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



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

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think+

opinion and editorial

Hot off the Press

by Paula Braitstein

The BCPWA Society is thrilled to announce the launch of the 3rd edition of the *Positive Living Manual* on December 1, 2004, World AIDS Day. The manual contains a wealth of information on some of the major issues and questions facing PWAs today, from current antiretroviral information, to recommendations on how to disclose your HIV status to a child.

This manual is all about taking charge of your life through making informed decisions. Like the mission of the BCPWA Society, it is about not letting ignorance and fear rule what you do.

Making informed decisions can be a very empowering experience. But what if you make a decision and then can't execute it? For example, what if the best HIV treatment for you is unavailable because a bureaucrat decided it isn't a "cost-effective therapeutic option"? Or what if you decide to treat your hepatitis C, and are then told you don't qualify? Suddenly, empowerment can feel very disempowering.

The federal government recently announced \$10 billion for health care. It's true our health care system needs more money invested in it. It's also true that our healthcare system needs an overhaul à la Romanow. But better health, on both individual and societal levels, is about more than paying doctors and nurses what they're worth, or buying new equipment.

The most significant improvements in health worldwide have come not from technology, but from improving people's standard of living, and from following basic principles around sanitation / hygiene, diet, and lifestyle. The government's \$10 billion won't lift thousands of women, children,

and their families out of cycles of poverty and violence. Nor will it decrease the loneliness and isolation that are often at the root of various illnesses and conditions, including addiction to drugs and sex. I wonder when the last time BC Minister of Health Services Colin Hansen went involuntarily hungry, or deliberately did something to harm himself just to get some care and attention. I wonder if he understands what health really means.

It's time to stop thinking about health and health care as synonymous with medical intervention, and time to start thinking about it in terms of who we are and how we are in our families and in our communities.

The *Positive Living Manual* isn't a tool for a quick-fix solution to the complexities of being HIV-positive.

But if you want to be an empowered consumer, then reading the manual is a great first step. The next step is putting your decisions into motion and stepping up to the plate to overcome the obstacles you'll inevitably encounter. To do that, you'll need to see the big picture and remember that while viruses and bacteria can cause disease, it is the social and economic determinants in our lives that actually shape our health.

If there's one thing I've learned from 12 years working with PWAs, it's that health is nothing if not a state of mind. +

If you would like a copy of the *Positive Living Manual*, email manual@bcpwa.org or call 604.893.2250.

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

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REALITY BITES

News from home & around the world

BCPWA's new board of directors

The BCPWA Society held its Annual General Meeting on August 21, 2004, where a new board of directors was elected. The new executive is: Paul Lewand, chair; Glyn Townsend, vice-chair; Derek Bell, treasurer; and Robert Nickerson, secretary. Directors-at-large are Doug Perry, Malsah, Mike Dilworth, Rodney Little Moustache, and Stuart Hossack.

Board chair Paul Lewand was a co-founder and chair of the Caribou AIDS Information and Support Society. He has been a board member of the BCPWA Society for five consecutive years, serving as the board secretary for the past year and a half. During his seven years of volunteering for the BCPWA Society, he has worked in the Support Department, Membership Services, Fund Development, and Volunteer Coordination.

Abbott asked to pull Kaletra promotions

Materials used by Abbott Laboratories to promote Kaletra overstate the medicine's effectiveness and fail to warn about risks in taking the drug, the US Food and Drug Administration (FDA) said in a letter sent to the company. They asked the drug manufacturer to pull the promotions.

The FDA cited a poster and a print advertisement that appeared in the May 2004 issue of *POZ* magazine. The print ad asks: "Where do you see yourself in 5 years? Talk to your doctor about Kaletra." It presents five photographs of a man, with captions indicating the photographs were shot in 2000, 2001, 2002, 2003, and 2004. The man appears healthy in all of the pictures.

The FDA said that the promotions imply that the individual featured has

been healthy over the past several years because he takes Kaletra.

Source: Chicago Sun Times

Passing of founding POP coordinator



The Canadian AIDS community has lost an important and outspoken advocate. Michael Linhart, the founding coordinator of the BCPWA Society's Prison Outreach Program, passed away on October 27. Linhart also served on the Board of Directors of the Canadian HIV/AIDS Legal Network for many years, up until the time of his death.

Linhart was one of the first inmates to speak openly of his HIV-positive status and to speak out about HIV/AIDS issues in prisons. To the end, he fought for the rights of prisoners living with HIV/AIDS to proper care and for the right of all prisoners to protect their health. He was passionately involved in advocating for harm reduction in prisons.

Initial NNRTI-based HAART regimens sustained longer

Initiating highly active antiretroviral therapy (HAART) based on a non-nucleoside (NNRTI) may provide a better chance to achieve durable treatment and to avoid the need for multiple salvage therapies than protease inhibitor (PI)-based HAART, according to a study in Montreal.

A total of 440 patients initiated PI- or NNRTI-based HAART during the study period from January 1998 to June 2003. Almost one in three patients modified

their initial HAART regimen during the study period: 63 percent of those on PI-based HAART and 47 percent of those on NNRTI-based HAART.

Overall, the median time to treatment modification was 2.1 years for those initiating with NNRTI-based HAART compared with 1.6 years for those starting PI-based HAART. Patients starting PI-based HAART were a third more likely to change their initial HAART regimen than those starting NNRTI-based HAART.

The study's authors note that more follow-up is necessary to determine if this translates into improved clinical outcomes.

Source: aidsmap news

BCPWA website gets new look

The BCPWA Society's website, www.bcpwa.org, is currently undergoing a makeover. Once completed, the redesigned website will be fresher, friendlier, more upbeat, and more user-friendly. The new site will retain all of the information available on the current website, but will also include more resources and ways for members to stay up-to-date and informed.

Increased risk of cardiovascular events on HAART

Incremental new data from the DAD (Data collection on Adverse event of anti-HIV Drugs) trial, which last year reported a 26 percent increased risk in the frequency of heart attacks per year of antiretroviral drug exposure, has found that HAART also increases the risk of stroke and other cardiovascular or cerebrovascular events (CCVEs) such as angioplasty or bypass surgery by the same amount.

DAD is an observational study established to track long-term antiretroviral safety;

REALITY BITES



it involves over 23,000 HIV-positive people in eleven cohorts in three continents. The first finding, published in 2003, was that during over 36,165 person-years of follow-up, 126 people suffered a heart attack, or myocardial infarction (MI), 36 of which were fatal.

In this analysis, an additional 81 patients experienced at least once CCVE other than an MI.

The authors conclude “the results of this study further support the hypothesis that [antiretroviral therapy] is associated with increased risk of atherosclerosis.” More follow-up is necessary to determine whether the risk continues to increase with the length of antiretroviral therapy.

Source: aidsmap news

Peg-interferon causes serious eye problems in co-infected

Treatment with pegylated interferon alpha-2b (PegIntron) and ribavirin can cause serious eye problems in people coinfecting with HIV and hepatitis C, according to a study at the National Institutes of Health in the US.

Optic neuropathy, including retinal haemorrhage, cotton wool spots, and decreased colour vision, has been reported in individuals receiving interferon therapy who are mono-infected with hepatitis B or hepatitis C. However, these are the first reported cases of serious eye problems developing in HIV and hepatitis C co-infected patients receiving therapy with pegylated interferon.

Investigators recommend that patients co-infected with HIV and hepatitis C and treated with pegylated interferon and ribavirin receive regular ophthalmic monitoring.

Source: aidsmap news

Illinois law permits organ donors with HIV

The Governor of Illinois has signed a bill allowing people who are HIV-positive to donate organs to other people with HIV, a provision that he called the first of its kind in the US.

Details of the plan still need to be sorted out. Advocates said it would essentially require the creation of a separate organ donor pool in the state just

for those with HIV. Organ donors would continue to be screened for infection, disease, and other problems.

In the past, people with HIV were not considered good candidates for organ transplants because of their reduced life expectancy; drug treatments were far less advanced and life expectancies of potential HIV-positive organ recipients were far shorter.

Their most common organ need is a liver, since the livers of people co-infected with HIV and hepatitis C tend to fail especially swiftly.

Source: New York Times

Increased risk of oral contraceptive failure with nelfinavir

HIV-positive women taking oral contraceptives and the protease inhibitor nelfinavir are significantly more likely to experience contraceptive failure and become pregnant, according to a United States study published in the *Journal of Acquired Immune Deficiency Syndromes*. The researchers recommend that women taking nelfinavir should use additional contraceptive methods.

Investigators conducted a retrospective review of the records of 2053 HIV-positive women at an HIV clinic in New Orleans between 1997 and 2002. Forty-one women were identified as being pregnant and taking oral contraceptives in the same six-month period.

Further analysis revealed that eleven of these women became pregnant while using oral contraceptives. The researchers found that women taking nelfinavir were significantly more likely to become pregnant and that women prescribed indinavir were significantly less likely to become pregnant.

Source: aidsmap news ⊕



Photo: John Kozachenko

Mr. BC Leather Rob Kohl and BCPWA Society Chair Paul Lewand celebrate a successful launch of the Sex Positive guide at the PumpJack Pub on October 28, 2004.

The beast in the east

The AIDS epidemic is rampant in China, Russia, and Eastern Europe

by Caro Rolando

The AIDS epidemic is rapidly succumbing to Murphy's Law—that everything that can possibly go wrong, will go wrong. Just look at the effects the epidemic is having on China, Russia, Eastern Europe, and Sub-Saharan Africa.

Currently claiming approximately 20 percent of the world's HIV infected population, China's climbing rates of infection pose a huge threat to the global epidemic. With an estimated 801,000 to 1.5 million HIV-positive people, experts insist that unless sufficient action is taken immediately, figures in China could rise to as high as 20 million cases by 2010.

In 2003, Prime Minister Wen Jiabao took the first step towards ameliorating the situation by admitting the severity of the crisis. Even so, the underlying issue of discrimination is still prevalent, as most Chinese residents still regard AIDS as an illness that affects only injection drug users (IDUs), gay men, and sex trade workers.

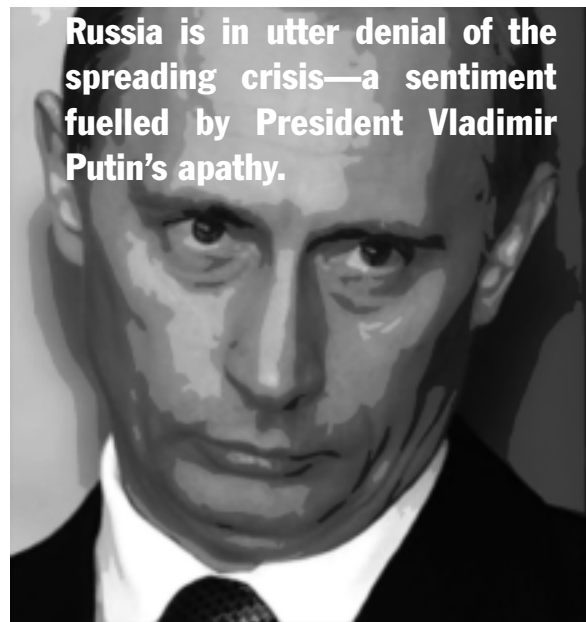
In reality, farmers and other citizens in rural China—who make up about 66 percent of the country's population—are equally affected by the illness. Despite this fact, the Chinese government's new public information campaigns are still primarily aimed at the perceived high-risk population groups, rather than at the general public. Consequently, the work of AIDS activists in the countryside is still unfavourably received. Indeed, government officials arrested several rural activists this year, in an attempt to cover up the epidemic.

However, compared with the current situation in Russia and Eastern Europe, China seems to hold some hope since the Prime Minister at least publicly acknowledges the problem.

The HIV epidemic in Russia also bears a relatively young face, with nearly 80 percent of infections affecting people under the age of 30, a large proportion of them part of the IDU and sex trade population. Unlike China, Russia is in utter denial of the spreading crisis—a sentiment fuelled by President Vladimir Putin's apathy. Thus far, he has not made a single speech acknowledging the presence of AIDS in the country, and he has allocated a paltry \$5.3 million US of the government budget for HIV/AIDS treatment. President Putin has refused to consider the count of PWAs in the country to be higher than the registered 300,000, though experts claim it is actually upwards of 1.4 million cases.

With the risk of reaching 20.7 million HIV-infected people by 2045, Russia is on the brink of collapse. And it is not alone. Its neighbouring states seem to be coming along for the ride.

According to a recent study by the German AIDS foundation, the infection claims twice as many young Eastern Europeans than Western Europeans. Could the epidemic eventually claim more lives in Russia and Eastern Europe than it has in Africa?



Home to 25 million people living with HIV, Sub-Saharan Africa remains hardest hit by AIDS, with two-thirds of the world's HIV/AIDS population, and a higher prevalence of infection among women than men. Some experts believe the epidemic has stabilized in this region for the time being, whereas others argue that the area may just be experiencing faster deaths than before. In either case, the situation is bleak; and it is expected to remain bleak unless there are changes in treatment access or new government projects in the foreseeable future.

The ever-growing AIDS epidemics in China, Russia, Eastern Europe, and Africa have the potential to infect the entire world. If we wish to maintain any hope, we must address the problem today, instead of waiting until it addresses us. ☹

Caro Rolando is a volunteer with the BCPWA Society's Communication Department.

Beyond the medical model

Canadian group brings different meaning to rehabilitation lives

by Glyn Townson

With the advent of highly active antiretroviral therapy (HAART) in the mid- to late- 1990s, many people with AIDS began to live longer. However, the new drug cocktails seriously affected quality of life. While the medical establishment had a number of clinical tools and tests to measure progression of the disease, these tests only revealed a small part of the picture. PWAs had all sorts of markers to measure disease progression, but no framework to deal with the more personal consequences of living with HIV disease and the side effects of the drugs used to treat it.

In the late 1990s, a multi-sector forum was held in Quebec City to explore the life and health-related problems that PWAs were experiencing. Whereas the medical establishment measured HIV in clinical terms, the forum addressed the physical, social, and psychological challenges associated with living longer with the disease.

The forum resulted in the formation of the Canadian Working Group on HIV and Rehabilitation (CWGHR), with “rehabilitation” defined in the broadest sense of the word. Anything that addresses disability-specific or related issues—forms of pain relief, managing employment, mobility difficulties, learning to live and die while optimizing function—all fall within this banner.

