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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 3,500 HIV+ members.

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# think +

opinion and editorial

## Selling safer sex to PWAs

by Glen Bradford and Wayne Campbell

**HIV** prevention campaigns rarely, if ever, address the reality of an HIV-positive person's life. Traditionally, HIV prevention messages have been directed at negative people, focusing on how to protect yourself from getting HIV. These messages send an unintentional signal that prevention is no longer our problem.

We need safe sex messages that speak to us.

Negotiating safer sex and using risk reduction to prevent transmitting or getting other infections is not easy. Those living with HIV know that disclosing our HIV status can lead to an increased sense of isolation and exclusion, making it difficult to disclose our status any time we try to be sexual with someone.

Safer sex requires the involvement of willing partners. For women, negotiating safer sex can be difficult because safe and low-cost, woman-controlled methods of HIV prevention do not currently exist.

Many of us have put ourselves in unsafe situations by mixing sex with drugs and alcohol. Low self-esteem may fuel a need for drugs to have a good time. Party drugs often decrease inhibition, which some people may feel they need to participate in the club or sex scene.

Preventing other sexually transmitted infections (STIs) is also an important issue for people living with HIV. Infections such as HPV, hepatitis B and C, herpes, and cytomegalovirus (CMV—a member of the herpes family) remain major concerns. All these are potentially deadly infections in people living with HIV, but they can be prevented, to some

degree, through safer sex practices.

Be aware of both the real and theoretical risks as you discuss and negotiate safer sex. Every sexual behaviour or activity carries some level of infection risk. While it's generally believed that some activities are less risky than others, *low risk* obviously doesn't mean *no risk*.

Ultimately, we are all responsible for ourselves, and in the larger scheme of things nobody has the *right* to know everything about our lives. People you tell will have questions and make assumptions. Even if you have the answers, you may not want your life to turn into an educational crusade. However, as part of diverse communities, HIV-positive people have a moral responsibility to help keep our communities strong and healthy.

Less than a handful of organizations worldwide specifically direct HIV prevention towards positive people. The BCPWA Society is developing prevention campaigns directed towards HIV-positive people. Our first target group will be HIV-positive gay men. Other groups we will target include positive intravenous drug users and positive women.

We want to know what you think should be included in a prevention campaign of this kind. Sign up for a focus group or email us at [prevention@parc.org](mailto:prevention@parc.org). Don't let your voice go unheard. No one knows better than you do about living with HIV. ⊕

*Glen Bradford and Wayne Campbell are board members of the BCPWA Society.*

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

# REALITY BITES

News from home & around the world

## BCPWA renovations underway

The BCPWA Society is in the midst of relocating some of its services into the second floor offices of the Pacific AIDS Resources formally occupied by AIDS Vancouver. All BCPWA services will now be located on the second floor, with the exception of the Treatment Information Drop-In office, which shall remain in the PARC Library.

BCPWA is confident that the new space will better serve the needs of the membership. The completion date for renovations is mid to late October. However, please expect delays.

## Tenofovir and ddI interaction

Preliminary data from the BC Centre for Excellence in HIV/AIDS and Gilead, the makers of tenofovir, suggest that taking tenofovir at the same time as ddI (Videx) may result in an increase in the amount of ddI in the blood.

What this means is unclear. Some argue that ddI should be given in full doses on an empty stomach without tenofovir. Others argue that a reduced dose of ddI

could be given together with tenofovir without food restrictions.

Research to date is based on serum (blood) levels of the drugs, which may or may not be relevant to the safety and toxicity of ddI. Toxicity is better correlated with the amount of drug that penetrates infected cells, rather than the amount of drug circulating in the blood.

Possible side effects from excessive ddI include peripheral neuropathy, pancreatitis, and liver function test abnormalities.

## Grapefruit warning

Health Canada is advising people not to take certain drugs with grapefruit juice. Substances in grapefruit interfere with how the body handles certain drugs. Consuming grapefruit juice or grapefruit sections can increase, or less commonly decrease, the effects of some drugs, which could lead to serious or even life-threatening adverse reactions. As little as one glass of grapefruit juice can cause this effect.

Certain drugs and health products used in the treatment of several medical conditions are known to cause this effect. The conditions are anxiety, depression, high blood pressure, HIV/AIDS, cancer, irregular heart rhythms, infections, psychotic problems, erectile dysfunction, angina, convulsions, gastrointestinal reflux, high cholesterol levels, and organ graft rejections.

If you are taking medication for any of the conditions listed above, do not to drink grapefruit juice or eat grapefruit in any form until you have talked to your doctor or your pharmacist about the potential for an adverse reaction.

## Heterosexual anal sex a major concern

A study investigating the risk of HIV transmission from HIV-infected men and their monogamous female partners found that 62% of the HIV transmissions were believed to be due to anal contact. Researchers reported that the risk of transmission for each individual anal contact was 10 times higher than the risk for each individual vaginal contact.

In countries such as Brazil, studies have reported up to 60% of adults practice anal sex. It's estimated that in the US, women are seven times more likely than men who have sex with men to engage occasionally in unprotected receptive anal intercourse.

The authors say that anal sex is relatively common in many regions of the world, and more frequently reported among people at high risk for getting HIV, including intravenous drug users, sex workers, and adolescents. They also reported that condom use is lower for heterosexual anal sex compared to vaginal sex.

Source: NATAP

## Multivitamins recommended for all

In a recent issue of the Journal of the American Medical Association, authors recommend that all adults take a daily multivitamin. A significant portion of the population gets sub-optimal amounts of vitamins. The elderly, heavy drinkers, and women in their childbearing years, are among the populations who are at risk for problems due to sub-optimal vitamin intake.

Researchers reviewed studies of nine key vitamins and chronic diseases. The vitamins studied included folate, carotenoids, and vitamins B6, B12, D, E, A, C and K.

photo Naomi Brunemeyer



BCPWA marchers and Starbucks staff participate in this year's Vancouver Pride Parade and Festival.

# REALITY BITES

News from home & around the world

“Inadequate intake or subtle deficiencies in several vitamins are risk factors for chronic diseases such as cardiovascular disease, cancer, and osteoporosis,” the authors wrote.

Multivitamins often contain the entire recommended daily doses of vitamins and other ingredients such as calcium. However, they should not be relied on for adequate amounts of calcium. As well, the iron content of most multivitamins may not be appropriate for men and non-menstruating women.

Source: *The Medical Post*

## Drug maker announces price freeze

GlaxoSmithKline (GSK) announced that it has implemented a two-year freeze in the U.S. list price of the company's entire portfolio of anti-HIV products through January 2004.

GSK will continue to provide its HIV drugs free of charge through its Patient Assistance Program for eligible low-income U.S. residents without prescription drug benefits. GSK has made this decision to help address some of the needs of the financially embattled AIDS Drug Assistance Programs (ADAPs), which are experiencing shortfalls in funding.

According to the National ADAP Monitoring Project's 2002 annual report, this crisis has resulted in 10 states imposing waiting lists or restrictions to their programs. Consequently, hundreds of patients may be denied access to critical medicines.

## Amprenavir warning

Product labelling has been changed for Agenerase (amprenavir) capsules and Agenerase (amprenavir) oral solution to reflect new precautions related to use of

Agenerase with methadone, and with oral (hormonal) contraceptives.

Co-administration of amprenavir and methadone can decrease plasma levels of methadone. Agenerase may be less effective in patients taking these agents together. Alternative antiretroviral therapy should be considered. The dosage of methadone may need to be increased when co-administered with Agenerase.

People taking Agenerase should not use hormonal contraceptives because birth control pills containing ethinyl estradiol/norethindrone have been found to decrease the concentration of amprenavir. This may lead to loss of virologic response and possible resistance to Agenerase. Alternative methods of non-hormonal contraception are recommended.

Source: *NATAP*

## Kaletra and methadone withdrawal

A recent study concluded that there is no need to increase methadone dose when starting Kaletra.

The research followed 18 patients who were on a stable methadone dose for at least one month prior to starting Kaletra. Researchers monitored patients for withdrawal symptoms during the first four weeks after starting Kaletra.

The authors concluded that 24 out of 25 patients tolerated Kaletra without any complaints or reported adverse events. Use of Kaletra and methadone at the same time did not result in withdrawal symptoms. However, as a precaution it is recommended to monitor for opiate withdrawal because there can be patient variability.

Source: *NATAP*

## Group fears merger of drug giants

The European AIDS Treatment Group (EATG) is worried about a possible merger of the pharmaceutical companies Bristol Myers Squibb (BMS) and GlaxoSmithKline, the world's second largest drug company. This proposed merger would raise conflicts, especially in the HIV/AIDS arena, where the merged company would control half of the approved antiretroviral agents.

Both drug makers have been struggling in the last year because they have been unable to discover enough new drugs to make up for products that are now losing their patent protection.

The EATG fears that a merger would likely delay further development on any new compounds against HIV that either company was working on. A previous merger between BMS and DuPont Pharma has delayed clinical development of several drugs in the DuPont portfolio, and possibly the BMS drug atazanavir as well. ⊕

photo John Kozachenko



Kristi Yuris, BCPWA's new prison outreach coordinator, spoke at the Prison Justice Day Rally. Every year on August 10, prisoners and activists demonstrate on this international day of solidarity.

# In the name of the children

*Stephen Lewis makes impassioned plea to African religious leaders*



*On June 10, 2002, Stephen Lewis, special envoy of the UN Secretary-General for HIV/AIDS in Africa, addressed the African Religious Leaders Assembly on Children and HIV/AIDS in Nairobi, Kenya. The following is an abridged version of his speech.*

“I want to speak with direct and sometimes uncomfortable frankness, so I appeal to all of you, at the outset, to let the milk of human kindness flow through your veins and to treat me with compassion.

There has never been anything like the HIV/AIDS pandemic. Comparisons with the Black Death of the 14th century are wishful thinking. When AIDS has run its course—if it ever runs its course—it will be seen as an annihilating scourge that dwarfs everything that has gone before.

What it leaves in its wake, in country after country, in every one of the countries you represent, are thousands or tens of thousands or hundreds of thousands or, eventually, even millions of children whose lives are a torment of loneliness, despair, rage, bewilderment, and loss. That doesn't mean orphan children can't be happy; it simply means that at the heart of their individual beings, there is a life-long void.

The numbers are overwhelming, the circumstances are overwhelming, the needs are overwhelming.

I wish to suggest to all of you, as religious leaders drawn from across the continent, that it is time, it is well past time that you summoned your awesome reserves of strength and followers and commitment to lead this continent out of its merciless vortex of misery. There is no excuse for passivity or distance. No excuse for immobility or denial. No excuse for incremental steps when you, collectively, have the capacity to rally both Africa and the world if you choose to do so.

The timing could not be better. Let me tell you why, and bare my most protected inner thoughts in the telling. I think we may have reached a curious and deeply distressing lull in the battle against AIDS. Over the last two years, much has happened. The political leadership of Africa has come alive to HIV/AIDS, conferences have been held in profusion, from Durban to Addis to Abuja to New York to Ougouadougou. PLWAs have raised powerful and insistent voices, the Global Fund has been established, goals and targets have been set, drug prices have been

driven down dramatically by generic manufacturers, there are more data and analysis and reports and commentary and studies and sheer newspaper copy available than any library on earth could accommodate, and significant numbers of modest interventions are being pursued.

So it isn't that things have ground to a halt; it's just a cumulative feeling of inertia rather than energy, of marking time, of oh-so-slowly gathering forces together for the next push, of incrementalism raised to the level of obsession.

It's not only that we can't rest on our laurels; it's the fact that the laurels are fig-leaves. Let me be brutally honest. In the dead of night, I sometimes think to myself that we're losing the war against AIDS ... although I do recognize the feeling for what it is: an unwarranted moment of despair. What we need is another massive shot of adrenalin to take the battle to the next level, and you, your eminences, the representative religious leadership of Africa ... you are the shot of adrenalin, the energizing force, the catharsis of faith, hope, and determination which can propel us forward.

Who else, beyond yourselves, is so well-placed to lead? Who else has such a network of voices at the grassroots level? Who else has access to all communities once a week, every week, across the continent? Who else officiates at the millions of funerals of those who die of AIDS-related illnesses, and who better understands the consequences for children and families? Who else works on a daily basis with faith-based,

community-based organizations? In the midst of this wanton, ravaging pandemic, it is truly like an act of Divine intervention that you should be physically present everywhere, all the time. I ask again: Who else, therefore, is so well-placed to lead?

So where is that leadership? There are notable exceptions as there always are. Some of the finest work combating AIDS on the continent is done through religious communities. But you will admit that, overall, the involvement of religion has been qualified at best.

I want to suggest, in the strongest possible terms, in the name of all the children, infected or affected, to seize the leadership, re-energize the struggle, and turn the pandemic around.

We understand the difficulties. We know that certain of the faiths have problems around sexual activity and the use of condoms. We know that there are internal struggles around the leadership roles of women ... not to be taken lightly when gender is such a visceral part of the pandemic. We know that the religious leadership at all levels of society needs training in order to do an effective job in educating your adherents. We know that even amongst religious leaders, there are numbers who are HIV-positive and have themselves felt the lash and pain of stigma from colleagues. Religious leaders are human; they face the same challenges and foibles as other mortals.

But religious leaders invoke a higher level of morality; that's why every contentious issue must be treated afresh. And if ever there was an issue which bristles with moral questions and moral imperatives it's HIV/AIDS. The pandemic, in the way in which it assaults human life, is qualitatively different from all that has gone before. There is no greater moral calling on this continent today than to vanquish the pandemic.

No one expects you to do it, one faith at a time. Somehow, you must come together, in a great religious partnership, so that everyone is involved, at every level. Nor can you do it by faith alone. You have to extend the partnership to representatives of civil society, to associations of PLWAs, to the UN family, to women's groups everywhere, to the private sector, and to government itself. The pandemic demands that you move beyond the protective insularity of religion.

There should be a series of targeted interventions. Religious communities provide vital care to the ill and the dying at village level. Religious leaders can confront stigma from every religious podium in every community, changing the values of the community through repetition and education, week in and week out. Religious leaders should lead a campaign to abolish school fees throughout the continent because whether it's fees, or the costs of registration, books, or uniforms, vulnerable and orphaned children, invariably penniless, are denied the right to go to school.



Let me take the argument further still. Religious leaders must do something about the mothers who are infected and are dying prematurely, leaving behind those orphans who wander the landscape of Africa, soon to be an entire generation seething with resentment and fear.

What will the religious leaders do about it? Surely, in the face of such a violation of fundamental moral tenets, you have an obligation to intervene.

And that takes me to my final proposition. In the last analysis, religious leaders are the best chance to influence the political leadership of the North as well as of the South. You have contacts everywhere. You have brother and sister churches and mosques and temples on all the continents. They support you, they often fund you, they show solidarity with you. Your religious sway is not just Africa, it's the world.

Religious communities historically have followed one of two tracks. There was the religious leadership which successfully fought for the eradication of slavery in the Congo; the eclectic leadership which supported the conscientious objectors in the Vietnam War and helped, thereby, to bring that foul war to an

**“It is well past time that you summoned your awesome reserves of strength and followers and commitment to lead this continent out of its merciless vortex of misery.”**

end; the Islamic and Hindu leaderships which supported UNICEF's immunization campaigns in Asia and the Middle-East, overcoming the fears of the citizens and doubtless saving millions of children's lives; the Judeo-Christian leadership that resisted the infant formula companies and supported the right to breast-feeding.

And then there was the other, woeful track; the religious leadership that supported apartheid; the religious leadership that was complicit in the genocide in Rwanda; the religious leadership that was silent during the holocaust.

No one wants a choice between the two. It's simply that when the history of the AIDS pandemic is written, you want it said that every religious leader stood up to be counted; that when the tide was turned, the religious leaders did the turning; that when the children of Africa were at horrendous risk, the religious leaders led the rescue mission. It's what all of us beg you to do; I submit to you that it's what your God, of whatever name, would want you to do.” ⊕





# Testament to a trailblazer

by Devan Nambiar

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*Devan Nambiar interviewed Ashok Pillai, president of the Indian Network of People Living with HIV, on September 7, 2001. Ashok passed away peacefully on April 19, 2002, at the age of 31.*

Ashok Pillai was the most outspoken public figure in HIV activism in India. He spoke with unparalleled passion and spirit. His integrity, his dedication to the truth, and his anger at the apathy of the government to the needs of people living with HIV/AIDS laid the groundwork of AIDS activism in India. His unbounded energy complemented his vision.

He tested positive in 1989 when he was in the army. He left the army and kept his status in silence for three years. His family was supportive when he disclosed his status to them. He attended his first HIV meeting in 1996. "I come from a small simple village, and I had no idea of HIV or what would happen to me," he said. "Everyone told me, 'You will die right away.'"

