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features



treatment
information





**British Columbia
Persons With AIDS Society**

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

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Glyn Townson – chair, Jeff Anderson, Ken Buchanan, Wayne Campbell, Michael Connidis, Sam Friedman, Rob Gair, Derek Thaczuk

Managing editor Jeff Rotin

Design / production Britt Permien

Copyediting Alexandra Wilson

Contributing writers

Angela Birnie, Kenn Blais, Michele Blanchet, Paula Braitstein, Anne Drummond, Rachel Grainger, Ross Harvey, Diana Johansen, R. Paul Kerston, Audrey Le, Paul Lewand, Carole Lunny, Margarite Sanchez, Julie Schneiderman, Kath Webster

Photography Britt Permien

Director of communications & education

Lisa Gallo

Acting director of treatment information and advocacy

Jane Talbot

Coordinator of treatment information

Zoran Stjepanovic

Subscriptions

Taz Yaremko

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living⊕ magazine

1107 Seymour St., 2nd Floor
Vancouver BC V6B 5S8

TEL 604.893.2206 FAX 604.893.2251

EMAIL living@bcppwa.org

BCPWA ONLINE www.bcppwa.org

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opinion & editorial . . .

Persistence pays off

by Paul Lewand

After six months of waiting, a handful of BC Centre for Excellence in HIV/AIDS (BCCfE) patients have finally been given access to new antiretroviral medications. I was one of six HIV-positive people in BC who were identified last summer as having no drug options left; we were all suffering from a strain of the HIV virus that had become resistant to all available drugs. The news was devastating as we struggled with low T-cell counts and high viral loads.

We were encouraged, though, by reports from the UK of positive trial results of two new drugs, TMC 114 and TMC 125. However, Health Canada told us we'd have to wait a short while until they would allow access to the drugs through their Special Access Program (SAP).

As the short while grew into a long while and one of the individuals waiting for the drugs died, we began to wonder what was holding things up. Apparently, Health Canada was concerned about the lack of Canadian data on the drugs. It was only a series of fortunate coincidences—the looming federal election making local politicians more susceptible to criticism; one of the patients, Tiko Kerr, being a prominent Vancouver artist; extensive media coverage; Dr Julio Montaner from the BCCfE going well beyond the call of duty; inspired political activism by the BCPWA Society; and the unwavering determination of many individuals—that eventually led to the approval of TMC 114 and TMC 125 for the five surviving patients.

In the end, though, the drugs weren't even accessed through SAP but through

a special clinical trial created to allow the five surviving individuals to begin new drug regimens that included the new drugs. The sad thing is that they still aren't available to other people who now need them. At very least, it should be easier next time to convince Health Canada to allow access to these drugs, since there will be data showing that the drugs are safe.

I believe that none of us who were involved in the case from the start was really prepared for what it would take to gain access to these new treatments. The whole experience, while extending my own life expectancy, also taught me a number of valuable things. Most important was the great feeling of participating in actual grassroots political action, and in discovering that there are still people and organizations out there that will go beyond the call of duty. I sincerely thank all those who helped in the fight. I also learned that while the Health Canada's SAP does have its flaws, things can change and wrongs can be righted. It takes determination and cooperation, but if we are willing to do the work, and we do it together, there is no doubt that we will make things better.

While we won't know for several years how beneficial the new drugs are, initial results are promising. To date they have significantly reduced the viral load, with minimal immediate side effects, for each of the four individuals currently involved in the small drug trial. ⊕

Paul Lewand

is the chair of the BCPWA Society.



REALITYBITES

News from home & around the world



More income support allowed

As of March 1, 2006, British Columbians receiving Persons With Disability or Persons With Multiple Barriers income support will be allowed to earn up to \$100 more per month, which will raise the allowable monthly earning level from \$400 to \$500.

When the earning exemption is combined with the disability rate, persons with disabilities on income assistance now have the opportunity to have a monthly income of \$1,356. For individuals receiving the Monthly Nutritional Supplement Benefit, the amount jumps to \$1,581 per individual and \$2,421 per couple.

Persons with disabilities in BC continue to be provided with full shelter, low-cost bus passes, and enhanced medical coverage including the Medical Services Plan (MSP), no deductible for PharmaCare, dental and optical coverage, and medical supplies.

Commercial Fortovase discontinued

In May 2005, Roche Canada announced the company's intention to discontinue the commercialization, and voluntarily withdraw the marketing authorizations, for saquinavir in soft capsule formulation (Fortovase) and zalcitabine (Hivid) in all countries where these products are licensed.

Hivid distribution in Canada was discontinued on February 28, 2005. At that time, Roche recommended that all patients on zalcitabine should be transitioned to an alternative treatment option in the intervening two-month period.

Further details about the withdrawal of Fortovase in 2006 will be forthcoming.

U.S. to quarantine PWAs travelling to AIDS conference

The US government has eased immigration restrictions for non-citizens with HIV to attend the Chicago Gay Games in July. The Gay Games received a designated-event status, which will allow HIV-positive athletes and spectators to apply for a single-entry B-2 travel visa that will be issued on a separate form from the passport. No questions about HIV status will be asked at the port of entry.

There will be an arduous process, however, for PWAs travelling through the US en route to the International AIDS Conference in Toronto. Many travellers with stopovers in the US would normally require visas just to pass through for a few hours.

Visitors will be forced into special holding areas at the US port of entry until they board their planes to Toronto. "They will be basically quarantined at the airport, whether or not they have HIV, just because they're attending an AIDS conference," complained Dr. Frenk Guni, director of international affairs for the National Association for People with AIDS.

Source: PlanetOut

MSF to hand over HIV treatment in Cape Town

After five years of groundbreaking work in HIV/AIDS treatment, Medecins Sans Frontieres (MSF) are preparing to pull out of their most successful South African program.

They began offering antiretroviral therapy (ART) in the poverty stricken Cape Town township of Khayelitsha in 2001, when the provision of anti-AIDS

drugs in the public sector was still illegal.

MSF committed to a five-year plan to treat 180 patients in Khayelitsha, which has the largest concentration of HIV/AIDS patients in South Africa. A model of best practice in implementing antiretroviral therapy, it proved the feasibility of providing ART in the poorest conditions and with the weakest patients.

MSF have started reducing their role in providing drugs, staff, and other resources to the Khayelitsha clinics. The provincial health authority for the Western Cape expects to take full control by mid-2007.

But, given the government's approach to HIV/AIDS treatment in the past, a deep-rooted scepticism remains among patients and staff about the province's ability to sustain the program once MSF has pulled out.

Source: Canadian Labour Congress

Researchers develop vaccine against hep C

Researchers at the University of Saskatchewan's Vaccine and Infectious Disease Organization (VIDO) have developed a vaccine candidate for hepatitis C, leading to hope in the fight against a disease for which no vaccines are yet available.

VIDO is the first in Canada to show that this vaccination technique may be effective against HCV. The study was published in this month's *Journal of General Virology*.

The team produced a vaccine candidate that decreased the amount of a carrier virus expressing hepatitis C virus (HCV) protein in mice by 100,000 times compared to the control.



REALITYBITES

News from home & around the world



Heart attack risk elevated by PI treatment

The increased risk of heart attack seen in patients taking antiretroviral therapy is caused by protease inhibitors (PIs) and not non-nucleoside reverse transcriptase inhibitors (NNRTIs), according to a study presented at the Thirteenth Conference on Retroviruses and Opportunistic Infections, held in Denver in February. The study showed that this was partially due to the changes in blood fat levels caused by PIs.

The Data Collection on Adverse Events of Anti-HIV Drugs (D:A:D) is an observational study that set out to assess the long-term safety of HIV treatment. It involves over 23,000 HIV-positive people in 11 cohorts based in three continents. Last year, results from the study showed that the risk of heart attacks increased by 17 percent with every year a patient spent on antiretroviral therapy.

The study has now collected enough data to allow the detection of a difference between drug classes in the risk of heart attack, or myocardial infarction.

Source: Aidsmap

A link to artery wall thickening?

At the recent Thirteenth Conference on Retroviruses and Opportunistic Infections in Denver, investigators from the University of California in Los Angeles reported the latest results from ACTG 5078, a study examining the effects of anti-HIV treatment on the thickness of artery walls.

The thickness of the walls or *intima media* of the carotid artery in the neck

can be measured with ultrasound scans. Previous studies have shown that increased wall thickness is linked to an increased risk of heart attack.

To assess the change in carotid intima media thickness over time, investigators analyzed three groups: 44 HIV-positive people treated with protease inhibitors for at least three years, 46 HIV-positive people who had never received PIs, and 46 HIV-negative people.

After taking measurements at baseline and every 24 weeks, they found no statistically significant differences in the rate at which the artery wall became thicker between the three groups.

Source: Aidsmap

TMC114 works better with Fuzeon

Interim data presented at the 2005 Interscience Conference on Antimicrobial Agents and Chemotherapy conference in Washington, DC show that adding enfuvirtide (Fuzeon) to the investigational-boosted protease inhibitor TMC114, more than doubles the proportion of patients reaching undetectable levels of the virus.

This latest study provides further evidence that Fuzeon makes undetectable viral loads more achievable for patients failing on their current therapies, when used in combination with the latest HIV drugs. This effect has also been seen in other Fuzeon-boosted protease inhibitor combination trials, including with lopinavir/ritonavir (Kaletra) and tipranavir/ritonavir.

Insulin resistance in HIV-positive kids

HIV-positive children have higher rates of resistance to insulin than children without HIV, according to the results of a study from the University of Genoa in Italy. This puts them at an elevated risk of developing diabetes and cardiovascular disease later in life.

Metabolic changes in HIV-positive patients have been linked both to HIV itself and to HIV treatment, notably with protease inhibitors. Although many studies have concentrated on adults, experts are concerned that children infected with HIV may also be at risk of these changes, one component of which is a decrease in the body's responsiveness to insulin, the hormone that helps regulate blood sugar levels.

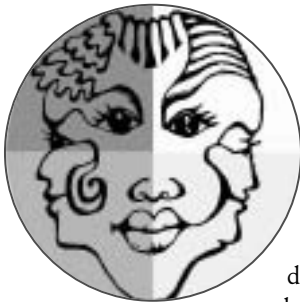
The investigators measured the degree of insulin resistance in a cohort of 47 HIV-positive children, adolescents, and young adults aged three to 23 years. They presented their findings at the Thirteenth Conference on Retroviruses and Opportunistic Infections. ⊕

Source: Aidsmap

Bringing women's issues to the forefront

The Blueprint for Action advocates for equal representation of HIV-positive women and girls' issues in AIDS strategies

by Carole Lunny



The Blueprint for Action on Women and HIV/AIDS is a dedicated group of Canadian advocates working to advance HIV-positive women's advocacy issues. The Blueprint coalition—made up of healthcare advocates, people living with HIV/AIDS and other diseases, doctors, nurses, researchers, and community groups—formed in 2004

in response to both the growing crisis of increasing rates of infection among the female population and the continued failure of national AIDS strategies and events to equally represent HIV-positive women and girls' issues, given that they represent over 50 percent of the epidemic worldwide.

The Blueprint coalition is an inspiring group of people, working to complete projects on tight timelines. Together they have created a list of recommendations and demands to stop the HIV/AIDS epidemic among women (including transgendered women) globally that requires adequately funded, sustained, and ongoing responses from all stakeholders.

In the beginning, 30 individuals from across Canada met to create the Blueprint to change the social, emotional, medical, and financial obstacles faced by women living with HIV. They formed several initial committees, including: legal, ethical, and human rights; public policy and determinants; stigma and discrimination; prevention, care, diagnosis, and treatment; communications; International AIDS Conference 2006; and research. Many more committees have since formed and Blueprint coalition is working to include women and girls' issues on government and conference agendas worldwide.

In preparation for the XVI International AIDS Conference in Toronto in August 2006, the coalition released a manifesto on World AIDS Day, December 1, 2005. The manifesto was launched in many cities across Canada and in many countries, including Rwanda, Thailand, South Africa, and the US. The Blueprint Manifesto outlines what is required to effectively address the needs of women and girls living with HIV around the world, presenting these requirements as a series of demands in the long tradition of political activist manifestos. The

demands are specific to six areas: legal, ethical, and human rights; research; stigma and discrimination; diagnosis and treatment; prevention and education; and care and support.

The overarching demand of the manifesto is the inclusion of adequate and sustained resources, including financial and human resources; culturally and linguistically sensitive incentives; and participation of women with HIV as an integral part of the solution-making and decision-making process.

In order for the manifesto to be effective, it needs to be endorsed by individuals and by community, institutional, and research groups, including all our national and international partners and members. For more information on how to get involved, please refer to the sidebar.

The coalition is currently working to develop indicators in preparation for a report card that will be launched in August at the AIDS Conference. Other committees are working hard to develop a Web site, recruit renowned women spokespersons, and organize a women's march and a commemorative art display at the AIDS Conference, to name just a few projects. ☺

How to get involved

You can read and download the Blueprint Manifesto from www.mapleleafmedical.com. Look for the logo of a women's face looking three ways. From that link, you can email the prime minister and let the government know you support this initiative.

You can also email the coordinator of the Blueprint coalition, Jes Smith, at jess@cdnaids.ca to express your support, or to volunteer on a coalition committee.

Carole Lunny is the treatment outreach coordinator for the BCPWA Society, the national women's representative for the Canadian Treatment Action Council, and the chair of the Research Committee of the Blueprint for Action on Women and HIV/AIDS.





