CANADIAN TREATMENT ACTION COUNCIL

CTAC
Canadian Treatment Action Council

INSIDE

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Blueprint for Action:

Care, Treatment, Support, Prevention and Diagnosis

by Kim Thomas, Canadian AIDS Society

AS MANY OF YOU ARE ALREADY AWARE, *Blueprint for Action on HIV/AIDS in Canada: Towards 2006 (Blueprint)* is now a thriving coalition of over 60 organizations and many individual members. This past April, *Blueprint* hosted a national meeting in Ottawa where 30 participants came together to ratify the agenda for *Blueprint* and begin identifying areas for advocacy over the coming year. During the meeting, four additional committees were struck to look at a range of issues. We're pleased to report that among these four, a committee on Care, Treatment, Support, Prevention and Diagnosis (CTSPD) has been created, with Barby Skaling from *Healing Our Spirits* as chair.

The committee has been charged with identifying priorities and with articulating what kind of response we would like to see from government, corporations and the public regarding the priorities we identify. At a recent meeting, we came up with a list of priorities that cover a broad range of issues around CTSPD. In brief, they fall under three categories: care, treatment and support; Aboriginal and other cultural issues; and infections and drugs. The priorities are as follows:

Care, Treatment, Support

- Ensure that women-specific treatments and information are freely and widely available; develop strategies for women who are afraid of disclosing their status to their partners
- Provide support for mother-to-child education regarding treatment (i.e., assistance for parents needing to divulge a child's condition) and treatment for the child
- Ensure that there is a systemic post-approval surveillance system for women and their treatments
- Collect data on how stigma and discrimination create barriers for receiving support and care, breaking it down by sex and age

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Blueprint for Action: Care, Treatment, Support, Prevention and Diagnosis

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In preparation for the **International AIDS Conference**, *Blueprint* has begun advocating for the full integration of women's issues into the conference as well as equal representation among presenters.

- Provide health care professionals with gender-specific information
- Improve access to primary care doctors
- Establish national standards of care and treatment
- Provide treatment for lipodystrophy
- Coordinate treatment information across Canada
- Provide a strong voice for youth, trans- and two-spirited women
- Investigate literacy factors
- Ensure that appropriate and sufficient treatment, care and prevention services are brought to women in prisons

Aboriginal issues

- Provide culturally sensitive care, treatment and support
- Engage in intensive capacity building for health staff in the north
- Develop strategies to combat institutionalized racism, the lack of medical professionals, issues around confidentiality and the lack of rehabilitation services for those suffering from addiction in aboriginal communities

Other cultural issues

- Ensure access to care for children of women from endemic countries
- Provide primary service providers with culturally specific responses for women to enable them to disclose their status to partners and children
- Provide culturally specific information in other languages
- Develop a strategy for sharing information with other agencies

Infections and drugs

- Advocate for more research on Hepatitis C
- Study the side effects of antiretrovirals on women and their ability to work and parent families
- Research the effects of treatment on women's hormonal cycle
- Advocate for more research on, and higher awareness of, microbicides
- Advocate for female-specific clinical trials that take into account reproductive issues
- Push for women-specific data in clinical trials
- Push for female participation in clinical trials
- Advocate for trials on complementary and alternative therapies

For a first run, it's quite a list and there is still much work that needs to be done on these recommendations. However, we believe we're on the right track. The next steps include consulting our communities, after which we will develop a formal list of these demands for release and endorsement this fall in time for World AIDS Day this year. This will give us the opportunity to seek a response and prepare a report that will be released at the International AIDS Conference held in Toronto in August of 2006.

In preparation for the International AIDS Conference, *Blueprint* has begun advocating for the full integration of women's issues into the conference as well as equal representation among presenters (both invited and in abstract selection processes) and in the granting of scholarships. To date, members of *Blueprint* have met with representatives of the Conference Organizing Committee and have received positive feedback on the request, indicating that there is support for gender equity within the conference planning process. We will continue to monitor and push this agenda to ensure that women's issues are well represented in Toronto 2006.

For further information please contact Barby Skaling at Healing Our Spirits: skaling@healingourspirit.org. ■

What's the hold up?