CWGHR is a unique organization in that it represents all parties affected by HIV/AIDS on a national platform. Members include PWAs, representatives from AIDS service organizations, community-based organizations, government agencies (both provincial and federal levels), the employment sector, healthcare providers, social workers, and private businesses.

In developing its concept of rehabilitation, CWGHR adapted the International Classifications of Functioning Disability and Health (ICF) from the World Health Organization. The ICF offers a standardized language and a framework to describe health and health-related components of well-being, such as education and labour. This framework adapts well to an HIV model, as it divides these components into three main concepts that describe health issues beyond the level of disease.

The first concept, impairment, refers to problems associated with the actual disease, such as breathing difficulties, nausea, diarrhea, and neuropathy. Impairment can be associated with any area of the body.

The second concept, activities, describes the barriers to normal functioning caused by the impairments, such as difficulty walking, carrying groceries, performing housework, or taking care of oneself.

The third component, participation, deals with the various roles that people play in their lives and how they interact with their environment and community: going to work, being a sexual partner, or any activity considered normal for their age, gender, and background.

These three concepts give a meaningful framework to categorize all of the consequences of living with HIV/AIDS beyond the medical model. They provide the opportunity to identify issues and to generate discussion. The process allows us to develop solutions and respond to the broader problems faced by people living with HIV.

The BCPWA Society has participated in CWGHR since its inception. The organization’s first representative was Tom McAulay, a past director of the BCPWA Society, who is still involved as a member of CWGHR’s Education Committee. In addition, past BCPWA chair Glen Bradford brought the issue of income security to CWGHR’s Income Support Committee, which deals with issues such as CPP disability and private LTD insurance programs. BCPWA Society researcher Francisco Ibáñez-Carrasco currently co-chairs the CWGHR board.

Future articles will explore some of the research, knowledge development, and education that CWGHR is pursuing, and how these issues affect those of us living with HIV.

For more information, visit the CWGHR website at <www.backtolife.ca>. ⊕

Glyn Townson is a board member of the BCPWA Society, and the Society’s representative on CWGHR.

Payback time

Class action successfully wins back CCP lump sum payments

If you signed a document between May 1, 1997 and January 14, 1999 giving your Canadian Pension Plan (CPP) back pay to the BC Ministry of Human Resources, you may be eligible to receive 50 percent of your lump sum retroactive pay.

A class action lawsuit has successfully reached a settlement with the BC Government. However, the settlement payouts can only occur if 700 individuals eligible for the settlement complete the necessary legal documents by April 5, 2005.

The class action suit challenged the legality of the government's actions. During the period from May 1, 1997 to January 14, 1999, the province of BC did not have the legal authority to require disability applicants to sign over their CPP lump sum payments. Since January 14, 1999, new legislation does give the province this legal authority. It is now law that all disability applicants assign their CPP lump sum payments to the government. This means that only individuals who signed over their CPP lump sum payment to the province during the designated time frame are eligible for the settlement. You are not eligible for the settlement if the government received your lump sum payment at any time after January 14, 1999.

If you assigned your CPP back pay to the Ministry during the designated time frame, you probably already received a package from the class lawyers. This package contains important documents. If you want to receive 50 percent of your back pay, you must fill out Form A in your package and send it to the class lawyers before the deadline.

Even if you now live outside of BC, or if you still live in the province but are no longer receiving BC disability assistance, you are still eligible for the settlement if you signed over your CPP lump sum payments at any point between May 1, 1997 and January 14, 1999.

There is no cost to participate in the settlement. The class lawyers' fees are paid by the interest on the total settlement amount and by the provincial government.

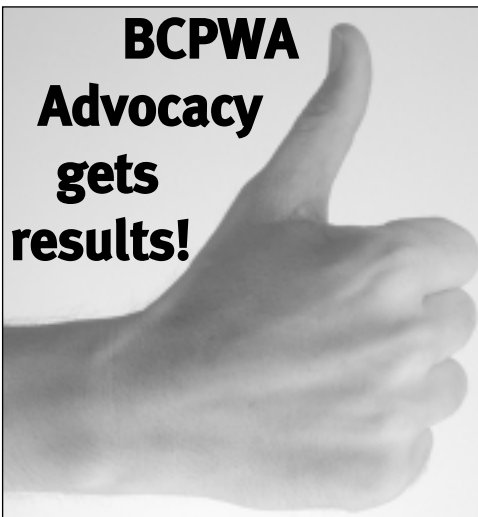
If you have any questions about your entitlement, phone the class lawyers at 1.800.537.1136 or email them at cpp@doakshireff.com.

Contact the class lawyers if you have not received a package and you think that you may be eligible, or if you are a beneficiary of someone who has died who may have been eligible. A beneficiary can be someone named in a will or, if there is no

will, family members identified under the law, including same-sex spouses.

If you do not agree with the settlement, you can opt out of the class action by completing Form C no later than April 5, 2005. Note that by opting out you cannot change your mind at a later date if you want to be included in the class action, and you will not receive any money from the settlement. If you do change your mind later, you will need to start your own legal action with your own lawyer in order to obtain compensation for the CPP retro pay. ⊕

If you currently receive disability assistance from the Province of BC, the settlement may affect your welfare benefits. If you plan to accept the settlement offer, please contact the BCPWA Society advocacy department immediately (tel: 604.893.2223; email: advdesk@bcpwa.org) to discuss the possible implications to your welfare benefits.



**BCPWA
Advocacy
gets
results!**

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

- ▼ **\$30,258.95** in debt forgiveness.
- ▼ **\$60,770.12** in housing, health benefits, dental and long-term disability benefits.
- ▼ **\$31,750.00** in Monthly Nutritional Supplement Benefits.
- ▼ **\$369,925.00** into members' hands for healthcare needs, from grandfathered Schedule C benefits.

Home dismal home

Living below the poverty line with HIV

by Lisa Gallo

Bedbugs infest his sleeping quarters. Rodents used to scurry across his floors until he painstakingly sealed off every crumbling gap in the walls and baseboards. Now he only hears the rodents inside the walls. The nights are punctuated with the shriek of sirens and angry, desperate residents high on drugs or alcohol. This is where Rob, HIV-positive and living below the poverty line, makes his home.



Rob in his apartment.

There is nothing extraordinary about his story. In fact, almost 50 percent of HIV-positive individuals in BC are living in poverty, according to the results of a 2002 survey conducted by the BC Centre for Excellence in HIV/AIDS and the BCPWA Society.

The prevalence of people with HIV living in this desperate state is largely due to inadequate disability funding. Disability benefits, which have never offered adequate financial support, have been frozen since 2000. During that time, the cost of living in BC has increased by 6 percent.

People with HIV/AIDS living on provincial disability funding are eligible for just \$786.42 per month and a special monthly nutritional supplement of up to \$225. The ministry allocates only \$325 to housing, yet the average cost of a one-bedroom suite in

Greater Vancouver is \$750 per month, a reality that leaves people struggling to cover basics such as food and clothing, or—as in Rob’s case—resorting to substandard, unsafe housing.

Before he was diagnosed with HIV three years ago, Rob, 44, was a skilled tradesperson working in auto-body repair, construction, and furniture refinishing. However, two years ago he was forced to accept disability due to poor health, chronic fatigue, and HIV-related sensitivity to the chemicals used in his work environment. Unable to afford a conventional apartment, he found a room in a low-rent, single-occupancy hotel for \$500 a month. Rob insists that he lives in one of the better examples of low-cost housing available in Vancouver. “A little further east, things get a lot worse,” he says.

Poor quality shelter can compromise the health of HIV-positive individuals in several ways. Unsanitary and inadequate bathroom and kitchen facilities can expose them to an elevated risk of infection and make it difficult for them to prepare nutritious meals. Rob shares the use of a two-stall bathroom—infrequently sanitized and often downright filthy—with another dozen or so residents on his floor. His kitchenette does not have an oven, only a turn-of-the-century cast-iron hotplate with only one functioning element. Then there are his unwelcome “roommates”: the mice and bedbugs. Staying healthy under these conditions is a challenge.

Currently, 11,000 people are waiting for safe, habitable cooperative or low-income housing alternatives in British Columbia. Rob has been on a waiting list for two years, with no indication that a space will open up for him anytime soon.

In the September 5, 2004 edition of *The Province*, BC Minister of Human Resources spokesperson Richard Chambers stated that meeting the needs of people with disabilities was one of the Ministry’s priorities and that they would examine it in next fiscal year. “Providing higher rates for people with disabilities could be a possibility with a balanced-budget situation.”

With the next provincial election in May 2005, now is the time to write to the Honourable Susan Brice, Minister of Human Resources, to let her know that British Columbians living in poverty need increased support now, more than ever. You can email the Minister at mhr.minister@gems7.gov.bc.ca, send a letter by mail to PO Box 9058, STN PROV GOVT, Victoria BC, V8W 9E2 or call 604.660.2421 or 1.800.663.7867 (toll-free) and ask for Susan Brice. ☎



Lisa Gallo is the director of communications and education for the BCPWA Society.

PAYING THE PRICE

HIV takes a particularly heavy toll on sex trade workers

by Melissa Davis

No one from the de Vries family has ever been able to explain exactly how or why Sarah ended up on the streets. She was the youngest of four children, adopted by the family when she was less than a year old, and raised in the affluent Vancouver neighbourhood of Point Grey. At that time, more than 30 years ago, adoption agencies didn't really consider issues of race and ethnicity when placing children with families. In her early

years, Sarah appeared to be happy and well adjusted.

However, as a multi-racial child within a white family and a mainly white social and cultural environment, Sarah experienced a great deal of pain and anguish as a youth. She endured many covert and overt expressions of prejudice at school—from malicious teasing and insults, to chasing and physical assaults. She ran away from home several times during her early teens.

continued on next page

**Just another day, just another death,
Just one more thing for you to forget,
You and your soft sheltered life,
Just go on and on,
For nobody special from your world
is gone.**

**Just another Hastings Street whore
Sentenced to death.**

No judge, no jury, no trial, no mercy.

**The judge's gavel already fallen,
Sentence already passed.**

— Sarah Jean de Vries (1969–1998)

Many of the details of Sarah's story remain sketchy—particularly the dramatic transition from life in a prosperous suburb to the streets of Vancouver's Downtown Eastside (DTES). Somewhere along the way, she developed a heroin addiction, then started turning tricks to support her drug habit. At some point, in between the birth of her daughter Jeanie and her son Ben, Sarah contracted HIV and hepatitis C.

Apart from the unusual circumstances surrounding her privileged upbringing, Sarah's story isn't so different from countless other women living and working in the streets of the DTES. The vicious cycle associated with the sex trade and drug addiction is reflected in extreme poverty, homelessness, hunger, violence, mental health issues, and medical problems, including HIV and hepatitis C.

The vectors of transmission

HIV and sex trade issues have been explored, analyzed, and discussed from virtually every possible angle over the past two decades of the AIDS movement—from epidemiology, to geographic and sociological trends, and from matters of social policy to legal issues.

In the early years of the epidemic, the first reported cases of heterosexual transmission diverted attention from talk of the "gay plague". Sex workers were targeted as "the vectors of transmission" into the heterosexual population.

Much of the literature during that period argued vehemently for the decriminalization of prostitution as an essential HIV prevention initiative within the sex trade. In 1989, The World Health Organization (WHO) issued a statement arguing that laws restricting the legal rights and freedoms of prostitutes effectively hinder HIV prevention efforts.

Several years later, the Canadian HIV/AIDS Legal

Network devoted two consecutive issues of its *Canadian HIV/AIDS Policy & Law Newsletter* to the subject of prostitution. The October 1995 issue provided a comprehensive literature review, while the January 1996 publication proposed prostitution law reform, including changes to the Criminal Code, and advocated for the decriminalization of the sex trade. Sex workers and AIDS activists have argued for decriminalization for well over a decade.

A vulnerable population

Today, more than 20 years and roughly 20 million global AIDS deaths later, the research grows more sophisticated, but the rhetoric is mostly unchanged. Study after study identifies and reinforces the stigmatization and vulnerability of sex trade workers. Research frequently relates the cross-cultural marginalization of women in general to the experience of women in the commercial sex industry. Findings are presented and recommendations are put forward.

The UNAIDS Technical Update: Sex Work and HIV/AIDS, released in June 2002, analyzed many of these issues and statistics from a global perspective and proposed numerous proactive responses to existing challenges. The report identified various social and lifestyle factors that increase sex trade workers' vulnerability to HIV infection. These factors include: social stigmatization and marginalization; limited access to health, social, and legal services; limited access to HIV prevention information and means of prevention; limited skills and power to negotiate safer sexual practices (particularly with sexual partners who are injection drug users); the experience of physical and/or sexual violence; and the absence of protective legislation.

The UNAIDS report also outlined a three-tiered approach to HIV prevention among sex trade workers: prevention of entry into the sex trade; protection of sex trade workers; and assistance in transitioning out of sex work. Each of these approaches, the report states, can be addressed on individual, community, and social policy levels. Consequently, proposed strategic approaches to improve the protection of sex workers include the expansion of peer education initiatives, the provision of care for sex workers living with HIV/AIDS, and the development of a clear policy framework for sex work.

The UNAIDS Technical Update isn't radical thinking. The benefits of peer education and outreach were documented long before the AIDS movement. Medical care and support is (at least for the time being) the right of all Canadians—and it should be a basic human right in all countries. And activists have been advocating for policy frameworks and legal reform with respect to sex work since the epidemic began.

On the local level

Yet, sex trade workers continue to be a vulnerable, disenfranchised population, and the situation in Vancouver is no exception. According to a recent study conducted by the BC Centre for Excellence in HIV/AIDS, female sex trade workers in Vancouver's DTES are extremely susceptible to both acute and chronic drug-related health problems, including serious infections and overdose as well as exposure to HIV and HCV. The results of the study were reported at the XV International AIDS Conference in Bangkok, Thailand in July.

Researchers surveyed 159 women attending an evening program for female sex trade workers through the Women's Information and Safe House (WISH) drop-in centre. Although many of the survey participants reported living on income assistance or disability benefits, 40 percent of the women identified "street work" as their main source of income. All but one of the survey participants reported active illicit drug use. Almost all of them had been previously tested for HIV and hepatitis C. Among those tested, almost one-quarter reported testing HIV-positive, and two-thirds of them reported testing positive for HCV.

