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The British Columbia Persons With AIDS Society seeks to empower persons living with HIV disease and AIDS through mutual support and collective action. The Society has over 3,500 HIV+ members.

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# think + opinion and editorial

## Here comes trouble

by *Glen Hillson*

For several years, we have decried the whole arsenal of HIV drugs for their side effects, everything from disfiguring to life-threatening. At the same time, those drugs have saved many lives that would have expired by now, my own included.

The other favourable aspect of HIV drugs in British Columbia is that they have been easily available to us through the BC Centre for Excellence in HIV/AIDS (BCCfE). Anyone who needed them could get them, and need has been defined in a very reasonable way. Ease of access is a strong motivator for people to get tested and, if infected, to seek medical care. As such, it is also an excellent prevention strategy. All that is very likely to change soon.

The BC government is sending out messages that it wants to take a big slice out of the number of future infections and enroll more people who already have HIV into medical care. Highly commendable indeed.

However, close examination of the government's more tangible actions makes it impossible to reconcile its words and deeds. So let's look at what the government has done or is doing:

It has made HIV/AIDS a reportable illness, which will deter many people from getting tested.

It is actively reducing the amount that PharmaCare spends on drugs. So-called Fair PharmaCare will increase drug costs to 70% of BC citizens.

The rumour is that the budget for HIV drugs is frozen, yet there is no outcry from government about skyrocketing prices. The newest drug to be licensed, Viread, is priced double that of other reverse transcriptase (RT) inhibitors. The next drug that will make it to market is four times the price of any HIV drug out there now!

Higher prices and more people on treatment can only mean that the BCCfE will run out of money for drugs part way through the year. Then what? Regional health authorities are set to disembowel the network of community-based organizations. Is the BCCfE next on the firing line?

The government has removed incentives for people to get tested and to seek medical care at the same time it says it is intent on getting HIV/AIDS under better control in BC. The government has made no new investments in care and no investments at all in prevention. Regionalization is leading to the demise of the community AIDS movement.

The bottom line is that more British Columbians from all walks of life will get infected. They will become ill sooner and die faster. How long will we sit on our hands and coo at the sound of soothing words? Soon it will be too late to act—if it isn't too late already. ⊕

*Glen Hillson (Feb 11, 1952– June 12, 2003) was the chair of the BCPWA Society until the time of his death.*

*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



## Skills-building symposium

The 4th Canadian HIV/AIDS Skills Building Symposium will take place from November 20-23, 2003 in Calgary. There will also be a pre-conference session on community-based research and HIV-positive people on November 19.

The event offers skills training and networking opportunities under eight learning streams: Prevention; Care/Counselling/Support; Treatment; Human Rights, Legal, Ethical and Policy Issues; Organizational and Community Development; Community-Based Research; International Action; and Rehabilitation.

For more information, contact Shaleena Theophilus, program development coordinator, at (800) 499-1986, ext. 136 or shaleena@cdnaids.ca, or visit the Canadian AIDS Society website at [www.cdnaids.ca](http://www.cdnaids.ca).

## New surgery for facial wasting

Montefiore Medical Center researchers have developed the first known, long-lasting surgical solution for PWAs. Approximately 50 percent of people with HIV experience lipodystrophy, which includes facial wasting after treatment with highly active antiretroviral therapy (HAART). To date, all cosmetic solutions for HAART-induced facial wasting have been short term.

In a study of five patients with HIV, researchers found that a graft of the deep layer of skin and its attached fat, called dermofat, can be transferred from the abdomen to the cheeks of patients to correct the wasting look, and the benefits have lasted up to two-and-a-half years.

Source: *PR Newswire*

## Deputy minister cashes in

Robin Ciceri, the deputy minister of the BC Ministry of Human Resources,

received \$15,400 on top of her annual salary of \$154,000. Ms. Ciceri received the 10% bonus for 2001-2002. The bonus was a reward for streamlining service delivery, cutting the growth in disability benefit payments by 2 percent, tightening income assistance eligibility requirements to cut caseloads by 2 percent in the first year, and cutting appeal times for welfare.

*Monday Magazine* published the salaries and bonuses received by deputy ministers in their May 1 - 7 issue. For the full list, visit [www.mondaymag.com/editorial/18\\_2003/newsCHART.gif](http://www.mondaymag.com/editorial/18_2003/newsCHART.gif).

## Methadone-Pegasys interaction study

At the Digestive Disease Week Conference in Orlando, researchers from Johns Hopkins University Medical School concluded that the combination of methadone and Pegasys was safe and well tolerated.

The researchers conducted a 4-week study evaluating interactions between methadone and Pegasys. They found methadone exposure levels increased by 10 percent to 15 percent during the first 4 weeks of taking methadone and Pegasys together, although no patient reduced their methadone dose during this 4-week study.

In this study, methadone did not have an impact on the pharmacokinetics (drug levels) of Pegasys or the pharmacodynamics of Pegasys. Therefore, dose modifications of Pegasys are not required.

Source: *NATAP*

## Serostim on black market

Serostim, a drug used to counteract wasting in people with HIV/AIDS, has become one of the hottest sellers on New York's multimillion-dollar black market

in prescription drugs. Especially popular among bodybuilders, Serostim—one of the most expensive AIDS drugs on the market—works by mimicking natural human growth hormone and adds pounds of muscle in a few months.

Despite efforts by Serostim's maker, Serono Laboratories, and law enforcement to ensure it only goes to patients who need it, the drug remains plentiful in the city's gyms. And PWAs are often the suppliers, according to some of New York's leading AIDS doctors. One Manhattan physician told of a PWA who sold his supply to pay the rent.

In response to complaints that doctors were incorrectly prescribing the drug, the New York Health Department began requiring physicians last year to get state approval before prescribing it.

Source: *New York Daily News*

## Needle exchange battle in Courtenay

The North Island AIDS Society (NIAS) approached Courtenay Council last month to air its frustration at being shut out by the city's Community Drug Strategy Committee. NIAS was responding to recent criticism of their needle exchange program, in particular how they dispose of and account for spent needles.

Executive director Phillip Haines said that NIAS hands out 6,000 needles each week in Comox Valley, and sees a 98 percent return rate. Returned needles are then incinerated through a biomedical waste disposal system. He wants the city to help NIAS recover the remaining 2 percent of spent needles. "There are at least 100 stray needles found by the city parks department each year," he said. "We want to keep track of these needles."

# REALITY BITES



Haines said he wants to work with the committee to make sure the municipality can minimize risks associated with drug abuse, but he also wants certain politicians to stop grandstanding.

*Source: Comox Valley Echo*

## Phase II clinical trial of ThGRF

Theratechnologies announced that it has enrolled a first patient in a new Phase II clinical study for ThGRF, its growth hormone-releasing factor analog, in HIV-related lipodystrophy.

The trial was designed based on the favourable clinical profile of ThGRF observed in previous studies as well as on recent reports demonstrating clinical benefits with recombinant growth hormone in HIV lipodystrophic patients.

Theratechnologies will be conducting this Phase II study in 5 to 7 centres in Canada and the US to assess the safety and

obtain preliminary efficacy data of ThGRF.

Lead investigators are Dr. Steven Grinspoon, director of the Program in Nutritional Metabolism at the Massachusetts General Hospital, and Dr. Julian Falutz, director of the HIV Metabolic Clinic at the Montreal General Hospital. Up to 60 patients will receive a daily subcutaneous injection of two doses (1mg, 2mg, or placebo) over a period of 12 weeks in order to measure reduction of visceral and truncal adiposity.

## Palliative care program cuts

Local activists have launched a letter-writing campaign to protest the elimination of acute palliative care beds, including the closure of the entire Respite Program, at St. Paul's Hospital in Vancouver. This means that patients who need specialized in-hospital end-of-life care will be denied. Activists argue that in-hospital palliative care provides

patients in acute stages of end-stage illnesses with care that is not available in general hospital units, in hospices, or in long-term care facilities.

There are no known plans to increase hospice facilities to replace these acute care services, and community home care services are already overextended.

For a list of what you can do to protest these cuts, contact the BCPWA Society at [info@bcpwa.org](mailto:info@bcpwa.org).

## Complimentary tickets for BCPWA members

The BCPWA Society offers pairs of tickets to members who are registered with the Support Department. Tickets distributed recently include ballet, Vancouver International Children's Festival, musical theatre, rock concerts, the symphony, and theatrical plays.

Drop by the Member Services counter at BCPWA and complete a yellow registration form and they'll add you to their list of members wishing tickets. The list is presently up to 400 names, so please be patient, you will get a call from them offering tickets.

Many members are on the list but their phone numbers are not up-to-date. Please update your information by filling out the yellow registration form again. They can't give you tickets if they can't reach you.

photo Ruth Marzetti



*Three volunteers at this year's BCPWA Society Volunteer Recognition event, having a cozy old time. They took part in the wildly successful Fashion Show. The event took place on May 7th at the Stanley Park Pavillion.*

# Un-Fair PharmaCare

*Many people will now have to pay more for drugs*

*by Ross Harvey*

When the BC Liberal government introduced its Fair PharmaCare initiative (since re-christened Fair PharmaCare by some) on February 24, the immediate and widespread response was confusion. Who would have to pay, and how much more? Were some things no longer covered? And what the hell was up with that May 1 deadline-but-not-really?

Some of the dust has settled, and we can now fairly confidently describe the program's, um, highlights.

First, of the little less than one-quarter of British Columbians (950,000) who receive any PharmaCare benefits at all (who, in other words, actually have to buy covered prescription pharmaceuticals to a total annual cost high enough to cause PharmaCare coverage to kick in), 29 percent (280,000, or about seven percent of all British Columbians) will see their PharmaCare coverage increase. For those 29 percent, their costs will go down, at least marginally. Seventy-one percent (670,000, or about 17 percent of all British Columbians) will pay more. Some will have to pay a lot more. Anyone born after 1940 with a combined family net income of more than \$40,000 will pay more. Seniors born before 1941 with a combined family net income of more than \$20,000 a year will pay more.

Second, and consequently, the government expects these changes will save roughly \$90 million a year. Much of that

money will come out of the pockets of seniors—people over 65 years of age—who are deemed “well-off” by the government. Table 1 shows the changes that will affect people generally. Seniors will be hit with additional changes. For example, seniors used to pay no deductible at all; PharmaCare covered 75 percent of their drug costs right from the get-go. Now, a deductible of 1 percent of annual family net income per year kicks in at the \$33,001 level (\$330 per year at that level), rising to 2 percent at the \$50,001 annual family net income

**The government expects to save roughly \$90 million a year, much of that coming out of the pockets of seniors.**

level (\$1,000 per year at that level). In addition, changes in the maximum amount paid by a senior family before PharmaCare coverage hits 100%—which used to be \$200 per year for all seniors—instead will be calculated as 1 percent of annual family net income up to \$33,000, 2 percent of annual family net income between \$33,001 and \$50,000, and 3 percent of annual family net income over \$50,000.

Although it's impossible to know at this point, it is reasonable to predict that somewhere between one-third and one-half of the \$90 million the government is

hoping to save will come from seniors with an annual net family income of between \$15,000 and \$40,000. Fully 50 percent of all PharmaCare beneficiaries in 2001 were 65 or older. That same year, seniors composed a little less than 15 percent of the overall population.

Third, prescribed HIV/AIDS drugs distributed through the BC Centre for Excellence in HIV/AIDS (BCCfE) will remain covered 100 percent. No one receiving antiretrovirals or other HIV/AIDS drugs in BC will have to pay a penny for them. Unfortunately, because PharmaCare has capped the total amount of money it gives to the BCCfE, despite the ever-increasing number of persons requiring treatment, it is possible the BCCfE may have to stop funding related drugs, such as the anti-infectives intended to prevent opportunistic infections. If the BCCfE is forced to take this step, then such drugs would thereafter be available only through “special authority.” And, unless otherwise covered, the recipient would have to pay for them up to their new annual PharmaCare deductible.

Fourth, persons subsisting on BC Benefits (welfare) or who are receiving Medical Services Only (MSO) coverage will continue to have 100 percent of their PharmaCare-covered prescription drug costs paid.



Table 1. Winners and losers under Fair PharmaCare<sup>3</sup>

Family net income	Old deductible	New deductible	Difference in deductible	Old maximum paid <sup>2</sup>	New maximum paid <sup>2</sup>	Difference in maximums	Total possible differences
10000	600	0	+ 600	2000	200	+1800	+2400
15000	600	0	+ 600	2000	300	+1700	+2300
20000	600	400	+ 200	2000	600	+1400	+1600
25000	800	500	+ 300	2000	750	+1250	+1550
30000	800	600	+ 200	2000	900	+1100	+1300
35000	800	1050	- 250	2000	1400	+600	+350
40000	800	1200	- 400	2000	1600	+400	0
45000	800	1350	- 550	2000	1800	+200	- 350
50000	800	1500	- 700	2000	2000	0	- 700
55000	800	1650	- 850	2000	2200	- 200	- 1050
60000	800	1800	-1000	2000	2400	- 400	- 1400

<sup>1</sup> The "deductible" is the amount individuals or families pay before PharmaCare kicks in and thereafter pays 70% of covered costs, up to the individual's/family's "maximum" cost.

<sup>2</sup> The "maximum" is the total amount individuals or families pay—including their 30% share after their "deductible" is reached—before PharmaCare pays 100% of all additional covered costs.

<sup>3</sup> Thanks to the Canadian Centre for Policy Alternatives for this table. Check out their complete analysis at [www.policyalternatives.ca/index.html](http://www.policyalternatives.ca/index.html).

Fifth, it is absolutely essential that you register for the new Fair PharmaCare program, or you may not be covered. Yes, the government has said that persons receiving BC Benefits will be registered automatically, but the BCPWA Society is advising its members to register themselves regardless, just to be sure.

When you register, you must provide

- ▼ your BC CareCard (Medicare) number for you and all co-insured members of your family;
- ▼ your date of birth and the dates of birth for all co-insured members of your family;
- ▼ your Social Insurance Number(s); and


▼ your net income from line 236 of your last year's tax return(s) or Notice(s) of Assessment.