Common Drug Review process prolongs the wait for drugs at the provincial level

by Jane Hamilton, Best Medicines Coalition

THE COMMON DRUG REVIEW (CDR) is a single process for reviewing new drugs and providing formulary listing recommendations to participating publicly funded federal, provincial and territorial drug benefit plans in Canada. All jurisdictions are participating except Quebec. Before CDR, each province did reviews completely on its own.

Unlike decision-making processes in most other countries, in Canada the CDR process excludes participation by patients or consumers in its drug reviews. As of the end of December 2004, Canadian Expert Drug Advisory Committee (CEDAC) had reviewed and had recommended against any coverage for 60% of the drugs that it had reviewed, and had recommended restricted coverage for 13%. Canadians who rely on publicly-funded drug programs for prescription drug benefits are concerned that the CDR appears to be working as a barrier to access to new medicines.

There are also a number of issues within the CDR process that pose significant risks to patients including: delays in the process that restrict timely access to life saving drugs; lack of transparency; the exclusion of patient and relevant stakeholders from the submission and decision-making process; and the inability to appeal a decision.

The Canadian Treatment Action Council (CTAC) has expressed concerns regarding the decision not to recommend Viread (tenofovir), a nucleotide drug used as part of a combination therapy in both treatment naïve and treatment experienced people, for listing on provincial drug reimbursement plans. As a result, in Ontario, where approximately 40% of people with HIV/AIDS live, tenofovir is not listed for formulary reimbursement.

Interestingly, Health Canada has approved tenofovir under the Notice of Compliance with Conditions (NOC/c) policy because according to their findings it has demonstrated promising benefit and possesses an acceptable safety profile based on a benefit/risk assessment. An international clinical trial with over 600 participants compared antiretroviral agents, including tenofovir, and found that after three years of treatment tenofovir and d4T (another antiretroviral agent) had comparable viral suppression. In addition, International AIDS Society Guidelines recommend as a dual nucleoside reverse transcriptase inhibitor backbone either AZT or tenofovir with either 3TC or FTC. These guidelines are based on clinical data and clinical practice worldwide, which CEDAC appears to have ignored in reaching its decision.

Despite mounting scientific support for tenofovir, the CDR process found no evidence demonstrating that the drug has a therapeutic advantage over appropriate comparators in treatment experienced patients and also found that tenofovir is more costly than other NRTIs. CTAC is concerned that the CDR decision does not appear to be consistent with good scientific evidence and appears to be based merely on price comparison.

"The decision not to recommend tenofovir also made no exemption for patients already accessing the medication through the Expanded Access Programme," said Louise Binder, CTAC Chair. "This means that patients relying on tenofovir could well lose their medication and be put on a new regimen that is covered by the provincial formulary. This nullifies the physician's decision, puts the health of these patients at risk and creates issues of liability."

CTAC is actively seeking a full reassessment of the CDR process and demanding that tenofovir is fully listed on provincial drug reimbursement programs. Our position is that the CDR process is fatally flawed and does not allow participation of relevant stakeholders either in the decision making process or by providing an opportunity to make submissions to CDR and overall, the process creates less timely decision making. ■

Taking Charge of Lipodystrophy

Lipodystrophy is a complex syndrome affecting HIV-infected people who take antiretroviral therapy. It groups together several symptoms that are characterised by an abnormal distribution of fat mass on the body and metabolic changes. Three distinct entities have been described: lipoatrophy (fat loss in the face, on legs, arms and buttocks), lipoaccumulation (fat deposits in the abdomen around the internal organs, and in breasts, the neck and under the skin), or mixed syndrome, which include both lipoatrophy and lipoaccumulation.

by Martin Mailloux, LIPO-ACTION!

SINCE 1996, PEOPLE LIVING WITH HIV have experienced the effectiveness of antiretroviral treatments (ARVs) to fight HIV. ARVs have increased life expectancy and improved the health condition of people living with HIV, however these benefits have come with a number of costs, including the stigmatizing marks of lipodystrophy.

On October 16, 2003 LIPO-ACTION! was born. Its mandate is to find and advocate for solutions to the problems of lipodystrophy faced by people being treated for HIV infection.

For more information about the causes and effects of lipodystrophy, visit www.natap.org and www.facialwasting.org websites.

