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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 3,500 HIV+ members.

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think +

opinion and editorial

The problem with HIV certification of doctors

by Paula Braitstein

Treating people living with HIV/AIDS has always been a challenge for physicians and other healthcare providers. A well-established link exists between whether a patient's physician has experience with HIV/AIDS and how well, or how poorly, HIV-positive patients will do medically. The situation today, with upwards of twenty licensed antiretroviral drugs, a plethora of complications from those drugs, and multiple concurrent issues for people living with HIV/AIDS (such as mental illness, addiction, hepatitis B or C co-infection, and poverty) is more complex than it has ever been. Yet, the stakes for people living with HIV/AIDS are as high as ever.

The states of California and New York are contemplating legislation that would require physicians to become "certified" to treat people living with HIV/AIDS. Until last year, legislation was already in place in California that required HIV-positive patients to be referred to HIV specialists. The next step in the legislation will be to define what an HIV specialist is. Although the criteria to be used are not yet clear, it is proposed that physicians will be required to have provided direct and continuous medical care to at least twenty HIV-positive people over the preceding 24 months; to complete at least 30 hours of continuing medical education (CME) in the diagnosis and treatment of HIV-positive patients; and to be currently certified in infectious diseases.

Sounds great, right? But consider this: over 10,000 people are living with HIV/AIDS in British Columbia and

already there aren't enough primary care providers to go around. Consider how long you already have to wait to see one of the doctors in the Immunodeficiency Clinic at St. Paul's Hospital in Vancouver. And consider how a certification protocol like this would affect people living in rural areas.

While we need doctors to know a lot about HIV disease, we also have to recognize that treating HIV often also means treating depression, hepatitis C, and/or addiction. Should doctors who treat HIV also have to become certified in these areas? Or does certification in HIV mean doctors will also need to have expertise in these other areas? While 30 hours of training doesn't sound like a lot, physicians—the good ones, anyway—are already stretched to, if not beyond, their limits. Becoming a specialist in infectious diseases means many more years of training after graduation from medical school.

Given the amount of time and energy required for working with the array of health issues of people living with HIV/AIDS and given the number of people requiring this time and knowledge on the part of healthcare providers, we should think very carefully about the implications of requiring physicians to become HIV certified. Rather than improving the quality of care received, we may end up simply reducing access to the relatively high quality of care we already have. ⊕

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

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

REALITY BITES



SARS and PWAs

Severe Acute Respiratory Syndrome (SARS) is a continuing concern in Canada and abroad. To date, there have not been enough cases of SARS to determine accurately whether it poses a particular risk to PWAs. However, Luc Montagnier, the French researcher who was the joint discoverer of HIV, has expressed concern that the death rate from SARS could be much higher among HIV-positive people.

As of the time of writing, all confirmed cases of SARS in B.C. have been among people who travelled recently to certain areas of Asia and healthcare providers who have had direct contact with those travellers.

Symptoms of SARS include a fever of 38 degrees Celsius or higher, plus a dry cough, shortness of breath, or difficulty breathing. PWAs with one or more of these symptoms should contact their healthcare provider. Other symptoms of SARS may include muscle aches, headaches, and sore throat.

Health Canada is posting regular SARS updates on its website at <www.sars.gc.ca>.

New faces at BCPWA

The BCPWA Society is pleased to welcome new staff members. Lisa Gallo is our new director of communications. Lisa



Lisa Gallo

photo Britt Permen

holds a Marketing Management diploma from the British Columbia Institute of Technology, and she is currently working on her Public Relations certificate from Langara College. Most recently, she worked at BC Hydro in Business Communications and Public Relations. Her accomplishments include BC Hydro's Stellar Achievement Award.

Alexandra Regier is our office manager. She holds an Honours MA in Psychology. Alex worked as administrator of the Research Unit in Health and Behavioural Change at the University of Edinburgh in Scotland before moving to Vancouver in 2000 and working in Technical Services at Vancouver Public Library. She currently volunteers at WISH, a drop-in centre for female sex trade workers in the Downtown Eastside.

More PharmaCare changes

The BC Ministry of Health Services launched "Fair PharmaCare" on May 1. The intent is to provide more equitable access to prescription drug users. The program combines the existing major PharmaCare plans—the universal plan and seniors' plan—into one new plan, with access based on families' ability to pay.

According to the Ministry's website, "the new approach focuses PharmaCare financial assistance to British Columbians who need it most: the lower your income, the more assistance the government will provide for your prescription drugs." The Ministry promises that "overall, the vast majority of BC families will pay the same or less for their prescription drug costs."

To register for Fair PharmaCare, you must be a resident of B.C. for at least three months, be registered with the Medical Services Plan, and have filed an income tax return for the relevant taxation

year. To register, call toll-free in B.C. at 1.800.387.4977 or visit the website at <www.healthservices.gov.bc.ca/pharme/plani/planiinfo.html>.

YouthCO's new toll-free number

YouthCO AIDS Society has launched a new toll-free, national phone line, 1.877.YOUTHCO (1.877.968.8426). The toll-free line offers easy access to YouthCO's resources for young people living with HIV and/or hepatitis C, service providers, parents, teachers, community educators, and youth with questions.

YouthCO offers prevention education and support programs to young people under the age of 30 in the Lower Mainland of BC. With over eight years of peer-driven youth education experience, the Prevention Education Department represents a wealth of knowledge in the area of developing youth capacity and skills to educate other young people about HIV/AIDS and hepatitis C. The Positive Youth Program provides support to young people living with HIV and/or hepatitis C through counseling, peer support, and social activities.

Tenofovir approved in Canada

Health Canada granted approval for sale of the drug Viread (tenofovir). The drug is intended for use as part of combination therapy for the treatment of HIV/AIDS. Tenofovir has already been approved by regulatory authorities in the European Union and the United States.

Because health care is administered by Canada's provinces and territories, it will be months before tenofovir appears on their subsidized drug lists or formularies. One factor that may affect the speed at which tenofovir appears on formularies

REALITY BITES



will be its cost. Currently, no Canadian price has been selected by the company. In the U.S., one month's supply of tenofovir costs USD \$433 (\$640 CDN).

Source: *CATIE News*

PWAs in Pakistan thrown out of hospital

A non-governmental organization working with people living with HIV/AIDS in Pakistan has expressed outrage after three HIV-positive patients were allegedly thrown out of a hospital in the North West Frontier Province due to discrimination.

Maimoona Masood Khan, chief executive of AWARD, maintained that misconceptions about how HIV is contracted were responsible for the patients being thrown out. "This kind of behaviour is going to make this issue go underground and if this happens it will come back as a full-blown epidemic."

HIV carries huge social stigma in this deeply Islamic society and very few people are open about their HIV-positive status. There are an estimated 80,000 HIV-positive people in Pakistan out of a population of 140 million. However, official figures are much lower. Only 1,942 cases of HIV and 231 cases of full-blown AIDS were reported toward the end of last year.

Source: *IRIN News*

Parliamentary hearings on HIV/AIDS

In March, the Parliamentary Standing Committee on Health held three hearings on the Canadian Strategy for HIV/AIDS (CSHA). The hearings were granted in response to a request from HIV/AIDS Coalition members.

Committee members from all parties asked questions and made statements

that suggest that the majority of MPs understood and accepted arguments for doubling the budget of the CSHA.

In her summarizing remarks, the Committee Chair, Liberal MP Bonnie Brown, said: "I don't think we're going to find too much opposition within the committee to coming up with a report that recommends what you're looking for but it will probably require more support from us as individuals and from you and the people you serve to make that push into a reality in the sense of dollars. But I think you and the previous witnesses have touched our souls on this and I think you'll probably see some action."

AIDS drug priced at record \$20,500

Drug manufacturer Roche has priced its new HIV drug Fuzeon(T20) at a record 18,980 euros (USD \$20,570) a year, fuelling controversy about the cost of AIDS treatments. Roche said the high daily cost of 52 euros—more than any other AIDS drug on the market—reflected the complexity of manufacturing the product, which involves more than 100 production steps.

The Swiss healthcare company believes the twice-daily injection could have peak sales of up to USD \$740 million.

Source: *Reuters*

Newspapers ignore risks of new drugs

The information that Canadians get on new prescription drugs from daily newspapers is incomplete and may promote unrealistic expectations about the benefits of new drugs, according to a study

released by the Canadian Centre for Policy Alternatives. The first of its kind in Canada, the study examined stories in Canada's 24 largest daily newspapers about five major prescription drugs launched in recent years.

The study found that newspaper articles more often emphasize the benefits of new drugs, while little attention is paid to possible harms. Sixty eight percent of the articles examined made no mention whatsoever of possible adverse effects, and when identified, these harms were usually downplayed and mentioned towards the end of the article.

The authors acknowledged that reporting on pharmaceuticals isn't easy for journalists. "Pharmaceutical companies make it very easy to write favourable stories about new drugs, while independent drug information is harder to find," said one of the study's co-authors. ⊕

Correction

For more information about the BCPWA Society's involvement in the development of the five-year strategic plan for the Canadian Strategy on HIV/AIDS, contact BCPWA board member Jeff Anderson at 604.646.5313. Incorrect information appeared in the March/April 2003 issue of *Living +*.



Proposed changes to the distribution of provincial gaming funds through the direct access program have raised concerns among local charities about access to gaming revenues.

According to the Gaming Policy Enforcement Branch (GPEB) section of the Government of British Columbia Web site, the province will receive an estimated \$660 million dollars in 2002/2003 from gaming revenue. Of the \$660 million, \$133 million will be allocated to community organizations—\$73 million through commercial bingo hall affiliations and \$60 million through the direct access program.

The GPEB anticipates that 3,300 organizations will have applied for funds through the direct access program in 2002/2003. This number represents a 35% increase in demand from the previous year, although available funds have only increased by 1.2%. Because of the exponential growth in the number of community organizations applying for funds, Solicitor General Rich Coleman asked the GPEB to propose changes to the program in order to relieve the strain on these allocated funds.

Several proposed changes were cause for concern among community organizations throughout the province:

The use of funds will now be program-based, whereas previously the focus was

on overall organizational structure. This change means that charities will have to apply for funding for particular programs.

Organizations previously applying for funds through both the direct access program and bingo hall affiliation must now choose between one of the two streams of funding.

A program deriving more than 50% of its funding from federal or provincial government grants and/or contracts would be ineligible. Since many AIDS organizations receive a substantial portion of their funding from the federal and provincial governments, approval of this criterion would have seen the closure of many programs and/or significant reduction in program delivery because of layoffs of the personnel who implement them.

Local organizations may receive a maximum of \$100,000 annually for any combination of program and capital project costs. An organization delivering a province-wide program may receive a maximum of \$250,000 annually. These funding caps were always in place, but they have now been formalized.

In a parliamentary session on March 4, MLAs Lorne Mayencourt and Jenny Kwan raised the issue of how these changes would impact the ability of community organizations to access gaming revenues. As a result, the government made a number of modifications. While the use of funds

will indeed be program based, organizations can continue to apply for gaming revenue through both the direct access program and bingo hall affiliations. The 50% government funding restriction was raised to 75% after the tremendous negative impact was successfully conveyed to the GPEB and the Solicitor General through numerous public forums. In particular, meetings organized by the Bingo Council of BC and by Lorne Mayencourt provided exclusive opportunities for charitable organizations to voice their concerns.

For the BCPWA Society, the news is generally positive. The Society only applies for direct access funds, receives less than 75% of its funding from governmental sources, and provides province-wide programs, so the impact of the changes will be minimal. As the grant is now program based, the BCPWA Society will have to evaluate how it “fits” within a grant structure on a program-by-program basis. As with Gay Bingo, a fundraiser for Friends for Life, don’t clear your card unless a winner has been announced. You just might be surprised to find that the game is still on! ⊕

James Ong is a co-director of development for the BCPWA Society and enjoys gay bingo.

Hats off to our heroes

AccolAIDS awards banquet brings BC AIDS community together



The 2nd annual AccolAIDS, a partnership with Granville Island and the Granville Island Public Market, brought British Columbians together on April 27 at a sold-out awards banquet to honour the people who work tirelessly in the BC AIDS movement. The moving tributes were a testament to their tremendous achievements.

The winners of 2003 AccolAIDS awards are:

VanCity Savings Credit Union Award for Social, Political and Community Action

Philip Owen, the former Mayor of Vancouver, led a local and national debate on drug use and addiction in urban Canadian cities, arguing for the implementation of an integrated four-pillar approach of prevention, treatment, enforcement, and harm reduction.

BCPWA Society Kevin Brown PWA Hero Award

William E. Sandquist, a.k.a. "Unk", is a founding director of the HIV/IDU Consumers' Board. He has been a driving force for meaningful change for PWAs and injection drug users in Vancouver's Downtown Eastside.

Bristol-Myers Squibb Award for Science, Research and Technology

The Vanguard Project is an ongoing study of HIV rates and risk factors among young men in the Lower Mainland between 15 and 30 who have sex with other men. A project of the BC Centre for Excellence in HIV/AIDS, the research findings have provided invaluable information regarding individual health and the health of the community.

Merck Frosst Award for Philanthropy

The Shooting Stars Foundation and executive director Kendra Sprinkling have raised hundreds of thousands of dollars for AIDS organizations in Vancouver through various fundraising events such as Starry Night, since 1985.

Hoffman-LaRoche Award for Health Promotion and Harm Reduction

Evanna Brennan and Susan Gilles, nurses with the Vancouver Coastal Health Authority, have delivered home care nursing services to a population of marginalized people in the Downtown Eastside for 15 years. Their holistic and humanistic approach responds to physical needs and social factors with sensitivity and respect.

Schering Canada Award for Service Delivery

The 25 nurses in Ward 10C at St. Paul's Hospital have demonstrated a remarkable combination of skill and experience, compassionate attention and deep commitment to the highest quality of nursing care to their ward, a 21-bed specialized HIV/AIDS unit.

GlaxoSmith Kline in partnership with Shire BioChem Award for Innovative Programs

YouthCO AIDS Society's Prevention/Education Department has had great success in reaching affected and at-risk youth populations with such innovative initiatives as the Speakers Bureau, Theatre Troupe, Resources Development, and the Choices Project.