He spoke with a smile at the injustice inflicted on HIV-positive people in India. As an outspoken PWA, he endured much criticism. He was evicted, refused accommodation, refused treatment by a dentist, discriminated against by society at large, and regarded by the government and NGOs as too outspoken.

Ashok refused to take HAART medication. "I can only take anti-HIV medication if it is available to all HIV-positive persons in India," he insisted.

## **The state of HIV/AIDS in a corrupt country**

India has identified its HIV-infected population at a permanent 3.9 million people. However, world statistics peg that number much higher, at 7–10 million.

Indian government statistics state that after 1992 HIV infection rates dropped, in part, because of increased awareness. Not so, said Ashok. He argued that no widespread change in behaviours has occurred and that stigma and paranoia about HIV have increased.



How the government statistics were collected remains questionable. The reality is that fifty percent of the newly infected are under 25 years old. It is no longer just the poor who are contracting HIV. The middle and upper classes are also becoming infected.

India ranks in the top five of most corrupt countries in the world. "The needs of the PWAs cannot be fulfilled by the government," Ashok insisted. "The government's biggest strength is that the people know no better. When large powerful government-funded agencies play the bully, no one questions." The meek look on as vocal activists are singled out. He sighed with a smile at the apathy of his peers who are afraid to speak out.

In 1992, India was given US\$84 million to spend on fighting HIV/AIDS between 1992 and 1997. When only half the money was spent, the other half had to be returned. An extension was requested and the balance was then spent in two years on conferences, travel and accommodation, workshops, strengthening blood banks, and technical support to warrant further funding.

India was given another US\$232 million to spend between 2000 and 2009. But experts estimate that for every one rupee the Indian government spends on HIV projects, only 10 paise—one tenth—will reach HIV-positive people. India spends less than one percent of GDP on HIV or health.

In 1999, the Supreme Court of India passed a ruling that HIV-positive people cannot get married. In spite of that, PWAs are getting married with complete disclosure to each other. In a land that preaches morality to the nth degree, few practice it. Given that marriage is ingrained in Indian cultures as a right, when that right is removed, it devalues a person to the level of a pariah, a social outcast.

Ashok observed that PWAs have a more difficult and stressful time dealing with the courts and laws, than dealing with the actual diagnosis of HIV. The government has failed to protect PWAs and their rights or offer any support to them when they are demoted, lose jobs, get evicted, or are forcibly tested. Because of the strong social stigma attached to HIV, the whole family suffers pariah status.

## HIV activism in India

Indian Network of People Living with HIV (INP+) is a non-profit national organization for PWAs. It offers counselling, provides referrals, distributes information, and encourages networking to promote the well-being of HIV-positive people. Formed in 1997, it has a membership of approximately 1,000 positive people from all around India, according to 1999 data. Current data are not available because most newcomers refuse to fill out data on personal information.

As a co-founder and president of INP+, Ashok was very aware that HIV activism is 15 years behind the western world, still groping in the infancy stage. With only two paid staff and volunteer board members, the workload can be heavy to meet the needs of the increasing infected population. Other umbrella PWA groups have formed in various cities throughout India.

**“I can only take anti-HIV medication if it is available to all HIV-positive persons in India,” Ashok insisted, and refused to take HAART.**

INP+ is the unified voice of people living with HIV, according to Ashok. He was not thrilled about having so many PWA organizations. He felt it was a bureaucratic method to keep consumer groups divided and create division and favouritism. “When there is division of the PWA groups, it weakens the collective voice of a people already drowned by the bureaucrats, red tape, and cultural values and morality codes. As a collective, we have power. In power lies strength.”

## Cultural needs and marriage proposals

Glossy pharmaceutical literature from conferences is useless paraphernalia to the HIV-positive consumer in India. This information is not culturally sensitive or appropriate for the different regions of India.

Members’ needs range from the possible to impossible. The majority needs money for daily living. Because state social services such as welfare or long term disability insurance are non-existent, members face the reality of starvation and eviction. Access to HIV treatment is a top priority right now, plus finding sensitive doctors to care, treat, and monitor patients on HIV medication.

A few members also expect to find a bride or groom who is HIV-positive. Request for positive brides is high on the list. Ashok himself had his share of marriage proposals from women who want to “take care” of him, he noted with a laugh.

Ashok mentioned that working with international AIDS funding organizations can be challenging because they are not at all familiar with India’s grassroots movement or the needs of those whose lives are in tatters.

## Lack of ethics at testing sites

The quality of counselling at the HIV testing sites, which are mushrooming in India, is problematic. The information provided by clinical staff is often inaccurate or downright bizarre. Advice varied from “don’t eat spicy food before a test” to “avoid spicy food after a positive test.” Diagnoses sometimes took the form: “We have found the HIV virus in your HIV test.” Very seldom are newly diagnosed persons informed that the HIV test only detects the antibodies to HIV, not the virus itself. Sometimes the positive test is not confirmed with the “Western Blot” test.

Another grave concern is the lack of confidentiality at these HIV testing sites. Most HIV test recipients discovered that their peers, families, colleagues knew their status before they themselves did, causing much anguish—loss of jobs, enforced break-up of marriages, coercive HIV testing of siblings, and ostracizing by neighbours, relatives, and community. An HIV-positive test in India for a woman is equated to being a prostitute; for a man, to being gay. Ostracism is feared more than death itself. HIV/AIDS equals promiscuity.

Lack of transparency in clinical trials is also a problem. With low literacy levels and lack of knowledge of HIV treatment issues, advocates at INP+ wonder if study participants are aware of their rights of informed consent and access to effective therapy. It is believed that verbal explanations are given to study participants in the presence of a witness. This method is not transparent to the general public or PWA advocates for patients’ rights. As most research studies go, rumours of data being “milked” to fit the needs of the government bureaucrats are not uncommon.

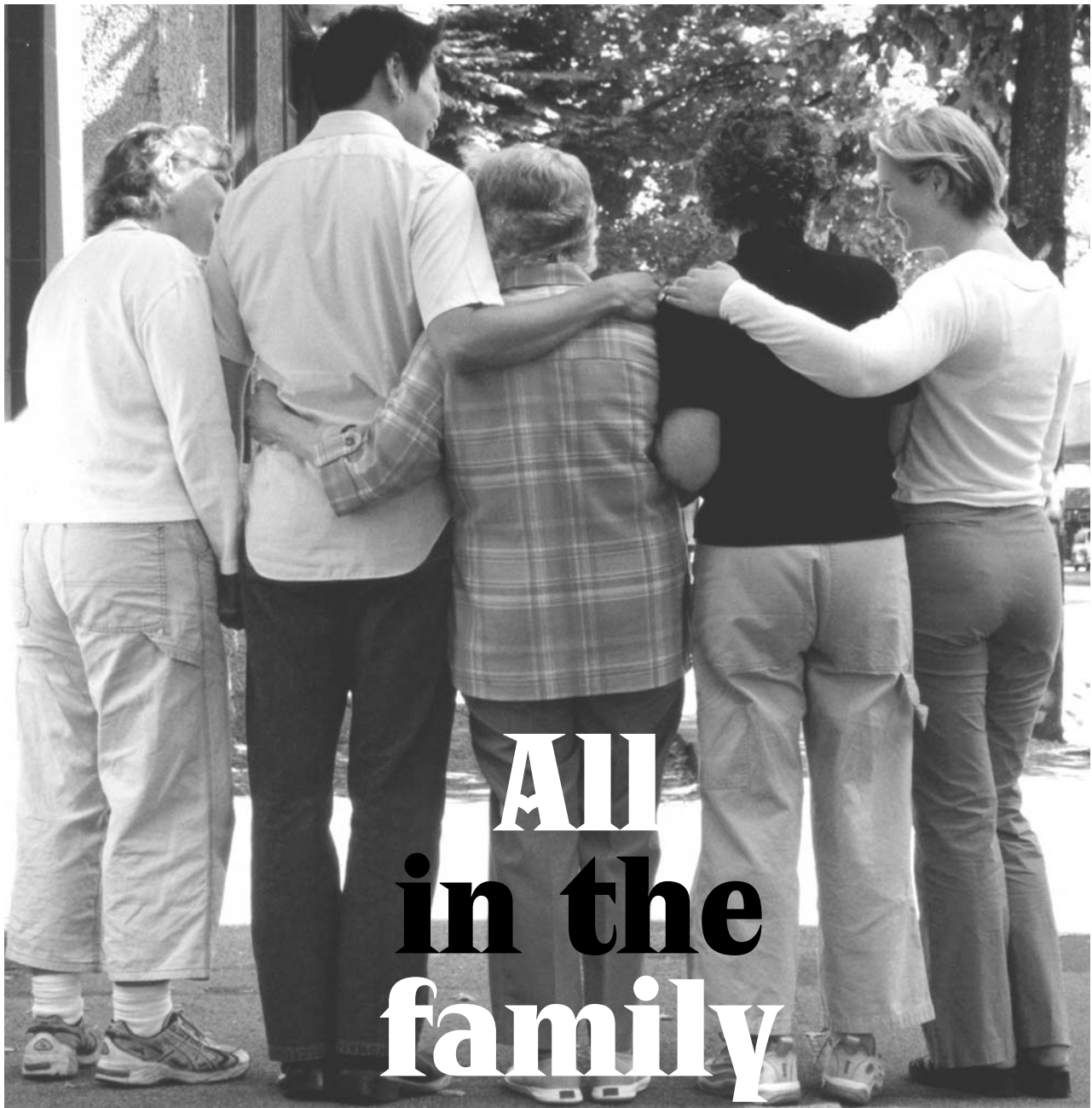
## Grim future prospects

“AIDS kills 15 times the number of people killed in the Gujarat earthquake,” health policy expert Siddharth Dube wrote in a recent article. “In the past 15 years, 2 to 2.5 million people have died of AIDS. AIDS is the second largest killer next to TB.” Based on current figures of infected Indians, he estimates that over 10 million Indians will die each year. “The government has yet to tackle how to deal with children orphaned by AIDS. Even if the World Bank funds are used successfully, 8 million Indians will become infected by 2005. If there is a complete failure of the project, then 5% of all adults will be infected.” ⊕

*Indian Network of People Living with HIV (INP+) can be reached via email at [inplus@vsnl.com](mailto:inplus@vsnl.com), or visit their website at [www.inplus.org](http://www.inplus.org).*

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





# All in the family

*HIV/AIDS is a rollercoaster of emotions for loved ones, too*

*by Trena White*

The impact of HIV/AIDS isn't limited to the infected person. It also takes a toll on family members—the affected. Having an HIV-positive family member alters relationships between the infected and affected, changes entire family dynamics, and brings on external pressures such as stigma. One of the challenges of discussing the experiences of the affected family members is not diminishing what the HIV-positive person goes through. Yet whatever the relationship to the infected person, there can be no doubt that family members experience severe stress

and anxiety, and this needs to be acknowledged.

One of the first difficulties for family members is the shock of hearing the diagnosis. Everyone deals with it differently, and the resulting emotions range from rage and sadness to disbelief and denial.

"The day Janet found out, she came to my apartment and told me," says Ruth Pritchard, sister of AIDS activist Janet Connors. "I threw a tin of coffee across the kitchen. I remember being so angry and sad and just a whole host of emotions. It was the late '80s, and there wasn't much hope."

**Perhaps the biggest strain is watching a loved one become increasingly ill.**



Sometimes the anger is directed at the infected person, particularly if one partner feels the other jeopardized his or her health, whether knowingly or not.

After the initial shock and denial, family members experience a grieving process very similar to that of the PWA. After the diagnosis, “people move into a bargaining stage. ‘I’ll do anything if that doesn’t happen to me,’” explains Judy Capes, a social worker with Living Through Loss Society in Vancouver. “Then there’s usually anger. Sometimes the next stage is despair or depression, lots of tears and fears. Then at some point it moves into acceptance.”

### **The need for support networks**

For a family to move through this process and to support the infected person, it is essential for family members to find their own support networks to deal with their overwhelming emotions. Disclosing the diagnosis and their concerns can help move them out of the initial stage of paralysis, but the question naturally arises: Whose information is this to share? Who has the right to tell others about an HIV diagnosis?

Ideally, disclosing HIV should be the prerogative of the PWA, but when a family has been asked to keep silent about a diagnosis, they are effectively cut off from their own support network. They may find the stress of keeping the secret from other family members intolerable. In some cases, this stress can lead to unwanted disclosures.

In 1992, Margaret Antoine of the Stoney Creek band near Vanderhoof, BC, received a phone call from her son’s doctor, who said Eugene had full-blown AIDS. Eugene asked her not to tell anyone because it was a “shameful illness.” But, she says, “I had to tell my family. I was so shocked. I didn’t know much about the sickness. All I knew was that there was no cure for it.”

Eugene didn’t speak to his mother for a few months afterwards and isolated himself from the family. Eventually, they did repair their relationships.

Some people do keep the secret from the rest of the family, which can lead to tension when eventually other members discover they have been excluded from the knowledge of the infection. The excluded may experience feelings of betrayal and question the intimacy of the relationship: Why did they tell you and not me?

Disclosing HIV infections within a family can be even more complicated when children are involved. Lori Sheckter, social worker at the Oak Tree Clinic in Vancouver, works with families to cope with and adjust to HIV diagnoses. She often helps clients disclose to their children through “partial truth-telling.”

“You give them a small amount of information at first, and then when they ask questions, you give them more and more

information,” she says. “It’s not actually lying. It’s just talking to them at their developmental stage.” Whether the parent or the child is infected, parents experience great stress in explaining the illness to children. For other family members, especially siblings, planning for the future of a child of a positive parent, particularly if they will be the child’s guardians, may be difficult and extremely stressful.

Disclosing HIV infection can change the relationship between infected and affected. At times, a family member or partner will feel intense worry or sadness (grief) and struggle with whether it’s okay to share their worries with the PWA, who already has enough to deal with. “How do you scream, ‘Just f— off and take your drugs!’” asks Pritchard. “You can’t because I’ve never taken the drugs. But *you* need to take them because I’m scared, and they’re what’s keeping you alive.”

### **Becoming a caregiver**

One of the most significant ways that personal relationships can change is when a family member becomes a caregiver to the infected person. Caregiving brings its own set of physical and emotional stresses. Balancing the patient’s needs with one’s personal needs can be tricky for a caregiver. They might feel they have to be strong for the other person while denying their own emotions about the illness.

When Robert (a pseudonym), a person with HIV himself, became a caregiver for his partner, “it didn’t change the relationship, but it changed the content of it.” They still had open communication and were emotionally close, but their daily and long-term concerns changed.

Being excluded from caregiving can be equally stressful and trigger feelings of helplessness. When Vera Geysendorpher’s son Marc was ill with AIDS, his partner was a protective primary caregiver who found it hard to allow other people to assist with Marc’s care. “It was difficult, being powerless as a parent, not being able to do anything for your child,” says the BCPWA volunteer. Eventually Marc’s partner accepted the family’s support.

Another challenge for families is as informational or emotional go-between. When one family member is privy to information about the illness, that person may be expected to explain the situation to the others. Pritchard's 75-year old mother tries to stay very positive around Connors and goes to Pritchard with her fears. "She asks, 'Is this the end?' What she wants to know is, 'Is Janet dying?' and I feel a tremendous need to lessen her concerns."

### Strained family relationships

Family dynamics often change when a family member discloses his or her HIV status. The effect can be negative or positive—or both. "Whatever the family dynamics are, you can be sure that around death or a diagnosis of this kind, those things are going to be heightened," says Living Through Loss Society's Capes. Feelings of resentment may surface if a person feels their infected sibling is getting so much attention or if one family member is burdened with the responsibility of being the primary caregiver. Other family members may feel guilty about not doing enough.

Because everyone grieves differently, some members may detach themselves from the family and try to avoid dealing with it. Others may feel the need to discuss it and share their feelings, changing the way they interact with each other. These different types of reactions can all cause severe strain on family relationships.

### After the initial shock and denial, family members experience a grieving process very similar to that of the PWA.

Robert found relations with his in-laws changed drastically after his partner passed away. The family was split along religious lines, and the obituary in particular caused problems. "[His] sister wanted to hide that he had HIV, and to me, that was an insult to [my partner] and me, and our friends."

However, illness can also bring a family closer together and strengthen family relationships. It can also contribute to the forging of more open and honest relationships between family members.