Sex trade workers continue to be a vulnerable, disenfranchised population, and the situation in Vancouver is no exception.

The WISH drop-in centre has been a familiar fixture in the DTES since the mid-1980s. Originally a program of the Anglican Street Ministry for Youth operating out of St. Michael's Anglican Church on the east side of the city, the drop-in shifted its mandate in 1986 to provide support services exclusively to women. Although funding for the program was discontinued in 1987 following a community effort to eliminate prostitution in the Mount Pleasant area, WISH relocated shortly thereafter to the DTES through the generous sponsorship of First United Church.

Almost 20 years later, WISH is a registered non-profit organization that operates year-round, six nights per week, providing female sex trade workers with hot meals, showering facilities, hygiene items, clothing, and make-up. In addition, WISH offers on-site nursing services, referrals to alcohol and drug detoxification and rehabilitation facilities, as well as homeless shelters. The drop-in centre also operates a literacy program, with a variety of related services, as well as a transition program for women wishing to leave the sex trade and develop new employable skills. More than 200 women from the DTES visit the centre and use its services each night.

Numerous support services, addiction programs, and health programs have emerged over the years in an effort to

address the specific issues facing women and men working in the sex trade in Vancouver.

The importance of outreach and counselling

Although male and transgendered sex trade workers in Vancouver represent a smaller proportion of the industry as a whole, outreach efforts remain important. Since this population is concentrated in a different region of the city, support services are focused in the Downtown South area.

Boys R Us is a drop-in centre and support program operated by Vancouver Coastal Health in partnership with Three Bridges Community Health Centre as well as several area AIDS organizations, including BCPWA Society, AIDS Vancouver, and YouthCO AIDS Society. The drop-in is open three evenings per week, Tuesdays to Thursdays, and provides meals, condoms, lubricant, and clean needles to approximately 30 male and transgendered sex trade workers who use the service on a nightly basis.

"Boys R Us is staffed by a small group of volunteer trained counsellors," explains Mike, the staff representative from the BCPWA Society. "Most of us volunteer on the same night each week, to give drop-in participants a sense of consistency and comfort. The atmosphere is very informal, very relaxed—no structured topics for discussion—just a safe place for the guys to hang out and get information and support if they want it."

Occasionally, visiting street nurses provide health-related services such as hepatitis B vaccinations and flu shots. Participants are also referred to Three Bridges Community Health Centre, where healthcare providers are both non-judgmental and sensitive to the specific medical needs of male and transgendered sex workers.

For Sarah de Vries, it's too late for position papers, research studies, drop-in centres or addiction programs. Sarah disappeared in the early morning hours of April 14, 1998 from the corner of East Hastings Street and Princess Avenue in the DTES. She is listed among the more than 60 women, most of them sex trade workers and drug addicts, who have vanished from the DTES since the mid-1980s. More than three years after Sarah's disappearance, during a massive police search at the Port Coquitlam farm owned by Robert Picton, her DNA was discovered on the property.

What we need is an implementation plan—less paper, more action. ⊕



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

A view from the inside

An inmate tell his own story

by Chris

People often wonder what it would be like to be a PWA in prison. In particular, they wonder what types of resources and services are provided to HIV-positive inmates. The following testimonial is written by Chris (a pseudonym), an inmate from the Regional Treatment Centre in Abbotsford, BC. His story illustrates the very real need for positive tools for HIV-positive inmates.

Seven months after I arrived in jail in late 1993 I found out that I was HIV-positive and had been for 6 or 7 years. Finding out this information didn't faze me all that much because since I'd arrived at jail I had just about lost the will to live because of what I had done and I had no hope for anything in the future. The HIV to me on one hand was an exit plan from my life, but it also took away what little hope I had.

I came to the regional treatment centre in June of 1995. It's a prison/ hospital type of place, it's multifunctional. This place with the head doctors and nurses helped me a lot. I was super depressed and thought about suicide daily, my real life was gone and I was just more or less waiting to die. I wasn't angry or anything that I was in jail, I was where I should be, it was just very difficult to go through the motions of every day knowing that it was more or less just a waste of time.

In early 1997 my blood count went down to low and my white blood cells were shot and I figured 1998 would be my last year. I wasn't looking forward to the AIDS illness but I was looking forward to my life being over. In late 1997 the doctor put me on a new drug cocktail and my blood count went up to 230 and my viral load became undetectable, which meant my life was being prolonged. I wasn't exactly happy with that news

and for the next few years I still continued to wait to die. But I didn't know if I was going to or not, I didn't want to grasp onto life and then have it fade away on me. I was a little angry during this time because this wasn't supposed to be happening. I had prepared for it and living was a bit hard to accept.

In 2002 I realized life was going to keep on continuing and I was faced with a possible future, something I had never contemplated. I had totally given up on life beyond jail. Now that HIV is a treatable chronic illness the medications only last so

In 2002 I realized I was faced with a possible future, something I had never contemplated. I had totally given up on life beyond jail.

long and being that I'm more negative than positive when it comes to my future I try not to think too far ahead. I don't know if I have 3 or 5 or 10 years left to live, so it makes it hard to want to plan. Hope can be a really good thing but it can also be a devastating thing.

I am grateful now for the 6 extra years I've gotten to live so far. I've had a number of good experiences and learned a lot through this time. I guess that's the way I look at it now, every year's an extra year, time I'm lucky to have. ☺

If you would like to become involved with the Prison Outreach Program call or visit the BCPWA Society website at <www.bcpwa.org> for more information.

We need people like you. BCPWA has volunteer opportunities in the following areas:

Website maintenance > Communications

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Writers > living☺ magazine, Communications and Positive Prevention

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Benefits of becoming a volunteer:

- ◆ *Make a difference in the Society and someone's life*
- ◆ *Gain work experience and upgrade job skills*
- ◆ *Find out more about HIV disease*

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

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Another Kind of Drug Deal



Responding to the HIV/AIDS epidemic in Eastern European and former Soviet Union prisons

by Thomas Kerr and Ralf Jürgens

Throughout most of the world, the primary response to problems associated with illicit injection drug use has been to intensify law enforcement efforts in order to limit the supply and use of illegal drugs. This strategy has contributed to an unprecedented growth in prison populations worldwide. It has also led to concerns regarding HIV/AIDS within prison settings. However, several countries in Eastern Europe and the former Soviet Union (fSU) have recently made significant progress in this area.

As injection drug use continues to drive the HIV/AIDS epidemic in Eastern Europe and the fSU, increasing attention is being paid to the relationship between incarceration and HIV/AIDS in this region. For example, in the Ukraine, where 69 percent of HIV infection is linked to injection drug use, an estimated seven percent of the prison population is HIV-positive. In Latvia, half of newly diagnosed cases each year are among prisoners. In Poland, approximately 20 percent of all people living with HIV/AIDS have spent time in prison or pre-trial detention centres.

High rates of initiation into injection drug use within prison settings are fuelling the HIV epidemic in Eastern Europe and the fSU.

High rates of initiation into injection drug use within prison settings are also fuelling the HIV epidemic in Eastern Europe and the fSU. In one study in Russia, where 20 percent of prisoners reported injecting drugs while incarcerated, 14 percent of these individuals indicated that their first injection occurred within a penal institution. While drug users typically inject less frequently in prisons, studies have demonstrated that they tend to inject in a more high-risk manner than they otherwise might in community settings. This tendency is often due to limited access to information and materials, such as sterile syringes or chlorine bleach, which can offset risks.

Unfortunately, governments have typically followed the philosophy and practice of zero tolerance when responding to

disease transmission caused by injection drug use in prisons. Prison officials often increase penalties, tighten security measures, and heighten surveillance to discourage or prevent drug use. Such “law and order” solutions to public health problems in prisons imply that any amount of drug use is unacceptable and that abstinence is the only worthy goal. These notions persist despite an established body of scientific literature demonstrating that addiction is a chronic and relapsing condition, shaped by a multitude of behavioural characteristics and social-contextual factors, that may not be amenable to abstinence-based programs.

In general, prison authorities around the world have been slow to implement effective programs to reduce drug-related harms. Yet, prisoners are still part of the broader community. Various international laws and guidelines dictate that prisoners are entitled to the same level of health care and protection as the general population. In recognition of this “principle of equivalence,” countries such as Moldova, Kyrgyzstan, and Poland have introduced various harm reduction initiatives, including educational programs, methadone maintenance therapy, bleach distribution, and needle exchanges in prisons.

The failure to provide measures that have scientifically proven to reduce drug-related harms, and the practice of punishing those addicted to drugs, simply exacerbates drug-related harm among a group of highly vulnerable members of society. The containment of the HIV epidemic in Eastern Europe and the fSU will depend, in part, on the willingness of prison authorities to move beyond zero tolerance and to support evidence-based approaches based on principles of HIV prevention and harm reduction. ⊕

Thomas Kerr (l) is a research associate at the British Columbia Centre for Excellence in HIV/AIDS.

Ralf Jürgens (r) is the former executive director of the Canadian HIV/AIDS Legal Network.



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Safer tricks of the trade

Helpful tips for sex trade workers

by Lucia Terra

Working in the sex trade—getting dates, as well as developing and maintaining a regular clientele—depends, in part, on safeguarding your health. Being vigilant about safer sex practices is the only way to prevent exposure to sexually transmitted diseases (STDs), including HIV. But insisting on safe sex with every trick, every time, isn't always easy. It requires a certain level of knowledge about STDs, especially risky and safe practices. It also requires that this information, as well as alternative sexual practices, be communicated to johns with a combination of clarity and firmness as well as tact and diplomacy.

In general, commercial sex is viewed as a high risk activity in which HIV and other STDs can be contracted and spread. Since it is assumed that both clients and sex workers have multiple sexual partners, the need for safe sex practices is perhaps more obvious in the sex trade than between sexually exclusive couples.

Ideally, the sex industry as a whole would be involved in making commercial sex safer, since creating and maintaining a safe sex environment depends partially on the client's inability to obtain unsafe services. General practice agreements would prevent clients from bargaining with sex trade workers for unsafe services and lower prices. However, this tactic requires a concerted effort by the sex industry, so at best it is a long-term enterprise.

Even when there is no agreement on the need to take preventive measures, it is important for sex workers to know how

to sell safe sex. On a practical level sex workers can make their work safer by employing a number of approaches.

The delicate art of negotiating condom use

In order to effectively negotiate safer sex, it is important to understand the reasons why clients reject the use of condoms. Often they complain of decreased sensitivity or failure to maintain an erection. Clients may also claim to be free of STDs; or, where medical examinations for sex workers are compulsory, they might assume that you are free of STDs.

You may find it difficult to refuse a client who insists on having sex without a condom. However, if a john is reasonable, he may be open to being educated about safe sex and condom use. Communicating this information requires tact, confidence, and accurate information. Also, incorporating an arsenal of creative, sexually skillful, safe techniques into your repertoire of services is the most effective method of all—and will be met with the least amount of resistance from clients.

Even if your client agrees to wear a condom, it can slip off or break if it doesn't properly fit, if the penis isn't erect, or if too much lubricant is used. You can avoid most problems through proper condom use. But if a condom breaks during sex, you need to douche or wash your vagina or anus immediately, or rinse your mouth with antibacterial mouthwash, to reduce the amount of semen present.

You can also use two condoms at the same time to reduce the possibility of condom failure. However, avoid lubricated condoms or adding lubricant in this case, because it may cause the condom to slip. Using a female and male condom together is not recommended since they are made from different materials, which can create friction and cause breakage. Use all condoms properly and with care; remove them after each use, and dispose of them safely.

Another option is the female condom, which both female and male sex workers can use. Because this device can be inserted (vaginally or anally) before working, it allows a greater degree of control when negotiating safer sex with clients. The female condom is also a useful alternative for people with latex allergies and for females who are menstruating.

Another alternative when negotiating safer sex involves offering services that don't require condoms, such as oral sex, kissing, non-penetrative sex, and fantasies.

Although it's possible to reuse a female condom, it isn't recommended. And in every case, you should position your client's penis into the female condom to prevent it from slipping in between the condom and the vagina or anus.

Suggesting safer alternatives

Another alternative when negotiating safer sex involves offering services, such as kissing, non-penetrative sex, and fantasies. Even though oral sex is considered a low-risk activity for HIV transmission, use condoms to avoid contracting other STDs. And, while there's minimal risk of HIV transmission through kissing, you can still get herpes, glandular fever, gonorrhea, and syphilis. External ejaculation is an option if the sperm doesn't reach mucosal membranes, open cuts, or sores.

When clients are looking for different sexual experiences, it's a good opportunity to sell safer sex services. In safe sex fantasies, there is no skin broken and there is no contact with blood, semen, or vaginal fluids. Such fantasies include erotic talk and teasing, dressing up and playing sexual fantasy roles, voyeurism, and fetishism. Always place a condom on dildos before you use them, and wash dildos and sex toys after each use.

Avoid risky activities including piercing, tattooing, and scarring (if done, always use sterile equipment) and fantasies involving urine, feces, or blood.

No viable alternatives to condoms

As an alternative to condoms, microbicide jellies and lubricants are still a long way from being commercially available. Even then, they will not provide the same level of HIV protection as condoms: at best, they are initially expected to be only 50 percent effective. In addition, vaginal microbicide research

is much further ahead than research on rectal microbicides.

Spermicides are designed to kill sperm and they don't necessarily reduce the risk of HIV transmission. In fact, they could irritate the skin in the anus or vagina, thus increasing the risk of HIV exposure.

In terms of other products, if you're using personal hygiene products, don't use anything with harsh chemicals or detergents; these items aren't suitable for use in the anus or vagina since they break down the body's natural protection against infections. The same is true for vaginal drying agents (using herbs and other substances to dry and tighten the vagina for "dry sex").

As for lubricants, use only water-based products with condoms since oil-based lubricants can damage and cause breakage. Female condoms are already lubricated, but you can use extra lubricant, both water- or oil-based.

Learning to be careful

Learning to recognize visible indicators of STDs will help you remain safe. Keep in mind that many STDs might not have visible symptoms. However, carefully inspect every client's penis for lesions, warts, unusual discharge, or other signs of STDs.