The morphological impact of lipodystrophy cannot be reduced to a question of aesthetics. It is a complex syndrome with serious consequences on the health, physical integrity and quality of life of people living with HIV. It causes visible and measurable bodily deformations that stigmatize and can also handicap. In addition to the increase in risk for cardiovascular diseases and diabetes, lipodystrophy has a serious impact on treatment and mental health. For instance, because of the visible signs of lipodystrophy, many people living with HIV/AIDS wish to discontinue their treatment, which can put their health at serious risk. Others delay treatment, thereby risking dangerous reductions in CD4 counts. Many people who are affected live in great psychological distress and isolation. According to one source, "These morphological changes can lead to anxiety, depression, loss of self-esteem, and damage the social and professional life."[1]

The members of the LIPO-ACTION! Committee are working to ensure that the problems associated with lipodystrophy are recognized and addressed.

Demanding Action!

Action is needed now! LIPO-ACTION! has three demands which it presented on June 10th of this year to the Québec Minister of Health and Social Services, Mr. Philippe Couillard, and to 34 other influential members of the National Assembly. These are:

1. Setting up a systematic program of prevention and diagnosis of lipoatrophy and lipoaccumulation

A. Prevention

For lipoatrophy, if the exact causes are not yet recognized, the associated cause is known. The simplest and most direct method of avoiding this problem for most patients is to change ARVs upon the appearance of the syndrome. However for lipoaccumulation, neither the cause nor the associated cause is as well-determined, so a more individualized response is required.

LIPO-ACTION! asks the Ministry to establish an educational program for HIV clinicians and to provide pertinent information on morphological changes caused by lipodystrophy to people living with HIV/AIDS in order to prevent this syndrome before patients find themselves severely affected.

B. Diagnosis

Many people living with lipodystrophy reported that their physicians refused to take their stigmatizing and physically or emotionally painful conditions seriously. Our doctors told us that there was no way to diagnose these morphological changes,

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[1] (Lipodystrophy Syndrome, A Guide for Health Professionals, Ministry of Health and Social Services, Government of Québec, 2005, p.8.)

Taking charge of lipodystrophy

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The members of the LIPO-ACTION! Committee are working to ensure that the problems associated with lipodystrophy are recognized and addressed.

while these techniques are available to any dietician and in most Québec hospitals.

We ask that clinical standards of care for all people living with HIV/AIDS in Québec include access to means of diagnosis of lipodystrophy by evaluating bodily changes caused by lipoatrophy and lipoaccumulation.

- Anthropometric measurements, such as measuring cutaneous folds, analysis by electronic bio-impedance, etc.;
- Radiological techniques, like DEXA scan (dual-energy X-ray absorptiometry), ECG, tomodensitometry and magnetic resonance imaging (MRI).

2. Access to reparatory interventions for facial lipoatrophy caused by ARVs

a. Inclusion of reparative techniques in the Quebec Healthcare Insurance Plan (RAMQ), along with adequate reimbursement
b. Inclusion of two injectable filling products, Sculptra (New-Fill) and Bio-Alcamid, on the list of products and drugs covered by the RAMQ, upon their approval
c. Issue directives on HIV care standards, including monitoring the development of lipoatrophy and informing physicians of its cause in order to plan for a change of medications to stop its progression.
d. Transfer of Viread (tenofovir) from the "list of exceptions" to the regular list of ARVs as it prevents facial lipoatrophy.

3. Access to reparative procedures for certain morphological manifestations of lipoaccumulation (particularly "buffalo-hump") caused by ARV therapy

a. Inclusion of reparative techniques for "buffalo hump" in RAMQ
b. Issue directives on HIV care standards, including monitoring the development of lipoaccumulation and the use of well-known solutions (e.g. in the presence of lipoaccumulation in the abdominal cavity in a patient taking indinavir [Crixivan], change to a less toxic protease inhibitor)
c. Financial support from the Quebec government to encourage an expanded access research program for Theratechnologies' leading-edge peptide TH9057, which can reduce excess visceral fat accumulation, thus making the peptide accessible to more people who need it.

LIPO-ACTION! encourages other community groups to present similar demands to their own provincial governments. For more information about these demands, which are included in a document entitled "Preventing and Treating Lipodystrophy in Québec in 2005," visit www.cpahvih.qc.ca (available in French and English). Also available is an accompanying video entitled "Break the Silence with LIPO-ACTION!" (available in English soon) at www.exorbitas.com/lipo-action.htm.