To register, go to <https://PharmaCare.moh.hnet.bc.ca/> or phone 1-800-387-4977. Even though the new Fair PharmaCare program began May 1, it's not too late to register. ⊕



Ross Harvey is the executive director of the BCPWA Society.

## BCPWA Advocacy gets results!



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

- ▼ **\$67,596.58** in debt forgiveness.
- ▼ **\$102,649.55** in housing, health benefits, dental and long-term disability benefits.
- ▼ **\$31,405.99** in Monthly Nutritional Supplement Benefits.
- ▼ **\$568,111.14** into members' hands for healthcare needs, from grandfathered Schedule C benefits.



*It's now mandatory to report HIV to the BC Ministry of Health*

*by Jeff Anderson*

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**A**s of May 1, 2003, people in British Columbia who are tested and diagnosed with HIV must be reported to provincial health authorities. HIV now joins such diseases as tuberculosis on the list of reportable diseases tracked through the provisions of Schedule A of the Health Act Communicable Disease Regulations of BC. British Columbia and Quebec are the only provinces in Canada to do so. In accordance with the new regulations, regional health officials have been trained to inform “at risk contacts” of those newly diagnosed and so to be notified of their possible exposure to HIV.

While developing his report for the Minister of Health, Medical Health Officer Dr. Perry Kendall was confident the new regulations brought through Order in Council will allow provincial epidemiologists to track the epidemic better and protect the health of British Columbians through so-called “partner notification.” Newly diagnosed people may voluntarily share the names of people “at risk”— those who came into sexual contact with them or who may have recently shared injection drugs with them. Provincial health officers have assured the public that “community” nurses have now been adequately trained to effectively inform and counsel people at risk.

The controversial new regulations require individual physicians, who make up the majority of testing personnel, to report confirmed cases of HIV and, for the first time in BC, to provide information to a database of persons testing positive for HIV.

Most health activists and people with HIV voiced concerns that the regulations are unhealthy to people newly diagnosed with HIV and further stigmatize people who are already likely to be marginalized by social or cultural status. In an interview with the Victoria Times Colonist, Victoria activist Ruby Black voiced concerns about the safety and health of the newly diagnosed. “I know what I went through and what others went through when they were first diagnosed. I can’t stand the thought that they have to worry about this, too.”

### **Strong opposition from stakeholders**

In recommending the new regulations through the “Provincial Health Officers’ Report on HIV Reportability,” Dr. Kendall admitted that “stakeholders’ views were almost unanimous in opposing reportability.” In Victoria, the Prostitutes Empowerment and Education Resource Society (PEERS) surveyed their members and Linda Poffenroth, an officer of the Capitol Health Region, submitted views of sex-trade workers to Dr. Kendall. “As far as Reportability is concerned, these women would not be tested for HIV infection if they thought their name would be known by anyone in authority since this might risk a visit from (the Ministry of Children and Families).”

During rollout of the new regulations, government officials reminded the public that subjects could offer initials instead of their actual names. However, the vast majority of HIV tests are conducted at doctors’ offices, where pseudonyms could be linked to patient names, date of birth, or other identifying data. This risk to the privacy of those being tested was cited as enough of a threat to prisoner safety and a deterrent to prisoner cooperation that Corrections Services Canada recently refused to follow provincial governments in enacting the controversial provisions in Canada’s federal prisons. Similar threats to those outside the prison environment, such as women and others in abusive relationships, did not deter provincial officials from recommending that the Minister of Health enact the regulations.

Groups initially selected by Dr. Kendall for consultation, including the BCPWA Society, denounced the move as dangerous and unnecessary. In a letter to Dr. Kendall, BCPWA Society chair Glen Hillson asserts, “It will dramatically discourage and dissuade people from getting tested for HIV...particularly women of ethnic minorities and youth. Nominal testing would lead to decreased physical

and emotional safety for those people who test positive. HIV remains associated with major stigmas and discrimination. People living with HIV/AIDS are frequently physically attacked and socially isolated as a result of their serostatus, and nominal testing and partner notification will escalate these problems.”

### **A spurious rationale**

Dr. Kendall dismissed such concerns, saying that increases in HIV diagnoses in BC “demand more of a public health response than we are presently providing.” AIDS groups and activists were unmoved by the rationale, noting that other methods could be used to track epidemiological developments. They also claimed that the new regulations were recommended by the Medical Health Officers of BC long before the incidence of HIV was again on the rise.

Additional reasons for opposing the new regulations include concerns about unauthorized access to the names of people with HIV, unauthorized disclosure of test results by health officials, lack of informed consent to test, inadequate counselling practices by provincial health employees and doctors, and untimely notification of those exposed to risk of HIV through sexual contact or needle sharing.

### **Health activists and people with HIV voiced concerns that the regulations further stigmatize people who are already likely to be marginalized by social or cultural status.**

HIV groups have voiced concerns about current pre- and post-test counselling practices, and stated objections to the new pre- and post-test protocols implemented by the province. Most studies have found that people who contract HIV learn better about the effects and ramifications of the disease from others who have experienced it. Persons who contract HIV are best positioned to understand the tremendous emotional impact of the diagnosis and offer one-on-one assistance to the newly diagnosed. Despite this knowledge, the province failed to include people with HIV in either designs or delivery of contact tracing or counselling efforts.

### **Health care experts voice skepticism**

Health care providers and experts also questioned the stated purposes and benefits of the new regulations. Patricia Rodney, a professor and researcher in medical ethics, said that she did not believe that mandatory reporting will necessarily lead to better mobilization of health care services, a higher standard of pre-post test counselling, or better con-

tact management. “We operate in a health care system that is reeling after a decade of cost constraint,” she said. “Unless there is ongoing attention to planning, implementation, and evaluation, there is a danger that mandatory reporting would be implemented without the supports that should accompany it.

Rodney cited many examples where well-meant policy change had fallen short on implementation and had not been properly evaluated: de-institutionalization of the mentally ill without follow up resources; early discharge of patients from hospital with inadequate home care support; and harm reduction programs where needle exchange is available but detox and counselling resources are scarce. “Given that mandatory reporting entails at least some limitations to patient/client autonomy,” she said, “it is incumbent on policy makers to make sure that real benefits materialize.”

Provincial officials forged ahead with enactment, despite admitting in the official report that “beneficial impacts (of the regulations) on the HIV epidemic, i.e. (preventing) spread of the disease, are not established.”

There has been little evidence, however, that objections raised by community groups are substantiated by studies. With so little evidence to support the proposed positive effects on the epidemic or to support opposing them, the Provincial Medical Health Officer’s Report “recommends...the impact of making HIV reportable should be the subject of an evaluation. If the net impact is determined to be a negative one (as measured against preset criteria), steps should be taken to remedy specific problems, or HIV should be taken off the list of reportable conditions.”

Such general recommendations, however, have no force in law, and few in community are confident the province will reconsider removal of HIV from the list of reportable diseases in the foreseeable future. ⊕



*Jeff Anderson is a board member of the BCPWA Society.*



# The art of nursing

*Award-winning ward 10C nurses set the gold standard*

*by Trena White*



**W**hen Meryl heard that St. Paul's Hospital planned to open an HIV ward, she wanted to work there; she felt empathy for AIDS patients and the stigma she saw attached to them throughout her early nursing career. Trudy decided she wanted to work in HIV/AIDS nursing after a ride-along she took in a health van in Vancouver's Downtown East Side while a nursing student at Kwantlen College. Andrew has always worked in the field, and he even snuck in some nursing on the side during his stint as executive director of AIDS Vancouver. Julie

was actively recruited into a nurse leader position for HIV/AIDS patients. Now she wouldn't want to work anywhere else.

These four nurses make up part of a multidisciplinary team of nurses, physicians, pharmacists, and social workers on ward 10C, a 21-bed HIV/AIDS unit at St. Paul's Hospital in downtown Vancouver. They all took different paths to the ward, but they all chose to work there and are passionate about their work. They show a fierce commitment to their patients' needs and find their work enormously gratifying.

Ward 10C is the largest inpatient HIV/AIDS ward in Canada. It was established in February 1997 after more than a decade of internal efforts to create a specialized unit that could adequately address the complex needs of HIV/AIDS patients.

Irene Goldstone is the director of Professional Education and Care Evaluation at the BC Centre for Excellence in HIV/AIDS, also based in St. Paul's Hospital. She came to the hospital in 1982 as director of nursing for the medical ward and witnessed the beginning of the AIDS epidemic. In 1985, Goldstone and her head nurse closely examined the work involved in caring for people with AIDS. Factoring in feeding patients, ambulating them, giving them medications, and changing bed linens, they determined that it took 9.5 hours of nursing care each day per patient.

At the time, most patients were admitted into the hospital towards the end of their illness, and were often completely debilitated by AIDS. It was clear that they needed an enormous amount of attention and that they had unique health care needs. St. Paul's Hospital created a rotating system among its medical wards, where each ward would take a turn being on call to accept HIV/AIDS patients.

"The idea was that the patients would be evenly distributed across the four teaching units, and the burden of care would be carried as equitably as we could manage," says Goldstone. However, it eventually became clear that HIV/AIDS patients would do better in a dedicated ward.

Ward 10C has quickly built a reputation for its high-quality care. On April 27 of this year, the 25 nurses on 10C won an AccolAIDS award for Service Delivery from the BCPWA Society.

### Patients with multiple health problems

But their work isn't easy. The ward generally deals with acute care patients with very low CD4 counts who are barely coping in the community. A patient might be admitted to the ward for wasting and then shortly thereafter be diagnosed with a multitude of other complex health concerns, such as pneumonia, gastroenteritis, and mycobacterium avium complex (MAC).

"None of our patients seems to come in with just one thing," says Julie Foreman, the ward's clinical nurse leader. "It all spirals and gets bigger and bigger and bigger."

The ward provides a range of healthcare services, from acute care to rehabilitation and palliative care. This complexity of health issues is one of the nurses' biggest challenges, but it also affords them the opportunity to learn about a variety of healthcare issues and to grow as nursing profes-

sionals. "It's very rewarding because it's scientific, blended with human compassion and caring," says Trudy Robertson, who joined the ward in February 2003. New research is constantly being integrated into the ward, which allows the nurses to stay up-to-date.

The 10C patients range in age from early 20s to 60s and come from all socioeconomic backgrounds. About one-half are gay men and one-half injection drug users (IDUs), although the ward is seeing a trend towards patients who formerly used injection drugs but still have addictions. These patients have been stigmatized for both their lifestyles and their infections.

### A foundation of respect

The ward is devoted to ensuring its patients receive the best care in an environment that legitimizes the patients' needs. The nurses reject the stigma that has been associated with HIV/AIDS for decades and are dedicated to ensuring their patients receive the respect and care they deserve and require. Their work takes on an advocacy role that isn't normally seen in nursing positions, making it a unique professional environment.

The 10C nurses serve as advocates when bridging gaps between patients and other care providers, helping to build relationships between them. Foreman cites the interactions of a patient and a speech therapist. "When he gets frustrated, he starts becoming vulnerable," she says. "Vulnerability is a bad thing on the streets, so he gets up and walks away." The therapist feels the patient is being uncooperative and may relinquish therapy, which in turn reinforces the patient's belief that he shouldn't have trusted the therapist in the first place.

The nurses believe the ward has a mistaken reputation at the hospital for being a challenging unit where the "bad patients" go. Often, casual nurses don't want to work there. However, if they do work there, they often note afterwards that the experience wasn't so bad, as if they had expected the ward to be wild and out of control.

"There's the sex and the evil and the homo and the junkie and the adulterer," Andrew Johnson says wryly.

The nurses on 10C try to eliminate those stigmas. Goldstone notes that back in the early days of the AIDS epidemic, the stigma assigned to AIDS patients (and the stigma ascribed to AIDS nurses) was very high. When she carpooled for weekend mountaineering trips, she would simply introduce herself to other people in the car as "an administrative nurse at St. Paul's" to avoid dealing with the inevitable response: "You work *there*?" People would move away from her when they learned she worked with AIDS patients.

**The nurses believe the ward has a mistaken reputation at the hospital for being a challenging unit where the "bad patients" go.**



**Their work isn't easy. The ward generally deals with acute care patients with very low CD4 counts who are barely coping in the community.**

Stigma still attaches itself to AIDS nurses, but it's no longer about fear of contagion. Now it's subtler. Neighbours or acquaintances have asked, "How do you work with *those* people?" suggesting that their patients are dirty or don't deserve nursing care.

### Breaking down barriers

However, it's *those* people the 10C nurses love to work with. There is a strong attachment on the unit between the patients and nurses. Meryl Aldcroft has worked as a licensed practical nurse (LPN) on the ward since 1998, the year after it opened. "Whether you're in the hospital or not, you still care what's going on with the patients," she says. "We'll phone each other to say, 'So-and-so is back on the ward, or so-and-so has died.'"

Many patients are standoffish or mistrustful during their first couple of admissions, but after a while, they begin to open up.

For example, many of the 10C patients won't just jump on a stretcher and head down for an X-ray when they need it. "They need to question you again as to why they need an X-ray. Then it's, 'I need a cigarette first. I need something for my pain first. I need to have something to eat first,'" Foreman says. "And what makes the 10C nurses special is they know

that dance, they know how to do it, and they know how to do it well. They are the art of nursing, but underneath that art they're doing all of those assessments at the same time."

These barriers don't exist in the same way for the non-using patients on the ward, but those patients can present their own challenges. The hospital sometimes receives letters from men who've re-entered the community saying how grateful they are for the ward and its nurses, but that they didn't feel safe because of the IDUs. The nurses take care to balance the diverse needs of their patients, to ensure everyone's comfort. As the ward's tips on caring for IDU patients says: "Management of these situations is a skill that develops with experience."

### Forming close bonds

Because the patients often stay on the ward for extended periods and re-enter the ward after being in the community, the nurses and patients get to know each other and build relationships. "Sometimes you're a big brother, sometimes you're a mother, and sometimes you're a Sunday school teacher," says Johnson.