Do-it-yourself

Advocacy and empowerment in AIDS service organizations still isn't the norm

by Jeff Anderson

Give a man a fish and he can feed his family for a day; teach a man to fish and he can feed his family for a lifetime. So it is with AIDS services. Others can help us secure our rights, but if we learn to attain them for ourselves and our peers, we can apply those lessons to other struggles in our lives. The success of the empowerment model is well documented. More PWAs in BC turn to peers for education

than any other place except their doctor.

The BCPWA Society formed 20 years ago because people with HIV were desperate to achieve more than the goals set for them by the agencies that existed at the time. The organization has based successful programs and services—from the first AIDS Walk to the Complementary Health Fund to PWA-only voting and board composition—on its mission to empower persons living

with AIDS and HIV disease through mutual support and collective action.

This paradigm seems almost obvious; in fact, most national and international agreements and strategies trumpet the necessity of PWA voice, vote, and empowerment. Yet within AIDS service organizations (ASOs), empowerment programs are still the exception to the norm, even in BC. Most AIDS services in BC are envisioned and provided by



**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 October 2005 and November 2005 is:

- ▶ **\$77,882** in debt forgiveness.
- ▶ **\$135,000** in housing, health benefits, dental and long-term disability benefits.
- ▶ **\$23,370** monthly nutritional supplement benefits
- ▶ ***\$2,250** in ongoing monthly nutritional supplement benefit for children

**New benefit secured for HIV-positive children in BC.*

social service organizations, instead of developed by PWAs responding to their own needs. Those PWAs who can advocate for themselves, do so. Those who cannot advocate for themselves are usually abused by others, without remedy.

It's still rare for an ASO to permit HIV-positive clients to initiate projects or advocacy in response to injustice or needless suffering. That was the case when PWAs at the Dr. Peter Centre in downtown Vancouver met to discuss their struggles to advocate for themselves within the healthcare system. This issue was backed by a poll that revealed that clients of the Centre needed help with mistreatment at St. Paul's Hospital. The Vancouver HIV Peer Advocacy Action Group (VHPAAG) was thus formed, with hospital issues at the top of their agenda. Their aim was to document mistreatment, identify patterns of stigma, and develop a plan to seek improved treatment and justice.

The Centre, however, wouldn't endorse the group, and they were careful to distance themselves from the VHPAAG lest the peer group's advocacy efforts upset community relations. The Centre did supply a meeting room and brokered a meeting between hospital officials and the VHPAAG. The VHPAAG relayed their major

contentions to the patient advocate at St. Paul's Hospital. The patient advocate and the hospital's chief of HIV/AIDS eventually agreed to meet with all clients at the Centre.

It's still rare for an ASO to permit HIV-positive clients to initiate projects or advocacy in response to injustice or needless suffering. That was the case when PWAs at the Dr. Peter Centre in downtown Vancouver met to discuss their struggles to advocate for themselves within the healthcare system.

Reports of mistreatment uncovered a pattern of stigma, which suggested that discrimination was greatest outside the hospital with emergency personnel and medics, and lessened as PWAs moved further into the hospital system. PWAs had the least difficulty with personnel in the palliative ward.

The meeting between PWAs and hospital staff was respectful and passionate. For some, this was the first time they felt respected by hospital staff. Some wanted greater access to their patient records to ascertain that information is up-to-date, and others wanted a new approach to treating persons with HIV.

Following the meeting, PWAs in the hospital were invited by the hospital to voice their concerns to ward supervisors, and if necessary to speak to the patient advocate. In addition, while hospital officials did not acknowledge the depth or degree of complaints, they did agree to establish a dialogue with PWAs about the hospital's "addiction services." It isn't clear, though, why they are lumping individual PWA complaints into addiction services.

Though not all of VHPAAG's aims were accomplished, the process gave a sense of dignity and achievement to those who had been disrespected. The process was a collective success for a group that has had too few successes in the past. ☺

Jeff Anderson is peer leader of the Vancouver HIV Peer Advocacy Action Group.

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

Web site maintenance > Communications

Administration > Internet research, filing, database management, reception, etc.

Special events > AccolAIDS Awards Gala and WALK for LIFE

Writers > *living* ☺ magazine, Communications

Workshop development and delivery > Communications and *living* ☺ magazine

Benefits of becoming a volunteer:

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

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

volunteer @
BCPWA

Where's the beef?

The provincial government created the *Priorities for Action* but has failed dismally to take any action or responsibility

by Ross Harvey

In September 2003, BC's Ministry of Health posted a document in an obscure corner of its Web site without announcing it. The document, cumbersomely named *Priorities for Action in Managing the Epidemics – HIV/AIDS in BC: 2003-2007*, was the closest the provincial government was willing to get to an actual strategy for dealing with HIV/AIDS.

Along with a good analysis of the state of the HIV/AIDS epidemics in BC (and the costs to the provincial treasury), the document set out four goals to be achieved in the five-year period of 2003 to 2007. The two most ambitious goals were to reduce the incidence of HIV infection by 50 percent and to increase the proportion of HIV-positive individuals who are linked to appropriate care, treatment, and support services by 25 percent.

While the document set out a series of key strategies for attaining its goals, it was oddly silent on who was to implement these strategies and how they would be achieved.

But there was a problem. While the *Priorities for Action* document set out a series of key strategies for attaining its goals, *it* was oddly silent on who was to implement these strategies and how they would be achieved. Indeed, the Ministry soon retreated into a kind of sullen insistence that it had come up with the plan and now it was time for everybody else—especially the newly consolidated Health Authorities—to implement it as best they could. With no additional money.

As the BCPWA Society pointed out in response, “the provincial Health Ministry must act; it is not enough for it to adopt ‘Priorities’ and pledge its implementation. The Ministry must, as well, produce the substantial additional funds essential to that implementation. To do otherwise would be to expose the pledge embodied in the document’s adoption as a contemptible deception.”

So there it sat. Good analysis. Good ideas. No new money.

Then, in September 2005, the Ministry sneaked another new document onto the back pages of its Web site. This one turned out to be the first annual progress report on how we were all doing in reaching the provincial Health Ministry’s goals for 2004—the first full year following publication of *Priorities for Action*.

Predictably, we’re not doing well.

To its credit, the progress report provided a superior overview of the state of HIV/AIDS in BC. But then, in an apparent attempt to show progress in meeting *Priorities for Action’s* goals, the progress report devoted most of its pages to a description of numerous programs operating in BC intended in one way or another to combat HIV/AIDS and its effects. Fair enough. But most of the programs cited either predate the original priorities (like YouthCO’s Speakers Bureau or AIDS Vancouver’s Case Management Program) or are operated without any significant provincial government funding (like the Positive Women’s Network’s Women and AIDS Virtual Education (WAVE) program) or both (like BCPWA Society’s Prison Outreach Program).

And the bottom line?

Well, it’s almost impossible to know how many new HIV-positive British Columbians have been connected with the array of care, treatment, and support services available. We do know that the BC Centre for Excellence in HIV/AIDS continues to enrol new patients in its Drug Treatment Program, which has received substantial new PharmaCare funding—almost doubling from \$35 million in 2000/01 to \$61 million in 2005/06. But community-based agencies providing care and support find it almost impossible to serve new clients within the constraints of existing budgets.

And as for that 50 percent reduction in new infections goal: from 2003 to 2004 the number of persons testing newly positive for HIV jumped from 421 to 457—an 8.5 percent increase. To attain that 50 percent reduction goal in five years, we now have to secure a 59 percent reduction in four.

Far from moving closer to those 2003 *Priorities for Action* goals, we’ve been losing ground. ☹



Ross Harvey is the executive director of the BCPWA Society.

Together at last



Our new HIV/AIDS national action plan is entitled “Leading Together.” Whether we have the collective leadership to pull it off remains to be seen.

by Jeff Anderson

In the fall of 2005, a plan which took four years to develop slowly seeped from the federal government printing house and into the consciousness of governments and AIDS organizations across Canada. The story of how it

developed, who has endorsed it—and more importantly, perhaps, who has not—tells the story of Canada’s strengths and weaknesses though 20 years fighting HIV and AIDS.

continued on next page

Canada's first ever national action plan for HIV/AIDS, *Leading Together: Canada Takes Action on HIV/AIDS (2005-2010)*, marks several historic firsts. It is the first national plan to cover all sectors of HIV activity, the first to consider all jurisdictions from local to international, and the first to set goals for the country. Perhaps most importantly, it is the first plan to offer a coordinated monitoring commitment to track and report progress.

That we have a Canadian action plan at all is itself good news. Whether this plan can improve AIDS programs and services or health outcomes for persons with AIDS is unknown. The biggest challenge may be whether we have the leadership—in government, among PWAs, and throughout the HIV sector—to transform the plan into an agreed upon commitment to its aims and principles.

Because this is breaking new ground for Canada, the mechanisms to monitor, assess, and adjust the plan to a changing epidemic do not yet exist. The plan is unique and complex; it demands a deliberate and comprehensive approach by PWAs and AIDS stakeholders to take advantage of new approaches and new signposts, in order to ensure success.

The path to a collective national action plan

For years, our leaders were criticized for not having a broad-based plan to deal with HIV/AIDS. In April 2000, Health Canada held a national stakeholders meeting in Montreal among people involved in the AIDS sector—social service and healthcare providers, funders, and people with HIV/AIDS—to develop consensus for charting the future of AIDS goals and policies. One of the workshops identified the need for a plan in which every PWA and every AIDS organization in Canada could see themselves. Workshop participants expressed a need for a coordinated approach to prioritize the various research, treatment, prevention, and support programs.

The only organization equipped to provide the resources and gather the communities to develop such an action plan was Health Canada. Therefore, a volunteer Steering Committee with a strong component of PWAs was formed to develop a process involving as many affected persons and AIDS groups as possible. Health Canada supplied support services to the committee. Approximately 40 of the AIDS community's boldest thinkers met in Sainte-Adèle, Quebec in December of 2002. The group developed some brilliant ideas that were sifted through further stakeholder consultations.

For framing purposes, the plan is divided into six sections: Prevention; Care, Treatment, and Support; Global Issues; Awareness and Sustainable Funding; and Front-Line Capacity.

The process of collaboration, consultation, agreement on goals, and evaluation produced a challenging and informative plan to improve the health and well-being of PWAs. A wide array of AIDS expertise, from government, AIDS organizations, and vulnerable populations, inspired and developed the frame-

work. Whether these same groups go on to make the national action plan's aims their own, and effectively respond to the causes and needs identified in the plan, will be a major challenge; these are pan-Canadian, AIDS-community goals, and it may prove difficult for specific governments and groups to adopt responsibility for collective goals.

Because this is breaking new ground for Canada, the mechanisms to monitor, assess, and adjust the plan to a changing epidemic do not yet exist.

Moreover, Canadians have never planned an HIV response involving all facets of local, national, and international activity. But because there is so much to gain by an efficient health system and so much to lose when it fails, effective health planning is championed by most of us involved in the AIDS sector.

What can be gained through public health planning is enormous. When all stakeholders participate, they better define who they are to the public and themselves, and Canadians can witness the interaction between goals, leadership, and service delivery. With so much confusion about government and health bureaucracies, and about who does what for HIV/AIDS in our communities, we need a clear vision of our national intention; we need to know, who accepts responsibility to act and who among our community, governments, and politicians will show leadership.

A SMART approach to planning

Several approaches were integrated in this landmark planning process. The Sainte-Adèle participants considered and prioritized HIV needs using a complex theory of orthogonal sets. This process forced participants to combine some issues, and drop others where support among colleagues was limited. The team exercise produced a binder of issues, which was refined further—through consultations in every major jurisdiction in Canada, and among most major organizations and populations with HIV concerns—to ensure the highest level of contribution possible in the Canadian response to HIV/AIDS. To develop goals, the team used the “SMART” method of planning, so that goals are specific, measurable, achievable, realistic, and time-based.

During my years working within the HIV community, the hardest part has been acknowledging the weaknesses, lapses, and failures in our approaches. No one wants to admit shortcomings. We PWAs feel uncomfortable confronting people

who sincerely try to make things better for us, and we often “shoot” those who speak difficult truths. And while it is natural to hold the largest government responsible for success, services are mostly provided locally. Health Canada, for example, once planned solely for their own activities, yet many of us held their Canadian Strategy on HIV/AIDS responsible for our local successes and failures. The Canadian action plan, however, avoids blaming and organizational attacks by developing sector-wide goals so we can quantify our successes and shortcomings, not as organizations but as work sectors. No one government or organization is responsible for our successes or failures.

Learning from failures at the BC provincial level

The trend to take responsibility at each jurisdiction for activities and successes appears a good one. Several jurisdictional plans, including BC’s *Priorities for Action in HIV* have stumbled badly, and we can learn from those mistakes. In BC, the province played fast and loose with language to avoid responsibility for including PWAs and service providers in designing their plan and its goals and governance.

**Every developed country
in the world has a
national PWA organization
to participate in the
monitoring and governance
of national plans—every
country except Canada.**

Our planning failures as a province are spectacular. In 2003, the provincial government set goals for what local communities should achieve in terms of lower infections and increased services. Yet the province did not take even partial responsibility for achieving the goals, did not provide new funding, and did not establish a shared approach to planning and governance. (See the preceding article “A Low Priority” in this issue of *living* ☉.) Not only are the aims of the 2003 plan widely off the mark, the government now seems to take credit for innovative community services they do not deliver, deflect responsibility for gaps in service, and ignore principles of PWA participation in goal setting and evaluation. The BC government has yet to sign on to the national action plan.

