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British Columbia Persons With AIDS Society

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

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think+

opinion and editorial

At Home and Abroad

by Louise Binder

Canadians define themselves as a nation by their social programs, particularly universal healthcare. We see Canada as a country that supports universal human rights and is responsive to the needs of its citizens. Yet between this belief system and the reality of drug access is a huge gap, both domestically and in international policy.

These two areas are inextricably linked. The solution to one has potentially serious implications for the other. Internationally, prevailing opinion says that developed countries should pay more for drugs than developing countries. We have larger markets; we can afford to pay more; we should subsidize the cost of drugs accessible mainly to us. Research and development are built into the cost of these drugs. We should also require drug companies to direct a portion of their research to areas that may not be lucrative but in which research is sorely needed, such as conditions that do not have a large profit-generating market. After all, we give pharmaceutical companies 20-year patents for the drugs they market, and subsidize research through direct government funding and tax credits. The pharmaceutical industry ranks as the most profitable in the world year after year.

It's not too much to ask that government regulate towards equitable global pricing. We should drop the ban on generic manufacture in Canada of drugs meant for the peoples of developing countries.

The problem with a single country like Canada doing this alone is the pressure that will be brought to bear. Drug companies want us to abandon drug pricing protection in Canada, even the limited amount of the Patented Medicine Prices Review Board. They do not want pricing protection here because the US market, much larger than ours, is mainly unregulated. We set a "bad" example. They threaten that if we tighten our rules any further, they will simply stop marketing drugs here.

As it is, Canadians with HIV/AIDS do not have universal access to treatments. Provincial ministries of health decide what we receive based on the impact each drug has on their drug reimbursement budgets. If we agree to pay whatever the companies ask (which I am not suggesting at all), either to ensure access to the drugs in Canada or to subsidize the price of drugs in the developing world or both, we will ultimately lose access. Provincial health budgets just will not be able to respond to unregulated, escalating costs. Consequently we could not subsidize drugs in the developing world either.

Canada can be a leader in resolving this critical global issue. We must support the principles of universal healthcare and access to treatments, and champion these principles in both the developing world and the rest of the developed world. Canada should use its international position to bring together other governments to create a common drug pricing strategy that will recognize the need for access in both the developing and developed world, with prices here that subsidize prices in the developing world. ⊕

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

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

REALITY BITES

Community Based Research

Western Canada's first Community Based Research (CBR) Program for HIV/AIDS has begun, hosted at BCPWA. Dr. Francisco Ibáñez-Carrasco joins BCPWA's staff as the research technical assistant for the CBR program. The program is funded by Health Canada and housed at the new Prevention Department of the BCPWA. The mandate of the CBR Program, in collaboration with an Advisory Committee, is to support BC HIV/AIDS community organizations in all aspects of their research. The support ranges from preparing funding proposals to implementation. In community based research, people living with HIV/AIDS are active collaborators in research. The CBR program will strive to motivate and prepare community organizations for new research projects that include PWAs' direct participation. Soon, the CBR program will outreach province-wide. You can reach Francisco at 604.893.2281 or at Francisco@bcpwa.org.

Dr. Francisco Ibáñez-Carrasco

New BCPWA Support Groups: AA & NA

Two new support groups have begun at BCPWA: Alcoholics Anonymous & Narcotics Anonymous. Twelve Step Groups are fellowships who share their experience, strength, and hope to solve common problems and help each other with the process of recovery from addiction, providing steps to living a more functional life. Since the beginning of the HIV epidemic, "positive" members of Twelve Step Groups have used the steps to address the difficulties of living with HIV. Friends, lovers and care-givers who are not HIV-positive also find that the stresses of being affected by HIV can be lessened through the support and understanding of others in such groups. The BCPWA Society has a foundation of Twelve Step thought, through one of the founders: Taavi Nurmella, a past member of A.A. Please call Mike at 604.893.2258 for more info.

Positively Sober (A.A.) Wednesdays 7:30 PM in the Board Room.
New Hope (N.A.) in the Lounge, Thursdays 7:30 PM.

Important New Pharmacokinetic Data for Reyataz *in Combination With Viread*

Important new pharmacokinetic (PK) data concerning the coadministration of Reyataz™ (atazanavir sulfate) and Viread® has been released by Bristol-Myers Squibb Company. Currently under review at the US Food and Drug Administration, the recommendations state that clinicians should use caution when administering unboosted Reyataz with Tenofovir DF. Unboosted Reyataz may be less effective due to decreased atazanavir concentrations in patients taking Reyataz and Tenofovir DF. As a result the coadministration of unboosted Reyataz with tenofovir DF may lead to loss or lack of virologic response and possible resistance to Reyataz. Reyataz has been approved in Canada.

www.thebody.com/fda/bristol_warning.html?m8

Genetically Modified Vaginal Bacteria Could Serve as HIV Prevention

Researchers have genetically modified bacteria normally present in the vagina in hopes that it could be used to protect against HIV infection, according to a study published in the Sept. 8 online edition of the Proceedings of the National Academy of Sciences. Researchers from Stanford University Medical Center genetically modified a strain of Lactobacillus jensenii — bacteria abundant in mucous secreted by the mucous membrane lining the vagina — to produce the protein CD4, which binds to HIV. Once HIV latches onto the protein, the virus is destroyed by other substances, such as lactic acid, that naturally occur in the vagina. Researchers said that the findngs could lead to the development of a vaginal suppository that women could use once per week to prevent HIV transmission.

www.thebody.com/kaiser/2003/sep10_03/hiv_prevention.html?m13

Canadian HIV/AIDS web community launches www.POZCanadian.com

POZCanadian.com launched this fall, a member-based, non-profit Canadian web community providing support; news about traditional and alternative treatments; resources; book reviews and organizations; discussion forums; personals; chat and e-mail.

POZCanadian.com is meeting a demand for HIV- positive Canadian web users, who have been signing up quickly. The site is secure — individuals can remain anonymous.

www.pozcanadian.com or contact: webmaster@pozcanadian.com

REALITY BITES

Structured treatment interruption in patients with multi-drug-resistant HIV

A study recently published in the New England Journal of Medicine has very important implications for structured treatment interruptions. This randomized study was designed specifically to assess rates of disease progression and/ or death following a structured interruption of treatment. The researchers hypothesized that stopping treatment for 16 weeks would cause wild-type virus to become dominant again, enabling better virologic control and immunologic response when treatment re-started. Although equal numbers of deaths occurred in each group, significantly more primary disease progression was observed in the group that interrupted treatment. And although the CD4 cell count recovered after re-initiating treatment, it remained consistently lower in the treatment-interruption group than in the control group for 20 months. Nearly half of all disease progression indicators occurred in patients with a baseline CD4 cell count of less than 50 cells/mm3. The two most common primary disease progression events were esophageal candidiasis and P. carinii pneumonia (PCP).

Possible cause of dementia in HIV-positive people discovered

Dr. Chris Power, a neurology professor at the University of Calgary, headed the research reported in Nature Neuroscience. They found that HIV breaks down molecules in the brain, turning them into toxic enzymes. The enzymes kill neurons or brain cells, which causes dementia in about 20 per cent of those infected with HIV. The team also found a lead on a potential treatment. A pre-existing drug called prinomastat seemed to get into the brain and protect neurons effectively, but has only been tested in tissue samples and on mice. They're hoping to move to human trials soon. With the testing and protocols, the drug likely won't be available for another five to 10 years. In the meantime, they hope the research can be used to gain insight into other dementia-related diseases such as Alzheimer's.
Source: CBC

Two years after historic UN session on HIV/AIDS, Member Nations fall short

Two years after a historic session of the United Nations General Assembly on HIV/AIDS, many UN Member States will not meet basic AIDS prevention and care goals set in 2001 unless efforts are dramatically scaled up, according to the UN Secretary-General and the Joint United Nations Programme on HIV/AIDS (UNAIDS). "We have come a long way, but not far enough," said UN Secretary-General Kofi Annan. "Clearly, we have to work harder to ensure that our commitment to the fight against AIDS is matched by the necessary resources and action." The reports state that the current pace of activity on HIV/AIDS is insufficient to meet the 2005 goals agreed to by all nations at the Special Session. The goals focus on rapid expansion of HIV prevention, care and impact alleviation programs and are seen as vital to achieving the UN Millennium Development Goal of halting and reversing the epidemic by 2015. For a report summary, see www.unaids.org/html/pub/Media/PressReleases01/UNGASS_Pressrelease_2003_en_doc.

Nasal Spray for HIV treatment

A nasal spray of a synthetic protein fragment called Peptide T may be successful in lowering the amount of latent HIV-infected cells, according to preliminary results of a small human pilot study. Latently infected cells contain a "reservoir" of HIV that fuels the disease but cannot be reached with antiretroviral drugs, according to the Journal. Although there was no change in the patients' viral loads, after 32 weeks on the nasal spray, levels of HIV in a key type of white blood cell was significantly reduced. The next step is placebo-controlled trials.
http://www.thebody.com/kaiser/2003/sep30_03/hiv_nasal_spray.html?m16#

Daily Combo Halted.

A study examining the effects of a once daily 3 drug combination of 3TC, abacavir, and tenofovir in treatment-naive patients was recently halted because it was found that approximately 50% of patients receiving this therapy had a low virologic response, compared to only 5% in another group receiving 3TC, abacavir, and Sustiva. Another study of 20 patients on 3TC, abacavir, and tenofovir also showed a poor response.

At this point no one is really sure why this has occurred. Speculation is that it might be a drug interaction between abacavir and tenofovir, resulting in decreased drug efficacy. The Centre for Excellence is closely monitoring all patients on any combination involving tenofovir and abacavir. At this point they are NOT recommending that people stop their medications. If they have questions or concerns they should discuss them with their physician. ⊕

Representation Agreements

Planning for what you want

by Raymond Campeau

Autumn has come and life is getting busier. The heat of summer has passed and the cool breezes of autumn freshen our outlook, clear our minds, and inspire us to act. Suddenly, it is time to organize personal affairs.

For HIV-positive people, clearing and vetting what we value, or don't need, is an important part of this process. Decisions have to be made: whom can you really trust, whom can you count on, and who will be there for you? In case of sickness or incapacity, you need to know whom you can turn to for support. I find it a vigorous personal inventory, an incredibly life-affirming act, declaring my true wishes and true values. It is a time of making decisions for the future. Many people put this organizing off until it is too late.

Tools to help loved ones put our wishes into action are available. Not only do they confirm your wishes for your life, but they also provide your trusted supporters with guidance. Two types of legal documents enable you to put your choices in writing, an enduring power of attorney and a representation agreement.

An *enduring power of attorney* is a tool for planning for the disposition of financial and property matters only. It cannot address more personal issues such as healthcare.

A *representation agreement* grants your representative the broadest reach in health and personal care matters. It can also grant powers for financial decisions. Two types of representation agreements are available, agreements with standard powers (also known as a section 7) and agreements with additional power (also known as a section 9).

The standard power agreement does not require legal consultation and does not need to be notarized. You can draft it yourself. You require two people to witness your signing of the document. They, in turn, must complete a certificate of witness. The person to whom you grant power over your finances and healthcare is called your representative. He or she must also sign the agreement, but witnesses to the representative's signature are not required. Your representative must complete a certificate of representative.

It is a vigorous personal inventory that can be incredibly life affirming.

You must appoint a *monitor* unless your representative is your spouse or a trust company. The other exception to the monitor rule is if you grant financial powers to at least two representatives and direct them to act together. The monitor is a safeguard to make sure your wishes are carried out and your representatives act honestly and are fulfilling their obligations.

What a representative can do on your behalf

A standard power agreement allows for routine management of financial affairs and handling of minor and major healthcare issues. This standard power agreement does have limits. It is absolutely critical that the representative be aware that the regulations list seven activities that do not constitute routine management of an adult's financial affairs. The full list is found in Section 2 of the regulations. Examples of prohibited actions by the representative include purchasing or disposing of real estate; using or renewing credit cards; and guaranteeing a loan. This power does not allow the representative to make a decision regarding the refusal of life-supporting care or treatment.

Agreements with additional powers.

These agreements confer sweeping powers to the representative. Those powers include selling real estate, refusing life support, and making temporary arrangements for the care of minor children. These powers are very broad, and consultation with a lawyer is therefore required by law.

An enduring power of attorney and a representative agreement are the legal tools for an appointed person to act on your behalf regarding the day-to-day running of your life. You may only need one of these documents, but some people prefer having both. They are available for your benefit.

The most important action you can take today is to get started on a care plan for tomorrow. ⊕

Raymond Campeau is currently an assistant to the Treatment Information Program and Advocacy Department.

愛滋病毒和压迫

Behind the Great Wall

Activists in China struggle against HIV and their government

By Jeff Anderson

A Eurasian AIDS epidemic is coming. Over the next 25 years, this epidemic will match or exceed the entire worldwide epidemic to date. Conservative projections place the growing epidemics in Russia, India, and China at 66 million infections over the next 25 years, compared to the current world total of 65 million. Those on the frontlines of the fight against AIDS today face a weary public suffering from urgency fatigue and world governments consumed with terrorism.

In China, even with immediate action, the costs and effects of current cases will be felt for decades to come.

At current rates, incidences of HIV are doubling every 18 months in China and will continue at that pace throughout this decade. Like most governments, China was slow to admit HIV existed, but the Chinese government now date the country's first cases in 1985. In 2000, health authorities in Beijing announced that 600,000 Chinese were HIV positive. In July 2002, UNAIDS set the number of PWAs in China at 850,000. Beijing did not dispute that figure. Just two months later, however, the Chinese Ministry of Health raised the official estimate to one million. Some suggest the total is much higher.

Recent years find increasing accounts of beatings, detentions and official reprisals against activists and people with HIV.

A million HIV cases were reportedly contracted from the mid-1980s to mid-1990s through unsanitary government-approved blood-buying stations, but it was not until 2001 that the Chinese central government acknowledged responsibility for spreading HIV. Foreign Affairs, the staunch American international affairs publication, states that "the province of Henan alone might already have 1.2 million HIV carriers."

The Chinese government has responded to HIV/AIDS with violence and repression.

China is at the precipice of a health disaster. In 2000, approximately 30,000 new infections occurred. By 2012, some estimate at least one million, perhaps four million new infections will occur each year, leading to conservative cumulative estimates of 32 million new HIV cases by 2025. Worse case scenarios predict a "severe epidemic" by 2025 of 100 million people with HIV/AIDS. By then, deaths will have risen to 20 or even 60 million. This imminent wave of infections is developing in the usual high-risk groups: two-thirds of current persons with HIV are heroin addicts who shared injection equipment, the next largest group is people infected by tainted blood products and needles, and the third largest group is gay men, especially in the major cities of Beijing and Shanghai.

Backlash and Reprisal

"Silence equals death" has been a truism of AIDS from the beginning. Governments consistently denied the extent of the epidemic in western countries, Africa, and now in China. China's struggle is compounded by little public awareness of HIV and the particularly oppressive response of government and police officials. In rural China, entire villages have been devastated. People are desperate for treatment and support. Worse still, accounts of beatings, detentions, and official reprisals against activists and people with HIV are increasing.

As recently as last June in a small farming village in Henan province, police beat and harassed people with HIV and their families. Of the 3,000 residents in Xiongqiao village, approximately 700 have been diagnosed HIV positive, and 400 of them have developed AIDS, according to locals. Agence France-Presse (AFP) reported, "Hundreds of police officers and hired thugs stormed an 'AIDS village' in central China last month, smashing TVs and windows, indiscriminately beating up residents and arresting 13 farmers, villagers said." Many more

individuals were reported arrested. Desperate rural farm families are unable to pay for HIV medicine and to support their families. One woman interviewed by AFP said farmers had repeatedly gone in groups to government officers to report that local officials had not issued monthly government subsidies of about 200 yuan (US$24) for HIV medications. Poverty in rural China extends far beyond HIV and includes increased fines for exceeding the official one child per family policy. County officials even demand a share of harvests.