For female sex workers, menstruation increases the risk of HIV transmission. If you are working during your period, offer alternatives to vaginal sex, use female condoms, or use small sponges to control the flow of blood. Taking an oral or an injectable contraceptive throughout the entire menstrual cycle will prevent bleeding, but don't make this a regular practice.

For transgendered people, safe sex should include practices used by both male and female sex workers, as well as practices that take into account unique situations such as care following sex reassignment surgery. Post-operative transsexuals should pay particular attention to appropriate vaginal lubrication to prevent lesions and diminish the risk of infection.

All sex workers should incorporate safe practices not only when working, but also when having sex with their partners.

Finally, sex workers cannot be singularly responsible for protecting against transmission of STDs. Other people who influence commercial sex should also take responsibility for making the sex trade safer—this includes clients, owners and managers of commercial sex establishments, people who act as links between clients and sex workers, and policy makers who establish regulations that affect the sex trade. ⊕

For more detailed information on safer sex in the sex trade, visit <www.chestella.org>

For more information on female condoms, visit <www.femalehealth.com/theproduct.htm> or <www.avert.org/femcond.htm>.

For more information on Nonoxynol-9 and other microbicides, visit <www.global-campaign.org>.



Lucía Terra is a volunteer writer for Living + magazine.

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.

Blocking co-receptors

by Tom Mountford

In the near future, we will start looking at HIV from an entirely different perspective: according to the entrance it uses to infect the body's cells.

Some immune system cells carry receptors for chemokines (chemical messengers) which are used by HIV to gain access to CD4 cells and macrophages. In early stages of infection, the virus adapts to use the CCR5 (R5) co-receptor on CD4 cells to gain entrance, infect the cells, and begin replicating itself. This R5-using virus is very slow moving. In later stages of HIV disease, viruses are adapted to use the CXCR4 (X4) co-receptor. This X4-using virus is far more lethal; it quickly becomes predominant and accelerates disease progression. While the R5-using virus is like an occasional sniper, the X4-using virus operates more like a weapon of mass destruction. In addition, viruses can also be dual-tropic (expressing both X4 and R5 co-receptors).

There are advantages to maintaining a predominantly R5-using virus population and delaying the switch to the X4-using virus population. Research has shown that approximately 35 percent of long-term non-

progressors have a mutant form of the R5 receptor. Because these alterations in the pattern of R5 expression indicate a reduced risk of disease progression, blocking this target for viral entry has clear benefits. Recent studies confirm that X4 and dual-tropic viruses can be suppressed and the relative proportion of R5 increased, potentially deferring disease progression associated with the presence of these more aggressive X4 viruses.

However, there may be problems with inhibiting co-receptors. Over time, use of agents which block the R5 co-receptor may favour the emergence of more lethal viruses than those using the X4 receptor. Research conclusions are mixed, but overall they lean towards the belief that the development of drug resistance to an R5 antagonist does not necessarily indicate a switch to an X4 phenotype. Some researchers have also suggested that a R5 blocker may be most effective when someone has a relatively high CD4 count, because the virus will have less ability to exploit a wide range of chemokine receptors.

Another argument supporting the use of R5 inhibitors is that the virus's ability to use other co-receptors may not be as significant as previous theories sug-

continued on next page

gest. Researchers at Aaron Diamond Centre, for example, found that although HIV can use other co-receptors to enter cells, the virus does not replicate in cells where the R5 co-receptor is missing or blocked.

Little is known about the different chemokine receptors among the various types of immune cells, or how important certain receptors might be. It also remains questionable whether all the cells infected by HIV can be protected by blocking the same chemokine receptors.

There are also many unanswered questions with respect to fusion inhibitors. One issue concerns the fact that genetic differences affect the expression and activity of co-receptors, which may result in substantial variation in the effectiveness of fusion inhibitors. Another identified problem is the difficulty of achieving adequate drug levels due to the influence of food when the drug is taken orally.

In addition, the necessity of maintaining peak or trough levels of the drug for effectiveness is unclear. If the key requirement for efficacy is that all receptors are blocked, peak levels will be more important because saturation is key. On the other hand, some researchers consider trough levels to be more important, because HIV needs to engage with multiple R5 receptors to gain entry to a cell; in this case, even if all receptors are not blocked, viral entry could be substantially limited.

Potential side effects also remain a huge unknown. Short-term studies of chemokine inhibitors have shown

no evidence of immunological toxicity. However, it is still uncertain whether or not interference with particular chemokines could induce other unwelcome immunological effects in the long-term. Since the chemokines in question can use several different receptors, it is hoped that other immune functions will not be affected. Chemokines are necessary for certain inflammatory reactions, and blocking particular receptors may lead to adverse consequences, especially in individuals with a prior history of opportunistic infections. Researchers will need to consider the subtle and profound long-term effects of inhibiting R5 receptors.

Finally, the blocking of the X4 co-receptor may prove to be dangerous as its role is much more important in many areas; in fact, X4 abnormalities observed in studies of mice ultimately proved lethal. Serious long-term consequences of blocking this co-receptor may take over five or six years to develop, and controlled studies of one or two years may not provide the long-term outlook to avoid adverse events. ⊕



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

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Life without meds

How one long-term survivor has made it through the years

by Nicole Kiyooka

During John Lavallée's 50 years, he has faced multiple health issues. In 1987, he was diagnosed with hepatitis C, followed by an HIV-positive diagnosis in 1991. He had surgery for throat cancer in 2001. A tracheotomy now helps him to breath properly; he speaks by placing a finger over the surgical incision on his throat.

From the time that Lavallée learned that he was HIV-positive, he made a conscious decision not to take any HIV medication. Other than having some difficulty speaking because of the tracheotomy, he appears to be in very good health. He is an energetic personality.



Nicole Kiyooka: When did you make the decision to not take any HIV medication?

John Lavallée: I have never taken any HIV medication since being diagnosed HIV-positive. But I did take medication for nine months when I had my tracheotomy in August of 2001. It was hard on me, so, I stopped taking it and I haven't taken any since then. I was very happy not to worry about the side effects. I have no regrets. It was not based on what my doctors said. My life has improved with not having to go to the doctor's every day. It was strictly a personal decision.

NK: Why did you make the decision to not take any HIV medication?

JL: I have no fear of death. I'm not scared. Eliminating fear adds to the quality of my life. It's not about being scared or fearing what will happen next. I feel wonderful. I can walk from here [Seymour Street] to Commercial Drive!

NK: Who or what do you look to for support in maintaining your positive attitude?

JL: It's something I've learned during my life. It's more of a progression. You grow up with different experiences and people in your life that shape the way you feel about life. I read books about life after death, positive thinking, and spirituality. If the front cover looks interesting, I'll pick it up. I've been having massages, reflexology, Reiki, and acupuncture since 1991. That's where I put my money. I'd much rather do that than take pills. Advocacy has been a tremendous part of my life—it helped with my throat can-

cer. The CHF [Complementary Health Fund] through the BCPWA Society has helped me with massages and vitamins. The Friends for Life Society has also been a great help in my life.

NK: What are the negative and positive issues you've faced in your life, as an HIV-positive individual with a visible physical disability, a tracheotomy?

JL: Living on disability is negative. I am broke after three weeks. I have no addictions. Money issues are a factor. Lack of money is stressful. People also assume that just because you have a disability that you should devote your life to doing commercials or giving talks to people. They forget that we are people, too. I've been at Friends for Life for five years now—doing mailouts, picking up pastries, and helping with special events. I volunteered for ten years at AIDS Vancouver with the food bank. Getting out and volunteering is important. It's important to get out of the house and do something. I've been a volunteer ever since I was diagnosed HIV-positive.

NK: What does being a long-term survivor mean to you?

JL: It means that I'm on the right track, following the right track. I'm not ashamed of having throat cancer, hepatitis C or being HIV-positive. Pride and dignity in one's life are important, regardless of whether or not you have an illness. Pride and dignity in oneself and other people. ⊕

Nicole Kiyooka is a Vancouver-based writer.



A tale of two futures

AIDS is not the same disease that it used to be

by Glyn Townson

During a recent HIV support group meeting at the BCPWA Society, a group of us were having a spirited discussion about the various classes of HIV drugs that are currently available, and their potential side effects and benefits. A newly diagnosed member of the group felt that some of us long-term survivors were being a bit too pessimistic; he thought we might be needlessly intimidating another young, newly diagnosed male facing his first round of medications.

Then, a few weeks ago, the editor of *Living +* received an irate voice mail message from a reader. He complained that we were fear-mongering when a recent article in the magazine

stated that it is “simply not true” to claim that the HIV epidemic is under control in Canada, and that it is no longer a killer. How could he possibly allow his HIV-positive partner to read this magazine, the caller asked, especially after her own doctor had told her she had nothing to worry about.

I began to realize how different HIV disease has become, and how someone who is newly diagnosed, and is just starting on highly active antiretroviral therapy (HAART), will experience the disease much differently than a long-term survivor who has lived with HIV since the beginning of the pandemic.

The changing face of HIV/AIDS

During the last 20 years of this epidemic, I have lost over 150 people—including two family members and a partner—to HIV disease. It surprises me that most newly diagnosed people I meet don't know anyone who has died from AIDS complications.

The face of HIV disease has changed dramatically over the years. With the advent of many new powerful drugs in the mid-to late-1990s, coupled with better tests and screening procedures, the death rate finally plateaued and, for the first time, began to slow down. With proper treatment and management of both the disease and many opportunistic infections, most people feel that HIV can now be viewed as a manageable, chronic condition rather than a death threat.

But this wasn't always the case. In the early 1980s, few services were available to those living with HIV, and it was predominantly viewed as a gay disease.

And old timer's perspective

I tested positive in May 1985, shortly after anonymous testing became available. Post-test counselling was limited, and what was available painted a pretty bleak picture. There were no drugs specifically designed for HIV at that time. Many friends became ill and some died very quickly.

From the mid-1980s to the early 1990s, life felt like a war zone. Quite often, men had to face the ordeal of simultaneously disclosing both their HIV status and their sexual orientation to their families. The gay community was slowly being annihilated. Many day, evening, and night watches were spent bedside at St. Paul's Hospital, as friends and partners wasted

Some of us older activists must still deal with the reality of years of experimental treatment and the unknown side effects of the new drugs.

away. Some had learned of their HIV status, or discovered tell-tale purple lesions—Kaposi's sarcoma—and, unable to bear the pain of what lay ahead, committed suicide. It seemed as though there was a funeral or memorial service every week.

I joined the Vancouver Persons With AIDS Society (now known as the BCPWA Society) in 1987. At the time, I was still able to work full-time, pursue continuing education, and travel. However, in February 1996, my health took a nose-dive and my HIV status deteriorated to AIDS. Unable to return to work, I went onto long-term disability and, eventually, CPP disability.

Fortunately, as my health declined, the new antiretroviral therapies became available. These new medications saved

many lives, including my own; however, they also came with challenges. Some of us taking these new high-powered drug combinations began to experience strange, unexpected side effects as our immune systems kicked into high gear. In July 1997, with my CD4 cell counts up and my viral load numbers down significantly, I developed a case of shingles that involved multiple nerve roots. I was hospitalized for over three weeks.

When newer HAART combinations were introduced, I didn't experience diarrhea, bloating, or fatigue—just a bit of nausea. However, I lost most of my body hair and started wasting. I lost 70 pounds in five months. As the pounds disappeared, hard fat deposits began to form around my mouth and waist (referred to by some as “crix belly”). I watched myself transform from a burly bear into a hairless otter in the matter of months.



Glyn Townson in 1998.

My doctor added three new HIV drugs to my arsenal, for a total of seven drugs. During the first few weeks on this new regimen, I again experienced nausea, fever, and fatigue. But after roughly three months, the side effects subsided and I started gaining weight. Blood work indicated that the new HAART combination had stopped the virus in its tracks.

Unfortunately, my liver was not happy, my blood sugar levels increased, and diarrhea returned with a vengeance. After another viral breakthrough, I decided to take a medication holiday rather than take additional drugs. I was able to stay off medications for over two years. That holiday came to an abrupt

continued on next page

halt when my immune system again began to fail, and my health started to deteriorate quickly.

My experiences have been much the same since then: new drugs added to my regimen, as they become available—followed by severe side effects, another medication holiday, plummeting blood counts, a bad chest infection, and then on to yet another new drug regimen.

The newly diagnosed experience

The picture is vastly different now for people who are newly diagnosed. Jim (a pseudonym) is a 28-year-old gay male, of South Asian descent, and born and raised in Vancouver. He was diagnosed with HIV in early July 2004. He believes that he probably seroconverted about three years ago, around the time he was exposed to hepatitis B. Though he recovered from the hepatitis, he contracted a number of other infections, including Giardia.

Someone who is newly diagnosed will experience the disease much differently than a long-term survivor who has lived with HIV since the beginning of the pandemic.

Persistently unwell, he decided to get tested for HIV. A health nurse from the Downtown Infectious Diseases Clinic telephoned him with his test results and gave him information about what services and support groups were available to a newly diagnosed person. With those referrals, he was encouraged to explore the BCPWA Society, AIDS Vancouver, and the support groups offered through St. Paul's Hospital in downtown Vancouver. He contacted the BCPWA Society, became a member, and joined the Wednesday night Body Positive support group.

Jim attended his first support group following an appointment with his doctor. His CD4 count was below 200 and his viral load was way out of range at over 100,000. Overwhelmed, he wanted to talk to other HIV-positive people about the meaning of these numbers and whether or not to proceed with the medications that his doctor recommended.

After only a few weeks on HAART, Jim's CD4 cell count climbed above 200 and his viral load dropped to below 2,000. His main complaints were about the drug-related side effects, such as fatigue, nausea, diarrhea, and general lack of energy.

Jim works on a contract basis in the hospitality industry and, fortunately, he can adapt his work schedule to meet his current health requirements. He has some worries about his work schedule until the side effects settle down, but is confident

about returning to full-time employment. At present, he is more concerned with the side effects from the medication than he is about being HIV positive.

Jim lives at home and decided to disclose his HIV status to his parents and siblings. They have been very supportive, but he worries that they need as much support and information as he does about learning to live with HIV.

