treatment of people with HIV. Manufactured by Bristol-Myers Squibb, Reyataz only needs to be taken once daily with food and has a low “pill burden” (two pills each day).

Reyataz appears to have minimal impact on lipid parameters such as triglycerides and cholesterol. The most frequently reported adverse events among patients in the clinical trials were nausea, infection, headache, vomiting, diarrhea, abdominal pain, drowsiness, insomnia, and fever.

Source: *The Data Lounge*

Cirque du Soleil accused of HIV bias

Lambda Legal is charging Cirque du Soleil with violation of state and federal laws following the dismissal of a highly qualified gymnast from a major part in its “Mystere” show this spring over sudden concerns about his HIV infection.

Matthew Cusick has been living with HIV for 10 years and disclosed his HIV status without incident before beginning any training with the troupe. After four months of training, Cirque du Soleil offi-

cialists told him that he no longer had the job, despite being given a fine bill of health from Cirque du Soleil’s own doctor, whose notes said Cusick was a “healthy athlete” who “should be able to perform.” His viral load was undetectable in two comprehensive medical exams by the doctor.

Cirque du Soleil’s attorneys said the company was acting as a “socially responsible employer” that has an obligation to avoid “known safety hazards.”

South African deregisters nevirapine

South Africa’s Medicines Control Council (MCC) announced it will deregister nevirapine for single-dose mother-to-child transmission prevention (MTCTP). The MCC’s position contradicts a recent World Health Organization press release, which states that short-course nevirapine for MTCTP should be part of the minimum standard of care for HIV-positive women and their children.

Treatment Action Campaign (TAC), which fights for affordable treatment for people with HIV, claims that the MCC has not provided the public with any new sci-

entific information to support its reversal.

According to TAC, nurses and doctors in public hospitals and clinics around South Africa have expressed dismay at this decision because it undermines the sustainability of the public sector MTCTP program, which has the potential when it is fully rolled out to prevent approximately 30,000 babies from contracting HIV every year.

New support groups in Surrey

Surrey Hospice Society is offering two new support groups. The first group is for families and loved ones of persons diagnosed with HIV or have died from AIDS-related illness. Meetings will be held on the first and third Monday of each month, from 10:30AM – NOON.

The second group is for individuals living with a diagnosis of HIV, who wish to explore grief and loss issues. Meeting will be held on the second and fourth Monday of each month from 7:00PM – 8:30PM. Both groups will meet at Oak Avenue United Church, at 102nd Street and 128th Avenue in Surrey. For more information and registration, contact Cori at 604.543.7006. ☎

photos: John Kozachenko



The dazzling BCPWA Society float at this year’s Vancouver Pride Parade.



Polli&Esther’s Closet volunteers held a garage sale in Vancouver’s West End. They raised \$400 toward new socks and underwear for PWAs.

Our readers respond



Government's rationale for HIV reportability

Dear Editor:

In his article "Branded" (Issue 25, July/Aug 2003), Jeff Anderson does an excellent job describing the responses of the many HIV/AIDS advocacy and support groups with whom I consulted between January 2000, when the issue of HIV reportability was first tabled, and February of 2002, when my final report was released.

Although I did not in the end agree with them that the balance of evidence favoured leaving the situation at the status quo, their (your) input was invaluable in reinforcing the primacy of informed consent, protection of non-identifying disclosure when that was desired, the voluntary and anonymous basis for partner notification, and the increased sanctions against unauthorized disclosure that are inherent in the regulations and policy frameworks that have been adopted by government and public health officials.

The information that convinced me to make the recommendations that I did was the clear evidence from the published evaluative literature that assisted, voluntary, anonymous, partner notification was effective in finding persons at high risk who didn't know that they were at risk, who subsequently made changes, got tested, etc., and who by a large majority were pleased to have been notified and supported the program.

This information, coupled with a lack of evidence of harms—for example, no jurisdiction that looked for it could find evidence that public health involvement dissuaded persons from being tested—convinced me that the only ethical course was to recommend that public health become involved in partner notification, a process started by creating a legal framework for the confidential test information to be forwarded to medical health officers.

We are committed to a rigorous evaluation of the outcomes of reportability in British Columbia. Should the evaluation show harms that outweigh benefits, or no benefit, my ethical obligation would be to recommend removal of HIV from the list of reportable conditions.

My full report can be found at www.healthplanning.gov.bc.ca/pho/other.html.

Sincerely, P. R. W. Kendall,

*MBBS, MSc, FRCPC,
Provincial Health Officer*

PWAs not welcome in US

Dear Editor:

While "The Travel Bug" (Issue 24, May/June 2003) recognized that "the US has one of the most repressive policies" for HIV-positive people who want to enter that country, the problem is grossly understated. In the law, HIV-positive people are not even wel-

come to change airplanes in the US while en route to a third country. It is true that you can apply for a special waiver to enter the US if you have HIV, but people who have sought special waivers by going to US Consulates have reported rude and ignorant treatment and, sometimes, denial of the waivers they are asking for. Having applied, your HIV status is on permanent record at the Consulate. If you're successful at obtaining a waiver, there is a note permanently entered on your passport, making your HIV status known to officials of any other country you may want to enter.

In practice, HIV-positive people can and do get around this by lying or smuggling. You can try to enter the US just like anybody else, with meds in your luggage, but you can't be certain that your airline ticket will be refunded if you're denied entry. Or you can leave your meds at home, lie to the immigration officer, and jeopardize your own health. HIV-positive people are placed in the situation where it is easiest to enter the US by means of deceptive (and therefore illegal) behaviour. HIV may not be a crime, but entering the US is.

Terrence Higgins Trust is campaigning to try to convince the British government to protest this appalling situation to the American government. HIV-positive people in Canada need the same sort of advocacy.

Name withheld upon request



Community partners making a difference in AIDS WALK 2003

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 works to fulfill one guiding principle: "No one living with AIDS should live with hunger." That's a bit easier to achieve thanks to their partnership in 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. AV provides services to people with HIV who require assistance in 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 PHA volunteer honorarium program, and contribute to emergency financial support to enhance the quality of life for Asian PHAs 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. Money raised at the WALK will be used to provide massage/bodywork, workshops, individual counselling, support groups, meals served in a warm social environment, and care for individuals 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 and affected by HIV/AIDS. WALK proceeds will assist aboriginal PWAs with

emergency funds, moving expenses, food vouchers, and participation in the APHA retreat and the annual Christmas Dinner.

McLaren Housing Society of BC has provided safe, affordable housing to PWAs on very low incomes since 1987. Currently, McLaren manages 52 apartment homes at Helmsken House and Seymour Place and 32 portable housing subsidies in downtown Vancouver. This year's WALK funds will go directly towards rent subsidies to help reduce the long wait list, which now has over 170 people.

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

South Fraser Community Services Society is excited to be a partner of AIDS WALK 2003. Funds raised will support the Djaeff Mahler Grocery, a food bank celebrating its second year of operation this July. This weekly food bank partners with AIDS Vancouver, the Mahler Foundation, the Surrey Food Bank, and many community organizations in providing a weekly supplement to people living with HIV.

Wings Housing Society works towards ensuring that every person living with HIV/AIDS has adequate, affordable housing. Wings provides 113 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 organization working to involve youth ages 15-29 from all communities in addressing HIV/AIDS and related issues. It provides educational initiatives and support services to youth infected with or affected by HIV/AIDS or hepatitis C. WALK proceeds will be used to support the Positive Outreach Program, which provides peer counselling, monthly dinners, and outings. ⊕

Participate in AIDSWALK 2003

Vancouver was the first city to mobilize an AIDS WALK in Canada. This year we celebrate our 18th year of commitment and action. More than 130 Walks, coordinated with the support of AIDS WALK Canada, will take place across the country on the weekend of September 20 and 21. Mark Sunday, September 21, 2003, in your calendar and join us at Upper Ceperley Park in Stanley Park.

Where the money goes

All proceeds from AIDSWALK 2003 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 10 Community Partner organizations.

Forming a team

Walk with your friends, family, or work colleagues. Registering a team is easy. Just call 604.915.WALK and ask for your Team Captain Kit.

Prizes

Pledge prizes are awarded for money brought in prior to and on the WALK day only. One commemorative AIDSWALK 2003 pin will be issued to each individual Walker or Team Captain who collects pledges on or over the following gift amounts:

- For pledges over \$250:
a Joe Average 250 Club pin.
- For pledges over \$500:
a Joe Average 500 Club pin.
- For pledges over \$1000:
a Joe Average 1000 Club pin.
- For pledges over \$2000:
a Joe Average 2000 Club pin.

Pick up an AIDS WALK pamphlet for information about Individual Walker Awards.

3 easy steps to get involved

Step 1

- ▼ Call 604.915.WALK or
- ▼ Fax us at 604.915.9256 or
- ▼ Email us at walk@bcpwa.org or

Return your completed registration form to:

AIDSWALK
BC Persons With AIDS Society
1107 Seymour St., 2nd Floor
Vancouver, BC V6B 5S8

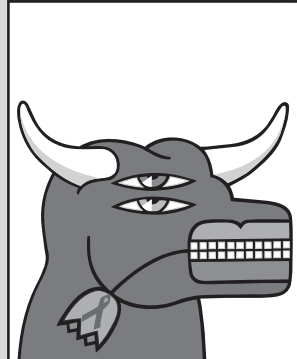
Step 2

Collect Pledges

Step 3

Walk the WALK

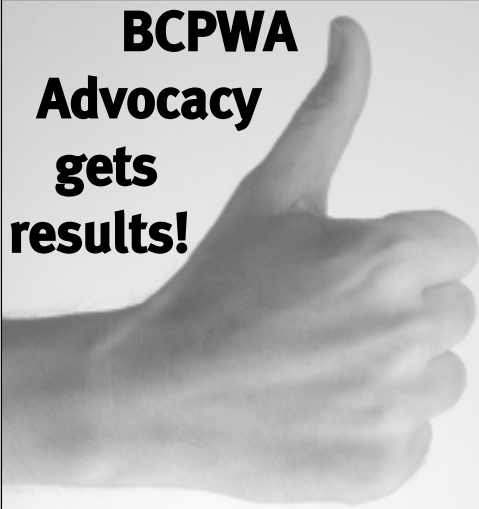
A I D S W A L K 0 3



STANLEY PARK
VANCOUVER
SUNDAY SEPTEMBER 21

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**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 June and July 2003 is:

- ▼ **\$27,461.89** in debt forgiveness.
- ▼ **\$74,566.00** in housing, health benefits, dental and long-term disability benefits.
- ▼ **\$22,185.00** in Monthly Nutritional Supplement Benefits.
- ▼ **\$377,708.76** into members' hands for healthcare needs, from grandfathered Schedule C benefits.
- ▼ **\$6,000.00** secured back for our members in dietary allowances

Casting a wider PharmaNet

Informed consent form will allow PWAs to voluntarily opt into system

by Paula Braitstein

Several years ago, the British Columbia government began PharmaNet, a province-wide network linking all pharmacies into a central set of database systems. The intention of PharmaNet is to improve patient safety by ensuring that regardless of where you get your drugs dispensed from, the pharmacist will know all the prescription medications you are taking, as well as all your reported clinical conditions and allergies. So the pharmacist will know, for example, if you have hepatitis C and are allergic to Septra. It is also intended to facilitate claims processing and reduce fraud.

Currently, the only drugs that are not tracked by PharmaNet are antiretrovirals. This exception resulted from concerns about confidentiality and privacy, especially in small towns where your pharmacist may also be your neighbour. Many people in this situation would prefer that their neighbours didn't know that they are HIV-positive. The BCPWA Society and other community members successfully lobbied for the exclusion of antiretrovirals because too many people living with HIV are at risk of stigma and discrimination.

The downside to this exclusion is that antiretrovirals often have many life-threatening drug interactions, and if your pharmacist doesn't know about everything you are taking, he or she has no way of trying to protect you from these interactions.

However, PharmaNet has finally come up with a way to protect the privacy of HIV-positive people while still offering the opportunity for pharmacists to know about all your drugs. They have

developed an informed consent form that will allow you to opt in to the PharmaNet system. You can sign the form when you pick up your antiretroviral prescriptions. If you choose not to sign the form, your antiretrovirals will not be listed. Before you decide not to sign, you should fully understand the risks.

If you choose to opt in, pharmacists, their assistants, and hospital emergency rooms will be able to access your file. The PharmaNet system contains data on all the drugs dispensed to you, reported drug allergies and clinical conditions, and patient demographics, such as your personal health number, name, address, gender, date of birth, and claim information (your social assistance number and the name of your private insurer). You can choose to protect your file with a password to minimize the risk of people accessing it without your knowledge.