International Exposure Takes Effect

The extent of the spread of HIV/AIDS in Henan became better known last year after the most prominent HIV/AIDS activist in China, Dr. Wan Yanhai, head of the Beijing-based Aizhi Institute (www.aizhi.org), published lists of people who died in Henan province of HIV/AIDS related illnesses. He was arrested on suspicion of "leaking state secrets," but he was released one month later because of the international outcry.

As Human Rights Watch (HRW) and the Canadian HIV/AIDS Legal Network prepared to present their first International Award for Action on HIV/AIDS and Human Rights to Dr. Wan, Amnesty International issued an urgent action alert about his arrest and hundreds worldwide protested Dr. Wan's detention. Not released in time to receive his award in Montreal, his wife spoke in his stead, and her intensity burned hotly. This September, Dr. Wan traveled to the annual general meeting of the Canadian HIV/AIDS Legal Network, and I had the opportunity to speak with him. He spoke cautiously about whether external civil pressure was helpful. He asked for treatment and technical assistance directly to local support groups and for inter-governmental pressure to educate officials about international expectations for health and human rights.

Most telling of all was his statement of the most pressing issues for PWAs in China today. Without hesitation, he noted the "lack of political support for PWA leadership. We need information and resources to start organizations of people with HIV to present their feelings and opinions, to speak freely." He confirmed he does not have HIV, and he pleaded for PWA group leadership.

At the time of the arrests in Henan, a county police official said the arrested farmers, some believed to be AIDS sufferers, face sentences of three to five years in jail. He accused the farmers of being "bullies." He said, "They beat up the Wulong township's police station director and deputy township director and the local family planning director."

"Persecuting HIV-positive protesters is doubly outrageous given that the state was complicit in their infection in the first place," charges Joanne Csete, director of the HIV/AIDS program at Human Rights Watch. HRW charges that Liu Quanxi, who headed the Henan Province Department of Health, ran the region's blood business during the 1990s, when millions received tainted blood. He was promoted in February to deputy director of the Chinese Communist Party's health committee. Chen Kaiyuan, who headed up the Henan Communist Party and blocked all media access to the AIDS-plagued villages and arrested locals who gave information to foreign reporters, was recently named president of the Chinese Academy of Social Sciences.

"We need information and resources to start organizations of people with HIV…".

Despite official intransigence, China does have some encouraging numbers to report too. The smaller percentages of infections among women (about 20%) and the reportedly high use of condoms among female prostitutes (over 50%) may account for the relatively low 2002 UNAIDS estimates of 4000 HIV-infected children and 7,600 orphans. But, studies show that infection rates are soaring among prostitutes and "wash house" girls. Good news can be found in the IDU communities where use of clean needles increased by half in two years to 45% in 2001. In the drug treatment arena, a Chinese herbal concoction known as "626 series" is used to detoxify drug users. The medications are believed by the treatment directors to be safe, effective, easy to use, cost-effective, and free of side effects. Chinese herbal medicines are being developed to contribute to HIV treatment regimens. An herbal medicine called Gong-min Anti-HIV "was reported to restore the immune system and eliminated herpes lesions among formerly immuno-compromised AIDS patients."

Government officials speak of HIV as a problem confined to Henan bloodsellers and intravenous drug users in Yunnan Province. "In the long run, we do see that more openness and transparency will be there," regarding HIV in China, insists Dr. Sun Gang, head of the UNAIDS program in Beijing. "But we still need more proof of it in the short run."

If the history of effective public policy can be wed to empowered activism and flexible health policy, China stands a reasonable chance of greatly improving prospects for tens of millions of Chinese in the next quarter century. ⊕

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

Step 1

Facing HIV in the South Asian Community

Manju Sidhu, Pam Gill, and Parm Poonia

A new report published by the Step 1 Project details the great myths, deep denial, contradictory information, and outright discomfort with HIV/AIDS prevalent in the South Asian community of the Lower Mainland. Although widely discussed elsewhere, HIV/AIDS remains invisible and dismissed for the majority of South Asian Canadians.

Funded by Health Canada and co-sponsored by YouthCO AIDS Society and the Asian Society for the Intervention of AIDS (ASIA), the Step 1 Project assessed the level of HIV/AIDS awareness and support in the South Asian community of the Lower Mainland. In a comprehensive report released in March 2003, Step 1 gave voice to the realities of HIV/AIDS in the South Asian community, revealing its true impact and the changes needed to bring the disease to light.

graphic by Herman Mahal

"I'm so grateful that someone is out there and talking about my reality because I'm unable to. It gives me hope that our community will start understanding and accepting those who are living with HIV".
— an HIV-positive South Asian woman

For a community that is relatively proactive on health issues such as cancer and diabetes, South Asians have by and large ignored HIV/AIDS. The topic cannot be addressed without confronting issues of sex, sexuality, religion, immigration, extended family, culture, and language barriers. These are issues that the South Asian community is often reluctant to discuss.

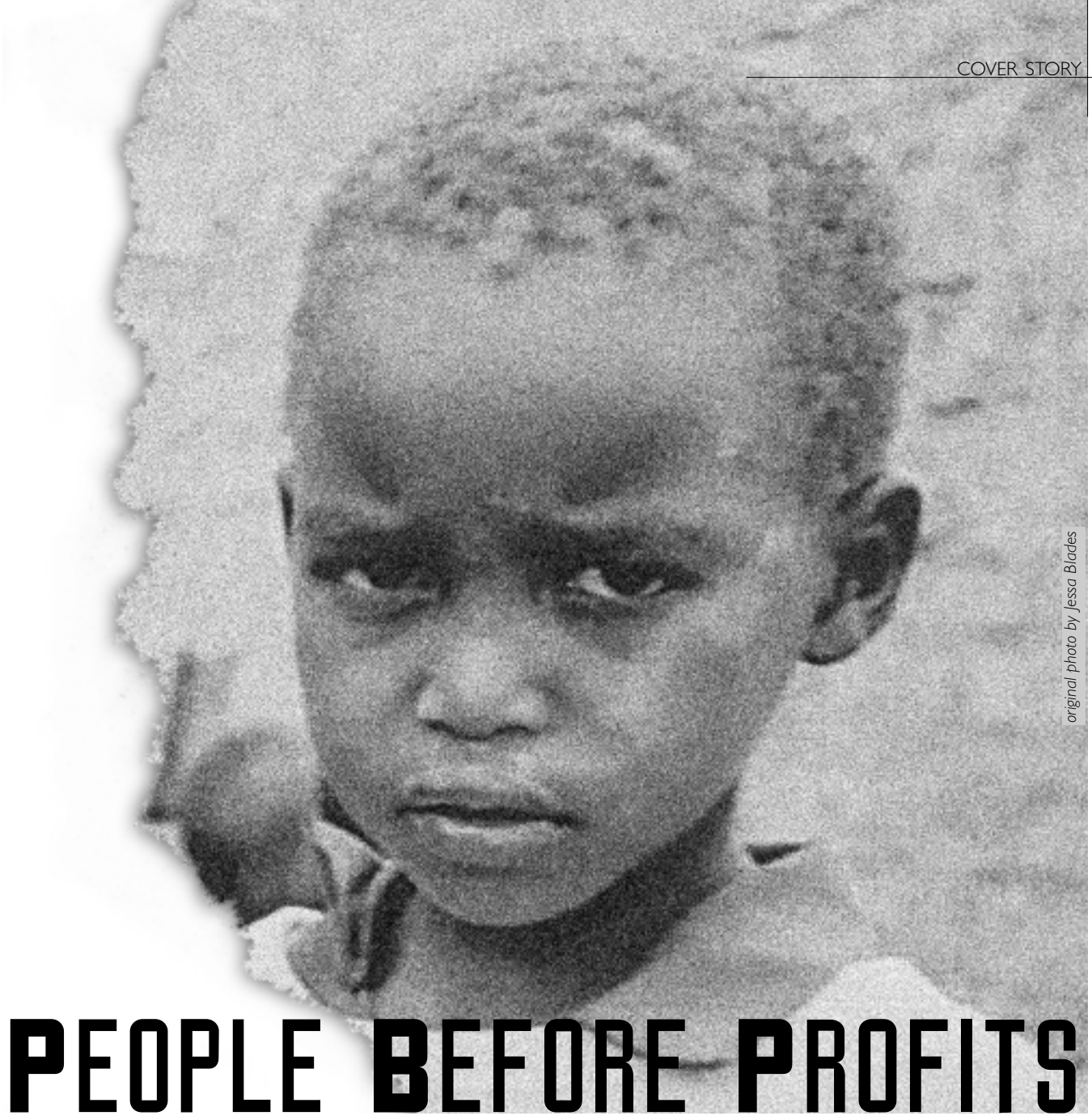
For the South Asian community, HIV/AIDS does not have a place in families, relationships, homes, or marriages. One popular South Asian myth says that HIV/AIDS happens only to non-monogamous, white, heroin-injecting prostitutes and gay men. Statistics show that the South Asian community does not accept messages about HIV/AIDS prevention and is one of the lowest testing communities in Canada. Local South Asians living with HIV are not receiving needed care, support, and services.

The needs assessment examined the complex realities of being South Asian and living with HIV. The insight it provided into HIV/AIDS awareness and obstacles among South Asians, from ideas of what HIV is to rates of transmission, prevention, testing, and disease progression, is invaluable. Step 1 exposed the barriers faced by mainstream agencies in serving diverse communities and explored how to increase the capacity of those agencies to respond in a meaningful way. Step 1 took stock of current resources and successful models to enhance services and fill gaps for South Asians concerned about HIV/AIDS.

The documented barriers, concerns, and recommendations were many. More advocacy, activism, and resources are needed to make an impact. The report, "Step 1 Project, HIV/AIDS, & South Asian Communities: An Approach to Addressing HIV/AIDS for South Asian Communities," opens the door for people wanting to help and to change how South Asian communities respond to HIV/AIDS. For those already doing the work, Step 1 validates and strengthens our collective vision. Most importantly, for those living with HIV/AIDS, Step 1 provides hope that change is coming.

For a copy of the report, please contact the Step 1 Team at 604.789.0907 or at step1team@yahoo.ca. ⊕

Manju Sidhu, Pam Gill, and Parm Poonia are South Asian community advocates and activists who have worked and volunteered within the HIV/AIDS sector for over 10 years.



original photo by Jessa Blades

PEOPLE BEFORE PROFITS

An equitable access to AIDS drugs in Africa

by Blake Shaffer

A recent charity campaign by Oxfam in the UK was titled "Don't forget Africa!" Forgetting the world's second largest and second most populous continent may seem ludicrous, but the reality is that Africa has been forgotten. In economic terms, the world has certainly made little effort to affect the stagnant (or even negative) growth rates that pervade most of sub-Saharan Africa. But nowhere has the neglect been so alarming in the face of such overwhelming need as the case of the African AIDS crisis.

continued on next page

Africa is in a state of emergency. AIDS has killed nearly 20 million people in Africa and has left 12 million children orphaned. Roughly 30 million people in Africa are infected with HIV or have full-blown AIDS. That's approximately three-quarters of the worldwide total. In Botswana and Swaziland, the current rate of HIV/AIDS infection is nearing 40% and the number is closer to 50% in the 18–35 age group. The US Surgeon General has recently compared the African AIDS epidemic to the plague that decimated much of Europe in the Middle Ages. The economic and social impacts of this epidemic have been devastating. Despite these staggering figures, the rest of the world pays little attention.

Although drugs cannot yet cure AIDS, significant progress has been made in prolonging life through medication. The development of antiretroviral (ARV) drugs in the mid-1990s has allowed those infected to lead more normal, healthier, longer lives. The drugs have been shown to reduce the amount of HIV in the blood to extremely low levels. These drugs have provided hope for the afflicted and, in so doing, have helped slow the spread of AIDS. Despite the success of ARVs, fewer than 60,000 of the nearly 30 million African people living with HIV/AIDS have received treatment. Why aren't these drugs reaching those in most need?

The simple reason is cost.

In the United Kingdom, the cost of treating an HIV patient is nearly £16,000 per year, over twenty times the average per capita GDP of sub-Saharan African nations. Throughout developed countries, drug cocktails alone cost between US$10,000 and $15,000 per year. Although national healthcare plans vary from country to country, governments pay most of that cost. These drugs are far beyond the reach of a country like Zambia, where the annual expenditure on health per person is a meager $14.

Why are drug costs so high?

Pharmaceutical companies—large multi-nationals primarily headquartered in the US and Europe—claim that the high prices are required to cover the research and development costs of creating the drugs. Patents on intellectual property (contracted in the Trade-Related Aspects of Intellectual Property Rights agreement of the World Trade Organization) grant these companies monopolistic controls over drugs for 20 years to guarantee that they can recoup these costs. Admittedly, pharmaceutical companies require profits to drive their business. However, the actual amount that it costs to develop AIDS drugs is a hotly debated issue. Some studies place the cost of developing a single drug to market at $800 million, but critics have countered with estimates ranging from $100–250 million.

That governments in the developed world often finance a large share of the research into important new drugs supports these claims of lower R&D costs. University discoveries, such as Yale's development of the antiretroviral drug AZT, play a large role in assisting pharmaceutical companies in the R&D phase.

What can be done to reduce prices?

Faced with international pressure stemming largely from their lawsuit against the South African government for ignoring patent laws in the face of a medical disaster, the five largest pharmaceutical companies have begun slashing prices of their ARV drugs for sale in low-income African nations. GlaxoSmithKline has reduced the price of its combination drug lamivudine/zidovudine (Combivir) from over $6000 (which it still charges in developed countries) to roughly $600 in African nations. Similarly, GSK has reduced the price of its other combination ARV abacavir sulfate/lamivudine/zidovudine (Trizivir) from nearly $12,000 to $1600.

This method of *differential pricing* is a step in the right direction. Africa currently represents roughly 1% of the revenues of pharmaceutical companies. Cutting prices will not have a drastic effect on profits. In fact, the reduced prices could spur otherwise impossible sales. However, for prices to remain low in the intended countries and for differential pricing not to have an effect on the developed markets of pharmaceutical companies, exports must be strictly controlled.

We will relish living in a world that's becoming more just, more uniformly wealthy and more secure for everybody.

One suggested cost-reducing method that poses a problem is *parallel importing*. The basic idea is in line with common trade strategy—search the globe for the lowest possible price and trade accordingly. However, with differential pricing, cheaper drugs destined for Africa could be diverted for sale in the black markets of developed countries. Such stories are already being told of drugs intended for Africa being resold in the Netherlands.

The most promising option is *compulsory licensing:* a government licenses a local company to generically produce a patented drug. The company must pay a royalty to the patent owner, usually 2–5%. Canada, in fact, had such a system throughout the 1980s and benefited greatly from lower drug prices and a booming pharmaceutical export industry. But faced with US pressure during NAFTA negotiations, Canada abandoned its compulsory licensing policies in the early 1990s. Drug prices have risen, although they remain less expensive than those in the US.

The advantage of compulsory licensing in Africa is two-fold. First, issuing generic licenses to domestic companies increases competition and, in turn, lowers drug costs. Large pharmaceutical companies should not be adversely affected because their share of the African market is minimal anyway. At least with compulsory licensing, they would receive royalties. Second,

the development of domestic pharmaceutical industries even for generic reproduction would provide much-needed economic stimulus for otherwise stagnant economies.

This point brings us to a fundamental link between development and AIDS.