As for the national action plan, after supporting the logistics and philosophy of the Steering Committee’s planning approach, the sole federal acknowledgment was buried in a November 27, 2005 news release to announce funding for the AIDS 2006 Conference in Toronto. In the news release, the then-Minister of State for Public Health, Carolyn Bennett,

recognized that the plan “lays out the optimal, ideal response to HIV/AIDS in Canada.” Minister Bennett gave a nod to the dedication of the plan’s creators and identified a need for plan monitoring and evaluating. Her comments do not provide the leadership needed by the frontlines and funders, though she called the plan “a blueprint for all sectors of Canadian society.”

Do PWAs have the capacity to ensure success?

How will people with HIV in BC and Canada play a role? This comprehensive plan requires a new national, regional, and local capacity. It requires leadership among persons with HIV to champion the opportunities, participate in each of the sectoral analyses, and demand success. But this is probably asking too much of Canadian PWAs. Every developed country in the world has a national PWA organization to participate in the monitoring and governance of national plans—every country except Canada.

Our lack of a comprehensive national PWA organization results in a fractured national response to HIV. Our current national non-governmental organizations have narrower mandates than a national PWA organization might have. Canada’s historical lack of PWA participation in policy and service provision even at the local level leaves us with perhaps the least participating PWA community in the developed world.

Whether we can cobble together a new capacity to monitor and champion this plan may determine whether we can implement new AIDS programs and services effectively. The cost of failure will be continued high new infection rates, continued poverty and homelessness for PWAs, and HIV services without inclusive structure or effectiveness.

In BC, we have perhaps the best financial and community assistance for PWAs, the lessons of the provincial plan, and a climate of activism. We could form an educated part of a national PWA response. Whether we, and the national PWA community, are up to the task is perhaps the toughest challenge PWAs in BC have ever faced. ☉

Read the entire plan

To read the entire national action plan document, *Leading Together: Canada Takes Action on HIV/AIDS (2005-2010)*, visit the Web site at www.leadingtogether.ca.

Jeff Anderson, a long-time PWA advocate, represented the BCPWA Society at the Montreal meeting in 2002, at Sainte-Adèle, Quebec, and is currently a member of the Steering Committee for the national action plan.





The odd couple

On the surface, private-public partnerships may seem like an inspired concept. But the reality is far from encouraging.

by R. Paul Kerston

P3 or not P3—that's the hot question. P3, or PPP, is the acronym for private-public partnerships, defined as any collaboration between public agencies such as governments and private companies. Increasingly, governments are turning to such partnerships to help with financing, design, construction, operation and maintenance of public infrastructure and community facilities and services. P3s can involve construction or operations or both, and always for a specified contract period.

Examples of P3s, both locally and abroad, suggest huge cost overruns that should cause serious concern, not to mention the profit-driven cuts that are not fully accountable to the public.

P3s are particularly hot in Vancouver right now because of the potential—and highly controversial—move of St. Paul's Hospital from its long-time downtown location near the West End to a new site near False Creek, which is a distance from the heart of the city. Partnerships BC, a government-owned company responsible for bringing together ministries, agencies, and the private sector to develop projects through public-private partnerships, is involved in that project.

As taxpayers cry out against escalating healthcare costs and lengthening wait times for medically required procedures, polls indicate we are ready for almost anything that will fix the system. However, caution is in order: P3s might initially seem to

be an intelligent solution because business is traditionally known for driving down costs in order to succeed. However, examples of P3s—both locally and abroad—suggest huge cost overruns that should cause serious concern, not to mention the profit-driven cuts that are not fully accountable to the public.

The public component of P3s

Public-private partnerships (P3s) are defined by the federal government's Industry Canada Web site as "a co-operative venture for the provision of infrastructure or services, built on the expertise of each partner that best meets clearly defined public needs, through the most appropriate allocation of resources, risks, and rewards."

Given those last words, perhaps it should be called R3 instead: our taxpayers' resources go toward servicing the debt on the project, there are typically huge risks associated with these contracts, and we can only hope for rewards after major cost escalations.

On its Web site, Partnerships BC states that it structures and implements partnership solutions that serve the public interest. The site goes on to say this approach makes better use of taxpayers' dollars in areas such as highways and healthcare facilities. It doesn't explain how the P3 approach is better (although the implication is that government cannot do these projects as well) and so fails to make a strong case for why partnership solutions are a better way to provide the facilities and services that are traditionally the government's responsibility.

Both the federal and provincial agencies were created to assist government with divesting itself of unwanted expenditure control and risk. The problem is that accountability follows typical business practices of secrecy. Further, although government can borrow more cheaply than business can, it is the businesses who borrow—but since the government pays the debt, taxpayers shoulder the burden of higher interest rates than would otherwise be the case.

Major cost overruns

Recent local press on P3s is quite negative, and for good reason. It all evokes the old saying that something must be rotten if millions of flies are drawn to it.

A perfect example of negativity in the press is the Sea-to-Sky Highway upgrade. That project is expecting cost overruns of \$312 million according to a recent front-page story in *The Vancouver Sun*—and that's only a current estimate. This includes an increase from \$1.7 to \$2 billion of taxpayer-funded service on the debt over the next 25 years, simply because BC's Ministry of Transportation isn't in charge. It's a P3 project, and many of the risks on the project are being borne by the S2S Transportation Group. But those are our public roads. The provincial minister responsible recently opened one section of the newly finished roadway and boasted about how quickly and under budget that section was completed. What he failed to mention was the cost overruns on the remaining sections of the highway.

Similarly, *The Georgia Straight* recently reported that the capital costs for the Abbotsford Regional Hospital and Cancer Centre have gone up a whopping 70 percent, and the service payments to the consortium of companies financing the deal's debt (with use of taxpayer dollars) more than doubled, as did the 33-year contract's operation costs. The BC Health Coalition estimates that the total cost overruns on the project are as high as 94 percent.

The problem with P3s isn't just local. Britain, with both P3 highways and hospitals, experienced similar escalated costs, as noted by no less an authority than the Association of Certified Chartered Accountants. They reported profits on roads and hospitals, in Britain, were between 50 and 70 percent. Interestingly, Britain's Auditor General and the UK's National Audit Office were apparently refused total access to the books.

So-called value for money

Even supporters of the P3 model no longer attempt to justify this form of privatization as money-saving. Instead, they now refer to P3 projects as "value for money." So, in the interest of identifying the truth, BC's Auditor conducted an audit on the Abbotsford project on that very issue. The results of that audit, which began roughly one year ago, have not been released.

While creatively-structured reports on how much value one gets for the public and private money spent might point toward partnerships, they completely miss the overall mark. The government only saves money on its shifted year-to-year costs—in time for each election—but the tax dollars spent are higher in the long run. Cost overruns and increased fees, plus a remarkable lack of public accountability, are more than just illogical. The International Monetary Fund doesn't approve of this bookkeeping practice, which seems like little more than creative accounting—or your basic con man's shell game.

The obvious reason why the P3 deals are shrouded in such secrecy stems from the private business interests; however, government dollars are involved and the public is demanding answers.

The lowdown on St. Paul's

So, how does all of this affect the downtown and West End communities in regard to St. Paul's Hospital? For one thing, there is considerable controversy concerning the purchase terms of the False Creek land areas, including questions about why it was done using a private society instead of the municipal government working directly with St. Paul's Hospital's Providence Health Care board of directors. Following known P3 examples of higher expenses, it stands to reason that this deal will sweeten some private interests and ultimately cost taxpayers more.

Furthermore, this deal brings the whole two-tier healthcare concept forward: the society that bought that False Creek land in anticipation of the St. Paul's move, Vancouver Esperanza, has directors with ties to the relatively new and controversial Cambie Surgery Centre. Despite assurances by the Centre that they offer basic healthcare services completely in line with BC's Medical Services Plan and only charge patients for extras which aren't covered, many people view this as a start down the long and slippery slope toward faster care for paying people.

Finally, one outcome of P3s is to make money, and the sale of the current Burrard Street site could fetch an estimated \$160 million dollars. Who benefits? Perhaps not the taxpayer, given the project secrecy and the usual cost overruns. No, it's the private investors that the province has mandated Partnerships BC to attract.

Could all this explain why the deal won't be discussed except in small, controlled "focus groups" and why requests for information and meetings are frequently denied by those involved in the St. Paul's deal? And, more importantly, should this concern the taxpayers and, in particular, the locals?

You bet.

Regardless of whatever defenses local operators frequently offer for public-private partnerships, the practice has been shown ineffective in such wide-ranging places as Nova Scotia, Ontario, Australia, Scotland, and England.

In England, worrisome hospital conditions include shoddily-run hospitals and medical staff cutbacks to meet projected expenses in a profitable manner. These cutbacks could hardly help us deal with our own emergency room delays and wait times for surgeries.

As the public considers various alternatives to fix our ailing national and provincial healthcare systems, it doesn't really look like the P3 model is the way to go—given its incredibly high cost overruns and poor accountability—for such an important, basic societal need as healthcare. ☹



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



THE THORNY TREE

*The Antiretroviral Treatment in Lower Income Countries (ART-LINC) Collaboration is a research collaboration of HIV treatment clinics in resource-constrained settings. As part of her job with the ART-LINC Collaboration Paula Braitstein travels to clinics and learns about what they do, how they do it, and what social and cultural contexts are affecting them. She's talked with local clinicians, researchers, and people infected and affected by the HIV epidemic in Africa, Latin America, and Asia. She reports on her observations in this first instalment of what will hopefully be a new regular column in **living** ☉, *The Thorny Tree*.*

No easy answers

Deciding on the best way to support children in Africa who are orphaned by the AIDS epidemic

by Paula Braitstein

Although nearly every country in the world has children aged less than 18 who have lost one or both parents to HIV/AIDS, sub-Saharan Africa is the most broadly and profoundly affected. UNAIDS (Joint United Nations Programme on HIV/AIDS) estimated that at the end of 2004, there were some 12 million children orphaned by AIDS on the continent, with the number increasing to 18 million by 2010, or even higher, depending on the extent of availability of antiretrovirals by that time.

While the definition of an orphan is a child where one or both parents have died, the concept of orphans also includes children who have been abandoned. It is not uncommon to hear of babies left at police stations in the middle of the night, or left behind in a maternity ward after an HIV-infected mother gives birth.

It is also becoming more common for parents or caregivers to bring a child to a hospital because they or the child is sick, often with AIDS, and then abandon the child at the hospital. Many children remain in hospital for extended periods, not because they're sick, but because there is nowhere else for them to go—nobody returns to claim them and the healthcare workers look after them until they find an orphanage or family who can care for the child.

While some parents are too sick themselves to look after their children, others have to work—for example, in mines or in the sex trade, where they cannot properly care for their children. Or, parents may feel that because of their own HIV infection, poverty, or other issues, their child will have a better chance with someone else.

Extended families unable to care for them

The problem is, though, that the governments rarely support extended families or communities to take on the responsibility of caring for orphaned or abandoned children. Many extended families are already stretched beyond their limits and cannot look after one more child, which traditionally is how most orphaned children would be accommodated. So, while they would be willing to look after one or two other children who are not their own, these families can't afford to feed them or send them to school. As a result, children often end up in orphanages, foster homes, in hospitals, or on the streets. The older ones often look after the younger ones in what are called child-headed households.

There is no question that the issue is a tearjerker, and I've shed a few tears at the sight of otherwise healthy children in hospitals because they've been abandoned. Or at the sight of a toddler in a foster home playing with a girl to whom he has become very attached, not knowing that he is about to be adopted by a white American family—meaning he'll be separated from the one person in the world with whom he has managed to form a real attachment.

Many people, myself included, see these children on television or travelling, or read about them in magazines and think about adoption. I have encountered and heard about numerous people (all Caucasian) from the US and Canada who are in various stages of the adoption process. But is adoption really the best solution? There are certainly no easy answers.

Losing their African identity

In the short term, it may well be better for the children to be adopted—assuming the adoptive parents have the right intentions and the capabilities to raise a child in a healthy, loving, supportive environment. They will have a much better chance of being fed, housed, clothed, and schooled. They will grow up in a family environment where parents dote on them. In many cases, however, their names will be changed, along with their sense of identity. It will be up to the adoptive parents to proactively support the children's connections with their African roots and culture and disclose the details of how they ended up where they are.

If adoption keeps them safe and happy in the short term, isn't that a considerable benefit? It will also give them an opportunity to pursue their dreams and abilities in the long term, an opportunity that in all probability wouldn't really exist otherwise.

The question is, though, what will this do to African communities in the long term? In theory, it could help, by virtue of fostering the youth who are today Africa's most precious resource. As they grow older, they can choose to return, to lead their countries of origin in peace and prosperity, to break the cycles of poverty and disease that created the very conditions that led them to be adopted in the first place.

But it could also weaken the fabric of African society and communities. By removing children from the situation, one removes (temporarily) the burden that has become Africa's, both to bear and to solve. It absolves African governments from having to take responsibility and act to support children in their communities and extended families. It also creates a world market for babies—let's face it, few people want to adopt older children—where the rich and privileged can free their consciences about "those poor AIDS orphans in Africa" by performing an act of charity.