### Stigmatization and isolation

Beyond the changes in interpersonal relationships, family members can also experience social stigmatization and isolation from friends, acquaintances, and strangers, albeit to a lesser degree than the HIV-positive person. The stigma varies, from friends refusing to discuss HIV/AIDS or acknowledge the person's infection to more blatant abuses, such as Antoine experienced on her reserve. "They called my home 'a gay home,' they threw snowballs at my house when AIDS was talked about.... They laughed and pointed fingers."

Rural living brings its own set of stresses. Deciding who to

tell can be tricky because in small communities everyone knows everyone and change within families is more noticeable. Rural families also have less access to resources, support groups, or AIDS organizations.

Culture and religion are also factors in how the affected respond. Stigma can play a much greater role in the experiences of families with non-European backgrounds. At the Oak Tree Clinic, Sheckter sees people of African descent being very secretive about HIV infections within the family. Because the African community in the Lower Mainland is fairly close-knit, they are often afraid of bumping into someone from their community or social circle at the clinic, in case word should get out to other people in the community. The pressure on these families can be intense to keep AIDS a secret.

Some non-English-speaking clients at the clinic refuse to use translators because the translator would be from the same ethnic community. The fear of breached confidentiality is too great. Since homosexuality is taboo in some cultures, if a person is both gay and HIV-positive, it is a double blow for the family. The family may not even be willing to accept that their child is gay.

### Dealing with death

Perhaps the biggest strain is watching a loved one become increasingly ill. Every time the person becomes sick, the family wonders if it's the end. The grieving process is emotionally exhausting because of the uncertainty of what's happening, and it is especially tormenting if the person is suffering.

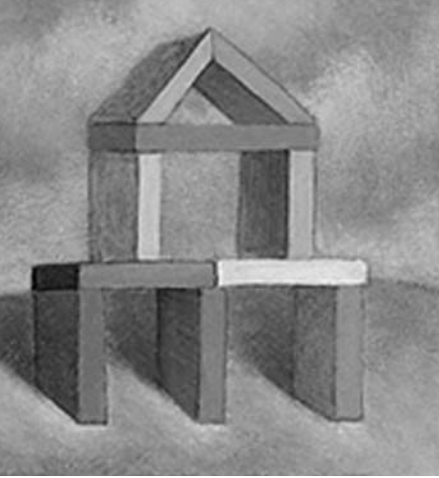
According to Capes, grieving an AIDS-related death is similar to grieving any death, except that "there's also what we call disenfranchised grief, and that's where the grief can't be publicly acknowledged in a way that it can be for something more socially acceptable." While that was more common in the beginning of the AIDS epidemic, it is still an issue for marginalized people, such as intravenous drug users.

For gay men or people working in AIDS service organizations, grieving AIDS-related losses has another dimension. Often a partner's or family member's death is not the first AIDS-related death they have experienced. After a while, the grief builds up and any new loss to AIDS brings up the previous losses. It's difficult for the person to cope with his or her own emotions, while providing support for yet another HIV-positive person.

"Where do the affected go? Do they go to the ASOs, or do they stay silent?" Pritchard asks. Certainly it does not serve themselves or the infected to stay silent. Family members of PWAs need to be able to support their loved ones effectively and to grieve in a healthy way. They need support themselves. The community needs to find a place for family members to receive support. ⊕



Trena White is a freelance writer based in Vancouver.



# How AIDS Walk 2002 community partners will use Walk funds

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

**A Loving Spoonful** is a collaborative community of volunteers, staff, donors, and supporters who deliver approximately 350 meals each week to primarily homebound people living with HIV/AIDS within Greater Vancouver. Walk proceeds will help to supplement this vital meal program.

**AIDS Vancouver** exists to alleviate individual and collective vulnerability to HIV/AIDS through care and support, education, advocacy, and research. Walk proceeds will help to support the AV Grocery. Each week, it feeds over 600 families and individuals living with HIV/AIDS. It is the only food bank in BC to offer perishable food items, such as milk and fresh produce.

**Asian Society for the Intervention of AIDS** is committed to providing culturally appropriate and language-specific HIV/AIDS support, outreach, advocacy, and education. ASIA's Positive Asians Dinner will receive AIDS Walk proceeds, as will the established ASIA Crisis Grant and Helping Hand Grant, which provide emergency financial support to Asian PHAs and their families.

**Friends For Life** enhances the lives of people living with life-threatening illnesses (primarily HIV/AIDS), as well as their families and caregivers. This organization provides emotional, psychological, social, and practical support in a safe, confidential environment. Walk proceeds will be used to support counselling programs, meals, social activities, group support and workshops, drop-in services, home-care, and massage therapy for PWAs.

**Healing Our Spirit's** mission is to prevent and reduce the spread of HIV/AIDS and to provide care, treatment, and support services to aboriginal peoples infected and affected by HIV/AIDS. Walk proceeds will assist aboriginal PWAs with emergency funds, moving expenses, food vouchers,

participation in the APHA retreat, and the annual Christmas Dinner.

**McLaren Housing Society** has been providing safe, affordable housing to people living with HIV/AIDS who have very low incomes since 1987. Currently, McLaren manages 52 apartment homes at Helmcken House and Seymour Place and 33 portable housing subsidies. The apartment homes are all conveniently located in south downtown Vancouver near social and medical services and St. Paul's Hospital.

**Positive Women's Network** supports women living with HIV/AIDS to make their own choices by providing safe access to services and resources. Walk proceeds will help to finance PWN's Housing Solutions for HIV+ Women program (portable subsidies in partnership with McLaren Housing Society).

**Surrey HIV/AIDS Support Network** provides prevention education and support services to people in the South Fraser region who may be infected with or affected by HIV/AIDS. They provide counselling, advocacy, and referral services to PWAs and coordinate regular support groups. Walk proceeds will be designated for the existing support programs, including the High Protein Food Bank opened in July 2001.

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

**YouthCO AIDS Society** strives to bring together youth aged 15-29 from all communities to address HIV/AIDS and related issues. As a youth-driven agency, they provide outreach, prevention education, training, volunteer opportunities, advocacy, and support to other youth. All Walk proceeds will be used within their Positive Youth Support Program for activities such as drop-ins, bi-weekly dinners, and their annual retreat. ☺

## Participate in AIDS Walk 2002

Over twenty years have passed since the first cases of AIDS appeared, leaving doctors and researchers perplexed and without answers. Since then, many medical advances have greatly improved the quality of life for people living with AIDS. Still, with an estimated 40,000 Canadians infected with HIV—perhaps as many as 12,000 in BC alone—the fight is far from over. Events like AIDS Walk play a critical role in increasing community awareness while raising much-needed funds for people living with HIV/AIDS.

### Where the money goes

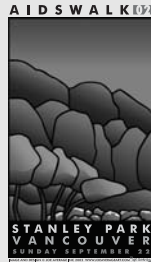
All proceeds from AIDS Walk 2002 go to direct services for persons living with HIV and AIDS in your community! These services are provided through the BCPWA Society or one of our 10 Community Partner organizations.

### Forming a team

Walk with your friends, family, or work colleagues. Registering a team is easy. Just call 604-915-Walk and ask for your Team Captain Kit.

### Prizes

Pledge prizes are awarded for money brought in prior to and on Walk day only. One commemorative AIDS Walk 2002 pin will be issued to each individual Walker or Team Captain who collects pledges on or over the following gift amounts:



- For pledges over \$250, you will receive a Joe Average 250 Club pin.
- For pledges over \$500, you will receive a Joe Average 500 Club pin.
- For pledges over \$1000, you will receive a Joe Average 1000 Club pin.
- For pledges over \$2000, you will receive a Joe Average 2000 Club pin.
- Pick up an AIDS Walk pamphlet for information about Individual Walker Awards.

### 3 easy steps to get involved

**Step 1** Call 604-915-Walk or  
Fax us at 604-915-9256 or  
Email us at walk@parc.org or  
Return completed registration form to:  
BC Persons With AIDS Society  
1107 Seymour St.,  
Vancouver, BC V6B 5S8

**Step 2** Collect Pledges

**Step 3** Walk the Walk

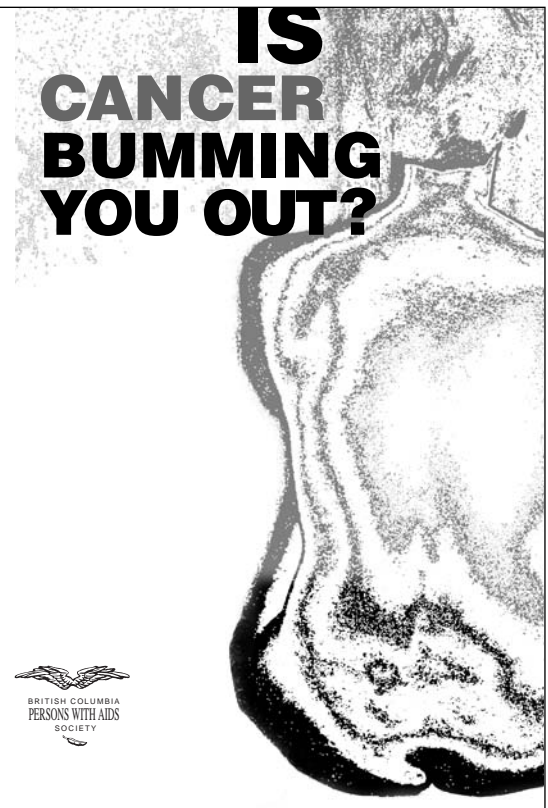
**Presenter:**  
**Dr. Karen Gelmon,**  
speaking on anal cancers

**Date:** October 2nd, 2002  
**Time:** 6PM–9PM  
Dinner provided

Brought to you by:  
**BC Persons With  
AIDS Society's  
Treatment Information Department**

**RSVP by September 25, 2002**  
**For registration and more info**  
**contact: 604.646.5309**

**Location:**  
**Coal Harbour Community Centre,**  
**480 Broughton Street**





# Inching closer to safe injection sites?



Recent developments paving way for a pilot project

by Thomas Kerr

It seems as though every other day another media report on safe injection facilities (SIFs) is released, and yet it is difficult to make sense of where we are with this contentious issue. Clearly some noise is being made, but how close are we to seeing SIFs operating in Canada? A look at some recent developments may provide some clues.

Following the release of the document “Reducing the Harm Associated with Injection Drug Use in Canada” in 2001, the Federal/Provincial/Territorial Committee on Injection Drug Use created a task group to examine the feasibility of a multi-site pilot study of SIFs. After several meetings, the task group recommended a trial and created a document specifying the minimum criteria for a pilot study of SIFs.

On the heels of these federal developments, SIFs gained support at the municipal level, and recently the Federation of Canadian Municipalities endorsed Vancouver Mayor Philip Owen’s resolution calling for a multi-city pilot study of SIFs. In the months following, Vancouver’s City Council took a courageous step by providing its endorsement of Mayor Owen’s resolution.

Further progress came in March of this year when the Canadian Centre on Substance Abuse organized a meeting in Ottawa that was attended by representatives of eleven municipalities interested in exploring the establishment of SIFs. One outcome of this meeting was a united call for the development of a legislative framework that would allow for a pilot study of SIFs.

In April 2002, the SIF pilot study overcame a major barrier when the Canadian HIV/AIDS Legal Network released its comprehensive legal and ethical analysis related to establishment of

SIFs. While acknowledging the need for alternative legislative frameworks, the report concluded that a pilot study of SIFs should proceed immediately and that existing ministerial exemptions could be used in the short term to allow for a pilot study.

A final and rather interesting development occurred when nursing staff at the Dr. Peter Centre disclosed that they had been supervising injections in the Centre’s Day Program with the full blessings of the Registered Nursing Association of British Columbia. While it is clear that the Dr. Peter Centre is not operating a safe injection facility, it appears that the supervision of injections has been recognized as being within the scope of best practices.

So, are we close to seeing SIFs operating in Canada? It is hard to say for sure. Perhaps with a ministerial exemption, some federal funding, and a sponsoring agency, a SIF could soon be coming to city near you.

However, those hoping to see a comprehensive harm reduction program implemented to help curb death and disease rates associated with injection drug use should keep in mind the work that may still lie ahead. For instance, in 1997 when a public health emergency was declared by the Vancouver/Richmond Health Board, the then Chief of Police and Provincial Medical Health Officer called a press conference to declare the need for SIFs and a new approach to the drug problem. Over five years later, the HIV epidemic and frequent overdosing among injection drug users continue. Little has changed for those in need of this service. ⊕

Thomas Kerr is community health researcher and a doctoral student in educational psychology at the University of Victoria.



Why  
another  
survey  
was  
needed

The BC Persons With AIDS Society and the BC Centre for Excellence in HIV/AIDS would like to thank you for taking the time to fill out our latest survey entitled, **For the Record**. We use this information to improve our programming at BCPWA and to understand the diverse needs of our membership. We apologize for any inconvenience receiving multiple copies of the survey. We have received a lot of feedback regarding the survey design and distribution which will help us to develop better strategies for future projects.

# A positive prevention primer

*BCPWA prevention campaign will target people with HIV*

*by Carl Bognar*

**P**revention efforts in BC and Canada are failing, and globally they're in a shambles. A glaring lack of leadership and co-ordination characterizes attempts to curb increases in new infections. HIV-positive people haven't been included in prevention strategies, yet they have much to contribute to this struggle. The BCPWA Society is working to correct this exclusion.

What does the word "prevention" mean to people who already have HIV? Traditionally, prevention can be categorized roughly into three types: primary prevention, secondary prevention, and tertiary prevention.

## Three types of prevention

Primary prevention programs usually involve raising awareness and providing education about a particular disease for people who don't yet have that disease. These types of programs are usually aimed at large groups of people—gay men or all high school students, for example. Clearly, primary prevention—at least as we currently think about it—isn't the primary mandate of the BCPWA Society, whose members already have HIV.

Secondary prevention means taking action to prevent or minimize the harm caused by a disease. Examples include harm reduction programs, such as needle exchange and methadone maintenance. Early detection of HIV infection through HIV tests is also a form of secondary pre-



vention because it allows people who are infected to get access to care and treatment at the earliest possible stage. This strategy minimizes damage and prevents the disease from getting out of control. In the US, the government is launching programs to increase early identification of HIV infection. It is estimated that up to one-third of Canadians who have HIV infection are not aware of it.

Early identification of HIV infection could also provide knowledge that will enable positive people to make informed and responsible decisions about their sexual activities. However, the idea that early identification programs will help to reduce transmission of HIV remains controversial because it seems to contradict other ideas

about prevention, in particular, that everybody should be taking precautions to limit the possibility of their exposure to HIV.

Tertiary prevention is focused on treating a health problem to lessen its effects, to maximize quality of life, and to prevent further deterioration. This type of prevention includes a wide range of services already provided by the BCPWA Society to its members, such as treatment information and counselling, access to nutrition, information about food and water safety, and income advocacy. Examples include medical treatments to prevent opportunistic infections, such as the use of Bactrim or Septra to prevent pneumocystis carinii pneumonia (PCP), or acyclovir to prevent outbreaks of herpes.

## PWAs and primary prevention

What would an increased focus on prevention at the BCPWA Society look like? People working on primary prevention programs are starting to think about the role HIV-positive people might play in primary prevention. Where are positive people in primary prevention messages? Almost all primary prevention programs thus far have been aimed at people who are negative. Early prevention planners were reluctant to include HIV-positive people in prevention messages, at least partly out of concern about further increasing the stigma against people who are positive. But, of course, new infections come from people who are already positive. As increasing numbers of

positive people live healthier lives, it is time to consider what makes prevention difficult from that perspective.

So far, prevention hasn't considered the needs of HIV-positive people. Nearly every positive person has wished that HIV transmission stopped with ourselves, but there has been no support for doing that, especially in the context of intimate and sexual lives. We are still entitled to intimacy and sex, even if we are positive.

A recent survey of gay men conducted by the Community-Based Research Centre found that almost all HIV-positive gay men felt that the gay community is divided by HIV-status, while few negative men felt that way. Other research shows that positive and negative men have quite different beliefs and expectations about whether their sexual partners will disclose HIV status in sexual encounters.

## Uncovering the social and medical issues

Positive men are left with a host of social issues they need to deal with. When is the best time to disclose to a partner? How do you handle rejection if you disclose? Who is entitled to know what facts about your life? How do you deal with the isolation from the larger community if you're open about your HIV status? How much of the burden of protection ought to fall on people living with HIV, and how much on people who are (or believe themselves to be) HIV-negative?

Medical issues, too, must be considered. If your viral load is under control, does that mean you are less infectious? (Probably yes, but you are still infectious.) Will barebacking expose you to strains of the virus that are different from the ones you are already carrying around? Does being exposed to different strains increase the likelihood of disease progression? Does it decrease the effectiveness of your treatments? Is it important to care about these issues—to sacrifice intimacy and some types of sexual activity—in the face of a life that will, in all probability, be shortened because of HIV anyway? How do all of these issues interact

to contribute to your decisions about sexual safety? Similar questions no doubt apply to injection drug users.