Underdevelopment feeds AIDS

The Panos Institute states that AIDS is both a consequence and cause of underdevelopment. It is not a coincidence that the spread of AIDS has been more devastating in the impoverished nations of sub-Saharan Africa than in the developed world. Nor is it a coincidence that Africa has been unable to cope with and recover from the epidemic. The resources were simply not available for prevention during the early years, nor are they available now to address the problem. The developed world has achieved some semblance of control over HIV/AIDS through ARV treatment, but poor African nations have been left to suffer and die.

Should treatment be denied for higher profits? No, of course not. Incentives for innovation must be maintained, but methods to protect intellectual property rights and make drugs accessible to targeted countries must be implemented. Pharmaceutical companies should ease their resistance to accessible pricing in countries where their current and potential market share is minimal anyway.

Of the nearly 30 million African people living with HIV/AIDS, less than 60,000 have received treatment.

Even with differential pricing and domestically produced generics, the price of drugs for AIDS would still be out of reach for the majority of Africans. How much should we as individuals, either through individual donations or via our governments, be willing to spend to help Africa in its struggle against AIDS? Morally, it is difficult to place a value on human life. The crux here is that the current cost of prolonging an HIV-infected African's life is comparatively low, making the international community's lack of active assistance a morally reprehensible inaction.

A consensus of will

The UN's Global Fund to Fight AIDS, Tuberculosis, and Malaria has been set up specifically to enlist the aid of the international community. However, the fund has received to date only US$3B of its $10B in annual contributions, so the ability of the fund to succeed is in question. The recent US decision to proceed with its own AIDS package compounds the problem because it targets specific countries, rather than working with the Global Fund. George W. Bush's announcement (Jan. 2003) of $15B in AIDS relief for selected African and Caribbean nations is not without strings. Not only has Congress required several trade concessions for countries to be eligible for funds, it included an amendment to the bill that requires a minimum of one-third of all prevention funds to be spent on promoting abstinence. "It's important that we not just send them money, but we send them [American] values that work," said Congressman Mike Pence [Republican]. International cooperation must greatly improve before any gains can be made.

Obviously, the strength of the moral argument alone will not sway all of society. An appeal to self-interest is required. For people to demand change, many will need to see that it is in their own best interest to do so. Would providing AIDS drugs to Africa improve our own lives? In economic terms, would the present value of our lifetime utility be increased?

The answer is overwhelmingly yes.

Some may say that they really only care about the next few years. I will leave those people be. However, for the great majority of us who are self-interested yet also care about future generations, I offer the following vision: an Africa with AIDS under control will be a more productive Africa. The devastating AIDS epidemic is markedly worse in young adults, the most productive sector of the population. The same people who advocate globalization should recognize the value of stronger African economies with developed markets with which to trade.

We should also remember that AIDS is a global threat and an increasing concern in the populous regions of Southeast Asia, India, and China. Allowing such a lethal virus free reign across Africa is a threat to the entire world. US Secretary of State Colin Powell has argued that helping Africa will lead to greater security in the fight against terrorism, the argument being that better living conditions leads to fewer reasons for violence.

John Sulston, the 2002 Nobel Laureate in Medicine, offers a clear statement of the result of transferring some of our wealth to health spending on Africa: "Perhaps it will feel uncomfortable at first for us rich 10%. But we'll get used to it, and indeed relish living in a world that's becoming more just, more uniformly wealthy, and more secure."

Ultimately, however, the solution must come from within the affected countries themselves. In providing drugs to Africa, we will be providing a source of hope. A hope that, with a bit of effort, will lead to increased prevention and confidence that the disease can be beaten. After all, when the outlook is bleak, people tend to act in despair. The power of humans to overcome when they believe they can is an immeasurable force. ⊕

Blake Shaffer received his Masters in Economics from the University of Cambridge, England. He currently lives and works in Vancouver.

Finding Options

Substance Abuse, Addiction and Disability

by Lawrence C.

Should alcohol and drug addiction be classified as a disability? Alcohol and drug dependence are widespread "chronic" conditions in Canada, according to a recent survey by Statistics Canada published recently in the Vancouver Sun. Unlike conditions more commonly thought of as chronic, such as heart disease and diabetes, few Canadians with addictions seek medical advice and treatment. Stigma and psychosocial problems associated with HIV increase the vulnerability of many people with HIV/AIDS to substance abuse and addiction.

Several of the physical symptoms of HIV are similar to those of substance abuse, including malaise, fatigue, weight loss, fever, diarrhea, and night sweats. AIDS dementia and drug intoxication can both lead to apathy, disorientation, aggression, and altered levels of consciousness. Sometimes recognizing substance abuse and addiction in the midst of HIV/AIDS can be difficult.

Substance abuse is the repeated use of a substance—anything from steroids to tranquilizers, alcohol to heroin—despite knowledge of its negative personal consequences. Addiction is a chronic dependence on these substances to the point that ceasing to use them causes severe physical and mental reactions. The basic sign of an addiction is a need to have the drug or substance. Drastic psychological or physical changes are also major indicators of addiction.

Psychological symptoms include:

- anxiety—worrying constantly
- depression—feeling blue and having uncontrollable mood swings
- dependence—relying on substances
- obsession and protection of supply—spending a lot of time figuring out how to get drugs
- compulsivity—stealing money or selling belongings to be able to afford drugs
- isolation and withdrawal—withdrawing from close relationships
- change of lifestyle—losing interest in school, sports, or hobbies that used to be important
- distortion of the truth—lying or keeping secrets from your friends and family
- negative peer association—hanging out only with friends who use drugs
- relapse—being unable to stop using after trying to quit
- loss of control—having money and banking problems, missing appointments, being disorganized.

Physical symptoms include

- change in sleeping patterns—sleeping in or having trouble getting to sleep
- change in eating habits—missing meals or eating less/more than usual
- change of weight for no apparent reason
- malaise—feeling sick and not having energy
- withdrawal—feeling shaky or sick when trying to stop using drugs
- tolerance—needing to increase the amount of drug taken to achieve the same effect.

The definition of disability in relation to addiction is hotly contested. For HIV-positive people, the link between addiction and disability can mean drastic changes. According to Canada

Pension Plan legislation, a person is eligible for disability benefits if he or she is diagnosed as having a severe and prolonged mental or physical disability. In British Columbia, however, the Employment and Assistance for Persons with Disabilities Act defines a person with a disability as someone who is at least 18 years of age with a severe physical or mental impairment that is expected to continue for at least two years. In both cases, addiction falls within these definitions. Other conditions also apply, such as the definitions of "severe" and "prolonged." A severe disability is an impairment that regularly makes someone incapable of pursuing any substantially gainful occupation. If a person's severe disability is expected to continue for a long time, it is said to be "prolonged."

Years ago, healthcare professionals began to acknowledge the reality of alcohol and drug problems as a disability issue. Gradually, they moved away from a moralist approach that advocated punishment. Healthcare professionals started moving towards a network of addiction treatment and harm reduction services, such as clean needle exchanges and safe injection sites. These services are grounded in the philosophy that people with substance abuse problems can be helped and that some of the harm associated with using can be reduced. But even seeking help can be challenging.

Recognizing substance abuse and addiction in the midst of HIV or AIDS can be difficult.

Thomas Kerr, a community health researcher, has identified addiction services and support in British Columbia. He has classified the services according to individual needs.

Outpatient treatment: For people with stable living environments, outpatient treatment involves an initial assessment, day treatment programs, referrals to other services, and various forms of counselling and support.

Residential treatment: People who lack stable housing and require a safe environment can participate in intensive live-in group therapy for 4–6 weeks.

Recovery houses: These facilities provide an alternative environment for people needing time away from drugs. Regular house meetings and a 12-step approach are often used.

Methadone maintenance: This substitution therapy reduces the harms associated with heroin use and is overseen by the BC College of Physicians and Surgeons.

Private counsellors and therapists: Many counsellors provide private substance abuse counselling, but clients are usually responsible for the cost.

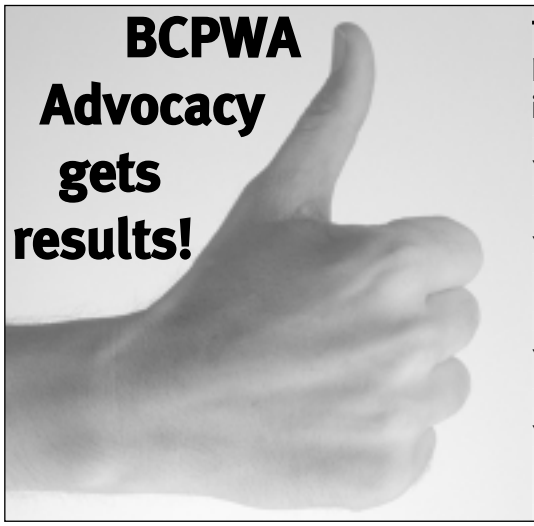
Support Groups: Various support groups, including 12-step programs such as Alcoholics Anonymous and Narcotics Anonymous, are available. Other support group programs, such as Rational Recovery and Women for Sobriety, are also available.

Special programs: Designed for marginalized groups such as pregnant women and people with dual diagnoses (eg. people living with substance abuse problems and mental illness), special programs such as detox, street nursing, clean needle exchanges, and safe injection sites provide basic outreach.

Substance abuse and addiction have drastic negative effects on individuals, but is addiction a disability? The government definitions of disability are unclear. Recognizing, treating, and coping with addiction are challenging and can significantly restrict individuals' daily activities. Clearly, addiction is disabling. People with addictions deserve respect, support, treatment, harm reduction, and any other services necessary to fight addiction.

Additional information on public health, addiction, and harm reduction can be found at the British Columbia Ministry of Health Services Web site: www.gov.bc.ca/healthservices ⊕

Lawrence C. is a member of the BCPWA Society.



The BCPWA Society's Advocacy Program continues to work hard to secure funds and benefits for HIV+ individuals. The income secured for August and September 2003 is:

- **$23,454.31** in debt forgiveness.
- **$67,696.08** in housing, health benefits, dental and long-term disability benefits.
- **$26,350.00** in Monthly Nutritional Supplement Benefits.
- **$377,708.76** into members' hands for healthcare needs, from grandfathered Schedule C benefits.

The Quandry of Love

by Maggie Atkinson

I found myself in the position of a prevention educator the other day. I was chatting with a young volunteer AIDS educator. Let's call her Mary. I asked what sparked her interest in AIDS, and she answered that her boyfriend has AIDS. She confided that they were having unsafe sex and that she couldn't tell anyone she knew because they would be too judgmental.

I felt judgmental too, but I did not think it would help matters to explode. I tried to explore with her why they weren't using condoms. After all, knowledge wasn't the issue.

Mary said she didn't like to insist on using condoms. It was clear that her boyfriend didn't like to use them. He told her that she would have to be the one to insist on using condoms because he didn't have the discipline to use them. Mary didn't like to use condoms either because she wanted to express her unconditional love for him. When I asked what she would do if the roles were reversed, she said she would use condoms because she wouldn't want to put him at risk. I explained that if he passed HIV onto her and if he had become resistant to some or all of the currently available drugs, she would also be resistant to them. It then came out that he is co-infected with hepatitis C. Mary's future was looking even bleaker to me.

I don't dwell on the negative aspects of being HIV positive because I find it depressing, and I don't like to complain. But I felt it necessary to dredge up as many negative aspects as possible for Mary. Here's some of what I told her.

HIV pervades every aspect of my life. Although meds are available, they don't work for everyone and they cause side effects. I have to take lots of pills and vitamin supplements every day. If I forget my pills, I worry that I could become resistant to my meds and die. HIV and the meds can make you look strange. I feel uncomfortable in social settings because of my thin face, arms, and legs. Strangers ask me why my legs are so thin. I hate having my picture taken.

The consequences of HIV are not only cosmetic. I have so little fat it hurts to sit or kneel on anything hard; even sitting in the bathtub is uncomfortable. I have to worry about cholesterol levels, nutrition, heart disease, blood sugar levels, diabetes, osteoporosis, liver or kidney disease, bone death, failing eyesight, yeast infections in my mouth, and numbness, tingling, and pain in my feet. My skin is so itchy that I sometimes scratch until it bleeds. I get very tired, and I get infections easily. And yet, my HIV is under control, and my viral load is undetectable.

I face and fear stigma and discrimination everyday in all areas of my life, including housing, employment, and access to daycare, medical, and dental services. When I run into old friends or acquaintances and they ask what I'm doing these days, it becomes a loaded question.

Disclosure is a very difficult issue. Whom do you tell and when and how? If you are dating, it is extremely difficult to tell someone you're HIV positive. Even if they seem accepting at first, they may eventually become afraid.

I could only scratch the surface in my time with Mary.

Although I often focus on what I gain from being HIV positive, when a friend of mine recently told me that he tested positive, I cried. That made me realize that deep down I felt bad for anyone in this position, even myself I guess.

So what happened with Mary? She and her boyfriend have started using condoms. When she told him about our conversation, he recognized the risks they were taking. Now Mary is waiting for her HIV test results. Let's cross our fingers. ⊕

Maggie Atkinson is former co-chair of AIDS ACTION NOW! and the founding chair of Voices of Positive Women in Toronto.

PEP TALK: Morning After Therapy for HIV Exposure

by Rob Gair

With studies showing success of post-exposure prophylaxis (PEP) for occupational exposure to HIV, some are asking if post-exposure prophylaxis, (a morning-after pill for HIV exposure), is a viable prevention method.

In HIV/AIDS medicine, PEP refers to the use of antiretroviral medications immediately following an exposure to HIV. Within 72 hours of exposure an antiretroviral cocktail is administered for one month. PEP appears to decrease HIV seroconversion. Historically, the use of PEP has been restricted to occupational exposures in healthcare workers, generally caused by accidental injuries from sharp objects contaminated with HIV-infected body fluids. Only a very small proportion of HIV infections result from occupational exposures, and now the debate has begun about developing guidelines for patients seeking PEP for non-occupational exposures.

History of PEP

Concerns about occupational exposures to HIV became real in 1988 when a US healthcare worker became infected after cutting her finger on a broken test tube filled with HIV-infected blood. In 1997, an international retrospective case-control study involving approximately 700 healthcare workers exposed to HIV between 1988 and 1994 was released. The study identified four factors that increased the risk of HIV infection: injuries with devices that were visibly contaminated with blood, injuries that were deep, injuries that involved direct access to veins or arteries, and exposure to blood from patients in advanced stages of AIDS.

The study was not designed to evaluate the effectiveness of post-exposure prophylaxis. The investigators were surprised, therefore, to discover that post-exposure treatment with zidovudine (Retrovir, formerly AZT) reduced the risk of seroconversion by approximately 81%. This data is subject to serious limitations, but it was the only way to gather the information, and it became the framework for early PEP protocols that were officially instituted in 1998.

Non-Occupational Exposures

Since 1998, the use of PEP following occupational exposures has been standardized in most healthcare centres. However, the vast majority of new HIV infections occur outside occupational settings, and PEP has not been formally studied for other types of exposures. Nevertheless, it appears reasonable to conclude that if PEP works in occupational settings, it would also work for non-occupational exposures. Of course, this assumption must be balanced with the knowledge that PEP does not prevent HIV seroconversion in every case. Failures have occurred, and the use of PEP following exposure does not guarantee that HIV infection can be prevented.

Sexual Assault Victims

PEP is currently provided to sexual assault victims under guidelines for the treatment of sexually transmitted diseases to prevent HIV infection. In 1996, the Sexual Assault Service at Children's & Women's Health Centre in Vancouver and at Vancouver General Hospital were the first centres in North America to offer PEP to victims of rape. To evaluate its effectiveness, team members gathered data for the first 16 months of the program. During this time, 71 patients considered at risk for HIV infection accepted PEP. However, only eight of the 71 completed the full 28-day course of medications (12 did not return for follow-up; 51 stopped their medications early).

Will knowledge about the availability of PEP open the door to increasingly risky sexual behaviours?