Want to get involved? Contact us at lipoaction@yahoo.ca. ■

On a personal note...

A personal perspective of living with lipodystrophy and lipoatrophy from a CTAC member.

I'm feelin' pretty cheeky these days.

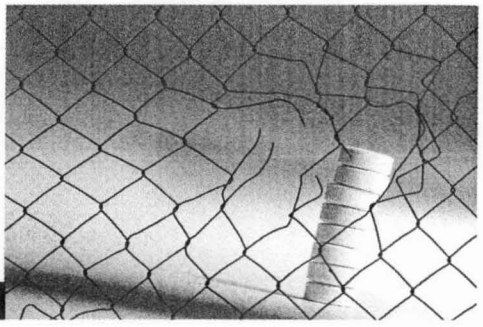
I'm one of the fortunate few who enrolled at the right time and who met the criteria for a study to determine the viability and durability of Radiesse, a calcium compound which is injected under the skin to counter the facial wasting of lipoatrophy. As I was undergoing the 30-minute and moderately painful procedure, I looked up at Dr. Carruthers and said: "I never in million years would have thought I'd be undergoing cosmetic surgery." He looked me straight in the eye and said, "No, this is not cosmetic surgery. It's a procedure to rectify the disfigurement caused by HIV anti-retroviral therapy."

I used to look in the mirror and sigh with stoic resignation... "badge of honour" and all that. Now I look in the mirror and, well, smile with absolute delight... "Hey, good lookin', good to see you back!"

Anonymous, Vancouver, BC

This is article #2 in a series entitled "Access 101" which explains the different steps in approving drugs for sale in Canada. The first article, entitled "Access 101: The lowdown on treatment access through clinical trials" appeared on page 6 of Volume 7, Issue 2. It is available online at www.ctac.ca/english/newsletter.html .

Access 101: The Therapeutics Products Directorate and the drug approval process



by David Garmaise

THE THERAPEUTICS PRODUCTS DIRECTORATE (TPD), which is a unit in the Health Products and Food Branch of Health Canada, is responsible for:

- approving all new pharmaceutical drugs and medical devices; and
- providing special access to experimental therapies not yet approved for sale in Canada.

Why is this of interest to people living with HIV/AIDS? The decisions of the TPD affect everyone's access to new and emerging therapies. Treatment access advocates play an important role in making sure that new drugs are approved on a timely basis and that people can access experimental therapies in special situations.

Approval of New Pharmaceutical Drugs and Medical Devices

So, what authority does the TPD have? Under the *Food and Drugs Act* and its accompanying regulations, the TPD has the authority to regulate pharmaceutical drugs and medical devices for human use. All new drugs and devices must be approved by the TPD before they can be marketed in Canada. To obtain approval, a manufacturer must present substantive scientific evidence of a product's safety, efficacy and quality.

Impact on access

New HIV/AIDS drugs will not be available for sale in Canada unless they are approved by TPD.

The length of time required for the approvals process has an impact on when new drugs actually become available.

Examples of HIV/AIDS-related pharmaceutical drugs approved by the TPD in recent years are Efavirenz (Sustiva), Abacavir (Ziagen) and Tenofovir (Viread).

For their part, the manufacturers (i.e., the pharmaceutical companies) must submit a New Drug Submission (NDS) for each new drug. The requirements for NDSs are onerous. Each NDS must contain the following five components (known as "modules"):

- **Module 1** - information concerning the application; information on the proposed labelling (e.g., product monograph); and some summary information.
- **Module 2** - summaries of the information found in Modules 3, 4 and 5; and a Table of Contents for the information in these modules.
- **Module 3** - information on the quality of the drug being submitted.
- **Module 4** - information on the non-clinical studies that have been conducted on this drug.
- **Module 5** - information on the clinical studies that have been conducted on this drug.

Although the TPD is a government entity, the manufacturers pay a fee to have their submissions reviewed. For submissions for new HIV anti-viral drugs, the fees are in the range of $100,000 to $250,000, depending on the complexity of the review. However, the TPD says that these fees do not cover all of the costs of the reviews.

How long does the approvals process take?