If HIV-positive people are going to be included in primary prevention, we need to have a clearer picture of what the issues are, how they are interrelated, and what we might do about them. We would also benefit from having the opportunity to talk with each other about these issues. Here the distinctions between primary and tertiary prevention get blurred. This type of approach

**Almost all primary prevention programs thus far have been aimed at people who are negative.**

has the potential to reduce the spread of HIV and at the same time improve quality of life by giving us the support and strength and knowledge to deal with these issues openly and with confidence.

## Ownership through peer-driven programs

One lesson we have clearly learned from other types of HIV prevention programs is that the most effective programs are the ones that have been designed by peers based on knowledge derived from specific communities, such as younger gay men, injection drug users, and serodivergent couples. Effective prevention isn't something that is done to a community; it should be done with community. This means ownership. Prevention programs for positive people should be designed by positive people.

These types of peer-driven action programs are starting to emerge in a few cities. In San Francisco, a consortium of AIDS service organizations and consumer organizations has launched a prevention campaign targeted primarily at positive people. The campaign includes a range of activities, such as workshops on living with HIV, safer sex cruising, staying healthy, and disclosure. Check out their website at [www.hivstopswithme.com](http://www.hivstopswithme.com). The goals of the campaign include devel-

oping HIV-positive role models and moving HIV-positive people into the forefront of HIV prevention. The George House Trust in Manchester, England, is also developing programs especially targeted to positive people.

There are good reasons to include PWAs in prevention planning. One of the major lessons in HIV prevention has been the need to develop local responses to the epidemic: what works in one place and with one subpopulation won't neces-

sarily work in other places, or even in the same place with different subpopulations. Even more, we have learned that the involvement of community in itself can be a powerful tool in prevention, a type of community development that may be more effective than media campaigns.

Since including HIV-positive people in prevention planning is a new idea, no foundation exists to build upon. We need to find ways to bring PWAs together to discuss these issues and to figure out appropriate courses of action, starting from the ground up. So far, there are very few models.

More HIV-positive people are alive than ever before. Rates of new HIV infection appear to be rising. All levels of government seem interested in tackling this problem. Now is the time that HIV-positive people should be looking for support to be included in prevention planning, for our own benefit and the benefit of all those who are not yet infected. ☺



*Carl Bogner is a freelance researcher interested in HIV and community-based research.*

## information

TREATMENT INFORMATION  
PROGRAM MANDATE &  
DISCLAIMER

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

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



## Ode to ashtanga

by Ron Rosenes

About four years ago, I found yoga, or perhaps yoga found me. I was searching for a new way to work out. I was tired of the gym routine: the boring cardio machines and schlepping heavy weights in an effort to build a body like those in the men's magazines. I have always weighed about 140 pounds, I've been HIV-positive for close to 20 years, and I fight a daily battle to maintain my weight. No way am I ever going to look like Antonio Sabato Jr. Senior maybe, if you squint. From Europe.

I decided to check out a yoga studio. Now this agnostic finds his way at least three or more times every week to the Temple of Yoga.

Yoga is not to be confused with a workout. It is a practice, although the *ashtanga yoga*, or power yoga, to which I have become addicted is not for wimps. The Sanskrit origin of the word yoga means "to yoke or harness." It is also translated as "union." It refers to hooking up the individual mind to the higher—or universal—consciousness, or more simply, to the union between mind and body. I was very skeptical at first about the mystical aspect of learning the choreography of *ashtanga asanas*, or poses, but when I reached the rest period after an

hour and a half of *ashtanga*, I felt both a sense of calm and elation that was superior to a gym experience. It was something more than the release of endorphins that occurs with any strenuous exercise.

In traditional *hatha yoga*, a posture is performed, followed by rest. It may be right for you if your energy is limited. *Ashtanga*, however, is distinguished by the connecting movement between postures, accompanied by a powerful breathing technique and the resulting "heat" that allows the body to become both strong and flexible at the same time. Iron bends with heat and so it is with the body. That is why it is important to warm up before stretching. In *ashtanga*, we accomplish that with the series of *Sun Salutations*.

According to a Zen proverb, "Only when you can be extremely soft and pliable can you be extremely hard and strong." This is the yin and yang of yoga: "pushing", using your arms and your legs to raise the weight of your body, and "pulling", going deeper and deeper into every posture using your concentration and your breath to get you there. It feels as if I am asking my mind to give my body permission to go deeper into every pose. As if the mind is knocking on the door of

the body, saying, "Let me in." When you are in class, listening to the teacher, breathing long slow breaths in unison with your classmates, breaths that slow the heart rate and calm the mind, that is when the magic happens. All you have to do is focus on the task at hand, going deeper into the pose. You forget your

A lot has been written about "mindfulness," about being in the moment, focused, centered. Yoga simply forces you to pay attention to the physical matter at hand and challenges you to go further. The strength that derives from pushing makes you solid, grounded, powerful. The flexibility that comes from pulling makes you fluid, compassionate, sensitive.

I am definitely less stressed and writing to deadline with a happy face. Problems with my back and rotator cuff are much improved.

Find a place to start yoga, perhaps at a class organized by your local AIDS service organization. Take the time to be good to yourself. And thank yourself for taking the time. ⊕

**According to a Zen proverb, "Only when you can be extremely soft and pliable can you be extremely hard and strong."**

to-do list, your difficult relationships, your iffy health. By focusing on the pose, you begin to realize it is possible to shut out the noise. That is when you are practicing yoga. I don't necessarily get to that place every time I practice, but after four years, I am simply amazed at my progress.

To me, yoga is like a dance, and I am the klutz who is finally able to learn the choreography. I haven't mastered it yet. It is like building a sandcastle two grains at a time.



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



**Theatre Positive**  
presents  
*Dancing With My Dead Lover*  
and *Other Stories*

**theatre POSITIVE** A support program of the BC Persons With AIDS Society



Vancouver Fringe Festival September 6–15, 2002  
Theatre Positive Venue 7: Lind Hall  
Check Georgia Straight or Fringe Program for Showtimes and Ticket Information  
Fringe Information 604.257.0366



# Time for a holiday

*Managing drug resistance with structured treatment interruptions*

*by Mona Loutfy and Natasha LaPierre*

**S**tructured treatment interruption (STI) is a new investigational approach to managing HIV-positive people who are experiencing treatment failure. Also known as a planned drug holiday, STI means that all antiretroviral drugs are stopped for a certain period of time before a salvage (or the next combination of antiretrovirals) regimen is started.

The theory behind a planned drug holiday is that withdrawal of drugs may cause the patient's virus, which has developed drug resistance, to decrease, thereby allowing a more sensitive wild-type virus to re-emerge. This may make the virus easier to treat with a new drug combination. Restarting drug therapy several weeks or months later may result in more prolonged lowering of the viral load, rather than if the drugs were switched right away.

The planned drug holiday may also allow for the disappearance or improvement of side effects that have occurred with the previous treatment and allow the patient to tolerate the new combination better. Many people who have undergone STIs have found it more motivating to start a salvage regimen.

## What we know about STIs

About half a dozen studies on STIs in virologic failure have been presented. All have shown that among roughly 2/3 of patients, the virus reverts to the more sensitive wild-type virus. Studies reveal that if this happens, viral suppression has a better chance with the salvage regimen, at least over the short term.

The CD4 cell count decreases in most people who take a planned drug holiday. As a result, there is a potential risk that complications of HIV could arise, especially if the prophylactic agents, such as Septra, that protect against opportunistic infections are not continued.

In addition, the resistant virus does not completely disappear. It just resides dormant in small numbers. When drugs are re-introduced, these resistant strains will come back and predominate.

## What we don't know

Not enough is known yet about how best to use STIs. Therefore, planned drug holidays are still experimental and should only be done in the context of a study or under the supervision of a doctor.

Whether the resultant reversion to the more sensitive wild-type virus, which leads to increased viral suppression, will last for a prolonged period of time is not known. We also don't know if the CD4 cell count can be recovered when the salvage treatment is started. Nor is it clear which patients are most likely to experience benefit or

harm from STIs, a critical piece of information for patients and healthcare providers to have.

## The Canadian STI Trial

To better answer some of these questions and to properly assess the risks and benefits of STIs, investigators from the Canadian HIV Trials Network are conducting the Canadian STI Trial. This study will enroll approximately 200 HIV-infected volunteers across Canada who have a HIV viral load >1000 copies/mL despite being treated with combination antiretroviral therapy and who are considering changing their antiretroviral drugs to a new drug combination. Participants must have at least two new drugs that have not been used previously available to be included in the new combination.

Half of the participants will switch to their salvage regimen immediately and the other half will have a treatment interruption of 12 weeks before starting the new drug combination. Selection for a drug holiday will be random, which means neither the participant nor the doctor will have a choice. This process of randomization is crucial because it protects the trial results from any bias and enhances the validity of the results.

Participants will be monitored for a total of 15 months. Investigators will explore a number of different outcomes, including viral response, CD4 count response, safety, and quality of life. For more information, please visit the Canadian HIV Trials Network website at [www.hivnet.ubc.ca/ctn.html](http://www.hivnet.ubc.ca/ctn.html) or call 1.800.661.4664. ☎



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*Mona Loutfy is presently a CIHR post-doctoral fellow at Montreal General Hospital, specializing in clinical HIV research.*

# Grief, rage, dignity — and hope

Report from the XIV International AIDS Conference in Barcelona, Spain

by Paula Braitstein

Summarizing the XIV International AIDS Conference is one of the most daunting and humbling professional tasks I've faced. How can I paraphrase Nelson Mandela, Bill Clinton, Zackie Achmat, and the many other passionate, insightful, and tireless speakers? How can I describe the daily interruptions in conference proceedings by ACT UP or another activist group that wanted to make a point? Or convey even a fraction of the information from the 9,000 oral and poster presentations on everything and anything to do with HIV/AIDS?

How can I conceivably express the grief, rage, dignity, and hope—the emotions that set the tone of the conference, as they have set the tone of the epidemic?

By the end of the first day, I swore I would never go to another international conference. I was suffering from sensory overload. The crowds and lines were more than my cushy little Canadian self could handle, and I felt lost within the magnitude of the experience.

Then on the last day I completed my evaluation of the conference. One of the questions was “Which ONE of the following do you think is the most important objective of the International AIDS Conference?” The possible answers were

- > sharing information and experiences about the response to HIV/AIDS;
- > sharing latest developments and discoveries;
- > establishing new partnerships with other HIV/AIDS organizations;
- > fostering a global sense of togetherness and community;
- > regular stock-taking of where we all are;
- > building consensus and unity about future priorities and actions;
- > other.



photo Kath Webster

Though the conference addressed all these objectives, in my mind the most important contribution was fostering a global sense of togetherness and community. It built on the momentum and spirit of the 2000 AIDS Conference in Durban, South Africa, and left a strong sense of hope.

I realized that the HIV epidemic in British Columbia, as difficult as it is, is only a tiny microcosm of what the rest of the world is facing. The conference reminded me that complacency is too easy and too dangerous.

## The work that lies ahead

The conference also helped me understand that we already have many of the answers and most of the tools we need to halt this pandemic in its tracks. We need to implement harm reduction strategies for both drug use and risky sexual behaviour. Women have got to be empowered economically and politically. We also need to fund and sustain public healthcare. “Investing in health is investing in sustainable development,” said Zackie Achmat,

leader of the Treatment Action Campaign activist group in South Africa, in a plenary session video from South Africa. He was sick with pneumonia and unable to travel.

Antiretrovirals need to be available to every infected person in the world. “If we can get Coca Cola and McDonalds to every corner of the world, why not antiretrovirals?” asked Joep Lange, incoming president of the International AIDS Society.

## “AIDS is a war against humanity.” — Nelson Mandela, closing speech.

And we need to eradicate homophobia and AIDS-phobia. In his closing speech, Nelson Mandela asserted that “Stigma, discrimination, and ostracism are the real killers.” Although I became frustrated with the same messages being repeated over and over again, Mandela rightly said, “When you keep quiet you are signing your own death warrant; say what you need to say a hundred times.”

An impressive amount of work is happening around the world at all levels, and it’s making a difference. People are talking; people are listening. The global acceptance of collective responsibility is a shimmering light in the distance to be sure, but the light is there.

### A growing epidemic

So what is the state of the pandemic? In 2001, five million new HIV infections occurred and three million people died of HIV-related causes. Approximately 40 million people live with HIV/AIDS today, of whom 12 million are between the ages of 15 and 24 and of whom two-thirds are girls and women. Ninety-four percent of people living with HIV/AIDS live in developing countries, which, in many instances, are rapidly undeveloping because of HIV. In seven countries, more than 20% of adults are HIV-infected. At present, 14 million children are orphaned by HIV/AIDS, and as many as 25 million children could be orphaned by HIV/AIDS by 2010.

In southern African countries, one in three adults is infected with HIV. I remember being in Durban for the 2000 AIDS Conference and looking around at the people on the city bus and thinking, “One in three of you is HIV-positive.” Thirty percent of pregnant women under the age of 19 in southern Africa are HIV-positive.

The good news, I suppose, is that over the past few years, the epidemic appears to be stabilizing at 30% prevalence in Africa. The bad news is that Eastern Europe, India, China, and the Caribbean are glowing embers of red-hot epidemics—and the governments of these countries do not seem to be learning from the mistakes of others. Russia now has more HIV infections than all of Western Europe combined.

How can we really understand these incomprehensible numbers? Try to imagine the twin World Trade Centre towers going down *twice every day*. That’s how many people worldwide die of AIDS every day. From the time the conference began to the time of the closing plenary session, 48,000 people died of HIV/AIDS. That’s four times the capacity of the stadium where the plenaries were held.

Reinforcing that message and giving new meaning to “putting your money where your mouth is” was Zackie Achmat. He declared that until everyone who has HIV has access to antiretrovirals, he would refuse to take the drugs himself, despite having access. Talk about leadership and political will.

### The economic reality of political will

A lot of talk was devoted to political will in the wake of the United Nations General Assembly Special Session on AIDS (UNGASS), where the UN countries decided to devote \$10 billion per year to fight AIDS. This money is known as the Global Fund. Not only is this target not enough—it will only provide antiretrovirals to a few million people of the 40 million infected—but countries have so far coughed up only about two billion dollars.

Canada has so far pledged \$100 million, the US has pledged \$450 million, Zimbabwe \$1 million, and Nigeria \$10 million. If the distribution of pledges were based on a percentage of GDP, Canada would give \$243 million, the US \$3,479 million, and neither Nigeria nor Zimbabwe would give a dime. If that doesn’t shame the United States—and Canada—nothing will. (Four hundred and fifty million dollars might sound like a lot of money, but, as Bill Clinton pointed out, the US spends \$1.3 billion per month on the war in Afghanistan).



photo Kath Webster

### The emotional heart of the conference

The conference was not only about politics and science. It was also an emotional experience. Two choirs gave a touching and symbolic performance as a part of the official conference cultural program. One choir was comprised of 25 boys from Swaziland, aged between 11 and 16, all of whom have been orphaned by AIDS and many of whom are or were street-involved. The second choir was a group of about 40 girls of the same age from Catalonia, the autonomous region of Spain in which Barcelona lies. The two groups alternated and then sang together at the end.

*continued on next page*



photo: Kath Webster

The boys were rough around the edges. Although they carried themselves with an independence and haughty attitude that presumably comes from having to fend for oneself at an early age, they also seemed like typically insecure and giggly children, in part because of the presence of the girls. I had a lump in

**“Justice will come when those who are not injured are as indignant as those who are.” – Thucydides, from the closing plenary speech by a PWA activist.**

my throat throughout the performance thinking about the grief and the lives of those boys, but I decided that it was patronizing and disrespectful to those kids to pity them. What most clearly stood out was not the grief or the hardship, but the dignity, self-respect, and sense of community that the boys displayed, all the while being typical boys.

An excerpt from that evening’s program sums up the conference experience:

“This concert is a present for the world which really believes in hope as a tool to live and survive all the pandemics. In the grandest and most famous music hall of Barcelona we invite you to sing together with these young voices coming from deep Africa and Catalonia. We will learn how to walk in the face of AIDS while feeding our souls and making a real commitment with life, dignity, and hope.” ⊕



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

## TREATMENT NEWS FROM BARCELONA

### Hemoglobin

A low hemoglobin level is the major biochemical marker of anemia. Researchers investigated the role that anemia and elevated liver enzymes (AST) play in HIV disease progression. They found that moderate to severe anemia—as determined by hemoglobin measurements—independently predicts mortality. Moderate AST elevation also predicts mortality but is potentially confounded by hepatitis B and C, low CD4 count, and alcohol use.