Boehringer Ingelheim Above and Beyond

Pat White has been clinical secretary to Dr. Julio Montaner since 1991. She has been the personification of compassion, gentleness, perseverance, strength, positivity, and enduring hope for hundreds of clinic patients and helped lighten their burden.

Changes to CPP tax refund program

Recent changes to the Canada Pension Plan tax refund program apply only to BCPWA Society members who receive CPP and welfare payments and who have to pay taxes.

Currently, if you are receiving CPP benefits, the welfare department checks with CPP to find out the amount of your gross CPP benefits. The ministry deducts dollar for dollar your CPP money from your welfare cheque. CPP benefits are taxable, so at the end of the year, the welfare department gives you the money to pay your tax on your CPP benefits.

This system has now changed.

CPP payments are still taxable and are still deducted dollar for dollar from your welfare cheque. But now welfare is going to give you extra money on your monthly cheque with which to pay your taxes. This means you will not be able to ask welfare to pay your income tax for you at the end of the year or reimburse you for any CPP benefits tax that you paid.

Contact CPP directly and ask them to deduct every month the same extra amount that welfare is now going to give you. That way you will not have a CPP benefits tax

bill at the end of the year. The toll-free number for CPP is 1.800.277.9114.

A word of warning: If you simply spend the extra welfare money and do not contact CPP to take the same amount off, you will have an income tax bill at the end of the year that you must pay. The welfare department will not help you because it will have already given you the extra money for the taxes on your CPP benefits.

If you have any further questions, contact the BCPWA Society Advocacy Department at 604.893.2223. ☎

A prickly issue

Needle exchange programs are long overdue in Canadian prisons

by Ralf Jürgens

Prisons are high-risk environments for HIV and hepatitis C transmission, because injection drug use is prevalent but prevention measures are inadequate. In a 1995 survey conducted by the Correctional Service of Canada, 11 percent of 4,285 federal prisoners self-reported having injected since arriving at their current institution. Injection drug use was reported to be particularly high (23 percent of prisoners) in the Pacific region.

While bleach is available in provincial and federal prisons in BC, sterile injection equipment is not. The scarcity of needles often leads to needle-sharing. Prisoners told members of the Expert Committee on AIDS and Prisons (ECAP) that often 15 to 20 people use one needle.

Because of these factors, providing sterile needles to prisoners has been widely recommended. In 1994, ECAP concluded that making injection equipment available in prisons would be "inevitable."

Nevertheless, nearly 10 years later, no Canadian prison systems have yet started pilot needle distribution projects. Those opposed to making needles available have said that it would be seen as condoning drug use. In reality, needle distribution is a pragmatic public health measure that recognizes that injection drug use in prisons exists, notwithstanding all efforts to eliminate it. *Not* undertaking pilot needle distribution studies in the face of knowledge that HIV and other infections are being transmitted in prisons could be seen as condoning the spread of infections among prisoners and the public.

Canada can and should learn from the increasing number of prisons internationally that have established needle exchange or distribution programs. In Switzerland, some prisons have distributed sterile injection equipment since the early 1990s. Sterile injection equipment first became available to prisoners in 1992 at Oberschöngrün prison for men. Ten years later, distribution continues, has never resulted in any negative consequences, and is supported by prisoners, staff, and the prison administration. Initial scepticism by staff members has been replaced by their full support. Staff members realized that distribution of sterile injection



equipment is in their own interest. Before the distribution started, they were always afraid of sticking themselves with a hidden needle during cell searches. Now, prisoners are allowed to keep needles, but only in a glass in their medical cabinets over their sinks. No staff member has suffered needle-stick injuries since 1993.

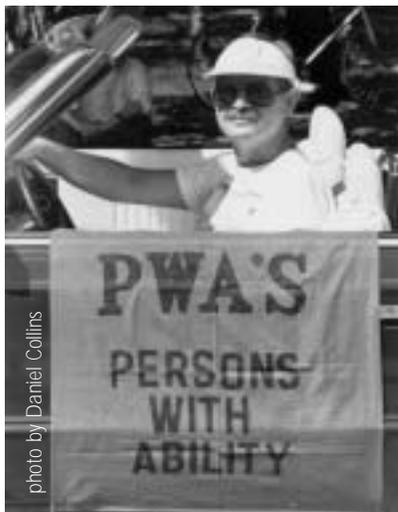
In June 1994, another Swiss prison, Hindelbank institution for women, started a one-year pilot AIDS prevention program including needle distribution. Hindelbank's program, which was evaluated by external experts, had very positive results. The health status of prisoners improved, no new cases of infection with HIV or hepatitis occurred, needle-sharing decreased significantly, and drug consumption did not increase. Needles were not used as weapons. Only about 20 percent of staff did not agree with the installation of the needle-distribution machines. Following the first evaluation, they decided to continue the program. Many other prisons in Switzerland, Germany, Spain, and an increasing number of Eastern European countries have since started their own programs.

Both the Canadian federal prison system and the BC provincial system should finally implement pilot needle-exchange projects. This approach would recognize that prisoners, even though they live behind bars, are part of our communities. Most prisoners eventually leave prison to return to their communities, some after only a short time inside. Some prisoners enter and leave prison many times. Prisoners deserve the same level of care and protection that people outside prison get. They are sentenced to imprisonment, not to infection.

For more information on needle exchange in prisons, visit the Canadian HIV/AIDS Legal Network's Web site at <www.aidslaw.ca/Maincontent/issues/prisons.htm>. ⊕



Ralf Jürgens is the executive director of the Canadian HIV/AIDS Legal Network. From 1992-94, he was the project coordinator of the Expert Committee on AIDS in Prisons.



Remembering our past

Kevin Brown's legacy of empowerment and dignity

by Jackie Haywood

Kevin Brown—mild-mannered librarian, rural schoolteacher, avid bowler, softball player, and costume designer. This man's unlikely destiny would lead him to successfully face off against government, homophobes, and the scientific community as an openly gay Canadian living with AIDS.

Kevin was a bespectacled blond, a tidy, well-turned-out man who cared politically and passionately about his community and his peers. He dug in against being categorized as a "client" of AIDS Vancouver, organizing others who desired autonomy for PWAs to pursue political action and make decisions based on their self-defined needs.

**"I am not going to let myself be a victim."
— Kevin Brown, 1989**

In 1986, Taavi Nurmela, Warren Jensen, and Kevin spearheaded, along with a handful of other courageous men, the rental of the small upstairs office on the corner of Bute and Davie to house the PWA Coalition. Among this group of pioneers, Kevin emerged as a leader, spokesperson, and visionary.

Kevin stood up to medical professionals, questioning them and insisting that they make information available to patients regarding treatment options, access to drugs, and alternative medicines. When this approach faltered, he and others protested on the steps of the legislature in Victoria to demand a viral testing lab in

Vancouver. In 1986, they had a groundbreaking meeting with the federal Minister of Health in Ottawa regarding the release of prohibited prescription drugs on compassionate grounds.

A kind, funny, intelligent man, Kevin quickly became the first visible face of AIDS across Canada. The media loved him. He was articulate, tenacious, and savvy. It became evident that PWAs were the experts and Kevin the purveyor of the message. Kevin became a master at orchestrating the media. He was the proud, passionate, middle-class, educated face of AIDS, a man whose firm tone and ability to convey both the fears and collective pride of PWAs commanded attention and inspired others to come out about their disease.

I am extremely proud and constantly energized by the memories of working alongside him, meeting his family, and being a guest in his home. After battling PCP for years, his pace ultimately slowed. Donning his grey down jacket and winter toque, he would make his way up Davie Street and climb the steep stairs to our offices. I have an image in my mind of looking out the window on crisp cold days and seeing Kevin, moving slowly, smiling and talking to people who stopped him as he made his way in to tackle another day on the job for PWAs.

Kevin died on May 9, 1989, leaving behind a legacy of empowerment and activism in the fight for the right of PWAs to live with dignity and respect. ⊕



Jackie Haywood is director of support services for the BCPWA Society.



**BCPWA
Advocacy
gets
results!**

The BCPWA Society's Advocacy Program continues to work hard to secure funds and benefits for our members. The income secured for January and February 2003 is:

- ▼ **\$28,008.14** in debt forgiveness.
- ▼ **\$43,468.00** in housing, health benefits, dental and long-term disability benefits.
- ▼ **\$22,160.00** in Monthly Nutritional Supplement Benefits.
- ▼ **\$380,069.55** into members' hands for healthcare needs, from grandfathered Schedule C benefits.



Caring and coping

How healthcare workers handle stress and burnout

by *Trena White*

Paul Harris is a street nurse working primarily in HIV/AIDS outreach. He usually works in a medical clinic in Vancouver's West End, but sometimes he works with the disadvantaged people in the city's Downtown East Side, where many of his clients don't have access to housing or basic healthcare. A large part of his work involves HIV testing, and he is often the first person to tell patients they are HIV-positive. His job requires him to be consistently compassionate and non-judgmental and to maintain a positive outlook despite the emotional demands of his work.

Yet, Harris doesn't seem to find his work unusually stressful. When asked how challenging these demands are, he shrugs and says, "You have to believe in what you're doing."

Regardless of their fields, many healthcare workers report high levels of stress caused by heavy workloads, resource shortages, vague work roles, and poor patient prognoses. When the pressure is extreme and prolonged, it can cause burnout, a stage of stress in which workers no longer function normally. They become emotionally exhausted and detached from patients and colleagues. They become disinterested in their work and more susceptible to health problems.

Burnout is well-documented in AIDS care, which would suggest that the field is highly stressful. But is it any more challenging than other healthcare fields? And what determines whether workers in this field cope healthily with their jobs, as Harris seems to be doing?

The stress faced by most healthcare workers is compounded in chronic care situations. AIDS seems to be a particularly taxing field, often compared in research on stress and burnout to cancer care and geriatrics. A British study compared AIDS care with oncology and found that the two fields are more similar than different. In both fields, workers report that their most common stressors are building relationships with patients who inevitably seem to decline; overwork; and relationships with colleagues. All workers surveyed in the study reported stress-related symptoms, ranging from exhaustion to sadness and agitation.

Another study showed that 41 percent of healthcare workers in a wide range of fields and positions find working with HIV/AIDS one of the more stressful parts of their job. And burned out AIDS caregivers show more intense stress symptoms than their colleagues in oncology.

It's clear that AIDS care is a stressful line of work. But what are the unique challenges in AIDS healthcare?

The emotional toll of AIDS work

The most obvious characteristic of AIDS healthcare is that it is very emotional work. HIV/AIDS healthcare workers are the first to tell their patients that they're HIV-positive. They administer treatments that may not work or that cause serious side effects. They deal with the frustration and anxiety of PWAs, as well as the grief of families and partners. They are often close in age to their patients and closely identify with their patients' emotional distress.

All these factors take an emotional toll on healthcare workers, which explains why most find the personal interactions with their patients the most challenging and rewarding at the same time.

Yasmin Winsor is a street nurse from the BC Centre for Disease Control (BCCDC) who spends most of her time working in Vancouver's Downtown East Side. She says the most stressful part of her work is seeing people not having their basic needs met, and "society not caring for people who are really marginalized.... You see some people get better, you see some people die, you see some people on this treadmill of life."

Dr. Jack Forbes, medical director of the Oak Tree Clinic for women and children with HIV/AIDS, says the thing that makes AIDS care different from other forms of healthcare is the high degree of anxiety among his patients. "You can imagine a

seropositive mom who's just had a baby and doesn't know if it's positive, and she comes to me for testing." He constantly deals with people whose lives are in crisis.

While patient interactions can be very stressful for healthcare workers in this field, they do have the reward of developing close, long-term relationships with their patients and receiving enormous gratitude from both patients and family members. However, this bonding can make work more challenging when a patient's health deteriorates.

Stigmatization by association

At the beginning of the AIDS epidemic, healthcare workers in the field faced secondary stigmatization for working with PWAs. Many worried that they would lose patients or have trouble attracting new clients to their practice if it became known that they worked in HIV/AIDS.

They also had fears of contagion based on a lack of understanding of HIV transmission. "Nurses were putting gloves on, and patients were locked away in rooms and eating on paper plates," says Dr. Robert Voigt, a general practitioner at Vancouver's Spectrum Health Clinic.

That has changed dramatically and is less relevant now, although healthcare workers are more likely to find working with HIV-positive clients stressful if they have little experience with HIV/AIDS or negative attitudes towards infected people. This



finding suggests the importance of continual in-service education for healthcare workers who don't deal primarily with HIV.

Another unique challenge for HIV/AIDS care is the uncertainty involved in treating AIDS-related symptoms. Health workers in AIDS care are significantly more likely than workers in cancer care to be stressed by the appearance of new infections or symptoms in their patients, which is not surprising, given that infections and treatments are often unpredictable.

Dr. Voigt says it is very difficult to recruit physicians into HIV/AIDS care for this reason. "It's very intimidating because things are changing much more rapidly than in any other area," he explains. "You're giving drugs before they're even licensed, and you may not know the side effects." He faces a constant "onslaught of life and death situations."

To keep up on treatment advances, he attends three or four HIV conferences a year, reads online journals, and draws on the knowledge of his colleagues.

The responsibility of being the gatekeeper

The nature of HIV/AIDS means that healthcare workers in the field also work across medical professions and hold the responsibility for arranging patient care in a range of fields. This challenge is so significant for HIV/AIDS healthcare workers that many also devote personal time to working with external agencies and professions, adding to their heavy workload.

For example, many AIDS caregivers have both a personal and professional attachment to their field and choose to donate their skills to AIDS service organizations by lobbying government, serving on boards, or training volunteers. Most of these activities are done in their limited spare time, and it can be a challenge to balance their schedules.

Dr. Voigt says he stopped doing committee work about four years ago. "It was taking away too much time from my obligations to patient care, and I didn't accomplish as much as I had hoped."

Paul Harris says part of his work involves partnering with other health organizations such as WISH, a drop-in center for women sex-trade workers, or the Vancouver Coastal Health Authority. He is cognizant of what he terms "meeting creep." "It's a debate," he says. "Where are you going to have the most effect on people—partnering and developing programs or on the street, working one-on-one?"