It can take a *considerable* amount of time. The TPD has established a target of 45 calendar days to screen an NDS and 300 calendar days to review it. If there are deficiencies in the submissions, these timelines can be significantly extended.

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Access 101

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The TPD has a *priority review policy* for NDSs for a serious, life-threatening or severely debilitating illness or condition where there is substantial evidence that the drug provides either (a) effective treatment of a disease or condition for which no drug is currently marketed in Canada, or (b) a significant increase in efficacy over other drugs already approved. The targets for priority reviews are 25 calendar days for screening and 180 calendar days for review. Only some HIV/AIDS drugs have received priority review.

Often new drugs become available in the United States several months before they become available in Canada. This is due to two factors:

(1) usually, new drugs are submitted for approval in the US before they are submitted in Canada;

(2) the approvals process usually takes much longer in Canada than it does in the US. In fact, the TPD almost never meets its NDS review targets when it comes to reviewing HIV/AIDS drugs.

Special Access Programme

The purpose of Special Access Programme (SAP) is to provide access to drugs that have not (yet) been approved for sale in Canada. The SAP will consider an application from a physician for a drug for a patient with serious or life-threatening conditions, when conventional therapies have failed, or are unsuitable, or are not available.

Approval of requests to the SAP is on a case-by-case basis. In each case, the consumer's physician has to fill out an application form and submit it to the SAP. When the SAP approves an application, it authorizes the manufacturer to sell the drug to the applicant (i.e., the physician) for use with the patient in question.

Decisions on each application are usually made fairly quickly, sometimes within 24 hours. Often the manufacturer will not charge for the drug being provided, though this is not always the case.

Impact on access

When the consumer has exhausted other options, the SAP can sometimes provide access to a promising but still experimental drug that has not yet been approved for sale in Canada.

Related Programs

The Health Products and Food Branch is also responsible for:

- monitoring the safety, effectiveness and quality of therapeutic products after they have been approved for sale in Canada (i.è., post approval surveillance);
- approving new biologics and genetic therapies; and
- regulating natural health products.

Further information

The TPD website contains a number of documents related to the drug review process, many of which are designed to assist manufacturers with New Drug Submissions. See www.hc-sc.gc.ca/hpfb-dgpsa/tpd-dpt/index_drugs_e.html.

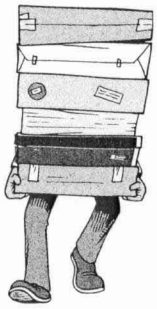
For a general description of the SAP, see TPD's Fact Sheet on Special Access Programme – Drugs at www.hc-sc.gc.ca/dhp-mps/acces/drugs-drogues/sapfs_pasfd_2002_e.html. ■

Canadian AIDS Society *Société canadienne du sida*

Canadian AIDS Society Leadership Award

Congratulations to our Chair, Louise Binder, who was the recipient of the 2005 Canadian AIDS Society Leadership Award!

Also acknowledged posthumously for his dedication to the AIDS community was Bob Mills, former CTAC Board and Council Member.



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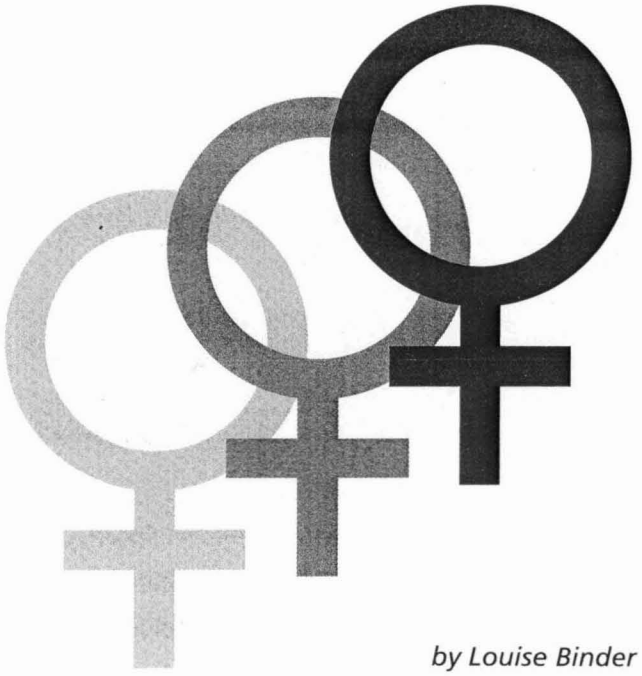
WOMEN'S ISSUES: UPDATE

Women-specific treatment: more research is needed



by Louise Binder

TREATMENT SPECIFIC FOR HIV+ WOMEN is an area which is still lacking in sufficient research, and not much information is available. Even at a recent Conference on Retroviruses and Opportunistic Infections (CROI), only a few studies were presented that focused on answering questions about HIV/AIDS and women.