Reasons for not completing the regimen included problems with side effects or fear of side effects and discovery that patients were HIV positive prior to the assault. The eight patients who fully completed the program were at the highest risk for HIV infection and none of them seroconverted. This study shows the obvious difficulty of getting people to adhere to PEP drug regimens for the full length of treatment. After the data were analyzed, the program was changed so that PEP was offered only to those at a high risk for contracting HIV.

Consensual Sex

Men who have sex with men (MSM) have great potential to benefit from PEP. In the 1990s, HIV infection rates stabilized among MSM, but recent data shows an increasing rate of infection, particularly in younger men. Several issues need to be considered when contemplating the widespread use of PEP for MSM. Perhaps the most contentious of these is whether or not knowledge about the availability of PEP will open the door to increasingly risky sexual behaviours.

The scientific data is inconclusive. Two studies, one in MSM and another involving heterosexual couples, found little evidence that availability of PEP leads to increased risk-taking. However, a 1998 survey of single MSM found that those who were less educated and those who tended to use illicit drugs or engage in high-risk sex were more likely to rely on PEP to prevent themselves from becoming infected with HIV.

A recently published San Francisco study examining the feasibility of PEP after sexual and injection drug exposure found that approximately 12% of participants sought a repeat course of PEP for additional exposures. This finding highlights the concern that PEP may cause increased risk-taking, but the authors do not believe it constitutes proof of such behaviourial changes. They make the case that delivery of PEP provides a rare opportunity to counsel and educate individuals about risk reduction because people seeking PEP are motivated to avoid infection.

Cost

A single four-week PEP treatment regimen can cost up to $1000 (lab and medical fees not included), making cost a major factor influencing availability.

The sexual assault study estimated that to prevent one HIV seroconversion, 140 patients would have to be treated at a cost of about $100,000 total. This amount may seem high, but it is cheaper than the estimated $150,000 a single seroconversion costs the health system. However, comparison of these costs is more complex than it seems. The use of PEP to prevent an HIV infection places the cost burden on a single program over a relatively short period of time, whereas costs associated with an actual HIV infection are spread throughout the healthcare system over a number of years.

More recent data from a local survey estimated that it would cost a minimum of $800,000 per year to provide PEP to "at-risk gay and bisexual men" in Vancouver's West End. This amount would double the current budget for all accidental exposures in BC and not address the rapid growth of HIV infections among injection drug users. At least one critic suggests this analysis "greatly overestimates the cost of an HIV PEP program for this population." The same group then studied actual costs of providing PEP following sexual assaults and occupational exposures. They determined that program expenditures were already double the anticipated amount, and they estimated they were spending approximately $500,000 to prevent one HIV infection. However, they also determined that approximately 50% of program participants would never have received PEP if the guidelines had been followed properly. Nevertheless, they argue that since costs are already high for the MSM population, expanding access to this group would overwhelm the program.

Summary

The use of PEP following accidental HIV exposures in healthcare workers has been shown to reduce the incidence of HIV seroconversions. However, occupational exposures remain low. Consideration has been given to offering PEP to higher-risk groups, specifically non-consensual heterosexual sexual exposures and intravenous drug users. Experience in sexual assault clinics shows that it is difficult to get the majority of sexual assault victims to complete the full four-week regimen.

Concerns about MSM using PEP as a primary means of HIV prevention appear to be unfounded. The long-term benefits include possible prevention of infection and opportunities to educate people about risk reduction. The cost of providing PEP is a major factor hindering expansion of availability and little consideration is given to potential long-term cost savings. Certainly, the social and human costs of HIV infections are enormous and every effort should be made to ensure that people have access to prevention programs best suited to their needs. ⊕

Rob Gair is a pharmacist at the BC Drug & Poison Information Centre.

TREATMENT INFORMATION PROGRAM MANDATE & DISCLAIMER

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

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

The Scoop on Poop

An integrated approach to managing diarrhea

by Ron Rosenes

Despite great advances in the treatment of HIV/AIDS, many of us still have the runs. In the era before HAART (think pre-1996), fifty percent of PWAs experienced diarrhea associated with active disease related to HIV or another pathogen (bacteria, parasite, fungus) that flourishes in a compromised immune system. According to investigators at New York University, the problem of diarrhea persists in the HAART era in nearly 40% of people living with HIV.

You call this living? Not when you are afraid to venture from home to get the groceries for fear of public humiliation. The effect on quality of life can be quite devastating when you reduce your food intake for fear of the consequences. The anxiety and fatigue that result from chronic diarrhea may also contribute to the high degree of depression in our community. So what, if anything, has changed, and how can you solidify your approach to this problem?

The answer lies in working out an algorithm of treatment with your care providers that draws on the richness of experience found in both western and complementary and alternative medicine (CAM). In other words, we must take an *integrated* approach to treatment. What is an algorithm you ask? It is a formula for dealing with a problem that eliminates as many confounding factors as possible. It is a step-by-step move towards a solution. Think of it as a formula for healing.

Chronic diarrhea is even more challenging to understand and treat in the post-HAART era because it can be a common side effect of medications. Diarrhea as a side effect can be a brief hassle while starting therapy or a new drug combination, or it can be a long-term complication associated with a particular drug. People taking the protease inhibitors (PIs) nelfinavir or ritonavir or boosted drugs such as lopinavir/ritonavir (Kaletra) are likely to experience chronic diarrhea.

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Bug or Drug?

The western approach to dealing with diarrhea usually starts by determining whether a specific bug is present and then prescribing appropriate treatment for it. If your doctor has had your stool samples examined umpteen times and they all come back negative, then drug-induced diarrhea may be the cause. (It's the drug, not a bug!). The western approach might then recommend using dietary interventions such as a low-fat, high-fibre diet and, if that doesn't work, anti-diarrheals such as loperamide HCl (Imodium) or diphenoxylate hydrochloride and atropine sulfate (Lomotil).

The results of a study led by Dr. Anita Rachlis of Sunnybrook & Women's hospital in Toronto were presented at the Paris IAS Conference in July and suggest a successful algorithm for treating nelfinavir-related diarrhea. This small study of 18 individuals (including two women) was conducted over nine weeks. In week 1, there was a washout of all anti-diarrheal medications to assess the degree of the problem and to eliminate other potential causes. In weeks 2 and 3, participants were counselled about diet and offered supplements of the enzyme lactase in case of lactose intolerance, another potential cause of diarrhea in people who have difficulty digesting dairy products. Participants also took fibre supplements (psyllium) such as is found in Metamucil and similar products, which help to absorb water in the intestine and bulk up the stool. In weeks 4 and 5, participants took calcium carbonate at a dose of 1,250mg twice daily or double that amount twice daily if insufficient improvement occurred after 48 hours at the lower dose. In weeks 6 and 7, participants were offered Imodium if needed. In weeks 8 and 9, participants were allowed to use whatever combination was working for them, and the protocol was assessed. The results showed significant reductions in diarrhea and in the number of bowel movements, down from an average of three to an average of two per day.

Despite great advances in the treatment of HIV/AIDS, many of us still have the runs.

Of course, larger studies are required, but it appears that nelfinavir-related diarrhea can be managed successfully with a step approach and a combination of diet management, fibre, calcium, and anti-diarrheals. Calcium has long been known to have a non-specific constipating effect, so it might help with other types of drug-related diarrhea. And it's good for your bones! The word on the street is that psyllium fibre may also help with diarrhea linked to ritonavir. Start with a teaspoon of fibre mixed into water or juice in the morning and at night. Increase to the amount that offers the most improvement. Keep in mind that psyllium fibre may interact with meds, so take fibre at a different time from meds until more research is completed on this potential interaction. Meanwhile, score another bonus! Fibre may help reduce elevated cholesterol.

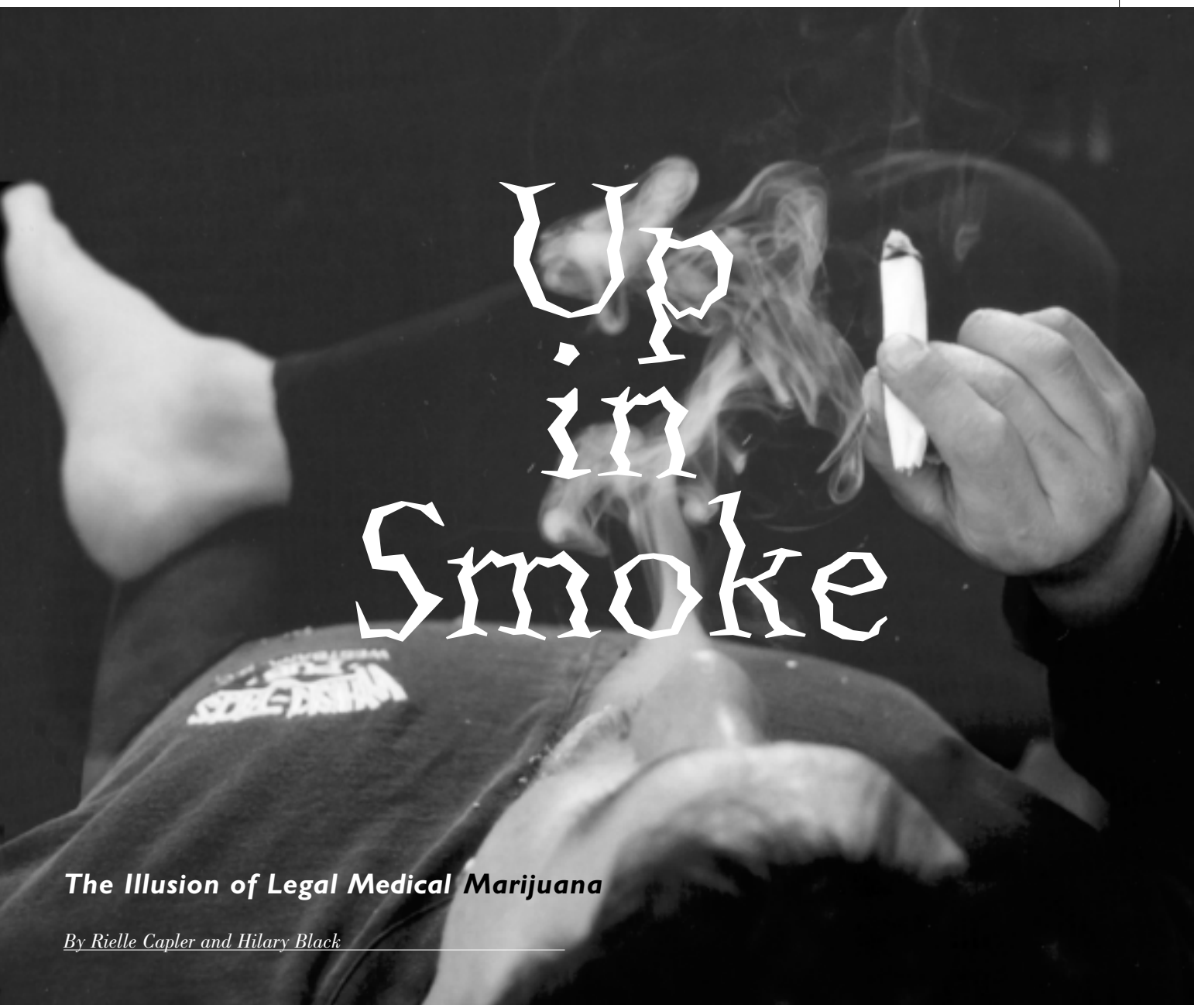
Complement Approaches

If the gut has been ravaged over time by HIV disease, compounded by poor nutrition, frequent infections, and the use of antibiotics, anti-parasitics, and other medications, you may also consider the use of probiotics containing acidophilus and other friendly bacteria to re-establish a healthy balance of fauna and flora in the intestinal tract. Studies show good results in reducing diarrhea with L-glutamine, an amino acid that is available in powder form. Participants in one study, dosed at 10g three times daily, reported significant improvement.

Some people have found relief from chronic diarrhea through Traditional Chinese Medicine (TCM). A growing body of research demonstrates the benefits of acupuncture on the gastrointestinal system. In the TCM view of the body, the spleen includes pancreatic function, enzyme release, digestion, absorption of nutrients, and production of waste. In TCM terms, the kidneys govern water metabolism and are related to all metabolic processes, including the re-absorption of water in the large intestine. Needling selective points along the channels associated with these systems has been shown to restore normal GI function for some people. Many practitioners also treat with herbs to correct deficiencies in the spleen and kidneys. Remember to share your therapies with your healthcare providers and get them to check for possible drug-herb interactions.

Many alternatives to heavy-duty anti-diarrheals are available. Try them according to your own formula of step-by-step introduction. And remember, an algorithm a day keeps the doctor away. ⊕

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



Up in Smoke

The Illusion of Legal Medical Marijuana

By Rielle Capler and Hilary Black

Cannabis prohibition in Canada has been under fire in our upper courtrooms and legislatures with much media attention this year. While the courts have forced movement on the cannabis laws, our government has resisted progress, buckling under the pressure of the US whose war-on-drugs agenda is ever-present in our debates and decisions.

Most Canadians believe cannabis should be accessible to those living with HIV/AIDS, but few HIV- positive people can access it. Cannabis alleviates nausea, stimulates appetite, reduces both depression and anxiety, and diminishes pain. This power to control disabling symptoms and improve quality of life gives cannabis a reputation as an effective medicine for people living with HIV/AIDS, particularly those with Wasting Syndrome.

An impression of decriminalization, and stalling by Health Canada, pose to keep access to medical marijiuana out of reach.

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Creating the Impression of Decriminalization

Last Spring, Justice Minister Cauchon tabled Bill C-38, a cannabis Reform Bill, in response to the Canadian public's desire to ease up on pot laws. C-38 was spun as a "decriminalization bill" on the premise of replacing criminal records for possession under 15 grams, with fines of $200-$1000. The Bill calls for increased sentences for growers and distributors.

Such reforms would lead to a more entrenched black market, noted the activist community, and fail to address the harms of prohibition that could be greatly diminished with regulation. Bill C-38 would punish users, again, especially those who could not afford such hefty fines.

Our government has resisted progress, buckling under the pressure of the US, whose war-on-drugs agenda is ever-present.

Uproar ensued in the House of Commons upon learning that the Justice Department took the Bill to the United States for input before bringing it to Parliament. The US influence doubled the proposed fines and jail terms. This summer, Liberal backbenchers looking for stronger laws were caught asking the US to help defeat C-38 by threatening delays at the border. At opening of Parliament in September, one of those same backbenchers tabled Bill C-446, that calls for a US-style mandatory minimum imprisonment for cannabis growers.

These Bills require three readings each in parliament followed by royal assent from the Senate. The Senate's Special Committee on Illegal Drugs unanimously recommended full legalization of cannabis, noting in their thorough 800-page report that the plant is relatively harmless and has important medicinal applications. Libby Davies, who sat on the House of Commons Special Committee on Non-Medicinal Use of Drugs also called for full legalization in her minority report.

Laws on Trial

While some politicians attempt to make cannabis laws more repressive, some judges are hammering away at the unjust laws. The Parker decision in 2000 stated that people should not have to give up their liberty to secure their health, and ordered the government to change the laws regarding cannabis possession and cultivation within one year.

Pot possession became legal in Ontario through the Rogin decision. The province's highest court declared the laws unconstitutional because they had not been changed as ordered by the court in the Parker decision. Lower courts in Nova Scotia, PEI and BC made similar overturns in court, setting precedent for other judges to make similar decisions. If appealed by the government and upheld in higher court, possession of cannabis will be legal in those provinces as well.

Health Canada's Sham Medical Cannabis Program

Instead of changing laws to make cannabis accessible for medical users as ordered by the Ontario Court of Appeal, Health Canada created a series of regulations known as the Medical Marijuana Access Regulations (MMAR).