Then and now

Listening to other people's experience on HAART is important. Each person responds differently to the medications. Many are fortunate and are able to tolerate fairly simple regimens with few or mild side effects. Others experience more severe reactions; some of these can be devastating.

Support groups, such as the BCPWA Society Body Positive group and the Carnegie Community Centre group in Vancouver's Downtown Eastside, are invaluable for peer-to-peer information. These groups offer understanding, practical support for issues such as body image problems associated with this disease, and emotional support and encouragement.

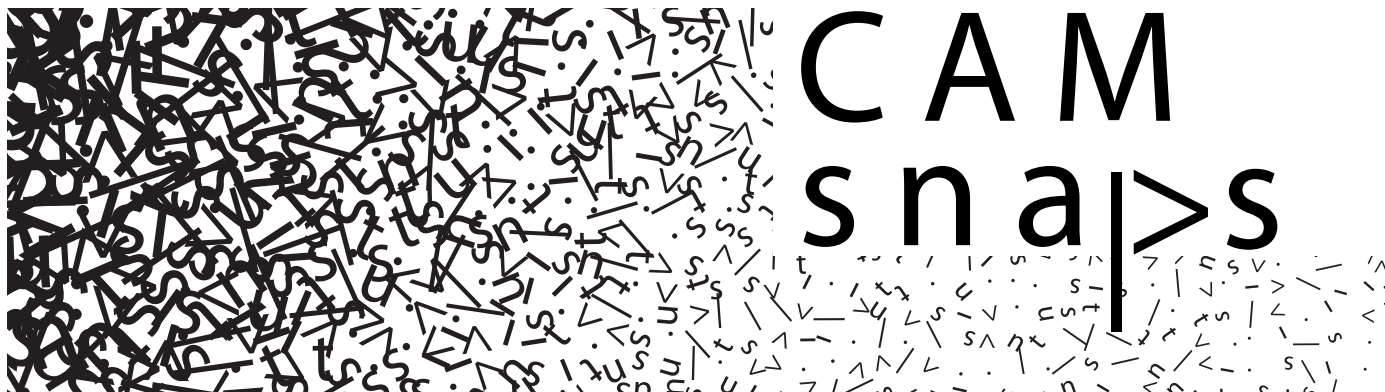
Since the mid-1990s, the AIDS pandemic has shifted considerably and now includes a large injection drug user population. Women are also increasingly affected. The issues around treating these new populations also create new challenges. There are also people who require HAART but don't have stable housing or they have other barriers to obtaining or taking medications at the required times.

At a recent forum held at the Carnegie Centre, Dr. Brian Conway stated: "Anyone newly diagnosed with HIV, provided with proper medical intervention and medication, would likely die from causes other than HIV." That is encouraging information to those newly diagnosed. But some of us older activists—though we are hopeful about this new information—must still deal with the reality of years of experimental treatment and the unknown side effects of the new drugs currently in the system.

Some people believe that HIV can be easily managed. Although the reality of living with HIV is better than it once was, there is no reason to let our guard down, especially with respect to prevention strategies. While there were reports in the late 1990s that HIV would be a thing of the past with the arrival of protease inhibitors, the virus continues to be a cunning and treacherous adversary. The mortality rate in BC may be down, but the number of people contracting HIV continues to rise. ⊕

Glyn Townson is a board member with the BCPWA Society.





by Tom Mountford

Tooth loss

Tooth loss is a major issue for people with HIV. Maintaining the ability to chew food is vital for digesting and absorbing nutrients from food. Proper absorption of food helps some drugs (including antiretrovirals) and supplements work effectively.

The rising rate of bone deterioration in the HIV infected population has recently gained medical attention. Most physicians now highly recommend calcium and vitamin D supplementation, as well as baseline bone mineral density tests to prevent and treat bone deterioration. In addition to skeletal bone loss in the hips and limbs, oral bone and tooth loss are correlated with bone deterioration in other parts of the body. A study among elderly people showed that calcium and vitamin D supplements aimed at preventing osteoporosis also had a beneficial effect on tooth retention.

Another study explored whether conventional black tea and herbal tea eroded dental enamel. The researchers also questioned whether herbal tea eroded dental hard tissues to a greater or lesser extent than conventional black tea. The study compared a conventional black tea, typhoo, with an herbal tea comprised of black currant, ginseng, and vanilla. Test results revealed tooth surface loss in both the conventional black tea and the herbal tea. However, the erosive effect of the herbal tea was five

times more severe than the conventional black tea.

The cumulative effects of regular herbal tea consumption may therefore be a long-term concern in tooth loss.

Yoga and sleep

Study results reported in a recent issue of the journal *Cancer* suggest that yoga can help ease sleep disruptions that often accompany cancer treatment. Research participants were either being treated for lymphoma or had completed their course of treatment in the past year. One group participated in Tibetan yoga classes for seven weeks, while the other group did

Yoga may improve cancer patients' ability to sleep by helping them cope with the stress caused by their illness.

no specific intervention. The patients who took yoga classes reported that they fell asleep faster, slept better and longer, and used fewer sleep medications than patients in the other group.

Yoga may improve patients' ability to sleep by helping them cope with the stress caused by their illness. Investigators believe that by incorporating spiritual and mental elements, therapies such as yoga can help manage issues such as

the psychological impact of dealing with a life-threatening illness and the side effects of treatment. Stretches and yoga poses can help the individual regain some of his or her physical conditioning and manage fatigue, while breathing and relaxation techniques can help a person deal with intrusive thoughts, such as fears of cancer recurrence or death.

The combination of gentle exercise, focused breathing, and meditation in Tibetan yoga may be especially helpful. All postures are low impact, and simple movements are easily adapted for people with limited physical mobility. With a focus on breath control, the exercises can be done sitting on a chair or the floor.

Unlike the more commonly practiced Hatha yoga, a Tibetan yoga program incorporates a combination of mind-body-breathing, and does not necessarily include stretching, balancing, or inverted poses that can be problematic for people with cancer to perform.

To avoid injuries that may result from balance or weight-bearing poses, consult your doctor before starting any yoga program. ⊕

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



Beating the blues

Holistic approaches to treating depression

by Devan Nambiar

HIV is a magnifying glass to one's life: if you have not dealt with certain issues, it will bring them to the surface. People living with HIV/AIDS are constantly negotiating quality of life and personal needs in an uncertain future of mental and physical health. Our life experiences and belief systems dictate our state of mind in this world of instant gratification. Add HIV, compromised health, and the psychosocial challenges of alienation, stigma, fear, ignorance, anxiety, lack of self-esteem, lack of confidence, and disclosure, and you potentially have all the makings for a life sentence of depression.

Depression is common among PWAs. Physiologically, scientists believe it is caused by the breakdown or deficiency of three chemical messengers in the brain: serotonin, norepinephrine, and dopamine. It can vary in severity from low-grade to long-term, or clinical depression. An assessment by a healthcare practitioner is carried out and includes a psychological evaluation. Depending on the diagnosis, treatment can include any combination of pharmacological interventions, lifestyle changes, counselling, holistic therapies, as well as vitamins and supplements.

Doctors are paying more attention to mental health in PWAs and great achievements have been made in the chemical treatment of depression.

Antidepressant drugs work by increasing the levels of the neurotransmitters serotonin, norepinephrine, and dopamine. These drugs typically take approximately four to six weeks to take effect and dosages may need to be changed or adjusted in order to achieve the best result.

Antidepressants do have their own side effects, but it is a question of weighing benefits against risks and disadvantages.

As many a gay man I have known has said: "Once I took my happy pill, the world was tumbling with colours and joy."

Looking beyond antidepressants

Most of the antidepressants that are currently prescribed will help people living with HIV/AIDS to resume their daily lives; however, they are not a panacea for depression. Many studies have shown that antidepressants work best in combination with psychotherapy: cognitive, behavioural, interpersonal, or solution-focused. Psychotherapy has a synergistic effect.

It also helps to do some personal introspection. Meditation is an invaluable tool for self-assessment and for developing self-awareness. This practice can assist you in getting in touch with your thought processes before they take root in your mind, and it will help you understand how you react to affirming or destructive thoughts. Best of all, meditation is free—you simply have to make time for it.

Nutritional supplements can also help treat depression. A supplement known as 5 hydroxytryptophan (5-HTP) is a form of the amino acid L-tryptophan. It helps boost levels of serotonin and may be as effective as prescription medications in the treatment of depression. However, side effects include anxiety, confusion, and drowsiness. Also, 5-HTP should not be taken with over-the-counter cold remedies containing pseudoephedrine or with other prescription antidepressants.

S-adenosyl-L-methionine (SAME) is a naturally occurring molecule that is present in almost every tissue and fluid in the body. It fuels numerous vital body functions. The body uses SAME for optimal functioning of proteins, nucleic acids, fats, hormones, dopamine, and serotonin. The liver also uses it to produce the antioxidant glutathione. In a pilot study of 20 PWAs, SAME improved quality of life and mood with no adverse side effects. It is widely prescribed in Europe for depression.

Vitamin B complex contains the full range of B vitamins. There are no known interactions with prescription medications. Vitamin B complex is important for nerve function as well as energy. In addition, PWAs can get B12 injections.

Researchers have discovered a link between mood disorders and the presence of low concentrations of omega-3 fatty

Most of the current antidepressants will help PWAs get on with their daily life, but they are not a panacea for depression.

acids in the body. Omega-3 enhances the ability of brain cell receptors to understand mood-related signals from other neurons in the brain. In other words, the omega-3s are believed to assist the smooth and efficient running of the brain's entire traffic pattern of thoughts, reactions, and reflexes.

A study at Harvard Medical School discovered that omega-3 fatty acids found in salmon, mackerel, tuna, sardines, and other deep sea, cold-water fish may have a positive effect on mood. In the study, a group of bipolar patients received fish oil or olive oil (placebo) plus lithium and divalproex sodium. After four months, 65 percent of the fish oil recipients demonstrated improvement related to their moods, compared with only a 19 percent change in the olive oil group.

Hormone levels can affect depression

Many PWAs, including women, have a low level of testosterone in the body. This androgenic or "male" hormone is important for muscle growth, libido, energy level, and mood. Symptoms of low testosterone include depression, fatigue, as well as a decreased interest in sex and food.

Testosterone therapy can increase energy and the libido as well as improve mood. However, the side effects can include acne, shrinking testicles, aggressive behaviour (roid rage), and feeling very agitated or restless. It can also decrease high-density lipoprotein (HDL), commonly known as the good cholesterol. In tests carried out on women, the low-dose testosterone patch did not cause any signs of masculinization.

Testosterone is available in gel, cream, patch, or injection formats. People using a gel/cream should avoid physical contact for 30 minutes to prevent the testosterone from being absorbed by the other person. Avoid testosterone therapy if you have prostate cancer or an enlarged prostate, or if you are diagnosed with polycythemia (excess red blood cell counts).

If you are considering testosterone supplementation, it is a good idea to include a testosterone test with your other blood work, to obtain baseline measurements of testosterone levels in your blood. Also, testosterone ranges can vary among different laboratories.

PWAs typically have low levels of dehydroepiandrosterone (DHEA), which is secreted by the adrenal glands and converted to estrogen and testosterone. While DHEA production usually decreases with age, these hormone levels can be determined through a blood test. DHEA was introduced as a youth hormone supplementation and a mood regulator in the 1980s, though it is still not available in Canada and must be purchased in the US. In studies with DHEA, some HIV-negative women experienced side effects such as greasy skin, acne, and body hair growth. Women with hormone-related diseases such as breast cancer should probably avoid DHEA. Discuss supplementation with your doctor.

An inactive thyroid gland, or hypothyroidism, can also cause depression. The thyroid helps with the body's metabolism. In hypothyroidism, the body isn't producing enough hormones from the thyroid gland. Symptoms of hypothyroidism are lethargy, very low metabolism, sleepiness, and low energy. Check with your doctor and ask to be tested for: thyroid-stimulating hormone (TSH); tri-iodothyronine (T3), which is free; and thyroxine (T4), which is also free.

Things to keep in mind

St. John's wort is not recommended for people taking antidepressants. It is also not recommended for PWAs on antiretroviral therapy. In particular, scientists found that St. John's wort reduced blood levels of the protease inhibitor indinavir (Crixivan).

Marijuana can have negative effects if you are suffering from depression. It can increase depression, anxiety, nervousness, and can also reduce motivation.

Optimal mental health requires an integrative healthy lifestyle, including maintaining healthy nutrition, exercising, socializing, quitting smoking, moderating consumption of alcohol and recreational drugs, and getting help to deal with life's challenges. Always speak to your doctor, pharmacist, and/or naturopath before you embark on a course of self-medication with complementary therapies. ⊕

Recommended reading:

▼ Feeling Good by *David D. Burns, MD*

▼ www.clinical-depression.co.uk



Devan Nambiar is actively involved in HIV advocacy, research, and integrative health.

Ask the dietitian

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

Outrunning the runs

by Ellie Schmidt

Sometimes I have diarrhea so bad that I can't leave my place. What can I do? Please help.

Clients ask me about diarrhea more than any other issue. It can be a serious concern, resulting in rapid weight loss, dehydration, and malabsorption of necessary nutrients. Since there can be many causes, talk to your doctor about it sooner rather than later. Here are some of the strategies that my clients have found helpful to manage the symptoms and possibly alleviate the problem. Remember that everybody—and everyone's body—is different, so you may need to try different remedies to figure out which approach is the best one for you.

Replace lost fluids. It is very easy to become dehydrated when you have diarrhea. Drink as much as possible, and as often as possible. However, avoid alcohol, all carbonated beverages, coffee, chocolate flavoured drinks, and caffeinated tea since these fluids all stimulate the bowel, as does smoking.

Drink flavoured sports beverages such as Gatorade and PowerAde to replace electrolytes (minerals such as sodium and potassium). Eat canned soups and crackers, which are high in sodium. To replace potassium, eat potatoes, bananas, and diluted fruit juices.

Eat soluble fibre, which bulks up the stools and slows the intestine, thereby reducing diarrhea. Foods high in soluble fibre include oatmeal, white rice, baked and boiled potatoes, bananas, apples, and pears.