Mother to Child Transmission (MTCT)

Several presentations dealt with the issue of using single dose nevirapine (a treatment used in a number of developing countries) to prevent MTCT. Use of single dose nevirapine, from the non-nucleoside class of drugs (NNRTI), has been shown to reduce transmission by more than 50%. This is a wonderful result for women wanting to have children; unfortunately, a single mutation in the virus at K103N will confer resistance to this class of drug, and resistance may even occur with just a single dose. The studies presented at CROI also showed that this mutation stayed detectable in the women's blood for as long as one year after giving birth.

Preliminary results from one study, however, suggest that single dose nevirapine used during a first pregnancy does not make its use in a second pregnancy less effective in avoiding transmission to any significant degree.

The question is what impact will this resistance have over time for women's treatment options and for their children? Studies have shown that drug resistance persists even after it can no longer be measured in the blood. Thus, if a person stops and restarts therapy, resistance can reappear, making the therapy ineffective.

Clearly, the best treatment for a pregnant woman is one which is best both for her and for her fetus. Therefore, a combination therapy that avoids the NNRTI class is preferable. SUSTIVA has been shown in monkey trials to harm the fetus. Additionally, nevirapine itself has been shown to cause liver toxicity, in some cases very serious toxicity. In fact, women with CD4s over 250 should not take this drug at all.

Doctors often prescribe combinations containing the protease inhibitor nelfinavir and two nucleosides.

Other studies – in brief

In a small trial where participants were on either protease inhibitors or non-nucleoside containing regimens, taking 2 grams of fish oil (brand name Maxepa) three times a day reduced fats in the blood (triglycerides and cholesterol) to normal in 22.4% of those taking it, compared to only 6.5% in the group not taking it. These fats are associated with body shape changes or lipodystrophy which can impact women more than men.

In another trial looking at strategies to reduce lipoatrophy or limb wasting, researchers found that a regimen containing nucleoside drugs and a non-nucleoside created more limb wasting than a regimen with the protease inhibitor kaletra and a non-nucleoside. There was no difference between men and women in the result. Other problems with this regimen included increased fats in the blood with kaletra and the

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Women-specific treatment

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possibility of more central nervous side-effects (including depression) with efavirenz. Studies have shown that HIV+ women are more prone to depression than men.

A large study with 24% female participants showed that for each additional year on combination antiretroviral therapy, the risk for myocardial infarction (MI) or heart attack increased by 1.17-fold. Although the rate of MI was higher in men, the relative increase in risk is similar in men and women.

While these studies presented at CROI provide some information regarding treatment for women with HIV/AIDS, they still do not go far enough towards answering women-specific treatment questions. More trials with a higher percentage of women participants and trials answering women-specific treatment questions are needed to determine what treatment options are best for HIV+ women. There also needs to be a stratification to look at specific populations of women. ■

On a personal note...

What barriers stand in the way of accessing the HIV treatment that you need? Do you have a story to share about how you advocated for access to a treatment or therapy for yourself or on behalf of someone else? We want hear your stories! The next issue of the newsletter will have an article on women and HPV, and an article on drug dispersement programs in Alberta and BC. If you have a story to share about access to treatment related to these stories, tell us! Contact the CTAC office (see page 12) for more information. *Confidentiality will be respected. We may not print all stories submitted.*

by Sugandhi Wickremarachchi

AFTER A LATE START EARLIER THIS YEAR, the Tools for Action workshop series is starting to pick up steam! Made up of nine learning modules, the capacity-building project focuses on building and strengthening peoples' skills to advocate for treatment access and lobby for improvements to the larger "system."

Several of the modules have been offered at different in-person events, such as:

- The Dialogue Conference organized by Voices of Positive Women in Toronto, May 28;
- CTAC Council's Skills Building Day in Calgary, June 6; and,
- CATIE's Skills Building Conference in Ottawa, June 20.