These relationships are integral to the nurses' appreciation of their work, but they also make it difficult when the nurses lose patients. Foreman says one of the most challenging parts of her job is "learning when to let go of our patients, knowing when it is that we stop treating them aggressively and when to start palliating." The nurses hold memorial services every few months to honour and remember the patients they have lost. These services help them to grieve in an environment of continual loss.

Despite the losses and challenges, the work brings with it deep and inherent satisfaction. Says Johnson: "To see through the eyes of someone who's not trustful, who opens up and thanks you, who suddenly feels like they belong, that they have some value—that's a really profound thing."

The community cherishes these nurses because they understand their patients and provide devoted care without judgment. In turn, the nurses say that working on the ward has taught them tolerance, patience, humour, acceptance—and how to accept support themselves. ⊕



Trena White is a freelance writer living in Vancouver.



# One-stop shopping

*Spectrum Health offers more comprehensive care through population-based funding*

*by Dr. Robert Voigt*

**S**pectrum Health was launched in October 1999 after a year of planning. Founded by Drs. DeWet, Murphy, Voigt, Willoughby, and Woodfall, the clinic aims to provide comprehensive care for our clients, many of whom are gay and infected with HIV and AIDS. As a group, we noticed that care for our clients, especially HIV-positive patients, was spread over several venues. We had hoped to develop a clinic where medical care, pharmacy dispensing, nutritional advice, and social support could all happen in one location.

Although we had talked for many years of joining as a group, it did not become practical until the federal government started primary care reform. Funds were transferred from the federal to the provincial governments, and we were then given assistance in developing the infrastructure of the clinic. In establishing this clinic, we were required to convert our clinical records to an electronic format and to switch from fee-for-service billing to population-based funding.

## **Population-based funding**

Under a fee-for-service billing system, when a client enters an examination room and is greeted by the doctor, the doctor can send a bill to the Medical Services Plan (MSP) for providing a service. The fee is the same for any service in a general practitioner's office; there is no difference in the fee for



a 30-second visit and the fee for a 30-minute visit.

By contrast, with population-based funding, reimbursement is based on how complex the client is, not on how many visits are made. In this system, developed by Johns Hopkins

University, the level of complexity is based on the number of different illnesses a person has and how complex those illnesses are. Regardless of whether a person comes to the clinic once or a hundred times in a year, the clinic is paid a set amount for that client.

The physicians at Spectrum Health are not actually told how much they are reimbursed for any given client. Rather, lump sum payments are made for the care of all clients registered at the clinic. The down side of this arrangement is that if a client of the clinic goes to a GP outside the clinic, MSP does not pay for that service, Spectrum Health does. As a result, we encourage our clients to get all their health-care at the clinic.

## **The benefits of the system**

The major advantage of this system is that longer appointments can be booked to deal with clients' problems in a less rushed manner. Unlike many clinics, we do not have a "one problem-one visit" policy. Our clients are welcome to come with a list and deal with all their issues on one visit.

Under the fee-for-service system, MSP would not reimburse for services provided by anyone but a physician. In many instances, a physician is not only unnecessary, but is not even the best person to provide the service. Under population-based funding, nurses can perform tasks that they are trained to do and, in fact, perform them better than physicians. This is the most significant difference between the two systems.

People have tried to compare us to the Health Maintenance Organization (HMO) system in the US, but we are quite different. Under the HMO system, only treatments that are approved by the HMO can be provided and only under certain circumstances. Our clinic has no such constraints, and we can treat our clients as we see fit, without interference—except from PharmaCare.

### The healthcare team

Moving to a clinic situation from private offices posed challenges for both the staff and physicians and for patients. However, those patients who have embraced the system now feel a great sense of comfort knowing that if their own physician is not available, a team of nurses and physicians with expertise in HIV is ready to care for them.

Currently, the Spectrum Health staff includes two clinical nurse specialists. These nurses, who function at a very high level within the profession, perform triage, assess and treat minor medical problems, follow stable clients, and do most of the STD diagnosis and treatment, as well as travel medicine. In addition, they assist in the methadone program. If they assess a client who requires more medical intervention, the physicians are on hand to assist with those problems. In order to maximize continuity of care, the clinic has been organized into teams. Under this arrangement, the clients have the advantage of seeing one of a limited number

of healthcare providers, and they can develop relationships with the nurse and physicians in each team. We do not want to operate like a walk-in clinic. We believe it is important to have providers who know who you are and with whom you have a good relationship.

**With population-based funding, reimbursement is based on how complex the client is, not on how many visits are made.**

Our pharmacist has been seconded from the BC Centre for Excellence in HIV/AIDS. Her primary role is to counsel clients who are starting, changing, or having problems with antiretroviral medications. She also monitors people who are having difficulty with adherence and assists in making drug regimens more tolerable. She is available for consultation on difficulties with side effects and means of decreasing side effects. We had hoped that all of our clients would be able to pick up their HIV medications on site. However, space constraints have prevented that from occurring. A dietitian and, at times, a counsellor are available for consultation at the clinic.

We continue to grow and learn how to provide better service, and we are already looking at the possibility of expanding our space once again. We want to continue to evolve and improve the care and service we provide, and with the help of our clients, we will learn from our shortcomings and build on our strengths. ⊕

*Dr. Robert Voigt is a general practitioner at Spectrum Health in Vancouver.*



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# Let's talk about it!

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

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

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

CARL BOGNAR, PREVENTION COORDINATOR

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prevention@bcpwa.org FAX: 604.893.2251

**B**CPWA members Melody Escallier and Mark O'Hara, sent us an excerpt from a play they are writing called "Conversations with Faith". In this passage, they look at disclosure of HIV status in sexual situations. Watch for Melody and Mark among the cast of BCPWA's Theatre Positive production at the Vancouver Fringe Festival on September 4-14, 2003.

A Canadian court ruling has made clear thinking about disclosure more important than ever before. We will provide more information about the legal requirements to disclose in a future issue of *Living +*.

**Faith:** A complete stranger? I don't want to hear about it.

**Bill:** He was so good.

**F:** Did you tell him?

**B:** It was completely safe.

**F:** And what if the condom broke? It could happen.

**B:** Great! So now safe sex is not even safe at all.

**F:** It's so easy for gay men. You don't worry about disclosure.

**B:** Promiscuity is part of gay culture.

**F:** Get real, Bill! Who gave gays the corner on promiscuity? I just think people have a right to know.

**B:** Like I said, it was safe. If I get all caught up worrying about condoms breaking, well, let's just say I won't be having sex ever again.

**F:** I wish I could be more like you. What if I have sex without telling him and we want to see each other again? I couldn't do it because I didn't tell him the truth to begin with. They have a right to know!

**B:** I have safe sex with one man and don't disclose, and I no longer have a sense of morals?

**F:** Once?

**B:** Well, maybe three times. I've always been safe. At least I am trying to contain the stuff. Sometimes the need just consumes me.

**F:** Bill, I know you'd like a real relationship.

**B:** This isn't about having a relationship. Yes, I think I should tell people, but sometimes I just need sex. It's not like I'm screwing my way around the world.

**F:** Look Bill, I'm not judging you. In fact I wish I could do it too.

**B:** Well, it may help to lay off the paranoia about condoms breaking. Every time I've had sex, that voice was there in my head. "I have to tell him. I have to tell him." And I just can't.

**F:** What are you afraid of?

**B:** You already know the answer. I can tell everyone and never have physical contact again. How many people stick around once they know?

**F:** That's the problem. If we're too scared to talk about it, how can we expect other people to accept us? We're really not that much different. Maybe we should just tell the next guys we're attracted to and keep trying until we find the right ones.

**B:** Look, I don't I want to start every conversation with an ending. I'd like to know that we are actually going to start a relationship before I unleash my deep, dark secret. I'd like to know that a person is worthy of the information. Someone I can trust.

**F:** Are you saying that you can have sex with people who are not worthy of the information?

*[More conversation ensues about whether to disclose when having safe sex and before park sex.]*

**B:** You mean you would actually have sex without disclosure? You're so bold. Suddenly your morals just go out the window!

**F:** It's not about being bold. It's about being touched without the stigma hanging over my head. It's not all about sex you know! Maybe I'm just scared?

**B:** You're not alone. Like I say: there is always that little voice in my head, and most often the voice wins out. ⊕



# The lowdown on going down

*Research still indicates that oral sex is low risk*

*by Rob Gair*

The extent to which HIV is transmitted through unprotected oral sex is a matter of debate. On February 20, 2003, the BC Centre for Disease Control published a full-page warning in Xtra West about the risks of getting syphilis from oral sex. No one appears to dispute that syphilis and gonorrhea can be transmitted through oral sex, but a statement at the bottom of the page warning that “blow jobs can transmit HIV” generated some controversy. Some say the warning promotes awareness and discussion about the risk of HIV transmission via oral sex. Others are concerned it may cause unnecessary fear because it does not put the issue into context. Men who have sex with men (MSM) commonly engage in unprotected oral sex. As long as ejaculation does not occur in the mouth, the risk is generally perceived to be so low as to be negligible. The research examining this issue is a confusing mixture of epidemiological studies and case reports, all with varying methodologies, many with low numbers of study subjects.

## Options Project, San Francisco

At an opportunistic infections conference in early 2000, a group of researchers presented preliminary data from a San Francisco study showing that eight of 102 recently seroconverted men (7.8%) were classified as cases of “oral sex transmission.” These findings might be alarming if interpreted at face value, and certainly they caught the attention of the mainstream media and other researchers. However, often overlooked is that only one of the eight men was classified as a “probable” case because a partner corroborated his report of exclusive oral sex. The remain-

ing seven were classified as “possible” cases. One reported only oral sex, and four reported only protected anal intercourse, but no partner corroboration was available. Two reported only unprotected anal sex with a documented HIV-negative partner. It’s noteworthy that one of the men subsequently reported a single risk encounter that eliminated him from the oral risk category. This example demonstrates that oral sex transmission can be easily overestimated because other risk factors often are not initially revealed and standards for investigating cases of reported oral transmission are lacking. The authors concluded that “unprotected oral sex is lower risk than anal or vaginal sex, but still has a risk of HIV transmission.”

## Vanguard Project, Vancouver

In contrast, Vancouver researchers found no cases of HIV transmission attributable to oral sex. The Vanguard Project is a long-term study looking at sexual behaviours and their association with HIV seroconversion in a group of HIV-negative gay and bisexual men aged 18–30. The study started in May 1995 and participants were followed with an annual HIV test and questionnaire. By March 2000, over 850 men had entered the study and some had been followed for nearly five years, although it is not clear how many had been followed for how long. Of the 850 participants, 790 remained HIV-negative. Those who became HIV-positive reported only known high-risk behaviours such as unprotected anal sex or needle-sharing. None reported oral sex as a cause for their infection. Furthermore, approximately 90% of those who remained HIV-nega-

tive reported having engaged in receptive oral sex in the previous year without using a condom. Unfortunately, the oral sex data for this study has not been officially published.

### **Collaborative Seroincidence Study, USA**

In 1999, a US group published data from one of the few studies attempting to quantify per-contact risks for HIV infection. Over 1500 MSM were followed semi-annually for up to 18 months with questionnaires asking about sexual behaviours during the previous six months. The study analyzed six types of sexual contact, including oral sex. The authors estimate that the risk of contracting HIV from unprotected receptive oral sex is approximately 1 in 2500 contacts, much less than known high-risk activities, such as unprotected receptive anal intercourse with an HIV-positive partner (1 in 120 contacts). However, the accuracy of this type of data is hard to establish. Obviously, since these are per-contact risk numbers, the risk increases as the number of sexual contacts increase. Other studies confirm increased HIV infection rates in people with multiple partners.

**An ad in XTRA West warning that “blow jobs can transmit HIV” generated some controversy.**

### **Department of Health Review, UK**

The most comprehensive review of the literature on oral sex and HIV transmission to date was published by the United Kingdom Department of Health in June 2000. Experts reviewed evidence from almost 30 epidemiological studies, 13 independent case reports, 17 papers discussing female-to-female transmission, and more than 20 related papers. Of the more than 12,000 individuals studied in these various reports, 39 cases of HIV transmission through oral sex were identified. Of course, this finding cannot be interpreted to mean that only 39 of 12,000 got HIV from oral sex because the manner in which this information was retrieved differs significantly from study to study. As well, many flaws exist in the collection of this type of data. Acknowledging that some cases may result from reluctance or embarrassment to report other high-risk behaviours, the authors consider reluctance to report unlikely to be a factor in all reports. Further, they suggest more cases than have been published in the literature are likely. Still, it would appear from this review that the incidence of HIV transmission through oral sex is very low. The entire report can be viewed at <[www.doh.gov.uk/eaga/oralsexdocfin.pdf](http://www.doh.gov.uk/eaga/oralsexdocfin.pdf)>

### **Health Canada Review**

After reviewing over 20 case reports, epidemiological studies, and other related papers, Health Canada, in its own review of the literature, concludes that oral sex is a lower risk activity than unprotected anal or vaginal intercourse and that unprotected

receptive fellatio with ejaculation is a potential risk factor for HIV transmission. This report also acknowledges the difficulty in assessing risk because patients “may under-report higher-risk activities”. The report can be viewed <[www.hc-sc.gc.ca/pphb-dgspsp/publicat/epiu-aepi/hiv-vih/oral\\_e.html](http://www.hc-sc.gc.ca/pphb-dgspsp/publicat/epiu-aepi/hiv-vih/oral_e.html)>.

### **Centre for AIDS Prevention Studies, San Francisco**

Recently published data from the US confirms low risk in a group of MSM who practice oral sex exclusively. Clients were required to give a six-month history of sexual practices before knowing the results of their HIV tests. Getting the history before the client knows his HIV status may increase validity by reducing the number of clients who may be embarrassed to report riskier activities following an HIV-positive diagnosis. Of more than 10,000 clients who sought HIV testing in a two-year period, 239 men were eligible for the study and able to participate. No HIV infections were detected in this group of men, thus the estimated probability of orally acquiring HIV was zero in this study. Obvious limitations to this study are the relatively small numbers of people and the short period over which sexual behaviours were examined. Also, very few individuals in the general population practice oral sex exclusively, so this zero-risk data cannot be applied to the general MSM population.