Healthcare workers face the challenge of connecting their patients to various professionals, such as immunologists and dermatologists. They also take responsibility for connecting patients to non-medical resources. For example, Yasmin Winsor says a large part of her work involves connecting people to resources such as housing, income assistance, and detox programs. For Winsor, this doesn't mean additional work; she sees it as an integral part of her job.

Whether or not partnering causes additional workloads for healthcare workers seems to depend largely on the expectations of the workplace. Are the employees in a clinic given the time to con-

nect with external agencies as part of their regular work, or is it considered non-essential work that should be done in their spare time?

The need for good coping strategies

Healthcare workers use a range of coping mechanisms to deal with the stress they face on the job. Most use healthy coping strategies such as exercising and socializing outside of work. They may discuss their concerns with colleagues or friends. Others just continue with their work and throw themselves into it even more when facing difficulties.

However, work stress is not just personal and should not be left to the individual to cope with on his or her own. A lot of the stress faced by healthcare workers can be reduced by organizational changes in the workplace.

Winsor says her work stress is manageable, in large part because her team at the BCCDC is very supportive. Her colleagues use humour in their work and are comfortable discussing their work concerns with each other. She credits both the team members and management with creating a supportive workplace. The street nurses work four-day weeks, which gives them time to relax from their work, and they participate in weekly team meetings where they plan and debrief. They attend an annual group retreat, and they are encouraged to be active in decision-making for the organization.

It is important to understand the consequences of stress and burnout—high employee turnover and the loss of experienced employees. AIDS care is a field in which its workers have specialized knowledge, where treatments change rapidly, and it is difficult to recruit new healthcare workers. The consequences of burnout in this field are potentially very serious.

There are reasons to believe that healthcare workers in this field will experience more stress and burnout in the future. The number of people diagnosed with HIV or AIDS is increasing. A general climate of fiscal constraint in Canada means budgets are being tightened or cut for some peripheral healthcare organizations. Moreover, healthcare workers are increasingly responsible for working with larger patient groups—not just HIV-positive patients, but partners, families, and friends.

Healthcare organizations must consult with their employees about what they need to manage stress and stay motivated. That could take the form of weekly debriefing meetings, in-service training on new treatments, or counselling opportunities. Private practitioners also need to be aware of their own limitations and how best to cope with their stress. Healthcare workers are valuable resources, and it is in the interest of healthcare organizations to take concrete action against stress and burnout, so they can retain their talent. ⊕



Trena White is a freelance writer based in Vancouver.

What makes AIDS care different from other forms of health care is the high degree of anxiety among patients, says Dr. Jack Forbes.



The travel bug

Planning your next trip if you're HIV-positive

by Lawrence C.



Your HIV status should not stand in the way of travel, according to thousands of HIV-positive Canadians who continue to travel the globe every year. However, horror stories concerning medication supplies and traumatic border crossings have prompted some travel industry representatives to urge HIV-positive persons not to travel at all. Yes, travel can be risky for PWAs. But good planning and a working knowledge of local and international customs and regulations usually results in a successful travelling experience.

Get information, insurance, and vaccinations

When planning your trip, find out as much as you can about your travel destination from friends and travel agents. The Internet is a great resource with hundreds of travel Web sites. It's important to know about climate, people, culture, weather, health services, food, and accommodations. Remember that the risks associated with camping, such as drinking and swimming in contaminated water and exposure to insects, are much more problematic than those associated with a luxury resort.

Hygiene standards and access to medical care in other countries may differ from those in Canada. Infectious diseases not common in Canada may be widespread in other countries. Health Canada strongly recommends contacting a travel medicine clinic or doctor six to eight weeks before departure.

Based on your individual risk assessment, a healthcare professional can determine your need for vaccinations and preventative medication. They can also advise you on precautions to take to avoid illness and disease. For a list of travel medical clinics, contact Health Canada or visit their Web site at <www.hc-sc.gc.ca>.

Make sure you have comprehensive travel insurance. Your insurance should cover HIV-related illness, accidental injury, and medication. Ideally, your coverage should allow for an emergency return flight and reimbursement for cancellation. In the past, it was difficult to find insurance for people with HIV, but now it is available. The travel newsletter *Out & About* recommends several travel insurance carriers. Visit their Web site at <www.outandabout.com>.

Some vaccines contain live virus, so consult a healthcare professional for help deciding which vaccines you should get. Yellow fever, oral polio, measles, tuberculosis, and oral typhoid are all vaccines that contain live virus. Vaccines that do not contain live virus or bacteria include tetanus, diphtheria, typhoid injection, typhoid, rabies, hepatitis A and B, polio injection, meningitis, flu, and pneumococcus. Although few vaccinations are required for entry in most countries, common vaccines such as those for hepatitis A and B, pneumococcal diseases, flu, and tetanus should be up-to-date. The risk associated with vaccinations is usually far less than the risk of contracting the disease.

Malaria is potentially life-threatening, but using anti-malarial drugs and avoiding insect bites can prevent it. Normally, these anti-malarial drugs are taken one to two weeks before travelling and continued for four weeks after returning from the trip. If you experience flu-like symptoms after returning from your trip, contact your doctor.

Ensuring safe food and water

Developing countries often pose the greatest risk of infectious disease because of poorly developed infrastructures for sewer and water services. Contaminated food and water can cause a variety of diseases such as hepatitis A and traveller's diarrhea. These problems are easy to prevent by following a few simple guidelines. Exposure to potentially infectious food and water should be avoided. In general, avoid raw fruits, salads, and vegetables, raw or undercooked seafood and meat, tap water, ice made with tap water; unsealed bottled water, unpasteurized milk, dairy products, and food and beverages from street vendors. Hot foods, bottled beverages, coffee, tea, wine, and beer are usually safe to drink when travelling.

Medication considerations

One of the most difficult aspects of travelling with HIV infection is staying on schedule with medication dosage. In order to maintain optimum benefits from antiretroviral therapy, it is important to take your medication on time with the necessary food requirements. Travelling across multiple time zones can complicate things. If possible, carry your own food and drink. When travelling from west to east, take each successive dose one hour earlier. When travelling east to west, take each successive dose one hour later until the travel destination is reached. Jet lag associated with travel across time zones may further complicate adherence to therapy. If needed, post notes in the hotel room and rental car to serve as daily reminders or invest in an electric timer. Ensure you have enough medication to last you for your entire trip. Packing a little extra wouldn't hurt.

Keep drugs in prescription containers in an inconspicuous part of your luggage. Carry one copy of your prescription with the drugs and another copy in a separate piece of carry-on luggage. If you're carrying a syringe, bring a doctor's note explaining that the injecting equipment is for your personal medical use. It could be helpful for your pharmacist to provide you with small-labelled containers that do not include the prescription monograph, as this usually indicates medication is used for HIV. Pack enough medicine in your carry-on luggage to last until you can get replacements if your luggage is lost.

If your drugs require refrigeration, a reusable ice pack and a hotel with a freezer should be all you need. In developing areas, ask before you go. Do not plan to buy ice in convenience stores as you travel. It may not be available.

Make sure you know of any possible drug interactions between your HIV medications and other drugs such as anti-

malarial drugs. Some drug interactions may increase or decrease the effectiveness of your drug regime.

Entry restrictions and travelling to the US

More than fifty countries restrict the entry of immigrants and travellers with HIV infections. While restrictions primarily affect only long-term travellers, it is wise to check with the embassy of the country well in advance of any travel. Many countries, especially in Europe, have no specific prohibitions on entry by persons who are HIV-positive. For a specific country's requirements, call the embassy or consulate, or see the comprehensive listing at <www.aegis.com/topics/travel.html>.

Unfortunately, the United States has one of the most repressive policies, which can deny entry to people who

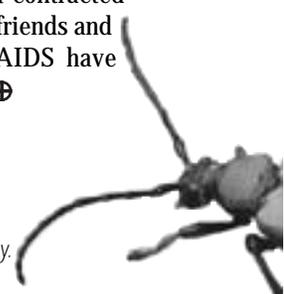
More than fifty countries restrict the entry of immigrants and travelers with HIV infections. The U.S. has one of the most repressive policies.

are HIV-positive. According to the 1996 US Immigration and Nationality Act, you cannot get a visa or be admitted to the US if you are HIV-positive: "Any alien who is determined (in accordance with regulations prescribed by the Secretary of Health and Human Services) to have a communicable disease of public health significance, which shall include infection with the etiologic agent for acquired immune deficiency syndrome...."

In practice, HIV tests are given only to those who want to stay stateside permanently. If you are HIV-positive and you want to visit the US, two specific waiver policies have been implemented. The Routine HIV Waiver Policy may be granted for admission to the US for 30 days or less to attend conferences, receive medical treatment, visit close family members, or conduct business. The Designated Event Policy facilitates the admission of HIV-positive persons to attend certain "designated events" that are considered to be in the public interest, such as academic and educational conferences and international sports events.

If you experience a fever or any flu-like symptoms after returning home, see your doctor in case you contracted an infectious disease. Otherwise, gather your friends and show off your pictures. People with HIV/AIDS have every right to fun-filled travel. Bon voyage! ☺

Lawrence C. is a member of the BCPWA Society.



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:

CARL BOGNAR, PREVENTION COORDINATOR
BCPWA 1107 SEYMOUR ST., 2ND FLOOR
VANCOUVER BC V6B 5S8

prevention@bcpwa.org FAX: 604.893.2251

by Rick Marchand

Xtra West recently ran a full-page ad telling gay men that they were at risk of getting syphilis. Although many people appreciated that resources were spent on providing this information, I also heard many criticisms that the ad could have been better.

Image:

Is this image a spoof on "gift givers" and "bug chasers"? Sometimes images can give the reader a meaning that was never intended. Paying attention to current language and trends in gay culture is an important part of creating an educational health ad.

Increasing number of cases of syphilis in BC:

What were the numbers? What was the increase? Many gay men want to know the information so that they can make informed decisions about sexual safety. I called the STD helpline but still didn't get any syphilis statistics.

Protect yourself:

Tell us how! Health campaigns need to tell the target audience what they can do about the situation. This ad does not mention the word "condom". Is that a good thing? Many older guys may know about syphilis, but what about the younger guys?

PS: Blow jobs can transmit HIV and gonorrhea:

Many who are involved in gay men's health thought that the emphasis on oral sex transmitting HIV was unfortunate. The risk of getting HIV through oral sex is low. In Canada, the emphasis has been on letting gay men know that unprotected anal sex is high risk. Yet, there haven't been any campaigns in BC on anal sex in years.

Symptoms:

The ad tells us what can happen if syphilis is left untreated. But what are the symptoms? This might help me decide if I should go to a doctor or clinic for a test.

Contact information:

It's not clear that the BC Centre for Disease Control ran the ad. The Bute Street Clinic at the Centre, mentioned in the ad, is a BCCDC program and used by many gay men for STD and HIV testing. If you phone the resource line listed in the ad, you get a nurse who has plenty of medical information, but

nothing on the size of the syphilis outbreak. Who is a credible source of information about STDs for gay men? ☎



Rick Marchand is a director of the Community-Based Research Centre in Vancouver

Charting a path for prevention

by Carl Bognar



Over the past few months, we have been rethinking prevention strategies, trying to imagine what they should look like from the perspective of HIV-positive people. This may sound like armchair philosophizing, but we need to be up-to-date on the latest literature, convey our new ideas to as many people as possible, and try to figure out what we need to do. Surprising as it is, HIV prevention has rarely considered the needs and concerns of HIV-positive people. All prevention efforts to date have been directed towards keeping HIV-negative people HIV-negative.

The newest thinking in prevention is that the issues faced by people living with HIV are clearly part of the prevention equation. BCPWA Society members, as HIV-positive people, need to be involved in helping us figure out what role the BCPWA Society should play in prevention. We are probably the largest organization of HIV-positive people in Canada, so we clearly need to hear the voices of HIV-positive people while we are developing our plans for the future.

We made our first effort to listen to HIV-positive people at a forum on prevention at the Positive Gathering in October 2002. At the forum, we asked participants to discuss situations in which they had found it difficult to practice safer behaviours. We noticed that HIV-positive people indeed reflected ideas that are appearing in the still meagre literature from other countries where positive prevention is gaining ground.

Even more interesting was participants' expressed relief at finally having the opportunity to talk about important and personal issues in a safe environment.

Promoting dialogue in *Living +*

In our effort to listen to the voices of people with HIV as we develop our positive prevention efforts, we started a regular feature in the last issue of *Living +* that will be devoted to letters, comments, and questions from our members and other readers. We look for the greatest possible participation and hope that readers will share ideas and concerns for general discussion. Anonymity will be assured.

Effective HIV prevention will not be accomplished merely by telling people what to do. While education is still an important part of prevention, the issues faced by HIV-positive people are too complex to be resolved by knowledge alone. If we accept a definition of "positive prevention" that places the concerns of HIV-positive people at the forefront, then dealing with issues such as rejection, isolation, depression, fear, illness, love, and loss becomes critical. We need to organize our thinking about what HIV-positive persons might need by working through their needs at each stage, from the time a person thinks they might be HIV-positive until the time they walk into the light.

A few programs are available to people who are newly diagnosed. This stage may be particularly perilous for the efforts to

halt the epidemic because current protocols for treating HIV may mean a lapse of several years between diagnosis and the start of treatment. Treatment is a point of connection with HIV services, as clearly evidenced by our popular Treatment Information Program. But what is going on between the time of diagnosis and the time when treatment begins? It's probable that

Effective HIV prevention will not be accomplished merely by telling people what to do.

many newly positive people are unconnected to other HIV-positive people during the period when they are feeling most at sea, lacking in the skills and personal strength and experience that are needed to navigate safely through a new life as an HIV-positive person. The epidemic just might begin to make further inroads into our communities because newly diagnosed people are disconnected from other people with HIV for a longer time than before.