Three modules will be presented at the National Skills Building Symposium in Montréal, October 27-30:

- *Tools and Strategies: Level 2* (to be presented in French);
- *Women and Access to Treatment* (to be presented in French); and,
- *Treatment Access Among First Nations, Inuit and Métis Peoples* (to be presented in English).

Throughout the year, the modules will be delivered as tele-workshops: workshops delivered via teleconference to a small group of participants. So far, we've had two very successful tele-workshops made up of participants from across the country and with wide-ranging backgrounds and experiences. More tele-workshops are being scheduled and will be announced soon. The tele-workshops are free and open to all CTAC members and members of project partner organizations (a full list is available on our website).

For more information or to register for the workshop series, please contact Sugandhi Wickremarachchi at (416) 410-1369 or Sugandhi@ctac.ca. Information about these modules will be available on CTAC's website. ■

Strategies for success

CTAC's Five-year Strategic Directions

by Tony Di Pede

The world of HIV/AIDS is ever changing and it is important to ensure that the work of CTAC always addresses gaps in access on many levels. Thus the Board decided that it was time again to review CTAC'S governance structure and strategic directions in order to ensure that we are operating effectively and meeting our mandate.

What was determined from this review was that the Council should have greater influence on the Board's decision-making by ensuring advocacy reflects what people living with HIV/AIDS want. Ideally, the flow of communication from Council should feed information to the Board for action at both national and provincial levels. Measures required to enhance Council's role include:

- adding representation for substance users, prisoners (and former prisoners) and people from endemic countries;
- ensuring we are aligned with the Federal Initiative;
- ensuring that every Council member is involved on a CTAC committee or advocacy issue.

Five strategic objectives were developed to strengthen the organization. They are as follows:

- Sustain and enhance access to treatment for all people living with HIV/AIDS. The focus here will be on Women and Aboriginal issues.
- Influence public policy around broader healthcare issues so that it facilitates and improves access for people living with HIV/AIDS. This will primarily deal with Legislative renewal and National Pharmacare.
- Increase public awareness, and consumer and community capacity to support sound public policy in relation to HIV treatment access issues. Skills building and mentoring will be key components to this initiative.
- Develop and sustain vibrant and effective provincial/territorial membership networks.
- Develop and sustain a strong organization that is able to fulfill all of its objectives.

A full report on Strategic Directions will be available on our website at www.ctac.ca, or you may contact the CTAC office to receive a copy (see page 12 for office contact information). ■

Newsletter Survey Results

by Theresa Wojtasiewicz

Overall, the results from the Newsletter Survey indicated that CTAC's newsletter is doing its job in bringing you the information you need about access to treatments in a form that is easy to read and accessible. There were indications that there were some things that could be improved, and a few things that could be added to the newsletter to broaden its scope in information delivery, and the Newsletter Committee is taking these items under serious consideration.

Among them are more articles on:

- Aboriginal access to treatment
- Skills building
- Rural access issues
- Regional access issues
- Access for those with low incomes or who are on social assistance
- Access to treatment for prisoners
- Complementary and alternative medicine
- Youth access to treatment issues

To complement the more technically oriented articles, it was suggested it might be helpful to illustrate a particular access experience by putting in a "Personal Perspective" as a sidebar to the article; for example, someone who encountered a problem, did something themselves about it and solved the problem. (Names of individuals sharing their stories would be protected by an alias, if anonymity is requested.)

The Newsletter Committee will also be looking for more articles from other groups and individuals involved in access to treatment issues.

CTAC is committed to continue bringing you timely and important information on access to treatment issues, and we thank the respondents for their time in answering the questions and for their candid comments. ■

CALENDAR OF EVENTS

SUMMER 2005

● **September 6th-9th**
AIDS Vaccine International Conference
Montréal, Québec
Contact: (418) 658-6755 or
aidsvaccine2005@agoracom.qc.ca

● **September 21st-24th**
Interscience Conference on Antimicrobial Agents and Chemotherapy (ICAAC)
New Orleans, Louisiana
Contact: (202) 942-9248-or icaac@asmusa.org

● **October 4th-7th**
Canadian Aboriginal AIDS Network AGM
Regina, Saskatchewan
Contact: 1-888-285-2226 or info@caan.ca

● **October 16th-17th**
Canadian Treatment Action Council AGM and Skills Building
Moncton, New Brunswick
Join CTAC at its AGM and for a day of skills building in Moncton! All members are welcome to attend. Contact the CTAC office (see contact information on page 12) or visit www.ctac.ca for details and to register for the events.