The MMAR program issues licenses to legally possess and cultivate cannabis, or to have a caregiver grow it on one's behalf. To qualify for a license, a physician and, depending on the condition, one or two specialists must complete lengthy forms. These forms must be filled out annually to renew the licenses. Another part of the MMAR program is a $5.75 million cultivation contract with Prairie Plant Systems in Flin Flon Manitoba to grow cannabis for research purposes.

Only 10 people were deemed eligible to receive cannabis from Health Canada. Most license holders, having lost faith in Health Canada's ability to produce a worthwhile supply, did not even apply. Indeed, a test by Canadians for Safe Access at a licensed laboratory found the Prairie Plant product to be of extremely low potency, containing high levels of heavy metals and arsenic, probably due to the chemical phosphate fertilizers used in the non-organic growing. The powdered buds, leaves and stems have been returned by several of the recipients who consider it disgusting and far from medicinal.

The Canadian Medical Association, the Colleges of Physicians and Surgeons, and the Canadian Medical Protective Association have advised doctors to boycott the MMAR program. They feel they were not sufficiently consulted in drafting of the regulations, that there are liability issues, and that they are not the appropriate gatekeepers for herbal medicine.

The MMAR were found unconstitutional in Ontario's Supreme Court, as they give only the illusion of access to medical cannabis, and are extremely difficult and burdensome to navigate. The scheme was rejected as an unacceptable substitute for legal reform. Health Canada was given 6 months to supply cannabis to license holders, with the court even suggesting licensing compassion clubs to do this. At the last possible moment before the July 9th deadline, Health Canada produced a temporary scheme to have Prairie Plant cannabis distributed by doctors. Once again, Health Canada neglected to ask approval of the doctors to play the role of medical marijuana dealer.

Sabotage of HIV/AIDS Research

Although Health Canada insists that cannabis cannot be considered a medicine until it goes through the rigorous scientific testing usually reserved for pharmaceutical products, they canceled funding for the first clinical trials for HIV/AIDS in

Canada that were to evaluate the therapeutic effects of smoked cannabis.

The Community Research Initiative of Toronto (CRIT), who over the last three years planned and developed the study, were shocked. Participants were about to begin enrolling. CRIT, until recently the only AIDS organization in Canada dedicated solely to HIV/AIDS community-based research, was devastated, unable to continue its work.

Health Canada's affront to the HIV community and to compassion led to the resignation of Dr. Gregory Robinson, an AIDS patient and one of two patient representatives on the MMAR's Office of Medical Cannabis Access Stakeholder's Advisory Committee.

Prohibition Unconstitutional?

Judicial courts are sending clear messages to the government that they want guiding decisions on medical marijuana laws' constitutionality. Such guidance will hopefully arise from a constitutional challenge presented to the Supreme Court of Canada that questions the criminal prohibition of cannabis possession and distribution.

Most license holders did not even apply, having lost faith in Health Canada.

Activists David Malmo-Levine, Randy Caine and Chris Clay, with lawyers John Conroy, Paul Berstein and the BC and Canadian Civil Liberties Associations appeared before the 9 Supreme Court Judges in May. They argued that all harmless people should be protected under our constitution. Since cannabis use and dealing are not inherently or significantly harmful, people who engage in such activities should be protected. The high court will likely announce its decision by the end of the year. A Supreme Court ruling striking down cannabis prohibition would trump all lower court decisions and all current laws and regulations.

Compassion Clubs

With 5.75 million dollars spent on its cultivation program and 3.8 million on administrative costs, Health Canada has distributed licences to only 500 people and sub-standard cannabis to 10. At the same time, with no tax-payer money, compassion clubs across Canada have provided high quality medicinal cannabis to over 5000 people.

The BC Compassion Club Society (BCCCS) currently serves 2500 members. To become a member, the BCCCS requires a confirmation of diagnosis from a physician, naturopath or doctor of Traditional Chinese Medicine. The BCCCS agrees with the CMA that physicians should not control access to cannabis.

The BCCCS values people's autonomy to make decisions about their own health care. It considers cannabis as one of many medicinal herbs, one especially effective for symptom relief. In some diseases, cannabis staves off illness progression. Much of the healing seen at the BCCCS occurs when cannabis is used in combination with other natural medicines available at the Wellness Centre, where members have access to certified clinical herbalists, nutritionists, counselors and Drs. of Traditional Chinese Medicine.

The BC Compassion Club engages in civil disobedience each day its doors are open.

Members of the BCCCS are oriented on the safe and effective use of cannabis, including dosage, strain selection, and methods of ingestion. They can select from varieties effective for specific symptoms such as nausea, appetite stimulation, energy, sleep and pain. The cannabis available is clean, high potency and mostly organic. Also available are cannabis baked goods and cannabis tinctures.

Poverty is a major issue for most people living with terminal, chronic and debilitating diseases. Many medical marijuana users struggle with the cost of their medicine. A donation program at BCCCS attempts to assist people living in poverty. It is imperative that the costs of this medicine be covered by Healthcare insurance as they are for other effective medicines.

It has been painful watching Health Canada drag their feet in response to the needs of the medical community and the demands of the courts. They have sabotaged their own research, created programs destined to fail, and neglected to fulfill their public promises. While the BCCCS actively campaigns for legal change and the development of reasonable regulations, it will not wait for government to standarize access to medicinal cannabis.

There is a dedicated community across the country determined to give those in need access to high quality medicinal cannabis, regardless of the risks. The BCCCS has been distributing cannabis to those in need for nearly seven years, engaging in civil disobedience each day its doors are open. We shall build progress one small step at a time.

For more information, visit www.thecompassionclub.org ⊕

Rielle Capler (MHA) works in Policy, Planning, Research and Communications at the BCCCS

Hilary Black is the founder of the BCCCS where she sits on the Board of Directors and works in Communications.

Pump it up

Steroids need help to make Muscle

by R. Paul Kerston

Steroids are often thought to be a cure for the wasting associated with HIV. Steroids, however, are not a solution on their own. Although they do provide important chemicals for building muscle, they do not actually build muscle by themselves.

Lower levels of testosterone that accompany HIV can result in fatigue, muscle wasting, low sex drive, impotence, and loss of facial or body hair. These symptoms can increase as the disease progresses. Wasting is the unintentional loss of 10% or more of usual body weight, caused in HIV-positive persons by malnourishment and chronic severe diarrhea, among other things. Because wasting-induced weight loss is accompanied by loss of critical muscle, replacing muscle is a major goal.

Anabolic steroids are both natural and synthetic derivatives of testosterone. Prescribed in much lower doses than are used for athletic purposes, testosterone steroids used in conjunction with exercise may offset wasting and its accompanying weakness.

Anabolic refers to the process that creates new protein, fat, and complex carbohydrates. "Both physicians and HIV-positive people report positive results with weight training or progressive resistance exercise in building and maintaining adequate stores of lean body mass and increasing weight, strength, and endurance before symptoms of HIV-associated wasting appear." Physical exercise is required to boost muscle mass because steroids only provide chemicals for the anabolic process.

Individuals should act sooner, rather than later, for steroid use to be effective. Sometimes a *bioavailability testosterone* test is performed to determine a person's acceptance of steroids. Dr. Richard Taylor confirms that people with testosterone levels in the low and low-normal range seem to have a better response to steroids than those with already extremely low levels.

Steroids have long been classified with narcotics as controlled substances. Doctors must request special authorization, mentioning both HIV as well as wasting for permission to prescribe them.

Testosterone can be administered orally, intra-muscularly, and subcutaneously. Oral preparations, though, appear unsafe for the liver. They can reduce HDL (the "good" cholesterol) and increase LDL (the "bad" cholesterol), neither of which is good for the cardiovascular system. Most anabolic steroids are delivered by intra-muscular injection. A dermal (skin) patch used in the US is available in Canada, but British Columbia's medical services plan will not pay for it. It only covers intra-muscular injections of steroids.

At levels prescribed for HIV wasting, site-injection soreness is the most common side effect. Other side effects include increases in facial and body hair, oily skin or acne, male pattern baldness, water retention, and joint stiffness. Regular liver function tests are important, particularly when HAART regimens are also involved.

Generally, people with HIV and wasting can tolerate steroid treatments. One author feels that the standard *Physicians' Desk Reference* may not provide accurate and up-to-date information on steroids because it may "pre-date newer research and may incorrectly portray the primary and side effects of anabolic steroids." The *Anabolic Reference Guide* contains the best list of possible side effects according to that author.

Note: A nine-month interruption in the availability of nandrolone decanoate (Deca-Durabolin), one common anabolic steroid, has ended, and it should now be available in pharmacies as usual. ⊕

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

5 Five Habits of Highly Effective HIVers

by David Thorpe (reprinted from MedsHealth/Poz Magazine, September 2003)

Do long-termers share some special X-factor that keeps 'em kicking? That's what PWA and self-empowerment pioneer Michael Callen asked 13 such folks for his 1990 classic book, Surviving AIDS. Callen, who died in 1993, identified a willingness to try untested treatments, a belief in survival, and a clear purpose for existence as crucial factors contributing to longevity. POZ revisited the book with therapist Michael Shernoff, a long-term slow progressor (lucky genes!) who has treated about 200 HIVers. With the good doc's update, Callen's strategies remain essential for long-term living.

1. BELIEVE. Callen's long-termers believed, against all odds, that they could defy death. Now, Shernoff says, HIVers "need to believe they can have a meaningful quality of life."
2. BE AGGRESSIVE. Callen's pals asked questions, read studies, explored alternative treatments, and refused to take no for an answer. "Now more than ever," says Shernoff, "HIVers should not be passive patients."
3. STAY CONNECTED. A support network is key (for Callen, it was other AIDS activists). Shernoff says 20 years of research doesn't lie: friends and family keep you alive.
4. GET A LIFE. Callen observed an "ineffable quality of joie de vivre-friskiness" among his cohort. Shernoff recommends "sustaining a sense of the meaningfulness of your life," be it a job, lover, kids, pets, personal mission, or sheer orneriness.
5. ACCEPT UNCERTAINTY. Shernoff's post-protease addition: "We're Westerners and expect definitive answers. But HAART makes up the largest uncontrolled clinical study in history. Don't be angry when your doctor says, "We don't know." ⊕

Have your BIA checked

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

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

Michele Blanchet, RDN, of Gilwest Clinic, will discuss the results with you.

When: Tuesday, Nov 18 & Dec 16

Time: 2:00 – 5:00 PM.

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

How: Call ahead to book an appointment at 604.893.2243 or drop by the TIP office.

For more accurate results, please:

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

Comfort Foods

It may be time to shed the comfort food blanket.

Pamela Fergusson

It is Saturday night, and I sit in front of a computer, not flirting in a chat room, but actually trying to work. Recently, I have gone back to school, and on Monday, I have to submit this article and write an exam. As I sift through some of the research I've found about comfort foods, I become increasingly aware of the little pile of study snacks sitting on my desk.

I am not hungry. I am eating to reward myself for studying on the weekend when I would rather be out dancing. Or maybe I am a little stressed out about my exam, and eating helps me calm down. Whatever the reasons, I know that as individuals and as a society, our relationships to food are complex.

For most of us, eating is about much more than taking in nutrients. Food may be a friend or an enemy, a support system, a coping mechanism, a temptation, an addiction, a way to show love, a way to achieve control, or a source of comfort. Living with HIV adds new layers to that relationship. Good nutrition and building a healthy relationship with food is an important part of living well. Comfort foods, as part of that healthy relationship, can help support our physical, mental, emotional, and spiritual health goals.

Every person's idea of comfort food is different. It goes back to the food we ate at our grandmother's house or what our mom gave us when we were sick or feeling sad. It could be anything: beef stew, mashed potatoes, macaroni and cheese, chocolate chip cookies. The list goes on. Often comfort foods are high in carbohydrates and fat, but low in fibre. Rarely do they include vegetables or fruit, unless you count pumpkin pie. What all these foods have in common is that they make us feel better.

It's in the chemistry

Researchers have recently discovered that eating comfort foods can help cut off the hormonal rush caused by chronic stress. Mary Dallman, a professor of physiology at the University of California, San Francisco, found that when rats ate foods high in fat and carbohydrates, a metabolic signal helped to quiet the rats' chronic stress feedback system. Eating "seems to be an important feedback pathway—it's your body telling your brain, 'Things are getting better, calm down,'" said co-author Norman Pecoraro.

Living with HIV can put your body and your mind through chronic stress, a situation that can lead to frequent comfort food cravings. "There is no doubt that eating high fat and carbohydrate comfort foods cheers people up and may make them feel and function better," writes Dallman and her research team in the September 30, 2003, issue of the Proceedings of the National Academy of Sciences. "However, habitual use of these foods, perhaps stimulated by abnormally elevated concentrations of cortisol as a consequence of underlying stressors, results in abdominal obesity," they write. "Unfortunately, this type of obesity is strongly associated with type-2 diabetes, cardiovascular disease, and stroke." These same diseases are now emerging as complications of HIV because of the side effects of drug therapies.

Not very long ago being infected with HIV meant an inevitable battle with wasting. Nutritionists encouraged almost everyone with HIV/AIDS to make every bite count by eating foods high in nutrients, including protein, fat, and even sugar. Comfort foods were a big part of that picture. Today with the increased use of HAART, HIV-focused nutrition has become more complex.

Now eating is about living

Blanket statements advising people with HIV/AIDS to consume high-energy foods are no longer valid. Although many PWAs continue to struggle to gain weight, others are trying to lose weight or to gain muscle and lose fat. People are living longer, healthier lives with HIV, and balanced nutrition is important to support and maintain those advances.

So does that mean no ice cream? Of course not, every kind of food has a place in our lives. I encourage everyone to put guilt aside when evaluating eating behaviours. If eating comfort foods helps us cope with stress, if we successfully self-medicate with chocolate brownies, then that is just another good reason to eat them. As if we needed any more reasons! No one understands your relationship to food better than you do. I try to remember that "a tree is known by its fruits," or, in this case, a brownie (or a plate of brownies) is known by its aftertaste.

Do your comfort foods make you feel just as good the next day, emotionally and physically? Does your use of comfort foods fit in with your health plan? Does your use of comfort foods feel balanced to you? Are there any important issues in your life that you are avoiding though eating? Don't be hard on yourself! Be fair and honest when you ask these questions.

Comfort in place.

The HIV-positive community is a vibrant, multifaceted group of people facing many different issues. Comfort foods might hold very different places in your life, depending on your social support network, age, access to food, and the stage of your disease. Respecting individual needs and individual wisdom about how to fulfil those needs is important for the community and the people who work with it. At the same time, we have some collective responsibility for each other. We have all rejoiced as over the years living with HIV has become more about living than about dying. Although many challenges still occur in life with HIV, more and more people are able to celebrate their lives by making healthy choices, such as pursuing an active, healthy lifestyle with a balanced diet.

I have often heard HIV-positive people talk about how they are afraid to keep a fit and healthy body weight because their friends and family will think they are sick. They like to keep an extra layer of fat to prove that they are healthy.

As the picture of HIV changes and new therapies and their side effects impact health, keeping that extra layer of fat is becoming more unnecessary and unhealthy. As a community and as a society, we should continue to move away from the fear and the stigma of HIV. By promoting a healthy lifestyle and a healthy body image within the community, we help establish new norms. We can help to change the way HIV is perceived.

Some of those changes are already happening. Many of the AIDS service organisations providing food in the Lower Mainland used to have comfort food-laden menus, but now they offer healthier options. Ellie Schmidt, Dr. Peter Centre nutritionist, explained that "providing comfort and care through food has always been and still is a big part of the program at the Dr. Peter Centre. The needs of our clients have changed a lot over the years, but our goal of providing the best nutrition to support people living with HIV is constant. The people in our program are all HIV positive and, therefore, have many nutrition issues. Weight loss, poor appetite, nausea, and diarrhea are still problems, but we also have many clients who are eating well and may now need to be concerned about their cholesterol levels or their blood sugar levels, due to new side effects of the medications. We have responded by adopting a 'heart healthy' menu; including more fruits, vegetables, and whole grains and by reducing fat and simple sugars."