Mentoring newly diagnosed people

To respond to these issues, we are considering launching a new peer-counselling program based on a mentoring system. A newly positive person would be matched with an HIV-positive volunteer who would provide guidance through that first difficult time. People with HIV prefer to receive information from others in the same situation and to have the opportunity to discuss important issues with other HIV-positive people. Professional counsellors have skills that are important for dealing

with some situations. But there is no substitute for experience when providing the kind of empathy and understanding that people sometimes need when facing difficult times. We haven't worked out the details of our new program yet, but we already know that we will need to rely on a cadre of trained volunteers to help us to deliver these services.

An insightful HIV-negative friend suggests that we should also be looking beyond—to the void that is left after we are gone. The epidemic has impacts that ripple out to those around us—our friends, families, and colleagues. These people can easily be left with feelings of loss, guilt for things not said or not done, and guilt for merely surviving.

Yet, while some support is available for grieving partners, little support is available for the thousands of others who are affected by the losses inflicted by this epidemic. Perhaps a prevention approach that includes concern for those left behind would result in a renewed dialogue about HIV in the community at large and renewed bonds between the affected and the infected. With barriers of silence broken down, genuine dialogue between HIV-positive people and the rest of the population would be much easier, and the task of prevention would be made much simpler.

We would like to know what you think about these ideas. Perhaps you have other suggestions for new programming. See page 14 for ways that you can contact us to make sure that your views are heard. ☺



Carl Bognar is the prevention coordinator for the BCPWA Society.

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

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

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

When: Tuesday, May 27

Time: 2:00 – 5:00 pm.

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

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

For more accurate results, please:

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

Have your BIA checked



TREATMENT INFORMATION
PROGRAM MANDATE &
DISCLAIMER

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

The Treatment Information Program endeavors to provide all research and information to members without judgement or prejudice. The program does not recommend, advocate, or endorse the use of any particular treatment or therapy provided as information. The Board, staff, and volunteers of the BCPWA Society do not accept the risk of, nor the 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.

Palliative care eases the pain

by Dr. Claire Talbot

The first hospices for care of the dying were established in Britain. The best known is St. Christopher's Hospice, established by Dame Cicely Saunders in 1967. When programs began in Canada in 1974, the term "palliative care" emerged as a way to emphasize the role of active treatment of distressing symptoms.

The Latin word *palliat* means to cloak or mask, thus to cover over a disease by masking its symptoms. In 1990, the World Health Organization defined palliative care as "the active total care of patients and their families by a multi-professional team when the patient's disease is no longer responsive to curative treatment." As my daughter bluntly explained to a friend, "My mum looks after people who need care but are beyond repair."

Not just for the terminally ill

Palliative care is most commonly associated with care of the terminally ill, especially those suffering from cancer, as they near the end of life. In recent years, this notion has been expanded to include the use of expert pain and symptom management at any stage of a disease. This new idea of palliative care is particularly appropriate in the management of AIDS, in which a long progression of acute illnesses can be interspersed with relatively good health. Treatments aimed at relieving pain and suffering are used in conjunction with aggressive therapies aimed at curing a malignancy or opportunistic infection.

In 1987, a working group of Canadians knowledgeable in the fields of AIDS and palliative care produced a document entitled "Caring Together." They identified the needs of AIDS patients as falling into eight categories. In order of priority, they were psychological support, interpersonal relations, service

Palliative care has been expanded to include the use of expert pain and symptom management at any stage of a disease.

delivery, symptom control, bereavement support, independent living, legal and financial issues, and respect for lifestyle, culture, and religion. Interestingly, symptom control, traditionally considered the highest need, appears fourth. Bereavement support was seen as important throughout the illness, as persons with AIDS often experience multiple losses prior to their own death. Such losses could include the death of friends or family members to AIDS, as well as the inability to work and decreasing mobility and strength.

These multiple needs are met by a team of providers including, but not limited to, nurses, doctors, social workers, physiotherapists, occupational therapists, volunteers, music and art therapists, spiritual care workers, and pharmacists.

continued on next page

Extending independent living

In the course of an illness, adjustments may need to be made in the home environment as progressive loss of function occurs. The intent is to enable independent living for as long as possible. Changes can include the provision of canes, walkers, railings in the bathroom or kitchen, or special beds. Assistance with shopping, cooking, or cleaning may be necessary. Nurses can phone or visit to review symptoms and medications. They can help to assess the best way to manage escalating situations. Also available are home visits by social workers, volunteers, physiotherapists, occupational therapists, and hospice physicians. When the burden of care becomes too great at home, "respite" hospital stays are available for one-week pre-booked periods to provide a rest for caregivers. If care at home cannot be continued, then transfer to a hospital, hospice, or other care facility can be arranged.

British Columbia now has a new drug benefit program that covers the cost of all medicines and equipment required for the management of palliative symptoms. This program is intended for use by people whose estimated prognosis is less than six months. Since drug costs are covered in hospital, this program makes it easier for people to remain at home for the end of life if that is their wish.

Symptom management and treatment

In the area of symptom management, advances are being made in the under-

standing and use of both medications and procedures to improve quality of life. The advances are backed by research and communication among the members of this relatively new field of healthcare. AIDS is a multi-system disease, and it is possible that several parts of the body will be affected and need attention at the same time.

Pain is a common symptom and can arise anywhere in the body. Treatment varies depending on its cause and location. For example, the burning nerve pain caused by infection with herpes zoster (shingles) or by pressure from a tumour can be alleviated by medications originally used to treat depression or seizures. Pain from an internal organ caused by distention or pressure may be helped by procedures to remove excess fluid or relieve obstruction. Bone pain is often helped by anti-inflammatory medications. The pain and swallowing difficulty caused by yeast infection of the mouth and esophagus require treatment with anti-fungal agents.

Narcotic medications such as morphine or hydromorphone (Dilaudid) are often used in palliative care because they offer excellent relief for most types of pain. Several types of narcotics are available for this type of use, but trial and error sampling may be required before the best medication at the best dose is achieved. Continuous monitoring is important as conditions can change from day to day. People may have several causes of pain at the same time, and each one needs appropriate assessment and intervention.

Trying to manage all symptoms

Aside from pain, other symptoms that frequently arise are nausea, breathlessness, anxiety, confusion, depression, diarrhea, constipation, lack of appetite, itching, insomnia, coughing—in short, almost anything that can happen to a body, mind, and soul as it becomes ill and approaches death. Many of these symptoms can be effectively managed, and none should be accepted as simply an expected and inevitable part of the illness. Care of the mind and soul are made easier as the body becomes more comfortable.

When planning a treatment program, it is important to ask questions. Is the cause of the symptom reversible? Is there more risk for suffering or harm from the investigation or treatment than for potential relief? What does the patient want? Where does the patient want to be? The patient and family or friends are central at all times to any decision making process.

Palliative care now forms an essential part of the spectrum of services available to people with AIDS. For more information about hospice/palliative care in your area, please contact the BC Hospice Palliative Care Association at 604.806.8821 or 1.877.422.4722. ☎



Dr. Claire Talbot is a member of the palliative care team at St. Paul's Hospital in Vancouver.

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

Up and coming

Several new antiretrovirals are being tested in people

by Paula Braitstein

Protease inhibitors

TMC 114: Researchers studied 50 patients who had failed several protease inhibitors (PIs). The patients were given TMC 114 twice a day in doses of 300, 600, or 900mg boosted by 100mg of ritonavir. For the first two weeks of the study, boosted TMC was the only new drug these patients received. HIV viral load dropped a mean of 1.35 logs in the 14 days after TMC was added. Five subjects had severe adverse events during the short study period, mostly gastrointestinal or central nervous system. One patient had an episode of hepatitis.

Fos-amprenavir: A reformulation of amprenavir that dramatically reduces the tablet volume required to achieve therapeutic exposures. The drug has been investigated in a number of different ways, including unboosted in treatment naive patients, boosted in a QD regimen, and boosted in a twice-daily regimen. The new formulation looks as effective as nelfinavir. Diarrhea and rash are the most common side effects.

Tipranavir: This drug's novel chemical structure means that it may be effective against a wide range of viruses resistant to currently approved PIs. It is now moving into phase 3 clinical development that could potentially lead to its approval.

Nucleosides

DAPD (also called amdoxovir): This drug has shown effectiveness against nucleoside resistance. A small study in 18 treatment-experienced patients examined ophthalmologic (eye) findings in patients on DAPD combined with an optimized background regimen. After 12 weeks on DAPD, average CD4 counts increased by 55 cells. Median viral load reduction at week 12 was -0.90 log. Eleven of 18 patients discontinued, five due to ophthalmologic problems (lens opacities that did not affect visual acuity), four due to virologic failure, and two who withdrew or were non-adherent.

FTC: The FTC 301 study is a randomized, double-blind, double-dummy comparative study of FTC versus d4T with a backbone of didanosine and efavirenz in 571 treatment-naive individuals. The study was stopped after an interim analysis performed on data collected through 24 weeks indicated superiority for those individuals randomized to FTC.

Entry inhibitors

Pro 542: This was a small phase 1 study of 12 people. Pro 542 is administered by IV infusion. Patients were either on no antiretroviral therapy or on stable therapy. Pro 542 has been found to be synergistic with T-20 in vitro. Overall, the mean maximal change in viral load was about -0.25 log copies/ml. In patients with advanced HIV and drug-sensitive virus, viral load reduction was about -0.5 log, and reduction was sustained for 4–6 weeks. No resistance developed.

T-1249: This was a 10-day study of 53 treatment-experienced patients who were all on an optimized background therapy, including T-20. The viral response to the new fusion inhibitor was related to the duration of prior T-20 exposure. In other words, though effective, it is cross-resistant to its sister drug T-20. Since the company is pricing T-20 at over \$20,000 per year, who knows whether T-1249 will ever make it to a pharmacy near you.

Other antiretrovirals

TNX-355: This is a truly novel drug—an anti-CD4 monoclonal antibody. TNX-355 is a humanized form of the mouse antibody 5A8. It recognizes a unique part of the CD4 and inhibits entry of HIV after it has bound to the cell. This small phase 1 study looked at 30 HIV-infected patients enrolled in five dose groups, single doses of TNX-355: 0.3mg/kg, 1.0mg/kg, 3.0mg/kg, 10.0mg/kg, 25.0mg/kg by IV infusion. All thirty patients had HAART experience and 19 of 30 were failing at study entry. Each dose, except the 0.3 mg/kg, reduced viral load. However, viral load did not rebound to baseline immediately after the single dose was administered. In the highest dose (25.0 mg/kg), mean change in viral load was -1 log by day 7 and remained at a -1 log reduction until day 21. At day 28 viral load was about -0.75 log. Apparently, the drug was well tolerated, and optimal doses are 10 and 25 mg/kg. ⊕



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



TAKING A BREAK

The benefits and risks of structured treatment interruptions

by Zoran Stjepanovic

A few years ago, researchers introduced to the world an unnamed patient from Berlin who, after a series of interruptions in his drug therapy, maintained an undetectable viral load. The Berlin Patient, as this person was called, was involved in a clinical trial for newly diagnosed patients. This individual started a triple-drug regimen and then went off HIV medication after two weeks because of a bacterial infection. After stopping medication for three days, the viral load increased. When this individual restarted therapy, the viral load became undetectable once again. Four months later, the Berlin Patient went off HIV therapy, and this time the viral load remained undetectable.

This reaction generated significant interest and study in the area of treatment holidays, or structured treatment interruptions (STIs). STIs can occur in a variety of ways: short cycle (such as seven days on/seven days off), long cycle (several months off HIV therapy), or treatment holidays (longer periods of time without HIV medication). An individual would choose structured treatment interruptions for many reasons: preventing, delaying, or reversing side effects; preventing treatment burnout or pill fatigue; or the possibility of using STIs to overcome drug resistant virus. Many studies are being conducted in this area, and people need to be fully informed of the risks and benefits of structured treatment interruptions.

What clinical trials show

When conducting clinical trials on STIs, researchers take into account a number of different factors. One of the most important questions is whether viral load goes back down to undetectable levels once therapy is restarted after a treatment holiday. If viral load does not respond to therapy after an STI, drug resistance may have occurred during the drug holiday. Another area of research is whether STIs help trigger components of the immune system responsible for fighting HIV. If STIs do help boost the immune system, it may be possible for some individuals to take longer drug holidays provided that their immune system maintains control of the virus. Clinical

Taking HIV drugs every other week may lead to fewer side effects, but a big danger is the development of drug resistance.

trials also look at whether structured treatment holidays can help alleviate side effects and how long it takes side effects to return once therapy is restarted.

Some studies have shown that individuals who had undetectable viral loads prior to a structured treatment interruption were able to bring their viral loads back down to undetectable levels upon restarting therapy. However, some people were not able to control their HIV upon restarting treatment, even though they may have had undetectable viral loads before stopping therapy. In some of these cases, individuals needed additional drugs or different drug regimens to bring their viral loads back down to undetectable levels.

Other studies have shown that structured treatment interruptions following early treatment of acute HIV have led to spontaneous control of HIV infection—stable CD4 counts and limited or no viral rebound for several months without HIV drugs. This spontaneous control occurred for a *small* number of individuals in an uncontrolled setting. These results have not been easy to reproduce in similar *uncontrolled* settings.

The current guidelines do not recommend taking antiretrovirals until CD4 counts fall between 200 and 350 cells/mL. Many people initiated therapy under previous guidelines and started anti-HIV drugs much earlier. These people may consider a structured treatment interruption, but it is imperative that they discuss this option with their doctor. Taking a treatment holiday is a big decision. You need to discuss this possibility with an HIV specialist who would take into account whether you have ever had a CD4 cell count below 200 or if you have ever had an AIDS-related condition. If you decide to stop treatment, monthly monitoring of CD4 counts and viral load levels is required for the first six months and then quarterly after that. Some individuals may develop symptoms similar to seroconversion when they stop treatment.

In one study from Boston, a group of patients began treatment soon after they were infected. When they started on a structured treatment interruption, their immune systems were boosted. Some of these patients maintained low viral loads (less than 5000 copies) in the absence of treatment. Researchers will need to follow-up with these patients for a while longer to see how long they can keep their viral load levels low without treatment.

It is still not completely known if drug holidays lasting only a few weeks or months will help prevent or reverse side effects. A few studies have found that some side effects, such as cholesterol and triglyceride level increases, can be partially limited with brief drug holidays. However, more research is needed in this area.