PharmaNet complies with BC's law to protect individual privacy, including the Freedom of Information and Protection of Privacy Act. While this safeguard affords a certain amount of assurance, there are no guarantees that your privacy will not be breached in some way. However, in spite of privacy concerns, many people would prefer to reduce the risks associated with drug interactions. At least now you have the choice. ⊕

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

The ups and downs of HIV

a community forum presented by the Treatment Information Program of the
British Columbia Persons With AIDS Society

Date: Wednesday October 15 2003, 6PM to 9PM

Location: Carnegie Center 401 Main Street, Main Floor Theater

Topics:

- ▼ HIV and depression
- ▼ Mental Health issues
- ▼ Drug interactions between HIV meds and psychiatric medications
- ▼ HIV and Crystal Meth psychosis

Contact: 604.893.2274

RSVP by October 3 2003

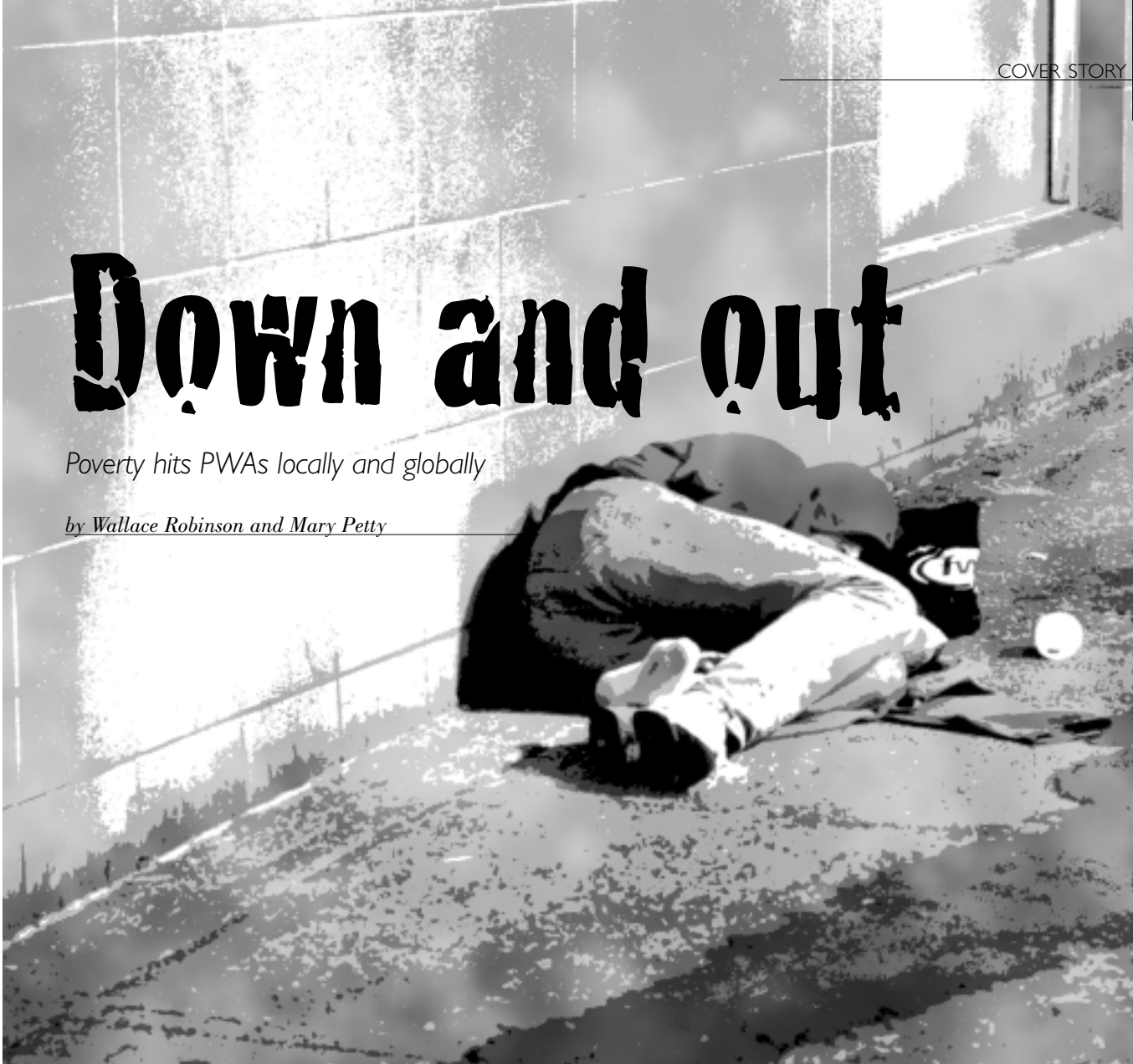


Supported in part by an unrestricted educational grant provided by AbbottVIROLOGY

Down and out

Poverty hits PWAs locally and globally

by Wallace Robinson and Mary Petty



AIDS and poverty are profoundly and cruelly intertwined. Poverty increases your chance of contracting HIV and then developing AIDS, and AIDS increases your chance of becoming poor.

The relationship between HIV/AIDS and poverty is a vicious cycle affecting millions of people around the world, especially in sub-Saharan Africa. The United Nations Development Programme describes how HIV/AIDS infection in a

family can lead to loss of work and income, inability to pay for medical treatment, and children dropping out of school or being orphaned. When these effects occur within multiple families, the whole community becomes destabilized. And when multiple communities are affected, the nation loses its economic strength; health services and education decline, which affects programs and education about AIDS prevention; and so the cycle continues.

The epidemic of HIV/AIDS in the world's poorest countries is a depressing issue. It is difficult enough to live with AIDS day today or to grapple with the challenges of AIDS in our own community without having to think of the global inequalities about which we feel simultaneously guilty and powerless. Given the amount of worldwide economic resources, living in poverty in 2003—whether in Botswana or British Columbia—is an injustice. It is morally repugnant that the collective wealth of just 84 people, the world's richest 84, is greater than the gross domestic product of China, a country of 1.3 billion people. To put it another way, the richest 1 percent make as much as the poorest 57 percent of the world's population.

Poverty in Canada

Inequitable distribution of wealth is one of the persistent criticisms about Canada contained in the United Nations Human Development Report. Canada is consistently low on the Human Poverty Index, the Report's measure of wealth inequalities within a country. In 2003, Canada fell to 12th place of the 17 most industrialized countries on this index.

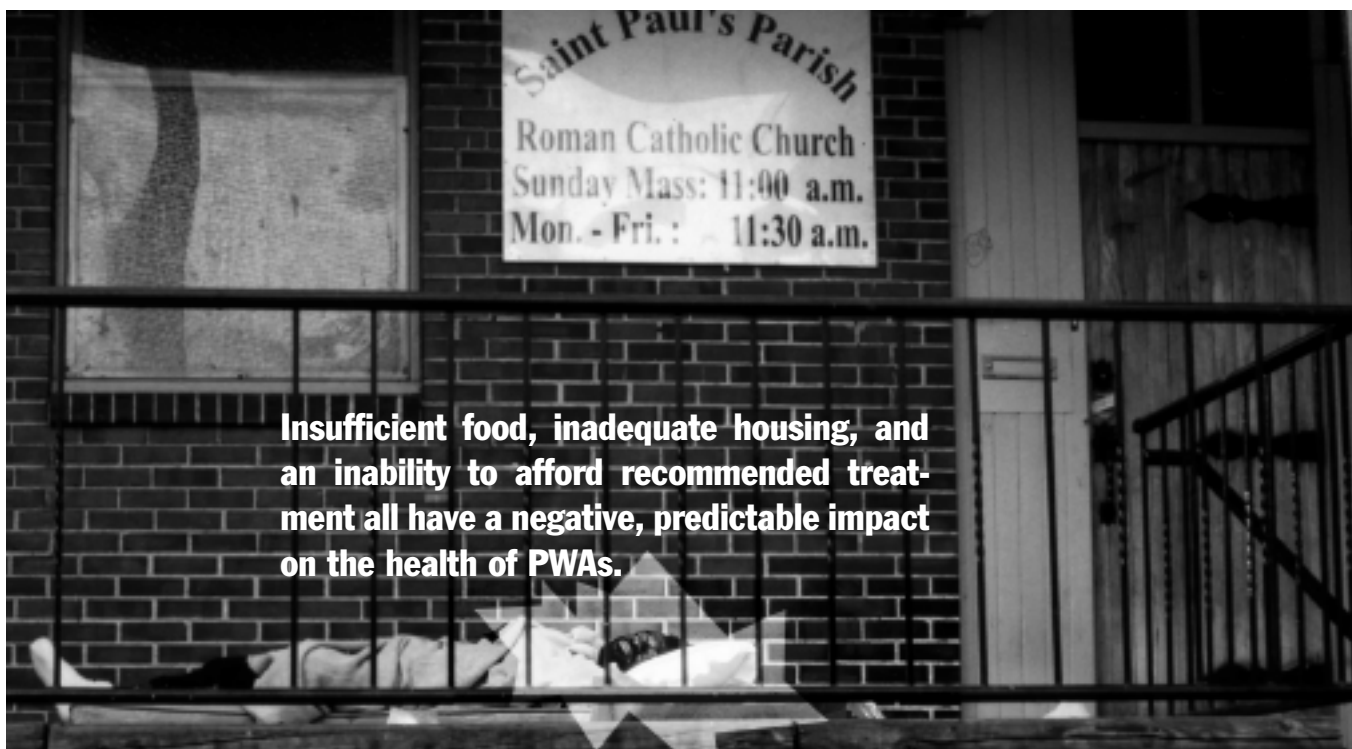
Human rights groups criticize Canada for cuts to social assistance, lack of social housing, the number of aboriginal people living in poverty, and the number of people—including people with disabilities—living below the poverty line. The National Council of Welfare reports that a single British Columbian on provincial disability benefits in 2002 received only 51 percent of the income needed to reach the “poverty line” (poverty lines are complicated and controversial formulas used to identify how much income is required for spending on

necessities). Even a person living with HIV/AIDS who received full disability and Schedule C benefits was receiving only roughly 75 percent of the income needed to attain poverty line income status for a single person in BC.

People living with HIV/AIDS on CPP disability benefits, on private pensions, or having to work part time for health reasons are also likely to be living below the poverty line. So are seniors or single parents living with HIV/AIDS. “There are families in which all members, kids and adults, are positive,” says Miranda Compton of AIDS Vancouver. “Or families in which the parents—expected to be the breadwinners—are positive and too sick to work.” She adds that many of these parents would like to work and attempt to work, but decent jobs are scarce. “Welfare offers no supports to help people actually get decent jobs. They get low wage or seasonal jobs...with no sick time or benefits and most often the jobs bring in no more than income assistance.”

Living with HIV/AIDS and poverty

Poverty is a very personal experience. A lack or loss of income reduces a person or family's control over the circumstances of their lives and limits choices. HIV/AIDS workers and volunteers in this province see many people who are unable to afford nutritious (frequently more expensive) food and many people who are unable to afford enough basic food. People live in substandard or sub-optimal housing. Many people cannot afford medications or complementary medical care not covered by health plans. Insufficient food, inadequate housing, and inability to afford recommended treatments all have a negative, predictable impact on the health of people living with HIV/AIDS.



Insufficient food, inadequate housing, and an inability to afford recommended treatment all have a negative, predictable impact on the health of PWAs.

For people living in poverty, meeting friends for coffee or going to see a movie—things that those of us who are able to work sometimes take for granted—become unaffordable luxuries. These kinds of activities foster social relationships and quality of life. They lessen isolation and depression that, if not kept in check, can negatively impact the immune system and overall health.

Talk to community organizers, workers, or anti-poverty activists today in BC, and you will hear about unprecedented levels of desperation among people living in poverty. Some of this desperation is a result of recent provincial policy changes designed to cut the Ministry of Human Resources (MHR) budget by \$582 million over three years by reducing benefits, tightening eligibility rules, and introducing waiting periods and time limits.

An individual or societal failure?

These policy changes and the language of “personal responsibility” reflect the gradual, insidious shifting of societal values from solidarity to individualism. BC’s cuts to income assistance, like other “welfare reform” measures across the US and Canada over the past decade, represent an attack on the poor, a view of poverty as individual failure, rather than a failing of social structures and economic policies. “It has never been easy to be poor in affluent North America,” says Dara Culhane, an anthropologist at Simon Fraser University, “but the poor and the ill—particularly people with stigmatized conditions like HIV/AIDS—are increasingly scapegoated, demonized, and targeted as the cause of everyone’s declining fortunes, and the embodiment of widespread fear and insecurity about the future.”

Canada is consistently low on the Human Poverty Index, the UN’s measure of wealth inequalities within a country.

Alarmed at increasingly desperate conditions facing the people with whom they work, HIV/AIDS workers and volunteers help people juggle meagre resources in hopes of avoiding disasters such as homelessness and the inability to obtain life-saving medications. “If someone who is self-employed, like an artist, suddenly becomes sick, they are expected to live with absolutely no income for three weeks or more,” says Miranda Compton of the new three-week waiting period to receive income assistance. “Unless they have friends or family who can help, they will stand to lose their housing and will likely become sicker. The extremely limited mechanisms of the past, meant to prevent homelessness and starvation, are gone.”

Vicki Bright has worked for many years with people living in Vancouver’s Downtown Eastside and notes that HIV-positive women are particularly vulnerable under the new rules. “The waiting periods, increased demands for paperwork, mandatory reporting to MHR offices, and drastic cuts to things like crisis grants force women who’ve been trying to leave work in the sex trade to work even more,” she says. “Add the fact that many positive women have kids to support. You can hardly say that they have choices.”

What you can do to help

Poverty is a pervasive problem globally and locally, and it is a personal crisis for many people living with HIV/AIDS. As you read this article, you may feel powerless to do anything about it. However, we can all do something to make a difference.

HIV/AIDS and anti-poverty agencies in our community need your support. If you have some spare time and energy, consider volunteering. Donate financial support, if you can. Join the AIDS WALK on Sunday September 21, or sponsor someone who is walking in this annual event, which raises funds for various local agencies supporting men, women, and children in our community living with HIV/AIDS. Think about what you can do personally to make a difference in the lives of others who are affected by poverty and living with HIV/AIDS.

Easter Armas-Mikulik decided to do something. “Back in 1984, I made lunch daily, often chicken soup, for a dear friend who was dying from AIDS,” she recalls. “One night, on my way home, I had a life-changing experience. I witnessed a person from the neighbourhood, a successful architect, eating out of a garbage can. He was skin and bones, and I felt ashamed and helpless. I asked myself: ‘What has happened to our humanity, why is he alone, why isn’t anyone trying to save his life with chicken soup?’ From that day on, I knew I was going to do whatever it took to feed people living with HIV and AIDS.” Easter helped found A Loving Spoonful, which now delivers over 100,000 free nutritious meals annually to people with HIV/AIDS in Greater Vancouver.