### **Conclusion**

Evidence suggesting that HIV can be acquired through oral sex has accumulated from case reports and population-based studies. Most claims come from people who deny other risk activities. There appears to be agreement that the risk is low and recent evidence confirms low risk. Just how low is difficult to quantify because the only way to conduct a meaningful assessment is to study large numbers of people who practice oral sex exclusively over a long period of time. This kind of study would be virtually impossible to execute from a cost and logistics perspective, not to mention the difficulty of finding sufficient numbers of individuals who practice oral sex exclusively. On the bright side, that large numbers of individuals are required to produce enough cases for a worthwhile analysis confirms a low risk.

Despite a lack of optimal data, a few things are clear. The risk of acquiring HIV through oral sex is very low, but it is not likely to be zero and may increase under certain conditions. Receptive partners who have mouth or throat infections and who are exposed to ejaculate may be at increased risk for acquiring HIV. By far, the majority of people get HIV through higher-risk activities such as unprotected anal or vaginal intercourse and needle-sharing. ⊕



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



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

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

# Denial in the west

*by Ron Rosenes*

Just when you thought it was safe to take off your SARS mask, along comes West Nile (WN), yet another virus that pays no heed to increased security at the border. People with HIV are no strangers to the global jet-setting habits of the latest crop of viruses, whether they arrive by plane or on the wings of a pesky mosquito. Just how much do we have to fear as West Nile makes its way north and west across the continent to British Columbia where human infections are expected to show up for the first time this summer?

**Do not listen to the media.  
Breathe deeply and read this  
article instead.**

Writing from Toronto, my first suggestion is that you learn the big lesson of SARS: do *not* listen to the media. You're bound to overreact to the level of fear generated to get your attention. Breathe deeply and read this article instead.

Studies show that of one million people who live in an endemic area—that is, an area where WN is found—20,000 will be exposed to the virus. Eighty percent, or 16,000, will show no symptoms. Some 4,000 may have flu-like illness with fever, headache, and possibly a rash or swollen lymph nodes, from which they will recover.

Now here's the bad part: of the initial million people, perhaps 130 will develop encephalitis (brain swelling) or meningitis (inflammation of the brain or spinal cord lining). Symptoms in these cases may include high fever, severe headache, stiff neck, nausea, confusion, profound fatigue, muscle weakness, and even loss of consciousness and paralysis. The rate of mortality is about 10 percent, which brings us to the unlucky number 13.

Is it more unlucky if you are HIV-positive or living with AIDS? A recent study presented at the Conference on Retroviruses and Opportunistic Infections in Boston suggests that PWAs fare about as well as the general population. Lest you think this is really good news, researchers reported on only two patients with HIV and WN. In the words of Dr. Carlos del Rio of Atlanta, "One fared well, while the other died." The patients had similar viral loads and CD4 counts. They were tested for WN by ELISA, the type of test used to detect antibodies to the virus, not the virus itself. The patient who died had a history of tuberculous meningitis, which had weakened his immune system considerably. Little is known about disease progression in people with HIV/WN co-infection (that pesky co-infection word!), but it seems that a low CD4 count and living to be older than 50 can lead to a rougher ride with West Nile. Big surprise.

*continued on next page*

We don't know much about HIV-positive children and WN, but evidence suggests that in the general population, the risk for developing serious forms of the disease is small. It appears to be worse for adults than children. It's not that kids never come down with WN, but that they hardly ever do. Of the 201 people who died in the US last year, none was younger than 24.

In terms of blood supply, in the US, where WN has been around longer, the Centers for Disease Control believe the "benefit of getting blood or organs far outweighs any potential risk of getting WN virus transmission from blood or organs." Still, the memory of HIV in the blood supply haunts us all, and there has been a case of WN transmitted through an organ transplant. While HIV and hepatitis can remain in the bloodstream for life, WN virus appears to last only a few weeks.

It is not surprising that folks are searching for the best way to repel the *Culex pipiens* mosquito that is "patient zero" in the chain of infection. This is the female of the common northern house mosquito, one of eighty species in Canada that pick up the WN virus from birds and spread it to another ten species that spread it to us. The virus buck stops here: it cannot be spread from one person to another—or back to a mosquito, or other animals for that matter.

(Mosquitoes cannot spread HIV. First, mosquito stingers are composed of two tiny "straws," one that spits anti-clotting saliva to thin your blood and another that is used to sip your blood. Second, HIV might be able to get into the mosquito, but it cannot replicate and get out. For that, it needs human CD4 cells. By contrast, West Nile infects the gut cells in the mosquito and replicates like crazy. It then gets into the saliva and that gets into you when you are bitten.)

By now, you have no doubt read umpteen articles on removing standing water from around your home, wearing long pants and sleeves, and avoiding the outdoors at dawn and dusk. But you're still not sure about repellents. In a word: DEET. DEET (chemical name: N,N-diethyl-meta-toluamide) is the chemical ingredient in the most commonly used sprays and oils with

names like Off! and Muskol. A study published last year in the *New England Journal of Medicine* compared the efficacy of various insect repellents using the old arm-in-cage technique and showed that DEET-based products provided complete protection for the longest duration. A typical product with around 25% DEET has a mean protection time of 301.5 minutes.

The less DEET in the product, the shorter the duration, so check the label. As for the botanical repellents tested, they only provided protection for a mean duration of less than 20 minutes. So it's buyer beware with Skin-So-Soft and other products containing citronella. They work, but must be reapplied frequently. Also debunked are Vicks VapoRub, garlic, vitamin B1, fabric softener sheets, catnip oil—which could be fun for cat lovers—and wrist bracelets that are either scented or emit vibrations to make the "skitters" think you're a dragonfly.

If you or your children eat a lot of bananas, you may want to rethink that. There are wise grandmothers who say the oil of the banana is an attractor.

If DEET makes you nervous or if you have concerns about using it on children, you may want to consider a product recently launched called Off! Botanicals that contains an ingredient based on the lemon eucalyptus plant. The manufacturer claims it will provide protection from mosquitoes for up to two hours. For precautions on using DEET, especially with children, and to learn more about West Nile, you can visit several government websites: Ontario Ministry of Health <[www.health.gov.on.ca/index.html](http://www.health.gov.on.ca/index.html)>; Health Canada <[www.hc-sc.gc.ca/pphb-dgsp/wnv-vwn/](http://www.hc-sc.gc.ca/pphb-dgsp/wnv-vwn/)>; and Centers for Disease Control and Prevention <[www.cdc.gov/ncidod/dvbid/westnile/](http://www.cdc.gov/ncidod/dvbid/westnile/)>.

No matter how you look at it, West Nile brings a whole new meaning to playing safe this summer, so get smart and get outside. ☺



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

# Electroacupuncture and peripheral neuropathy



by Zoran Stjepanovic

In the March/April 2003 issue of *Living +*, I reviewed a chapter on homeopathy from *AIDS and Complementary & Alternative Medicine: Current Science and Practice*. In this issue, I'll review the chapter on electroacupuncture.

Writers Mary Lou Galantino and Sunday Eke-Okoro discuss neuromuscular manifestations of HIV and the use of electroacupuncture to treat peripheral neuropathy. Peripheral neuropathy results from injury to the peripheral nerves. HIV can cause nerve damage, and certain HIV medications can cause damage to the peripheral nerves—an unwelcome side effect. When peripheral neuropathy first develops, people often report a tingling or prickling in the toes and sometimes in the fingers. Over time, the tingling gradually spreads up the feet or hands and can result in pain. People who have severe peripheral neuropathy may experience extreme pain, which, of course, affects their quality of life.

Aspirin and acetaminophen are commonly used to treat mild to moderate HIV-related neuropathic pain. For more persistent and severe pain, codeine and oxycodone may be used. Alternative and complementary approaches to treat peripheral neuropathy, such as acupuncture, are also available. Based on Traditional Chinese Medicine, acupuncture involves inserting needles at specific points of the body, which encourages the production of endorphins to reduce pain.

With electroacupuncture, tiny electrical currents are used instead of needles. Using these electrodes is not as invasive as having needles inserted in your body. In a small trial conducted by the authors, non-invasive electrodes were placed at specific acupuncture points on the body parts for 20 minutes per day for 30 days. The study was designed for home stimulation, so the participants applied the electrodes themselves. Individuals in this study were assessed both before and after electroacupuncture with a medical outcomes study (MOS), a

30-item questionnaire measuring quality of life. The participants reported that their pain levels were reduced after using the electrodes. The researchers therefore argue that the use of electroacupuncture may have caused a release of the body's own endorphins and enkephalins, which inhibit either pain or pain transmission.

The use of electroacupuncture as a treatment appears to have some benefits. It is non-invasive, and individuals can apply it in the comfort of their own home. The evidence from this trial appears to show that electroacupuncture may be able to alleviate some of the pain associated with peripheral neuropathy.

However, this small trial sample had only seven participants. Many unanswered questions remain. Were the participants taking medications for their peripheral neuropathy during electroacupuncture therapy? Have these participants had acupuncture before (with needles) or was this their first experience with acupuncture? How did the researchers know whether the participants were applying the electrodes correctly if the participants were doing it themselves at home? At what point did participants feel that their pain was subsiding? What kinds of questions about quality of life were asked before and after taking this therapy?

This chapter lacks the detailed information required to make an informed decision about the possible benefits of electroacupuncture. Although the authors did present an interesting approach to treating peripheral neuropathy, further investigation is needed. The sample size was, after all, too small to provide definitive answers. ⊕



Zoran Stjepanovic is the treatment information coordinator for the BCPWA Society.

# A guessing game

*Women need devoted HIV research*

*by Kath Webster*

**W**orldwide, the majority of people infected with HIV are women. In Canada, women represent an increasing proportion of reported HIV cases. They accounted for 26% of new positive HIV test reports in the first half of 2002, compared to just below 10% a decade ago. For young women, the situation is worse. In 2001, women accounted for nearly 45% of positive HIV tests among those aged 15–29 years old. In many developing countries, these numbers are even higher.

These increases point to the need for women-specific research and treatment. As a woman with HIV, I am constantly on the lookout for treatment information focusing on women. It's not easy to find. I attended the International AIDS Conference in Barcelona last year, and I was appalled each time I discovered that women typically made up only about 10% of clinical trial participants. Why are women not participating in



trials? Contributing factors may include lack of childcare that enables participation in clinical research and lack of awareness among women of enrolling trials.

The key treatment issue for women has remained the same since the advent of HIV drugs, according to Louise Binder. “We are so under- and unrepresented in the clinical trials that it’s hard to feel any sense of security that the results are truly applicable to us.” She adds that women take drugs that are deemed safe, potent, and durable for men without knowing what they might experience. “As a result, we are probably receiving higher doses of the drugs than we need, creating serious side effects and toxicities,” says Binder, who is chair of the Canadian Treatment Action Council and chair of Voices of Positive Women. “This, in turn, can lead to adherence problems and treatment failure.”

## Current research on women's treatment

Few current studies of large cohorts in North America focus on women. The Canadian Women's HIV Study (CWHS) has been following the health and symptoms of HIV infection in 743 women since 1993. It is the only cohort devoted to HIV-positive women.

The Vancouver Oak Tree Clinic, the women and family HIV centre for BC, is conducting several smaller treatment-related studies, including one that is currently enrolling that looks at the impact of antiretroviral (ARV) therapy on bone density. One upcoming study will focus on the safety and toxicity of ARV therapy use during pregnancy. Another will look at gender differences in body fat redistribution, hyperlipidemia, and impaired glucose tolerance associated with protease inhibitors.

Two significant American cohort studies are the Women's Interagency HIV Study (WIHS) and the HIV Epidemiological Research Study (HERS). The WIHS is a multi-site observational study of the clinical, laboratory, and psychological aspects of HIV infection in women. Its cohort includes 2,641 women both HIV-positive and negative. The HERS has an epidemiological focus and operates in tandem with WIHS.

## Opportunistic infections and co-infections

According to the Canadian Women's HIV Study (CWHS), the prevalence of opportunistic infections has declined dramatically from 31% in 1993 to 2.1% in 2002. Throughout the study, the most common opportunistic infection diagnosed in women has been *Pneumocystis carinii* pneumonia (PCP), followed by wasting syndrome and esophageal candidiasis. No woman in this study has died from cervical cancer.

A study of hepatitis C (HCV) co-infection showed that of 296 HIV-positive women from the CWHS cohort, 39% of them tested positive for HCV. These women were more likely to have a history of injection drug use and to be aboriginal. The co-infected women also appeared to be more immune-compromised, with nearly 24% of them having fewer than 200 CD4 cells. Despite their poorer health, these women were less likely to be on antiretroviral therapy. This lack of treatment may be related to the marginalization of this population or, perhaps, to difficulties tolerating ARVs because of the effect of HCV on the liver.

The effect of highly active antiretroviral therapy (HAART) on cervical dysplasia (abnormal cell growth on cervix) in HIV-positive women was studied in the CWHS cohort. Of 643 women, 20% had a type of dysplasia. HAART was associated with improvement of the dysplasia despite co-existing immune suppression (that is, a CD4 count less than 500).

In a US study involving 2,133 HIV-positive and negative women from the WIHS cohort, researchers tracked the incidence of invasive cervical cancer over a seven-year period. They concluded that the cervical cancer rate in HIV-positive women was not significantly greater than that among at-risk HIV-negative women.

## Side effects of antiretrovirals

Denise Becker, a board member with the BCPWA Society, has noticed that many of the HIV-positive women she knows who are doing well are experiencing more side effects from their HIV medications. "I believe that unless side effects are studied, particularly new studies of women who may have different side effects than men, we will see more women succumbing to the disease," she says. "While we recently reached a plateau of AIDS-related deaths in the Northern Hemisphere, I believe we will see a rise in mortalities as tolerance to medications is reduced, the virus mutates, and resistance develops."

Several recent studies have been conducted on adverse events or side effects of ARVs. In one study with 1,408 participants from the HIV Ontario Observational Database (of whom only 11% are women), men and women on protease inhibitors had similar rates of lipodystrophy symptoms (central fat gain, peripheral fat loss, and metabolic changes). One exception was that men on saquinavir tend to have more metabolic changes than women who are on the same drug. Fat distribution changes were also studied within the WIHS cohort over an 18-month period. The study compared HIV-positive and negative women. The incidence of both peripheral fat loss and central fat gain were double that of HIV-negative women.