Structured intermittent therapy

Treatment interruptions can also occur for short periods. Some studies have shown that individuals who take HIV medications every other week may maintain virologic control for 32 to 68 weeks. For some individuals, this approach can be difficult to adhere to and success has only been demonstrated under the best possible circumstances (for example, patients beginning therapy with high CD4 cell counts and no evidence of pre-existing drug resistance). Taking HIV drugs every other week may lead to fewer side effects such as elevated cholesterol and triglyceride levels. The big danger with this kind of approach is developing drug resistance.

Two separate trials from Thailand and Spain have investigated intermittent therapy. In the Thai trial, individuals participated in one of three groups: continuous therapy (no STIs), short-cycle intermittent therapy (one week on/one week off), and CD4 cell count guided treatment (stop treatment if CD4 count >500, restart if CD4 <350). Individuals in the continuous therapy group spent 100% of the study's duration on medication. Short-cycle intermittent individuals spent 59% of the time on therapy, and those in the CD4 cell count guided group spent 33% of the study's duration on medications. The one week on/one week off group demonstrated a 40% failure rate. Researchers attribute some of this failure to drug resistance and the extensive treatment histories of patients in this group. All individuals in the CD4 cell count guided therapy group experienced virologic resuppression upon restarting therapy.

In the Spanish trial, therapy was reinitiated upon a drop in CD4 cell counts to <350 cells/mL, or an increase in viral load to >100,000 copies/mL. At the end of the 48-week trial, 43% of those who stopped therapy remained off therapy. Of the 57% who restarted therapy, all achieved resuppression, and two-thirds of them were able to reinterrupt therapy.

At the recent Conference on Retroviruses and Opportunistic Infections in Boston, studies were presented on partial treatment interruptions and their effectiveness against HIV. In this scenario, a partial treatment interruption, in which components of combination therapy that are no longer active are stopped while the rest of the regimen is maintained, may be a useful strategy for

continued on next page



some patients. One patient whose regimen consisted of abacavir, stavudine, efavirenz, and nelfinavir saw his viral load decline from 100,000 copies to 1000 copies/mL of blood. After more than a year, this individual started developing drug resistance, and experienced significant toxicities. He stopped taking nelfinavir and was still able to maintain a stable viral load. This finding was confirmed in a cohort of 15 patients.

Multiple drug resistance and STIs

Another area in which STIs could be an option is for those who have demonstrated multiple drug resistance. The rationale for STIs in this circumstance is that by taking a structured treatment interruption, wild-type virus will revert back and outgrow drug resistant variants. However, caution is critical in this area because of the conflicting results reported from clinical trials. Some studies have shown that STIs in this situation are associated with a rapid rebound of viral replication and decreases in CD4 levels. It can also take many months to regain lost CD4s. STIs are not recommended as a routine approach in the management of multiple drug resistant HIV.

Despite the intense interest in drug holidays, many questions regarding structured treatment interruptions remain unanswered. Of course, most people would prefer to take drug holidays and to not have to think about taking their medications on time, dealing with side effects, and improving the quality of their lives. But

One of the most important research questions is whether viral load goes back down to undetectable levels once therapy is restarted.

the risks, including emotional risks, are real. Some people who have been off HIV therapy and need to go back on may find it emotionally difficult. The effectiveness of using STIs to help boost the immune system or in cases of drug resistance is still being studied. Drug holidays may be an option for those who started HIV therapy early when CD4 counts were above 350, for example, but this possibility should be discussed with a doctor.

Do not take your own unsupervised drug holiday. Cases of people taking their own drug holidays have resulted in undesirable outcomes, such as CD4 cell counts plummeting, viral loads soaring, and opportunistic infections developing. In many cases, individuals have had difficulty reaching an undetectable viral load level after restarting therapy. It is imperative to talk to your doctor about treatment interruptions to see whether they would benefit you. ⊕



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

A short-sighted vision

First Ministers sign the Health Care Renewal Accord 2003

by Tony DiPede

On February 5, 2003, Canada's first ministers—the prime minister and the provincial premiers—reached an agreement about the future of Canada's healthcare system called the Health Care Renewal Accord 2003.

The Accord includes

- ▼ \$9.6 billion in new federal funding over the next three years
- ▼ a \$2.5 billion new one-time supplement to relieve existing pressures
- ▼ the establishment of a Health Care Reform Fund of \$16 billion over 5 years to ensure provision of primary care, homecare, and catastrophic drug coverage countrywide
- ▼ the introduction of a new funding mechanism called Canada Health Transfer (CHT), which will provide for predictable annual increases in healthcare funding from the federal government
- ▼ \$1.5 billion for diagnostic/medical equipment and training to improve access
- ▼ \$600 million to develop a national system of electronic patient records
- ▼ the creation of a six-week compassionate care leave benefit under EI to care for the gravely ill
- ▼ \$1.3 billion over five years for aboriginal healthcare programs
- ▼ the creation of a Health Council to report on the Accord's implementation

The federal government has provided much needed new money, but the amount falls far short of the \$15 billion recommended by Roy Romanow. The Health Care Reform Fund will fund three new programs—primary care, homecare, and catastrophic drug coverage—to ensure that all Canadians have access to them. Although the federal government should be applauded for this initiative, few conditions have been placed on the use of the money, raising the possibility that healthcare funds could be diverted elsewhere. Because the provinces have complete discretion, no hope remains for uniform national standards.

Some components of the Accord are beneficial. The creation of the CHT is very good because it ensures stable predictable funding over the next five years. The \$1.5 billion earmarked for equipment is critical to reducing waiting lists and improving access. Quality care requires access to the most advanced equip-

ment. The creation of a compassionate care benefit will provide excellent and much needed support to caregivers.

Other aspects of the Accord may cause some concern. Electronic patient records, for example, may be useful for health planning, but creating an electronic database introduces an extremely high risk of loss of privacy. The federal privacy commissioner has raised alarms about privacy protection issues. Although some money has been allocated to aboriginal healthcare programs, no real strategies are presented in the Accord to improve healthcare outcomes for Canada's First Nations peoples. The proposed Health Council will be able to report only on implementation of the Accord, not on the performance of the whole system. The Council will not report directly to Parliament; it will report to first ministers and be controlled primarily by the provinces. The provinces have consistently failed to comply with the current reporting requirements of the Canada Health Act, so it is doubtful they will deliver on this new arrangement.

So what have the first ministers really accomplished? The federal government significantly increased funding, but the amount is far less than was recommended and required. No real accountability mechanisms are mandated, and the reporting structure of the Health Council is extremely weak.

The first ministers failed to address privatization, one of the biggest threats to our public healthcare system. Allowing private operators to open clinics, provide services, or build hospitals results in higher costs to patients, helps people jump the queue on waiting lists, and diverts healthcare resources to fund profits not services.

The bottom line for people living with HIV/AIDS is the same as for all Canadians.

While our leaders have tried to give the impression that they have saved the system, they have not yet begun to do what is necessary. The fight to protect our healthcare system must continue. ⊕

Tony DiPede is a board member of the Canadian Treatment Action Council, and has been on boards of Toronto People with AIDS Foundation, Canadian AIDS Society, and the Ontario AIDS Network.



Getting over the hump

An integrated approach to lowering lipids

by Ron Rosenes

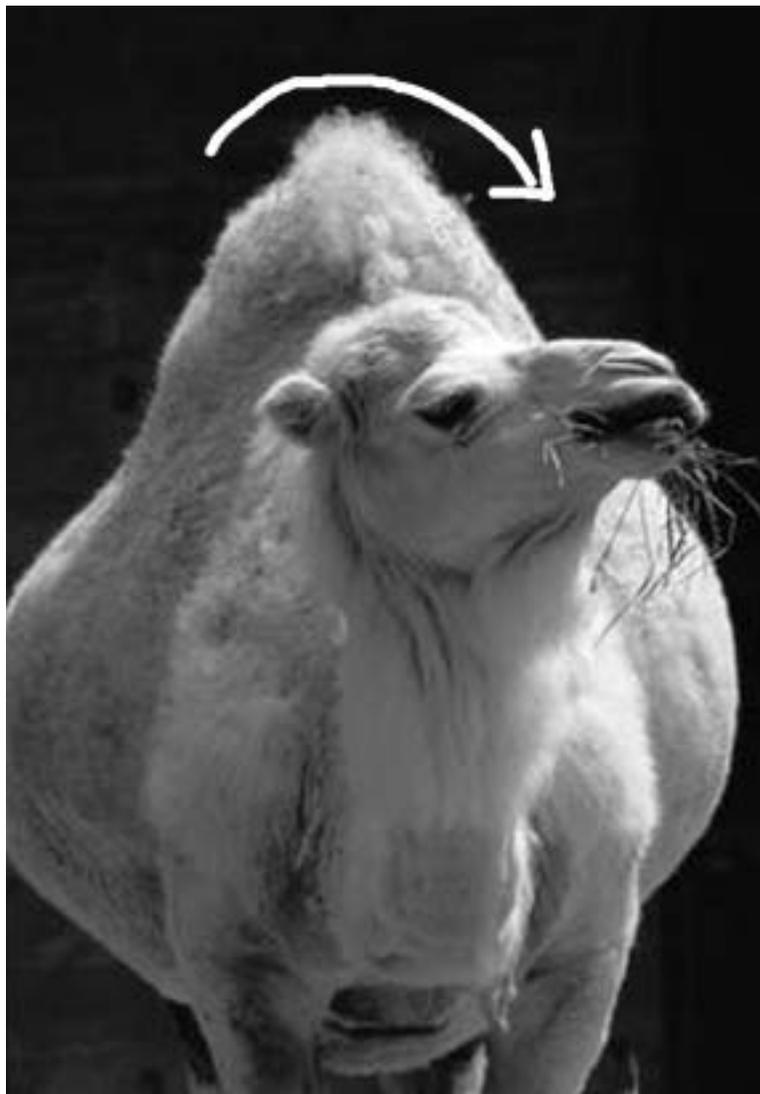
People on highly active antiretroviral therapy (HAART) have many good reasons to take an integrated approach to lowering lipids (fats) in the blood, but actually doing it is easier said than done. The recent Conference on Retroviruses and Opportunistic Infections (CROI) in Boston shed more light on this increasingly complex subject, but study findings raise more questions. Two things are clear: HAART-recipients are at increased risk for heart attack, and elevated lipids play a role, albeit poorly understood, in the syndrome called lipodystrophy.

Lipodystrophy is fat accumulation in all the wrong places, such as visceral fat deep in the belly, or the infamous “buffalo hump.” Lipoatrophy refers to the wasting of the fat layer below the skin. Some people have eroticized the lean look and popping veins that characterize fat wasting, but most of us avoid looking in the mirror, especially if we look like we could carry our change in our cheeks.

Determining the cause of the problem

Elevated lipids are just one factor underlying the metabolic disorders that may lead to lipodystrophy and lipoatrophy. The development of insulin resistance because of the body’s inability to process glucose could play a role, as could mitochondrial toxicity, or impairment of the ability of cells to produce energy and process waste material. Disruption of these metabolic processes, due in some measure to drug toxicity, appears to be linked to the underlying cause of physical alterations, but we still lack sufficient information to pinpoint specific drugs or to discount the role of HIV itself.

Several studies reported in Boston advance the discourse on the role played by elevated lipids in causing body shape changes. The D:A:D study (Data Collection on Adverse Events of Anti-HIV Drugs), a prospective observational study of about 23,500 persons with HIV infection on antiretroviral therapy, noted a 27% increased risk of heart attack for each year of HAART exposure up to seven years. That alone is sufficient inducement to lower lipids. The study identified other risks that



may outweigh HIV therapy, including age, male gender, genetics (family history of cardiovascular disease), diabetes, smoking, and alcohol consumption. Obviously, risk can be reduced by limiting tobacco and alcohol intake.

If you believe you are at risk for cardiovascular disease, bring it to your doctor’s attention. Too many heart attacks go undiagnosed because care providers were focused on the virus and not on the whole person.

Update on FRAM study

There was also an update in Boston on the Fat Redistribution and Metabolic Change in HIV Infection Study (FRAM), a study designed to find out what factors contribute to body changes experienced by HIV-positive individuals. FRAM researchers are estimating the prevalence of fat redistribution, insulin resistance, and hyperlipidemia (elevated fats) in a cross-sectional survey of 1,200 HIV-infected patients on protease inhibitors (PIs) and 300 HIV-negative subjects from another study (CARDIA) for comparison.

Preliminary findings caused a stir at the 2002 International AIDS Conference because they revealed a disconnect between the typical fat accumulation in the belly or back of the neck and overall fat wasting. Although the FRAM study appears to

unlink lipodystrophy and lipoatrophy, doctors and community people noted the difficulty of drawing this conclusion because of the limitations of the study, including the lack of data on women. Besides, the study is cross-sectional—it represents a snapshot in time and does not tell us how people got to the point where they reported on changes they had observed in themselves. That requires a longitudinal study following people over time and using objective measurements.

However, in Boston the headline on the FRAM study was that lipoatrophy is the predominant body shape change experienced by people with HIV. As more data are analyzed, it appears that, contrary to what we may think or see, subcutaneous fat loss is more significant than fat accumulation. Researchers are still evaluating data from this study.

What you can do about it

If you are contemplating antiretroviral therapy, talk to your doctor about avoiding drugs that are known to elevate lipids. Seek a regimen that offers “a good lipid profile.” If you are on HAART and have an elevated total cholesterol level, or if the proportion of LDL (the bad, lousy cholesterol) to HDL (the good, healthy cholesterol) is too high and the triglyceride level is also high, consider switching to a regimen with a better lipid profile. Encouraging news, for example, about the PI atazanavir, is that it does not appear to increase lipids. Health Canada has not yet approved it, but it can be obtained through an expanded access program.

You may not be able to remove the underlying cause of elevated lipids simply by switching regimens, and there are no silver bullets for a body fat makeover, but you can improve your heart health and achieve benefits that will enhance and extend your life. We all know this but choose to ignore it when depressed or lacking motivation. Don't give up all your vices at once, but don't be surprised when one good habit leads to another.