You can also play a role by advocating at local and provincial levels for more compassionate policies and programs for people living with HIV/AIDS and people living in poverty during this era of “welfare reform.” Lobby the Canadian government to meet its financial commitment to the Global Fund to Fight AIDS, Tuberculosis, and Malaria and to institute national policies to eliminate poverty, hunger, and homelessness.

We need to rethink poverty as an issue of social justice. The elimination of poverty is a social good for all—not just for the poor. As individuals who may not be poor at present, we need to realize that we are all potentially a paycheck away from poverty—and not to live in fear of this reality but to accept the changes that it demands.

While we advocate for people living with HIV/AIDS and in poverty, we need to think globally, act locally, and link the two conceptually. We need to re-introduce the idea that social and economic structures, rather than individual failure and dependency, cause poverty. And that global economic conditions, worldwide poverty, and the AIDS pandemic affect all of us, no matter where we live. ☉

Mary Petty and Wallace Robinson are social workers with the HIV Program and the Infectious Disease Clinic at St. Paul’s Hospital in Vancouver.





No flash in the PAN

Network incorporates as a society

by Malsah

Many years have passed since I first participated in discussions of what was to become the Pacific AIDS Network (PAN). In the fall of 1995, about thirty individuals, many of whom were HIV-positive, from over a dozen AIDS service organizations gathered to discuss this issue.

PAN has achieved many of its goals over the years. It has been a strong and influential voice in BC and across this country. It has affected public policy and many of the decisions of government. PAN effectively stalled regionalization until the BC Liberal government took power. PAN's successful lobbying efforts resulted in the creation of the BC Ministry of Health's HIV/AIDS Division and the HIV/AIDS Advisory Committee, which included strong community representation. The provincial Liberals abolished both of these entities shortly after taking office.

PAN has proven to be essential, viable, valuable, effective, and sustainable. The efforts and unity of PAN resulted in increases to provincial funding, a profound increase in awareness and understanding in government and the larger society, a shift in public attitudes, and the integration and sharing of knowledge and resources. PAN's networking has provided PWAs with opportunities to offer direction and raise important issues to service providers.

PAN has evolved over the years, the most notable change being a shift to decision-making through a democratic vote when consensus cannot be achieved. The organization has also changed its regional boundaries to coincide with the latest incarnation of health authorities, which added two more seats to the Working Group, making it ten seats plus one for the agency of record until PAN's fall meetings.

After several years of debate and deliberation, PAN is now in the process of what will undoubtedly be the most significant

change in its history. The organization is now incorporated as a legal entity recognized and empowered under the Societies Act of BC and eligible to apply for federal charitable status. The legitimizing of PAN may provide greater funding opportunities and consolidate its position as an effective AIDS service organization.

Some changes to PAN's structure and how PAN operates will likely result. However, the desire of the membership and that of the PAN Working Group is to remain as similar to the existing PAN model as possible. The extent to which PAN remains the same will be determined by its membership at its fall meetings.

The PAN Working Group is now a Board of Directors under the Societies Act. The bylaws submitted to Victoria as directed

PAN is now in the process of what will undoubtedly be the most significant change in its history.

by the membership do not accurately, or in the opinion of some, remotely reflect the structure and operations of PAN as we know it. At the fall meetings, the intent is to determine bylaw amendments and, perhaps, constitutional

amendments. This process will establish the foundational documents that truly reflect the desired PAN model of the membership. This exercise may prove arduous and is fraught with challenges. Ultimately the Registrar of Companies will decide what is acceptable.

As a strong and long-time proponent of incorporation, I look forward with great enthusiasm to the discussions and decisions of the fall meetings. I encourage strong debate and continue to discuss this very important matter amongst my peers. Check out the PAN website <www.pan.ca>. Do not hesitate to contact members of the PAN Working Group to discuss the matter further. ⊕

Malsah is the chair of the BCPWA Society and a member of the PAN Working Group.



Feds unveil new strategic plan for HIV/AIDS

by Jeff Anderson

This summer and fall Canadian stakeholders in the response to HIV will be pouring over a new, Health Canada-led, five-year collaborative plan to combat HIV/AIDS. The first “pan-Canadian Strategic Plan for HIV/AIDS” will replace the federal Canadian Strategy on HIV/AIDS, which was created in 1997.

The new plan seeks to fulfill Canada’s global commitments to fight HIV/AIDS, as part of the Declaration of Commitment on HIV/AIDS created at the 2001 UN General Assembly Special Session on HIV/AIDS (UNGASS). As a member nation, Canada has agreed to “ensure the development and implementation of multi-sectoral strategies and financing plans for HIV/AIDS that address the epidemic in forthright terms.” The Declaration also requires participating countries to “involve partnerships with civil society and the business sector and the full participation of people living with HIV/AIDS ... resourced to the extent possible by national budgets.”

This new plan is the best evidence to date that the federal government intends to fulfill its promise to Canadians and the world. The federal Minister of Health will announce the Strategic Plan on World AIDS Day, December 1, 2003.

To make the best use of limited resources, we should all work together to determine what needs to be done in Canada, who should do it, and how our shared objectives could be attained. This philosophy makes this strategy different from all those before it. This new “pan-Canadian” strategy seeks to incorporate the lessons we’ve learned from the first twenty years of the epidemic and contribute sensible objectives and outcomes needed to change our response from the crisis mode which began our struggle to a more strategic, collaborative approach for the future.

In the past, governments, health professionals, people with HIV, and communities have developed separate approaches toward common goals. The new collaborative approach was identified by stakeholders at a meeting in Montreal in April 2002. Last December, in Ste. Adele, Quebec, 35 experts in HIV/AIDS assembled to answer

the question, “What should Canada do to optimize the response to HIV/AIDS over the next 5 years?” Their response formed the first steps of a strategic plan designed to be responsible to, and to be carried out by, all stakeholders in Canada.

Health Canada is committed to implementing the activities and objectives in the Strategic Plan for which it is responsible and to oversee the long-term viability of the Plan. All other levels of government and significant stakeholders will contribute their expected outcomes and vision to the plan during the summer and fall.

The main goals developed in the Strategy are to

- ▼ Raise awareness of HIV’s impact
- ▼ Collaborate with other sectors to address broader factors (social, economic, environmental) that contribute to the epidemic
- ▼ Optimize the voice and participation of those infected and affected
- ▼ Continue to develop and share knowledge
- ▼ Reinvigorate prevention efforts
- ▼ Provide effective, comprehensive care and treatment
- ▼ Develop effective organizations and provide appropriate resources
- ▼ Participate in global efforts to stop the epidemic.

The draft Strategic Plan seeks your comments and recommendations on what we need to do in our communities. The more insights and contributions the plan receives, the better it will reflect the needs of people with HIV. Give government direct input from people with HIV.

To read a copy of the draft Strategic Plan, visit the Health Canada website at

<www.hc-sc.gc.ca/hppb/hiv_aids/can_strat/direction/canadian_response.html>. ⊕



Jeff Anderson is a community activist, past treasurer of the BCPWA Society, and longtime BCPWA volunteer.

Let's talk about it!

"Let's talk about it" is dedicated to promoting dialogue.

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

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

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Our first forays into providing HIV-positive people with opportunities to discuss the challenges involved in HIV prevention have clearly demonstrated that they want to talk. Providing the opportunity to share these issues in a safe and respectful environment allows us to learn that other people face the same problems. Just talking can be healing, as revealed in this thank you note our Retreat Team received recently from one of the participants:

*Letter to Jackie Haywood,
director of support services, BCPWA
Society*

Dear Jackie,
Thank you for the incredible and extremely fulfilling experience at Loon Lake. I was amazed by the event and it left me with a new enthusiasm for life and a new vitality in dealing

with HIV. I had taken a few knocks with the disease over the past couple of years, which challenged my hope and confidence. This retreat has put my life into perspective and I returned to the city with a strength and positive energy that I have not felt before.

The Retreat Team is a remarkable troop of people who came together very synergistically and I could not have asked for better guidance and support during my stay at the Lake. What a pleasure to have the luxury of bodywork during the retreat! Both therapists I met with were very giving and, like magicians, took away pains I didn't know I had. The icing on the cake was our Cabaret Night put together by Ron. I enjoyed his inviting and natural ability to get people excited about performing and making the participants feel like "Canadian Idols" for a moment.

Really, the best part was seeing people open up and be themselves: openly discussing and telling their stories about living with HIV. From my own experience of living with HIV for the past 17 years, I know how detrimental it is to be unable, or perhaps not allow myself the freedom, to express what the disease has meant to me. Simply having the time, space, and safe environment to share my feelings with others dealing with the same issues is a very important part of healing and focusing on what is essential in life.

Thank you so very much for this wonderful gift of healing and support.

Sincerely yours,
Owen

Mighty mouths

PWAs need to speak out about the issues in order to stop the spread of HIV

by Carl Bognar

Slowing the epidemic of HIV must involve HIV-positive people. It's a simple yet powerful idea. Efforts to involve HIV-positive people directly in prevention are still in their infancy, at least as far as complex and sophisticated programming is concerned.

Simpler ideas, such as telling people to use a condom every time and workshops on safer sexual practices and techniques, have had some impact on key target groups. Research shows, for example, that a far higher proportion of gay men uses condoms—and uses them more consistently—than heterosexuals. Still, the epidemic smoulders.

Discussions at Loon Lake retreat

We need to gain a better understanding of the issues in order to strengthen ourselves as individuals and as a community, so that we can play a role in stopping the epidemic. Once again, BCPWA Society members have shown that they want to talk about the issues they face as PWAs. At the Society's Loon Lake Retreat in July, 30 of the 40 retreat participants chose to spend a summer evening in a classroom-style environment discussing the way they deal with issues as HIV-positive people. The high turnout was a surprise, given that attendance was voluntary and competing activities included canoeing, swimming, sitting by the fireside, or simply relaxing.

The group was a mix of straight, gay, bisexual and transsexual people, and represented a range of ethnicities, ages, and stages of HIV disease, from the newly-diagnosed to long-term survivors. Participants discussed two questions: What are the barriers to maintaining safer behaviours? What can BCPWA do to help you to overcome those barriers?

The energy in the room was electric. There was no shortage of issues raised. They identified many barriers, including:

*age, alcohol,
anger, anxiety
condom fatigue
denial, depression, disclosure,*

*discrimination, drugs
experience
fear, frustration,
guilt,
intimidation
judgement
loneliness, loss
passion, pleasure
rejection, responsibility
self-control, self-esteem,
self-image, shame,
silence, stigma*

One of the more compelling statements emerging from the session was that “we as positive people still have guilt and are ashamed of the fact that we are HIV-positive.” Shame and guilt present a significant impediment to HIV prevention. They are part of the problem, not the solution. They lead people to remain silent about their situation and shut down communication between partners. Prevention campaigns based on encouraging disclosure by HIV-positive people, or programs intended to teach communication skills to HIV-positive people, need to be supplemented with programs that deal with the underlying issues of shame and self-esteem. This flies in the face of some critics of HIV prevention, such as gay columnist Dan Savage, who thinks that the solution to the epidemic of HIV is to guilt HIV-positive gay men into behaving responsibly.

Systemic issues versus individual problems

Throughout the course of the epidemic, HIV-positive people have discussed issues in support groups. However, we have typically dealt with these issues as individual problems, thereby treating them as clinical or psychological problems. Further, we have neglected to link these difficulties to their impact on the ongoing spread of the epidemic. A number of Loon Lake participants commented that, once we get beyond the perception of HIV-positive people as members of risk groups (primarily, gay men and injection drug users), it is evident that

all HIV-positive people face common issues. Perhaps prevention activities aimed at HIV-positive people do not need to be segregated according to personal characteristics. The issues we face are systemic, they cross risk groups, and they are not, by and large, the result of individual psychopathology.

The BCPWA Society needs to hear from its members to help identify these issues. We need to understand what kinds of supports and services our members need to prevent the spread of HIV. There is very little research—and therefore very little information on which to build effective programming—about why people choose to use, or not use, protection.

One of the problems is that prevention research hasn't

As HIV-positive people, we need to document our needs and develop new programs based on those needs.

moved very far beyond looking at risk behaviours. There is a body of research that tries to identify the types of people who do or don't use protection. This notion that condom use is about types of people is probably a fundamental flaw in thinking. It is more likely that the decision about safe behaviours is based on the characteristics of the situation in which sexual activity takes place, with whom it's taking place, and how people are feeling at that particular time. Researchers seem to have made the mistake of trying to identify the "dangerous" people, in the hope of targeting specific subgroups of people with prevention programming.

The timing is right

We must find creative, non-blaming, respectful and supportive ways of helping HIV-positive people to avoid spreading the infection. At the BCPWA Society, we are only at the beginning

of developing new programs, and we are taking tentative steps towards designing some interesting new initiatives.

Effective programs are not developed in a vacuum. Funders want to know that they are funding programs that have a good chance of working. Anyone who has ever winced at the amount of taxes they pay will understand why. As HIV-positive people, we need to document our needs, and develop new programs based on those needs. The evening at Loon Lake might have looked like a support group, but it also allowed the BCPWA Society to begin to uncover important issues.

This is an ideal time for the Society to be working on this type of initiative. On December 1, World AIDS Day, Health Canada will announce its new HIV/AIDS action plan for the next five years. Draft versions of this document are in circulation through the entire spectrum of people working in HIV issues, from basic scientists to prevention programmers, community developers to epidemiologists. There are two major themes emerging in the action plan that will lend significant support to BCPWA Society's efforts to develop positive prevention programs. One theme is Health Canada's desire to support the participation of HIV-positive people and organizations of HIV-positive people in all aspects of programs and services that affect our lives. The second theme is Health Canada's goal to reinvigorate HIV prevention efforts by finding ways of encouraging HIV-positive people to take a leadership role in prevention efforts and initiatives.