A sense of displacement

What happens, then, to the children as they get older? Their sense of otherness will become stronger as they grow up, when their awareness of being black in a Caucasian family and community becomes stronger, especially as more and more people ask why. They may choose the streets and drugs as a way of annihilating feelings of displacement, identity disconnection, and not really belonging either to their adoptive families or communities.

Indeed, the discussion is reminiscent of the adopting out practices of First Nations children, a practice that in Canada has been condemned by Aboriginal peoples across the country for many of these very reasons.

Among the African people I've spoken with on the subject, there is no consensus. Some take a "Screw political correctness and get those kids somewhere where they'll be fed and educated" attitude. Others are dead set against orphanages,

HOW YOU CAN HELP

Guess what—there is something you can do to support children to stay in their communities. An arrangement has been made with Indiana University (IU), which operates a large and incredibly impressive HIV clinic in Eldoret, Kenya to accept and distribute donations to pay for school fees for children who have been orphaned or abandoned. All the money goes directly to paying school fees, whether primary or secondary school or university, and none of the money will be used for administrative or other purposes, with the possible exception of grants made to kids for clothes, books, or food.

The people working at the IU centre in Eldoret have been there for a long time and know the communities, orphanages, and people very well. They are highly trusted and respected and many people turn to them for their help. Don't expect a tax receipt and don't expect a thank you, but you can request communication with the child you support.

- ▶ Primary school fees for a year are \$150 US
- ▶ Secondary school fees for a year are \$1,000 US
- ▶ University tuition for a year is \$1,000 US
- ▶ University tuition (including books, room, and board) for a year is \$2,000 US

Support children to stay in their communities. Help them find their own way. Help them make informed choices. Help them to go to school.

To contribute: contact rpettigr@iupui.edu for tax deductible US donations that go to general orphan care, or jsidle@iupui.edu for information regarding direct donations that can go to specific individuals.

even in Africa, because they feel that communities and extended families should bear the responsibility. In the meantime, there are 12 million kids in sub-Saharan Africa in need of food, care, and safety. ☺

Paula Braitstein is the epidemiologist and project manager of the ART-LINC Collaboration (Antiretroviral Treatment in Lower Income Countries Collaboration). She is the former BCPWA Society senior policy advisor on health promotion.



The housing squeeze

The subsidized housing wait list grows as affordable housing options decrease for Lower Mainland PWAs

Over 800 HIV-positive Lower Mainland residents are currently living without access to affordable, adequate shelter. The number of HIV-positive men, women, and children lingering on wait lists for subsidized housing has hit an all-time high in the province of BC, and the people closest to the problem confirm that the rapidly increasing numbers are cause for concern.

"The situation definitely qualifies as a crisis," says Ken MacDonald, the executive director of Wings Housing Society, the largest provider of housing for people with HIV in Canada. "Right now we just can't meet the need."

JoAnne Fahr, the executive director of McLaren Housing Society, agrees. "Since 2002, we've experienced a 60 percent increase in the number of people wait-listed for housing, and the trend will accelerate if the government doesn't allocate more resources to the problem."

Although single-room occupancy hotels protect residents from the physical dangers and psychological damage of life on the streets, they don't meet people's basic needs.

Compounding this crisis is the fact that the maximum monthly pension amount that a person on disability can expect has been frozen at \$856.32. Yet according to the Canadian Mortgage and Housing Corporation, the average rent for a one-bedroom apartment in Vancouver is \$774 per month. That makes it impossible for many PWAs to afford adequate shelter.

With conventional housing out of their reach, many HIV-positive individuals are forced into homelessness. The luckier ones manage to subsist in one of the many single-room occupancy (SRO) hotels in Vancouver's Downtown Eastside area. Although



by Rachel Grainger

these hotels protect residents from the physical dangers and psychological damage of life on the streets, they don't meet people's basic needs.

Roger, a HIV-positive Lower Mainland resident, has been on a subsidized housing wait-list for over three years. "I'm paying \$385 for a single room," he says. "I can't afford to pay more and I don't have much money for everything else I need: food, bottled water, vitamins, clothing, and transportation. Usually there's nothing left before I get to the end of the month." He often has to cut back on the nutritious foods and supplements he knows are critical to maintaining his health.

Although almost half of Roger's income goes towards shelter, his residence is little more than a squat. The bathroom and kitchen that he shares with seven other residents are filthy and in bad repair. "It's a dive," he says. "The worst part about living here is the cockroaches and mice. They're everywhere and there's nothing you can do about them."

Apart from the psychological effect of living under these conditions, it's a serious health hazard for people who live with compromised immune systems. Poor sanitation can quickly lead to health complications for HIV-positive individuals, especially when other related health issues—such as hepatitis C in Roger's case—compound their susceptibility to other illnesses.

The situation will only worsen as the Downtown Eastside area gradually gentrifies. Fewer and fewer SRO units are available to shelter the overflow of people, many of them disabled, who are currently wait-listed for subsidized housing. And as the cost of living increases, the freeze on disability benefits means that the housing options available to people scraping by on disability pensions will continue to shrink.

Roger has his fingers crossed that he'll find a place in a subsidized housing complex soon. But for now, like the 800 other HIV-positive people in the Lower Mainland, he can only wait for a chance to live with a little comfort, security, and dignity. ☹



Rachel Grainger is a volunteer for the BCPWA Society's Communications Department.



treatment. information

TREATMENT INFORMATION PROGRAM MANDATE & DISCLAIMER

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

The Treatment Information Program endeavours to provide all research and information to members without judgment 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, or 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.



Keeping tabs on drug toxicity

by Derek Thaczuk

Antiretroviral use is a trade-off between the upside (efficacy) and the downside (toxicity) of the drugs. We have to know as much as possible about the advantages and disadvantages before making educated treatment decisions. But serious drug toxicities may not be recognized until after medications are approved. In fact, it is estimated that serious side effects of over one-half the drugs in Canada are detected after approval.

The post-approval surveillance system (PASS) is a process for tracking these adverse drug events (ADEs) after drug approval. Evidence suggests that the existing Canadian PASS does not collect timely or complete data. With the hope of improving the system, the Canadian Treatment Action Council (CTAC), a national PWA organization dedicated to treatment issues, is currently concluding the PASS Study—a community-based research project of ADE reporting.

continued on next page

Different data collection methods

Researchers from the BC Centre for Excellence in HIV/AIDS designed and conducted the PASS Study research protocol. Importantly, though, the whole project was overseen by stakeholders, including PWAs, healthcare professionals, government, and pharmaceutical representatives. By evaluating several community-based side data collection methods, the study identified important issues about the ways in which this kind of data is collected.

The specific data collection methods were:

- ▶ a bilingual, toll-free phone line for participants to call
- ▶ data collection forms, which could be faxed or mailed free of charge
- ▶ one-on-one interviews, held at community agencies in Toronto, Vancouver, and Montreal
- ▶ four focus groups with Aboriginal people, held in rural and urban areas.

The first three methods yielded a total of 1,070 adverse drug reports between November and July 2003. In addition, more adverse reports were collected at the focus groups among a total of 22 Aboriginal people.

All of the collection methods succeeded in gathering data, but to vary-

ing degrees. Only 97 responses were collected through the mail and fax method. The toll-free line needed a great deal of staff time and training, but surprisingly yielded even fewer responses: only 40 completed interviews. Personal interviews required the most resources, but also gathered by far the most—and the most useful—data, with a total of 933 reports.

Various reporting challenges and issues

There were many reporting challenges, including the respondents' ability to remember and identify ADEs; difficulty linking specific drugs to specific ADEs; and separating out specific ADEs from overall "lived experiences."

These challenges showed that the current PASS system—which gathers information by having healthcare professionals fill out forms at the request of individuals who experience specific physiological ADEs—could learn significant lessons about large-scale community-based reporting. The information gathered by the PASS Study into community-based data collection methods was generally consistent with existing clinical information—that is, these methods could prove feasible to the scientific community.

But the PASS Study confirmed that what is important to the medical community and what is important to PWAs may overlap, but does not always coincide. A trade-off is involved: at one extreme, professional ADE reporting focuses on specific medical problems (such as liver or kidney damage). However, medications have other important long-term impacts on quality of life—on-going nausea or sleep disorders, for example, or medications' high cost—and many of these long-term social effects may be missed by the narrower kind of reporting. But broader and more inclusive reporting makes it harder to sift out the clinical information needed for medical purposes.

Large-scale PASS systems will have to accommodate both needs, allowing clinical information to be reported as accurately as possible, but also allowing for the social, emotional, and financial hardships, and the difficulties with the healthcare system, that result from living with HIV/AIDS and its associated medications. ⊕

Derek Thaczuk is a freelance consultant and medical writer with 11 years involvement in the HIV community.



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On December 9, 2005, protesters distributed leaflets outside the campaign office of The Honourable Ujjal Dosanjh, former federal Health Minister, to demand access to TMC114 and TMC125.

Fighting for life

A huge controversy exploded when Health Canada refused to approve the TMC drugs for five dying men

by Rob Gair

When protease inhibitors exploded onto the market in the mid-1990s, everyone thought we had struck the mother lode of HIV therapy. The enthusiasm was justified because these drugs ushered in the advent of highly active antiretroviral therapy (HAART), which combined antiretroviral drug classes to provide an effective treatment cocktail.

HAART dramatically improved HIV therapy and quality of life for those living with HIV/AIDS, but despite its huge benefits there have been many problems. People who have used these medications for a long time know about side effects and inflexible drug regimens, about refrigerating medications, taking handfuls of pills, and the seemingly inevitable problem of drug resistance. After only one decade of HAART, there are increasing numbers of individuals who either cannot tolerate certain medications or who have developed resistance to the point where there is nothing left to choose from among almost 20 commercially available HIV drugs.

When people get to the stage in which they've run out of HIV drug options, they enter into "salvage therapy." Generally

this approach means taking not just three antiretrovirals at a time but five or more and maybe having to take injections or prophylactic antibiotics as well to prevent opportunistic infections—all with the goal of keeping the virus at bay until a new medication enters the market. Which brings us to another problem: for various reasons, the current market for new HIV medications has entered a dry spell. Sure, there are some exciting new HIV drugs in the pipeline but some of the more promising ones are still a few years away from pharmacy shelves.

The promise of TMC114 and TMC125

Two new noteworthy antiretrovirals are from Belgian manufacturer Tibotec. TMC114 (darunavir) and TMC125 (etravirine) have shown promise in phase II clinical trials for people with highly resistant HIV. Phase III trials are currently underway (see Figure 1 for an explanation of drug phases) and normally this stage must be completed before a drug is eligible for regulatory approval. However, both TMC114 and TMC125 have received fast-track status by the US Food and Drug Administration,

Figure 1: The phases of drug development**Phase I**

A new drug is tested in a small group of 20 – 80 people to determine a safe dosing range and identify side effects.

Phase II

The drug is tested in a larger group of 100 – 300 people to see if it is effective and to further evaluate safety.

Phase III

The drug is given to a large group of 1,000 – 3,000 people to confirm effectiveness, monitor for side effects, and to compare it with commonly used treatments. When drugs complete this phase they are eligible for regulatory approval.

which means they could be available in US pharmacies as early as this summer.

TMC114 is a new generation “non-peptide” protease inhibitor (PI), chemically related to amprenavir (Agenerase). It was developed after an extensive search for a PI with high-potency activity against both wild-type HIV and multi-resistant strains. Test tube studies showed high binding strength to the protease enzyme and low tendency for development of resistance.

More recently, results were presented from phase II clinical trials in almost 300 HIV-positive patients who had extensive experience with other antiretrovirals (ARVs) but were failing their current drug regimens. After 24 weeks, 39 percent of patients who received ritonavir-boosted TMC114 at a dose of 600 mg twice daily were able to achieve undetectable viral load, compared to only seven percent for those receiving a regular “optimized” ARV treatment. The most common side effects were headache and nausea, which were reported in 17 percent of patients. Six percent of patients had a “serious increase” in their triglyceride levels.

Last November, TMC114 and TMC125 gained notoriety when news broke about five BC PWAs who were failing salvage therapy and needed access to new medications.

TMC125 is a non-nucleoside reverse transcriptase inhibitor (NNRTI), in the same class of drugs as nevirapine (Viramune) and efavirenz (Sustiva). This class of ARV is particularly prone to developing resistance. TMC125 was specifically designed to be flexible so it could fit tightly into the pocket of the reverse transcriptase enzyme. The flexibility of the molecule also allows it to adapt to changes in the pocket shape that occur when resistance develops.

Four phase II clinical trials examined the effectiveness and safety of TMC125 in patients who had previous resistance to other NNRTIs. Most of the studies showed improved outcome after switching to TMC125. However, one study comparing TMC125 to a PI in patients with previous NNRTI resistance found after 12-weeks that those getting the PI were more likely

to have undetectable viral loads. The most common side effects appear to be nausea, diarrhea, and rash. Of interest is recent data suggesting that a new “multi-layered” tablet offers improved drug absorption, allowing for a lower daily dose. This new formulation will be used in the phase III trials.

The media brouhaha

Last November, TMC114 and TMC125 gained notoriety when news broke about five BC HIV-positive individuals who were failing salvage therapy and needed access to new medications. Their specialist, Dr. Montaner, chose these medications because of the favourable phase II clinical trial results. Because the drugs have not yet passed regulatory approval, Dr. Montaner contacted Health Canada’s Special Access Program (SAP) for permission to acquire these medications from the manufacturer. The application was ultimately denied because the SAP was concerned about a lack of clinical evidence examining the use of the two medications in combination.