**"We are probably receiving higher doses of the drugs than we need, creating serious side effects and toxicities," says Louise Binder.**

An ongoing study at Oak Tree Clinic is investigating the relationship between antiretroviral therapy and bone density in women. Assessment is complete in 83 women, and, so far, 40% of these women had abnormal bone density according to DEXA scans. Also, 43% of them had low levels of calcium. Preliminary results show the importance of assessment and treatment for osteopenia and osteoporosis in women on antiretrovirals.

In terms of neurological complications, a controlled US study tested for peripheral neuropathy, AIDS dementia, and neuropsychological problems in 48 HIV-positive women, 48 HIV-negative women, and 52 HIV-positive men. The results indicated that there was no gender difference in progression of HIV-related neurological disease.

Protease inhibitor use and the incidence of diabetes were studied in the WIHS cohort. The participants included 1,785 non-pregnant women both HIV-positive and HIV-negative. Protease inhibitor use was associated with a three percent increase in the risk of developing diabetes. Routine screening is necessary, especially for older and heavier patients.

*continued on next page*

## Therapeutic drug monitoring

Therapeutic drug monitoring (TDM) is a relatively new tool that measures drug levels in a person's body. It determines the peaks and troughs over the course of a day. This information could be especially useful to women who are usually prescribed the same drug doses as men despite weighing much less. It may prevent side effects, if drug levels are too high, or resistance, if drug levels are too low.

## At the International AIDS Conference in Barcelona, women typically made up only about 10% of clinical trial participants.

A study from the Netherlands of 100 women and 268 men showed that women tend to have much higher levels of nevirapine and efavirenz than men do. Although these data need to be confirmed with controlled studies, they may explain why women tend to have more severe rash and liver toxicity than men when on nevirapine. The clinical relevance of TDM has not yet been confirmed. People on ARV therapy who are interested in TDM should speak with their doctors.

In BC, TDM is currently only available through research protocols at St. Paul's Hospital in Vancouver.

## Nutritional issues

Treatment decisions also have a powerful impact on nutrition issues. The current practice to delay antiretroviral therapy until much later in the course of HIV disease means that health and immune function must be supported by nutrition and lifestyle. "In the last few years, there has been a tendency to rely more on potent drug treatment to maintain a strong immune system, and less attention has been given to nutrition," says Diana Johansen, dietitian at Oak Tree Clinic. "Now, there needs to be more emphasis put back on nutritional interventions and, hopefully, a resurgence of nutrition research."

Johansen adds that the other important nutrition issues have to do with toxicity of the antiretrovirals. Metabolic complications, body composition changes and fat redistribution, and gastrointestinal complications such as diarrhea all require nutrition therapy to improve symptoms and decrease long-term health risks.

## Women in the Downtown Eastside

HIV-positive women in Vancouver's Downtown Eastside (DTES) face additional treatment issues. Addiction has such control over some women's lives that taking care of health is not always a priority, according to Liz James and Yasmin Winsor, both registered nurses with the Street Nurse Program. They note that women may need to work the streets or deal drugs to provide for their habit and

often for their partner's habit too. Inadequate and unsafe housing, partners, pimps, dealer violence, extreme poverty, mental health, and abuse all pose further barriers to accessing healthcare.

James and Winsor add that the current healthcare system does not address the service needs of HIV-positive women in the DTES, and they voice a need for safe and accessible women-centered healthcare located directly in the community. Women in the DTES may feel distrustful or fearful of mainstream services. They may feel unsafe and be on the run from police, dealers, or abusive partners. They may feel that they have disappointed their healthcare provider. Keeping appointments or waiting for long times in drop-in style clinics is often difficult. Some women who need methadone services are not necessarily receiving comprehensive healthcare.

However, some positive steps are being taken. Several physicians advocate on behalf of women and provide excellent care; one even provides home visits to women who are especially marginalized and hard to reach. The Downtown Community Health Clinic runs a well-attended women-only evening once a week.

## Looking for statistical significance

To answer all the questions raised by men-centred trials, Binder insists that we ultimately need drug research that includes statistically significant numbers of women. When should women start ARVs? What potential side effects do women experience, and how can we manage them? What is the relationship between HIV medications and women's monthly and life cycles? What are the potential drug interactions between ARVs and female contraception and hormone replacement therapy?

Binder also feels that women need a unique treatment information strategy geared to their distinct needs. "Some women are leading lives in which they rarely put themselves first, and they don't have the time and energy to sift through treatment information."

Other women's treatment issues also deserve attention and require discussion. Prevention strategies, sexually transmitted infections, cardiac events, menopause, and hormone replacement therapy are a few. More focus on addiction issues, including methadone use and access to treatment, is also critical.

Women are gradually getting more attention in the HIV research world. If issues surrounding access to clinical trials for women are addressed, the number of women enrolling in trials will inevitably increase. We will continue to expand our knowledge about the unique needs of women within the context of this virus and find more effective and innovative treatment methods for women.⊕



Kath Webster is a treatment information counsellor at the BCPWA Society.

# Switch glitch

*The adverse effects of HAART can be different for transgender persons on hormone replacement therapy*

*by Glenda Meneilly*

**H**ormone replacement therapy (HRT) is an important part of the transition process for transgender persons. Estrogens and progesterone produce feminine physical attributes, and the androgen testosterone produces male characteristics. Anti-androgens block testosterone effects. Many different hormone products and regimens have been used, with none being superior.

HRT results in both desired and undesired effects. The desired effects of estrogen and anti-androgens given to male-to-female (MTF) transsexuals are increased breast growth, redistribution of fat around the hips, softer skin, and decreased body hair, muscle strength, and testicle size. Unwanted effects include depression, diabetes, and abnormal liver function, especially in those with hepatitis C. Estrogen increases the risk of blood clots in the legs or lungs, especially over age 40.

## **Abnormal accumulation or loss of body fat, a long-term side effect of HAART, could compromise desired body shape changes.**

The desired effects of testosterone for female-to-male (FTM) transsexuals include voice deepening, decreased breast size, weight gain, decreased hip fat, increased facial and body hair, and increased muscle strength. Unwanted effects include acne, increased blood cholesterol, and abnormal liver function.

The risk of HIV infection is high in transgender people because of marginalization, drug use, or sex trade work. In countries where HRT or needles are not readily available, transgender people face the added risk from sharing needles used for intramuscular injection of black market hormones. Although no studies have compared response to HRT in HIV-positive and negative persons, there is no reason to expect that effects would differ. Similarly, no evidence is yet available to show that HRT administration alters the course of HIV infec-



tion. However, there are some potential differences in adverse effects to highly active antiretroviral therapy (HAART) in transgender persons on HRT.

All non-nucleoside reverse transcriptase inhibitors (NNRTIs) and protease inhibitors (PIs), especially nevirapine and ritonavir, have been shown to cause abnormal liver function, particularly with hepatitis C. Both estrogen and testosterone can cause liver toxicity, so close monitoring of liver function is important.

Long-term side effects of HAART include abnormal accumulation or loss of body fat (increased abdominal fat and breast size, and loss of fat in limbs, face, or buttocks). Such effects could complement or compromise desired body shape changes with HRT.

Another long-term side effect of HAART is an increase in cholesterol, triglycerides, and blood sugar levels, increasing the risk of heart disease. This problem occurs more often in men on HAART, as testosterone also increases cholesterol and triglyceride levels. Estrogens and anti-androgens administered in MTFs have favourable effects, decreasing LDL (bad) and total cholesterol and increasing HDL (good) cholesterol.

FTMs receiving testosterone also have increased cholesterol and triglyceride levels. FTMs on HRT and HAART should try to reduce other risk factors for heart disease by exercising, stopping smoking, and reducing weight, fat intake, and blood pressure. Some may require lipid-lowering drugs. (Avoid lovastatin or simvastatin when taking PIs.)

Some HIV patients treated with HAART have decreased bone density, which could lead to osteoporosis or fractures. Transsexuals treated with HRT do not have an increased risk of osteoporosis because both estrogen (MTF) and testosterone (FTM) increase bone density. It is not known whether this effect will prevent or improve HAART-related decreases in bone density.

Some PIs and NNRTIs have been shown to decrease estrogen levels, possibly resulting in failure of oral contraceptives. Theoretically, they could reduce the effectiveness of estrogens, although it is unlikely because the dose of estrogen used in MTFs is 2–5 times higher than that in oral contraceptives. Another drug that can decrease estrogen levels is rifampin, which is used in HIV to treat MAC and tuberculosis. No studies have examined either of these in the context of hormone replacement therapy. ⊕

*Glenda Meneilly is a clinical pharmacy specialist at the Oak Tree Clinic in Vancouver.*

# The painful truth

*There's a different standard of pain management for HIV-positive women in prisons*

*by Anne Marie DiCenso*



**W**omen living with HIV/AIDS often experience pain related to their disease. This pain can vary from uncomfortable to debilitating and from sporadic to chronic. For many, whether they are drug users or not, such pain is an unfortunate yet routine part of their daily lives.

Women cope with HIV-related pain in different ways. Some manage pain effectively by using relaxation, meditation, massage, diet, exercise, or alternative medicines. For others, pain management is best accomplished using medication, possibly—but not necessarily—in combination with one or more complementary therapies. Few medical professionals, social workers, or AIDS counsellors would take issue with this approach. For most PWAs, using prescribed pain management medication is seen as a reasonable and necessary option for coping with HIV-related pain.

The issue becomes clouded if the HIV-positive woman is a drug user or in prison or both. These circumstances often change medical and social service providers' perceptions of a woman's pain and the options they may make available to her for pain relief. Unfortunately, the specific needs of HIV-positive women who are drug users have generally been ignored by health and social service providers. This vacuum in knowledge has led to prejudice and stereotyping that has overwhelmed the principle of equality of access to healthcare in Canada.

Women prisoners are labelled as bad girls, bad mothers, untrustworthy, and uncaring. They are considered failures in a much harsher way than men are. They are not seen for who they really are; their real life situations are not taken into account. A

woman prisoner's role in her own healthcare may be suspect on the grounds that she doesn't seem to care enough about it to stop using drugs. This reasoning automatically brings healthcare providers to the conclusion that if a woman prisoner cares about her health now, it must be a ruse to get more drugs.

## The challenges of accessing pain medication

For many women drug users—whether or not they are incarcerated—access to prescription pain management is reduced or eliminated. Medical professionals are often reluctant to prescribe narcotics to these women because they fear that they are more likely to become addicted to pain medication, or they assume the patient is fabricating or exaggerating her pain in an attempt to secure drugs to get high.

These judgments are often unfounded. People who use drugs are not necessarily addicted to them. It is, therefore, incorrect to conclude that they are more prone to dependency on prescription pain management medications than people who do not use drugs. In fact, a person with a history of street drug use who has not developed a dependency may be less likely to become addicted to prescription narcotics than a non-user with no drug-using history to evaluate.

Besides, drug users who are dependent or addicted generally stick to a particular drug of choice. That they are seeking prescription pain management medication from a physician could be an indication that the street drugs they are using are not fulfilling this role (perhaps because the individual has developed a tolerance to the drugs).



Whatever the case, the important issue is not to overlook or dismiss the HIV-positive woman's genuine need for pain relief because she is using street drugs. That would be discrimination.

Imprisonment compounds the issue. An incarcerated HIV-positive drug user's access to her street drug of choice may be reduced, sporadic, or eliminated completely, depending upon the availability of street drugs in the prison. This problem often creates a dual-pain issue. Not only may the woman be facing the pain of withdrawal, she also may be experiencing new HIV-related pain that the street drugs were effectively masking. However, prison doctors will often question the legitimacy of specific requests for pain medication because the woman had not previously visited a doctor seeking pain relief. Prison is sometimes the first time many women living with HIV/AIDS seek medical treatment for HIV-related pain.

### **The perception of drug-seeking behaviour**

Assuming that the user wants medications solely to get high discounts the possibility that the person may have many other medical issues besides drug use. It is unfair to assume that the only reason a drug user does anything is to get drugs.

The perception of drug-seeking behaviour is a significant barrier confronting women prisoners with HIV/AIDS and a difficult prejudice for many medical and social service professionals to overcome. In the face of constant and persistent pain—whatever its cause—it is natural that a person will try to find avenues for pain relief. In prison, women PWAs often do not have the option of even attempting many of the non-narcotic options for pain relief. Such therapies as alternative medicines, massage, stress reduction, and relaxation exercises are generally out of the question, either because prisoners are denied access to private, quiet space or they have no means of accessing help to learn such tools.

Doctors who treat women going through withdrawal, an often debilitating condition that leads to irritation and extreme stress, do not see the need to prescribe pain medications because they feel this withdrawal phase will pass. It is difficult for most of us to be compassionate toward drug users because of our tendency to judge. Even the most empathetic person may feel that drug users need to solve their own problems.

Withdrawal is a very painful process and can be quite difficult for HIV-positive people because of the expulsion of vitamins and minerals that can occur during that time. Our response needs to be based on health management rather than moralistic grounds. This can be difficult for many healthcare providers because their aim is to get people off street drugs, even if that is not the choice of the drug user.

It seems counterproductive to take away one method of coping by denying a woman drug user access to pain management based solely on our need to stop drug use. Pain medication is provided in a monitored setting and must be taken in front of healthcare professionals in prison settings.

### **Fear of disclosure**

On the street as well as in prison, drug users have few reasons to trust healthcare practitioners. When a woman is working the street or using drugs, she is engaged in illegal activity that separates her from the mainstream community. This makes it difficult for her to speak honestly with healthcare practitioners about the amount of drugs she is using, when, and why. She is at risk of having her children taken from her, being judged, and being sent to jail. These risks may be too high a price to pay to deal with medical needs, and she may choose not to seek medical treatment.