We are ready to talk. Health Canada is ready to listen. The future looks good, indeed, for positive prevention. ⊕



Carl Bognar was the prevention coordinator for the BCPWA Society. He is now a project coordinator at the BC Centre for Excellence in HIV/AIDS.



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

The Treatment Information Program endeavors to provide all research and information to members without judgement or prejudice. The program does not recommend, advocate, or endorse the use of any particular treatment or therapy provided as information. The Board, staff, and volunteers of the BCPWA Society do not accept the risk of, nor the responsibility for, damages, costs, or consequences of any kind which may arise or result from the use of information disseminated through this program. Persons using the information provided do so by their own decisions and hold the Society's Board, staff, and volunteers harmless. Accepting information from this program is deemed to be accepting the terms of this disclaimer.

Children and antiretroviral therapy

by Dr. Jack Forbes

Worldwide, an estimated 3.2 million children under age 15 were living with HIV/AIDS in 2002. More than 90 percent of these children live in sub-Saharan Africa and account for 90 percent of the deaths of children. In North America and Western Europe, about 15,000 children are HIV-positive, but less than 200 of them died in 2002. In Canada, 114 children died of AIDS from 1984 to 2001, and only two deaths have occurred since 1998.

Drugs available to adults are not always available for children because of toxicity, formulation, or a lack of clinical trials conducted on children.

In the developed world, the causes of death in HIV-positive children has changed. Before 1998, infected children died from opportunistic infections such as *Pneumocystis pneumonia*, tuberculosis, and atypical tuberculosis.

Since 1998, unspecified pneumonia, heart disease, and septicemia are the most common causes of death of children in North America.

The dramatic decrease in mortality and morbidity in HIV-positive children in North America is a result of the effectiveness of antiretroviral therapy. However, treating children involves unique considerations because most children acquire HIV through perinatal mother-to-child transmission. The immature immune systems of infants are more profoundly affected by HIV than the immune systems of adults.

Getting children to adhere to meds

Antiretroviral drugs will often perform differently in children because of pharmacokinetic (how drugs work in the body) differences. Drugs available to adults are not always available for children because of toxicity, formulation (that is, whether it is in tablet, capsule, or liquid form), or a lack of clinical trials conducted on children. These studies are expensive and difficult to perform because few children can participate and most have had prior antiretroviral therapy.

continued on next page



A particular challenge in treating children with HIV is their ability to adhere to the medications. Taking three drugs twice every day is difficult, especially for children and their caregivers. It often dominates the day. Taking certain medications on an empty stomach, with food, or after food requires a strict routine that changes every weekend! Palatability of drugs is a major issue—even those with liquid formulations taste dreadful. Ritonavir and efavirenz need special manipulations to try to mask the taste.

The challenges of ensuring antiretroviral activity while avoiding toxicity and resistance are similar for adults and children. Unfortunately, the physical features of lipodystrophy are also seen in children, who may show significant fat wasting in subcutaneous tissues. These effects occur particularly in the face and limbs. Children may also present with metabolic side effects such as raised triglyceride and cholesterol levels, although very few children have needed specific therapy to lower these levels.

The need for a supportive environment

For antiretroviral therapy to be successful in children, a comprehensive supportive care program must be in place. Children have to be in home environments able to support them to achieve success. This involves a nurturing environment with a daily routine conducive

to taking the medications. Special attention has to be paid to the effects of the medications on appetite and the function of the gut. Nutrition in a growing child is vital and ensuring these needs are met requires a well-balanced diet that may call for nutritional supplements.

The average age of infected children in British Columbia is 10 years. All BC children infected with HIV are in school and participate fully in their communities. Confidentiality and privacy in the schools are key issues, which often have to be dealt with on a case-by-case basis. Disclosure to children is difficult for all parents and caregivers. Disclosure is a process that takes place slowly over time and should start from about age 7 or 8. Children who know why they take medications and have frequent blood tests become more willing participants of the care team. Usually the common fears of inadvertent disclosure are unfounded.

To be successful in taking antiretroviral therapy, children must be willing to participate in their own care and have a dedicated parent and a team of health professionals trained in treating children. However, the true success of antiretroviral therapy in children lies in the courage of the child and the dedication and love of the parents.

Editor's note: From August 2003 to September 2004, Dr. Forbes will be based in Zimbabwe, working with the Elizabeth Glaser Pediatric AIDS Foundation on HIV mother-to-child transmission in Africa. The Foundation has numerous projects in sub-Saharan Africa and is currently making antiretroviral therapy available to roughly 250,000 pregnant women. We extend our best wishes to Dr. Forbes. ☺

Dr. Jack Forbes is a paediatric infectious disease specialist. He is co-director of Oak Tree Clinic at the Children's and Women's Health Centre of British Columbia and a clinical associate professor at the University of British Columbia.



Savour the flavour

Taste alterations can result from medications or infection

by Eileen Kabaroff

Many of us forget how much taste and smell affect our everyday lives. Think of all the tastes and smells you encounter on a typical day: fresh baked goodies at a bakery, exhaust from a car, the breeze off the ocean, chocolate melting in your mouth. We often take our senses for granted, but they serve many different purposes. They provide clues to the off-flavour or appearance of deteriorating food, they warn us about impending danger, and they encourage a healthy appetite and stimulate digestion.

Flavour is really the combination of several senses: taste and smell, but also touch (temperature and “mouth feel”). This sensation is what many of us associate with food and its wonderful properties.

As a dietitian working in the Downtown Eastside, I encounter individuals living with HIV/ AIDS who suffer from multiple side effects from medications and infections. A common side effect is taste or flavour alterations. This problem can be quite a depressing change for some. Food, after all, doesn't just nourish us physically; it is a significant aspect of our social and emotional well-being.

Taste and flavour alterations can result from HIV medications, infection, and depression. Medicine can affect taste sensation and perception in different ways. Some medications give foods a metallic taste, but others cause the loss of the entire sense of one taste such as sweetness and bitterness. A few medications can cause the loss of all taste sensations. Other medications decrease salivary flow, which results in dry mouth. Taste disturbances are often greater in individuals taking multiple medications.

Infections or medical conditions such as candidiasis (oral thrush), herpes (cold sores), and sinus infections can affect the tastes and smells of foods. Favourite foods may no longer provide the same pleasures.

Don't despair. You can fight back against diminished taste. Intensify the taste and aroma of food and experiment with the temperature and texture to make it more visually appealing. Here are a few tips:

- ▼ Try different herbs, spices, and lemon juice.
 - ▼ Add zeal to your meal by playing with the texture of your food. Texture adds to the mouth feel and flavour of food and can help compensate for lost taste and smell. Try crushed crackers on soup, nuts in fruit salad, and crushed cookies or cereal on ice cream or pudding.
 - ▼ Use strong-flavoured ingredients if possible, such as garlic, onion, aged cheddar, flavoured vinegar and oils, peanut butter, and butter.
 - ▼ Try different temperatures. Serve hot foods hot and cold foods cold rather than lukewarm to enhance flavour. For example, serve vegetable soup hot, try a hot bean salad, or serve yogurt and fruit mixed together cold. Extreme hot or cold temperatures may tend to lessen flavours. However, remember that food safety is always an issue. Foods should be kept hot or cold enough to keep bacteria from multiplying rapidly.
 - ▼ Make food colourful and attractive. Add bright peppers or tomatoes to salad. Add parsley to casseroles and dishes.
 - ▼ Nix the nicotine. Smoking deadens taste buds and affects your sense of smell.
 - ▼ Breath mints or lozenges can provide short-term relief and can help with salivary flow.
 - ▼ Zinc supplements have been shown in some studies to increase taste sensations. Consult your doctor or dietitian before trying this.
- Have fun with your food. Try new and exciting things with friends or family. Remember friendly dietitians are always available to help you create fun and flavourful meals that are nutritious and cost-effective. ☩



Eileen Kabaroff is a registered dietitian working at Vancouver Native Health Society. She is the project coordinator for the Aboriginal Diabetes Awareness Program and Teaching (ADAPT).

Report from Paris

*The 2nd IAS Conference on HIV Pathogenesis and Treatment,
July 13–16, 2003*

by Paula Braitstein

The International AIDS Society (IAS) sponsors one major international conference per year. Every second year, they organize the International AIDS Conference (held in Barcelona, Spain, in 2002) which addresses basic and clinical sciences, social sciences, epidemiology, and human rights. Between these conferences, they organize the IAS Conference on HIV Pathogenesis and Treatment, which recently took place in Paris, France.

At this conference, 1,227 presentations were given: 187 orals and 1040 presentations as posters. The following is a selection of presentations of particular interest and relevance. The complete book of abstracts will be available to the public at the PARC Library at 1107 Seymour Street, Vancouver. You can also check out the IAS website at <www.ias2003.org>, which has webcasts of some of the presentations.

Hepatitis B

Ten to fifteen percent of people living with HIV are co-infected with hepatitis B. The HIV drug 3TC, also known as Efavir, is an approved treatment for hepatitis B. Withdrawing 3TC from people either co-infected with hepatitis B and HIV or mono-infected with hepatitis B has resulted in a reactivation of the hepatitis B, leading in some cases to severe hepatitis and even death. The Swiss Cohort Study group (poster

992 at the conference) used its extensive database to examine liver function tests (LFTs), primarily AST and ALT, before and after 3TC withdrawal in people who were co-infected with HIV and hepatitis B.

Although 224 individuals with active hepatitis B had their treatment of 3TC interrupted, at the time of the presentation the investigators had only examined the charts of 87 of them. They found that 25 percent of these participants had a reactivation of their hepatitis B after stopping 3TC. Furthermore, of the people who experienced liver dysfunction after stopping the drug, nine percent of the reactions were considered grade IV, meaning they were severe, including two instances of liver failure. Changes in LFTs were seen as early as 48 hours after stopping treatment. All changes were noted within one month of stopping treatment.

If you have hepatitis B and you are taking 3TC, these data suggest that you should stay on the 3TC even if you don't need it any more for your HIV. Many conference presentations on hepatitis B and HIV mentioned that nobody should start HIV medications without including 3TC, tenofovir, or adefovir (two other hepatitis B treatments) in their combination therapy to prevent hepatitis B activation.

Hormonal contraception and the risk of HIV transmission

Controversy has been brewing about whether taking oral contraceptives can increase the risk of acquiring HIV by thin-

ning the mucosa of the vagina. A prospective study of 1,500 female sex trade workers in Mombasa, Kenya, examined this question (oral presentation 83). All the women were provided with free medical care and free condoms, and they came to the clinic study site monthly for STD screening and interviews.

Of the 1,500 participants, 250 women became HIV-positive, all through vaginal sex (no women reported either anal sex or injection drug use). In terms of contraception, 14 percent of women used the pill, 20 percent used Depo-Provera (injectable hormones), 2 percent used Norplant, 2 percent used an IUD (intrauterine device), and 60 percent either had had a tubal ligation or used no birth control.

After taking into account sexual behavior, condom use, and the presence of sexually transmitted diseases in the analysis, the investigators found that women who used Depo had twice the risk of becoming HIV-positive, while women who used the pill were 1.5 times more likely to become HIV-positive. Although biologically plausible, these data are inconclusive, and it would be ethically inappropriate to recommend that women not use hormonal contraception to prevent unwanted pregnancies.

HAART in people over 50 years of age

This study (oral presentation 85) was based on 3,015 individuals who started highly active antiretroviral therapy (HAART) in France between 1997 and 2001, including 401 people over the age of 50. It found that older individuals had a significantly slower CD4 response to antiretroviral therapy and didn't achieve as high a response by the end of follow-up. Although it appeared to take longer for the older people's viral load to become undetectable, at the end of six months the proportion of individuals whose virus had become undetectable was similar. This latter finding may have been due to improved adherence among older people. Defining clinical progression as the development of a new AIDS-defining event, people over 50 were 1.5 times more likely to progress clinically, which may have been related to their slower immune response to antiretroviral therapy.

Salvage therapy

Since the advent of HAART, four major approaches have been used to treat people whose virus has become resistant after using up two or more different combinations of drugs. These approaches have been to

- ▼ Continue on a failing regimen
- ▼ Take a drug holiday or structured treatment interruption
- ▼ Use a combination of new drugs from new classes
- ▼ Take "mega-HAART," a combination of 5–10 drugs.

It became clear during the conference that an important new strategy has emerged that may improve response to antiretroviral therapy for people on their third line of therapy or more. This entails taking a break from drugs for 3–6 months,

or as long as your CD4s can tolerate it, and then taking mega-HAART, preferably with drugs from classes that have not previously been taken, such as enfuvirtide (Fuzeon), a fusion inhibitor.

Oral presentation 114 summarized the state-of-the-art in "salvage therapy." It presented data that clearly showed that people achieved an improved virological response after stopping treatment for a period of time before re-starting with a new combination. This result is to be expected because after a drug holiday the majority of virus present in an individual will be wild-type and, therefore, will be more susceptible to drugs. Moreover, people who stopped treatment before re-starting had an improved CD4 response: they gained more CD4s faster and had a higher peak of CD4s than those who simply switched to a mega-HAART combination.

If you have hepatitis B and are taking 3TC, data presented at the conference suggest that you should stay on 3TC even if you no longer need it for your HIV.

By contrast, another presenter (oral presentation 119) found that a structured treatment interruption showed neither an immunological nor a virological benefit, so the jury is still out on that issue. If you are in this situation, remember to consider (in addition to the possibility of an improved immunological and virological response) quality of life issues, side effects, your ability to continue adhering, and how stable your CD4s are when you are off treatment.

Impact of gender and ethnicity on anti-retroviral drug levels

Gender and ethnicity are very complicated issues when it comes to antiretroviral drug levels. No hard and fast rules are possible because each drug is metabolized differently.