Choose a form of exercise that you enjoy. Try to combine weight-bearing exercise to help prevent osteoporosis and build lean body mass and aerobic exercise to build cardio-respiratory fitness. Exercise reduces cholesterol.

Choose a heart healthy diet. Eat a diet rich in fruits and vegetables. Include low-fat dairy products and foods low in saturated fat, total fat, and cholesterol. The more food is processed, the less likely it is to be heart healthy. Learn to read labels and avoid partially hydrogenated oils or margarines that contain trans fatty acids. Lean toward monounsaturated oils such as olive and sunflower.

Nuts are good. Almonds, brazil nuts, cashews, walnuts, pecans, and dry roasted peanuts are high in dietary fibre and can lower blood cholesterol.

Epidemiological studies suggest that people who consume black tea are less likely to experience heart attacks.

People who consume a lot of fish also have a lower risk of cardiovascular disease. The omega-3 fatty acids in fish are very beneficial in lowering plasma triglyceride levels. These “good” fats are also available in supplement form if you feel your intake is insufficient.

Dark honey is a good source of antioxidants, as well as a way to satisfy sugar cravings. Bee wax or polycosanol, available in supplement form, is a mixture of fatty alcohols derived from the wax of honeybees. These active substances lower cholesterol levels in several ways, including by blocking the formation of cholesterol in the liver. Polycosanol appears to have been well studied in clinical trials that have compared it with lipid lowering medications.

People are increasingly taking niacin for its ability to decrease LDL and plasma triglyceride levels. Although niacin is readily and cheaply available, it can be toxic. Some 40% of

There are no silver bullets for a body fat makeover, but you can improve your heart health and achieve benefits that will enhance and extend your life.

people are forced to discontinue it because of adverse reactions, including flushing, nausea, vomiting, pruritis, abdominal pain, and headache. Nor is it recommended for people who drink alcohol or who have diabetes, ulcers, liver damage, or gout. Another study presented at CROI suggested the risks around diabetes should not to be taken lightly, as people on long-term HAART are increasingly showing signs of glucose intolerance.

Talk to your healthcare practitioners

Talk to a nutritionist or naturopath, as well as your doctor, before starting a lipid-lowering program because mixing drugs, herbs, and vitamins can be risky. More PWAs with elevated lipids possibly related to their drug therapy are choosing to take lipid-lowering medications like atorvastatin calcium (Lipitor) in the statin class or gemfibrozil (Lopid) in the fibrates. The US National Institutes of Health Medline suggests that you take Lipitor at the same time each day and stay away from alcohol since it can compound liver damage. Medline also recommends great caution when taking niacin with Lipitor since it may increase the adverse effects of that drug on muscle and lead to kidney problems.

An integrated approach does not mean throwing the kitchen sink at the problem. It means sifting through the options, consulting your healthcare providers, listening to your body, and taking the time to discover what works for you. The integrated approach is not a panacea. It will not reverse lipodystrophy, though I believe it makes good sense to remove the underlying causes wherever possible. Gradually, you may see some improvement, though it may take as long as it took the body shape changes to occur in the first place. ⊕



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



Have faith

With spring comes a sense of renewal and hope

by Gary Paterson

Once upon a Biblical time, there was a good and righteous man named Job. Life was going well for him—family, friends, career, health. But then, out of the blue, disaster struck, and Job ended up poor, homeless, and painfully sick. That may be like hearing from your doctor that you’ve seroconverted, you’re positive, or that your T-cell count is down and your viral load is up. All of a sudden, life starts to fall apart!

Job’s friends rallied around. Although they began well, in silent, caring commiseration, all too soon they started searching for explanations—how can bad things happen to good people?—and they began to insinuate that Job must have done something wrong. It’s his fault; bad things only happen to bad people, they said. You’ve heard this before: AIDS is your fault. Sex or drugs—take your pick. “Not so!” said Job. “I may not be perfect, but I don’t deserve this. No one does!” Sometimes terrible things happen to ordinary people doing their best. It’s not a question of blame. Sometimes shit happens!

But Job could not rest here, for he was still a man of faith, albeit full of questions and doubts. And so he turned to God in anger, demanding an explanation. The human called the divine to account.

This is where the story becomes interesting, for God appeared, but not with an answer to the question “Why?” Instead, the “voice out of the whirlwind” called *Job* to account. “Who do you think you

are? I am God, the Eternal Creative Energy that moves in, through, and beyond the universe; and you—you are human dust.”

Now, that may not be much consolation, but—and I think this is the crux of the story—God *did* speak. Job may not have received answers to the questions he was asking, nor did he receive a miraculous cure or quick fix. But he had come face to face with God. And that’s enough!

The moment of human-divine encounter is, I believe, the beginning and centre of all spirituality. It is Moses approaching the burning bush; Buddha sitting under the Bo tree; Mary Magdalene being greeted by the risen Christ; Muhammad receiving the words of the Qu’ran. It is you and me, experiencing the divine breaking through the ordinary unfolding of life, reaching out to us through the “thin” places, as the Celts say, where the stuff of the universe is stretched so tightly that God’s light is able to shine through—thin places and people and events, in which the sheer wonder and grace of life catch us up out of ourselves into a new awareness of divine mystery. These are the moments when the “Why?” of AIDS is put aside and the gift of God’s presence is enough.

When such moments occur, our awareness shifts from despair and defeat to gratitude and trust. Even in the midst of illness, life should be savoured in the small moments of blessing: a good night’s sleep; a finch singing outside the window; morn-

ing coffee; the yellow trumpeting of daffodils; the warm voice of a friend; a lover's touch. The more things we can give thanks for, says Robert Bly, the stronger we are. Even as we live with HIV, we have room for much gratitude.

Further, such moments of radiance invite us to live our days with a new trust, recognizing this trust as the true meaning of faith, whose opposite is not unbelief, but fear. Trust that we are accepted; that we are embodied sparks of the divine, made in the image of God; that

Even in the midst of illness, life is to be savoured in the small moments of blessing. Even as we live with HIV, there is room for much gratitude.

"neither death, nor life...nor things present, nor things to come, nor powers, nor height, nor depth, nor anything else in all creation, will be able to separate us from the love of God..." (Romans 8:38-9).

The American poet Mary Oliver said it well:

To live in this world
you must be able
to do three things:
to love what is mortal;
to hold it
against your bones knowing
your own life depends on it;
and, when the time comes, to let it go,
to let it go.

(from "In Blackwater Woods")

All humans must learn these tasks: to love and to let go, to know gratitude and trust. Those living with AIDS are simply

forced to wrestle with this challenge more immediately. Illusions are fewer. Time is more precious. So often it is our poets who help us understand the wonder of grace, the fierce whirlwind voice, and the all-encompassing love of God. Listen to these words from May Sarton:

I am not ready to die,
But I am learning to trust death
As I have trusted life.
I am moving
Toward a new freedom
Born of detachment,
And a sweeter grace—
Learning to let go....
I turn my face toward the sea.
I shall go where tides replace time,
Where my world will open to a far horizon
Over the floating, never-still flux and change.
I shall go with the changes;
I shall look far out over golden grasses
And blue waters....
Praise God for His mercies,
For His austere demands,
For His light
And for His darkness.
(from "Gestalt at Sixty") ⊕

Rev. Gary Paterson is the minister at Ryerson United Church. He and his spouse, Tim Stevenson, have offered spirituality workshops with the BCPWA Society for several years. The next workshop is scheduled for spring 2004.

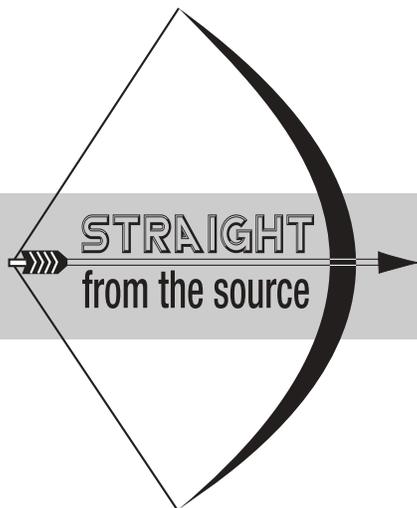


20th Annual International AIDS Candlelight Memorial & Vigil

8:00 PM, Sunday, May 25, 2003
Alexandra Park, Vancouver, BC
(across from English Bay)

www.aidsvigil.ca

candles supplied



what's new in research

A closer look at methadone maintenance

by Magdalena Piaseczna

Research shows that no single treatment or harm reduction strategy holds the key to resolving all the issues associated with injection drug use. Methadone maintenance treatment for opiate-dependent persons has been a viable harm reduction strategy since the 1970s in BC. Perhaps it is because methadone has been prescribed in BC for over 30 years that research in this area has faded.

Recently, however, data from the Vancouver Injection Drug Users Study (VIDUS) were analyzed to obtain a better understanding of current issues in methadone maintenance treatment. Previously gathered qualitative data from this cohort suggested that patients were often dissatisfied with their methadone treatment. The VIDUS data were used to conduct two studies that assessed the role of patient reports of dose adequacy on prescribed methadone dose and on treatment outcome.

Results from the first study showed that methadone doses in Vancouver are on average higher than in most clinics around the world, with an average dose of approximately 95mg per day. Patients' perceptions of dose adequacy were highly associated with the methadone doses that were prescribed. Unexpectedly, patients who reported that their methadone doses were too high had the lowest doses, while those who reported that their doses were too low were being prescribed the highest doses in this cohort. Although further data are needed to fully understand these results, methadone patients who feel that their doses are too low may require even higher doses. Their methadone prescribers, however, may be hesitant to raise doses higher because of dated attitudes towards methadone dose limits.

Results from the second study went a step further and analyzed the effects of dose dissatisfaction on HIV risk behaviours to determine whether dose satisfaction directly affected HIV risk behaviours such as injecting heroin and cocaine, borrowing and lending needles, and using condoms inconsistently. Results from these analyses showed that although crude methadone dose had inconsistent effects on these behaviours, dose satisfaction had predictable effects. Compared to those who reported they were satisfied with their dose, those who reported that their methadone dose was too low injected heroin more frequently and used condoms less frequently with regular partners.

By contrast, those who reported that their doses were too high used condoms more frequently with both casual and sex-trade partners. These results show that decreasing the prevalence of several HIV-risk behaviours may be contingent on maintaining higher methadone doses in those who request that their dose be raised.

Although VIDUS gathers limited data in the area of methadone dose satisfaction, these preliminary studies demonstrate the importance of patient satisfaction in methadone treatment. The above studies support the benefits of methadone treatment but suggest that issues may arise from differential implementation of this treatment, resulting in differential satisfaction with dose and, consequently, differential effects on important HIV-related outcomes. ⊕

Magda Piaseczna is a second-year Master's student in the department of Health Care and Epidemiology at the University of British Columbia.



Trial shows Canada ready to test vaccines

by Jim Boothroyd

Canadians have reason for hope despite last month's announcement of disappointing preliminary results from the international AIDSVax trial.

The international trial found that the vaccine failed in its main objective of protecting people from HIV infection. The study sample of 5,108 gay and bisexual men and 309 women at high risk of HIV infection in Canada, the US, and the Netherlands received seven injections of either the HIV protein formulation known as AIDSVax or a placebo.

No statistical difference occurred, however, between the proportion of volunteers who received the vaccine but became infected with HIV anyway and those who received the placebo and became infected: 5.7% of those on vaccine; 5.8% of those on placebo.

While the vaccine received a failing grade, Canadian sites outperformed all others in recruitment, taking just two months in 1999 to enroll 292 volunteers.

"The community of people at risk of infection understood the importance of the trial and showed great enthusiasm," said Dr. Michael O'Shaughnessy, national co-director of the Canadian HIV Trials Network. "Canada has shown that it is able to contribute significantly to vaccine trials and be a major player in future research."

New Canadian prophylactic and therapeutic vaccines are not expected to be ready for testing for at least three to four years.

When they are, however, the CTN will be in on the action. The Network has forged a partnership with CANVAC (Canadian Network for Vaccines and Immunotherapeutics) to test vaccines and immunotherapies developed by laboratory researchers.

The Canadian investigators were Dr. Robert Hogg and Dr. Julio Montaner in Vancouver, Dr. Ken Logue in Toronto, and Dr. Jean Vincedelette in Montreal.

Nevirapine equal to efavirenz

Nevirapine (Viramune) is as potent as efavirenz (Sustiva) in reducing the amount of HIV in the blood and restoring the immune system, according to results published last month from a major international trial.

The "2NN" trial compared the efficacy of the two most widely used non-nucleoside reverse transcriptase inhibitors (NNRTIs). Results published in February show that treatment failure was similar among the efavirenz and nevirapine arms of the trial.

Sponsored by Boehringer Ingelheim, the results of this trial also suggest that nevirapine either once daily or twice daily is a reasonable alternative to efavirenz. Dual non-nucleoside use, however, appears to offer no advantage.

The Canadian investigators were Dr. Julio Montaner and Dr. Brian Conway of Vancouver. ☎



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

CTN trials enrolling in BC:

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

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

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

CTN 169 — DAVE: D4T or Abacavir plus Vitamin Enhancement
BC site: St. Paul's Hospital, Vancouver

P 175 — Nevirapine to Lower Cholesterol (SCHMALTZ) Trial

BC site: St. Paul's Hospital, Vancouver

P 177 — Nucleoside Sparing Trial

BC site: St. Paul's Hospital, Vancouver

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

How sweet it isn't

Insulin resistance and managing blood sugar

by Diana Johansen

The metabolic complications associated with HIV infection have been attributed to the toxicity of antiretroviral medications and often occur in people who are having a good response to treatment. This constellation of metabolic disorders has been compared to Syndrome X, a poorly understood condition that affects many North Americans regardless of HIV status. Syndrome X includes symptoms similar to those experienced in HIV infection, such as high triglyceride levels, insulin resistance, high blood pressure, and accumulation of abdominal fat. No consensus exists regarding treatment of Syndrome X other than to lose weight, exercise, and quit smoking.