Despite explanations about the clinical relevance of using these drugs in combination, and despite intense media pressure, the decision was not reversed on appeal. In the end, Dr. Montaner had no choice but to set up his own clinical trial for the five patients so the drugs could be used in combination under regulations outside the SAP.

The SAP’s official reason for denying access to these patients is not convincing because their own disclaimers state that special authorization “does not constitute an opinion or statement that a drug is safe, efficacious, or of high quality.” But Health Canada’s rejection of the application because of a lack of clinical evidence seems to be a comment on the perceived efficacy and/or safety of the drugs. However, it’s unlikely that a satisfactory explanation for their decision will ever be revealed. Perhaps the point is moot because the drugs will be used in combination during phase III trials. Early results from these trials should be available soon and, as long as the data is good, future patients may then be eligible for access under the SAP. ☉



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



How the Special Access Program works

by Sam Friedman

Health Canada's Special Access Program (SAP) provides access to health products that are not available for sale in Canada. SAP provides products only to people with serious or life threatening illnesses, on a compassionate or emergency basis and only when conventional therapies have failed, are unsafe, or unavailable. The Canadian Food and Drug Act's Regulations, sections C.08.010 and C.08.011, govern SAP policies. The SAP is not a way to acquire fast track approval of a new medication or a way to bypass normal clinical research review and approval procedures.

It is the responsibility of a practitioner to apply to SAP for access to specific products. A practitioner must fill out a special access request form and include all available evidence from medical literature and the drug's manufacturer to prove that the request is based on solid scientific safety and efficacy evidence. The practitioner must also ensure that patients who may receive special access are informed of all known possible risks and benefits of the product being requested and must keep medical records on the use of the product, blood work, side effects, drug interactions, and any adverse drug reactions.

The SAP does not conduct its own research nor does it evaluate the validity of the documentation by either the product's manufacturer or the medical literature provided in the special access request form; decisions to grant or deny a request are solely based on the information provided by the practitioner making the request.

Moreover, a SAP authorization to access a product does not constitute an opinion or statement of a product's safety, efficacy, or quality, though this information strongly influences decisions. The SAP limits the amount of a product released at one time to a six-month supply, after which the entire special access request process must be repeated. The SAP attempts to process special access requests for products already approved for access in 24 hours, and a

triage system ensures requests for life-threatening conditions take precedence over less urgent matters. Products not yet approved for special access can take considerably longer to process.

Regardless of whether the SAP approves a request, manufacturers have the final word on whether or not they will supply a requested product. Although there is no requirement that the manufacturer supply the product free of charge, they often do. When the manufacturers do impose a charge, the patient (their family or friends or community groups), their hospital, or a public and/or private insurance plan pays the cost.

The manufacturer also has the right to impose restrictions or conditions on the release of their product. They can restrict the amount of product released; require information on the patient(s) receiving the product; impose payment requirements and conditions on shipping. The manufacturer's shipment conditions are identical to the SAP's conditions—that products can only be shipped to the office of the practitioner who made the special access request or to hospitals or clinics with in-patient pharmacies. They cannot ship special access products to retail pharmacies and they must provide the practitioner with all of the manufacturer's information on the requested product, whether this information is public or confidential.

SAP forms, guidance documents, and the list of accessible products are all on the Health Canada Web site at www.hc-sc.gc.ca/dhp-mps/acces/drugs-drogues/index_e.html. ☺

Sam Friedman is a provincial and national AIDS advocate and activist. He is a CTN Community Advisory Committee member, a member of multiple BCPWA Society standing committees, and a regular contributor to *living* ☺.





How lipodystrophy affects HIV-positive women versus men

by **Audrey Le**

One of the most noticeable side effects that HIV-positive women experience at some point is a change in body shape due to lipodystrophy and lipoatrophy. Lipodystrophy and lipoatrophy are often mistakenly identified as the same disorder. Lipodystrophy refers to elevated blood lipids, fat gain, and fat loss—in other words, the abnormal distribution of fat throughout the body. While lipoatrophy (also known as peripheral wasting) may be grouped as a subcategory of lipodystrophy, it refers to the loss of fat in the face, abdomen, and/or in peripheral regions such as the arms and legs.

The progression of lipodystrophy is notably different in men and women. There are four key distinctions between the genders:

Morphological changes. Fat masses accumulate in different places in a woman's body. Women tend to have higher rates of increased cholesterol and triglyceride levels.

Fatty tissue composition. Women more often experience adipose tissue alterations.

Bone tissue composition. Women undergoing antiretroviral treatment suffer more often from osteopenia and osteoporosis.

Changes in hormone levels. Women with lipodystrophy have elevated levels of testosterone.

Morphological changes are the most visible symptom of lipodystrophy. Women tend to accumulate fat in the waist and chest, resulting in breast enlargement as well as overall weight gain. Women affected by this symptom need to change their bra size frequently. If you experience these morphological changes, don't buy too many bras until your breast size stabilizes. Fat may also deposit in the neck and upper back, creating a dorsal fat pad around the neck, resembling a hump.

While some people gain unwanted fat, those with lipoatrophy lose fat in very specific areas such as the face, arms, legs, and buttocks. In women, however, these incidences of lipoatrophy occur less frequently than does lipodystrophy.

Psychological problems may arise with the physiological effects of either lipodystrophy or lipoatrophy. Both syndromes

may result in diminishing physical and emotional well-being, leading to an increased risk of heart disease, diabetes, and depression. Women may experience a loss of self-esteem, because they find it difficult to accept widening waists and a loss or gain of fat in the facial area. Wearing skirts and low-rise pants may be more comfortable and flattering. Consulting with an aesthetician for make-up tips can help deal with some of the facial changes.

Studies have revealed a high correlation between lipodystrophy and lipoatrophy and highly active antiretroviral therapy regimens that include protease inhibitors and nucleoside reverse transcriptase inhibitors. Although scientists have observed some links between antiretroviral drugs and symptoms of lipodystrophy, they have yet to establish a cause and effect relationship; there is no reason to discontinue use of the antiretrovirals.

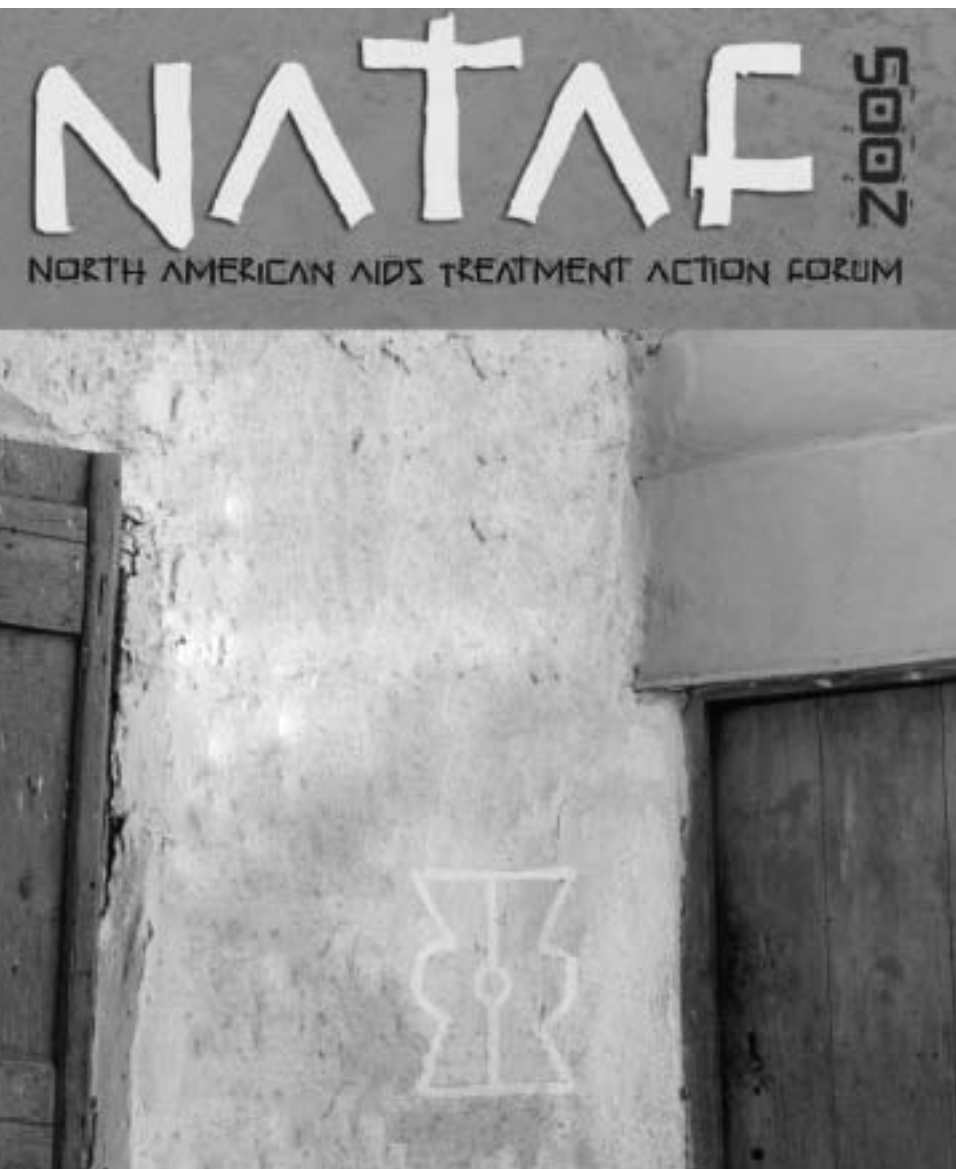
Until further research is done, it is important to monitor changes in your health frequently: keep your doctors' appointments, get regular lab tests, and report any changes in body shape. Recording body measurements and weight twice a year is also recommended.

There is no simple treatment for lipodystrophy. Lipid-lowering medications may alleviate some of the metabolic complications such as increased cholesterol, triglycerides, or glucose levels.

Because women are more prone to developing osteopenia and osteoporosis, it's important to increase your calcium intake, decrease caffeine intake, and stay physically active. As always, eating a healthy diet, exercising regularly, and giving up smoking will help decrease the onset of complications associated with lipodystrophy and lipoatrophy. ☺

Audrey Le is a volunteer writer and researcher for the BCPWA society.

Our members provide first-hand perspectives of the NATAF conference



The great divide

by Michael Connidis

The most recent North American AIDS Treatment Action Forum (NATAF) was held in Oaxaca, Mexico in November 2005. It was the first time that Mexico was the host country for this annual conference. In spite of some logistical problems and limited facilities, NATAF Oaxaca was an exceptional gathering. Most impressive was the number of Mexican delegates who represented a very broad spectrum of

people and communities; close to two-thirds of the 700 attendees were Mexican, due to generous scholarship funding from the Mexican government.

In all sessions, the huge disparity between the levels of HIV/AIDS care and treatment available in different areas of North America was evident; personal anecdotes and professional statements from delegates only served to underline



photo Kab Webster

the differences. In Mexico and particularly outside of Mexico City, services are woefully inadequate; it was almost embarrassing for Canadian and US delegates to talk about aspects of care and treatment that we consider standard but that many conference attendees could only dream about.

Here in Canada, we debate issues such as testing for resistance to antiretroviral (ARV) drugs, the need for therapeutic drug monitoring, and access to all alternate ARV combinations. We take for granted that our viral load will be checked every two to three months and that we'll receive results in a timely manner.

A person living with HIV in Mexico, however, is entitled to only three viral load tests per year. The reality is that most only manage two tests and it can take up to four months for results to return. Lab results may not be reliable due to mishandling or delays in receiving blood samples, lack of reagents, and variability in technical skill and procedures. Access to ARVs is limited to less than a dozen drugs due to trade agreements with the US (which restrict the use of cheaper generic drugs) and a lack of adequate funding from the Mexican government.

Trying to address HIV/AIDS in North America right now is like trying to drive a car while we're still assembling it. Care and treatment is being undertaken without the infrastructure and resources needed to ensure the best outcomes. The success of those people working to improve the situation is thwarted by the ignorance, stigma, and discrimination that abound in their respective communities. What we need is a vehicle that will provide the best treatment available to all people living in North America. This was addressed eloquently in the closing plenary of the conference, which outlined seven spheres of

action that need to be undertaken in order to address the HIV epidemic in North America.

- 1) **Stigma and discrimination.** To address stigma and discrimination by ensuring that: government policies, practices, and laws set the gold standard for people living with HIV/AIDS; public education and awareness is in place; social norms are changed; there is institutional reform in the private and public sector; there is democratic participation of individuals and communities in HIV/AIDS initiatives.
- 2) **Determinants of health.** To support advocacy around determinants of health for all populations.
- 3) **Harm reduction.** To develop a comprehensive, pan-country definition of harm reduction for all populations.
- 4) **Immigration.** To ensure that policies and government programs guarantee freedom of movement and pan-country access to services for all populations.
- 5) **Prevention.** To develop targeted prevention messages that will reach each of the affected populations in a meaningful way.
- 6) **Diagnosis.** To ensure comprehensive diagnosis programs that are appropriate to all populations.
- 7) **Access to care & treatment.** To ensure safe, affordable access to comprehensive care and treatment for all populations, as well as education around treatments, and resources to adequately train healthcare professionals.