In general, gender (sex, really, since we're talking about biology, not identity) is known to have important implications for drug levels. Women have greater bioavailability of drugs than men do, which is probably a result of overall lower weights in women, so that the same amount of drug is more concentrated than in men. The flip side of this is that men have an increased "distribution volume," meaning the drug has more physical territory to cover because men tend to be bigger. It is known, for example, that women have higher concentrations of lopinavir/ritonavir (Kaletra) compared to men and that the levels of both efavirenz (Sustiva) and nevirapine (Viramune) tend to be 20 to 30 percent higher in women compared to men. These higher concentrations may explain some of the increased side effects experienced by women with these drugs.

continued on next page

Although the reasons were not entirely clear, oral presentation 114 emphasized the belief that an independent effect of gender beyond weight occurs. Given that women are physiologically different from men and have different hormonal systems, this theory is certainly biologically plausible.

This gender issue becomes further accentuated in pregnancy. It appears that drug levels are actually considerably lower during the third trimester. In fact, in general they may be lower when a woman is pregnant, to the point of needing dose adjustments to prevent both resistance and perinatal HIV transmission.

Two important presentations addressed superinfection, or infection with two different strains of HIV at different times.

Ethnicity can be an important determinant of drug levels in terms of both genetics and environmental influences. For example, Chinese people are believed to more slowly metabolize drugs, which is perhaps related to the presence or absence of certain enzymes in the liver. Similarly, individuals of Japanese descent have a high frequency of slower metabolism, again believed to be caused by the lack of a particular enzyme. The presenter did, however, make the point that the data are inconsistent and far from being thoroughly investigated.

Although the presenter asserted that important differences between ethnicities exist at the molecular level, he could make no generalizations about drugs and ethnicities. The effects of drugs across broadly defined groups are not that predictable. For example, although a trend towards lower clearance of nevirapine among people of African descent has been identified, a tendency for people of African descent to have increased clearance of efavirenz, a different drug within the same class, has also been noted.

Superinfection

Two important presentations addressed superinfection, or infection with two different strains of HIV at different times. A study (oral presentation 73) from Geneva, Switzerland, reported finding superinfections in two injection drug users. They followed 136 drug users with HIV and found that the amount of HIV in the blood of five patients suddenly shot up after years of control without antiretroviral drugs. Tests confirmed that two of the five had a superinfection.

In another study (oral presentation 71), genetic tests on a superinfected woman showed the two viruses had mixed

and produced a hybrid that took over from the original virus. Although the development of a hybrid was not surprising—estimates put the number of mixed strains circulating in the world at 14—the report is the first documented case of two HIV strains, or subtypes, combining in one person to form a third strain.

Adherence

This topic is not cutting edge, but is still of supreme importance. While the presentation focused on adherence to hepatitis C treatments, the strategies were equally relevant to HIV treatments:

- ▼ Consider the factors that will make taking the treatment difficult, especially “contraindications” (factors that should rule out taking treatment) such as depression, psychiatric disorders, out-of-control drug/alcohol use, and severe liver or kidney disease.
- ▼ Carefully plan when you are going to begin treatment. Schedule time off work. Don’t start at a time that coincides with other major life events such as moving, changing jobs, or getting divorced.
- ▼ Start treatment around other major medical procedures or treatments. For example, if possible, take hepatitis C treatments before HIV treatments. Have your gallstone removed before starting treatment.
- ▼ Be sure that your family doctor is in the loop about when you’re starting treatment and what you’re taking.
- ▼ Use your doctors and/or nurses as supports and for information.
- ▼ Use available support groups and start going to the groups before you commence treatment.
- ▼ Before starting treatment, get detailed information about potential side effects and options for managing them.
- ▼ Consider weight reduction if you are very overweight, especially for hepatitis C treatments, because people who weigh less do better. Consider improving your level of physical fitness before you start treatment to improve your tolerance to the drugs.
- ▼ Reduce alcohol consumption, again, especially for hepatitis C, though alcohol use can severely affect your ability to adhere to antiretrovirals.
- ▼ Ensure you have pre-treatment tests of hemoglobin, liver and kidney function, thyroid function, and red and white blood cell counts. ⊕



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

Dementia not always a “brain drain”



I was diagnosed with AIDS-related dementia in April 1999. I have a problem with the whole article “Brain Drain” written by Zoran Stjepanovic (Issue 23, March/April 2003). I am a completely functioning member of society. I did develop encephalitis and became bi-polar, but these conditions in no way affect the way I function in society. Under “Tips for caregivers” in the article, it is made to seem that I am totally dysfunctional, and I am not. I give speaking engagements on a regular basis on HIV transmission and treatment. I pay a mortgage, balance my own chequebook, and do my own cooking and cleaning. I think more research should be put into future articles on this subject. The way I read the article, I should be a babbling idiot by now.

Yours sincerely,

Gary A. Ferguson

Dear Gary,

Thank you for your letter. I agree that we should do more research when writing future articles on HIV-associated dementia. I did some research and discovered that 30 percent of people with HIV will eventually develop cognitive impairment even with highly active antiretroviral therapy (HAART) and about 15 percent will develop dementia.

In my article, I wanted to show that even in the era of HAART, dementia could still be a threat. However, I do recognize that the severity of dementia varies.

A recent study looked at the progression of HIV-associated dementia treated with HAART. In this study, researchers used the Memorial Sloan-Kettering (MSK) dementia severity scale

and the HIV Dementia Scale (HDS) to assess outcomes. The MSK scale is used for clinical staging of HIV-

associated dementia based on functional, intellectual, and motor impairment. The scores range from 0 (normal) to 4 (most severe end-stage dementia). Hence, an individual with dementia could be at any of these stages, and those with lower end scores on the MSK dementia severity scale are more likely to be functioning members of society. In the US, the rate of HIV dementia in late stage disease ranges from 7–27 percent, whereas milder forms affect 30–40 percent of HIV-positive individuals, according to emedicine.com.

In a recent study, 29 percent of HIV-positive individuals taking antiretrovirals and living with dementia had improvements in MSK scores, 17 percent had worsening MSK scores, and 54 percent had stable or relatively unchanging MSK scores. These findings are dramatically different from the pre-HAART era, when dementia resulted in rapid deterioration.

When I wrote about healthy tips for people living with dementia, some of the items listed were targeted towards individuals living with severe dementia and their caregivers. These tips included writing important reminders to themselves, installing gas detectors and smoke alarms, and making kitchens and bathrooms safer. Still, tips like educating yourself about dementia, finding support, keeping active, and keeping a diary can be useful for any person living with dementia, even with lower MSK severity scores.

Zoran Stjepanovic

This joint ain't jumpin'

Glucosamine supplements can help arthritis

by Ron Rosenes

Has joint or muscle pain sent you on a wild goose chase to figure out the cause? Has your general practitioner referred you to a rheumatologist to sort it all out? If a knowledgeable HIV rheumatologist works in your area, you may get some answers. The underlying source of various types of arthralgia, or joint pain, that occur in people with HIV can be tricky to identify, even for the experts. In some instances, supplements containing glucosamine and chondroitin sulfate may help.

Dr. Keith Henry of the University of Minnesota School of Medicine says that up to one-third of people with HIV experience some form of joint pain. This pain may be caused by a form of reactive arthritis resulting from HIV disease itself, the side effects of certain antiretroviral medications, or heaven forbid, the ravages of time. So is it AIDS, is it the drugs, or is it just age? Probably all of the above! Paradoxically, joint pain can also be a transient problem related to the reactivation of the immune system in people who have recently begun treatment.

A common side effect

A quick look at the Canadian AIDS Treatment Information Exchange (CATIE) and Project Inform Web sites tells us that arthralgia is a fairly common side effect of certain drugs in all classes. Discuss with your care provider whether the drugs may in fact be the problem, whether the problem is intolerable, and whether a drug switch might be feasible if your viral load is below the limit of detection. If, on the other hand, you are diagnosed with a form of osteoarthritis (OA), you may be offered painkillers, supplements, or both, depending on the doctor.

Osteoarthritis is a "wear and tear" disease of the joints that is capable of causing acute inflammation, but mainly involves the degeneration of joint cartilage and the formation of bony spurs within various joints. Risk factors include high impact trauma, repetitive stress, and obesity. While OA is associated with advancing age in the general population, particularly in women over 50, symptoms may appear earlier in people with HIV.

In recent years, the effectiveness of glucosamine and chondroitin sulfate in relieving symptoms has been promoted

largely by word of mouth. Glucosamine, an amino sugar, is thought to promote the formation and repair of cartilage. Chondroitin, a carbohydrate, is a cartilage component that is thought to promote water retention and elasticity and to inhibit the enzymes that break down cartilage. The body manufactures both compounds, probably in decreased quantities as we age with HIV.

A growing body of supportive research

Sales of glucosamine, either on its own or combined with chondroitin, took off with the publication of *The Arthritis Cure* by American physician Dr. Jason Theodosakis in 1997. He is a specialist in preventive medicine at the University of Arizona College of Medicine and long time PWA ("person living with arthritis"). While many rheumatologists have been quick to attribute the growing reputation of glucosamine and chondroitin to the placebo effect, a growing body of research substantiates the claims being made.

A major Belgian study concluded that glucosamine not only relieved symptoms but also slowed cartilage deterioration.

In March 2000, a study in the *Journal of the American Medical Association* concluded: "Trials of glucosamine and chondroitin preparations for OA symptoms demonstrate moderate to large effects, but quality issues and likely publication bias suggest that these effects are exaggerated. Nevertheless, some degree of efficacy appears probable for these preparations."

Perhaps not a ringing testimonial, but there's more.

In January 2001, a major Belgian study of 212 patients with OA of the knee, published in *The Lancet*, concluded that glucosamine not only relieved symptoms but also slowed cartilage deterioration. Questions remain about the standardization of x-rays used in this study to record joint space changes, so the



sceptical among you may decide to wait until 2005 when the results are expected from a major National Institutes of Health study of 1,200 people with OA of the knee.

Monitor your blood sugar

While studies have generally noted very few adverse effects from either glucosamine or chondroitin other than increased intestinal gas and softened stools, animal research has raised the possibility that glucosamine could worsen insulin resistance. This possible side effect is a major concern for people on highly active antiretroviral therapy (HAART) regimens that may already put them at risk of developing adult onset diabetes. Glucosamine should not be confused with “glucose”. They are different substances that follow different pathways once ingested.

Clinical studies to date have not shown an increase in blood sugar levels or insulin in the general population; however, you should monitor your blood sugar if you are concerned and avoid glucosamine if you have been diagnosed with a blood sugar disorder. Before deciding to take glucosamine, consult your doctor or naturopath if blood sugar is a concern or if you have allergies to shellfish. Bear in mind that in most cases, allergies are caused by proteins in shellfish, not chitin, a carbohydrate from which glucosamine is extracted.

If you are taking chondroitin sulfate in addition to a blood-thinning medication or daily aspirin therapy, have your blood clotting time checked more often. Chondroitin

sulfate is similar in structure to the anticoagulant drug heparin, and the combination may cause bleeding in some people. Women who are pregnant and women who could become pregnant should not take these supplements. They have not been studied long enough to determine their effects on a child or on a developing fetus.

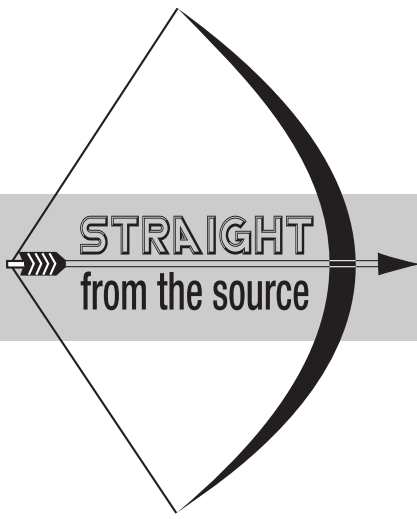
Human studies have shown that glucosamine and chondroitin sulfate may relieve arthritis pain and stiffness with fewer side effects than conventional arthritis drugs. Some people find they need to use both. The supplements can be taken individually or in combination capsules. The recommended daily dosage, the one used in the Belgian study, for example, is 1,500mg of glucosamine and 1,200mg of chondroitin daily.

Beware of purveyors of glucosamine in cream form—it’s a scam.

Be prepared to take the supplements for a month before you see or feel results. Overall, glucosamine and chondroitin have been getting very positive reviews from consumers, and that’s what counts. ⊕

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





Longer lives, better lives

by *Melanie Rusch*

With the introduction of the first drug to combat HIV in the late eighties, then protease inhibitors in 1996, and now today's multi-drug combination therapies, the lives of many people infected with HIV have been extended. Drugs buy invaluable time, but that time is often accompanied by unwanted, sometimes disfiguring, side effects and difficult dosing schedules, which lead to poor adherence and the development of resistant forms of HIV.

Important research continues into more tolerable drugs, modes of delivery that are not so cumbersome, and dosing schedules that are less complex, but what has been largely overlooked until recently is the quality of those additional years of life. Aside from drug side effects and the increasing number of symptoms experienced as the disease progresses, HIV-infected persons may also experience limitations in their ability to perform activities and difficulties participating in their regular life roles.

In 2002, the World Health Organization restructured the International Classification of Functioning, Disability, and Health to increase the comprehensiveness of the definitions of disability (see <www3.who.int/icf/icftemplate.cfm>). This report outlines three levels of functioning: 1) impairments of body structure or function, including both the physiological and psychological aspects of those impairments (such as peripheral neuropathy and the psychological effects of chronic pain); 2) limitations of the ability to carry out day-to-day tasks; and 3) restrictions of the ability to participate in life situations.