Consume simple foods that are easily digested. Foods that may be more easily tolerated include cereals, pasta, bread, plain cookies, puddings, eggs, lean meat, Jell-O, unsweetened canned fruit, bananas, cooked carrots, squash, yams, and potatoes.

You may need to reduce the amount of milk you drink. Try Lactaid, a specially formulated milk for lactose intolerant people, or soy milk as good substitutes. Some people can manage small quantities of low-fat cheese and yogourt.

Try eating small, frequent meals—five to six times each day. Eat every two to three hours.

Avoid very hot or very cold foods, which can stimulate the bowel.

Stay away from high-fat foods which often make diarrhea worse.

Limit sweets. Foods that are high in sugar often exacerbate diarrhea.

Glutamine is sometimes used to treat diarrhea. Try 10g a day.

Finally, 1000mg of calcium a day can also be beneficial. Ensure it is calcium with no magnesium added.

A colleague told me of an Asian congee (rice-based soup) recipe that clients found useful. Boil 125mL of white rice in 1.5 litres of water for one hour. Add small pieces of vegetable, meat, or chicken. Season with salt or soy sauce. Eat the congee several times a day.

Remember: if you have diarrhea, prepare simple meals that a young child would eat. Too much of any food can aggravate a sensitive stomach. Too much sugar, too much fat, too much roughage, too much spice, too much volume—all can make matters worse. Be gentle. You are the best judge of what foods and strategies will work for you. Not every suggestion will work, but keep trying! ⊕

Ellie Schmidt, RD, is a community nutritionist with Vancouver Coastal Health and the dietitian at the Dr. Peter Centre in Vancouver.



The BUZZ on multi- vitamins

*Preliminary research suggests micronutrients
can help slow HIV progression*

by Pamela Fergusson



There is a new buzzword in HIV nutrition: multiple micronutrients. The July 2004 issue of the *New England Journal of Medicine* includes an article by a research team led by Dr. Wafaie Fawzi detailing a six-year study conducted in Tanzania, Africa; the research found that combinations of daily vitamin supplements delayed the progression of HIV disease in a population without access to antiretrovirals.

Dr. Fawzi has published some exciting and cutting-edge research. Just a few years earlier, he surprised the international HIV research community by revealing that daily dosing of vitamin A actually increases the risk of mother-to-child transmission of HIV. These types of findings demonstrate the powerful role of nutrition in HIV/AIDS.

For a long time, people have viewed vitamins and minerals with a “more is better” attitude, or a belief that because it is natural it can cause no harm. Dr. Fawzi’s research shows us that although the impact of micronutrients can be positive, it can also be negative under certain circumstances, so we should proceed with care and caution. While vitamins and minerals certainly cannot replace antiretroviral therapy (ART), they may have a beneficial impact in countries where ART is not available. We are also learning more about the role that multiple micronutrients may play in complementing ART.

The overall nutrition and HIV picture

HIV damages the immune system and can lead to other infections, causing fever and diarrhea. Some of these infections can reduce

nutrition intake and/or interfere with absorption of nutrients, leading to weight loss, malnutrition, and wasting. As a result, the body weakens, making it more difficult to fight infections. Maintaining a healthy weight and eating a balanced diet can help to counteract this cycle and slow the progression of HIV.

Malnutrition occurs when your body is not getting enough nutrients. The condition can develop for a number of reasons: you aren’t eating enough, you aren’t adequately absorbing your nutrients, or you have high energy needs due to infection or injury. There are many factors involved in malnutrition, and although it is alarmingly common among people living with HIV/AIDS in developing countries, the condition is certainly not limited to these regions of the world. In Canada, malnutrition is usually linked to poverty, and sometimes to drug and alcohol misuse.

You may think that malnutrition is easy to identify, based on experience or observation, particularly images on television of the wasted bodies of starving people. However, it is not easy to diagnose. Increasingly, hidden malnutrition is being discovered in industrialized countries. This condition occurs when people of normal or even excessive weight are eating sub-optimal diets containing high quantities of sugar and fat instead of the foods that comprise a healthier diet: whole grains, fruit, vegetables, low-fat dairy, lean meats, and legumes.

The foods we eat consist of two groups of nutrients: macronutrients and micronutrients. The macronutrients are carbohydrates, proteins, and fat. These nutrients provide us with the calories that give us energy. The micronutrients are vitamins and

minerals. Vitamins and minerals are essential to our body's health; they are used for many important functions, including boosting immunity. People who become malnourished when they do not eat enough food may be suffering from both macronutrient and micronutrient deficiencies. People with hidden malnutrition are more likely to be missing the micronutrients. Regardless, any type of malnutrition will weaken the body's immunity and hasten the progression of HIV disease.

A low-cost intervention

The micronutrient combination used in Dr. Fawzi's trial consisted of vitamins B1, B2, B6 and B12, niacin, vitamin C, vitamin E, and folic acid. This multiple micronutrient combination was tested on 271 HIV-positive women in Tanzania. The women receiving the micronutrients had a lower risk of death and progression to end-stage AIDS compared to the women in the study who took a placebo pill. Multivitamins also resulted in significantly increased CD4 and CD8 cell counts.

Three years before the publication of Dr. Fawzi's study, Dr. Andrew Tomkins and colleagues from the Institute of Child Health in London, England published similar results in a study of 481 HIV infected Thai men on multiple micronutrients. Their slightly more com-

plex micronutrient mixture contained vitamin A, beta-carotene, vitamins D3, E, K, C, B1, B2, B6, B12, folic acid, pantothenic acid, iron, magnesium, manganese, zinc, iodine, copper, selenium, chromium, and L-cysteine. They also saw a significant reduction in the risk of death, especially among those people with the lowest CD4 cell counts, when compared with people taking placebo.

A Tanzanian study found that daily vitamin supplements delayed the progression of HIV disease in a population without access to antiretrovirals.

"It's a low-cost intervention that could result in major savings and be helpful to many individuals in terms of better quality of life," Dr. Fawzi said in the *New England Journal of Medicine*. The high-dose multivitamins with vitamins B, C, and E used for the study cost about \$15 for a year's supply; antiretrovirals in Tanzania cost roughly \$300 a year.

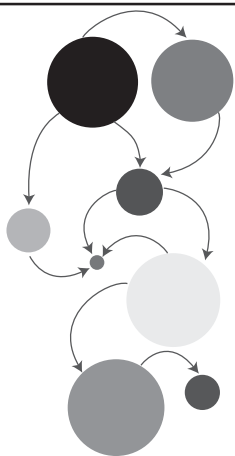
This research, though exciting, is preliminary and there is still much to learn about the interaction between micronutrients and HIV. A large trial is needed on the impact of micronutrient

supplementation among HIV-positive North Americans or Europeans who have access to antiretroviral therapy and better food security.

The World Health Organization's Technical Advisory Group on Nutrition and HIV/AIDS has reviewed the available evidence on micronutrient supplements and HIV/AIDS, and has concluded that adequate micronutrient intake is best achieved through an adequate diet. Concentrating on eating a balanced diet, according to Canada's Food Guide, will provide you with a healthy intake of both macronutrients and micronutrients. If you are interested in micronutrients, speak to a dietitian about good sources of such vitamins and minerals in food, and whether supplements might be appropriate for you.

Multiple micronutrients are not an alternative to antiretroviral therapy—neither in BC nor in sub-Saharan Africa. However, they may serve as a complement to ART for the Western world, and as a bit of hope for the HIV/AIDS crisis in developing countries. ⊕

Pamela Fergusson is a nutrition lecturer at University College Chester in the UK and works as a consultant in international HIV and nutrition issues.



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Popular booklet gives the low-down on clinical trials

by Jim Boothroyd

“Double-blind trial: Participants in this type of trial are divided into two or more groups: one gets the experimental treatment; the other gets the standard treatment or a placebo. Neither the researchers nor the participants know who is taking which drug until the trial is over.”

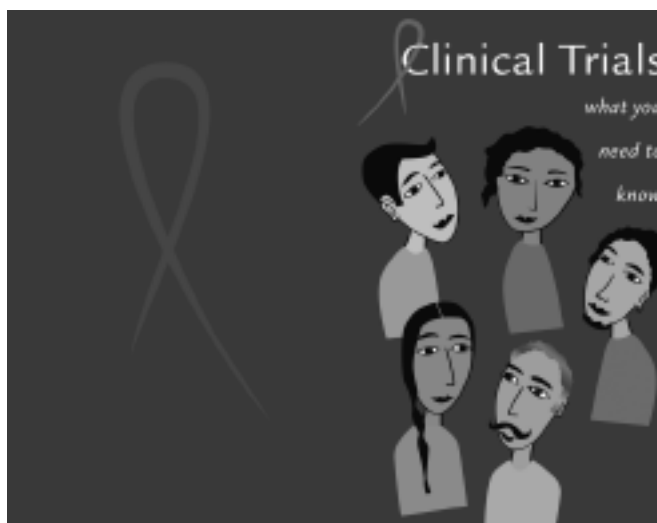
You'll find this definition, and 27 others, in the glossary of the third edition of *Clinical Trials: What you Need to Know*, recently published by the Canadian HIV Trials Network (CTN) in partnership with the Canadian AIDS Society.

Written in plain language for people living with HIV/AIDS and their families and friends, the popular booklet provides a wealth of basic information about clinical trials: how they are conducted, how to join them, and what to expect if you participate.

The text is arranged in a simple question-and-answer format. For example, the first main chapter, “About Clinical Trials,” addresses these questions, among others: What are the different types of trials? Who conducts trials? How do researchers assess results?

The next chapter, “Participating in Clinical Trials,” addresses other relevant questions, such as: Where can I find information about trials? How do I make a decision? What is an informed consent?

Other chapters discuss the stages of trial participation, the responsibilities of volunteers, the costs of trials, the procedures in cases of participants' illness, and the use of other drugs during clinical trials (heroin and ecstasy, as well as cough syrup and cold tablets).



One of the themes of the booklet is that people living with HIV/AIDS play key roles in research, as advisors to the CTN and as volunteers in trials.

For free copies of this publication, please visit the CTN Web site or call toll-free (see contact information below). ☎

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

Trials enrolling in BC

CTN 147 — Early Versus Delayed Pneumococcal Vaccination
BC sites: Downtown Infectious Disease Clinic (IDC) and St. Paul's Hospital, Vancouver

CTN 157 — Fenofibrate & L-Carnitine for Elevated Triglycerides
BC sites: Downtown IDC and St. Paul's Hospital, Vancouver

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

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

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

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

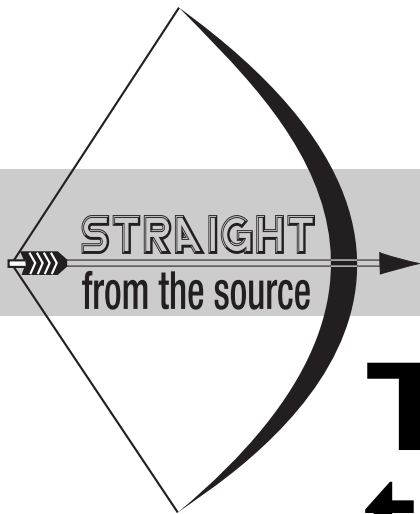
CTN 178 — Rosiglitazone Maleate (Avandia)
BC site: St. Paul's Hospital, Vancouver

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

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

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

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



what's new in research

The tricky teenage years

HIV-positive youth must deal with the challenges of adolescence and HIV

by Sarah Fielden

When was the last time you heard about an HIV-positive child or youth? There is little media coverage or published research devoted to this small but important segment of the Canadian population. HIV-positive children and youth are diverse in many ways, including their cultural backgrounds, medical outcomes, modes of transmission, as well as their family and social situations. Youth with HIV experience not only the ups and downs associated with adolescence and young adulthood, but also the multiple challenges of living with HIV.

Although there are less than 50 children born with HIV who are living in BC, many of them are fast approaching adolescence and young adulthood. Based on early outcomes of the disease in children, many of these youths were not expected to live to school age, let alone join their peers in high school and, subsequently, in the workforce. With developments in anti-retroviral therapies, coupled with the support of families, healthcare, and community services, many HIV-positive children and youth are living healthy lives and seem to be thriving in their surroundings.

A recent study conducted a broad assessment of the needs of older children with perinatally acquired HIV in BC. The investigation was conceived as part of a graduate research project at the University of British Columbia (UBC), and involved collaboration with other UBC researchers as well as the Oak Tree Clinic at the Children's and Women's Health Centre of British Columbia. The qualitative study consisted of focus groups and interviews with ten HIV-positive children and adolescents, ranging from nine to 16 years of age, plus 11 of their foster and/or biological family members, and 11 of their healthcare and community service providers.

The themes that emerged from the research ranged from issues around cultural identity to various health-related

concerns, including nutrition and medication. Stigma, sexual health, and mental health were among the major topics discussed in the focus groups and interviews. These issues may become increasingly important for the children and youth as they mature.

A family secret

Similar to their adult counterparts, children, youth, and their families fear disclosing their seropositive status to people in their communities because of the stigma associated with the virus. Experiences are mixed. Some children reported negative experiences such as losing friends; others have had strong support from friends, family, and community members. However, the study revealed that most children keep their HIV status secret.

Schools can be particularly troubling environments for HIV disclosure, with families and children fearing the reaction of peers, educators, and parents. Some families devise practical ways of allowing their children to enjoy routine activities without exposing their HIV status: parents may volunteer on school trips to ensure their child receives the care he or she needs.

"It's not really that great that I don't get to tell a bunch of people. But I kind of don't really want to, because I think they'd have a different opinion of me," said one teen. "Either they'd feel sorry for me, or they might look at me a lot different, or not like me because of this."

HIV-positive youth still perceive and remain sensitive to the public's ignorance. "It's not like you have a third eye or something," said another teen. "I can hug you, I can kiss you; you're not going to get it. People think that way. They're just way too paranoid and way too sketchy about everything. I don't think that people need to be educated in the way of what AIDS and HIV is—because obviously people know what it is—they need to know how people are with it."

Dealing with sexuality

The stigma of the disease influences many aspects of the lives of children and youth living with HIV, including their sexual and mental well-being.

Some of the young people involved in the research have already had sexual experiences. Like their HIV-negative peers, these youth receive sexual education from sources such as school educators, peers, family, clinicians, and the media. Families and professionals face the heightened challenge of educating HIV-positive youth not only about puberty, but also about the virus and its implications for future intimate relationships.