One theory in HIV research is that fat accumulation, high triglyceride levels, and glucose intolerance (high blood sugar levels) are caused by insulin resistance. Several studies have shown that the incidence of diabetes in HIV-infected people is growing and that it is significantly higher than in HIV-negative populations.

Insulin is the key to unlocking the glucose receptors on cells. It is produced by specific cells in the pancreas and released into the bloodstream in response to glucose in the blood. Glucose is the major fuel for cells and must get inside the cell through these receptors to do its work.

Measuring insulin resistance

Insulin resistance is a condition in which insulin is still being produced, but the cells are not responding to it—the key no longer fits into the lock. When glucose cannot get into the cells, they become starved for energy, which makes a person feel tired. Diabetes is diagnosed when this condition progresses to the point where blood glucose is higher than normal. Insulin has a role in regulating fat metabolism and a malfunctioning insulin response will also affect serum triglyceride levels.

Although measuring glucose in blood and making a diagnosis such as diabetes is straightforward, it is more difficult to measure insulin resistance when the blood sugar is normal. Normal insulin sensitivity is complex and varies widely based on factors such as age, ethnicity, and obesity. The most precise techniques to measure insulin are invasive, time consuming, and not

very practical. The gold standard is the hyperinsulinemic-euglycemic clamp. Insulin is infused into one arm and glucose is infused into the other arm, both by IV. Numerous blood samples are taken and measured.

Other similar tests involve infusing insulin with or without glucose and doing a series of blood measurements. These tests give a good idea of insulin sensitivity, but few people would want to go through these procedures and few labs are equipped to conduct them. Simpler tests include fasting insulin, a simple glucose to insulin ratio, and a homeostasis model assessment (HOMA) calculation of fasting insulin and glucose. In practical terms, these tests are rarely done except in research settings. Rather, assumptions are made based on the clinical presentation of symptoms of insulin resistance, such as high blood sugar levels, high triglyceride levels, and abdominal fat.

Diabetes and its treatment

Diabetes is diagnosed when fasting blood sugar is above 6.0. When food is eaten, it is digested in the stomach and small intestine. Small particles of sugars, proteins, and fats are absorbed through the intestinal cells into the blood stream where they are transported to the liver for processing. The sugar in the blood goes up, insulin is released, the sugar is taken into cells, and then the sugar in the blood goes down. There is a predictable concentration of sugar in the blood at fasting, one hour, two hours, and three hours after eating. If the sugar stays too high, it has to be cleared by the kidneys, which causes frequent urination and increased thirst. It is very important to keep blood glucose levels close to normal because high levels of glucose over time can damage very small blood vessels in the eyes, kidneys, and nerves. People with diabetes are also at much higher risk of developing heart disease.

Type I diabetes usually occurs in childhood or early adulthood and develops when the pancreas no longer produces insulin. Type I diabetes is treated with insulin injections and diet therapy.

In Type II diabetes, insulin is produced but does not work properly. It occurs most often in adulthood and is the usual type



of diabetes in HIV infection. Type II diabetes is linked to obesity, especially abdominal obesity. Strong genetic predispositions are associated with increased risk of diabetes. Canadian First Nations and African-American peoples are at high risk and having a family member with diabetes increases the risk.

Type II diabetes is treated first with diet, exercise, and weight loss. How well these strategies will work in HIV-infected individuals on antiretroviral medications is unclear. Sometimes insulin sensitizing medications, such as metformin (Glucophage) or rosiglitazone maleate (Avandia), are prescribed to make insulin work more effectively. In severe cases, insulin may be required.

Improving blood sugars through diet and exercise

Diet and exercise are always part of treatment for diabetes, regardless of type, severity, or cause of the high blood sugar levels. Because what we eat and how we use it is so intricately related to blood sugars and insulin levels, dietary intake profoundly affects blood sugar. Carbohydrates affect the blood sugar directly, whereas proteins and fats have a more indirect role in controlling the rate of digestion and absorption of carbohydrates. Carbohydrates include foods made from grain, such as breads, cereals, flour, pasta, and rice, as well as fruits, vegetables, and sugars. Milk and yogurt also contain carbohydrates in the lactose. Carbohydrates have a glycemic index, which is a measure of how fast the particular food will raise blood sugar.

One would naturally think that white sugar would have the fastest effect, but this is not so. In fact, potatoes have one of the highest glycemic indexes. Some experts recommend eating carbohydrates that have a low glycemic index, but many studies have shown that when carbohydrates are eaten as part of a mixed meal, the glycemic index loses much of its effect.

The current thinking is to count carbohydrates. In other words, have two to four servings of carbohydrate foods at each meal, depending on how many calories you need, and one to two servings for a snack. The key is to know which foods to count

and to be careful about serving portions, which are generally quite small. Fibre improves blood sugar control, so emphasize whole grains, fruits, and vegetables as the bulk of carbohydrate-containing food.

It might seem as if the best strategy would be to avoid carbohydrates altogether if they create problems. But carbohydrates provide the best fuel for cells, especially the brain, so we

Studies reveal that the incidence of diabetes in HIV-infected people is growing, and that it is significantly higher than in HIV-negative populations.

require a constant supply throughout the day. Because diabetes increases the risk of developing heart disease, a diet low in fat, especially saturated fat, is also recommended.

Exercise, particularly after a meal, will bring down blood sugar. Aerobic exercise such as walking is best.

Most HIV-negative people who get Type II diabetes are overweight. Obesity increases insulin resistance, and weight loss will usually improve blood sugar levels. Not all HIV-positive people with diabetes are overweight, and care must be taken not to lose too much weight when adjusting the diet for diabetes.

Managing diabetes in HIV infection is complex because of the many nutritional issues that can present simultaneously. A diabetes education centre and personalized nutrition plan from a registered dietitian will ensure good nutritional status and improved control of blood sugar levels. ⊕



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

The shape of the problem

Body image and eating disorders are a threat to immune systems

by Sarah Fielden

Along with other possible nutritional issues, HIV-positive people may be dealing simultaneously with eating disorders and body image concerns. Food takes on many meanings in people's lives and eating patterns can become destructive rather than nourishing. Eating disorders and body image emerge through our interactions with the world around us, and these interactions shape our feelings, our sense of self-worth, our coping strategies, and our health-related activities. In recent decades, eating disorders and body image problems have been increasingly recognized as a health concern.

Body image is a complicated concept that deals with what you think, feel, and do with respect to your body's shape, size, and form. Maintaining a positive body image can be especially difficult with HIV because of the weight fluctuations and fat redistribution that may occur. With lipodystrophy, people experience changes in physical appearance, so body image problems are a primary concern. Discrepancies between how you look and how you think you ought to look may give rise to body image dissatisfaction and disordered eating behaviours.

Eating disorders affect both men and women

Clinical eating disorders are severe disturbances in eating behaviours that can seriously compromise a person's physical and psychological health. The prevalence rates for anorexia and bulimia range from 5% to 10% of women and approximately 1% of men. Physical dangers of eating disorders may include rotten teeth, loss of bone density, physical weakness, kidney and heart damage, and death. Psychological problems related to or resulting from eating disorders include depression, guilt, shame, low self-esteem, moodiness, social withdrawal, perfectionism, and rigid all-or-nothing attitudes.

People with anorexia nervosa have an intense and irrational fear of body fat and weight gain even when they become noticeably underweight. They have a distorted body image, and they refuse to maintain a normal weight. Anorexia may result in irregular periods in women.

People with bulimia nervosa get into dangerous binge-purge

cycles. They can rapidly consume huge amounts of food—sometimes as many as 20,000 calories during a binge—and then compensate by repeatedly vomiting, excessively exercising, using laxatives and/or enemas, and skipping meals or dieting. They may be any weight and feel out of control when they eat. People with bulimia are excessively concerned with body shape and weight and tend to keep their eating behaviours very secret.

People with binge-eating disorder, otherwise known as compulsive overeating, will engage in behaviours similar to those of bulimics but without the compensating mechanisms. Like bulimics, they will feel out of control about eating and usually have feelings of guilt, disgust, and depression.

Beyond issues of body image, eating disorders can fulfill many needs in people's lives. A February 1998 bulletin from the National Eating Disorder Information Centre noted a long list of results that people derive from their eating disorders, including feelings of self-soothing; praise; admiration; attention and support; keeping the family or a relationship together; safeguarding against failure; avoidance of sexuality, memories, and feelings; and maintenance of a sense of control.

Warning signs of eating disorders

People can have degrees and combinations of eating disorders. Eating disorders and food and weight preoccupations are often



viewed on a continuum. You do not have to have a medical diagnosis of anorexia, bulimia, or binge-eating disorder to have your life disrupted by concerns about food, weight, and shape.

Some of the common signs of disordered eating include

- ▼ denial of hunger
- ▼ binge-eating and/or fasting
- ▼ noticeable weight loss or frequent weight fluctuations
- ▼ intentional vomiting to purge food
- ▼ excessive concern with weight, calories, food, and appearance
- ▼ distorted body image and feeling “fat”
- ▼ abuse of laxatives, diuretics, emetics, or diet pills
- ▼ excessive exercising
- ▼ unusual eating and food elimination habits
- ▼ social withdrawal
- ▼ perfectionist tendencies and over-sensitivity to criticism
- ▼ eating in secret
- ▼ guilt or shame about food and exercise

Immune systems compromised by poor nutrition

The body needs nutrients to develop and function normally. Eating behaviours such as dieting and eating disorders that disrupt regular patterns of food intake can have negative repercussions in all aspects of wellness. Everyone needs between 1200 and 4000 calories, depending on weight, activity levels, and health status. More importantly, everyone needs to eat enough to meet his or her own requirements.

Maintaining a positive body image can be especially difficult with HIV due to weight fluctuations and fat redistribution.

Consuming an adequate number of calories from various food sources is necessary to maximize overall health, especially HIV-positive people, whose immune systems can be rapidly compromised by poor nutrition. Nutrition deprivation or irregularity can not only starve the body and brain of energy but also cause a person's metabolism to slow down in order to conserve its energy stores. Limiting food can cause loss of key essential nutrients, such as vitamins, minerals, and antioxidants, and can contribute to a loss of bone density.

The following is a list of nutritional tips to prevent disordered eating and encourage normalizing eating.

- ▼ Eat breakfast. Breakfast is especially important. Breakfast foods tend to be high in nutrients such as vitamins, minerals, and fibre. Eating breakfast sets the tone for the rest of the day by ending your nighttime fasting and by preventing bingeing later in the day when hunger becomes uncontrollable.
- ▼ Eat three meals a day at regular times. Space out your meals

and snacks throughout the day, and try not to skip meals. Your body may not have a normal hunger reaction at first, so you may need to make yourself relearn normal eating patterns by eating at specific times rather than when you are hungry. Planning and preparing your meals ahead of time can help you to avoid getting hungry and resorting to consuming foods associated with guilt.

- ▼ Remember that all foods can fit into healthy eating. There are no good or bad foods. All foods contain nutrients that your body can use. When we label foods “bad,” people may unnecessarily restrict their food and create rigid food rules. A useful exercise is to write out your food rules in a list (such as, I will not eat ice cream) and slowly work on breaking your rules when you feel ready.
- ▼ Make eating a notable event. To begin to improve your relationship with food, approach meals as special events. Take time away from distractions to sit down, eat slowly, and savour the smells, tastes, and textures of your food.
- ▼ Refer to Canada's Food Guide. Canada's Food Guide can help you figure out the quantities and types of food that your body needs to function and be healthy. Viewing foods in terms of food groups rather than as calories and fat may help you to adopt healthy eating patterns.

The road to recovery

Just as there are no simple causes of eating disorders, there are no simple cures. Recovering from an eating disorder is a long process that requires professional guidance in normalizing eating behaviours, strengthening coping skills, enhancing body image and self-esteem, and dealing with past issues of conflict or abuse. The best treatments use a variety of different health professionals and approaches. People with eating disorders require intensive, specialized treatment and need to seek professional services as soon as possible.

Many community resources are available to help support people with disordered eating. Programs, support groups, personalized counselling, and educational materials are available for everyone: young people and adults struggling with body image problems and disordered eating; people in the acute stages of eating disorders; survivors of eating disorders; and families, partners, and friends affected by eating disorders. As well, services are available that address body image, eating disorder symptoms, and self-esteem. Two great places to find referrals and information are the Eating Disorder Resource Centre of BC (tel: 604.806.9000 in Vancouver, toll-free in BC: 1.800.665.1822) and the National Eating Disorder Information Centre (<www.nedic.ca>, toll-free: 1.866.633.4220). ☎



Sarah Fielden is an MSc student at UBC and a member of Vancouver Dietitians in AIDS Care (VDIAC).

Understanding liver biopsies

by Paula Braitstein

A liver biopsy is the most accurate way to determine the extent of liver disease, including fibrosis and cirrhosis. In a liver biopsy, the physician examines a small piece of tissue from your liver for signs of damage or disease. Liver biopsies can help detect cancer, infections, the cause of an unexplained enlargement of the liver, or reasons for abnormal liver enzymes that have been detected in blood tests. They can also help diagnose several liver diseases.

Preparing for a biopsy

Before scheduling your biopsy, the physician will take blood samples to ensure your blood clots properly. Be sure to mention any medications you take, especially those that affect blood clotting, such as blood thinners. One week before the procedure, you must stop taking aspirin, ibuprofen, and anticoagulants.

Advise your healthcare provider of any drug allergies you may have, medications you take, bleeding problems, and pregnancy. You will need to sign a consent form.

Don't eat or drink anything for eight hours before the biopsy. Plan to arrive at the hospital one hour before the scheduled time of the procedure. Your physician will tell you whether to take your regular medications during the fasting period and may give you other special instructions.

The procedure

A liver biopsy is minor surgery, so it is done at the hospital. During the procedure, you will lie on a hospital bed on your back with your right hand above or under your head. After marking the outline of your liver and injecting a local

anesthetic to numb the area, the physician makes a small incision in your right side near your rib cage. With the patient holding his/her breath, the biopsy needle is inserted quickly into the liver and withdrawn, which takes only a second or two. Suction through the needle, applied via an attached syringe, causes a small piece of liver—the biopsy—to be pulled into the needle and cut off from the rest of the liver. Other types of biopsy needles have a spring-loaded cutting mechanism to obtain the liver tissue without the use of the syringe suction. In some cases, the physician may use an ultrasound image of the liver to help guide the needle to a specific spot.