Preliminary evidence from a survey of HIV-infected persons in BC called "For the Record," which many BCPWA Society members completed, reveals very high rates for all three categories. Over 90 percent of people reported physical impairments or participation restrictions. Commonly reported impairments included diarrhea, headaches, fatigue, reduced libido, and concentration difficulties. Approximately 80 percent reported activity limitations. Examples of activity limitations include the inability to perform vigorous activities such as run-

ning or lifting heavy objects, moderate activities such as carrying groceries, other household chores, and sexual activities. The most common restrictions to participation in life situations were experienced in sexual roles, student/employee roles, hobby/sports roles, and financial roles.

With such high levels of impairment and disability among persons living with HIV/AIDS, several important questions arise. What factors have the greatest influence on these conditions? Does improvement of symptoms and side effects directly alleviate problems with limitations and restrictions? How does depression affect these experiences?

The interplay of these elements is not straightforward. A biological link between impairments, limitations, and the ability to remain active in normal life roles is not hard to envision. The actual extent to which impairments and activity limitations are experienced may also affect participation. Depression has been reported to compound problems with daily life activities and social roles, but social support has also been shown to alleviate depressive symptoms.

Studies are needed to obtain better estimates of the prevalence of impairments, limitations, and restrictions and to develop a better understanding of how they are connected. Despite such high prevalence, opportunities are available for interventions that offer help with daily activities such as keeping house or running errands. Support groups could help to reveal factors other than physical dysfunction that may be influencing the ability of HIV-positive persons to participate in their regular life roles. ⊕

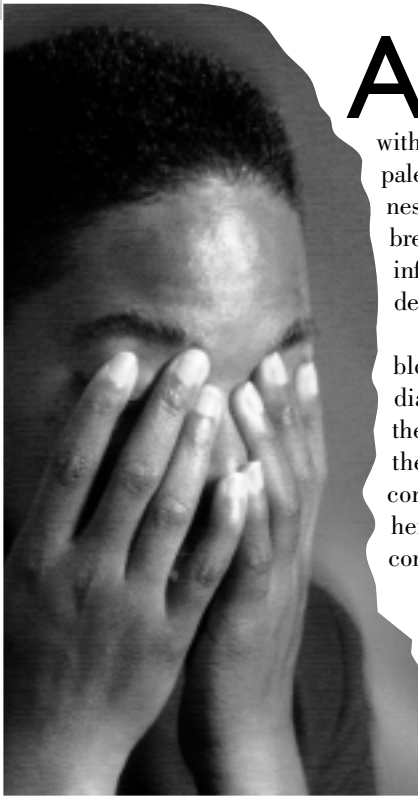


Melanie Rusch is a research assistant at the BC Centre for Excellence in HIV/AIDS and is currently completing her PhD in healthcare and epidemiology at the University of British Columbia.

Bloody tired

Anemia is a common cause of fatigue among PWAs

by Sam Friedman



Anemia, an abnormally low number of red blood cells, is one of the most common causes of fatigue in people with HIV. Common symptoms include paleness, a cold sensation, fatigue, weakness, palpitations, and shortness of breath. Almost 80 percent of HIV-infected individuals will eventually develop anemia.

Anemia is diagnosed by monitoring blood test values over time. A positive diagnosis is made when test values of the total number of red blood cells and the percentage of red blood cells are consistently below normal, and when hemoglobin and hematocrit levels are consistently below normal.

The production of red blood cells requires a natural hormone called erythropoietin, which is produced in the kidneys and stimulates bone marrow. Normal red blood cell production and maturation is also dependent on other factors, including an adequate source of nutrients such as iron, vitamin B12, folic acid, and trace minerals. When these and other basic nutrients are not present in adequate amounts, red blood cells are produced at a slower than normal rate and do not function optimally.

Because HIV-positive individuals require greater amounts of vitamins, minerals, and other essential nutrients than non-infected persons, eating a healthy balanced diet, including adequate supplementation, is even more essential. Adding certain foods or supplements to your diet may assist in dealing with anemia by providing the nutrients your body needs to produce red blood cells.

Inadequate hormone production, specifically erythropoietin (EPO), may also contribute to anemia. In addition to EPO, other hormones that stimulate red blood cell production, including adrenal hormones and testosterone, may be low in PWAs. Many HIV-positive people use hormone replacement therapy to raise these critical hormone levels to normal values.

Toxins, such as alcohol, that directly suppress bone marrow cells can lead to anemia. Certain infections, such as *Mycobacterium avium* complex (MAC), tuberculosis, fungal infections, and cytomegalovirus (CMV), can infect and destroy bone mar-

row cells. Non-Hodgkin's lymphoma, a cancer associated with HIV infection, can also damage bone marrow cells.

Many drugs used to treat HIV infection or its complications have toxic side effects on erythroid progenitor cells (immature red blood cells in the bone marrow). Drugs commonly associated with anemia include AZT and other antiretrovirals, Bactrim/Septra, ganciclovir, dapsone, pyrimethamine, interferon, ribavirin, and cancer chemotherapy. The likelihood of developing anemia when using these drugs increases as immune function becomes progressively impaired. AZT, the most common anti-HIV drug associated with anemia, causes 15–20 percent of patients taking it to develop anemia, though nearly all antiretrovirals have been associated with anemia. The nucleoside drugs—of which AZT is one—tend to be the worst.

Almost 80 percent of HIV-infected individuals will eventually develop anemia.

Blood transfusions are generally considered a safe and effective way of treating anemia-related fatigue caused by various HIV-related complications and medications, but transfusion reactions can occur (in 0.5–3 percent of cases) and can transmit infections such as malaria, syphilis, West Nile virus, and the Epstein-Barr virus. Anemic patients with fatigue usually feel better almost immediately after receiving blood transfusions. However, the benefits are typically short-lived and do not treat the underlying causes.

Procrit (recombinant erythropoietin) is a manufactured version of EPO. EPO stimulates bone marrow production of red blood cells, increasing hemoglobin levels and alleviating symptoms such as fatigue. Procrit is most useful in anemic patients who have relatively low erythropoietin levels in their blood. It is not covered by the BC formulary, so be prepared to pay between \$500 and \$2000 per month, depending on how much you need. Depending on the cause of the anemia, you may need to supplement with iron or take B12 shots. Good dietary sources of iron and B12 are molasses, dark leafy greens, and red meat or liver.

Editor's Note: We wish to thank Dr. Dave Forrest for his technical review of this article. ☺

Sam Friedman is a treatment counsellor with the BCPWA Society's Treatment Information Program.



Face the facts

Lots of options, but no quick and cheap solutions for facial wasting

by R. Paul Kerston

Many people feel that facial lipoatrophy (wasting) is a “dead giveaway” of HIV illness. The term lipoatrophy refers to a reduction in fat cells, most commonly in the face. The condition creates triangular recesses and deep folds on either side of the nose and mouth, plus a recess underneath the cheekbone. It is believed to be related to lipodystrophy.

The psychosocial issues related to the condition can lead to depression. Sufferers, including many HIV-positive people, may feel unemployable, and it can wreak havoc on one’s social life. In the words of one person: “It blows my cover.”

Scientists still don’t fully understand the causes of lipodystrophy and lipoatrophy. The conditions became more common following the introduction of protease inhibitors (PIs) in the mid-1990s, initially leading researchers to suspect that class of drug. The condition is now thought to be caused more by nucleoside reverse transcriptase inhibitors (NRTIs), principally d4T, though some feel it may be caused by both PIs and NRTIs.

Other little-understood mechanisms may include mitochondrial toxicity caused by NRTIs’ almost universal interference with an enzyme needed for the energy sources in each cell to reproduce. Other possible factors include increases in triglyceride and LDL (the bad cholesterol) levels, decreases in HDL (the good cholesterol), insulin resistance, and high blood pressure. However, different studies examining different issues have yielded different results, so it is difficult to draw any conclusions.

Start treatment early

In dealing with lipoatrophy, the best strategy is to initiate treatment options fairly early and not to expect total reversal of the process. Quick, long-lasting results and cheap possibilities are improbable. That said, some things do seem to work—for a while, anyway. The real problems are cost and durability.

British Columbia’s healthcare plan doesn’t pay for such treatments. The province contributes very modest amounts to unemployed people. BC seems unwilling to help pay for procedures which would allow people to return to work and earn an income. In the US, cash-outs of insurance policies are not uncommon for persons wanting to correct this facial change that has so much stigma attached to it.

Switching from d4T to abacavir or tenofovir has shown some results in facial lipoatrophy, though not quickly. Some studies of patients switching from PIs to non-nucleoside reverse transcriptase inhibitors (NNRTIs) have not found statistically significant changes in body composition. However, not all practitioners agree on the value of switching drugs. Saint Marc et al., at the 7th Conference on Retroviruses and Opportunistic Infections in February 2000, found switching from d4T to abacavir or Combivir (lamivudine/zidovudine) partially reversed wasting. At the same conference, Dr. Andrew Clark from South Africa wrote that switching from d4T to an alternate NRTI showed improvement in 10 out of 11 patients after six months.

Other medication options include treating dyslipidemia (cholesterol culprits of triglyceride, LDL, and HDL changes) and insulin production changes.

The promise of newer cosmetic options

Besides these possibilities, cosmetic procedures such as injections and surgery for filling out the face are available. Though complications from surgical options are infrequent, the associated risks must be considered. Both the cost of surgery and the duration of the results are serious concerns. Nevertheless, some of the newer procedures seem to be highly successful.

Silicone has long been injected into various body parts as filler. It has its share of known side effects and it isn't considered the best option. Nowadays micro-droplets can be injected, but they are not removable because of their composition. Silicone can cause complications, not the least of which has been the potential movement of the implant within the area placed. Years later, inflammatory reactions can occur. While current methods have reduced these worries, silicone remains an unpopular option.

Collagen, extracted from cows, can also be injected. However, it isn't considered a good option since its effects can disappear within one to three months. In addition, allergies to collagen occur in approximately 2 percent of patients.

Fat grafts for a "normal" look

Fat-grafting and facelifts are possibilities. The longest-lasting results have been seen with dermal/fat grafts in which the patient's own skin plus underlying fat was placed into the affected area. Treatment specialists have rated this the most natural for its results, but this option requires general anesthesia plus an overnight stay in hospital.

Gore-Tex fabric is a well-known product that can be placed within the skin and will fill out areas. However, the opacity of the skin can make the material visible underneath, particularly when the individual has a moderate to severe condition. Still, Gore-Tex fabric continues to have a good "correction," according to Vancouver dermatologist Dr. Alastair Carruthers.

Dr. Carruthers also notes that silastic implants attached to bone can fill out high cheek areas that are sunken, but they do lit-

tle to fill out the lower areas. However, Vancouver cosmetic surgeon Dr. Andrew Denton claims that in certain patients, these implants are effective even in lower cheek areas (called malar-submalar implants).

Perlane has shown good results after 9 months, compared to other methods which last for only 2 to 5 months.

Dr. Carruthers is conducting trials on the injection of silicone oil. Dubbed the SilSkin study, trials of this procedure have been underway since May. The injections are undetectable in the skin, unlike Gore-Tex. No down time is needed and no complications have been reported, though multiple injections and touch-ups are required. This treatment is expensive, though once it is approved the cost could go down. Enrollment in the study is closed and results are pending.

Finally, Dr. Carruthers advises against facelifts that require excess skin to be pulled back because there is no "fill" left in the face.

Perlane shows longer lasting results

A clinical trial currently underway in two North American locations involves the injection of Perlane, manufactured in Sweden by Q-Med. Made of hyaluronic acid, it has been used in Canada for four years and was recently approved for use in the US.

As of this writing, Perlane has shown good results after nine months, compared to other methods, which last for only two to five months. Only about 15 percent of the product appears to be "lost" over the nine-month period. The industry-standard cost, however, is about \$450 for a single syringe injection. The cost, coupled with the need for repeat visits, makes this an unreachable option for most people.

Nevertheless, before and after slides indicate a noticeable improvement in appearance. One patient told the performing physician that he felt he got his life back after the procedure. Dr. Denton per-

forms Perlane injections, and he says that although injection volume is insufficient to bring severe wasting back to almost normal levels, it's effective for people with mild to moderate lipoatrophy. People "shouldn't be dissuaded by the lack of permanence, given the very safe and effective nature of this product," he says. "The main consideration, as is the case for many cosmetic procedures, is cost." Dr. Denton recently submitted a request to the BC Ministry of Health to have this procedure covered by the Medical Services Plan.

Among other procedures, Botox, an injection procedure made famous by celebrities, is not useful for lipoatrophy because it is injected to reduce lines and wrinkles in muscle mass and doesn't help the loss of soft tissue such as subcutaneous fat.

Down the pike, a molecule larger than Perlane may be made available by the same Swedish company. This new product could lessen the number of expensive injections required.

There are innumerable references on the Internet to a product called either Nu-Fill or New Fill, which has been available in the UK for some time. It is made of the same material as the encapsulation on vaccines and time-release medications. New Fill procedures are also performed in Chicago, New York, and California.

The bottom line is an expensive one, but there seems to be more hope for individuals who decide to treat their condition early.

For further information:

www.thebody.com

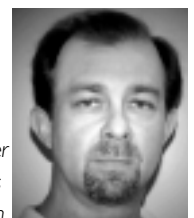
www.facialwasting.com

www.i-base.org.uk/f-basemeetings/lipo/ (New Fill)

"The Silicone Conundrum:

A Battle of Anecdotes," David M. Duffy,

Dermatologic Surgery (2002; 28:590-595) ⊕



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

Every silver lining has a cloud

Update on Pegatron access in BC

by Paula Braitstein

On June 12, 2003, the BC government finally announced its decision to provide Pegatron to people living with hepatitis C.

Pegatron is a combination drug that incorporates the pegylated version of interferon-alpha plus ribavirin. Its advantage is that it maintains a steady state in the blood for a week, enabling consumers to take it only once a week (still by injection). The drug levels stay at a constantly high level so that the impact on the virus is greater, but the side effects can actually be reduced (in many cases). BC was the last province to put the drug on its formulary.