### **The perception of drug-seeking behaviour among women prisoners with HIV is a difficult prejudice for many medical and social service professionals to overcome.**

When a woman drug user is in prison, it may be the first time in months or years that she has seen a doctor about her HIV concerns. However, confidentiality is difficult to maintain in jail. Disclosure of drug use, like disclosure of HIV status, can stigmatize a woman, and she may be monitored constantly for signs of using. In federal prisons, she may be mandated to provide urinalyses. Visits with children and family members could be cut and the possibility for parole reduced substantially.

When disclosing HIV status, women worry that all of the women on their range will find out and that correctional staff and even family members may be told. When in jail, fear of isolation, abandonment, judgment, and even violence become more of a concern because the women have nowhere to run and nowhere to hide.

So, then, how does a woman access pain medication in prison when she is HIV-positive and a drug user? Faced with prejudice, suspected of trying to scam drugs from the health unit, and threatened with either intolerable pain or denial of privileges, she is in a no-win situation.

The problem can only be addressed through education. Acceptance of HIV-positive drug users and a willingness to listen to their concerns is the key to building trust and coming up with a treatment plan that is acceptable to both the healthcare provider and the woman. We strive to achieve this balance out in the community; we strive to do this when we see anyone in pain. Why does this goal seem insurmountable when the woman happens to be incarcerated? Is it our prejudice that gets in our way? Perhaps we need to ask ourselves: whose needs are we trying to address—our clients' or our own? ⊕

*Anne Marie DiCenso is the executive director of Prisoners' HIV/AIDS Support Action Network.*



# Sneezin' season

*The joys of summer allergies*

*by Lawrence C.*

**A**llergy season has arrived. Let the wheezing, coughing, and sneezing begin! It's the time of year when flowers are blooming and trees are blossoming. Sometimes it's difficult to see their beauty and smell their fragrance because of dry itchy eyes and runny noses. Although we often associate allergies with spring and summer, you can develop them year round.

An allergy is an abnormal reaction to ordinarily harmless substances called allergens. They may be inhaled, swallowed, or come into contact with the skin. When this happens, your body alerts white blood cells to produce antibodies, which trigger the release of potent chemicals such as histamine, causing typical allergic symptoms. Some common allergens are pollen, mold spores, dust mites, animal dander, feathers, foods, medications, and insect stings.

**Antihistamines may be used to relieve symptoms, but take care that they don't interact with your HIV medication.**

Allergy symptoms can be mild, moderate, or severe. Mild reactions include sneezing, a constant runny nose, and watery, itchy eyes. Moderate reactions may include symptoms that spread to other parts of the body and cause itchiness or difficulty breathing. A severe reaction (anaphylaxis) is a rare, life-threatening emergency in which the body's response to the allergen is sudden and affects the whole body. In order to prevent allergic reactions, allergy injections can be given to help your body gradually build up immunity to allergens. Allergy shots are tailored to meet individual needs and, generally speaking, they are safe for PWAs. Antihistamines may be used to relieve symptoms, but care must be taken to ensure they do not interact with your HIV medication.

Sinusitis, which is common among people with HIV, is usually a result of bacterial or viral infections. Symptoms include nasal congestion, coloured discharge, pain, headache, and fever.

A proper diagnosis of sinusitis from your doctor is necessary to obtain optimal treatment for this infection. Treatment may consist of antibiotics, decongestants, or intranasal steroids. To help promote drainage and reduce inflammation, it may be helpful to provide hydration to the nasal cavity with steam or a cool mist humidifier.

Medications are clearly beneficial. However, some medications may cause adverse physical effects for some people. Only 5 to 10% of these adverse reactions are allergic, which means your immune system overreacts to the drug.

Only a small percentage of people exposed to a drug will develop a true allergic reaction. Drugs that commonly induce allergic reactions include penicillin and sulfa antibiotics (such as Septra), allopurinol (prescribed for gout), anti-seizure drugs, and anti-arrhythmia (heart) medications. When an allergic reaction occurs, your body releases large amounts of histamine and other chemicals in response to the drug.

The most common allergic reaction to a drug is hives, which occurs a few days to two weeks after treatment. However, in rare cases, a severe reaction called anaphylaxis may occur. If it does, watch for any of the following symptoms alone or in combination after you take a drug: a sense of warmth, flushing, itching, hives, swelling in the throat, asthma or wheezing, light-headedness from low blood pressure, irregular heart rhythm, nausea or vomiting, abdominal cramping, or shock. These symptoms require emergency attention.

Non-allergic reactions to medications have various causes that do not affect the immune system. Sometimes a lower dose of medication will relieve symptoms.

Spring and summer are the worst times for allergies to surface, whatever their causes may be. However, with testing, treatment, and precautions, there is no reason to stay inside. Take plenty of tissues and get outside to enjoy the sunshine. ☺

*Lawrence C. is a member of the BCPWA Society.*



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# Sink your teeth into oral health

*The importance of professional dental care*

*by the North Island AIDS Society*

**O**ral lesions are common in people with HIV infection. In fact, oral lesions may be the first indicator of HIV infection and lead to its diagnosis. Proper dental care is essential for treating and managing oral pain and infections. However, inadequate funding for dental visits may prevent people with HIV from accessing proper dental care.

Treatment of these HIV-associated lesions is essential for patients to continue oral nutrition and oral medications. Those involved in enhancing and prolonging the lives of infected people must recognize that dental care is an integral part of patients' overall medical care and that dental providers are part of their treatment team. The regular involvement of dentists in the care of HIV-infected patients will prolong their survival and enhance their quality of life.

## Signs and symptoms

**Kaposi's sarcoma:** Kaposi's sarcoma (KS) is the most frequent oral malignancy seen in people with HIV infection. Kaposi's sarcoma-associated herpes virus is implicated as a co-factor in the presentation of KS in HIV-infected people. The oral lesions vary in appearance from asymptomatic flat purple, red, brown, or blue discolorations to large multiple nodular growths. These lesions are associated with pain, bleeding, and inflamma-

tion and can interfere with chewing or talking. Management requires chemotherapy and radiation therapy.

**Lymphoma:** This condition is more rare than Kaposi's sarcoma and is generally more serious. Lymphoma is difficult to detect and may be a small lump in the mouth or in the region of the tonsils. The oral health team needs to refer patients with a diagnosis of this condition to an oncologist for treatment.

**Oropharyngeal candidiasis:** The three most common types of oral candidiasis are erythematous candidiasis, pseudomembranous candidiasis, and angular cheilitis. Erythematous candidiasis presents as red, flat lesions on the tongue or on the hard or soft palates. Patients complain of oral burning after eating or drinking salty, spicy, or acidic foods or beverages. It is one of the most common oral manifestations, yet it often goes undiagnosed.

Pseudomembranous candidiasis lesions are creamy white curd-like plaques inside the mouth and on the tongue. They can be wiped away, but they may leave a red or bleeding underlying surface. Angular cheilitis is fissuring of the corners of the mouth.

Researchers have found that unexplained candidiasis in healthy adults at risk for HIV infection was a predictor for the development of clinical signs of AIDS in 59% of these patients within



three months. Eighty percent of the individuals with more severe immunosuppression in this cohort developed AIDS within three months. Early identification of oropharyngeal candidiasis can therefore act as a possible early warning sign for more serious problems.

**Oral hairy leukoplakia:** This condition presents itself as a white, rough area found usually on the sides of the tongue. It does not wipe away and causes discomfort and difficulty when eating and swallowing. It is usually one of the first signs of HIV infection. It is caused by the Epstein-Barr virus.

**Herpes zoster:** The most frequent and severe recurring oral infection is caused by the herpes virus, which produces ulcers that are slow to heal in people with HIV infection. The symptoms of herpes include fever, oral ulcers, and painful gingival erythema, which causes rapid weight loss from the inability to eat.

**Oral warts:** These warts occur in groups anywhere in the mouth and are caused by the human papillomavirus (HPV). They are often painful and require removal by surgery or freezing. They can come back after treatment.

**Xerostomia:** Xerostomia, or dry mouth, is one of the oral symptoms of HIV. Many people with HIV report symptoms of dry mouth. This condition makes chewing and swallowing extremely difficult. Saliva is extremely important because it helps with the digestion process. Without saliva, food builds up around the teeth and clings to root surfaces and fillings. This build-up leads to rapid decay or breakdown of teeth. A reduced salivary flow means that it takes longer for the acid level of the mouth to decline after eating. Those with dry mouth can have a high level of acid in the mouth throughout the entire day.

**Oral ulcers:** These ulcers commonly occur on the inside of the cheeks and lips, but they may occur almost anywhere in the mouth or throat. They are bright red, round or oval sores that can take weeks or even months to heal if they go untreated. Pain increases when eating salty or spicy foods as well as rough or hard foods. Topical anesthetics or systematic analgesics may be used as pain relievers, but after continuous use, the taste buds may become numb, which decreases the desire to eat. A proper diet is essential for people living with HIV, so these treatments may be detrimental to patient well-being.

**Linear gingival erythema:** This condition is a periodontal disease that occurs in HIV-infected people. It presents itself as a red band along the gingival margin. Bleeding may occur.

**Necrotizing ulcerative gingivitis:** This painful infection can destroy the gums. It is often found between the teeth and causes frequent bleeding, a bad odour and taste in the mouth, and the formation of ulcers and sores.

**Necrotizing ulcerative periodontitis:** This severe form of necrotizing ulcerative gingivitis results in the bone beneath the gum being exposed or destroyed. The gums recede, exposing parts of normally covered teeth and bone. This extremely painful condition causes loosening or loss of the teeth.

### See your dentist regularly

It is essential to have regular dental treatments to remove plaque and necrotic soft tissue by scaling and irrigation with treatments such as 10% betadine. Severe infection may require antibiotic treatment.

Patients with indications for disease progression, a history of oral pathologic conditions, or reduced salivary flow—especially patients taking multiple medications as oral suspensions (common among children with HIV)—need to be seen by a dental professional at least once every three months. Intra-oral examinations will reveal changes in the oral mucosa, decreased salivary flow, and the status of the periodontium and teeth. The

significance of finding oral lesions is that they are early signs of immune suppression and disease progression.

The importance of a medical assessment of all dental patients cannot be overstated, but it is of particular importance for HIV-infected patients. An updated medical evaluation should be performed at each dental visit because changes in their medical conditions occur rapidly and sometimes unpredictably.

## Oral lesions may be the first indicator of HIV infection and lead to its diagnosis.

Oral infections in HIV-infected people are not only aesthetically displeasing, they are often painful and impair the normal function of the mouth. More research on oral viruses is needed to treat people who have compromised immune systems, specifically people with HIV. Many of the oral pathological conditions associated with HIV disease are first discovered by alert dental care providers. Oral lesions generally require the expertise of a dentist for correct diagnosis and management. Referral to a specialist trained in oral medicine, periodontology, or oral surgery may be required. The goal of these examinations is to identify disease and institute preventative, regular care. ⊕

*Questions or concerns about your treatment or health?*

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# Long-term results from first-line therapy

by Sean Hosein

**T**enofovir (Viread) is being studied in an international clinical trial, where it's being used as part of combination therapy in the initial therapy of PWAs. In this story, we report on preliminary results of a two-year study comparing the effect of the nucleotide analogue tenofovir to that of the nucleoside analogue d4T (Zerit, stavudine). According to the preliminary analysis, both drugs are equally effective. However, tenofovir appeared to cause fewer problems with cholesterol and triglyceride levels than did d4T. Readers should note that tenofovir has been approved for use in the following countries/regions:

- ▼ United States
- ▼ European Union (EU)
- ▼ Canada

European regulatory authorities will shortly approve the sale of tenofovir, as part of combination therapy, for use by HIV-positive people who have never previously taken anti-HIV drugs. *(Editor's Note: In Canada, the company is charging twice as much as other drugs in its class, so it may be a while before it is included on provincial formularies.)*

## Study details

At the start of the previously mentioned two-year study, the profile of the subjects was as follows:

- ▼ 25% female, 75% male
- ▼ age – 35 years
- ▼ average viral load – 81,000 copies
- ▼ at least 43% of subjects had a viral load greater than 100,000 copies

- ▼ average CD4 count – 280 cells
- ▼ nearly 40% of subjects had fewer than 200 CD4 cells
- ▼ about 63% of subjects were free from symptoms of HIV disease

Researchers randomly assigned subjects to receive one of the following combinations:

- ▼ tenofovir, 3TC (Epivir, lamivudine), efavirenz (Sustiva) and fake, or placebo, d4T (Zerit, stavudine)
- ▼ d4T, 3TC, efavirenz and fake, or placebo, tenofovir

## Results — changes in CD4 counts and viral load

Over the course of the study, there was a steady increase in the CD4 counts of subjects in both groups, averaging 260 extra cells.

Decreases in viral load were also similar in both tenofovir- and d4T-users. The proportion of subjects who reached a viral load below the 50 copy mark was as follows:

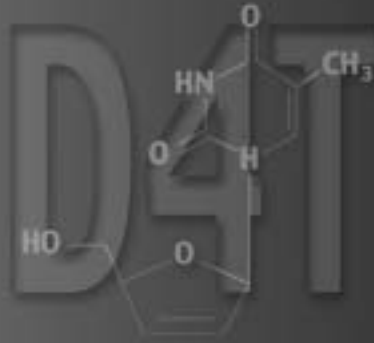
- ▼ tenofovir group – 78%
- ▼ d4T group – 74%

This difference was not statistically significant.

## Results — changes in lipids

Drugs used to treat HIV sometimes cause changes in lipid (cholesterol and triglycerides) levels in the blood. If these changes are maintained over prolonged periods, they can increase the risk of developing cardiovascular disease.