Comfort foods can help cut off the hormonal rush caused by chronic stress.

So what about the cravings for chocolate? What about late night movies with extra butter popcorn? No one is saying you have to stop doing the things you love. But why not try going for an energizing workout, having a long talk with a friend, or listening to your favourite music to soothe your stress? Make new traditions with your partner and your friends, like going for Saturday morning walks or going out dancing. When you do get together for a meal, try to introduce some tasty, healthier foods to the menu. And when you really want some of your grandmother's recipe apple pie or a bowl of peanut butter chocolate ice cream, savour every bite.

Comfort foods are still a part of living with HIV. They can be an important support when going thorough difficult physical or emotional times. Comfort foods can also be a way to show love and to make occasions special. They no longer have a place, however, as the automatic staple diet of the HIV-positive person. Although living with HIV can still be a source of chronic physical and emotional stress, PWAs can now approach that stress with new strength, hope, and healthier coping skills. ⊕

Pamela Fergusson is a Vancouver nutritionist. She is currently completing a Master's Degree in International Health in Sweden, exploring HIV and nutrition issues in the developing world.

Nutrition and HIV Care

Association of Nutrition Services Agencies (ANSA) meets in Vancouver

By Sue Moen

Local agency A Loving Spoonful hosted more than 160 ANSA member agencies at FoodFight 2003 in early September. More than 200 delegates from Canada, United States, England, and Africa met to support each other in their efforts to improve the nutritional health of PWAs. The conference theme, "Ten Years of Excellence," alludes to ANSA's beginnings at a conference in 1993.

Skills-building workshops and information sessions were presented by peers and other professionals in board development, fund development, administration, food services and distribution, volunteer management, client services, and, of course, nutrition. A Loving Spoonful staff and volunteers presented workshops highlighting Vancouver's unique client-based programming that emphasizes harm reduction. Delegates were "blown away" by the city's progressive attitude and levels of care, particularly for intravenous drug users and other marginalized populations.

Nutrition information for PWAs is the primary focus of this annual conference, and the American DPG meets at the same time. The broad range of therapeutic intervention options was evident in sessions entitled "The Use of Vitamin Therapy in HIV," "Nutrition Research and Interpretation," and "Nutrition Intervention for Hep C Co-Infection."

The workshop called "Nutrition Across the Spectrum: Substance Use, Medication Fraud, and Recovery" had the largest attendance and the liveliest discussion. Oak Tree Clinic dietitian Diana Johansen and Brooklyn Hospital Center AIDS treatment coordinator Jennifer Eliasi presented opposite points of view on using harm-reduction strategies in nutrition care within the HIV-positive drug-using population. Johansen presented the benefits of harm reduction that addresses the needs and contexts of addicts and the delivery of appropriate nutritional and medical therapies that deal with their realities. Eliasi's perspective was based on the abstinence model, an approach that essentially denies services until the client is clean and sober. The underlying theory of abstinence is that addicts cannot or will not benefit from intervention until they have ended their dependence on substances. Local delegates were shaken by some of the assumptions and models coming out of the United States.

Local delegates were shaken by some of the assumptions and models coming out of the United States.

This conference was a unique opportunity for local dietitians, PWAs, healthcare professionals, AIDS service organizations, and other agencies involved in food programs to network with peers, revitalize themselves, and explore the many possibilities for improving the nutritional status of PWAs. ⊕

Sue Moen is the executive director of A Loving Spoonful.

Coming Soon to a PHARMACY Near You ... or not.

What's new in antiretrovirals.

by Paula Braitstein

Enfuvirtide (Fuzeon)

Otherwise known as T-20, enfuvirtide (Fuzeon) is the first drug in a new class of antiretrovirals called fusion inhibitors. These drugs prevent HIV from fusing to immune cells.

One of enfuvirtide's major drawbacks is that you have to inject it into your belly. The other major drawback is its price: Roche's intended price for enfuvirtide (Fuzeon) will be consistent with the international median—meaning comparable to what the company charges in the United States. The expected per patient cost will likely be between $27,000 and $30,000. The principle side effects of enfuvirtide are local injection site reactions (ISR). Ninety-eight percent of patients have at least one local ISR. Other adverse events frequently reported were diarrhea (26.8%), nausea (20.1%), and fatigue (16.1%).

Enfuvirtide was approved by Health Canada in July 2003 for use in treatment-experienced people. Because of the extraordinary price of T20, the BC Center for Excellence has developed guidelines regarding who can access it. People will be considered eligible if their lowest ever CD4 count has been below 100 cells/mm3, they are resistant to at least two drugs in all other available classes of drugs, and they are unable to create a viable antiretroviral therapy combination without it. If a person doesn't have a significant virologic response to T20, they will be withdrawn from it.

Tenofovir disoproxil fumarate (Viread)

Health Canada approved tenofovir disoproxil fumarate in March 2003. In October 2001, Gilead initiated an expanded access program for people with limited treatment options. Approximately 1600 Canadians have been receiving tenofovir through this program.

Tenofovir is also indicated for people who have experienced virologic failure on other regimens. Tenofovir is a nucleotide drug (vs. nucleoside) but is considered part of the nucleoside reverse-transcriptase inhibitors class, like AZT and 3TC. A price in Canada has not yet been set, but a decision from the Patented Medicine Prices Review Board (PMPRB) is expected soon. In the US, the drug is priced to wholesalers at $4623 per year of therapy, considerably more than other reverse-transcriptase inhibitors. Gilead is asking for a high price in Canada (roughly $7000/yr per patient) too, and are threatening to not market the drug in Canada if they don't get the price they are demanding. Stay tuned!

The most common side effects with tenofovir in clinical trials were headache, muscle aches, and mild to moderate nausea, diarrhea, vomiting, and flatulence. Kidney side effects have been reported with the use of tenofovir. If you have known risk factors for kidney disease or a history of kidney dysfunction, think twice before using this drug. You should avoid taking tenofovir at the same time as other drugs that are also known to cause kidney toxicity.

Peginterferon alfa-2a (Pegasys)

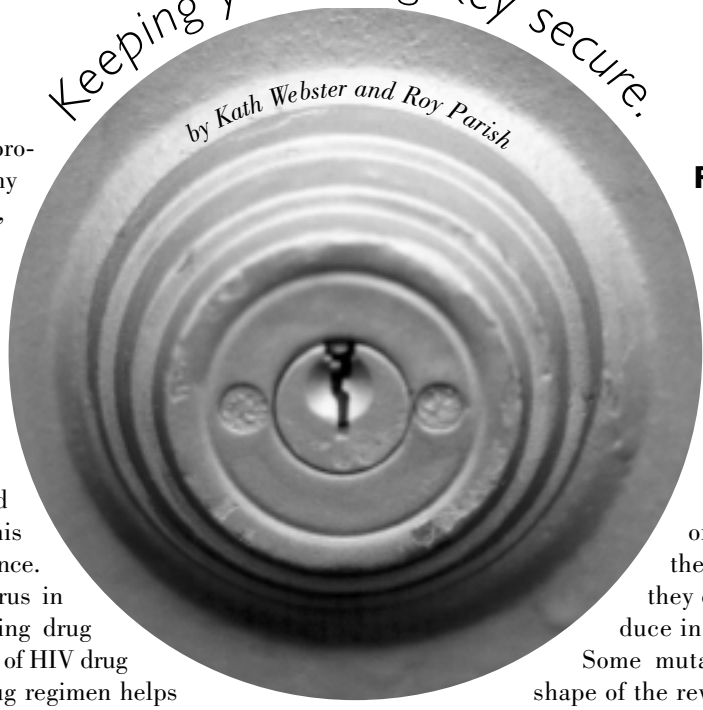
Hoffman-La Roche had a good summer. In June 2003, their version of pegylated interferon (a treatment for hepatitis C) called Pegasys was approved by Health Canada for use as monotherapy, which is surprising because a broad consensus exists among doctors and researchers that pegylated interferon is most effective in combination with ribavirin. Schering-Plough, the other manufacturer of pegylated interferon, is selling Pegetron, which is a combination of peginterferon and ribavirin. In conjunction with the approval for Pegasys monotherapy, a clinical study called the RAP protocol (ribavirin access program) has been initiated. The company is also seeking approval to market ribavirin, a generic drug, as well. ⊕

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

Resisting Resistance

Keeping your drug key secure.

by Kath Webster and Roy Parish



HIV drugs have prolonged many lives. True, we face side effects that range from irritating to dangerous, but popping our pills has provided most of us with hope and has boosted the quality of our lives.

The mantra that comes with starting HIV drugs goes like this: take your meds on time and don't miss a dose. Following this mantra can prevent drug resistance. Along with suppressing the virus in order to stay healthy, preventing drug resistance is one of the key goals of HIV drug therapy. Adherence to your drug regimen helps prevent the HIV mutations that let the virus run amok. We're in this for the long haul, and we want effective and easy-to-take drug combinations that will last us for years.

Drug resistance is a reduction in the ability of a drug or combination of drugs to suppress HIV reproduction in the body. In other words, HIV continues to multiply as if the drugs were not present.

To understand drug resistance, we need to understand how HIV reproduces itself in the body. After infection, HIV wastes no time and immediately starts attacking CD4 cells, the infection fighting cells of our immune system. The CD4 cell is taken over by HIV and, in a sense, becomes a factory for making more viruses. These in turn search out new CD4 cells to attack and disable. The life cycle of the virus relies on three special proteins called enzymes: reverse transcriptase, integrase, and protease, all of which enable the virus to interrupt the regular functions of the CD4 cell. For the drugs to effectively fight HIV, they must knock out the enzymes HIV uses, making it difficult for the virus to reproduce.

There are four classes of HIV/AIDS drugs:

- Nucleoside analog reverse transcriptase inhibitors (NRTIs), or "nukes," such as lamivudine (3TC)
- Non-nucleoside reverse transcriptase inhibitors (NNRTIs), or "non-nukes," such as efavirenz (Sustiva)
- Protease inhibiters (PIs) such as lopinavir/ritonavir (Kaletra)
- Fusion inhibiters such as enfuvirtide (Fuzeon, formerly T-20)

Resistance Starts

HIV reproduces itself millions of times every day. As it does so, it makes errors and mutations that result in slight differences in the genetic code of the virus. These genetic differences produce slightly different versions of the virus, which can be benign or fatal to it. They can inhibit the virus from reproducing, or they can allow the virus to reproduce in the presence of HIV drugs. Some mutations actually change the shape of the reverse transcriptase and protease enzymes, preventing the drugs from fitting properly onto the enzymes. HIV drugs work like a lock and key. If the shape of the lock, or virus, changes, the key, or drugs, won't fit properly into the lock. The drug becomes less effective against the virus and allows a low level of viral reproduction to continue.

When does resistance occur?

A degree of resistance may happen before treatment even starts. HIV mutations can exist in people who are treatment naïve (have never taken HIV drugs) so a person could become resistant to some HIV drugs even before taking them. Resistance can also start before treatment if someone is infected with a virus already resistant to the drugs. Studies indicate that 10–30% of all new HIV infections (those within the last two years) are mutant strains of HIV, resistant to at least one HIV drug.

Most drug resistance develops during drug therapy. Unfortunately, the drugs cannot completely shut down HIV reproduction and resistance can develop even with an undetectable viral load and perfect adherence to the regimen. When HIV becomes resistant to one drug, it can become resistant to other drugs in the same class. This problem is called cross-resistance. For example, if you are resistant to the protease inhibitor ritonavir, you may also develop resistance to other protease inhibitors.

Resistance Testing

Drug resistance can be measured. How resistant the virus is to different drugs can be determined prior to choosing a treatment regimen. The two drug resistance tests both require a standard blood sample, and they can be performed while a patient is on drug therapy with a viral load of at least 500 copies. Resistance tests can also be useful for people who are treatment naïve.

Genotype testing examines the genetic code of the virus and looks for specific mutations known to cause drug resistance. This test can assess which drugs might be the most effective for treatment-naïve people who are starting therapy.

Phenotype testing directly measures the sensitivity of the sampled HIV to different drugs. A phenotype test can be used to help identify an effective second or third combination after failing initial therapy.

A new type of resistance test uses a single blood sample to perform both genotype and phenotype tests at the same time.

Use resistance tests when HIV drugs stop working (viral load goes up, CD4 cell count falls) or when they fail to reduce viral load within a reasonable time. Pregnant HIV-positive women should have resistance tests to determine which drugs they can use to prevent mother-to-child transmission. Newly infected people can use resistance tests to determine whether they have contracted a resistant strain.

As with many medical tests, resistance tests are not flawless. The results can be extremely difficult to interpret, particularly for very treatment-experienced patients. Mutated strains of virus cannot be detected unless they are at least 20% of the total viral population. Also, the tests cannot detect resistance for people who have stopped taking HIV drugs.

Adherence

Drug resistance can limit your treatment options by reducing the number of drug combinations that may be effective for you. If you are currently taking HIV medications, take your drugs consistently and as prescribed to reduce opportunities for mutation. Here are some adherence strategies that may help:

- Don't skip or miss doses! Take your drugs as prescribed
- Take extra pills with you when you travel
- Use a pillbox to count out and organize your pills each week
- Use a beeper or have someone remind you
- Deal with a drug or alcohol problem if it is causing you to miss doses.

Other Factors

Other factors can also lead to resistance. Poor drug absorption because of side effects such as diarrhea or vomiting needs to be addressed immediately. If you are not absorbing what you eat, you are also not absorbing your meds properly, which could lead to lower than targeted drug levels in your blood and eventually to resistance.

If for any reason you are having trouble taking your meds or have pill fatigue or burnout, talk to your doctor before simply stopping your meds. An easier combination may be available that you can switch to. If you are considering a drug holiday or treatment interruption, make sure you are monitored by your doctor.

Drug resistance is not the end of the game. Fear not. Resistance comes in degrees, and most mutations deplete drug strength gradually. Besides, a mutated virus tends to have reduced viral fitness, so it reproduces more slowly and inflicts less damage on the immune system. If you have a lot of drug resistance, your doctor may increase the dosage of your drugs or prescribe a boosted protease inhibitor.

Drug resistance and the odds of developing resistance can be minimized. When you start to take HIV drugs, make sure your doctor has chosen a powerful combination for you. Learn about your medications and stick to your regimen. Maintain good communication with your doctor and have your viral load and CD4s checked regularly to ensure your drug combination is working well for you. ⊕

Kath Webster and Roy Parish are treatment counsellors with the BCPWA Society's Treatment Information Program.

Creatine

Considerations for supplementing to maintain muscle mass

by Tom Mountford

Creatine is a natural compound made by our bodies to deliver energy to muscles. Studies show that creatine supplements increase fat-free mass in weightlifters and is considered beneficial to athletes for sports requiring short, repeated bursts of high power. HIV-positive people are taking creatine to maintain muscle weight and lower cholesterol. However, creatine users must weigh the benefits against the range of possible side effects.

Creatine is produced mostly in the liver, but some creatine is formed in the pancreas and kidneys. These organs combine the amino acids arginine, methionine, and glycine to form creatine. Dietary sources of creatine are fish (tuna, salmon, cod) and meat (beef, pork). The body removes creatine with normal movement and exercise.

People with HIV/AIDS should think twice about creatine supplements.

Creatinine, a protein found in muscles and blood, is formed from excessive levels of creatine. High levels of creatinine in the blood indicate a breakdown of muscle tissue and may indicate myopathy in AIDS patients. Kidneys filter creatinine from the blood, so a kidney blood test will measure its build-up. Elevated creatinine phosphokinase often appears after muscle injury or exercise.