So, the drug has been adopted. Good news, indeed. Until you read the fine print.

For one thing, Pegatron isn't technically on the formulary. It is only available through Special Authority request. Each person who wishes to access the drug must have his or her physician fill out a form. That means more work for your doctor. It also means you can't just get a prescription and get it filled at the pharmacy. You will have to wait an undetermined amount of time before actually being able to take the drug.

And that's if you get it.

The biggest cloud to the silver lining of the government's announcement is that they have set criteria that will prevent very large numbers of people from even being allowed to apply to get it.

Here are the criteria for accessing Pegatron in BC:

- ▼ You must never have taken any hepatitis C treatment before, including regular interferon monotherapy or Rebetron combination therapy. Many people took these therapies because they had no other options.
- ▼ Your ALT (level of liver enzymes) must be at least 1.5 times the upper limit of normal on two consecutive occasions at least three months apart.

Then, if you are one of the lucky few who manages to meet these criteria, you can only stay on Pegatron if you meet further criteria:

- ▼ If you have genotype 1, 4, 5, or 6, you must have at least a

2-log reduction in your HCV RNA (viral load) by week 14. If you accomplish this, you can have another 34 weeks coverage; if not, you are out of luck.

- ▼ If you have genotype 2 or 3, the maximum period of coverage is 24 weeks, so if you aren't able to get rid of the virus in that period, you too are out of luck.

These criteria do not recognize possible benefits to your liver from staying on treatment even though your virus hasn't disappeared. Good data suggests that remaining on maintenance therapy can be beneficial. It's a way of hanging on until scientists find a cure or a vaccine. Unfortunately, the government doesn't see it that way.

The government has also identified a long list of people who can't access Pegatron. This list includes anyone

- ▼ Who doesn't have elevated liver enzymes (even though about 25% of people with scarring of the liver will actually have normal levels, which is why most clinicians do not consider liver enzymes an adequate guide to what's happening in the liver)
- ▼ Under 18 years of age
- ▼ Has decompensated liver disease
- ▼ Is an active alcohol abuser
- ▼ Has a high risk of non-compliance
- ▼ Is pregnant or lacks appropriate methods of contraception
- ▼ Uses illicit IV drugs or intranasal cocaine.

After waiting two years for a drug that is recognized worldwide as the best available treatment, the BC government establishes criteria that have little basis in evidence and are aimed more at keeping people from using this potentially life-saving drug than at keeping them alive and healthy. It's a strange contradiction to the government's mandate. ⊕

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



Important studies struggle to recruit participants

by *Jim Boothroyd*

Clinical trials are critical to advance HIV treatments and save lives—right?

Right.

Why, then, are so many people with HIV not participating in them?

If you have the answer to this question, giant pharmaceutical companies and legions of clinical investigators will want to speak with you today. Why? Because everywhere in the developed world, HIV trials are struggling to meet their recruitment targets.

Take OPTIMA, for example—a publicly funded international study that is examining one of the most pressing questions facing us today: how best to treat people with advanced HIV when their drugs fail.

Recruitment in the UK, US, and Canada has been slower than anyone predicted. Some say that eligible people are not participating because the study therapies—structured treatment interruptions and a regimen containing five or more anti-retrovirals—are available outside the trial. Others say potential participants are being taken by competing trials. And others point to the bigger picture.

Dr. Marianne Harris, a clinical investigator at St. Paul's Hospital in Vancouver (part of Providence Health Care), says that recruitment has become more difficult in a range of trials as patients' options increase.

"Most people have access to powerful combinations of anti-HIV drugs and can be more choosy than they were ten years ago, when few drugs were available and getting into a trial

could determine whether you lived or died," says Dr. Harris.

Today's trials are more likely to examine ways of fine-tuning the use of available treatments, she adds, and, however relevant, most are not as "sexy" as trials of new medications.

This theory seems plausible when you consider that trials of new drugs still recruit quickly—recent studies of T-20 (enfuvirtide) and tipranavir, for example.

Poverty and other cultural barriers faced by newer HIV populations may also be affecting recruitment. Trials have had little success recruiting HIV-positive injection drug users and aboriginal people, many of whom live in poverty. They have also struggled to recruit women.

Despite these challenges, investigators urge HIV-positive people to participate.

"Among HIV physicians, there's a lot of supposition about what works and what doesn't work, but the only way to know for sure is through randomized clinical trials," says Dr. Michael O'Shaughnessy, director of the BC Centre for Excellence in HIV/AIDS and national co-director of the Canadian HIV Trials Network. "Without people willing to participate, however, we'll never know." ⊕



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

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

CTN 171 — Cellcept (Mycophenolate Among Patients with HIV Receiving Abacavir)
BC site: St. Paul's Hospital, Vancouver

CTN 175 — Nevirapine to Lower Cholesterol (SCHMALTZ Trial)
BC site: St. Paul's Hospital, Vancouver

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

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

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

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

Flesh and blood



Living with hemophilia and HIV

by James Kreppner

Hemophilia is a hereditary bleeding disorder in which the body fails to produce some of the clotting factors needed to respond to a bleed. Many people believe that hemophiliacs bleed a lot from minor cuts. This is a myth. External wounds are usually not serious. Far more important is internal bleeding, or hemorrhaging, into joints, tissues, and muscles. When bleeding occurs in a vital organ, especially the brain, a hemophiliac's life is in danger.

These bleeds are often spontaneous and have no known cause, especially during the younger years as the body is growing and new blood vessels are being formed to facilitate bone growth. Knees, ankles, and elbows are the most common targets, and if the bleeds are left unchecked, individuals can suffer crippling effects as the joint damage is increased with each subsequent bleed.

Arthritic changes settle in over time with this continual damage, and severe hemophiliacs in the third world often suffer crippling effects. At international conferences, they are easily spotted by their limps, crutches, canes, or even wheelchairs. Any sport or vigorous exercise that can result in injury is not recommended for a severe hemophiliac without access to treatment options.

Advancements in the 1960s

The appearance of blood-derived cryoprecipitate (cryo) in the 1960s changed all this. Blood could be frozen and processed in such a way as to allow certain clotting factors to be precipitated out at very cold temperatures. The resultant blood fraction was high in the clotting factors that were in reduced supply in the blood of hemophiliacs. This product was stored frozen, and it could be reconstituted in under an hour. When injected intravenously through a push IV, it was remarkably effective in stopping hemophilia-related bleeding.

In time, the product was improved. Plasma was collected and pooled, and the relevant blood fractions (clotting factor 8 or 9 for hemophilias A or B, respectively) were freeze-dried into small bottles that could be stored in a refrigerator or even at room temperature. This treatment for hemophiliacs was so

effective that an observer would have been hard pressed to identify a hemophiliac from a non-hemophiliac in a crowd.

When the AIDS epidemic started in the 1980s, hemophiliacs were one of the first groups to feel the impact because of their reliance on blood products. Most hemophiliacs were infected with HIV and hepatitis C at that time. Since then, protective measures have been taken to improve the safety of the blood supply, including screening and testing. Viral inactivation measures were also introduced, including HIV nucleic acid testing (NAT) of donated blood and heat treatment. Finally, recombinant technology produced the clotting agents needed by hemophiliacs. This process uses an animal cell line that has been genetically engineered to manufacture the relevant protein, and some of the newest clotting products are now completely unconnected to donated blood.

Different risk factors

HIV in the hemophilia population can take different forms, as different modes of transmission appear to translate into different risk factors. For example, the rate of Kaposi's sarcoma is low among hemophiliacs. This difference may be a result of a lower risk of human herpes virus 8 (HHV-8) transmission, which may not be as readily transmitted through blood as through other routes. However, a slightly higher risk for non-Hodgkin's lymphoma, which may again be related to the risk factor of blood transfusion, has been reported.

Other complications particular to hemophilia involve the potential bleeding implications of some protease inhibitors (PIs). One theory is that the excretion of the enzyme that breaks down clots in the blood—which everyone eventually needs to do if their circulatory system is to continue working—is inhibited as the liver seeks to process the PIs. A build-up of this enzyme results, so clots last for shorter times than normal. If a person's clotting system is working normally, the increased levels of this enzyme do not present a problem as clots are easily rebuilt by a healthy system. However, if the individual is dependent on external clotting factors, the clot can break down prematurely and insufficient factors remain to help rebuild it.

While people with AIDS can sometimes develop autoimmune problems, among hemophiliacs, many of the infections and problems can also lead to bleeding complications. In my case, I developed a Crohn's-like syndrome, which involved inflammation in the intestine. Some bleeding can occur as a result of this syndrome even in people without bleeding disorders, but intestinal bleeding will, of course, be magnified by a concurrent bleeding problem such as hemophilia. During some past flare-ups, I have required numerous transfusions of red cells in order to make up for the blood loss.

While PWAs can sometimes develop autoimmune problems, among hemophiliacs, infections and problems can also lead to bleeding complications.

Another personal example of how HIV has interplayed with the bleeding condition involved an unknown lung infection that was apparently killing lung tissue and causing bleeding into my lungs. Interestingly, no bleeding would occur if I had just injected factor 8, but if I was not repeatedly injected or kept on a continuous drip, the bleeding quickly recurred. It became clear that if my factor 8 levels had been normal, I would not have had to experience the unpleasant sensation of feeling as if I was drowning in my own blood while fighting this infection.

Hepatitis C co-infection

Hemophiliacs shared many similar risks as the injection drug user population in terms of hepatitis C co-infection. Most HIV-positive hemophiliacs also have hepatitis C. We now know that the evidence firmly establishes that HIV accelerates the progression of HCV disease, and thanks to the HIV drugs, individuals are living long enough to experience the often serious impacts of their HCV infection. An increasing number of deaths in those co-infected are now caused by HCV infection rather than by HIV, which is one reason the issue of organ transplantation in co-infected patients has become so important.

For many years, surgeons hesitated to perform transplants on individuals with HIV. They doubted the wisdom of giving post-transplant immunosuppressive drugs to individuals with an already compromised immune system, and they also questioned whether or not it was a waste of an organ to give it to somebody who was likely to die from AIDS all too soon. But this thinking no longer reflects reality. And concerns about giving PWAs post-transplant drugs have been proven unfounded. In fact, recent data suggest that patients with controlled viral load tend to do very well post-transplant. However, these patients must carefully keep track of the drug combinations they are taking because some immunosuppressive drugs have interactions with some HIV drugs. As long as contraindications are monitored, combining immunosuppressive and HIV drugs should not be a significant problem because dosing can be altered to address interactions.

Although hemophiliacs may have their own spin on the effects of HIV—and all communities have their own particular issues—many questions are common among all HIV-positive people. What are the side effects of a particular drug? What are the risks of opportunistic infections or conditions? Activists in the hemophilia community also worry about making drug approvals more efficient and timely and about how quickly or slowly the medical community is acting to remove the discriminatory barriers in place for organ transplants in the HIV-positive community. We can only hope that by working in partnership with all communities with similar concerns that we can improve the treatment and lives of all persons living with HIV. ⊕

James Kreppner is a hemophiliac with HIV and HCV who was infected in the early 1980s. He is a retired lawyer, a member of the Community Advisory Committee to the HIV Clinical Trials Network, a member of the board of the HIV/AIDS Legal Clinic of Ontario, and a past co-chair of the Toronto People with AIDS Foundation.



Questions or concerns about your treatment or health?

BCPWA Treatment Information

You are welcome to drop by anytime Monday to Friday, 10AM to 4PM, at 1107 Seymour Street, Vancouver (down the street from St. Paul's) and you can even email us at treatment@bcpwa.org

**LOCAL 604.893.2243
LONG DISTANCE 1.800.994.2437**

Coming soon to a community near you

The BCPWA Society is on the road again with the ABCs program

by Carole Lunny



The ABCs of HIV Treatment and Care Program is conducted by the BCPWA Society in partnership with the BC Centre for Excellence in HIV/AIDS (BCCfE). The Vancouver-based program began in 1997 when funding was granted to conduct 20 presentations in British Columbia and the Yukon. In the last fiscal year, the ABCs program gave presentations to 47 community groups throughout the province and had 1767 participants.

Presentations are conducted in a wide range of settings: recovery centres, correctional institutions, community-based agencies, women's centres, conferences, councils and bands, AIDS service organizations, and support groups, to name a few. The ABCs team includes treatment information counsellors from the BCPWA Society who are HIV-positive, a registered nurse who specializes in HIV/AIDS, and an HIV primary care physician from the BCCfE. The nurse and doctor give presentations to other healthcare workers, and the counsellors give presentations to all the other groups.

The ABCs program does not provide prevention-specific information. The goal is to increase the quality and length of life for people living with HIV/AIDS by equipping them with the information and tools necessary to make informed treatment decisions. Treatment information covers a wide range of topics, but focuses on medications and complementary therapies for treating HIV, drug side effects, and immune reconstitution. Educational outreach activities include question and answer sessions, information booths, community forums, and slide presentations.

ABCs' presentations are interactive and are based on the priorities of participants. To that end, they are coordinated in conjunction with local HIV/AIDS education coordinators or host organizations, recognizing that these community contacts have expertise about the particular information needs of their constituents. Each workshop includes different stories and perspectives presented by

educators expert in current treatment information.

Funding for the program is dependent on extensive feedback and evaluation of the program's effectiveness and scope. Participants are encouraged to fill in an evaluation form to assess facilitator expertise, quality of learning experience, and method of presentation. Both written and verbal feedback has been positive.

All of our presentations and workshops are free. If you would like specific information regarding locations, times, and topics, please call the ABCs program coordinator at 1.800.994.2437, extension 309, or call direct at 604.646.5309. You can also email carolel@bcpwa.org for more information. ☎



Carole Lunny is the treatment outreach coordinator for the BCPWA Society.