Over the course of the study, researchers found that d4T users, compared to tenofovir users, developed higher levels of the following:



- ▼ triglycerides
  - ▼ cholesterol
  - ▼ LDL-cholesterol (low-density lipoprotein or “bad” cholesterol)
- These differences were statistically significant; that is, not likely due to chance alone. The proportion of subjects in each group who used lipid-lowering medication was as follows:
- ▼ tenofovir – 2%
  - ▼ d4T – 10 %

### Side effects

Tenofovir can cause kidney damage in some users. One indicator of this is the presence of higher-than-normal levels of the protein creatinine in the blood. The proportion of subjects in each group with this problem were as follows:

- ▼ tenofovir – 4%
- ▼ d4T – 3%

Other blood tests found less-than-normal levels of phosphorus, suggesting kidney dysfunction. This problem occurred in the following proportion of subjects:

- ▼ tenofovir – 6%
- ▼ d4T – 5%

These differences in creatinine and phosphorus levels between the two study groups were not statistically significant. Strangely, d4T has been used in North America for nearly a decade yet kidney dysfunction has not been previously reported to such an extent. It will be interesting to see how the elevated phosphorus levels in d4T users in this study is eventually explained.

### Side effects — changes in fat in the arms and legs

One of the side effects of treatment for HIV/AIDS is that sometimes fat under the skin in the arms, face and legs disappears. In this study, the fat content of the arms/legs was measured before and after the study using special scans called

DEXA — dual-energy X-ray absorptiometry. Technicians found that, on average, d4T-users lost nearly 3 more kilograms of fat in their limbs than the tenofovir users. This change was statistically significant.

### Other side effects

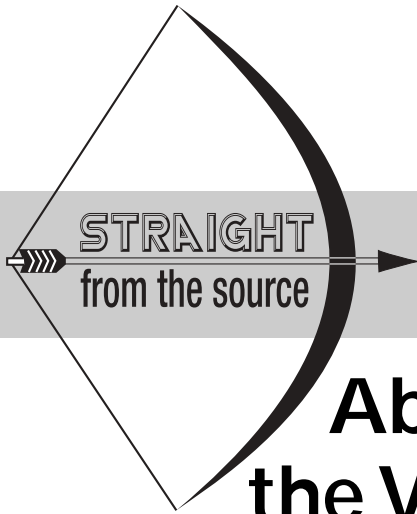
Some other side effects reported by the study team occurred in the following proportion of subjects:

- ▼ Damage to the nerves in the hands/feet (peripheral neuropathy):
  - tenofovir – 3%
  - d4T – 10%
- ▼ Higher-than-normal levels of lactic acid:
  - tenofovir – 0%
  - d4T – 1%

Overall, results from this study show that tenofovir is similar in effectiveness to d4T. Readers should bear in mind that the volunteers in this study had never previously used anti-HIV therapy. Results may be different in people who have used these medications in the past.

Another issue to consider is tenofovir’s impact on phosphorus levels. The body uses this mineral, together with calcium and magnesium to help build bones. The long-term impact of low phosphorus levels on bone health in tenofovir-users is not known. ⊕

*This information was provided by the Canadian AIDS Treatment Information Exchange (CATIE). For more information, contact CATIE at 1-800-263-1638.*



what's new in research

# Aboriginal people and the Vancouver Injection Drug Use Study

by *Dr. Patricia Spittal and Dr. Evan Wood*

**T**he Vancouver Injection Drug Use Study (VIDUS) is a cohort study involving over 1,500 injection drug users (IDUs) from the Downtown Eastside. Like most cohort studies in North America and Europe, the majority of participants are men. However, more than 500 women are enrolled in this study, of whom 40% self-identify as aboriginal. Twenty percent of the men enrolled in the study are also aboriginal, indicating that aboriginal people are disproportionately represented in this population.

Because the study is a longitudinal investigation, we are able to assess the proportions of people becoming HIV-positive over time. Recent analysis suggests that aboriginal people are becoming HIV-positive at twice the rate of as non-aboriginal people. Over 40% of the aboriginal men and women ever enrolled in the study are now HIV-positive. These rates are extremely concerning. We know of no other study indicating such an elevation in risk among indigenous IDUs living within an industrialized country.

As several aboriginal AIDS service providers have suggested, many First Nations youth end up on the street or in foster care because of abusive home situations, which are often directly or indirectly related to the legacy of residential school systems. The full impact of the multigenerational effects of the residential school system as they relate to HIV infection has yet to be determined. However, injection drug use is one commonly used means of coping with the complex effects of social dislocation, discrimination, and poverty.

Equally important in this discussion is the examination of the impact of access to free antiretroviral therapy for aboriginal people. Recent findings from a study conducted by Dr. Evan Wood indicate that high HIV/AIDS death rates persist among aboriginal people, particularly women, because of the lack of or only marginal access to antiretrovirals. One-third of HIV-

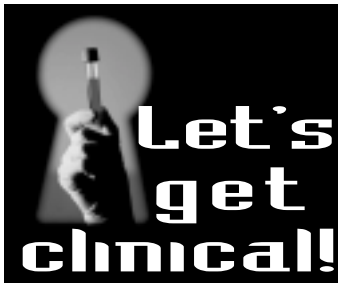
related deaths in this province between 1995 and 2001 were among people who had never received HIV treatment. The people who died were more likely to be aboriginal, female, and poor. Among those who accessed treatment, less than one-half received consistent treatment prior to death. Similar socio-demographic characteristics were associated with elevated rates of treatment discontinuation prior to death.

These data are grim. They reveal that not only are aboriginal people more likely to become infected with HIV, they are also less likely to receive treatment for HIV disease. The data are particularly worrisome for women.

Harm reduction approaches to drug- and sex-related harm and to HIV infection among IDU populations focus upon decreasing the negative consequences of drug use for communities and individuals and are desperately needed in BC. Harm reduction ethics acknowledge the importance of supporting users "where they are" in their addiction and acknowledge the limitations of abstinence-based programming. National and provincial health authorities are beginning to openly embrace the notion that harm reduction programs protect the fundamental health and human rights of some of the most marginalized people in this country.

However, current harm reduction programs remain underfunded, and many more services are desperately needed. Unfortunately, very little dialogue is taking place about how harm reduction strategies, including safe injection sites and heroin prescription, serve the needs of HIV-positive people who use injection drugs. By treating addiction as a health problem and not as a criminal justice issue, such programs have the potential to greatly improve the lives of persons at risk of and living with HIV. ⊕





# “Rosi” trial tests new way of limiting side-effects

by Jim Boothroyd

Are you taking anti-HIV drugs and experiencing high blood concentrations of fat and sugar or changes in your body fat distribution? If so, you might be interested in a new clinical trial that will test a novel method of limiting these effects and associated risks such as heart disease.

The study will examine the effectiveness of rosiglitazone maleate (Avandia), an insulin-sensitizer. In people with diabetes who do not need insulin, rosiglitazone maleate has been shown to make the insulin in their bodies work better and to help reduce high blood-sugar levels.

Investigators believe that the drug might have a similar effect in HIV patients and help to reduce high blood fat levels. People on antiretroviral HIV drugs often develop high levels of triglycerides and LDL (bad cholesterol) and low levels of HDL (good cholesterol). Rosiglitazone maleate can increase good cholesterol and decrease bad cholesterol in people with diabetes. Other drugs in the insulin-sensitizer class have been shown to slow down the formation of plaques in the blood vessels (which occur when levels of blood fats are abnormal), thereby reducing the risk of heart disease.

The investigators will also study whether rosiglitazone maleate affects the distribution of body fat.

Their single-site clinical trial (CTN 178) aims to enroll 50 participants through the HIV Metabolic Disorders Clinic at St. Paul's Hospital. Each participant will be required to make nine clinic visits over one year. Participants will be randomly assigned to one of two groups. The first will receive 8mg of the study drug, and the second will be given a placebo, though neither group will

know which formulation they are receiving.

At weeks 0, 24, and 48, trial nurses will conduct tests to measure body fat (a DEXA scan), intima-media thickness (IMT) of arteries, and brachial artery reactivity (BAR).

Among other criteria, participants must be 30–70 years old and have fasting blood concentrations of triglycerides higher than 2.3mmol/L and total cholesterol higher than 5.2mmol/L. Pregnant women, people with poorly controlled diabetes or high blood pressure, and people with evidence of heart disease will be excluded.

The study investigators are Drs. Greg Bondy and Julio Montaner.

## Co-infection trial opens

Canada's only known clinical trial for treatment of people co-infected with HIV and hepatitis C will begin recruiting soon at Vancouver's Downtown Infectious Disease Clinic. The pilot study (CTN 141) examines the effectiveness and safety of a combination therapy with simultaneous activity against HIV and hepatitis C in co-infected people. ⊕



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

## CTN trials enrolling in BC:

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

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

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

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

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

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

**CTN 178** — Rosiglitazone maleate (Avandia)  
B.C. Site: St. Paul's Hospital, Vancouver

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

# The nutritional road

*The role of diet when getting over alcohol and drug use*

*by Diana Johansen*

Use of alcohol and drugs such as cocaine, crack, methamphetamine, and heroin has effects on every system in the body. The mouth, tongue, and lips often have cankers and sores, and dental health is usually poor. The esophagus may become eroded with recurrent gastroesophageal reflux (heartburn). Esophageal varices (enlarged veins) can develop with cirrhosis of the liver. Gastritis, or inflammation of the stomach lining, is also common, especially with alcohol use.

And that's not all. Malabsorption of nutrients may occur in the small intestine because of poor intestinal health and lack of digestive enzymes. The liver, pancreas, and kidneys are all susceptible to damage that can have widespread nutritional and metabolic effects. Bowel function can change to either diarrhea or constipation, depending on the substances used. Individuals may also have low levels of hormones, especially testosterone for men and estrogen for women.

Nutritional deficiencies are common effects of organ damage and abnormal metabolism of nutrients. People usually eat poorly when using drugs or alcohol and become chronically undernourished. Not only is the amount of food inadequate, food choices tend to be less nutritious. Malabsorption, food intolerances, and increased excretion of nutrients can compound this problem. Over time, the body becomes depleted of body fat, protein, vitamins, and minerals.

## Brain chemistry and the food-brain connection

The brain is particularly affected by substance use. It communicates using chemicals called neurotransmitters. The mix of neurotransmitters present at any given time can affect mood, energy, appetite, and cravings. Neurotransmitters include dopamine (produces a feeling of pleasure and well-being), serotonin (increases well-being and relaxation and decreases depression), epinephrine (increases energy), and endorphins (act as natural analgesics, or painkillers, and produce pleasurable feelings).

The delicate chemical balance in the brain affects communication, excitation, and inhibition. Transmitters can be modified, increased, or decreased by nutrients, drugs, alcohol, and exercise. Nutrition affects the amount and types of brain chemicals by providing the substrate (building blocks) and regulators of neurotransmitter production.

Drugs and alcohol appear to cause a rapid release of large amounts of neurotransmitters, especially the feel-good ones, but they are used up faster than they can be replaced. This causes feelings of withdrawal.

The types of foods we eat affect neurotransmitters. If we eat

protein alone, dopamine and epinephrine increase, producing more energy and alertness, but cravings may continue. If we eat carbohydrates alone, serotonin increases, producing relaxation and satisfaction of cravings. Protein and carbohydrates together produce alertness and energy.

Nutritional abundance enhances neurotransmitter function and diminishes cravings for alcohol or drugs. The effects of nutrition on mood and behaviour are more subtle and slower than drugs and alcohol, but a balanced diet provides long-term stability of brain chemistry.

## Diet in recovery

One of the first goals in recovery is to replenish depleted nutrients. In the detox phase, food tolerance may be limited by withdrawal symptoms, so the gentle approach is used, with small frequent meals of easy-to-tolerate foods with adequate calories.

Many factors drive our nutritional needs and food choices. The most basic need is physical—to nourish the body. However, emotional factors have a strong influence. Our emotional relationship with food is affected by our experience with food rules and eating habits in our family environment during childhood, our ideas of good and bad foods, and the psychosomatic effect of food.

Other factors include our knowledge of food, nutrition, and cooking and our memories of prior experiences. Cultural influences, spiritual beliefs, heritage, dietary laws, and use of foods as therapy also impact choices. All these factors translate into nutrition behaviours.

Typically, a substance abuser has been undernourished for some time before starting recovery. Regulation of hunger and satiety (fullness) may not work well. These combined factors sometimes lead to overwhelming feelings of hunger and overeating. Sometimes eating behaviour is reminiscent of addiction. Many people gain weight rapidly, which is not only hard on the body, but it could trigger drug use if the weight gain is undesirable. It is important to develop a nutrition plan early in recovery to prevent this cycle.

## Basic nutrition plan for recovery

Carbohydrates, including grains (bread, rice, and cereal), whole fruits and vegetables, milk, and yogurt, generally make up about 50% of daily calories. The basic plan is to have three meals a day with 2–3 servings of whole grains per meal, 5–7 servings of fruits





# to recovery

and vegetables, and 2–3 servings of low-fat dairy products. Snacks and extra servings are added, if needed, for people who require more calories.

Protein makes up about 20% of daily calories. It provides building blocks for muscle and the immune system and also provides amino acids to make neurotransmitters. Protein comes mostly from dairy products and the “meats and alternatives” food group (all animal products, beans, tofu, peanut butter, nuts, and seeds).

Fat should provide the remaining 30% of daily calories. As a rich source of calories, fat can increase

blood levels of cholesterol and triglycerides. People who need to gain weight may require more fat to get the additional calories.

## Avoid sugar and coffee

Sugar is notorious as a “bad food,” especially in recovery. Intense sugar cravings are common, particularly among people on methadone. Large amounts of Kool-Aid, juice, candy, and sugar can contribute to rapid weight gain. Some people drink as many as 10–20 cups of coffee a day, with 2 or 3 teaspoons of sugar per cup, which can add an extra 500–1500 calories daily.

Sugar is not a “bad food” in moderation. Small amounts don’t really affect blood sugar any more than many of the other carbohydrates. However, in large amounts it can alter mood by changing the chemical make-up in the brain, and it can cause big swings in blood sugar levels. People in recovery may be more sensitive to blood sugar highs and lows, which may increase the risk of relapse.

Smooth blood sugar curves are achieved when meals contain a mix of carbohydrate, protein, and fat. Blood sugar goes up and comes down slowly, providing more stable energy that lasts longer and may help lessen sugar cravings.