NATAF has been addressing HIV/AIDS treatment issues in North America for over a decade. The gross disparities are clear and the above spheres of action show us a way to reduce the disparity and assemble a better vehicle for all. Such work requires a united effort—and adequate resources—that will mutually benefit all three countries

The host country for the next NATAF has not been announced, leaving the future of NATAF in doubt. But the important work being achieved through this multinational forum must continue. ☺

Michael Connidis is a member of the BCPWA Society and a member of the living ☺ editorial board.



Double struggle

by *Margarite Sanchez and Kath Webster*

The NATAF Conference in Oaxaca, Mexico was held from November 27 – 30, 2005. Immediately following NATAF, the Mexican National HIV/AIDS conference started on World AIDS Day, December 1. Between these two significant HIV/AIDS events, Oaxaca was buzzing with activity.

The energetic and stimulating atmosphere at the NATAF conference facilitated natural and easy networking among delegates. Sessions were well attended and participants were hungry for information and eager to discuss issues affecting them and their communities.

Mexico has had legislated universal access to medications since 2003. However, there are few medications available and approval is slow due to lack of funding and political will.

Mexico has less than a dozen HIV drugs available compared to Canada where there are over 20 approved HIV drugs. HIV/AIDS treatment and services have become more available in Mexico lately, especially in urban areas. It was encouraging to talk with Mexican health-care professionals who work in clinics that provide a variety of services. However, we also learned that quality of care varies greatly between rural and urban areas and between the poor and the rich.

Mexico has approximately 94,000 reported cases of HIV, but the estimated number of infected people is considerably higher—somewhere between 160,000 and 260,000. Just over 16 percent of reported cases are women. The most common mode of transmission for women is through heterosexual contact with a steady partner. In some rural parts of Mexico where HIV rates have been on the rise, migrant workers to the US may be playing a role. Studies have shown that male migrant workers tend to exhibit high-risk behaviours while residing in the

US. When the workers return to their villages in Mexico, their wives may then be at risk of contracting HIV.



photo Kath Webster

**NATAF closing ceremony slogan:
There is no one better to speak for us than ourselves.**

At the NATAF conference, four workshops focused specifically on women: Treatment Issues for Women; Pregnancy and HIV; Research Around Antiretroviral Use and Complications in Women; and Access to Timely and Permanent Reproductive Healthcare for Women. Overall, there was a minimal focus on women at the conference and some information was lacking, so two Canadian women who are treatment educators, Louise Binder and Shari Margolese, organized a very successful and informative satellite workshop on how HIV drugs affect women differently from men.

As in many other parts of the world, women with HIV in Mexico face numerous struggles. On top of dealing with the challenges of HIV, they have to deal with issues of oppression in a male-dominated culture where machismo rules. Many HIV-positive women don't have the option of disclosing their HIV status until their husbands die. This limits their ability to access care and support. Also, not surprisingly, women are underrepresented in AIDS organizations. The few women who are involved are often treated like token stakeholders and/or marginalized. This trend may be reversing: the HIV-positive Mexican women we met were well informed, dynamic, and committed to organizing locally and nationally.

The NATAF conference in Oaxaca was a success: it provided an opportunity to update our knowledge, network, and gain renewed inspiration in our work. The many facets of HIV/AIDS present serious challenges especially in a low income country like Mexico. Having the conference in Oaxaca with its warm ambiance and friendly people gave participants a balance between the severity of the issues and the importance of enjoying life. The fabulous opening candlelight procession and the closing fiesta confirmed that Mexicans really know how to celebrate life. ☺

Margarite Sanchez (l) is a founding member of the Gulf Islands HIV Support Group.

Kath Webster (r) is a researcher and educator for the Treatment Information Program at the BCPWA Society.



Ask the dietitian

If you have a diet or nutrition question, email it to dietitian@bcpwa.org or mail it to *living +*, BCPWA Society, 1107 Seymour Street, 2nd Floor, Vancouver, BC V6B 5S8.

Are red wine and chocolate good for you?

by Angela Birnie

“I’ve been reading about antioxidants in red wine, chocolate, and green tea. Are these foods really healthy?”

There would be a lot of happy people if wine, chocolate, and tea were the secret to eternal life. While these foods are high sources of flavonoids (a type of antioxidant), they haven’t proven to be our fountain of youth just yet. Some scientists have found potential health benefits in these foods, while others have found that red wine, green tea, and chocolate have no positive effect on our health.

Red wine is a moderate source of flavonoids, while white wine and beer have almost none. If you’re looking for antioxidants in alcohol form, red wine is your best pick. Potential health benefits of moderate red wine consumption include improvements in blood pressure, “good” cholesterol, and the functional quality of your arteries—any of which could lower your risk of heart disease. But that doesn’t mean your next dinner party should include a bottle of red wine per guest. The risks of excessive red wine consumption far outweigh the antioxidant benefits. Liver problems aside, alcohol can substantially raise triglycerides. If your triglycerides are already high—due to your highly active antiretroviral therapy (HAART) regimen or otherwise—alcohol will certainly worsen the picture.

Where chocolate is concerned, dark chocolate is your best source of flavonoids. It has twice the antioxidants of red wine. Milk chocolate only has one quarter the flavonoids of dark chocolate. Dark chocolate may also lower the risk of heart disease by lowering blood pressure, improving the functional quality of your arteries, and increasing the sensitivity of insulin. Unfortunately, chocolate also comes with a lot of calories, sugar, and saturated fat. While the saturated fat in chocolate is mostly stearic acid, which is less damaging to your heart than other saturated fat, too much chocolate could actually raise your cholesterol, triglycerides, and blood sugar. Besides, the chocolate sauce on your ice cream doesn’t cancel out the ice cream.

Brewed green tea has six times more flavonoids than red wine and over twice as many flavonoids as dark chocolate. (Brewed black tea has almost as many flavonoids as green tea, while the flavonoids in brewed oolong tea are comparable to dark chocolate.) Green tea may lower the risk of breast cancer in women and may lower blood pressure. While green tea is unlikely to be harmful, Starbucks’ frappucinos are the exception. A venti-sized Tazo green tea frappucino blended crème with melon syrup boasts almost 700 calories, half a day’s worth of saturated fat (10g), and over a third of your day’s quota of carbohydrates (97g)—a nightmare for your arteries and blood sugar. You could, however, order a non-fat, no- whip, no-syrup frappucino, but at that point you might as well drink plain green tea.

It’s too early to tell whether red wine, green tea, and dark chocolate have guaranteed health benefits. Even if they turn out to have a positive effect on disease risk, they’re unlikely to be deemed miracle foods. So, enjoy plain green tea, but have chocolate and red wine only occasionally.

And don’t forget about all the other flavonoid powerhouses. Gram for gram, blackberries, black grapes, cranberry juice, orange juice, grapefruit juice, kale, and buckwheat have as many flavonoids as red wine. Oranges, grapefruit, raspberries, red onions, and lemons are on par with dark chocolate. Blueberries and cherries are as packed with flavonoids as green tea. Capers top the list with twice the flavonoids of even green tea (though you’re unlikely to eat a bowl of capers).

Expand those flavonoid horizons! Dive into a bowl of berries—but go easy on the chocolate-covered ones. ☺



Angela Birnie is a registered dietitian at St. Paul’s Hospital in Vancouver.

Food fundamentals

These basic tips are a great starting point for developing a good nutrition regimen

by Michele Blanchet

Springtime is a great time to start a healthy diet. Good nutrition plays a role in building and maintaining a strong immune system and preserving lean body mass (muscle). If you have HIV, you have increased requirements for calories, protein, vitamins, and minerals. It's important for you to focus on nutrition before malnutrition and weight loss become a problem.

But are you overwhelmed by all the different nutritional information you read? Follow these basic steps and you're well on your way to better nutrition.

Start with healthy, well-balanced eating

- ▶ Eat a variety of foods each day to help make sure you get all the nutrients you need.
- ▶ Enjoy a generous amount of fruits and vegetables, and whole grain breads and cereals.
- ▶ Obtain good sources of animal and plant protein such as red meat, poultry, fish, eggs, beans and lentils, and nuts and seeds.
- ▶ Consume enough low fat milk products to meet your daily calcium requirements of 1,200 - 1,500 mg.
- ▶ Limit empty calories such as sugar and sugar products—like candy, pop, and alcohol—which displace other nutritious foods.
- ▶ Use good sources of essential fats such as olive oil, canola oil, non-hydrogenated margarine, flax oil, and cold water fish.

Increase your intake of vitamins and minerals

Try to get as many vitamins and minerals as possible from the food you eat, but also consider taking the following supplements each day:

- ▶ A complete multivitamin and mineral complex with iron, one containing at least 25 - 50 mg of B vitamins, and 400 mcg folate
- ▶ Vitamin E: 400 - 800 IU
- ▶ Vitamin C: 500 - 1,000 mg
- ▶ Calcium: 1,200 - 1,500 mg, which must be taken with a multivitamin for the vitamin D.

Exercise

Exercise is important to maintain muscle mass and strength, maintain or increase bone mass, reduce abdominal fat, and improve triglycerides, blood sugars, mood, and quality of life. If you're trying to gain lean body mass, do weight-bearing exercises. It's motivating to have your muscle mass and fat stores measured, using a bioelectrical impedance analysis, every six months.

Drink enough fluid and safe water

- ▶ Drink 8 - 10 glasses daily of water, diluted fruit juice, tomato or vegetable juice (such as V8), milk, herbal teas, decaffeinated coffee or tea, or broth.

- ▶ If your CD4 count is less than 200, drink bottled, boiled, or filtered water.

Prepare and handle food safely

Food contains bacteria that can be harmful if you have a weakened immune system.

- ▶ Cook foods—especially meat, poultry, fish, and eggs—until well done.
- ▶ Store leftovers appropriately in fridge, reheat them—only once—until steaming, and consume them within three days.
- ▶ Don't leave food at room temperature for more than two hours.
- ▶ Wash your hands before processing food.
- ▶ Avoid contact between raw and cooked foods.
- ▶ Avoid sushi, steak tartar, Caesar salad dressing and eggnog made with raw eggs, unpasteurized juices, uncooked sprouts, liver paté, and uncooked shellfish.
- ▶ Wash fruits and vegetables well.
- ▶ *When in doubt, throw it out!*

If you have any nutritional problems

If you find it difficult to meet your nutritional needs or have any of the problems listed below, talk to a dietitian:

- ▶ you've lost your appetite
- ▶ you need to gain weight or stop weight loss
- ▶ you're experiencing diarrhea, nausea, or vomiting
- ▶ you have a sore mouth or problems swallowing
- ▶ you're too tired to shop or prepare food
- ▶ you're unable to obtain proper nutrition due to financial difficulties. ☺

Read up and eat up!

For more information about HIV/AIDS and nutrition, visit the AIDS Nutrition Service Alliance Web site at www.aidsnutrition.org and look under "Publications" for helpful nutrition fact sheets.

Michele Blanchet is a registered dietitian with Vancouver Coastal Health - Gilwest Clinic, a Richmond clinic that provides a team approach to treating HIV and hepatitis C.





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**British Columbia
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The sunshine vitamin

On the “Wet Coast” you can’t rely on the sun for vitamin D, so find out where else you get it—and if you’re HIV-positive, you need it

by Diana Johansen

It was the study of rickets, a disease of weak and soft bones, which led to the discovery of vitamin D. As early as the 1600s, scientists were aware that something was needed to prevent rickets, but it wasn’t until 1922 that Edward Mellanby discovered these properties in sunlight and cod liver oil.

In the 1930s, scientists uncovered the chemical structure of vitamin D. This discovery took place during a prolific period of nutrition research in which scientists identified many vitamins, which are defined as substances that must be obtained from food. Even though we can theoretically make all the vitamin D we need, it is classified as a fat-soluble vitamin.

Vitamin D is made in the skin with exposure to UV radiation (sunlight), or is taken in through the intestines from food or supplements. It occurs in different forms, and D3 (cholecalciferol) is the most active. Once D3 is available in the body it must be activated, first in the liver—becoming 25-hydroxycholecalciferol, or 25(OH)D3, an intermediate metabolite of the vitamin D group—and then in the kidney where it becomes 1,25-Dihydroxycholecalciferol, or 1,25 (OH)₂D3. This activated product then performs the hormone-like activities of the vitamin. Without proper or sufficient activation, which can happen due to liver or kidney disease, vitamin D cannot function properly.

Vitamin D protects bones and more

Vitamin D is best known for its role in calcium and phosphorus metabolism, and in maintenance of bone density. When serum calcium levels become too low, activated D3 works to increase blood calcium levels. It does this in two ways: by increasing the efficiency of calcium absorption in the intestines, and by stimulating bones to release calcium to the blood. Bones act as a reservoir for calcium and other minerals and can become depleted as the body continues to work to maintain normal serum levels. Vitamin D protects bones by maximizing calcium absorption which then increases serum calcium levels. Thus bones do not have to release calcium from the skeleton.

People living with HIV are at higher risk of developing osteopenia (weak bones) or osteoporosis (very weak bones). There is evidence that PWAs are more likely to have low serum

vitamin D levels due to inadequate intake or defective activation of D3, making low vitamin D status a likely contributor to bone loss.

Vitamin D has another important function as a regulator of cell differentiation and growth. With adequate vitamin D, cells divide and specialize properly, a process that appears to have an important impact on autoimmune disorders and the development of some cancers. Most of the research on immune function has shown an inverse relationship between vitamin D status and autoimmune disorders such as muscular dystrophy and Crohn’s disease; as serum vitamin D levels go down, the severity of disease symptoms goes up. Whether vitamin D has a role in boosting the immune response to infections has yet to be determined.