ABCs on the road schedule:

Date	Location
Salmon Arm	Sept. 17, 2003
Revelstoke	Sept. 18
Prince George (BC CDC Conference)	Sept. 23
Aurora Conference UBC	Sept. 26
Lillooet	Oct. 3
New Aiyansh	Oct. 20 & 21
Alert Bay	Nov. 12 & 13
Hope	Dec. 3 & 4
Nanaimo	Jan. 14, 2004
Riverview Hospital	Feb. 10
Maple Ridge	Mar. 18
Yukon	Week of Apr. 12
Quesnel	May 10

Building better health professionals

Interprofessional HIV/AIDS course teaches students balanced approach to health care

by Logan Lee & Dr. M. Peter Granger



The University of British Columbia now offers a course called “Interprofessional Health and Human Services” that focuses on HIV prevention and care. This course is designed to prepare students in the health professions to respond effectively to the HIV epidemic and its consequences, both biological and social.

Experts from five disciplines—medicine, nursing, dietetics, social work, and pharmacy—participated in structuring this course, but over the next few years, experts from other fields may play a role. The main objectives of the course are to understand the roles and responsibilities of the other professions, to understand and practice concepts essential to effective teamwork, to explore values and beliefs related to professional cooperation, and to strengthen the partnership between interprofessional teams and individuals living with HIV. Achieving these objectives will help to improve the care provided to HIV positive individuals in the years to come.

The integrative approach of this course weaves together knowledge of the pathology, epidemiology, social determinants, and prevention of HIV. The strategic focus of the course centres on preventing transmission and predicting which individuals are most susceptible to infection. The remainder of the course educates health professionals in the care and treatment of individuals who are HIV positive. Students explore professional and personal values, beliefs, and attitudes they may possess relating to HIV infection. Physical, psychosocial, and spiritual issues confronting individuals at risk for, affected by, or infected with HIV are also discussed.

Many of the faculty members are directly involved in HIV/AIDS care and prevention. The core members of the faculty

are from UBC’s schools of medicine, pharmaceutical sciences, nursing, social work and family studies, and food nutrition and health, as well as from the BC Centre for Excellence in HIV/AIDS, AIDS Vancouver, and the Children’s and Women’s Health Centre of British Columbia. Members of community groups who provide education, support, and care to positive individuals also participate.

Students in this course are encouraged to acquire not just theoretical knowledge, but also the skills and abilities required by professionals to provide holistic and interprofessional care. Problem-based learning, presentations, and workshops provide the theoretical background these health professionals need. Students then gain valuable clinical experience in institutional and community settings where they shadow health and human service professionals who have expertise in HIV prevention and care.

During the clinical placements, students also meet with HIV positive individuals from the community to learn about their daily lives. Many of the students find this meeting an incredible opportunity to see what it is really like to have HIV and to learn about how people cope with the daily tasks and strict drug regimens.

No matter what their backgrounds, these students truly want to fight in the battle against HIV. The faculty members hope that when students finish the course they will be energized and interested in learning more about HIV. The HIV/AIDS course is constantly being evaluated to ensure that the curriculum effectively educates health professionals in how to prevent transmission and how to care for people who have HIV. ⊕

Logan Lee is a Masters Student in Physiology at UBC.

Dr. M. Peter Granger is the Director of the Division of Inner City Medicine for the Faculty of Medicine at UBC.

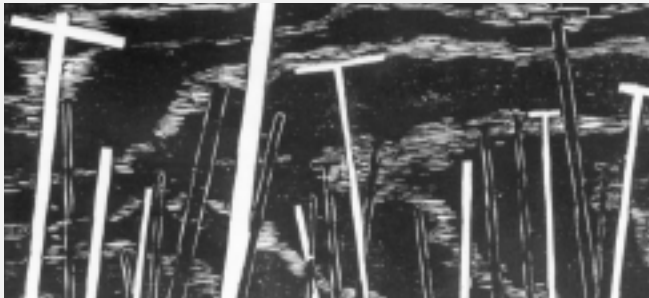


Acceso a medicinas contra vih-sida en Chile

por Sergio Plata

Chile se encuentra viviendo una transición democrática, después de vivir casi dos décadas bajo la dictadura militar del general Augusto Pinochet, sin embargo hay viejas prácticas que continúan siendo activas; la corrupción, la intolerancia y la violación a los derechos humanos.

Desde su aparición el VIH-SIDA sigue siendo una de las enfermedades que esta en lista de espera.



El constante atraso del gobierno para responder a la pandemia y la negación de los medicamentos para el tratamiento de las personas infectadas ha originado que los pacientes suspendan constantemente su tratamiento algunas veces por dos semanas otras hasta por un mes, algunos con suerte no han creado resistencia a ciertos medicamentos pero otros si.

Desde su aparición el VIH-SIDA sigue siendo una de las enfermedades que esta en lista de espera.

Hasta el día de hoy no existe un marco legal que proteja los derechos de las personas con VIH-SIDA, la discriminación disimulada y encubierta de los empleadores no permite que una persona infectada continúe laborando, argumentando muchas veces los despidos por "razones de la empresa".

El problema de la falta de medicamentos en el Instituto de Salud Pública es tan grave que se ha creado un mercado negro para la adquisición de los medicamentos a precios muy bajos. La organización "vivo positivo" reportó que en el año pasado existían más de 200 personas, sin recursos económicos, obligados

a conseguir clandestinamente los medicamentos. La manera de contactar a los proveedores es a través del celular o teléfono público y se paga en efectivo, por desgracia la persona corre el riesgo de adquirir los medicamentos adulterados o falsos. Las personas conocen el riesgo pero prefieren hacerlo a no tomar nada.

La falta de medicamentos contra el VIH-SIDA en Chile ha provocado la creación de un mercado negro.

La 5a causa de muerte en Chile es el SIDA y oscila entre los 20 y 45 años. El 80% (2,700 personas) viven con el VIH, aumentando cada año un 20%.

La organización "vivo positivo" en Chile, reportó que hasta el 31 de diciembre, 1999 existían 3450 casos de SIDA y 4,052 de VIH. Y 22327 han sido muertes por SIDA.

El 91.3% de los casos han sido por exposición sexual, 6.7% por contacto sanguíneo y el 2% por transfusión vertical.

El 98.7 son hombres, el 10.3% son mujeres. Las edades de las personas afectadas por el VIH-SIDA son entre 20 y 49 años son el 85.1%, menores de 20 años son el 2.5% y mayores de 50 años representan el 12.3%.

Se reportan anualmente 40,000 embarazos de adolescentes.

La situación en Chile es preocupante y es una verdad que no debe quedar inmersa en el aire y mucho menos hacer del VIH-sida un acto de corrupción. ¿Acaso no hay algún poder terrenal que detenga estas muestras de cerrazón?

Es urgente resolver este tipo de situaciones y no solo a través de la contemplación. Actualmente muchos gobiernos sufren de amnesia y lagunas mentales.

El panorama del SIDA continua siendo aterrador, el SIDA llevo hace más de dos décadas y esta aquí! De que hay avances no hay duda, pero tampoco hay duda de que el VIH-SIDA continua siendo una enfermedad incurable y mortal. ⊕

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:

Joseph (Joe) LeBlanc



"Joe is always present when you need him. When all other plans have fallen through, he appears and lends many helping hands. With his sparkling new scooter he tears around Downtown Vancouver bringing brochures and posters for the latest event he's helping to promote."

James Ong
Director of Development



Volunteer History

I have volunteered for AIDS WALK, the Lounge, and Polli & Esther's Closet. I have put up posters, and sold tickets at AccolAIDS. I also have volunteering experience with the Boy Scouts of Canada.

Started at BCPWA

September 2000

Why pick BCPWA?

Since I was diagnosed in July 1997, BCPWA and AIDS Vancouver have been there for support and guidance.

Why have you stayed?

I enjoy meeting members and try to help make their day a happier one. I enjoy putting a smile on people's faces.

Rating BCPWA

If it wasn't for BCPWA, I wouldn't get up in the morning. Now I have a better and happier life with volunteering.

Strongest point of BCPWA

Staff and volunteers are always there to help you out.

Favourite memory

How can I choose only one. I've had many memories, especially selling raffle tickets at special events.

Future vision of BCPWA

As long as I'm healthy, I will continue to help in any department at BCPWA and AIDS Vancouver, if they will have me.

Gain
and share your
skills for a
valuable cause

IF YOU HAVE

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

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

for further information and an application form **contact:**

volunteer coordination at 893.2298

adriaanv@bcpwa.org

or Human Resources at 1107 Seymour Street

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

where to find help

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

BC Persons With AIDS Society

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

A Loving Spoonful Location

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

AIDS Memorial Vancouver

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

AIDS Prince George

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

AIDS Resource Centre – Okanagan and Region

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

AIDS Society of Kamloops

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

AIDS Vancouver

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

AIDS Vancouver Island (Nanaimo)

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

AIDS Vancouver Island (Victoria)

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

ANKORS (Nelson)

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

ANKORS (Cranbrook)

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

Asian Society for the Intervention of AIDS (ASIA)

210 – 119 West Pender St,
Vancouver, BC V6B 1S5
604.669.5567
asia@asia.bc.ca, www.asia.bc.ca

Dr Peter Centre

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

Friends for Life Society

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

Healing Our Spirit

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

McLaren Housing Society

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

North Island AIDS (Campbell River) Society

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

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 V0N 2P0
250.902.2238
niac@island.net; www.island.net/~niac

Okanagan Aboriginal AIDS Society

202 – 1626 Richter Street,
Kelowna, BC V1Y 2M3
250.862.2481 or 1.800.616.2437
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)

250.881.5663
erikages@pan.ca; www.pan.ca

Positive Living North West

Box 4368 Smithers, BC V0J 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

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

Vancouver Native Health Society

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

Victoria AIDS Respite Care Society

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

Victoria Persons With AIDS Society

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

Wings Housing Society

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

YouthCO AIDS Society

203 – 319 Pender Street,
Vancouver BC V6B 1T4
604.688.1441 1.877.968.8426
info@youthco.org; www.youthco.org

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

Upcoming BCPWA Society Board Meetings:

Date	Time	Location	Reports to be presented
September 3, 2003	1:00	Training Room	Financial Statements – July / Executive Committee
September 17, 2003	1:00	Training Room	Written Executive Director Report / Standing Committee
October 1, 2003	1:00	Training Room	Financial Statements – August / Director of Treatment, Information & Advocacy
October 15, 2003	1:00	Training Room	Quarterly Department PHSA Report — Written Executive Director Report Executive Committee / Financial Statements – September — Director of Communications & Education
November 12, 2003	1:00	Training Room	Written Executive Director Report / Director of Support Services Standing Committee
November 26, 2003	1:00	Training Room	Financial Statements – October / Executive Committee

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

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phone _____ fax _____ email _____

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

Cheque payable to BCPWA



www.bcpwa.org

living+

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



Knickers in a knot

Caring for aging parents can be challenging

by Denise Becker

My parents had me late in life, so now at age 44 I am caring for infirm parents in their 80s. Being a patient and a caregiver has been stressful. Both parents are experiencing the pain, frustration, and sometimes the enlightenment of nearing death. I find myself directing them on a path I have already trodden. Occasionally, I forget to look after myself.

My father was diagnosed with prostate cancer in the late 1990s and is now receiving palliative care. Recently, I went to visit him in England for what, we both knew, might be the last time. Because we have both been diagnosed with terminal illnesses, we were able to talk frankly about our lives and the way in which people treat us differently. We were able to share things that families often leave unsaid.

I soon discovered that George Bernard Shaw's maxim "Old men are dangerous: it doesn't matter to them what is going to happen to the world" was not only true but perhaps a little understated. My father began sharing this new-found verbal freedom with people he hardly knew, much to my embarrassment. He thought nothing of going in with both barrels blazing on unsuspecting smokers outside the hospital doors. His wife and I had to continually hold him back from imparting his wisdom on unsuspecting bystanders.

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Upon my return to Canada, I had to take care of my mother, who recently suffered a stroke and is now exhibiting all the signs of dementia. She lives in a senior's home, but I take her to all her doctor's appointments and act as her translator. She speaks perfect English but doesn't seem to understand what the doctor tells her. If he asks her to go into his office, she looks at me and I point to the office. The other day he asked her to take a seat outside, and she obligingly picked up a chair and took it into the hallway. Then the receptionist asked her for her birthdate and, after

mulling it over, she replied, "I think it was a Friday."

After seeing three specialists with my mother in one week, I realized that I was starting to forget my meds and that my own health was beginning to suffer. My first clue that things were not right was a twitch that developed in one eye. I knew the twitch was there, but each time I looked in the mirror it disappeared.

One day, mom lost her purse and the twitch started again. The next day, she spent the morning trying on clothes and then left her house keys in the changing room. As we drove back across town to retrieve the keys, the twitch was more prolonged. On the third day, my mother told a doctor she lived in Abbotsford, though she lives in Kelowna. The twitch became a full flutter.

I went home, exhausted, and told Lloyd I was going to bed to relax and watch TV. The twitch was now incessant. I discovered that if I covered my eye with my hand, the twitch stopped and I could watch TV, but as soon as I removed my hand from my eye, the twitching started again.

I went to my chest of drawers and triumphantly pulled out a sock to tie around my eye, pirate-style. Darn it, it wasn't long enough.

Searching around the room, I finally spied the answer: my purple knickers. Placing them over my head, I found that I could look through one leg hole while keeping the rest of the underwear over my twitching eye. It worked! I lay on the bed, turned off the light, and finally felt comfortable.

Soon I heard a rustle in the background. I looked up to find Lloyd and my dog, Molly, staring at me from the bedroom door. My one eye stared back. Lloyd turned, shook his head, and went back to other room. "Come on, dog," he said in a muffled tone. "I think she's finally lost it."

I didn't care. I had found serenity. ☺



Denise Becker is a board member of the BCPWA Society.