## Ways to manage sugar cravings

- ▼ Eat routinely scheduled meals. Don’t miss any meals, especially breakfast.
  - ▼ Substitute fresh fruit for sweets.
  - ▼ Add less sugar to coffee, tea, cereal, and other foods. Use a sugar substitute to have sweetness without sugar or calories.
  - ▼ Limit juice to one cup per day. Avoid pop and Kool-Aid type drinks altogether. If you have a serious pop habit, drink diet pop.
- Caffeine is a common drug substitute in recovery, especially with lots of sugar. Caffeine causes energy highs and lows and can increase stress levels. Coffee, in particular, can cause stomach pain, heartburn, and bowel problems. Caffeine content of beverages varies widely: coffee can have 100–175mg per cup, whereas tea has 20–50mg, cola has 36–46mg, and hot chocolate has 6–42mg. An acceptable intake of caffeine is 200mg per day, or two cups of coffee. Decaffeinated coffee and herbal teas are good substitutes for hot drinks. Heavy coffee drinkers should cut back gradually because withdrawal can cause severe headaches for about a week.

## Other considerations

Rebound constipation is common in people who have used alcohol and stimulants such as cocaine. Methadone can be extremely constipating. Treat constipation with dietary methods rather than becoming dependent on laxatives. Initially, stool softeners or gentle motility agents such as lactulose may be helpful, but in the long term, fibre, fluids, and exercise work best. (For more information on fibre, see the January/February 2003 issue of *Living +*.)

A prolonged period of malnutrition is common prior to recovery, so take a multivitamin with minerals. Any additional supplementation must be based on individual needs. Individuals with liver disease need to be more cautious about vitamin supplements.

Recovery is a time to learn healthy eating behaviours for the rest of your life. Nutritional rehabilitation can boost the recovery process by replacing deficient nutrients and stabilizing energy and mood. Scientists continue to study the food-brain connection. The future may bring more strategies to manipulate brain chemistry with specific nutrients. For now, common sense and a sound diet provide the foundation for health and long-term recovery. ⊕



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



# Efectos de la diarrea en personas con VIH/sida

por Alejandro De Vivar

**La** diarrea es un padecimiento que pueden desarrollar las personas con VIH/sida y es importante conocer sus causas. La diarrea ocasiona la pérdida de agua del organismo y el peso corporal exponiendo la salud de la persona.

## ¿Qué genera la diarrea?

La diarrea es ocasionada por diferentes causas: infecciones oportunistas, bacterias, virus, parásitos, nuestra dieta, el estrés, etc. A todo lo anterior, se debe considerar también que un porcentaje de las personas con VIH/sida sufren de diarrea como efecto secundario de los medicamentos antirretrovirales que ingieren, así como otros medicamentos que son recetados por el médico para las infecciones oportunistas como antibióticos, inmunodepresivos, corticosteroides, antiácidos, excesivos anti-diarréicos, por mencionar algunos. Es importante identificar cuál de los productos anteriores ocasiona la diarrea con el objeto de que nuestros médicos nos den el tratamiento adecuado y efectivo.

Si padecemos de diarrea es importante conocer el conteo de las CD4 (Células D4) ya que, por debajo de 200, el organismo puede contraer infecciones oportunistas como la salmonelosis, tifoidea, cólera, giardiasis y otros tipos de virus y bacterias; el exceso de comidas grasosas y la baja alimentación rica en fibras también producen diarrea. En cuanto al diagnóstico para conocer las infecciones oportunistas del sistema digestivo, es necesario el análisis de las heces fecales. Por medio de exámenes de laboratorio se pueden detectar anomalías en la cantidad de sustancias que regulan el estado de la hidratación del cuerpo.

## ¿Que sucede si no nos preocupamos de controlar la diarrea?

Un descuido de la diarrea puede reducir la calidad de vida y desencadenar en la mortalidad. En circunstancias de gravedad se pierde peso rápidamente y se dificulta la atención médica. Un cuadro avanzado de diarrea puede tener como resultado el experimentar desnutrición con efecto negativo directo en el sistema inmunológico, exponiéndolo a infecciones e impidiendo por la misma diarrea el suministro de antirretrovirales o la absorción de medicamentos.

## Infecciones que producen diarrea

- ▼ La criptosporidiosis (parásito)
- ▼ La amibiasis (amiba)
- ▼ La infección de *Campylobacterium* (bacteria)

- ▼ La giardiasis (parásito)
- ▼ Shigella (bacteria)
- ▼ La lombriz intestinal oxiuros (lombrices)
- ▼ La salmonelosis (bacteria)
- ▼ Síndrome de irritación de intestinos (estrés emocional)

## Tratamiento

Existen medicamentos para el tratamiento de la diarrea, así como también puede incluirse los cambios en la alimentación (dieta) como parte del tratamiento. Es importante mencionar que ciertos medicamentos anti-diarréicos pueden ayudar más que otros, y para una mejor recuperación, más de uno actúan mejor que uno solo.

## La siguiente información es sobre medicamentos anti-diarréicos y de sus aplicaciones

- ▼ Glutamine: Es utilizado para casos de pérdida de energía por causa de la diarrea.
- ▼ Calcio: El calcio es conocido como un agente anticonstipación y puede reducir la diarrea e incluyen las formulaciones como el carbonato de calcio.
- ▼ Productos a base de enzimas del páncreas: Contienen amilasa, proteasa y otras enzimas del páncreas, reducen el número de evacuaciones, reducen la cantidad de grasa e incrementan la consistencia de las heces fecales.
- ▼ Nutrición: La siguiente es una lista de los cuidados que debemos tener en nuestra nutrición para mejorar los síntomas de la diarrea.
- ▼ Reducir el consumo de productos que contengan lactosa.
- ▼ Consumir productos alternativos a la lactosa como la leche a base de soya o arroz.
- ▼ Beber café descafeinado.
- ▼ Reducir las comidas con alto contenido en grasas.
- ▼ Tomar cantidades de vitamina C por abajo de los 2000mg al día.
- ▼ Tomar más líquidos. ☺

## BCPWA Treatment Information Program (TIP)

Ofrece información sobre tratamientos del VIH/SIDA.

Todos los miércoles 1:00PM a 5:00PM.

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

Llame a la línea directa: 604.893.2243

email: [treatment@bcpwa.org](mailto:treatment@bcpwa.org)

# Volunteering at BCPWA

## The Girls

by Thomas R.

Sometimes we walk past people and never give them a second look. We don't see the sorrow that a person feels, the pain they suffer, or the goodness in their hearts. Two such people who see people for these qualities are "the Girls"—May and Quita. Mae is a very young 77 going on 25, and Quita is her partner in crime. Together the two girls have made some huge differences in peoples' lives. They run a program to help convicts with HIV that are incarcerated or on the street. A lot of people would look at us and count us out with two strikes. One, we are in jail or have been in jail, and two, we have either HIV or AIDS.

Rarely will you meet someone who can look past all the stigma and love the person for who they are. May and Quita do just that. I was lost in a world of drugs and self-pity for many years when I ended up on Vancouver's Downtown Eastside. One night I shared a syringe with an HIV prostitute and soon after I was diagnosed with the virus. I felt alone and scared. I knew nothing about the disease or its effects. I kept right on shooting heroin and spiralling further and further into a hole. I had no idea there was anything out there until one night in the Vancouver Pre-Trial. I was sitting in the chair by the phone wishing I had someone I could call. I saw a flyer on the bulletin board that read: "HIV+. If so, you are not alone." My heart lept out of my mouth. The phone number given was a Godsend.

I was connected with May and right away I felt a trust that I had not felt in a long time. I was trying to find my girlfriend who was missing and presumed to be downtown shooting drugs. I let it all out that night to May. I went to bed and fell asleep with the first smile and untroubled heart in a while. The next day I called and May gave me a phone number to get in touch with my girlfriend. I never got to know Quita as well, but from what I can tell, they are cut from the same cloth. May never babied me, she told me straight out what it was I had to

do and not to do. She made me realize what I was doing to myself was self-destruction.

That was six years ago. For the six past years, I've had a best friend, a second mother and extremely loving relationship with May. She has been there for me when my girlfriend passed away (she was there for my Jenny right up until she passed on), and my accident, in which I was hit by a bus. She gives me hope when I feel hopeless, love when I feel unloved. What makes her so special is she does so unconditionally. It does not matter what time it is, I can call and she is there for me.

Very few people have the ability to come into prison and touch men's hearts. Men who would kill you for looking at them funny. Not only do May and Quita come in to see and talk to such people, but these men love and respect them. They both give up their time to come in and try to make a man who has been hurt, abused and distrustful of people forget his problems. These two ladies can walk into any prison in B.C and be known and loved and watched out for like a hawk. It is a beautiful thing to see a man light up and turn red from a kiss on the cheek from a lady who could very well be his mother. All I can say is I thank God every day that I looked at that bulletin

board. So if you are ever walking along and not paying attention to someone who has passed you by, remember you may have passed someone who could make a real difference in your life. I'm glad I never looked past that flyer, for if I had, I would have never gotten to know "the Girls". ☺



*Thomas R. is an inmate at Mountain Institution.*

# where to find help

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

## **BC Persons With AIDS Society**

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

## **A Loving Spoonful Location**

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

## **AIDS Memorial Vancouver**

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

## **AIDS Prince George**

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

## **AIDS Resource Centre – Okanagan and Region**

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

## **AIDS Society of Kamloops**

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

## **AIDS Vancouver**

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

## **AIDS Vancouver Island (Nanaimo)**

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

## **AIDS Vancouver Island (Victoria)**

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

## **ANKORS (Nelson)**

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

## **ANKORS (Cranbrook)**

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

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

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

## **Dr Peter Centre**

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

## **Friends for Life Society**

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

## **Healing Our Spirit**

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

## **McLaren Housing Society**

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

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

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

## **North Island AIDS (Courtenay) Society**

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

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

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

## **Okanagan Aboriginal AIDS Society**

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

## **Outreach Prince Rupert**

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

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

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

## **Positive Living North West**

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

## **Positive Women's Network**

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

## **Red Road HIV/AIDS Network Society**

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

## **Vancouver Native Health Society**

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

## **Victoria AIDS Respite Care Society**

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

## **Victoria Persons With AIDS Society**

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

## **Wings Housing Society**

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

## **YouthCO AIDS Society**

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

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

### Upcoming BCPWA Society Board Meetings

Date	Time	Location	Reports to be presented
June 25, 2003	1:00	Training Room	Written Executive Director Report / Financial Statements—May Standing Committee
July 9, 2003	1:00	Training Room	Director of Support Services
July 23, 2003	1:00	Training Room	Quarterly Department PHSA Report / Written Executive Director Report/ Executive Committee / Financial Statements—June
August 6, 2003	1:00	Training Room	Standing Committee
August 20, 2003	1:00	Training Room	Written Executive Director Report / Director of Fund Development
September 3, 2003	1:00	Training Room	Financial Statements – July / Executive Committee

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

For more information, contact:

Alexandra Regier, Office Manager

Direct: 604.893.2292

Email: alexr@bcpwa.org

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# DAZED AND CONFUSED

When your brain goes AWOL

by Glen Hillson

*Editor's Note: Glen passed away on June 12, 2003 at St. Paul's Hospital in Vancouver. This was the last essay that he wrote, just weeks before he was admitted to the hospital for the last time. It is a testament to his fighting spirit right up until the end. The bio that he wrote at the end of the article is now even more poignant.*

Lately, the word “befuddled” has taken on new meaning for me.

I was not blessed with the necessary attributes to be considered a heart-stopping athlete—unless competing in the 1988 Canadian Men's Curling Championship (a.k.a. the Brier) counts. I was not a great beauty of my generation. I have no knack for making money, and I am not rich. My one fallback has been a reliable lump of grey matter stuffed between my ears. Lately, there has been considerable doubt as to its whereabouts, as it seems to have been AWOL more than usual. Often, I feel like an Elmer Fudd for the new millennium.

It all started last November, at the time of my first ever overnight sojourn to “St. Paul's Spa,” where I was provided with liberal doses of narcotics by hospital staff. In addition to the turbo-charged morphine, I had a liver crash that caused a condition known as encephalopathy, which sends gremlins into your brain. Together, the morphine and encephalopathy were a nasty elixir that caused me to routinely doze off in the middle of conversations, phone calls, sentences, and even words—usually for only seconds, but sometimes for longer stretches.

When I was alone, the line between sleeping and hallucinating blurred. I would converse aloud with phantoms and lift non-existent spoons to my mouth. Months later, I was reminded of a television interview I had done at my bedside. Only when I was shown a videotape of the interview was I willing to accept that it was true, and I was then gradually able to reconstruct the event in my memory—what was left of it. On the ball I was not—more asleep than astute, most would say. Apparently, I suggested the same movie three nights in a row, which I watched with a friend.

I guess it was a real sleeper in more ways than one.

Once, while playing cribbage with another pal, I dozed off every minute or so for a few seconds. I'd awake and inquire, “How long was I gone this time?” As far as I knew, it could have been hours.

The grand episode was trip number two to St. Paul's Hospital, assisted by hunky and ever-so-sweet paramedics. This time, I was in a full-out coma for two days. The only sign of awareness I offered was to pucker at the request of a friend about to grease my dry and crackled lips.

As the experts were conferencing about the improbability of me waking up, I shot bolt upright and demanded a commode. At least I still knew my priorities. I attribute this sudden turn to the fact that when left alone with a robust lesbian friend she grabbed me by the shoulders, gave me a good shake, and ordered me to snap out of it. Resistance was futile.

These are just a few of the more profound examples of my befuddlement. While the mind was taking me on a surreal journey through inner space, those around me were somewhat concerned. I, however, was

often content to fill my days travelling where no man has ever gone.

What did I learn from it all? Well, accepting the help of others to perform even the most elementary necessities of survival was a challenging adjustment. Having more or less achieved that, I now realize that in my early years I probably should have engaged myself in the pursuit of wealth instead of pissing off those who did. You see, I now realize that I rather like people waiting on me and catering to my every whim.

Recently, my presence of mind has made a partial comeback. Last night I said, “Don't close the door,” which meant, “Leave the light on.” Minor by comparison, and really, every 51-year-old makes little goofs like that — right? ⊕

*Glen Hillson is our faithful correspondent from the other side of the looking glass.*