Vitamin D also plays an active role in contributing to proper neuromuscular function. As people get older, they lose muscle mass and strength as part of the normal aging process. This results in a greater risk of falling and bone fractures. Research among elderly participants shows that vitamin D deficiency is also associated with decreased muscle strength and increased susceptibility to falls. In some studies, vitamin D supplementation improved muscle strength, walking distance, functional ability, and body sway (which can cause falls).

Vitamin D deficiency has also been linked to higher rates of and faster progression of colon, breast, and prostate cancers. Evidence from test tube and animal studies suggests vitamin D plays an anti-cancer role.

Dr. C.F. Garland from the School of Medicine at the University of California in San Diego recently made newspaper headlines by reporting that vitamin D can lower the risk of cancer. He reviewed 63 observational studies and identified a link between vitamin D status and incidence of cancer, especially cancer of the colon. He noticed that the highest death rates from colon cancer occurred geographically in regions with the least exposure to sunlight and UV radiation. This led him to make an association between low vitamin D status and cancer incidence and progression, a concept that has generated much interest but is yet to be proven.



Some sources are better than others

Although we should be able to make enough vitamin D, many people have low serum levels. Serum levels of 25(OH)D₃, the form made in the liver, indicate whether a person has adequate vitamin D status. Sun exposure should be the most important source of the vitamin because only 10 minutes of direct sunlight on bare skin a couple of times a week generates enough vitamin D for the body's requirements.

However several factors decrease the effect of the UV rays, including winter light, living at a northern latitude like Canada, cloud cover, too many hours of the day with low sun, and pollution. Using a sunscreen greater than SPF 8 also prevents vitamin D synthesis in the skin. Given that we live in a rainy northern climate and that even when the sun comes out we slather on sunscreen, UV rays cannot be considered a reliable source of vitamin D.

Some foods contain vitamin D, either naturally or through fortification. These include oily fish (salmon, tuna, mackerel, and sardines), milk and fortified beverages (like soymilk), margarine, egg yolk, liver, and cod liver oil.

But the amount of vitamin D found in food is usually not enough to meet the recommended daily intake. That leaves us with supplements. Most multivitamins have 400 IU; calcium supplements may contain 200 IU, while vitamin D supplements range in value.

Some groups are more at risk of being vitamin D deficient, including the elderly, people who don't go outside often, dark-skinned people, people who keep covered or always use sunscreen in the sun, those with low dietary intake or malabsorption, people with liver or kidney disease, and possibly people living with HIV.

More isn't necessary better

Scientists are still debating how much vitamin D we need to get all of its benefits. It's difficult to set the right amount for dietary or supplement intake because the body also makes its own vitamin D. Currently, the recommendations for adults are 200 IU to 50 years, 400 IU for 50 - 70 years and 700 IU for people over 70. However, recently Dr. Garland and his team recommended that all adults should get at least 1,000 IU per day.

Vitamin D is one of those supplements where some is good but more is not necessarily better. It's possible to get toxic amounts of vitamin D, which can cause such symptoms as nausea, vomiting,

poor appetite, constipation, weakness, and weight loss. Also, calcium levels can get too high, which can result in confusion, an abnormal heart rhythm, and calcium deposits in the body. Problems are more likely to occur with over supplementation; toxicity is not caused by sunlight and probably not by diet. The upper tolerable limit is set at 2,000 IU per day.

Research on immune function has shown an inverse relationship between vitamin D status and autoimmune disorders such as muscular dystrophy and Crohn's disease.

Vitamin D has an important protective effect in the body. Many people don't get enough and therefore require supplementation. Make sure you get at least 400 IU daily and consider aiming for the 1,000 IU recommended by Dr. Garland. If you have low bone density, aim for 1,000 to 1,400 IU per day from supplements. Add up the vitamin D from all your supplements to make sure you aren't getting too much. Remember that calcium and vitamin D work together, so be sure to get adequate calcium as well. ☺



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



Proving the obvious, part II

In the last issue of living ⊕, we looked at clinical trial overkill. In this issue we look at who gets to say what's hot and what's not

by Derek Thaczuk

Last year, a Canadian research team turned the microscope on the clinical research process itself, to ask how much research is too much. The team found that a drug called aprotinin had been the subject of far more clinical trials than needed to determine its effectiveness. Aprotinin, used to control bleeding after cardiac surgery, had been the subject of no fewer than 64 randomized clinical trials between 1987 and 2002. However, analysis showed that published results from the first 12 trials should have been enough to put the issue to rest. In other words, a jaw-dropping 52 trials just did not need to be conducted.

Such a finding raises serious questions about research practices and priorities, especially in a hotly competitive area like HIV research. Proper clinical trials use a great deal of time and resources. What assurance do we have that these limited resources are spent on pressing issues, not wasted reinventing the wheel? In fact, what does shape research agendas? What are the realities that dictate which studies get done and which don't? We've gathered some interesting insights into this question through conversations with Canadians involved in medical research and ethics.

To put clinical trials in context, note that they constitute one of four main categories of HIV research. The other three primary categories, or tracks, are:

- ▶ social/behavioural science: how people think, feel, and behave
- ▶ epidemiology: measurements of the prevalence and spread of disease
- ▶ basic science: "test tube" studies in biochemistry and microbiology

As an example, let's look at a clinical trial that is currently enrolling participants. At Ottawa Hospital, psychologist Louise Balfour is recruiting patients for the STAART (Supportive Therapy for Adherence to Antiretroviral Therapy) Study. This trial will study people who are just about to begin antiretrovirals and test whether four weekly psycho-educational sessions can help develop skills for treatment adherence. The purpose is to measure whether these sessions actually increase medication adherence and virologic treatment outcome.

The steps to getting the go-ahead

How did the STAART study get the go-ahead? The final hurdle, before official approval to recruit patients, would have been an ethical review to ensure that participants are not exposed to undue risk and are made aware of any risks that might exist. For instance, the group not receiving the educational sessions might have poorer adherence, and therefore less successful treatment. However, that won't be known until after the study is analyzed. Given that there is currently no standardized preparation for most PWAs starting therapy, advising the control group of the risks of poor adherence serves to make the study ethically acceptable.

Proper clinical trials use a great deal of time and resources. What assurance do we have that these limited resources are spent on pressing issues, not wasted reinventing the wheel?

Before the ethical review, a scientific review process would have ensured that the study design was procedurally correct, and able to answer the intended question. Scientific review serves another purpose, though: it's one key place where the relevance of the study can be evaluated. The panel of reviewers can assess the scientific context of the proposal: the other research completed in this area and what questions remain to be answered.

This scientific review process is one place where the system unaccountably failed in the aprotinin saga. Reviewers should have distinguished whether new proposals tackled new questions, shed new light on existing ones, or at least served as useful confirmations. Since relatively few studies have been conducted to date in HIV treatment adherence, the field is generally regarded as ripe for research—a green light for STAART.

But reviews can only veto or approve proposals—they don't influence how the proposals are generated in the first place. The STAART study is an example of investigator-driven research, in which a principal investigator (an established researcher) instigates, develops, and carries out the trial, in collaboration with a research and/or advisory team. Other sectors generate research, giving us industry-driven research, which is originated and funded by the pharmaceutical private sector, and community-based research (CBR), which takes its lead from the HIV/AIDS community itself. Community-based

research tends to be social/behavioural, studying such areas as, for example, how prevention campaigns affect sexual behaviour. Actual clinical trials rarely take place in a CBR context.

Setting some controls

Theoretically, investigator-driven research could head anywhere. Naturally, though, the real world landscape is subject to some controls. Funders, for one, may set explicit research agendas—priorities in certain areas. The Ontario HIV Research Network, for example, actively encourages interdisciplinary research and favours proposals that demonstrate, among other factors, “how the work makes a contribution to knowledge, policy development, or practice,” and “consultation with the HIV/AIDS community in determining the relevance, design, conduct, and dissemination of results.”

But, as Dean Sharpe of the University of Toronto's Ethics Review Office puts it, “scientists also create a culture in the same way that any group of people do.” As in art or popular culture, interest in a particular field may hit a critical mass, after which it tends to perpetuate, while research in other fields has a harder time gaining momentum. (Still waiting for definitive answers on medical marijuana or complementary therapies, anyone?) Perceived prestige, likelihood of funding, politics, or the stigma that surrounds topics like marijuana and certain forms of complementary therapies—these all push researchers toward certain areas and dissuade all but the more renegade from others.

With respect to the aprotinin clinical trial overkill, Sharpe concedes, “researchers live in fear that they'll miss a reference somewhere. Maybe somebody studied your topic in Poland in the '70s and you should know about it, but you just don't.” Given that most information is much more easily available online these days, and that many journals now insist on such references before they'll publish, missing critical references should become less of a risk.

Louise Balfour's STAART study is a good example of a win/win situation, where a researcher's interest coincides with a gap in clinical knowledge. Hopefully, less desirable scenarios—the overkill of research into aprotinin on the one hand, and on the other hand, the reality of areas languishing for lack of definitive research—can be nudged toward this happy medium. ☺

Thanks to Julie Schneiderman from the Canadian HIV Trials Network and Dean Sharpe, Ph.D., from the Office of Research Services at the University of Toronto for their insights and contributions to parts 1 and 2 of this article.

Derek Thaczuk is a freelance consultant and medical writer with 11 years involvement in the HIV community.

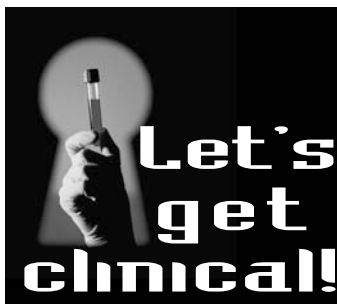
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604.893.2200



OutSMARTed: Surprise data halts trial enrollment

by Julie Schneiderman

The very same week that Dr. Brian Conway and his team at Vancouver's Downtown Infectious Diseases Clinic (DIDC) opened their doors to screen candidates for the SMART study (CTN 190, Strategies for Management of ART), the protocol permanently stopped enrollment. SMART was rapidly heading towards its international target of 6,000 participants worldwide. In 2005 alone, 2,615 participants were enrolled, 102 of them at ten Canadian HIV Trial Network (CTN) sites. To date, this is the largest cohort of HIV positive people.

An ambitious trial spanning more than 300 sites in 33 countries, SMART set out to compare the standard approach to antiretroviral therapy (ART)—regular use of ART to consistently suppress viral load—to a start/stop use of ART based on CD4 counts. Researchers believed it might take up to nine years to determine which of the two management strategies would better enable persons with HIV to live as long as possible while staying as healthy as possible. Yet only four years into the study, interim data indicates an approximately two-fold increased risk of disease progression in the CD4-guided strategy or drug conservation arm.

Based on recommendations by an independent data and safety monitoring board, trial enrollment was immediately suspended on January 10, 2006.

Many questions about the SMART study remain unanswered. And while early data are pointing to the benefits of viral suppression over drug conservation, researchers like Dr.

Conway fear that oversimplification of the findings may taint community support for other studies looking at ART management. "The study was examining whether participants did better on one very specific strategy over another," says Conway. "It would be irresponsible to apply these results to all forms of treatment interruption." DIDC received a five-year grant from the National Institutes of Health (funder of SMART) to study the use of time-limited ART (TL-ART) in people who have been recently infected with HIV. The results of the SMART study should have no impact on this and other important studies.

With or without SMART, Dr. Conway will continue to offer patients a full range of proven and experimental treatment options. Since joining the CTN in 2000, DIDC has been one of the leading recruiters of participants for CTN trials. They are currently enrolling a number of trials including OPTIMA (CTN 167—see listings below).

News releases, fact sheets, and other updates on SMART are available on the National Institutes of Health Web site at www.niaid.nih.gov, or the SMART study Web site at www.SMART-trial.org.



Julie Schneiderman

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

Trials enrolling in BC

CTN 147 – Early Versus Delayed Pneumococcal Vaccination
BC sites: Downtown Infectious Disease Clinic (IDC) and St. Paul's Hospital, Vancouver; Medical Arts Health Research Group, Kelowna General Hospital

CTN 167 – OPTIMA: Options with Antiretrovirals
BC sites: Downtown IDC, St. Paul's Hospital, and Viron Health, Vancouver; Cool Aid Community Health Centre, Victoria; and Medical Arts Health Research Group, Kelowna General Hospital

CTN 178 – Effect of Rosiglitazone Maleate (Avandia) on Blood Vessels
BC site: St. Paul's Hospital, Vancouver

CTN 189 – 3TC or No 3TC for HIV with 3TC Resistance
BC sites: Downtown IDC and St. Paul's Hospital, Vancouver; Cool Aid Community Health Centre, Victoria

CTN 213 – Dose finding and proof of concept study of Leukotriene B4 (LTB4) as ART
BC site: St. Paul's Hospital, Vancouver

To find out more about these and other trials, check out the **Canadian HIV Trials database** at www.hivnet.ubc.ca/e/home/ or call Sophie at the CTN 1.800.661.4664.



Tarel Quandt

December 11, 1965 – February 25, 2006

In Memoriam

by Melissa Davis

Tarel Quandt died peacefully at home in Vancouver, surrounded by family and friends. For three years, Tarel lived courageously with cancer, displaying optimism, determination, and selfless concern for others. Ultimately, she died as she lived: with integrity, dignity, and grace.