### T-20

T-20 (Enfuvirtide) is showing promise as a salvage antiretroviral drug. It is the first of a new class of drugs called fusion inhibitors that, in theory, prevent the entry of HIV into a cell, thereby thwarting viral reproduction.

Researchers presented two studies of people who had extensive experience of or showed resistance to all three currently licensed classes of drugs and who also had a plasma viral load of at least 5000 copies. Participants had been on antiretroviral therapy for an average of seven years and had previously taken an average of 12 antiretrovirals. The average CD4 count was 80.

All patients had genotype and phenotype resistance tests. On a random basis, some received T-20 while others did not. All received an “optimized antiretroviral strategy” based on the resistance tests.

No differences were evident between the groups in terms of rates of side effects. In the T-20 group, the main side effects experienced by the participants were diarrhea, nausea, fatigue, and peripheral neuropathy. However, participants in the T-20 group experienced on average a 1.5 log drop in viral load, compared to about 0.7 logs for participants in the control group.

After six months, participants in the T-20 group were twice as likely to have a viral load below 50 copies as participants in the control group. They proceeded to virologic failure more slowly and their CD4 counts increased by an average of 65 cells compared to 38 for the other participants. T-20 is administered by subcutaneous injection, and this was treatment limiting in 3% of cases.

### Epidemic of anal cancer?

Researchers examined the effect of highly active antiretroviral therapy on the incidence of anal intraepithelial neoplasia (AIN) among HIV-positive men who have sex with men (MSM) in San Francisco. AIN is abnormal cell growth in the anus and is precancerous. Researchers found among the 357 participants a baseline prevalence of 52% of AIN grade 2 or 3. Only 10% of the group had no AIN at all. After 24 months, two-thirds of the group had developed AIN 2 or 3. AIN progression was associated with a low CD4 count, exposure to more HPV subtypes, and HPV viral load levels. No association was established between progression and taking antiretrovirals.

Note: Anal dysplasia and anal cancer should be considered an epidemic in this population among MSM. Although men and women who have anal sex should be routinely screened for abnormal anal cell growth, existing screening tools are inadequate. Patients should demand that healthcare providers, government, and industry to find new ways to screen for and treat anal cancer. ⊕

# Women at greater risk of infection

*International AIDS conference emphasized highly vulnerable groups*

*by Diana Johansen (formerly Peabody)*

**W**omen make up approximately 50% of HIV infections globally, but recent trends suggest that they comprise a much higher proportion of new infections. In 2001, approximately 5 million new HIV infections occurred worldwide, two-thirds of which were among women and girls. Women are more at risk because of biology, power imbalance, economic dependence, desire to have children, transactional sex, violence, rape, incest, and cultural practices.

The physiology of the female genital tract makes women, especially young women, particularly vulnerable to HIV infection. Sexually transmitted illnesses (STIs) increase the risk further because the health of the mucosal barrier is compromised. Women may not seek treatment for STIs because they may have no symptoms or because treatment may be unavailable. Violence during sex increases the risk of transmission as well because of vaginal abrasions that are likely to occur.

**The physiology of the female genital tract makes women, especially young women, particularly vulnerable to HIV infection.**

Many reports were presented at this year's AIDS conference from around the world about the prevalence of violence, sexual violence, and incest in women's lives. In Tanzania, girls still undergo female genital mutilation, and rape of women and girls is common, especially by brothers-in-law. Very few acts of violent or coerced sex are acknowledged as rape because women fear being blamed. Condoms are rarely used. The traditional practice of *mkamwana*, in which a wealthy couple "marries" a young woman to act as a surrogate to bear children for the couple, can also be violent.

Another study looked at six sites in Brazil, Peru, and Thailand. Women were asked direct questions about whether they had experienced physical violence from their partners. Twenty-three to 61% of women answered yes, with a higher number reported in urban centres. Up to 28% had experienced violence during a pregnancy, and 10% to 47% had experienced sexual violence by their partners. Fifty

to 90% sought no help; those that did usually confided in a friend or parent. The researcher, Charlotte Watts, concluded that violence and the fear of violence prevented women from asking for safer sex and, possibly, from accessing healthcare during pregnancy.

A report from South African townships described the prevalence of gang rape of teenage girls. Fifteen percent of young men interviewed said they had participated in a gang rape. In many cases, the rape was arranged by the girl's boyfriend to teach her a lesson and was perceived as justified. A presentation from India reported that 75% of men and 40% of women admitted to violence within marriage.

Judging from these presentations, it seems that some communities perceive violence on a continuum from acceptable to unacceptable. Slapping a woman is acceptable, but beating her half to death is not. A husband hitting a wife for speaking out of turn is acceptable, but beating her because he is drunk is not. Gang raping a girlfriend for some infraction is acceptable; randomly gang raping an unknown woman is not. Several of the presenters described local initiatives to stop violence against women in their communities. These included peer outreach to women and men, counselling centres, and community watch groups.

Violence, rape, and fear of violence significantly impact HIV prevention efforts. Women are often unable to negotiate safer sex, and they may be afraid to get tested and participate in programs to prevent vertical transmission to their infants. The conference participants discussed women's need for more control over HIV prevention, including having access to female condoms and microbicides.

Although data was presented from the developing world, the issues that face women worldwide are similar. It reminds us that the social and cultural determinants of HIV transmission must be addressed if we are to have successful prevention and treatment programs. ⊕



*Diana Johansen (formerly Peabody), RD, is the dietitian at Oak Tree Clinic in Vancouver. She specializes in HIV.*



# MEDICARE ON LIFE SUPPORT

*Making sense of the national healthcare debate*

*by Glen Hillson*

*In the July/August issue of Living +, BCPWA Society chair Glen Hillson reviewed the history of Medicare and summarized the current debate. In this issue, he examines some of the themes that have emerged, as well as reactions from the AIDS community.*

## Determinants of health

Several years ago, Health Canada identified a list of what it called the social determinants of health. Government has made little investment since then to identify inequities and improve health outcomes using approaches based on these determinants. One positive product of the healthcare debate has been to increase awareness of the impacts of social determinants on health outcomes. Former Saskatchewan premier Roy Romanow has noted that “there is an ever-growing body of evidence that factors such as education, income, poverty, and social exclusion have a significant impact on health outcomes.”

## Objective indicators: evidence-based decision making

Another important theme that has emerged in the debate is the role of objective evidence in planning and evaluating. Different opinions have emerged and certain limitations to quantifying outcomes in a values-based paradigm have become apparent.

“It is important to form and apply evidence-based, rather than ideologically driven public policy,” said Stan Houston, MD, a University of Alberta professor and director of the Northern Alberta HIV Program, at the Roundtable on Society and Health held at University of Calgary on March 6, 2002. “But it is difficult to measure social circumstances such as social erosion, stress, social support, and sense of belonging and quality of life.”

**“Sometimes the measurable drives out the important.” – woman in the audience at the Roundtable on Society and Health, March 6, 2002**



## Prevention and health promotion

Virtually everyone involved in the debate seems to agree that increased emphasis on prevention and health promotion will result in a healthier population and a more effective, affordable system overall. Where the rubber hits the road is when different stakeholders are pinned down on the question of what a real commitment to prevention and health promotion might look like.

When the provincial governments of Alberta, Ontario, and British Columbia pay lip service to these uncontroversial principles, they leave the impression that they believe we cannot afford to ignore these strategies. Yet when pressed on what kind of real investment is needed, they start to squirm. Suddenly these approaches are cast as strategies that we can't afford in the context of ballooning healthcare spending.

Often, prevention and health promotion not only collide with the real driving forces behind privatizing healthcare (profit and private sector control), but they also conflict with moral values. Supplying clean needles, condoms, and water-based lubricants to prisoners, safe injection sites, and medical heroin are often as morally offensive to those who worship at the alters of big religion as they are financially loathsome to big business.

**“We could prevent up to 60 to 70 per cent of all cancers...up to 90 per cent of all cases of chronic lung disease, up to 90 per cent of diabetes—all the things that are filling up our hospitals and our doctor's offices and our graveyards.”– Dr. Andrew Larder, Medical Health Officer, East Kootenay Region.**

## PWAs and HIV/AIDS organizations testify before Romanow

In a brief submitted to the Romanow Commission, the Canadian AIDS Society emphasized the important role of the community-based AIDS movement as an example of the value and effect of community health initiatives. The paper also discussed the importance of understanding the impacts of the social determinants of health as they relate to HIV/AIDS. This awareness was closely linked to the need for more emphasis on prevention and health promotion.

“Community groups who take up the slack as health services are diminished can be more than stop gaps if properly funded,” the brief stated. “They can be a real alternative to high cost primary care where the needs of people living with HIV are addressed with compassion and a wealth of experience. Health reform must encompass looking at care provided in the community and integrating and supporting it to better serve Canadians and their health.”

Canadian Treatment Action Council board member Philip Lundrigan also testified before Romanow in St. John’s, Newfoundland. Lundrigan presented alternative options for containment of health costs.

On the matter of prescription drug prices and their growing share of total health expenditure, Lundrigan pointed to overly generous patent protection provided internationally through trade agreements and domestically by federal law. Lundrigan described Canada’s drug prices regulator—the Patented Medicine Prices Review Board—as not terribly effective at controlling prescription drug prices. The latest update of Fortune 500 top performing companies and industries in 2001 shows once again that the pharmaceutical industry ranked first for profit as a percentage of revenue at a whopping 18.5%. The second most profitable industry, commercial banks, showed profits at 13.5% of revenues.

Lundrigan called for development and implementation of pan-Canadian standards for healthcare. He said the standards should be aimed to improve quality of care for all Canadians by raising the standards to the highest levels available in the country.

Lundrigan also called on Romanow to look at direct-to-consumer advertising (DTCA) and recommended that the federal

government renew its commitment to disallow DTCA. The experience of other countries has shown that DTCA increases the usage of drugs and contributes to higher per unit drug prices.

## Conclusions

Although many in search of power and profit would have us believe that quality healthcare is no longer affordable to Canadians, citizens are increasingly skeptical of the dogma of business-controlled governments.

Canadians have repeatedly shown that they regard healthcare as an affordable, essential component of a civil society. It is our right, and it would be difficult to identify another single factor that goes further to defining our identity.

Canadians are more than sufficiently intelligent to realize that inserting an extra layer of cost into healthcare provision—profit—cannot make the system more affordable. They have rejected the notion that government bean counters and corporate shareholders have the right to set a course for a health system that ignores Canadian values.

The spoils of delisting products and services, instituting user fees, medical debit cards, and means testing, and increasing public insurance premiums have gone to high-income earners through tax cuts and investment opportunities. One wonders if, in 1974, then-Minister of National Health and Welfare Marc Lalonde foresaw these developments when he spoke of “the ominous counterforces that constitute the dark side of economic progress.”

Despite strong public support for a comprehensive universal health system, much of that system has already been sold off or diluted by international trade agreements. It may never be retrievable. That should direct us all toward recognizing the importance of maintaining and improving what is left. ☺



Glen Hillson is chair of the BCPWA Society.

## positively Happening

CLUB POSITIVE: to provide a complete and comprehensive listing of groups, initiatives, programs and institutions in British Columbia serving people touched by HIV disease and AIDS. P. ANTONIO: ENIGMAS: an HIV-based organization not currently listed in these pages. Please fill in this box if you wish to be included in future editions but it is not always possible.

| VANCOUVER   |                         |
|---|-------------------------|
| <b>Who to call</b>  | <b>FOOD &amp; DRINK</b> |
| <b>Parc</b> HIV/AIDS Resource Centre<br>1005 Burrard Street, Suite 202<br>Vancouver, BC V6Z 2Y4<br>Tel: 604.683.5237<br>Fax: 604.683.2525<br>Website: www.bcpwa.org | <b>HEALTH</b>           |
| <b>Parc</b> HIV/AIDS Resource Centre<br>1005 Burrard Street, Suite 202<br>Vancouver, BC V6Z 2Y4<br>Tel: 604.683.5237<br>Fax: 604.683.2525<br>Website: www.bcpwa.org | <b>ALUMINA SERVICES</b> |
| <b>Parc</b> HIV/AIDS Resource Centre<br>1005 Burrard Street, Suite 202<br>Vancouver, BC V6Z 2Y4<br>Tel: 604.683.5237<br>Fax: 604.683.2525<br>Website: www.bcpwa.org | <b>ALUMINA SERVICES</b> |
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| <b>Parc</b> HIV/AIDS Resource Centre<br>1005 Burrard Street, Suite 202<br>Vancouver, BC V6Z 2Y4<br>Tel: 604.683.5237<br>Fax: 604.683.2525<br>Website: www.bcpwa.org | <b>ALUMINA SERVICES</b> |

We have reduced our Positively Happening Section in the magazine in an effort to provide up to date accurate information on services available in the community.

Positively Happening can be found in its entirety on our website, [www.bcpwa.org/resources.php](http://www.bcpwa.org/resources.php). Please contact us at 604.893.2206 or [pozhap@parc.org](mailto:pozhap@parc.org) to be included in this listing.

BRITISH COLUMBIA PERSONS WITH AIDS

Check out the new interactive BCPWA website.

- Are you HIV+? Join a free chat room.
- Services? Post a question for our Bulletin Boards.
- About BCPWA? Explore BCPWA's programs and services.
- How can you help? Tell us what you think...

| CPR           | LDH            | AST        | ALT         | GGT        | ALK Phos      | BILI Total    | BILI Cono    | ANYLAB% Serum |
|---------------|----------------|------------|-------------|------------|---------------|---------------|--------------|---------------|
| U/L<br>50-260 | U/L<br>300-550 | U/L<br><40 | U/L<br>7-56 | U/L<br><50 | U/L<br>85-105 | umol/L<br><20 | umol/L<br><4 | U/L<br>30-110 |

# Deciphering your diagnostics

*Interpreting liver lab results*

by R. Paul Kerston

Our livers play a crucial role in digestion and in blood purification, food and toxin-clearing functions. Blood-related jobs include making albumin, a plasma protein, plus factors necessary for blood clotting. These two processes fail with cirrhosis of the liver. Another blood-related function is the use of enzymes to make a water-soluble by-product of red blood cells, bilirubin, before its elimination. When this process goes awry, bilirubin is stored in the skin and eye whites, which is called jaundice. Food functions include converting carbohydrates into glycogen for energy. The liver also makes toxins water-soluble for removal.

Using blood/serum, regular tests of the liver—particularly with HIV disease—are needed to monitor health and drug side effects. Crixivan (indinavir), for example, commonly causes bilirubin levels to rise, but this is not necessarily a problem. Generally, increased levels of liver enzymes in the blood can indicate irritation or damage to the liver. Up to six per cent of normal, asymptomatic people may have abnormal liver enzyme levels. Irregular liver test results may derive from problems other than with the liver itself, for example from heart or muscle problems since the liver works in conjunction with other organs and systems. Thus, despite a fair degree of precision in measurement, a patient's history is needed to place the results in proper perspective.

Liver function can be measured with tests of specific enzyme levels in the blood:

- Aspartate aminotransferase (AST): found in heart, skeletal muscle, kidney, brain, pancreas, lungs, and two forms of white blood cells: leukocytes and erythrocytes
- alanine aminotransferase (ALT): limited to just the liver
- alkaline phosphatase (ALP)
- gamma-glutamyl transpeptidase (GGT)
- lactic/lactate dehydrogenase (LDH)

Also measurable are bilirubin and albumin levels.

Increases in levels of ALT are often the result of short-term injury and not a long-term problem. Elevated and lower than normal values for both AST and ALT can indicate serious health issues, as well as recovery from conditions ranging from hepatitis to cirrhosis and cancer. With all viral indicators, such as HIV, excluded, persistently elevated AST and ALT levels, in the absence of alcohol as a factor, may result

from a condition known as fatty liver (steatosis) or the presence of other toxins.

Unusual alkaline phosphatase levels, which often rise sooner than bilirubin, may lead to diagnoses such as liver tumours or abscesses. Albumin is an important protein whose rise may indicate dehydration and which, when reduced, could indicate conditions of hepatic disease or malnutrition, among other possibilities. An increase in LDH levels results from illnesses such as leukemia, renal failure, or Pneumocystis carinii pneumonia (PCP). It may also be that teen nemesia mononucleosis. Considered in conjunction with other tests, an increase in LDH may indicate cirrhosis, hepatitis, or jaundice.