● **October 26th-28th**
The 4th International Conference on Urban Health
Toronto, Ontario
Contact: (416) 864-5486 or crich@smh.toronto.on.ca

● **October 27th-30th**
5th Canadian HIV/AIDS Skills Building Symposium
Montreal, Quebec
Register online at www.hivaids-skills.ca
For more information call 1-877-998-9991 or visit www.hivaids-skills.ca

● **November 25th-26th**
Ontario HIV Treatment Network Research Conference
Toronto, Ontario
Contact: 1-877-743-6486 or info@ohtn.on.ca

● **November 27th-30th**
North American AIDS Treatment Action Forum (NATAF)
Oaxaca, Mexico
Contact: (202) 483-6622 or conferences@nmac.org

CHAIR'S REPORT

SUMMER 2005

by Louise Binder

The top three things that keep me hopping mad

I RECENTLY GAVE A SPEECH about re-igniting people's passion for advocacy in AIDS. Of course, no one – including me – can give passion to people. They have to *feel* it. What I can do, though, is to point out the injustices that keep my passion for this work alive. Maybe they will resonate for you or remind you of others which you think are worth fighting for.

My top three at the moment are the growing barriers to access to treatments by the proliferation of federal and provincial bureaucracies; the increase in the number of infections in this country when we know how to prevent them; and the daily human rights violations we experience due to unrelenting HIV/AIDS stigma and discrimination. Due to space constraints I will only deal with the access to treatment issue.

In access to treatment issues, the Holy Grail for governments is apparently cost containment, no matter what the cost to human life and to the quality of life. How else could one explain its recent creation of a common drug review process (CDR) that never approves a drug that costs more than others in the same class, even when there is a clear need for it in drug experienced people? And, it is a system that refuses access to the decision-makers, while being immune from a Freedom of Information challenge. How convenient.

When you turn to its employers (the provincial Ministries of Health) for an explanation of these bizarre decisions, they say they have no control over that body, even though they – I mean we – foot the bill as taxpayers for it. How very convenient. But then they say that they are keeping their options open about following the CDR's recommendations in case they disagree with them. Talk about having your cake and eating it too.

If that isn't enough to curl your toes, look into the new infection rates and the human rights problems we have and I am sure that you will find the passion within you. ■

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CTAC POSITION PAPERS

Papers

- 2001 - "Improving our Health: The Need to Enhance the Post-Approval Surveillance System for HIV/AIDS Drugs in Canada", author: David Garmaise.
- 2001 - "Making Treatments Accessible: A Policy Paper on Determining Appropriate Pricing for Brand-name Pharmaceutical Treatments for HIV/AIDS in Canada", author: Glen Brown.
- 2000 - "Position Paper on Direct To Consumer Advertising (DTCA) of Prescription Medications", author: Phillip Lundrigan.
- 1999 - "Timeliness and Transparency: Assessing the Review Process for HIV Drugs", author: David Garmaise.

Permission is given to reproduce all or any part of the papers provided appropriate accreditation is given. Papers are available free of charge electronically at www.ctac.ca/english/position_papers.html or on hard copy from the CTAC office (see contact information below).

Organizational Mandate

The mandate of the Canadian Treatment Action Council (CTAC) is to work with the public and private sectors to:

1. **Support access to therapies and treatments** for people living with HIV/AIDS by informing research and public policy, and by promoting public awareness
2. **Provide mentoring and skills building** in these areas to people living with HIV/AIDS
3. **Encourage and facilitate the exchange** of related information to stakeholders

MEMBERSHIP

Membership applications are available by contacting the CTAC office or by visiting the CTAC web site at www.ctac.ca/english/membership.html.

Full Membership

- Person living with HIV/AIDS
- Group, organization and/or project with a substantive HIV/AIDS mandate

Associate Membership

- Any individual
- Group, organization and/or project whose substantive mandate coincides with the objectives of the Corporation

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