People with HIV/AIDS should think twice about creatine supplements.

Creatine draws water from the blood and other areas of the body to the muscles, causing dehydration and heat stroke. Creatine supplements might reduce the body's production of natural creatine. It may increase the concentration of HAART or other drugs, causing complications. Kidney stones can result and the side effects of some HIV medications, such as GI upset, bloating, and diarrhea, can worsen. A study in rats showed that prolonged creatine supplementation induces abnormalities in pancreatic insulin secretion and changes in glucose equilibrium.

Studies done in healthy, very athletic individuals suggest that creatine supplements do not affect kidney function, blood pressure, plasma creatine, or Creatine enzyme activity in the muscle, liver, heart and bone. But if you are HIV-positive, it may not be worth the risk. No studies have been carried out in people with HIV/AIDS. The effects are unknown.

Age affects creatine effectiveness. A study showed no difference between young and old men in blood or urine creatine after supplementation. However, older subjects had a relatively small increase in muscle phosphocreatine. In other recent research, creatine reduced cholesterol by 6% and triglyceride levels by 23% in patients with hyperlipidemia. This finding may tempt some to try it, but they will be risking further complications.

If you decide to try creatine, notify your doctor and have your blood urea nitrogen and creatine levels closely monitored. Nearly all research used creatine monohydrate, the cheapest form, and no research has confirmed the superiority of newer forms. A "cycling" strategy (taking creatine for 4–8 weeks followed by a one-month holiday) is supported by studies showing that once muscle stores are full, benefits continue for 4–5 weeks. Since uptake and storage increases when insulin is high, many athletes ingest carbohydrates with each dose. But taking creatine with fruit juice transforms it directly into creatinine, which stresses the kidneys. Only reputable manufacturers providing a certificate of analysis should be used because contaminants have been found in some creatine formulations. ⊕

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

Bring it Back

Advocacy for Respite Care

Jeff Anderson

Hundreds of people with HIV, cancer, and other terminal diseases were shocked when Providence Health Care, operators of St. Paul's Hospital, pulled the plug on its respite care program on April 22. Patients received a form letter with three weeks notice to vacate their beds. No public consultations were held, and no formal announcements of the cuts were made.

Activists, health professionals, and respite care service clients are determined to resuscitate the program in anticipation of an expected explosion of respite and palliative patient needs in coming years.

Respite care is relatively new. According to Providence Health Care, "patients pre-booked one week admissions to the palliative care [unit] to give patients, their caregivers, and families an opportunity to rest and regroup, as well as to receive any needed medical investigations, procedures, or treatments." The respite patient benefits from the synergy of the acute care setting, palliative care expertise, and a home caregiver. Respite care is said to prevent physical deterioration, lessen demand on the few acute palliative beds remaining, and allow patients to return healthier to homes and families.

The best advocates for respite care are largely dead, ill, or grieving. Many caregivers, clients, and supporters testified at a recent public forum in downtown Vancouver, in which both St. Paul's Hospital administration and the Vancouver Coastal Health Authority declined to participate. Healthcare professionals asserted that many lives would have been lost in a less-skilled, non-acute respite care setting.

Health professionals are concerned. In a September 26 Vancouver Sun front page article with the headline "Huge Bill Looms to treat city's AIDS patients," Dr. Julio Montaner, chief of AIDS research at the BC Centre for Excellence in HIV/AIDS, who treats many HIV-positive injection drug users, warns that "a wave of sick and dying AIDS patients is likely to hit Vancouver over the next few years."

It's not just HIV that concerns Dr. Montaner. "Most infected drug users also have hepatitis C and many have tuberculosis…. [This] means their health problems will likely be more severe and more complicated to treat. People are showing up with severe diseases we haven't seen in years." In the same article, Dr. Evan Wood, one of this country's foremost researchers in urban healthcare, states flatly, "The palliative care wards need to prepare for several thousand HIV-infected patients."

Palliative patients are fragile and need supervision. The simple cost effectiveness of respite care seems obvious.

Twenty-two years of fighting HIV/AIDS has taught health planners the value of the insights of both patients and health providers in establishing best practices. In this vein, Vancouver Coastal Health Authority appears poised "sometime this fall" to develop a more open process in shaping what is hoped to be a comprehensive plan for the full continuum of palliative and respite services needed.

Providence Health Care seems unmoved by the wisdom of its own staff. For activists, the extinguished program means patients will become more ill and need to access St Paul's more expensive acute care services instead of the cheaper respite beds.

In the form letter turfing out patients in 10D, St Paul's officials directed concerned people to contact Wendy Hansson, program director of Acute Services at Providence Health Care or St. Paul's palliative program physician leader, Dr. David Kuhl. The world-renowned Dr. Kuhl recently resigned from his position, and activists hope Providence restores respite care before more expertise is lost. This autumn will be crucial in deciding whether the emerging specialty of respite care will save more lives or die a quiet death at St. Paul's Hospital. ⊕

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

The Consumer's Voice

Advocacy for Drug Access: Submission to the Standing Committee on Health, Study on Prescription Drugs

by Louise Binder and Philip Lundrigan

The Canadian Treatment Action Council (CTAC) is a national volunteer organization whose mandate is to support access to therapies and treatments for people living with HIV/AIDS, to mentor people living with HIV/AIDS and enhance their advocacy skills, and to encourage and facilitate the exchange of related information to stakeholders. Many of the treatment access issues identified in CTAC's work plan are not specific to HIV. They impact many diseases and disabilities.

In response to the federal government's Standing Committee on Health's Study on Prescription Drugs and call for submissions, CTAC prepared a position paper. Here is a summary of CTAC's position and its recommendations to the Standing Committee.

Rising prices

As prescription drug prices continue to rise, provincial formularies and private insurers have begun to refuse coverage of the higher priced new drugs. When a new drug is added to a formulary, another drug is sometimes removed. For many illnesses, access to a broad range of prescription options is essential to customize treatments to individual needs, to maximize effectiveness, and to minimize toxicity.

Prescription drug prices are set internationally, based primarily on what the market will bear. Canada comprises about 2% of the international market, so if prices are restricted in Canada, pharmaceutical companies may choose not to sell their products in Canada rather than adjust their prices. Such a move by industry would also have enormous implications for research and development of new treatments in Canada.

Additional areas related to the complex drug pricing issue include compulsory licensing, intellectual property rights, international trade agreements, domestic patent legislation, and international patent laws and agreements. (See p.9 for article name on international drug pricing and access to HIV/AIDS drugs in Africa.)

Recommendations:

- That the Government of Canada immediately engage its international partners to explore ways to ensure that prescription drug prices are contained while not restricting access to new medicines in the process
- That the federal and provincial/territorial governments collaborate in the bulk purchase of prescription drugs to keep prices down.

Systems to review and control prices of all prescription drugs

Because prescription drug prices are set internationally, Canada's ability to regulate and control these prices is very limited. Both generic and brand name drugs should be subject to the same pricing review system in Canada.

Manufacturers who are concerned that they may not get a price in Canada similar to the US price for a drug are beginning to refuse to market drugs in Canada until the Patented Medicine Prices Review Board (PMPRB), the federal agency that regulates prices, provides a price review. Any solution to the pricing question is going to have to be a North American solution, not merely a Canadian one. There must be cooperation internationally to negotiate North American pricing for drugs.

The administration and delivery of healthcare, including reimbursement through formularies, falls to provincial and territorial governments, with each making its own decisions on the coverage of prescription drugs. The new Canadian Coordinating Office for Health Technology Assessment (CCOHTA) currently acts as a preliminary review body for all formularies and makes recommendations to all of the provinces/territories.

Recommendations:

- Create a transparent review process that solicits input from relevant stakeholders, including consumers and third party payers
- Continue to appeal WTO and NAFTA rulings that restrict Canada's ability to direct its own healthcare
- Reject international trade agreements that limit the Canadian government's ability to adhere to the Canada Health Act
- Ensure that all international trade negotiations place human rights (including the right to health) before private property interests.

Systems for reviewing new drugs

The prescription drug review and approval process in Canada continues to present challenges for access to new treatments. Canada's system lags woefully behind other developed countries and lacks transparency and accountability.

The review and approval of prescription drugs in Canada can take up to 26 months longer than in the United States. Meanwhile, compassionate and expanded access programs for drugs in development are largely at the discretion of industry. Many Canadians, for whom current therapies have failed or are intolerable, suffer a diminished quality of life and some die before they can access new treatments.

Recommendations:

The Government of Canada should immediately

- allocate sufficient resources to implement and maintain the recommendations of the Working Group on HIV/AIDS
- ensure adequate resources for review divisions with reviewers having the necessary qualifications and expertise
- establish and implement mandatory time frames for quality reviews with appropriate accountability
- increase transparency of the review process to include access to non-proprietary information about the status of the review and the rationale for any final decision made by the Therapeutic Products Directorate.

Monitoring of adverse effects and prescription practices

Canada requires a comprehensive, active, consumer-centred, post-approval surveillance system (PASS) that is internationally linked to other such systems.

It is true that idiosyncratic side effects can occur with prescription drugs, over-the-counter drugs, and complementary and alternative medications. At the same time, gathering, analyzing, and sharing side effect and prescribing practice data provides an opportunity to reduce the likelihood of inappropriate prescribing by physicians and dissemination by pharmacists.

Recommendations:

- Develop a post-approval monitoring system (PAMS) that is consumer-centered and includes effective reporting mechanisms from consumers and healthcare professionals
- Ensure, as a critical first step in the implementation of a PAMS, that the data management system adopted is robust and will accommodate the increased numbers and timely demands of the reports
- Develop and implement a variety of effective strategies for soliciting adverse and other drug reaction information from consumers and healthcare professionals
- Ensure an effective mechanism to broadly disseminate adverse drug reaction information to all stakeholders
- Encourage international liaison on drug safety issues.

Direct-To-Consumer Advertising (DTCA)

Prescription drug information should be delivered to consumers by a neutral third party that has no vested interest in any particular product. That third party should be able to provide accurate, balanced, and unbiased information, including information on non-drug alternatives. Direct-to-consumer advertising results in unnecessary and inappropriate prescription drug use, overstated benefits, minimized risk information, and increased prescription drug costs. At the same time, it does not result in better health outcomes and does not result in more informed consumers.

The US is the only country where DTCA is permitted. Investment in prescription drug advertising in the US has surpassed US$2 billion annually in recent years. Earlier this year, the European Union voted to uphold its ban on DTCA.

Recommendations:

- DTCA should be completely banned for prescription drug advertising in Canada
- Regulations should be tightened to provide a mandatory transparent review process for ads currently permitted
- A mandatory, transparent reporting system for violations should be implemented with adequate penalties and sanctions for violations
- Information on prescription drugs should be funded by industry and delivered by neutral third parties who have no vested interest in any product or service. ⊕

Louise Binder is chair of the Canadian Treatment Action Council.
Philip Lundrigan is vice-chair of the Canadian Treatment Action Council.

Pap Tests for Anal Cancer

Is what's good for the goose, now good for the gander too?

By Thomas Lampinen

HIV researchers and healthcare providers have been buzzing in recent years about anal cancer. Concern is rising among persons with HIV/AIDS who are now living longer that the incidence of anal cancer may be increasing. Anal cancer is a serious disease. Most researchers believe that early detection and treatment will improve survival rates and quality of life. But would HIV-positive men and women who are without symptoms benefit from periodic testing for anal cancer?

Anal cancer, which is different from rectal cancer, is a rare disease and occurs in fewer than ten men and fewer than 20 women per 100,000 people each year in British Columbia. Women who have previously been diagnosed with cervical cancer have an increased risk for anal cancer, as do gay and bisexual men. Both anal and cervical cancers are caused by specific strains of human papillomavirus (HPV). HPV is passed by skin-to-skin contact between sexual partners and infects cells found in both the anal canal and the cervix. Once inside these cells, HPV produces proteins that bind to and interfere with cell machinery that normally prevents the accumulation of cell mutations. Persistent HPV infection, common in HIV-positive men and women, is believed to cause the gradual accumulation of severely mutant cells in the anus and cervix that can eventually give rise to cancers at these sites.

Severely abnormal cells in the anus rarely revert to normal. However, their progression to cancer likely takes years, possibly decades. In that time, abnormal cells in the anus can be detected and treated before cancer arises. Cells can be sampled during a simple 15–20 second anal (Pap) test using a Q-tip swab that is inserted about an inch into the anus. Examination of these cells under a microscope can reveal severe abnormalities, prompting early treatment to prevent invasive anal cancer.

Pap tests have reduced cervical cancer deaths by almost 80%. The similarities between cervical and anal cancer suggest that anal Pap tests may be beneficial, especially for HIV-positive men and women. As obvious as this conclusion might seem, some very important issues need to be resolved first.

For example, Pap tests sometimes fail to detect severely abnormal cells present in the anal canal. Studies are determining whether direct visual examination of the canal by a specialist is a better approach.

A very important issue involves treatment. Standardized guidelines are available for the treatment of severely abnormal cells in the cervix but not in the anus. Research is needed to show that proposed treatments really do prevent the progression of severely abnormal cells to cancerous ones. They also need to estimate more accurately the likelihood of such progression to anal cancer if no treatment is provided.

These questions are not just academic. Less than 5% of women receiving Pap tests get referred for even possible treatment of abnormal cells in the cervix. By contrast, initial studies are finding that the *majority* of HIV-positive men and women do require fuller evaluation and treatment of severe anal cell abnormalities during the first few years of their anal Pap testing, even though doctors still cannot be certain that cell abnormalities will lead to anal cancer.

Despite the clear increased risk that HIV-positive men and women have for *severely abnormal* cells in the anus, it is less clear that their risk for *invasive anal cancer* is above normal as well. If anal Pap tests benefit only a small number of HIV-positive persons who are destined to develop invasive anal cancer, this benefit must be weighed carefully against the temporary discomfort, side effects, and very substantial costs associated with detection and treatment of abnormal cells in the *majority* of HIV-positive men and women. ⊕

Thomas Lampinen is a Clinical Assistant Professor of Health Care and Epidemiology at the UBC and BC Centre for Excellence in HIV/AIDS.

New guidelines to protect Pregnant women and children

By Jim Boothroyd

HIV-positive women should receive optimal antiretroviral therapy regardless of their pregnancy status. If they have undetectable viral loads while on antiretroviral therapy, they are to be encouraged to choose vaginal birth over caesarian section. And their newborns ought to receive antiretroviral therapy within 12 hours of birth for six weeks.

These are three of the 24 new guidelines for the treatment of HIV-positive women and their offspring published in the *Canadian Medical Association Journa*l in June.

The product of several years of work by a national team of physician-investigators, pediatricians, and community activists at the Canadian HIV Trials Network, they represent the Canadian consensus on how best to treat a fast growing HIV-positive demographic group.

The guidelines cover the full cycle from conception through to post delivery care.

In a commentary published by the *CMAJ*, principal author Dr. David Burdge of Vancouver and colleagues say that they hope the guidelines will benefit pregnant women and their offspring by minimizing the risk of mother-to-child HIV transmission and toxic effects of HIV therapy, and maintain the woman's long-term treatment options.

They note that physicians must balance "maternal risks and benefits with fetal risks and benefits." The basic principle is that "the pregnant woman should receive appropriate treatment for any medical or surgical problems, despite her pregnancy." And they add, "treatments must be undertaken only if the woman is in full agreement and understands the potential risks to both her and the fetus."

They advocate preconception counselling that addresses the woman's viral load and immunological status. They advise that pregnant women see an obstetrician with expertise in HIV. And they note, "there are many potential complications related to antiretroviral therapy and close communication between the woman's HIV specialist and the obstetrician is imperative."