Elevated liver enzymes can be caused by common drugs, including antibiotics, Tylenol, ecstasy, and cocaine. Regular use of party drugs could mask true conditions. Diseases such as viral hepatitis can also cause elevated enzyme levels. Approximately 60–70% of HIV-positive individuals have so-called abnormal liver functions test levels, but liver failure is generally considered uncommon in these individuals.

In HIV-positive persons, high alkaline phosphatase levels in conjunction with normal bilirubin levels may indicate drug side effects or opportunistic diseases such as mycobacterium avium complex (MAC), cytomegalovirus (CMV), histoplasmosis, or Kaposi's sarcoma.

Values for liver function tests vary depending on the laboratory, which accounts for discrepancies below, but they can be generalized as follows:

- AST: <36–41 units/litre (u/L)
- ALT: 7–45/56 units/litre (u/L)
- ALP: 35–105/150 units/litre (u/L)
- GGT: <50 units/litre (u/L)
- LDH: 300–550 units/litre (u/L)
- Bilirubin (total): 0.1–1.1/1.2 milligrams per decilitre (mg/dL)
- Albumin: 3.5–5.0 grams per decilitre (g/dL). ⊕



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

# Hard sell for soft gel

*Finding development money and other concerns discussed at microbicides conference*

by Janet Madsen

**M**icrobicide development is moving ahead, albeit with outstanding scientific, financial, and ethical challenges. The Microbicides 2002 Conference in Belgium in May offered many opportunities for discussion and debate.

One of the key questions in the scientific development of microbicides is still what they will be like. Microbicides, in such formats as gels and creams, will be used vaginally to prevent HIV infection. They will be so easy to use that there will be no need for the receptive partner to negotiate their use, as is common with male or female condoms. The ideal products will be substances that are so unobtrusive the partner doesn't even know they are in use.

Developing these ideal products has challenges. Dr. Guy Van Den Mooter from Belgium spoke about the issue of "fluctuation." Vaginal and cervical fluids fluctuate, menstrual cycles cause hormonal fluctuations, and drug absorption and residence time in the vagina varies—these are just some of the challenges in developing a consistently effective microbicide. The delivery method—gel, cream, suppository, intravaginal ring—is important too and will influence microbicide effectiveness.

Despite the challenges, almost 60 products are being researched. One of them, Carraguard, is in phase III trials and the furthest along in development. It is derived from seaweed and forms a gel that coats the vagina and the cervix, thereby preventing HIV from entering the epithelium cells.



Seaweed "chondrus" used to derive Carraguard.

Another big question with microbicides is where the development money will come from. Selling microbicides to funders is hard. There has never been a product like a microbicide. Even when we had the hope that Nonoxynol-9 could serve as a microbicide (it can't; in fact, it can make you more vulnerable to HIV infection because it can ex-

sively irritate tissue), it was developed as a spermicide. There's a lot of money to be made in birth control, but no one knows about the potential with microbicides. Pharmaceutical companies are reluctant to invest if they don't see a big return. The question is whether people will use—and buy—microbicides and whether they will actually be effective.

Advocates knew this going into the conference. The sessions certainly provided fuel for action. One study found that when American women were provided with a short description of microbicides, 63% said they would buy them. This number increased when they were given more information on the product. These are significant findings

**The ethical question that researchers can't avoid is how do you test these products in a way that doesn't put people at risk.**

that should spur further research and development in microbicides.

If that fails, we can appeal to the decisions makers' humane sides with potential prevention statistics. Using mathematical modelling, Dr. Charlotte Watts told delegates that "a 60% efficacious microbicide introduced into 73 low income countries could avert 2.5 million HIV infections over 3 years in women, men, and infants." The modelling is conservative, based on an estimate of reaching only 20% of the population accessing health services.

The ethical question that researchers can't avoid is how do you test these products in a way that doesn't put people at risk as you are trying to make products to protect them. Not only is there the issue of providing condoms for use and assuring people they won't "ruin" the study results if they use them, but there is the issue of language. As Dr. Kim Dickson-Tetteh pointed out, some languages have no accurate translation of terms like microbicide, placebo, informed consent, or different arms. How will researchers meet these challenges head on?

Microbicides 2002 showed that the need and will for microbicides exists now. To learn more about activist efforts in Canada, the Microbicide Advocacy Group Network (MAG-Net) is a group of organizations working to bring more awareness to the issue. For more information, contact Lilja Jonsdottir at the Canadian AIDS Society (phone: 613-230-3580, ext. 116; or [liljaj@cdnaids.ca](mailto:liljaj@cdnaids.ca)).

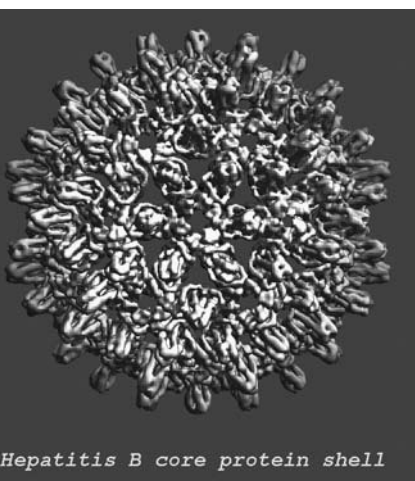
For more information about the conference, visit the conference website: [www.itg.be/micro2002](http://www.itg.be/micro2002). ☎

*Janet Madsen is the communications coordinator at Positive Women's Network.*

# The ABCs of hepatitis

*Hepatitis B often overlooked by PWAs*

by R. Paul Kerston



Hepatitis B core protein shell

**M**ore than 5% of the world's population has chronic hepatitis B, which is caused by the hepatitis B virus (HBV). Hepatitis B can cause serious or even fatal damage to the liver. Despite available vaccines and treatments, hepatitis B remains a serious disease.

In developed countries such as Canada, HBV is usually transmitted through contact with blood, semen, vaginal fluids, or saliva or from

mother to baby before or during birth. HBV is considered much more infectious than HIV. In young people, HBV infection is more likely to lead to chronic infection and long-term liver problems than in older persons.

## Symptoms

When initially infected by HBV, symptoms range from absolutely nothing—in most cases—to more severe symptoms such as jaundice, loss of appetite, pain in the abdomen, nausea, vomiting, muscle and joint aches, and fever.

Frequently, HBV-infected persons develop a protective immunity, often without their knowledge. However, in a minority of people, HBV continues to reproduce within the body long after the initial infection. Some of these people will become chronic carriers of the disease, which means that they can infect others for the rest of their lifetimes. This carrier status can occur despite the infected person experiencing no symptoms whatsoever. Of these chronic carriers, approximately one-quarter eventually develop chronic liver inflammation, which leads to increased risk for diseases such as cirrhosis or cancer of the liver. HIV-positive persons who contract HBV are at greater risk of becoming chronic hepatitis B carriers.

With hepatitis B, liver damage is not caused by the virus itself, but by the body's own immune system response of destroying the liver cells that host the virus. As a result of their already-impaired immune systems, HIV-positive indi-

viduals co-infected with HBV may experience less liver damage than others. Acute liver inflammation may occur in individuals with immune reconstitution from taking HAART (highly active antiretroviral therapy). However, because the body's impaired immune system doesn't clear HBV from liver cells as effectively in HIV-positive people, such individuals are thought to be more infectious than their HIV-negative counterparts.

## Diagnosis

One way to diagnose hepatitis B is by detecting antibodies developed by the immune system. If antibodies are detected, the body has rid itself of the virus after infection—often without one's knowledge. However, chronic carriers will have HBV surface antigens in their blood, instead of antibodies, for at least six months. Some of these persons also test e-antigen positive, which means that they are highly infectious. Twenty-five percent of people with HBV have both antigens and antibodies, which also indicates carrier status.

Another diagnostic test is measurement of alanine aminotransferase (ALT), a liver-specific enzyme whose level is usually elevated in chronic HBV infection. Bilirubin levels also rise. (*See the article on interpreting liver test results on page 26.*)

## Drug treatments

Four drug treatments for chronic hepatitis B are available, including the use of lamivudine (also known as Epivir or 3TC), the very same nucleoside analog antiretroviral drug often prescribed in combination HIV therapy (HAART). Lamivudine blocks HBV replication. In HIV, lamivudine is usually prescribed at 150mg, twice daily. For hepatitis B, the standard dose of lamivudine is 100mg daily for one year. It is recommended that this drug be stopped after a sustained period of more than two months of hepatitis B e-antigen (HBeAg) loss or the detection of antibodies to these antigens in the blood (seroconversion).

People must be monitored closely to identify reactivation, which is an indication for re-treatment. Lamivudine has few side effects and discontinuation of such therapy is rarely necessary for such reasons. HBV treated with lamivudine often results in what is known as a 4-log suppression of HBV DNA. In other words, this suppression is equal to going from



100,000 copies of the virus to only 10. Seventeen percent of patients using lamivudine for one year, prescribed as above, seroconverted; 32% showed loss of the e-antigen. Flare-ups of hepatitis B in persons co-infected with HIV/HBV upon switching off lamivudine to a new combination for HIV treatment are possible.

Two nucleotide drugs that were originally developed as HIV treatments are also active against HBV. Adefovir dipivoxil is a nucleotide that was discontinued from further development as an HIV treatment for safety reasons. It can be taken in lower doses for HBV treatment, thereby avoiding major toxicity. Another nucleotide, tenofovir, is not yet licensed as an HIV treatment in Canada but is available through expanded access.

## Interferon

The other drug for HBV treatment is interferon alfa/alpha (IFN). Interferons are proteins produced by host cells in response to viral infection. Of the three different types of interferon, only those produced by B lymphocytes and monocytes (two types of white blood cells) have been shown to be effective against HBV. Unlike lamivudine, IFN both augments the host immune response and works on the virus itself. The dosage is 5 million units daily, or 10 million units three times per week, given subcutaneously (under the skin) for four months. Side effects are common, including flu-like fever and chills.

Not everybody is considered suitable for IFN therapy. Doctors recommend waiting for more than six months before commencing IFN therapy because 5–10% of HBV e-antigen positive persons develop their own antibodies. Untreated cirrhosis of the liver is one reason not to initiate IFN treatment.

IFN is intended to permanently suppress viral replication or eliminate the infection completely. Twenty-five to 40% of patients in trials had e-antigens and HBV DNA disappear after treatment with IFN for 4–6 months. With those persons in whom therapy results in e-antigen negative status, the result is an inactive HbsAg carrier state—meaning they are not infectious—and about one-third of these people eventually lose the HbsAg altogether on their own. Side effects with IFN require close monitoring, optimally every 2–4 weeks, with complete ALT and AST testing plus a complete blood cell count.

## HIV and HBV co-infection

HIV-positive persons who are co-infected with HBV may not respond well to IFN. Lamivudine is better for such persons. In fact, lamivudine is considered safe and convenient, and it achieves a >30% HbeAg loss compared with IFN treatment's 30–40%. IFN requires uncomfortable injections and is associated with many side effects.

However, lamivudine requires longer treatment: one year

compared with four months on IFN. One other drawback to lamivudine is the emergence of viral variants and thus, resistance that has been measured at between 15–30% after one year of therapy, 50% after three years.

Data on combination therapy with both IFN and lamivudine is currently very limited.

## Other treatment options

Liver transplantation, another treatment option, is considered when the liver is seriously damaged. Earlier disappointments, including rejection, have been minimized by the use of drugs such as lamivudine and famciclovir.

Although some may consider a range of Chinese medicinal herbs, few trials have been conducted to date, and the evidence is currently considered too weak to make recommendations.

HBV is one of the leading causes of liver cancer in the world. Vaccination prevents not only hepatitis and cirrhosis caused by HBV, but also liver cancer. Universal vaccination for HBV has been adopted in 80 countries. In the US, universal vaccination was introduced for all newborns in 1991, although the vaccine became available as early as 1982.

Adults should take 10mg doses upon diagnosis, at 1–2 months, and at 6 months. Effectiveness is considered achieved in 95% of those who complete the full program of the three vaccinations. In those individuals who develop HBV antibodies as a result of vaccination, efficacy approaches 100% and such immunity lasts at least 10 years, if not for life. Lifetime immunity is believed to occur despite antibody levels dropping in a large number of such individuals after the 10-year mark.

A major issue of concern to health professionals treating co-infection of HIV and HBV is not only the effects of the two diseases on the liver, but also the side effects of drugs associated with treatment, or hep atoxicity. Liver enzymes help in the metabolization process and over-taxing this organ through high combinations of drugs can cause severe difficulties with high levels of these toxins not being properly metabolized or removed. Careful monitoring and consultation with health professionals is required. ⊕

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



# Where to vegan

*How to get all your nutritional requirements as a vegetarian*

*by Treena Hansen*

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**A**re you vegetarian or thinking about becoming vegetarian? Are you worried about maintaining a balanced diet in spite of your HIV? As HIV and AIDS-related illness progresses, a person's nutritional requirements may change. You may need to increase your calorie intake and protein intake to help build lean body mass. Evidence shows that deficiencies of vitamins B12, B6, A, and D and of the micronutrients zinc, folic acid, and selenium occur in people living with HIV.

## **Vegetarian diets**

Over 14 million people in North America consider themselves vegetarian. However, vegetarian diets vary. The foods common to all of the following vegetarian diets are fruits, vegetables, nuts, seeds, legumes, and whole grain products.

**Vegan** excludes milk, all other dairy products, meat, fish, seafood, poultry, and eggs.

**Lacto-vegetarian** includes milk and other dairy products but excludes meat, fish, seafood, poultry, and eggs.

**Ovo-vegetarian** includes eggs but excludes milk, all other dairy products, meat, fish, seafood, and poultry.

**Lacto-ovo** vegetarian includes milk, other dairy products, and eggs but excludes meat, fish, seafood, and poultry.

**Pesco-vegetarian** includes fish and other seafood but excludes milk, all other dairy products, meat, and poultry.

**Semi- or partial vegetarian** includes milk, other dairy products, poultry, and fish but excludes red meat.

These are the most common vegetarian diets. Less common vegetarian diets include macrobiotic and fruitarian. The macrobiotic diet includes unrefined/unprocessed grains such as brown rice and smaller amounts of fruits, vegetables, legumes, and sometimes milk and other dairy products. If you choose to follow a macrobiotic diet, do it with great care because nutritional deficiencies can

occur, especially a deficiency of vitamin B12. Fruitarians consume only fruits, nuts, seeds, and berries. This diet is not recommended because it lacks nutrients that are essential to your health.

No matter what dietary choices you make, the main goal is to achieve a daily balanced diet. That sounds easy if you are feeling well and able to eat. Sometimes a person living with HIV may have a poor appetite, AIDS-related wasting syndrome, or other problems associated with antiretroviral medication (elevated cholesterol/triglyceride levels) that require a diet change.

## **Macronutrients needed for energy**

The challenge, then, is to achieve an adequate nutritional intake from a vegetarian diet. Exploring the three macronutrients—carbohydrates, protein, and fat—and how the body uses them helps to explain how to achieve this.

**Carbohydrates** are the chief source of your body's energy. They are stored as glycogen in the liver and muscles, acting as a small reserve of energy for a short duration. Carbohydrates are the most readily available source of sugar for the brain and are a good source of fibre, too. Symptoms of carbohydrate deficiency include fatigue, constipation (low fibre intake), and lowered resistance to infection.

Sources of carbohydrates include sugar, grains, fruits, and vegetables. Excluding sugar, these foods are high in fibre and can help lower cholesterol and keep your bowels healthy. Sugar has no nutritional value and can affect your triglyceride levels.

The recommended amount of energy from carbohydrate foods is 55% or 275 grams based on a 2000-calorie diet. The percentage of carbohydrates can increase depending on individual needs.

**Protein** builds and repairs all tissues in the body and produces hormones, enzymes, and antibodies. Symptoms of protein deficiency include lower resistance to infection and growth failure.

If you drink milk and eat milk products, meat, fish, and poultry, it is easy to get enough protein. Non-meat/animal sources of protein include tofu, tempeh, soy beverages, nuts, seeds, nut butters, meat analogues, and grain products such as quinoa and amaranth. Vegetarian sources of protein, which can be less expensive than meat products, are very low in saturated fat and high in both cholesterol-reducing monounsaturated fat (MUFA) and polyunsaturated fat (PUFA).

Protein should supply 15–20% of your total energy, or 75–100 grams per day. The percentage of protein can increase depending on individual needs.

**Fat** provides a large amount of energy and supplies essential fatty acids that the body itself cannot produce. It helps to absorb fat-soluble vitamins A, D, E, and K. Fat protects and supports the body's major organs and is a structural component of the cell membranes of all major body systems. Besides its physiological functions, fat adds flavour to foods.

Symptoms of fat deficiency include dry, rough, itching skin and poor growth. Signs of fatty acid deficiency include hair loss, hair that's easily plucked, and dry, scaly skin.