“What do you say to them?” asked one concerned family member during an interview. “I mean, are you allowed to go out on a date? Are you allowed to make out with somebody? What do you do? Do you reveal your whole medical history to someone?”

With all the messages they receive about HIV, these youth may find it difficult to have positive feelings about their sexual and intimate relationships. As one healthcare provider stated: “Give them a positive approach to their sexuality... it can get tainted so easily. These kids are so in touch with community resources, and a lot of them know about HIV—seeing posters [about] safe sex—all that stigma, all that anti-sexuality... they need to feel positive about their bodies and sex.”

These young people have the unique experience of developing their sexual identity within the context of living with HIV.

These young people have the unique experience of developing their sexual identity within the context of living with HIV. They are facing, or inevitably will face, very complex decision-making around sexual relationships, disclosure, and the possibility of family and children of their own.

Trying to be just a kid

Many of the young people involved in the UBC study were energetic, and demonstrated a positive attitude about their lives. Like other youth their age, they enjoy activities such as skateboarding, holidays with family, as well as shopping, hanging out, and other social activities with friends.

But, in other ways, their lives are far from typical.

Unlike most children, many of the youth in this study have experienced the loss of a family member to HIV. Many deal with issues such as illness and poverty. They may feel anxious about their future, and burdened by their family secret. Some express feelings of being different from their peers. The stigma of their HIV status may also cause them to fear social rejection.

All of these factors make it more difficult for HIV-positive youth to request and access community support. However, many study participants stressed the need to feel good about themselves and to have their self-esteem nurtured.

Youth-specific programs needed

HIV-positive youth are far from a homogeneous group. As a result, effective service delivery requires creative approaches that are flexible and open. The children and young people involved in this study are fortunate to have strong family support, quality healthcare, and assistance from various community service providers. However, what is lacking is youth-specific social and community programs to assist them in their adolescent transition and adult lives.



The youth participants in this study proposed numerous strategies for promoting the health of HIV-positive young people through education and support, including:

- ▼ Peer support, such as a youth group, drop-in, mentor program, or e-group.
- ▼ Family support services, including a buddy system or education sessions for family members.
- ▼ Professional services, such as an outreach worker or wellness program.
- ▼ Educational programs for communities, such as school-based education programs and a media campaign to reduce the stigma of HIV.

The children and youth tended to favour programs that incorporated social and recreational components, which allowed them to interact with one another and have fun. Some of the challenges to these programs include financial constraints, confidentiality concerns, and providing effective outreach to the relatively small number of children, at differing ages and stages of development, dispersed throughout the province.

Adolescence and young adulthood is a period marked by uncertainty and transition—as young people struggle to establish their place in their communities and in the world. HIV-positive youth need to be equipped with the knowledge and capacity to embrace their futures. Family, friends, schools, healthcare professionals, and community service providers have a continuing role to play in facilitating this process for all young people infected with and affected by HIV. ⊕

Sarah Fielden is a student in the Individual Interdisciplinary Studies Graduate Program with the Institute of Health Promotion Research at UBC and a Michael Smith Foundation for Health Research graduate trainee.





Lofty goals, but still no access for all

Conference delegates demand greater commitment and resources

by Enrico Mandarino

As part of the “access for all” theme of the recent XV International AIDS Conference in Bangkok, Thailand, a major component of the conference focussed on global strategies to provide antiretroviral treatment to all people living with HIV/AIDS. There was considerable discussion about two key initiatives: the Global Fund to Fight AIDS, Tuberculosis and Malaria; and the “3 by 5” initiative.

How it's supposed to work

In January 2002, the Global Fund to Fight AIDS, Tuberculosis and Malaria was established as a partnership between governments, the private sector, and affected communities to coordinate large-scale funding for programs aimed at fighting these diseases. However, the Global Fund is more than just a funding mechanism. It represents a global, unified force.

In terms of the Global Fund's response to HIV and AIDS, there are “three ones” to consider: one AIDS action plan, one coordinating strategy, and one monitoring system. The Fund has Country Coordinating Mechanisms (CCM), through which local stakeholders submit grant proposals for consideration, and under which implementation plans are monitored.

Since its inception, the Global Fund has distributed \$3.1 billion US to 307 projects in 129 countries. Another \$1 billion US is earmarked for 200 additional programs by the end of 2004. Over the full five-year terms of all programs approved to date, the Global Fund will have invested over \$8 billion, and hopes to finance antiretroviral treatment for 1.6 million people.

For the forthcoming round of funding, the Global Fund has reached a critical point in time and needs at least \$1.4 billion US for 2004 and \$3.4 billion US for 2005 in order to continue providing grants to developing countries. At the conclusion of the AIDS Conference, the United Kingdom announced a new pledge of £154 million over the next three years to support the Global Fund. This new pledge doubles the UK's current commitment for the 2005—2007 period. In the US, the Bill and Melinda Gates Foundation recently pledged an additional \$50 million to the Global Fund.

Aside from the Global Fund, a new US President's Emergency Plan for AIDS Relief (PEPFAR) pledges \$15 billion—\$10 billion of it new money—over the next five years for HIV/AIDS care, prevention, and treatment. These monies will be applied to 15 of the most seriously AIDS affected countries, mostly in Africa and the Caribbean, which account for 70 percent of all infections. The Plan aims to treat two million HIV-positive people and prevent seven million new infections over a five-year period.

What delegates had to say

There was considerable debate at the AIDS Conference about the ambitious World Health Organization's (WHO) and UNAIDS' “3 by 5” initiative, which was created to address the lack of treatment in developing countries. The initiative aims to provide antiretroviral treatment to three million of the estimated six million people living with AIDS

indifference kills

photo Wayne Campbell

around the world, by 2005. The projected cost of this initiative is at least \$5.5 billion. The “3 by 5” plan represents a step toward recognizing antiretroviral treatment as a basic human right and providing universal access to treatment for all who need it. To date, 40 countries have committed to achieving the “3 by 5” objective, although only an estimated 400,000 AIDS patients are currently receiving antiretroviral drugs.

Canada recently committed CAD \$100 million to the “3 by 5” initiative over the next two years and has doubled its grants to the Global Fund. “We are personally especially grateful to Canada that took a great risk on the ‘3 by 5’ work at WHO and gave us an enormously generous donation,” said Dr. Jim Yong Kim, the director of the Department of HIV/AIDS at WHO.

UN Secretary-General Kofi Annan implored the US to inject \$1 billion into the Global Fund. However, the White House’s global AIDS coordinator, Randall Tobias, said, “it’s not going to happen.” He indicated that the US was only giving \$200 million to the Fund for next year.

UNAIDS executive director Dr. Peter Piot argued that even achieving the objective of three million people on AIDS-specific treatments by 2005 is not enough. He argued that antiretroviral therapy is still a rare commodity and will continue be for some time. “The result of that is always higher price, and also higher price in terms of power and control: who has access to it, and who comes first,” Piot said.

Critics claim that the US’s decision to launch its own program undermines the Global Fund’s unified strategy in favour of its own donor-driven agenda. In order to receive money from the US plan, developing countries must support sexual abstinence over condoms as a pillar of policy. The plan also undermines an international pact, the Doha Declaration, to provide inexpensive generic AIDS drugs to the developing world.

The US is said to be imposing bilateral trade agreements on developing countries that will not allow them to produce their own low-cost drugs. Critics are accusing the US of placing patent rights ahead of patient rights because it is imposing these stipulations on Free Trade Agreements and it is requiring Federal Drug Administration approval for drugs purchased with US funds.

Scaling up access to treatment

At the AIDS Conference, Dr. Kim argued that with commitment and adequate resources, success is possible in the fight against AIDS. However, there are many barriers to scaling up access to treatment. The high cost of antiretroviral drugs is a significant obstacle. Other critical barriers to increasing access to HIV treatment services in the developing world include the limited number of trained service providers—including doctors, nurses, pharmacists, lab technicians, and community health workers—and a very weak overall healthcare system in many countries. In addition, increased HIV treatment services must go hand in hand with comprehensive HIV prevention efforts.

One important issue that must be addressed in order to scale up treatment worldwide is institutional and human capacity. In the countries most affected by the AIDS epidemic, the disease itself is contributing significantly to the human capacity crisis. At least 100,000 healthcare and community workers must be trained in order to achieve the goal of “3 by 5”—and that is only the beginning.

Another challenge involves drug availability and decreasing prices. People in developing countries need access to generic drugs. More and more countries must move toward local production of antiretrovirals.

Intellectual property also remains a problem. A key priority is to help countries take full advantage of flexibility in global trade agreements for the purpose of expanding access to AIDS treatments. We need greater efforts to ensure that countries are aware of their rights. We also need to guard against the inclusion of stricter than necessary patent provisions in regional trade agreements, since they undermine important flexibility that is extended to low and middle-income countries.

Treatment access programs cannot succeed unless there is real progress and concerted efforts to address the social barriers of stigma and discrimination that make people vulnerable and drive them away from seeking care. Treatment programs must be designed with the needs of women and other vulnerable groups in mind. In addition, prevention initiatives are also crucial to the success of treatment initiatives. Without a greatly expanded prevention effort, treatment is not sustainable. ☪

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





The Scientific Stuff

by Enrico Mandarino

Many researchers returned from the XV International AIDS Conference in Bangkok with the impression that the scientific agenda has taken a backseat to other issues. This year, no major breakthroughs around new treatments, prevention, or a cure for HIV were reported. While there has been enormous progress in the scientific understanding of HIV, new discoveries now come in small steps. There continues to be incremental progress on antiretroviral drugs, which may offer new ways to manage the virus and reduce adverse side effects.

July's Bangkok conference offered some valuable contributions in the following treatment-related areas:

- ▼ Novel therapeutic approaches
- ▼ Safety, tolerability, and efficacy of antiretrovirals
- ▼ Long-term efficacy without resistance
- ▼ Treatment options for highly treatment experienced patients
- ▼ Drug comparisons
- ▼ Drug side effects
- ▼ Simplifying treatment

What's the best HIV treatment?

There are currently 20 anti-HIV drugs licensed in the US and up to 1,333 possible drug combinations for the treatment of HIV. Three clinical abstracts, highlighted during the closing ceremonies of the conference, describe HIV treatments which are currently considered "the best".

Less adverse side effects/toxicity and better lipid profile in first line therapy

Study 903 was a Phase III, three year trial to evaluate the effectiveness and safety of tenofovir (Viread) compared to stavudine (d4T). Results showed that both the tenofovir and stavudine therapies can be effective and durable in treatment naïve women. The major differences between the drugs

were in terms of side effects. Those taking stavudine in this study experienced increased lipid elevations as well as peripheral neuropathy and lipodystrophy. Lipodystrophy was observed in 3 percent of patients on tenofovir compared to 19 percent of those on stavudine. Peripheral neuropathy was observed in 3 percent of those on tenofovir and 10 percent of those taking stavudine.

The authors concluded that the drug combination tenofovir, lamivudine and efavirenz, has become a preferred regimen for initial therapy; this effective and non-toxic combination can be given once daily with long-term tolerability.

Long-term potency without resistance

Study 720 is the longest running study of lopinivir/ritonavir (LPV/r; Kaletra), with new five year data on resistance. The authors concluded that results of extensive genotypic resistance testing showed the absence of resistance in treatment-naïve patients receiving LPV/r.

Long-term survival

Which antiretroviral regimens yield the best odds of survival in San Francisco?

Using surveillance data from San Francisco, patients who had AIDS before 1997, and who were treated with antiretroviral therapy from the start, were analyzed to determine which combinations of initial regimens yield the best odds of survival.

The study included 310 AIDS deaths and 1,161 AIDS patients alive through 2002. Regimens considered included, at a minimum, one protease inhibitor (PI) or one non-nucleoside reverse transcriptase inhibitor (NNRTI).

The authors concluded that patients in San Francisco initiating AIDS treatment with either stavudine/3TC/efavirenz or zidovudine/3TC/efavirenz had significantly better odds of survival than patients initiating with other combinations.

Antiretrovirals

Nucleoside Reverse Transcriptase Inhibitors (NRTIs)

Reverset (*dd4FC*)

Reverset is a new, once daily oral NRTI with specific and potent *in vitro* activity against wild type HIV-1 and isolates resistant to zidovudine, 3TC, and other NRTIs. A Phase II, ten day monotherapy study showed that reverset has potent anti-HIV activity in both treatment naïve and treatment experienced patients.

Protease Inhibitors (PIs)

Indinavir boosted with ritonavir

NRTI sparing regimens were presented as an alternative for patients failing a nucleoside-based regimen. One study explored the effectiveness of switching patients from a failing double nucleoside regimen to a combination of ritonavir-boosted indinavir in combination with efavirenz. At 96 weeks follow-up, 69 percent of patients were able to achieve and sustain a significant decrease in viral load. Improvements in markers related to toxicity, including hemoglobin and liver enzymes, were also observed.

Fosamprenavir calcium (*Lexiva/Telzir*)

Fosamprenavir is chemically similar to an earlier PI called amprenavir (Agenerase). Its advantage is lower pill burden; patients take two pills twice a day, or one pill twice daily when boosted with ritonavir

Long-term treatment resulted in sustained virological suppression, continued immunological improvements, and no selection of PI resistance over a 96 week period. The ritonavir combination was well tolerated by patients, with relatively few dropouts due to adverse effects. Moreover, results showed that 96 percent of patients taking this combination with other antiretrovirals had undetectable levels of virus after two years.

Lopinavir (*LPV/r; Kaletra*) monotherapy?

A pilot study to evaluate the safety and effectiveness of LPV/r as a single agent therapy in antiretroviral naïve patients presented 48 week results. This study showed substantial increases in CD4 cell counts. In addition, there were no significant adverse effects reported and no genotypic/phenotypic resistance was observed.

This non-comparative data suggests a possible treatment strategy that is now being tested in two randomized clinical trials, one of which uses LPV/r for maintenance treatment following induction with combined therapy. Potential advantages of this regimen include lower pill burden, sparing of multiple classes of antiretroviral therapy, limiting toxicity, and decreasing costs.