Physicians are to discuss modes of delivery with HIV-positive women patients early in their pregnancies. Among other things, women should be made aware of documented evidence suggesting that C-sections decrease the likelihood of HIV-transmission to the fetus, in women who are not taking antiretroviral therapy and those receiving AZT (zidovudine) monotherapy.

However the authors state that in women on antiretrovirals with suppressed viral loads, "there is no documented advantage to caesarean section, and the added morbidity associated with caesarean birth relative to vaginal birth must be considered."

The full guidelines can be found online at www.hivnet.ubc.ca/ctn.html. ⊕

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

Trials enrolling in BC

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

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

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

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

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

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

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

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

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

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

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

ATAZANAVIR

por Alejandro De Vivar

Reyataz (Atazanavir sulfate) de la farmaceútica Bristol Myers Squibb es un nuevo inhibidor de la proteasa para combatir la infección por VIH/sida. En junio del 2003 fue aprobado en los Estados Unidos y se espera su aprobación en Canadá.

Este fármaco, al igual que otros de la familia de los inhibidores de la proteasa, actúa químicamente bloqueando la enzima de la proteasa y afectando la materia prima que conforma el virus que es necesaria para la reproducción de nuevas copias.

El 30% de los pacientes mostró muy altos niveles de bilirrubina sin provocar daño hepático, 10% ictericia (piel y ojos amarillos). Suspendiendo el medicamento desaparecen los síntomas.

Atazanavir es un medicamento que puede ser usado al inicio de una terapia por ser un fármaco de gran actividad y bajo número de comprimidos. También como tratamiento de rescate en pacientes que sufren los efectos secundarios de los inhibidores de la proteasa como lo son los asociados con el incremento de azúcares y triglicéridos o porque se ha generado resistencia -debido a que los estudios realizados no mostraron hasta ahora indicios de resistencia-.

Debido a que es un nuevo medicamento, las investigaciones aun continúan. Si esta tomando Atazanavir, asegurese de que su doctor tenga la última información sobre este medicamento.

¿Cómo se toma?

Su presentación es en cápsulas orales de 100 mg, 150mg y 400mg acompañados con alimentos una vez al día.

¿Cúales son los efectos secundarios?

El 30% de los pacientes mostró muy altos niveles de bilirrubina sin provocar daño hepático, 10% ictericia (piel y ojos amarillos). Suspendiendo el medicamento desaparecen los síntomas.

¿Cúales son sus ventajas?

Los niveles de triglicéridos y colesterol se mantienen muy cerca de lo normal porque al parecer Atazanavir no incrementa los niveles de azúcar o grasa en la sangre.

Para las personas que están predispuestas a enfermedades cardiacas es recomendable el uso de Atazanavir, así como también para la prevención de daño al corazón por los tratamientos a largo plazo. También es una buena opción para los pacientes que han mostrado alteraciones en sus lípidos por los inhibidores de la proteasa al aumentar considerablemente los niveles de colesterol y los triglicéridos.

¿Cómo actúa en interacción con otros medicamentos?

Atazanavir es metabolizado por el hígado como la mayoría de los antirretrovirales orales. Se debe tener precaución con Viagra, antihistamínica, sedante, antihongos o anticolesterol, así como con otros antirretrovirales. ⊕

BCPWA Treatment Information Program (TIP)

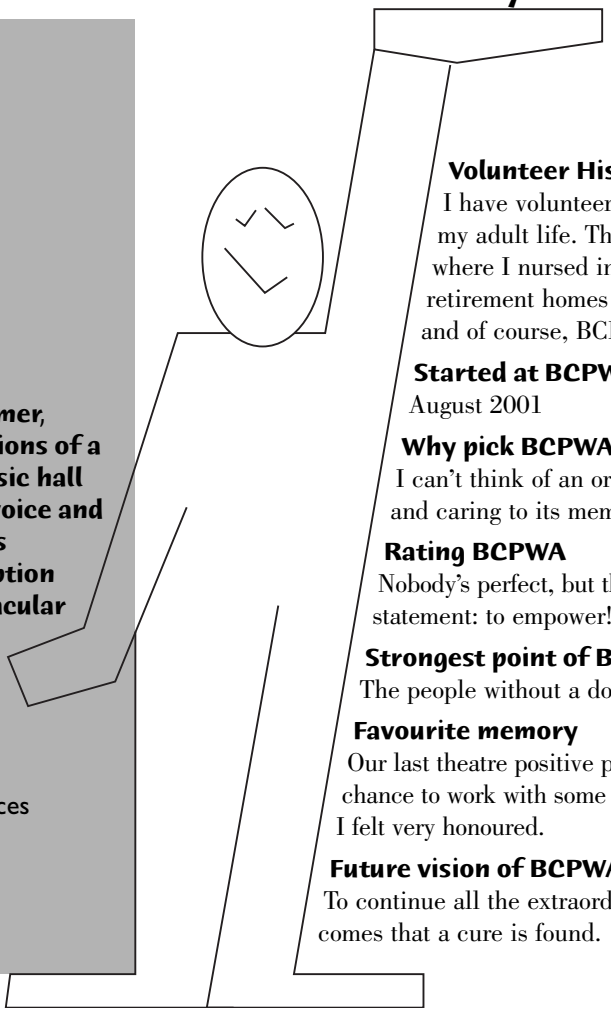
Ofrece información sobre tratamientos del VIH/SIDA.
Todos los miercoles 1:00PM a 5:00PM.
1107 Seymour Street, 2nd Floor, Vancouver, BC V6G 5S8
Llame a la línea directa: 604.893.2243
email: treatment@bcpwa.org

Volunteering at BCPWA

Profile of a volunteer: Melody Escallier

A character and a charmer, Melody conjures up visions of a turn of the century music hall chanteuse. Her lovely voice and engaging personality is appreciated from reception desk, to Retreat's spectacular evening performances, to center stage with Theatre Positive.
What a gal, what a gift.

Jackie Haywood
Director of Support Services



Volunteer History
I have volunteered for different organizations the majority of my adult life. The most rewarding have been the SPCA, where I nursed injured or sick animals back to health; visiting retirement homes to chat with residents, visit, or read to them; and of course, BCPWA.

Started at BCPWA
August 2001

Why pick BCPWA?
I can't think of an organization that is more dedicated, respectful and caring to its members and volunteers.

Rating BCPWA
Nobody's perfect, but they try hard to live up to their mission statement: to empower!

Strongest point of BCPWA
The people without a doubt.

Favourite memory
Our last theatre positive production 'West End Stories'. I had the chance to work with some wonderful and talented people. I felt very honoured.

Future vision of BCPWA
To continue all the extraordinary work the BCPWA does until the day comes that a cure is found.

Gain and share your skills for a valuable cause

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

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

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

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

where to find help

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

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

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

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

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

AIDS Resource Centre – Okanagan and Region
202 – 1626 Richter Ave,
Kelowna, BC V1Y 2M3
250.862.2437 or 1.800.616.2437
arc@arcok.com; www.arcok.com

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

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

AIDS Vancouver Island (Nanaimo)
201 – 55 Victoria Rd, Nanaimo, BC V9R 5N9

AIDS Vancouver Island (Victoria)
1601 Blanshard St, Victoria, BC V8W 2J5
info@avi.org; www.avi.org

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

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

Asian Society for the Intervention of AIDS (ASIA)
210 – 119 West Pender St,
Vancouver, BC V6B 1S5
604.669.5567
asia@asia.bc.ca, www.asia.bc.ca

Dr Peter Centre
1100 Comox St,
Vancouver, BC V6E 1K5
604.608.1874
info@drpeter.org; www.drpeter.org

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

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

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

North Island AIDS (Campbell River) Society
684B Island Hwy,
Campbell River, BC V9W 2C3
250.830.0787 or 1.877.650.8787

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

North Island AIDS (Port Hardy) Society
8635 Granville St, Ground Floor,
Port Hardy, BC V0N 2P0
250.902.2238
niac@island.net; www.island.net/~niac

Okanagan Aboriginal AIDS Society
202 – 1626 Richter Street,
Kelowna, BC V1Y 2M3
250.862.2481 or 1.800.616.2437
oaas@arcok.com; www.oaas.ca

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

Pacific AIDS Network c/o AIDS Vancouver Island (Victoria)
250.881.5663
erikages@pan.ca; www.pan.ca

Positive Living North West
Box 4368 Smithers, BC V0J 2N0
3862 F Broadway, Smithers BC
250.877.0042 or 1.886.877.0042
plnw@bulkley.net

Positive Women's Network
614 – 1033 Davie St, Vancouver, BC V6E 1M7
604.692.3000 or 1.866.692.3001
pwn@pwn.bc.ca; www.pwn.bc.ca

Red Road HIV/AIDS Network Society
Suite 100 – 2425 Quebec St,
Vancouver, BC V5T 4L6
604.879.8884 or 1.800.336.9726
info@red-road.org; www.red-road.org

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

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

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

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

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

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

Upcoming BCPWA Society Board Meetings:

Date	Time	Location	Reports to be presented
October 15, 2003	1:00	Board Room	Written Executive Director Report — Financial Statements / August — Director of Communications & Education
October 29, 2003	1:00	Board Room	Quarterly Department Reports — Executive Committee — Financial Statements / September — Director of Treatment, Information & Advocacy
November 26, 2003	1:00	Board Room	Financial Statements / October
December 10, 2003	1:00	Board Room	Written Executive Director Report — Executive Committee — Director of Development
January 7, 2004	1:00	Board Room	Standing Committee — Financial Statements / November

The BCPWA Society is located at 1107 Seymour St., 2nd Floor, Vancouver.
For more information, contact:
Alexandra Regier, Office Manager
Direct: 604.893.2292
Email: alexr@bcpwa.org

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

Cheque payable to BCPWA

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

Perennial Beauty

by Janet Conners

Monotherapy. Dual therapy. Triple therapy. Combination therapy. The cocktail. I've done 'em all. Who of us hasn't? Aren't we lucky that we live in a time that being a size three, nice and thin is sooo "in"?! When I look in the mirror, I see my poor old face, looking lined and tired, cheeks sunken, hairs growing out of my chin and neck, a belly getting bigger and an ass getting smaller.

God, don't you just long for the days when the worst side effect from a cocktail was a hangover. Remember when a cocktail was a scotch on the rocks or a screwdriver? Remember when throwing up from cocktails because we had drunk one too many meant that we were having fun? Hoo, yeah, those were the days.

Over the past few years, when I meet people that I haven't seen for a while, they tell how great I look. They often ask me if I have been working out with weights, because my arms look so great. If I am wearing a dress or shorts, they will ask me if I am running, because my legs look so great. I smile, look a little bashful at the compliment and say something like "Oh, pshaw!", secretly thrilled, in a warped kind of way, that I have achieved this "great look", at the age of 47. I also think, "Oh, man, if this is great, how bad did I used to look?".

I like to look for the "silver lining" to having AIDS. It helps me cope. Every once in awhile, I lift my cocktail glass, half filled with scotch that I can't actually drink anymore, and toast lipodystrophy. Let's just have a look at this word; lipodystrophy; the silver lining emphasises "trophy". Do I now have a trophy body? At last, with very little effort on my part, I have achieved society's idea of the perfect body. All I do is take a handful of pills four or five times a day and voila, thin thighs, bigger boobs and a small butt. Oh yeah, I got to have sex. Oh yeah, I got AIDS. Oh, yeah, the increased lipids and a pesky little heart attack — or was it a HAART attack? Oh, well, I look great.

When we PWAs are on these drugs, (chemotherapy really,) when we get together our conversations often turn to side effects. "I take carnitine for triglycerides" or "I drink lots of water to avoid kidney stones" or "I take half a gravol half an hour before I take my drugs." We all have our little tricks that we share with each other. Are we trading side effect tips or beauty tips? My friend Chuck suggests that I wax my chin to get rid of the hair. "Have you heard, there is a new plastic surgery for cheek implants." "The hair on your head is thinning, just use more product to make it look fuller." Constantly pale and washed out looking? Try the new MAC foundation. My favorite tip came from my late husband Randy, a hemophiliac who never had much of a butt. To create a fuller looking butt, use a wallet and a hankie; one in each back pocket.

Don't get me wrong. I am very happy about the other side effect from the drugs — LIFE! I do know that without these drugs, I would not be alive today. That's not too bad a side effect.

I know how lucky I am. I have access to drugs. I can afford the drugs, I can tolerate the drugs. Like many of us who survived pre-protease days, there are lots of events I had thought I would not live to see.

My son is 23. I thought I wouldn't live to see him finish high school.

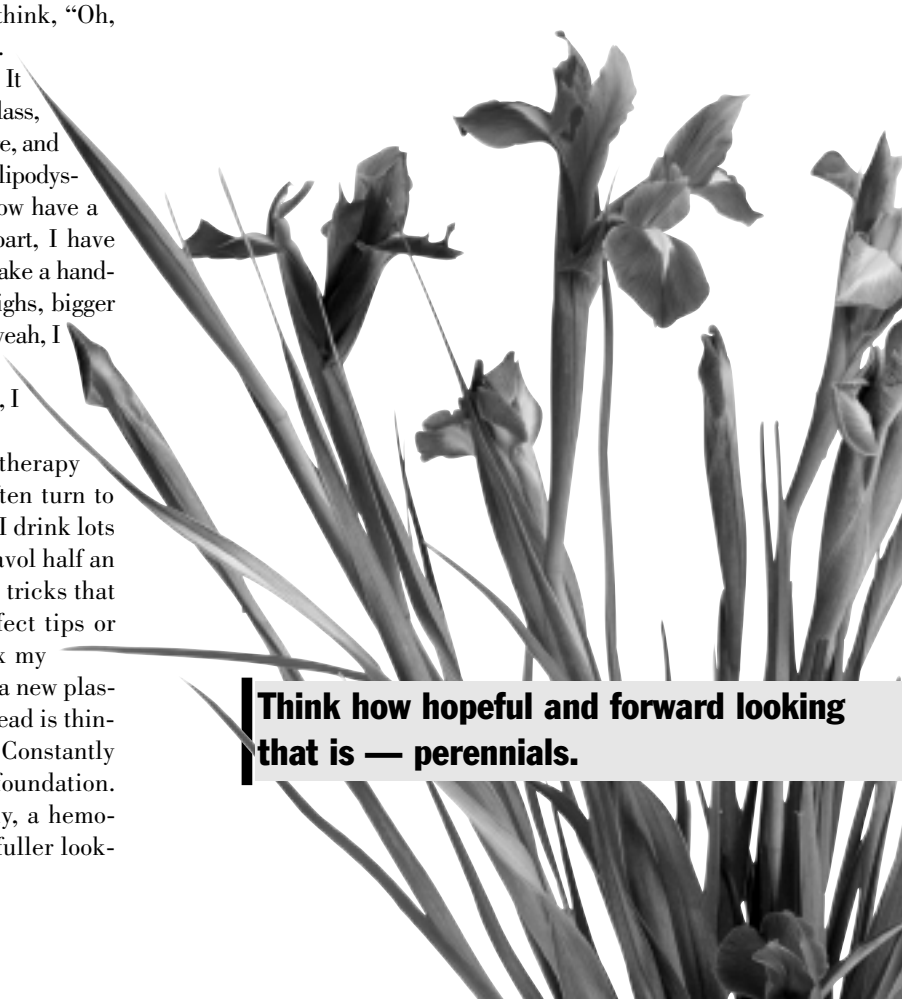
I am getting married next summer (and for those who know me, yes he is straight.). Imagine, planning an event a year in advance.

I have planted 4 gardens and they are all perennial. Think how hopeful and forward looking that is — perennials.

I went skydiving two weeks ago.

Silver lining, all, silver lining. ⊕

Janet Conners has been living with HIV since 1986 and has been an activist since 1990.



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