Tarel was born in Edmonton, Alberta. In her mid-teens, her family moved to Naramata, BC, where Tarel completed Secondary school. In the winter months, she could be found soaring down the slopes of local ski hills. An accomplished student, Tarel was the recipient of numerous academic awards and scholarships. She attended Simon Fraser University and Mount Saint Vincent University, receiving a BA in Women's Studies in 1989, followed by an LL.B. from Dalhousie in 1993.

Tarel was a passionate advocate for the rights and freedoms of marginalized and disadvantaged people, and these values influenced her legal career and personal life. Both her employment and voluntary work history centred on human rights activism, including her seven years as Director of Treatment and Advocacy with the BC Persons With AIDS Society. She is remembered by her colleagues for her contagious passion for social justice and her capacity to inspire confidence, action, and social change.

To know Tarel was to appreciate her many dimensions. She was, simultaneously, intellect and artist; independent spirit and nurturer; rationalist and spiritual believer. She was equally at ease mounting a legal challenge as she was singing acapella. And she derived as much inspiration from a well-constructed argument as from a meaningful church sermon. On her own and with Marc, Tarel experienced adventure through travel, mastered home renovations with her do-it-yourself attitude, cultivated an elaborate backyard garden, and shared countless playful and comforting hours with her faithful cocker spaniel, Chico.

Tarel is survived by her loving husband Marc Best; grandmother Virginia Conn; parents Peter and Louise; brother Greg, his wife Jacquie, and their children Aidan and Declan. She will also be greatly missed by Marc's parents Norman and Eve; sisters Cynthia and Janie, Janie's husband Carlos, and their son Teo, as well as by a cherished community of caring friends. ☉


Melissa Davis

*is the former director of fund development
for the BCPWA Society.*

Volunteering at BCPWA

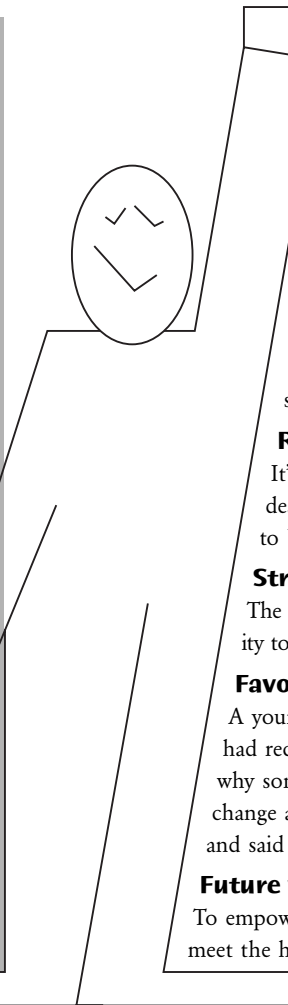
Profile of a volunteer:

John Bishop



“John isn't afraid to take risks, jump into the role of trainer, and develop member and volunteer workshops at the drop of a hat. His lively and ever-curious mind makes working with him a refreshing and inspiring experience.”

Teresa Stancioff
Coordinator of
Volunteer Services



Volunteer history

My only prior volunteer experience was at the age of 15, helping at a summer day camp for children with muscular dystrophy and cerebral palsy.

Why pick BCPWA?

Having recently retired, I missed the structure that work provides. Resuming full-time work wasn't an option. A close friend was volunteering at BCPWA's reception and encouraged me to give it a try.

Why have you stayed?

There is a tremendous sense of belonging. I enjoy what I'm doing, I'm learning new skills, and I enjoy the people I meet and work with. The staff always treat me with respect.

Rating BCPWA

It's an amazing place to volunteer. I respect the staff and volunteers a great deal. They are a diverse, dynamic, innovative, and exciting group of people to be around. I am inspired by them and proud to work with them.

Strongest point

The ability to make good use of my professional skills is very rewarding. The ability to try things I haven't done yet, to stretch myself, is challenging and renewing.

Favourite memory

A young man in his twenties came to reception, quite upset and agitated. He had recently lost several family members to HIV/AIDS and couldn't understand why something wasn't being done. I encouraged him to become part of the change and helped him fill out a volunteer application; when he left he smiled and said "thanks."

Future vision of BCPWA

To empower not only our members, but the organization itself so it can evolve to meet the huge challenges of the modern face of HIV/AIDS.



Interested in writing?

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

Volunteers should possess the following skill sets:

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

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

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

where to find help

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

A Loving Spoonful

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

AIDS Memorial Vancouver

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

AIDS Society of Kamloops

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

AIDS Vancouver

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

AIDS Vancouver Island (Victoria)

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

AIDS Vancouver Island (Cowichan Valley)

t 250.701.3667

North Island AIDS (Campbell River) Society

t 250.830.0787

North Island AIDS (Port Hardy) Society

t 250.902.2238

AIDS Vancouver Island (Nanaimo)

t 250.753.2437

North Island AIDS (Courtenay) Society

t 250.338.7400 or 1.877.311.7400

ANKORS (Nelson)

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

ANKORS (Cranbrook)

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

Asian Society for the Intervention of AIDS (ASIA)

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

BC Persons With AIDS Society

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

Dr Peter Centre

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

Friends for Life Society

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

Healing Our Spirit

3144 Dollarton Highway,
North Vancouver, BC V7H 1B3
t 604.879.8884 or 1.866.745.8884
e info@healingourspirit.org
www.healingourspirit.org

Living Positive Resource Centre Okanagan

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

McLaren Housing Society

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

Okanagan Aboriginal AIDS Society

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

Outreach Prince Rupert

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

e aidspr@rapidnet.net

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

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

Positive Living North

1–1563 2nd Ave,
Prince George, BC V2L 3B8
t 250.562.1172 f 250.562.3317
e info@positivelivingnorth.ca
www.positivelivingnorth.ca

Positive Living North West

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

Positive Women's Network

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

Purpose Society HIV/AIDS program

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

Red Road HIV/AIDS Network Society

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

Vancouver Native Health Society

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

Victoria AIDS Resource & Community Service Society

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

Victoria Persons With AIDS Society

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

Wings Housing Society

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

YouthCO AIDS Society

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

For more comprehensive listings of HIV/AIDS organizations and services please visit www.bcpwa.org.

Upcoming BCPWA Society Board Meetings:

Date	Time	Location	Reports to be presented
March 1, 2006	1:00	Board Room	Executive Committee / Financial Statements - January Director of Development
March 15, 2006	1:00	Board Room	Written Executive Director Report / Standing Committees
March 29, 2006	1:00	Board Room	Financial Statements - February/ Director of Support Services
April 12, 2006	1:00	Board Room	Written Executive Director Report / Executive Committee Director of Communications & Education
April 26, 2006	1:00	Board Room	Quarterly Department Reports / Standing Committees

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

For more information, contact: **Alexandra Regier, office manager** Direct: 604.893.2292 Email: alexr@bcpwa.org

BCPWA Standing Committees and Subcommittees

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

Board & Volunteer Development

Contact: Teresa Stancioff

t 604.646.5377

e teresas@bcpwa.org

Community Representation & Engagement

Contact: Ross Harvey

t 604.893.2252

e rossh@bcpwa.org

Education & Communications

Contact: Lisa Gallo

t 604.893.2209

e lisag@bcpwa.org

Positive Gathering

Contact: Stephen Macdonald

t 604.893.2290

e stephenm@bcpwa.org

IT Committee

Contact: Ruth Marzetti

t 604.646.5328

e ruthm@bcpwa.org

living+ Magazine

Contact: Jeff Rotin

t 604.893.2206

e jeffr@bcpwa.org

Prevention

Contact: Ross Harvey

t 604.893.2252

e rossh@bcpwa.org

Support Services

Contact: Jackie Haywood

t 604.893.2259

e jackieh@bcpwa.org

Treatment Information & Advocacy

Contact: Jane Talbot

t 604.893.2284

e janet@bcpwa.org

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Phone _____ E-mail _____

I have enclosed my cheque of \$_____ for living+

\$25 within Canada \$50 (Canadian \$) International

please send _____ subscription(s)

BC ASOs & Healthcare providers by donation: Minimum \$6 per annual subscription

please send _____ subscription(s)

Please send BCPWA Membership form (membership includes free subscription)

Enclosed is my donation of \$_____ for living+

* Annual subscription includes 6 issues

Cheque payable to BCPWA



living+

1107 Seymour Street

2nd Floor

Vancouver BC

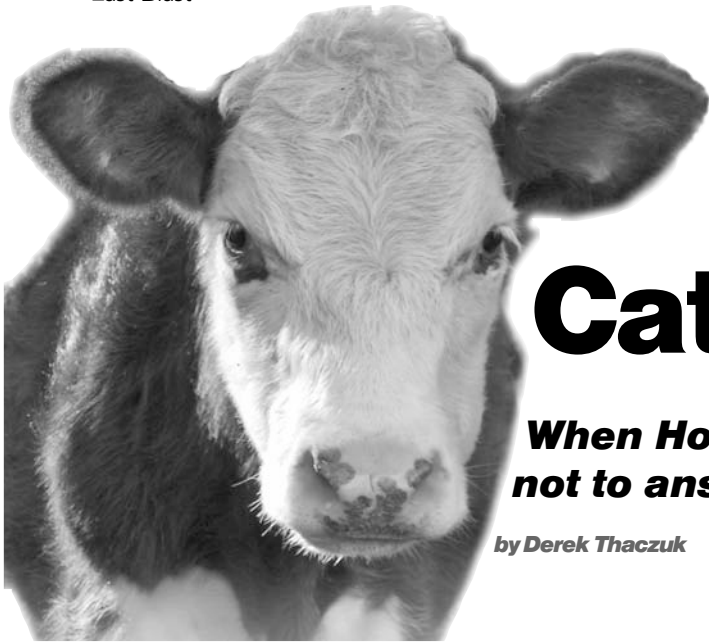
Canada V6B 5S8

For more information visit

www.bcpwa.org

e-mail to living@bcpwa.org

or call 604.893.2206



Cattle call

When Hollywood calls, sometimes it's best not to answer.

by **Derek Thaczuk**

We were the unlikeliest bunch of Midwestern truckers you'd ever hope to see. Mostly, we looked like a roomful of downtown Toronto homosexuals, on the make for a couple of bucks and a bit of fame—which is exactly what we were.

The screen test was advertised at all the local AIDS service agencies: HIV-positive men wanted for small part in major motion picture. Work with the stars and earn money. No acting experience required!

Well, cool. No wonder the place looked like Woody's on a Saturday night.

Rumour had it the star (unconfirmed) was Kathy Bates—impressive, if intimidating. (Right, I thought, this fine actress wants to be paired up with some rank amateur? At least she'd be in no danger of being upstaged.) The rest was a little vague, but I came away with the impression that the director had done *Mississippi Masala*, a film I admired. One thing was certain, though: the director, whoever he or she was, wanted "authenticity." This seemed to mean that, in order to cast an unwittingly HIV-positive Midwestern American trucker who's cheating on Kathy Bates, you head for—where else?—Toronto's gay village. Evidently the realism of casting someone who was actually HIV-positive outweighed any woeful inadequacies in, well, in any other authenticity department.

Let's start with the accent. Now, none of the casting people actually told us to try for an Iowa twang. In fact, I'm quite sure they specifically forbade us to try any such thing—voice coaching could come later. But, I'm sorry: put yourself in my shoes and just try a line like, "Hell, Arlene, I like sex. You know that." See if it doesn't come out, "Hayil, Ahhrlene, ah lahhk seyix. Yew know thayit."

"Ah lahhk sex" was one of, I think, three lines we had to read for the camera, each drawn from one stage of the story. The basic premise was that Arlene—or whatever Kathy's character was called—is married to a trucker. He fools around with men on the down low. He eventually gets an HIV test for some reason, which, naturally, comes back positive. Everyone freaks out; drama ensues. But Kathy stands by her man, nursing him through worsening sickness and dementia until, finally, he dies. I imagined the scenes perhaps too luridly: Ms. Bates picking me up and slinging me over her shoulder like a rolled-up carpet. Carrying my wasted frame past the cornfield into the beat-up old jalopy. Pity and scorn mingling on the face of the townsfolk as we chug and rattle past, my head—all tangled whiskers and wild stare—lolling on the seat.

To reflect this character arc, the screen test lines went something like this:

Lucid and matter-of-fact: "Hell, ah like sex." Not quite so lucid: "I need muh pills! Where's muh pills?" Completely demented, jabbering wildly, spit flying: "TV! TV! TV! Turn the #*\$@in' TV on!"

None of the movie people had warned us about this. Nobody had come along and said, "Oh, by the way, imagine your worst fears about a terrifying, undignified death. We'll be doing that at 11AM; make it rough." It didn't really matter; by the time we got to the last line I mostly just wanted it to be over. And then, mercifully, it was.

I never heard anything more about the movie, which is probably a blessing. But if, as they say, you learn from your mistakes, then Lord knows I learned a few things that day:

1. When you watch a professional actor and think, "I could do that," you are wrong.
2. Suppressed wincing are very painful to see in interview situations.
3. Some things in this world are just plain unbearable to watch.
4. I have now done some of those things.

And, next time I meet someone from the Midwest, I will actually listen to the way they talk. ☺

Derek Thaczuk is a freelance consultant and medical writer with 11 years involvement in the HIV community.