NEW Protease Inhibitor

Tipranavir (*TPV*)

Tipranavir is a PI with potent activity against multiple-PI-resistant virus. A study was conducted to evaluate the safety and tolerability of tipranavir alone and in combination with a second boosted PI, in highly treatment-experienced patients

who showed resistance. This analysis showed short-term safety and tolerability of tipranavir taken alone or with amprenavir, saquinavir, or lopinavir after four weeks of use. Current data indicates that tipranavir appears to remain active against strains of HIV-1 that are resistant to other PIs; phase III studies in clinical development are designed to confirm this data.

Entry Inhibitors

Enfuvirtide (*T-20;Fuzeon*)

Enfuvirtide is the first drug in its class to block HIV before it enters the CD4 cell. The drug is currently being used in treatment-experienced patients with advanced disease who have developed resistance to other anti-HIV drugs. There have been some promising results from clinical trials, particularly with respect to increasing CD4 cell counts following extended use (96 weeks). No new safety issues were identified during the studies, and there was no evidence of long-term or cumulative toxicities. The unique problem with enfuvirtide is that it must be given by injection, twice a day, and 80 percent of patients reported mild tenderness at the site of injection. The authors concluded that enfuvirtide-based therapy provides a significant long-term benefit.

Simplification

The Bangkok conference included numerous presentations on the subject of simplifying drug regimens and lowering pill burden which, in many cases, improves adherence to treatments.

Trizivir: three drugs in one single pill (*zidovudine/3TC/abacavir*)

This observational study evaluated the concept of induction/maintenance therapy with triple NRTI maintenance after quadruple induction therapy.

Forty-six antiretroviral naïve patients received the zidovudine/3TC/abacavir combination as well as LPV/r until viral load declined below detectable limits, after which the lopinavir was discontinued. The authors concluded that the induction maintenance strategy used was effective in suppressing viral load during Trizivir maintenance.

Another study enrolled 448 treatment-naïve patients to receive a four-drug induction phase of the Trizivir combination with efavirenz for 48 weeks. Follow-up at 96 weeks showed that 70 percent of the Trizivir/efavirenz group and 77 percent of the Trizivir only groups had undetectable viral loads. The authors concluded that simplification with a zidovudine/3TC/abacavir combination is a reasonable treatment option. ⊕

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



Anemia en personas con VIH

por José Gutiérrez

La anemia es un problema común en las personas con VIH. Y puede ocurrir en cualquier etapa de la infección. La anemia es una condición médica que ocurre cuando el número de células rojas (glóbulos rojos) se encuentra por debajo de la normalidad. Esto ocasiona falta de oxígeno para los tejidos del cuerpo. Muchas son sus causas y el tratamiento depende del origen.

Hay dos valores del laboratorio -que requieren muestra de sangre- que miden ciertos parámetros en las células rojas: hemoglobina (Hb) y hematocrito (Hto). La anemia se define, a menudo, cuando los niveles de hemoglobina se encuentran por debajo de lo normal (12 g/dl). Otros análisis de laboratorio que podrían ayudar a identificar el tipo de anemia son: conteo de reticulocitos (células rojas inmaduras), capacidad de conjugación del hierro, tasa hierro/TIBC, ferritina sérica, vitamina B12, y folato. También es importante descartar la pérdida de sangre interna, externa, menstruación, etc.

La anemia en las personas con VIH puede ocurrir en cualquier etapa de la infección y ha sido asociada con cortos períodos de sobrevivencia. Los síntomas habituales son: cansancio, fatiga, mareos, no dormir adecuadamente, irritabilidad, agitación, dolor de cabeza, náuseas, dolor abdominal, piel pálida, ansiedad y tristeza. Los síntomas pueden incluir lesiones orales, estomatitis angular (lesiones a los costados de la boca), problemas gastrointestinales, uñas quebradizas y cóncavas.

El tipo más común de anemia es la “anemia por enfermedades crónicas”. Hay muchos tipos diferentes de anemia que pueden afectar a la gente con VIH y las posibles causas son: infección por VIH y otras enfermedades crónicas, medicamentos para el tratamiento de VIH, infecciones oportunistas, desórdenes de la médula ósea, tumor o crecimiento celular anormal, deficiencia de hierro, folato, vitamina B12 y enfermedad renal.

Algunos factores que predisponen a la anemia son: progresión clínica de VIH a SIDA, conteo de CD4 menor de 200 cel/mm³, incremento de la carga viral, hepatitis C tratada con alfa-interferon y Rebetol. Las personas de raza negra o sexo femenino también tienen mayor predisposición a tener anemia.

Es muy importante informarse con su doctor para recibir un tratamiento apropiado. El doctor podrá ser el mejor guía a la hora de tratar los factores que causan la anemia y lograr incrementar los glóbulos rojos. Las indicaciones que los doctores suelen realizar para tratar la anemia son: hacer cambios en la dieta, tomar suplementos de hierro y/o tomar un medicamento para incrementar la producción de glóbulos rojos. En todos los casos se recomienda seguir las indicaciones de su doctor.

Si la anemia es debida a los bajos niveles vitamínicos o de minerales, el tratamiento que su doctor le prescribirá incluirá el agregado de ciertos alimentos y/o ciertos suplementos vitamínicos o minerales a la dieta. Con las pruebas de laboratorio adecuadas su doctor podrá realizar el diagnóstico de deficiencia nutricional y prescribirle una simple vitamina o suplemento mineral. Usualmente los doctores recomiendan consumir pequeñas cantidades diarias de multivitaminas y suplementos minerales. La anemia por deficiencia de hierro es la más común de las anemias por deficiencia nutricional. Y esta podría desarrollarse debido a la falta de hierro en la dieta, pérdida sanguínea o parásitos intestinales. El hierro se encuentra en los glóbulos rojos, y su papel primario es el transporte de oxígeno desde los pulmones al resto del cuerpo.

Las fuentes de alimentos con hierro son: carne magra (sin grasa), hígado de ternera, pollo o pavo de carne oscura, sardinas, judías, habas, hojas de mostaza, arvejas desecadas, espinaca en lata, nabo verde (rutabaga), brócoli, frutas desecadas, sandía, fresas, naranjas, jugo de tomate, cereales fortificados, panecillo de salvado, pan integral, avena, sopa de trigo, tortillas de maíz, etc. ☺

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:

Jeffrey Bear



Jeffrey is warm, helpful and full of humour – always keeping us on our toes with good natured pranks!

Ruth Marzetti,
Manager Information Technology

Volunteer history

I started volunteering at home as a caregiver with First Nations people in the early '90s, when there were few medications available. I then did some volunteer work with Healing Our Spirit, the Greater Vancouver Native Cultural Society, and then finally at BCPWA.

Started at BCPWA?

1998

Why pick BCPWA?

There didn't seem to be too many places to go to for help where I felt comfortable, until I came here in 1998. When I did finally come in for assistance, everyone was so helpful and friendly that I knew I wanted to be a part of it.

Why have you stayed?

Because the training and learning opportunities here are really good.

Rating BCPWA

Number One! For me, I didn't know a thing about computers and I was given a chance to learn. Now I am volunteering in the Internet Café as a team leader. That shows how much a person can grow and learn at BCPWA.

Favourite memory

My favorite memories would be the happy faces that I see everyday—Ruth, Marie, Mike, Jackie—and knowing that no matter where I am in the building, I can hear Billy's laughter ringing throughout the hallways.

Future vision of BCPWA

Keep the circle strong—it's working.



Interested in writing?

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

Volunteers should possess the following skill sets:

- Ability to analyze and distill information
- Excellent research and writing skills
- Ability to work independently

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

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

where to find help

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

BC Persons With AIDS Society

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

A Loving Spoonful Location

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

AIDS Memorial Vancouver

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

AIDS Prince George

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

Living Positive Resource Centre Okanagan

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

AIDS Society of Kamloops

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

AIDS Vancouver

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

AIDS Vancouver Island (Victoria)

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

AIDS Vancouver Island (Cowichan Valley)

t 250.701.3667

North Island AIDS (Campbell River) Society

t 250.830.0787

North Island AIDS (Port Hardy) Society

t 250.902.2238

AIDS Vancouver Island (Nanaimo)

t 250.753.2437

North Island AIDS (Courtenay) Society

t 250.338.7400 or 1.877.311.7400

ANKORS (Nelson)

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

ANKORS (Cranbrook)

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

Asian Society for the Intervention of AIDS (ASIA)

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

Dr Peter Centre

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

Friends for Life Society

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

Healing Our Spirit

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

McLaren Housing Society

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

Okanagan Aboriginal AIDS Society

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

Outreach Prince Rupert

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

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

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

Positive Living North West

Box 4368 Smithers, BC V0J 2N0
3862 F Broadway, Smithers BC
t 250.877.0042 or 1.866.877.0042
e plnw@bulkley.net

Positive Women's Network

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

Purpose Society HIV/AIDS program

40 Begbie Street
New Westminster, BC V3M 3L9
t 604.526.2522 f 604.526.6546

Red Road HIV/AIDS Network Society

804 – 100 Park Royal South,
W. Vancouver, BC V7T 1A2
t 604.913.3332 or 1.800.336.9726
e info@red-road.org www.red-road.org

Vancouver Native Health Society

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

Victoria AIDS Resource & Community Service Society

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

Victoria Persons With AIDS Society

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

Wings Housing Society

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

YouthCO AIDS Society

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

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

Upcoming BCPWA Society Board Meetings:

Date	Time	Location	Reports to be presented
November 24, 2004	1:00	Board Room	Executive Committee — Written Executive Director Report Financial Statements / October
December 08, 2004	1:00	Board Room	Standing Committees — Director of Communications & Education
December 22, 2004	1:00	Board Room	Written Executive Director Report — Financial Statements / November Director of Development
January 05, 2005	1:00	Board Room	Executive Committee
January 19, 2005	1:00	Board Room	Written Executive Director Report — Standing Committees Director of Treatment Information & Advocacy

The BCPWA Society is located at 1107 Seymour St., 2nd Floor, Vancouver.

For more information, contact: **Alexandra Regier, Office Manager**

Direct: 604.893.2292

Email: alexr@bcpwa.org

BCPWA Standing Committees and Subcommittees

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

Board & Volunteer Development

Contact: Paul Adomako

☎ 604.646.5377

✉ paula@bcpwa.org

Community Representation & Engagement

Contact: Adriaan de Vries

☎ 604.893.2298

✉ adriaand@bcpwa.org

Education & Communications

Contact: Lisa Gallo

☎ 604.893.2209

✉ lisag@bcpwa.org

Positive Gathering

Contact: Stephen Macdonald

☎ 604.893.2290

✉ stephenm@bcpwa.org

IT Committee

Contact: Ruth Marzetti

☎ 604.646.5328

✉ ruthm@bcpwa.org

Living + Magazine Subcommittee

Contact: Jeff Rotin

☎ 604.893.2206

✉ jeffr@bcpwa.org

Prevention

Contact: Paul Adomako

☎ 604.893.2225

✉ paula@bcpwa.org

Support Services

Contact: Jackie Haywood

☎ 604.893.2259

✉ jackieh@bcpwa.org

Treatment Information & Advocacy

Contact: Tarel Quandt

☎ 604.893.2284

✉ tarelq@bcpwa.org

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F*** 'em if they can't take a joke



A healthy dose of cynicism goes a long way

by Derek Thaczuk

Long-term survivor strategies always seem to stress one thing: a positive attitude. Don't let those clouds get you down. Find the silver lining and turn that frown upside down. When life hands you lemons, make lemonade. Turn

the other cheek and keep on truckin'. Tomorrow is another day and everybody sing!

Oh man, just kill me now.

I hate to be a wet blanket party pooper, peeing in the Cheerios. I'd love to be Mr. Chipper, but some days it just ain't in me. And you know what? Judging by what I see around me, there are plenty of others like me out there.

Don't get me wrong—I'm not out to spoil anyone's fun. In fact, I secretly love sunrises, flowers, hugs, and fluffy kitty cats. Even people! (Well, some of them. After all, you have to get the hugs from somebody.) But those candy-coated Mary Poppins/Little Orphan Annie types singing "Tomorrow! Tomorrow!" make me barf.

So how is it that I'm still alive and well after 14 years living with HIV? I listen to Tom Waits and Marianne Faithfull, not Britney Spears and show tunes. I'd throw a brick through the television if I had to watch Oprah and Dr. Phil. Give me John Waters and William S. Burroughs any day. (And Lord help Mary Poppins if I ever run into her. She'd be jammed into a chimney with that umbrella sticking out her rear.)

I think there's a closeted type of long-term survivor: the Sarcastic Cynic. Way back when, in my very first HIV support group, this became all too apparent. Right then and there, during a discussion of positive thinking for a positive life, the group pretty much split into two camps: the happy people, the silver-lining gang; and my crowd, the back-of-the-classroom types, shooting looks at each other and making little gagging gestures.

Most of us have made it through the years, each in our own way. Different strokes for different folks. I say: I won't rain on your parade if you don't make me hold hands and sing "The Rose" at mine.

But let's be serious for a moment. The world isn't all kitty cats and flowers—if it was, I wouldn't have to be a sarcastic S.O.B. The reality is, bad things happen to good people and, sad to say, we've all seen more than our share of bad things. Some hurt worse than others: betrayals and backstabbing, or people who hurt you when you're trying to help them. I get far angrier with those people than I do over some stupid virus.

When jasmine-scented candles and singing "Kumbaya" don't cut it, a good bitch session and lots of sick humour can work wonders.

So, what's a guy or gal to do when it's hard to rise above it? I try—Lord knows, we all try—to keep smiling, to forgive and forget, to find the positive, and to move on. But sometimes it takes a saint to do those things, and most of us aren't Mother Theresa.

That's when the Sarcastic Cynic takes charge. When jasmine-scented candles and singing "Kumbaya" don't cut it, a good bitch session and lots of sick humour can work wonders. Not everyone shares my sense of humour, but like Bette Midler said, "f*** 'em if they can't take a joke."

Maybe one of these days, while in yoga class or on a nature walk or in that ylang-ylang scented bath, I'll have that cosmic vision of all-embracing love and forgiveness. Until then, though, when life hands me lemons, I'll make kickass bourbon sours.

Cynical survivors, come out of your closets—this round's on me. ☺

Derek Thaczuk is a freelance writer and health educator who secretly cries at Disney films.