If you have to watch your cholesterol, remember that different types of fat exist. Unsaturated fats come from plants, and they include MUFA and PUFA. Sources of MUFA include olive and canola oils. PUFA can be found in sunflower, safflower, peanut, and flaxseed oils. These unsaturated fats help to decrease cholesterol. The other fat, saturated fat, usually comes from animals, but two plant sources high in saturated fat are palm and coconut oils.

The recommended total daily intake of fat is 30% of your total daily energy intake. That would be 67g of fat. If you need to lose weight, keep in mind that fat is high in energy, so try to limit your intake to 3–6 teaspoons of added fat per day. If you need to gain weight, use unlimited amounts of MUFA and PUFA.

## Vitamins and minerals

It is equally important to ensure you're getting sufficient vitamins and minerals from a vegetarian diet. Vitamins regulate all body processes and promote growth, health, and life. They enable our bodies to produce and use energy. Vitamins also participate in the formation of blood cells, hormones, neurotransmitters, and genetic material.

Minerals act as important components of many enzymes and form the structural components of the body, such as the bones. They are also involved in muscle development and contraction, blood formation, nerve signals, and body pH regulation.

Table 1 outlines good food sources of vitamins B12, B6, A, and D, and the minerals zinc, folic acid, and selenium.

Eating a variety of protein sources, fruits, vegetables, and whole grain products will help ensure adequate amounts of energy, vitamins, and minerals. All HIV-infected persons should take a multivitamin supplement. In combination with a balanced diet, it will help to reverse the vitamin and mineral deficiencies mentioned above.

Finally, fluids are a vital part of any diet. Water comprises 60% of our body weight. Water helps to transport nutrients, regulate body temperature, and lubricate our joints and digestive tract. It surrounds each cell in our body; without it, the cell would die. You should have at least 8 cups of caffeine-free fluid daily. ⊕



Treena Hansen is a registered dietitian at St. Paul's Hospital and is a member of the Vancouver Dietitians in AIDS Care (VDAC).

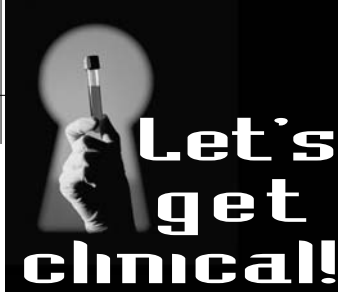
Table 1: Food Sources of selected nutrients

| Nutrient | Protein sources   | Calcium sources   | Fruits and vegetables   | Grain products            | Miscellaneous                 |
|----------|---|---|---|---------------------------|-------------------------------|
| B12      | Chicken, turkey, eggs   | Milk, cheese, yogurt, fortified soy & rice beverages                        |   |                           | Nutritional yeast             |
| B6       | Legumes, chicken, fish  |   | Potatoes with skin, leafy greens, bananas, green peas, avocado, carrots                           | Whole grains              | Nutritional yeast, wheat germ |
| D        |   | Milk, fortified soy & rice beverages  |   | Fortified cereals         |                               |
| A        | Eggs, fish  | Fortified milk, fortified soy & rice beverages, butter, fortified margarine | Dark green & yellow/orange vegetables, tomatoes, peaches, apricots, mangoes, papayas, cantaloupes |                           |                               |
| Calcium  | Fortified tofu, soy nuts, protein, almonds, textured vegetables | Fortified soy & rice beverages  | Fortified orange juice, leafy green vegetables  | Fortified instant oatmeal | Black strap molasses          |
| Selenium | Seafood, chicken  | Milk, cheese, yogurt  |   | Whole grains              |                               |
| Zinc     | Eggs, shellfish   | Cheese, milk, yogurt  | Leafy green vegetables, oranges, prunes, strawberries   | Whole grains              | Wheat germ, chocolate syrup   |
| Folate   | Legumes, nuts, peanuts, sunflower seeds                         |   | Leafy greens, avocados, asparagus, bananas, strawberries  |                           | Nutritional yeast             |

Whole grains: brown rice, millet, whole wheat couscous, barley, buckwheat, bulgar, rye, oats, whole grain bread and pasta, and fortified cereals.

Vitamin D helps with the absorption of calcium. It can be formed with exposure to the sun for just a few minutes. Remember that wearing sunscreen decreases exposures to the sun, which impairs vitamin D production.

Legumes: soybean, black beans, kidney beans, chickpeas, split peas, and lentils.



# Stopping therapy after intensification might yield benefits

by Jim Boothroyd

**P**reliminary results reported in May from a small pilot study at the Canadian HIV Trials Network (CTN) indicate people with chronic HIV infection—that is, people who have been infected for some time—might benefit from treatment intensification followed by long periods off antiretroviral therapy (ART).

The “proof-of-concept” study examined the effects of a novel form of treatment on ten adults who at the start of the trial had chronic HIV disease, HIV-1 RNA viral loads of less than 50 copies, and median CD4 cell counts of 385 per millilitre.

The therapy of each participant was intensified with ddI (didanosine or Videx) for six months, hydroxyurea for five months, a bone marrow stimulant called GM-CSF (granulocyte-macrophage colony stimulation factor) for three months, and a dose of the therapeutic vaccine Remune. Then, for participants who remained clinically healthy and had undetectable viral loads, all antiretroviral therapy was stopped, though Remune vaccinations were given at periodically.

Results presented after 104 weeks of follow-up indicate that all patients experienced viral load rebounds after stopping ART, and seven developed an acute retroviral syndrome (fever, headache, muscle pain, rash, and other symptoms associated with acute HIV infections).

After a median stoppage of 16 weeks, nine patients resumed ART. Viral load decreased to 50 copies, and CD4 counts increased. Levels of the immune factors IL-2 and IL-15 also rose.

During the stoppage of treatment, all nine patients had a viral rebound and three of these nine had a second antiretroviral syndrome. But peak viral loads and loss of CD4 cells were lower. After 21 weeks off ART, eight patients resumed therapy, and treatment at this time proved to be more effective in suppressing viral loads and allowing for growth of the thymus gland. (The thymus plays a critical role in the immune system by supporting the work of T-cells.)

Participants were able to stay off antiretroviral therapy for a median of 49.5 out of 80 weeks. Two of them were off ART for 80 and 44 weeks respectively, during which their viral loads remained below 10,000 copies.

Known as CTN 140, the innovative study is being conducted at a single site at the Université de Montréal’s Hôtel-Dieu Hospital by investigator Dr. Emil Toma.⊕



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

## Community guides Trials Network

The Canadian HIV Trials Network is reapplying for funding from the Canadian Institutes of Health Research, its main sponsor, under the next five-year cycle of the Canadian Strategy on HIV/AIDS.

Among other things, the Network will emphasize the importance of the HIV community in the development of Canadian clinical trials in the last eleven years.

Community activists and people with HIV/AIDS play a central role in the CTN, through the Community Advisory Committee (CAC), which reviews all trial proposals. This innovative approach has ensured that Network trials are socially as well as scientifically relevant.

## CTN Trials enrolling in BC:

CTN 110 (ESPRIT): Subcutaneous Interleukin-2  
BC site: Cool Aid Community Health Centre, Victoria  
CTN 145 (SILCAAT): rIL-2 to slow progression of HIV

BC site: Providence-St. Paul’s Hospital, Vancouver  
CTN 161 (Simplified Protease Inhibitor Trial or SPRINT)  
BC sites: Cool Aid Community Health Centre, Victoria;  
Providence-St. Paul’s Hospital, Vancouver; and Viron, Vancouver  
CTN 164 (Structured Treatment Interruption)  
BC sites: Downtown Infectious Disease Clinic (IDC), Vancouver  
and Cool Aid Community Health Centre, Victoria  
CTN 167 (Options in Management with Antiretrovirals or OPTIMA)  
BC sites: Downtown IDC, Vancouver; Providence-St. Paul’s Hospital,  
Vancouver; and Cool Aid Community Health Centre, Victoria  
CTN 169 (D4T or Abacavir plus Vitamin Enhancement or DAVE)  
BC sites: Providence-St. Paul’s Hospital, Vancouver

For more information about CTN trials, please visit the CTN website: [www.hivnet.ubc.ca/ctn.html](http://www.hivnet.ubc.ca/ctn.html) or call 1-800-661-4664.



# Shape shifting

*Scientists still baffled by lipodystrophy syndrome*

*by Katherine Heath*

In recent years, a newly emerging constellation of changes in body fat distribution and metabolic abnormalities has been reported among people using antiretroviral combination regimens for HIV infection.

The signs and symptoms of lipodystrophy syndrome can include including fat wasting from the face, arms, legs, and buttocks (peripheral lipoatrophy), increased visceral abdominal fat or breast enlargement (central lipohypertrophy), enlargement of the dorso-cervical fat pad (buffalo hump), insulin resistance, diabetes, and high cholesterol and triglyceride levels. It remains unclear whether such metabolic symptoms represent a single syndrome, two distinct syndromes, or are unrelated to each other.

It has been very difficult to determine the proportion of people on antiretrovirals who have these problems because no well-described or widely applied case definition or diagnostic criteria exist. Some studies rely on patient reports, but others use rigid physician-assessed criteria. Various studies have reported symptoms among 5–80% of patients exposed to various treatment regimens. Metabolic disorders are far less common, but they can go unidentified if additional laboratory testing for these problems is not included as part of routine care.

These symptoms often appear within the first two years of therapy. However, they may develop more rapidly or become apparent only after several years of therapy. Or they may never appear at all.

The exact causes of various metabolic and morphologic changes associated with lipodystrophy syndrome remain unclear. Many reports indicate a significant increase in patient-identified lipodystrophy associated with protease inhibitor use or identify specific proteases associated with various fat and metabolic abnormalities. Other reports have concluded that these abnormalities are not associated with type of therapy or may occur in the absence of protease inhibitors. Other studies indicate that nucleosides such as d4T (stavudine) may play a role in symptom

development. Some studies report that different drugs may be associated with different symptoms—some nucleosides in fat wasting, proteases in both fat deposits and high cholesterol or triglyceride levels. Several studies have also indicated non-treatment risk factors such as patient age and gender.

Overall, studies suggest that antiretroviral agents are a causative factor in the development of symptoms. However, symptoms are not likely to be the result of one specific cause; many factors are probably at work.

Regardless of the causes, the high number of persons living with HIV who are experiencing these problems is greatly concerning, particularly because treating these symptoms is difficult. While standard medications may prove successful in treating some symptoms, possible drug interactions and an already excessive pill burden reduce the acceptability of currently available therapies. Moreover, the possible implication for increased risk of cardiovascular events, suggested by abnormal metabolic profiles and abdominal fat deposits, raises the question of longer-term effects of lipodystrophy-associated symptoms.

At present, no evidence exists of increased risk among people with HIV for heart problems. But until more data becomes available over the next year or two, the focus remains on traditional approaches, such as stopping smoking, exercising regularly, reducing dietary fat, and monitoring body weight, as the cornerstones of a strategy to minimize any possible risk. ⊕

*If you experience any of these signs or symptoms, speak to your doctor about their possible causes and treatments.*

*Katherine Heath is an epidemiologist at the BC Centre for Excellence in HIV/AIDS in Vancouver.*



# Hormone anarchy

A chat with Vancouver endocrinologist  
Dr. Greg Bondy

by Glen Hillson

Over the past five years, several medical problems that do not have any apparent direct relationship with immune function have been observed in PWAs. Previously observed HIV-related conditions such as opportunistic infections and body wasting had a clearer connection to the interaction between the virus and the body's immune system.

More recently, metabolic disorders have become apparent as complications. These disorders interfere with how our bodies process the nutrients we consume by upsetting the balance of hormones produced by our glands. They can cause problems such as diabetes, lipodystrophy, facial wasting, abdominal obesity, bone loss, and coronary disease.

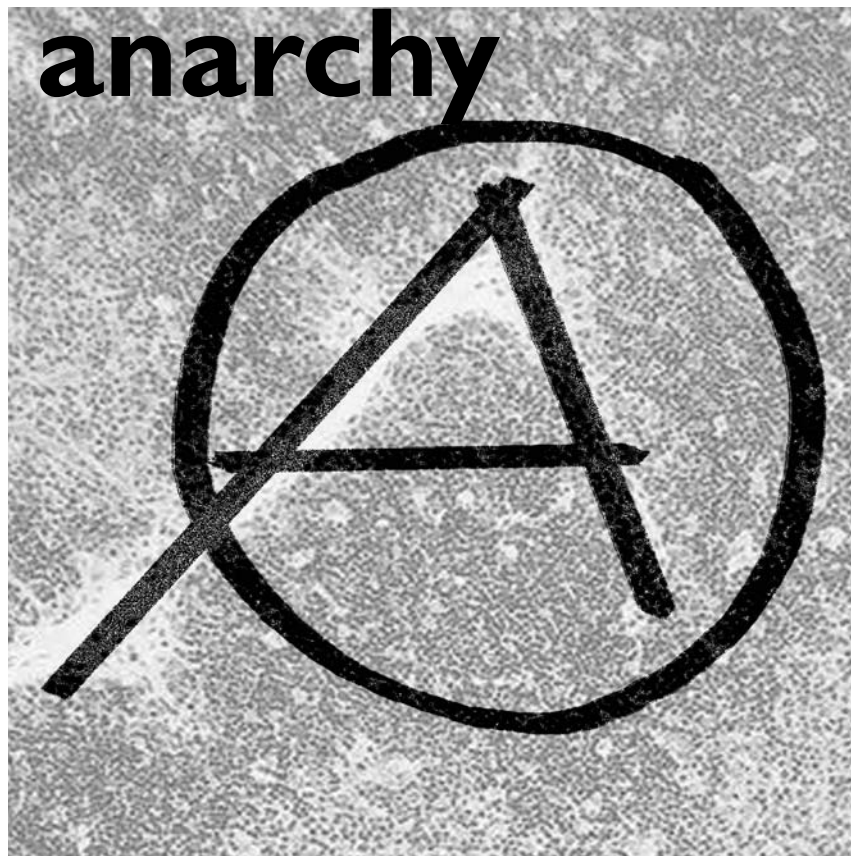
None of these metabolic disorders is trivial—they are large spectrum and serious. Facial wasting could be viewed as cosmetic because it isn't life threatening or known to make people ill, but it is one of the easiest ways to visually identify PWAs on antiretroviral therapy. It can devastate an individual's body image and has become a barrier to accessing treatment.

A much different kind of metabolic disorder is the disruption of lipid (fats such as cholesterol and triglycerides) levels in the blood. This disruption can result in clogging and hardening of arteries, leading to heart attack.

## A lack of information

The biological mechanisms of metabolic complications in HIV disease are only partially understood because they have only been observed since 1997. The lack of evidence-based information has resulted in conjecture and finger-pointing. It is important for us all to gain more knowledge about the respective roles of the virus, HIV medications, and aging in the occurrence of these events.

In some instances, a complication may be thought to arise solely from prescription drugs. In others, long-term survival is thought to be a contributor because many of these problems occur in the general population with as



much frequency as people get older. Often, a combination of factors may be involved. Treating these complications is often an exercise in guesswork because of the lack of knowledge about their causes and biological mechanisms.

Recently I met with Dr. Greg Bondy, an endocrinologist with a clinical practice in Vancouver. He spends much of his time at the Healthy Heart Clinic at St. Paul's Hospital, in addition to one day per week at the Infectious Disease Clinic at the BC Centre for Excellence in HIV/AIDS.

## Lipid disorders and heart attacks

Dr. Bondy's overall message is about heart disease. "Heart disease is very common in an aging population so we should not assume that in PWAs that medications are the only cause," he says. "Antiretrovirals are almost certainly a contributing factor, but this is more than offset by the benefits offered by the drugs. PWAs respond well to treatments for heart disease, and I would not want to see an exodus of patients from the HIV drug treatment program due to fear."

Among PWAs, lipid abnormalities (elevated total and LDL cholesterol and triglyceride levels, plus low levels of HDL cholesterol) observed with regular blood monitoring are often due to protease inhibitor use, according to Bondy. Elevated triglyceride levels, high LDL (the bad

kind of fat), and low HDL (the good kind) are known causes of arteriosclerosis, or blocked arteries due to the formation of plaque on the inside of these vessels. This condition diminishes the supply of blood to the heart muscle itself and can cause heart attacks. Elevated triglyceride levels are also a known cause of pancreatitis, which can be acute and even fatal. The pancreas is the organ tucked below the stomach that produces insulin for the conversion of sugars into energy.