You will need to hold very still so that the physician doesn't nick the lung or gallbladder, which are close to the liver. The physician will ask you to hold your breath for 5 to 10 seconds while putting the needle in your liver. You may feel pressure and a dull pain. The entire procedure takes about 20 minutes.

Recovery and possible complications

After the biopsy, the physician will put a bandage over the incision. You must lie on your right side, pressed against a towel, for one to two hours. The nurse will monitor your vital signs and level of pain.

You will need to arrange for someone to take you home from the hospital since you won't be allowed to drive after having the sedative. Go directly home and remain in bed—except to use the bathroom—for 8 to 12 hours, depending on your physician's instructions. Avoid exertion for the next week so that the incision and liver can heal.

A stinging pain will accompany the anesthetic needle and the injection of the anesthetic. The biopsy needle may be felt as a deep pressure and dull pain, sometimes felt in the shoulder, which is a result of irritation of the diaphragm muscle. This pain should disappear within a few hours or days. The level of discomfort may vary at the site of the biopsy, especially after the effect of the anesthetic wears off. Most patients have minimal pain, but some require medication for pain, which lasts up to a few hours. Your physician may recommend that you take Tylenol, but you must not take aspirin or ibuprofen for the first week after surgery. These medicines decrease blood clotting, which is crucial for healing.

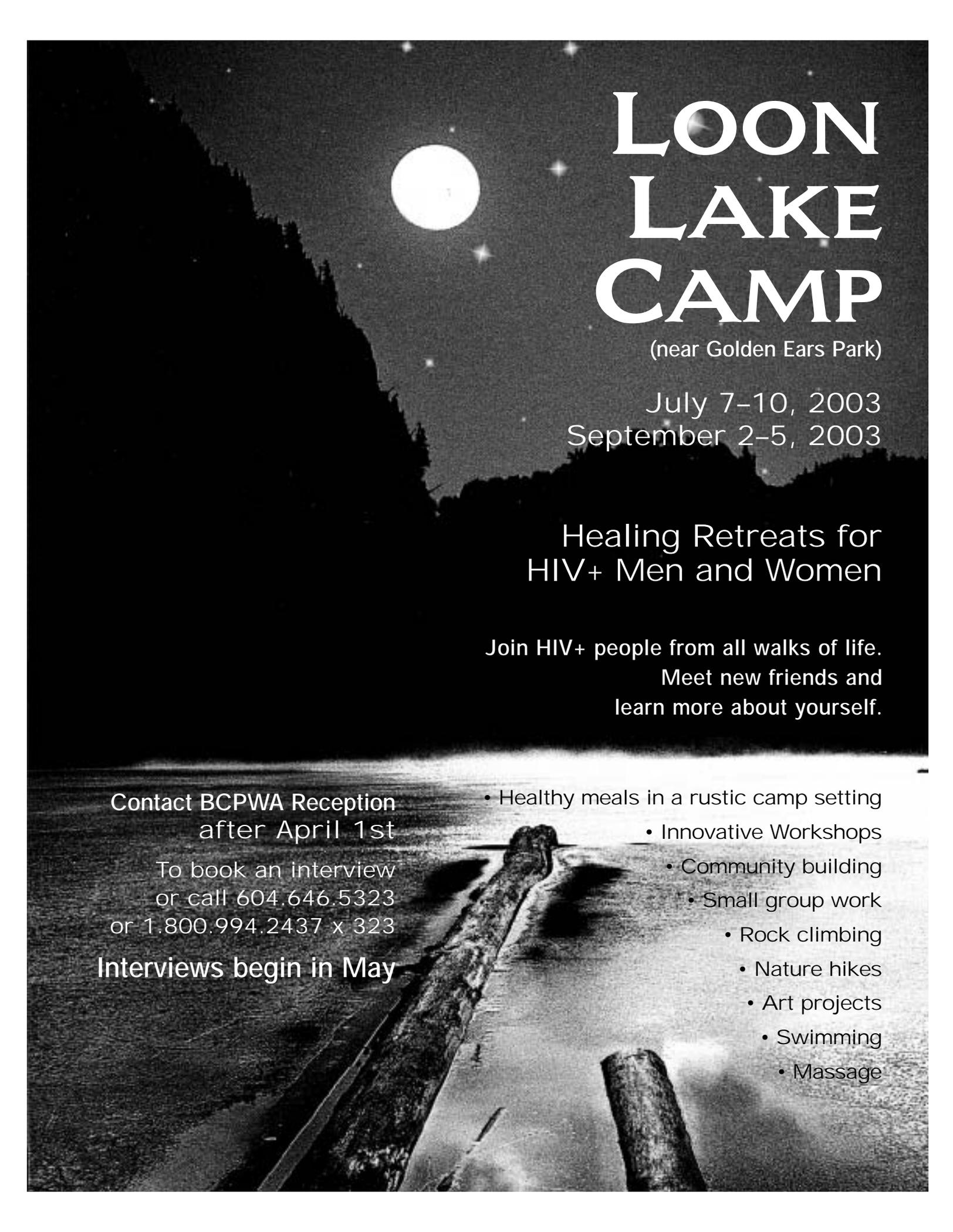
The most common complication of liver biopsy is bleeding from the liver at the site of the biopsy. The bleeding usually is not heavy enough to require blood transfusions. In rare cases, the bleeding may not stop and surgery is required to stop it.

Some biopsy statistics:

- ▼ risk of pain, 1 in 30
- ▼ risk of serious bleeding, 1 in 1,000 to 1 in 3,000
- ▼ risk of death, 1 in 10,000 to 1 in 17,000.

Risk of death in the past tended to occur in patients with cirrhosis and with the use of a larger biopsy needle. With ultrasound guidance, pre-biopsy group and screen, and smaller needles, death from bleeding shouldn't occur. ⊕

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



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Adolescencia; sexualidad mitificada

por Sergio Plata



El respeto a los derechos humanos y de la desigualdad de las personas es una determinante necesaria para promover con claridad e intensidad el bienestar humano, y en tiempos de VIH/sida, la educación sexual de los adolescentes es responsabilidad de las instituciones sociales y de las personas, incluyendo a la familia.

Uno de los problemas que enfrentan los padres con sus hijos es el contenido y la forma para abordar de forma clara su sexualidad, muchas veces las ideas conservadoras y moralizantes de los padres consideran que los adolescentes son incapaces de tener deseos sexuales y mucho menos ejercerlos con responsabilidad en un contexto real y concreto.

En nuestra cultura **la sexualidad de los jóvenes es administrada y controlada como un asunto de riesgo**, banalizando y vulgarizando los impulsos sexuales como reflejos de su inmadurez emocional. Es este un modo de pensamiento

En tiempos de VIH/sida tenemos que ser radicales desestigmatizando la sexualidad y el VIH/sida.

que por desgracia mistifica la sexualidad de los adolescentes como una experiencia precaria en su capacidad mental y física, marcando un modelo verdadero únicamente desde la biología, sin tomar en cuenta el proceso personal de cada joven, de su cultura, raza y género. No es lo mismo hablar de sexualidad de un adolescente de 16 años que vive en la ciudad de Sydney, Australia a otro que vive en un área rural en Chile, y tampoco es lo mismo la sexualidad de un muchacho heterosexual.

En muestras realizadas, la mayoría de los jóvenes prefieren no hablar de su sexualidad con los padres por temor a ser reprimidos y mucho menos hablar de su placer sexual y deciden guardar silencio. En tiempos de VIH/sida tenemos que ser radicales desestigmatizando la sexualidad y el VIH/sida.

¿Cómo abordar el tema de VIH/sida, de la sexualidad, del embarazo, de las enfermedades de transmisión sexual y del placer de la carne? si es la familia la que condena la sexualidad de los jóvenes. ¿Cómo entender sus necesidades si es el



conservadurismo y la intolerancia de la familia la que cuestiona su expresión sexual e inhibe el cuidado de su salud?

Con mil preguntas sin respuesta muchos jóvenes ejercen su sexualidad en secreto y en silencio, aprendiendo a jugar al sexo clandestino. La sexualidad de los adolescentes es una verdad y es a partir de una forma real y no formal la manera de conceptualizar dicha sexualidad. ⊕

BCPWA Treatment Information Program (TIP)

Ofrece información sobre tratamientos del VIH/SIDA.

Todos los miércoles 1:00PM a 5:00PM.

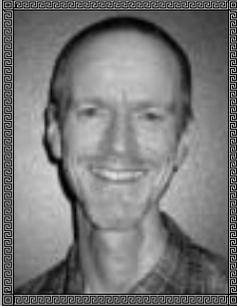
1107 Seymour Street, 2nd Floor, Vancouver, BC V6G 5S8

Llame a la línea directa: 604.893.2243

email: treatment@bcpwa.org

Volunteering at BCPWA

Profile of a volunteer:



"Dave's calm, intelligent, and thorough approach has given BCPWA a solid foundation on which to build prevention activities that genuinely meet the needs of all our members."

Carl Bognar
Prevention Coordinator

Dave Boyak

Volunteer History

I have volunteered for many non-profit organizations in Vancouver and Calgary. Currently I am the chair of BCPWA's Positive Prevention Standing Subcommittee. I'm a former member of BCPWA's Collective Advocacy Committee, Project Talk Confidentiality Policy Committee, Governance Structure Committee, and former chair of a Schedule C Subcommittee.

Started at BCPWA?

I started volunteering with the Collective Advocacy Committee in the spring of 2000, and was consequently invited to participate in other committees.

Why pick BCPWA?

I've admired the work that non-profit organizations offer to their specialized communities while often coping with limited resources. BCPWA is a unique society which attracted my interest, and which I can offer my skills and experience.

Why have you stayed?

Volunteering with BCPWA gives me a great opportunity to meet nice people, learn how a provincial society operates, and get involved in a complex environment of health and advocacy issues.

Rating BCPWA

BCPWA is a great organization to get involved with and express one's concerns and views.

Strongest point of BCPWA

The dedication of all the volunteers, and the persistence in achieving goals when most organizations would have long ago abandoned them.

Favourite memory

The special occasions that the board has invited me to attend have been most appreciated and will be fondly remembered.

Future vision for BCPWA

A healthy, happy life and future for all PWAs without the stigma.

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

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- law and advocacy skills, or
- research and writing skills, and
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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)

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

North Island AIDS (Courtney)

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

North Island AIDS (Port Hardy)

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

Okanagan Aboriginal AIDS Society

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

Box 4368 Smithers, BC V0J 2N0
3731 1st Ave, 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
April 2, 2003	1:00	Training Room	Written Executive Director Report / Standing Committee
April 16, 2003	1:00	Training Room	Director of Fund Development
April 30, 2003	1:00	Training Room	Quarterly Department PHSA Report / Written Executive Director Report/ Executive Committee / Financial Statements—March
May 14, 2003	1:00	Training Room	Standing Committee
May 28, 2003	1:00	Training Room	Written Executive Director Report/Director of Treatment Information & Advocacy / Financial Statements — April
June 11, 2003	1:00	Training Room	Executive Committee / Director of Communications & Education

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

For more information, contact:

Alexandra Regier, Office Manager

Direct: 604.893.2292

Email: alexr@bcpwa.org

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postal code/zipcode _____ country _____

phone _____ fax _____ email _____

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

Cheque payable to BCPWA



www.bcpwa.org

living+

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



Colour-coded fear

Know when to push the panic button

by Denise Becker

Those of you who have seen Michael Moore's documentary, *Bowling for Columbine*, will know that the movie looks at the American way of life and probes the issue of gun control. Moore aptly explores the reasons for the massive numbers of gun related deaths in the U.S. and disproves reasons such as culture, history, music, movies, and video games. What he leaves us with is a realization of what fear can do to our psyche. It is a profound movie, and everyone should make time in his or her life to see it.

Since watching the movie, I have been very mindful of when my fear has become irrational and have been somewhat surprised to discover that people have actually been afraid of me. Recognition of the U.S. government and its unsurpassed status as the number one fear monger in the world, I have categorized fear in three colour-coded "stages of heightened alert."

Not-so-red alert: phobia

This is not a fear, per se, but is better categorized as a phobia. I usually display this as a fear of heights and a fear of bears. Just putting me up on the 23rd floor of a building reinforces my phobia; I know that, at some point during the day, I will magically be magnetized towards the window and will duly be sucked off the edge to my doom.

Unfortunately for PWAs, many people treat AIDS in the same way. Yes, my friend, to them we are all walking, talking, ticking AIDS time bombs, set to explode any second and coat them in blood, saliva, and urine. You will know these people when you first tell them you have HIV and they scurry away into the kitchen to quickly wash whatever eating utensils you may have touched with your "infected" mouth.

Kind-of-red alert: uneducated fear

This is one of the worst fears. It is when people think they have

read and know everything about AIDS when, in fact, they kinda read something in a newspaper six years ago, they don't remember the article but they know it was about blood and infection. The really disturbing thing about this fear is that they think they know it all and aren't willing to learn any more. They're the healthcare workers who don't turn up at AIDS talks at hospitals. They're the parents who won't let their kids learn about it at school. They're the people who truly believe that AIDS is a "manageable disease like diabetes." Hey, buddy, just because you read a chapter don't mean ya read the whole dang book!

Red alert: justifiable fear

So, when is the fear a justifiable fear? Well, let's say you're one of those many people who went out on the town last night, met someone for the first time and got lucky. You've got a sick feeling in your stomach that maybe, just maybe, you didn't know everything about the person you were with. Now you're not feeling quite so lucky. You could put yourself on red alert, choose to put on blinders, turn over and look forward to the next sick feeling. The trouble is that you may be in for a sicker feeling than you thought and you might just find out when it's too late to do anything about it. PLEASE—this one's a no-brainer: get tested, get treated, get smart.

So next time you have a fear, just do the old red litmus test and see where your fears lie. I do it with every fear I have these days and I'm finding the results are pretty scary!☹



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