Although protease inhibitors disrupt lipid levels in the blood, a number of other factors also contribute to heart attacks. Advancing age increases risk of coronary disease in the general population, as do compound factors such as cigarette and alcohol use. Dr. Bondy notes that HIV causes chronic inflammation of blood vessels from long-term infection. He says that insulin resistance also causes coronary disease, making it common among people with diabetes.

The good news is that these conditions can often be managed—or, better yet, prevented. Diet and exercise are among the most effective means of preventing and managing lipid abnormalities. Bondy recommends thrice-weekly exercise that increases heart rate to greater than 110 beats per minute. Animal fats should be avoided. He says anyone over fifty years old should take a baby aspirin once daily to lower their total cholesterol levels.

Supplementation with niacin helps to increase the amount of HDL. He suggests a minimum daily dose of 1–1.5g and a maximum of 2g. The most common side effect of niacin is temporary hot flashes. Niacin is also sold in a non-flush formulation, which is 2–3 times more expensive than regular niacin. People with elevated liver enzyme levels should not take niacin. (See Issue 20 of *Living +* magazine for more information on niacin).

Omega-3 fatty acid supplements are beneficial for lowering triglyceride levels. However, not all Omega-3s are created equal in this regard. Local doctors, including Bondy, recommend taking three capsules of salmon oil daily. Flax seed oil and evening primrose oil also contain Omega-3 fatty acids but apparently do not have the same properties for lowering triglyceride levels. On the pharmaceutical side, a class of drugs known as “statins” are also prescribed for lipid regulation.

## Diabetes

Diabetes can occur at any age with varying levels of severity, usually depending on the type of diabetes. Diabetes results from resistance to insulin, a hormone produced by the pancreas and required for sugar to get into body cells. Without insulin, sugar cannot enter muscle cells.

When a person has insulin resistance, the pancreas continues to secrete insulin, but it doesn't do its job properly. Dr. Bondy confirms that protease inhibitor use seems to be associated with insulin resistance. The clinical

symptoms of poorly controlled diabetes are frequent urination, thirst, and blurred vision. Sugar is unable to enter cells and remains in the blood. Insulin resistance generally does not cause symptoms but increases the risk of developing heart disease and can progress to diabetes.

Once again, the good news is that there are effective means of preventing and controlling insulin resistance. When protease inhibitors cause insulin resistance and no other intervention is able to correct the problem adequately, it can be corrected by discontinuing protease inhibitor use and using alternate means of controlling HIV infection.

Exercise and diet are effective means of improving insulin function. Bondy recommends avoiding simple sugars such as candy and refined sugar in favour of complex sugars found in fruit and vegetables.

Prescription drugs such as metformins and TZDs are also used. Metformins have been around longer and are covered by Pharmacare. The disadvantages of metformins are that they must be administered three times daily and cause side effects including diarrhea and elevated lactate levels. Roseglytazone is one example of a TZD. Bondy feels it is more effective and has other advantages, including once daily dosing and no gastrointestinal side effects. One additional benefit of roseglytazone is that it helps maintain subcutaneous (under the skin) fat cells, which can help prevent facial wasting. TZDs are very expensive and are not covered by Pharmacare.

## Bone disease

A condition known as avascular necrosis has been identified as a complication of antiretroviral therapy. It is a very unusual form of bone loss because it is localized. The blood supply to the hip joint is impaired, which ultimately causes the deterioration and death of bone in the joint. Although more common and generalized forms of bone disease (ie osteoporosis or generalized thinning of the bone) have also been observed, Dr. Bondy did not think there was sufficient evidence to attribute these conditions to HIV disease or treatments.

Overall, my impression is that it is important to become informed about these conditions. There are different causes and combinations of factors, but over time research is likely to increase our understanding. ⊕

*Glen Hillson is chair of the BCPWA Society.*



## INFORMACION EN ESPAÑOL

# Tenofovir

¿Qué es Tenofovir?

por Sergio Pineda

**E**s un medicamento que se usa para el tratamiento de la infección por el Virus de la Inmunodeficiencia Humana VIH, es fabricado por Gilead Sciences. Recientemente fué aprobado en los Estados Unidos por la Administración de Alimentos y Fármacos (FDA) en octubre del 2001

Actualmente en diferentes ciudades de Canadá se estan llevando a cabo estudios clínicos del Tenofovir en un programa de acceso expandido para pacientes que tienen opciones limitadas de tratamiento, y se espera que muy pronto sea aprobado por las autoridades de salud en Canadá.

Tenofovir es un nucleótido análogo de la transcriptasa reversa (NTR). Este medicamento bloquea a la enzima transcriptasa reversa, cambiando el material genético (ARN) del VIH a ADN. Este cambio debe ocurrir antes de que el código genético del VIH se inserte dentro del código genético de la célula infectada.

Además de combatir al VIH, el Tenofovir ayuda a controlar al virus de la Hepatitis B y al Citomegalovirus.

### ¿Quién lo debe tomar?

No existen reglas absolutas acerca de cuando iniciar la toma de medicamentos antivirales, usted y su doctor deben tomar en cuenta el conteo de células T4 y su carga viral, los síntomas y su actitud acerca de la toma de medicamentos.

### ¿Que sucede con la resistencia a los medicamentos?

Muchas de las copias nuevas del VIH son mutaciones, estas son un poco diferentes

al virus original. Algunas mutaciones pueden continuar multiplicándose aun cuando usted tome el medicamento antiviral, cuando esto sucede los medicamentos dejan de funcionar, esto se conoce como desarrollo de resistencia.

En algunas ocasiones si el virus desarrolla resistencia a un medicamento, también será resistente a otros antivirales, esto se conoce como resistencia cruzada, sin embargo parece que Tenofovir tiene poca resistencia cruzada con otros medicamentos antivirales.

Es muy importante tomar los medicamentos antivirales de acuerdo a las instrucciones, la hora que corresponda y no saltar ni reducir las dosis, a esto se le llama "adherencia".

### ¿Cómo se toma?

Tenofovir se toma una vez al día facilitando la "adherencia", para adultos es una píldora de 300 mg. con alimentos.

### ¿Cuáles son los efectos secundarios?

Puede padecer efectos secundarios por un tiempo como por ejemplo: dolores de cabeza, hipertensión o una sensación de malestar general. Estos efectos secundarios generalmente mejoran o desaparecen con el tiempo. Los efectos secundarios más comunes del Tenofovir son las náuseas, vómitos y pérdida de apetito. En algunas personas el Tenofovir aumenta los niveles de creatinina y de las transaminasas. Estas enzimas estan relacionadas con la función del hígado y de los riñones. Los niveles elevados de éstas enzimas indican daño a dichos órganos.

### ¿Como reacciona el Tenofovir con otros medicamentos?

Tenofovir aumenta los niveles en la sangre de Didanosina (Videx). Las personas que toman los medicamentos deben tomar Tenofovir dos horas antes o una hora despues de tomar Didanosina. El Tenofovir es eliminado del cuerpo a través de los riñones, no es metabolizado en el hígado y por lo tanto no se espera que interactúe con muchos otros medicamentos. Sin embargo los medicamentos que terminan con "ovir" como Ganciclovir o Aciclovir pueden reaccionar con Tenofovir. Asegurese de que su doctor sepa de todos los medicamentos que esta tomando.

El Tenofovir se puede combinar con otros medicamentos para combatir al VIH. Generalmente se combina con un inhibidor nucleosido de la transcriptasa reversa (NTR), más un inhibidor no nucleosido de la transcriptasa reversa (INNTR) o un inhibidor de proteasa (IP). ⊕

#### Información en Español

BCPWA Treatment Information Program (TIP)

Ofrecemos información en español sobre terapias y tratamientos para la infección de VIH y SIDA.

Consejería individual es disponible todos los Miercoles 10:00AM a 5:00PM.

Visitenos a nuestra dirección:

BCPWA Programa de Información sobre los Tratamientos

1107 Seymour Street, Vancouver, BC V6G 5S8

A la entrada, a un lado de la librería "PARC"

O llamenos a nuestra línea directa: Tel: 604.893.2243

Información sobre tratamientos anti VIH via correo electronico nuestro email es [treatment@parc.org](mailto:treatment@parc.org)

# Volunteering at BCPWA

## Profile of a volunteer: Thomas Canty



"Thomas is the ultimate team player. He never lets a fundraising event pass without encouraging words and a thoughtful note to everyone in the Fund Development Department. His love for volunteering and his volunteer peers shows — through his energy, enthusiasm, and giving spirit."

Melissa Davis

### Volunteer History

Started on the AIDS Vancouver Helpline, then became an intake counsellor. In 1992, I helped at the AIDS Vigil in Ceperly Park, as well as the Registration table at the AIDS Walk. I have volunteered for the AIDS Walk ever since. Currently, I am one of the Team Captains for the registration tent.

### Why pick BCPWA?

I met some wonderful people at both BCPWA while volunteering at AV, so I jumped at the chance to help on the Vigil and the AIDS Walk. I was not only making myself feel good, but also helping a lot of people that I deeply care for.

### Why have you stayed?

As this cruel disease has slowly taken away people at BCPWA and AV who are like family to me, I have strengthened my resolve to stick it out for the long haul and be there when they announce the cure.

### Rating BCPWA

I think BCPWA has been doing an outstanding job in helping HIV-positive people live a better and healthier life. BCPWA has been a leader in fighting for the rights that its members deserve.

### Strongest point of BCPWA

That it cares about its members and their families.

### Favourite memory

Calling Melissa one minute before she went on stage at the AIDS Walk to announce the total pledges and telling her to add another sizeable chunk of money, hearing her calm response to my call, then hearing her get all excited when she announced the figure.

### Future vision for BCPWA

To keep doing the good work that they are doing. I think the Board has a great vision for BCPWA's future path.

**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  
or Human Resources at 1107 Seymour Street

**visit our web-site at [www.bcpwa.org](http://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).681.2122 or 1.800.994.2437  
bcpwa@parc.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 Prince Rupert**

Box 848 Prince Rupert, BC V8J 3Y1  
250.627.8823  
aidspr@rapidnet.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  
604.681.2122  
av@parc.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

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

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

## **Dr Peter Centre**

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

## **Friends for Life Society**

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

## **Healing Our Spirit**

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

## **McLaren Housing Society**

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

## **North Island AIDS Coalition (Campbell River)**

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

## **North Island AIDS Coalition (Courtney)**

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

## **North Island AIDS Coalition (Port Hardy)**

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

## **Okanagan Aboriginal AIDS Society**

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

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

250.881.5663  
erikages@pan.ca  
www.pan.ca

## **Positive Women's Network**

614 – 1033 Davie St, Vancouver, BC V6E 1M7  
604.692.3000 or 1.866.692.3001  
pwn@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

*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](http://www.bcpwa.org).*



# AGM

## British Columbia Persons With AIDS Society

Notice of Annual General Meeting

WHEN: October 26, 2002 at 11:00 AM

WHERE: Parkhill Hotel, 1160 Davie Street, Vancouver

REGISTRATION: 10:00 AM - 11:00 AM

MEETING BEGINS AT: 11:00 AM (Sharp)

The membership will meet to receive the Annual Report of the Directors, consider amendments to the by-laws of the Society, elect the Board of Directors of the Society for 2002/2003, and conduct other such business as is deemed necessary in accordance with the constitution and bylaws of the Society.

### Important Dates to Remember:

Last day Proxies are Mailed  
October 15, 2002

Last Day Proxies May be Requested for  
Picked Up October 21, 2002

If you have any questions or would like to receive a copy of the Society's Annual Report please call Joel N.C. Leung, Secretary, at 604.893.2263 and leave a confidential message. To ensure accuracy please spell your last name slowly in the voice message and leave a contact phone number. **A lunch will be served.**

### Upcoming BCPWA Society Board Meetings

| Date              | Time   | Location      | Reports to be presented  |
|-------------------|--------|---------------|--|
| October 02, 2002  | 3:00pm | Training Room | Standing Committee / Written Executive Director Report                   |
| October 16, 2002  | 3:00pm | Training Room | Director of Support Services Presentation / Written Departmental Reports |
| October 30, 2002  | 3:00pm | Training Room | Executive Committee / Written Executive Director Report                  |
| November 13, 2002 | 3:00pm | Training Room | Standing Committee / Written Departmental Reports                        |
| November 27, 2002 | 3:00pm | Training Room | Director of MVR / Written Executive Director Report                      |
| December 11, 2002 | 3:00pm | Training Room | Executive Committee / Written Department Director Report                 |

The Pacific AIDS Resource Centre (PARC) is located at 1107 Seymour St., Vancouver.

For more information, contact:

Katharine McEachern, Manager, Executive Operations

Direct: 604-893-2292

Email: katharin@parc.org

### Yes! I want to receive living+ magazine

name \_\_\_\_\_

address \_\_\_\_\_ city \_\_\_\_\_ province/state \_\_\_\_\_

postal code/zipcode \_\_\_\_\_ country \_\_\_\_\_

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#### I have enclosed the following for 6 issues of living+

- \$25 Canadian (non-BCPWA members)  \$40 USA  \$45 International
- I want to donate the above subscription to a PWA who can't afford it
- I am a PWA and can not afford the full subscription price
- Enclosed is my donation of \$\_\_\_\_\_ for living+
- Please send me more information about Planned Giving
- I want to become a member of BCPWA

Cheque payable to BCPWA



www.bcpwa.org

## living+

1107 Seymour Street  
Vancouver, BC  
Canada V6B 5S8

# Saving for a constant downpour

*The concept of medical savings accounts is all wet*

by Glen Hillson



The notion of medical savings accounts (MSAs) has bubbled up from the dark sludge of so-called innovative strategies embodied in the anything-but-great debate on how to gut Canada's healthcare system. It's one of those times when the changing landscape of the AIDS epidemic, combined with shifting political fortunes, leaves my head spinning like Linda Blair in "The Exorcist."

It seems like just yesterday that many of us with HIV/AIDS emptied our savings accounts and cashed in our retirement plans and life insurance. The ka-ching, ka-ching of cash registers and click, click of credit card-spending orgies resounded across the land. Those with disposable income were earnest about the disposing part.

When the drug cocktails arrived, many of us were newly broke and in debt. You know there's a problem when retail clerks cut up your credit cards with scissors, the ATMs respond with pre-recorded laughter, and your bank refers you to a loan shark.

The big boys who would dictate our thoughts and values have Medicare in their cross hairs. Their plan to save the world relies on people saving up health dollars like monopoly money for a rainy day. Hasn't anyone told these pinheads that a catastrophic, life-threatening illness like AIDS is more akin to tropical storm Mary than to a rainy day?

For most of us, saving is an artifact

from another lifetime. And our healthcare needs are not discretionary. We don't wake up in the morning and try to decide whether to spend this month's cheque on a new SUV or open heart surgery.

Medical savings accounts—which, by the way, have crashed and burned wherever they have been test driven—work like this: Each person gets a yearly allowance for healthcare. If you spend more, it comes out of your own pocket. If you spend less, you get to carry over the balance. The idea is to dissuade people from spending public

**Imagine going to your local medical ATM to withdraw a new kidney, only to discover you can't even afford hair plugs.**

healthcare dollars frivolously. Never mind that it hasn't been shown that overuse imposes strain on the system.

We'll be expected to diagnose ourselves and determine if we really need to see a doctor. In the past, we all just trotted off to the clinic because it was such a blast. With the MSA, you may find yourself suffering from a sore neck and headache, decide it's just a flu that will go away, and choose instead to keep saving for that organ transplant you've been fantasizing about. The next morning you

wake up with rigor mortis, having expired from meningitis during the night.

A recent study published by the Canadian Medical Association pegs the average annual cost of healthcare for one person at \$730. For a person with AIDS, that would pay for about two weeks worth of meds, with nothing left over for doctor visits, lab tests, and so on. Imagine going to your local medical ATM to withdraw a new kidney, only to discover you can't even afford hair plugs!

As some of America's largest corporations for institutionalized theft bite the dust in disgrace, I can't help but be skeptical of the notion of saving. We've barely grasped the concept of safer sex. Safer saving is a complete mystery. Imagine if your stored up medical credits had been entrusted to Enron. As the right wingers drag us toward an Americanized healthcare system, following an ideology of feed the rich and kill the poor, one can only imagine what would become of that colonoscopy you were saving for under the likes of George W. Bush. With any luck, they will include a buy now, pay later option.

So, if you're thinking you may need angioplasty, a liver biopsy, an MRI—don't wait! Soon you won't be able to afford it. And, oh yeah: Start stockpiling those meds. ☹

*In the past month, Glen Hillson has undergone a sigmoidoscopy, an upper GI endoscopy, a triphasic CT scan, a phlebotomy, blood tests, six doctor visits, and one trip to emergency. He's officially broke and needs a liver transplant.*