

# CANADIAN TREATMENT ACTION COUNCIL



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# HIV & Hepatitis C CO-INFECTION

A stylized, textured map of North America is positioned behind the main title text.

*by Pierre Côté, MD*

### **Epidemiology**

170 million hepatitis C (HCV) infections estimated worldwide include 0.02% of Europe's population and 6.5% in Africa. Closer to home, prevalence is estimated at 1.8% in North America.

In real terms, it is estimated that 240,000 people are infected with HCV in Canada. The number of people co-infected with HCV and HIV is approximately 13,000.

In Montreal, most co-infected people are injection drug users (IDUs). Cocaine use is high, which unfortunately often makes their behaviours riskier. Over 98% of HIV-infected IDUs are co-infected with HCV.

### **Description of the Hepatitis C Virus**

Before HCV was identified in 1989, it was referred to as non-A, non-B hepatitis. Since then, several genotypes have been identified. The one most often found in Canada is genotype 1, appearing in about 63% of cases. Unfortunately, hepatitis caused by this genotype generally does not respond well to standard treatment. The other genotypes most often encountered are genotypes 2 and 3, each found in 14% of cases.

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## Natural History of the Hepatitis C Viral Infection

When a person is infected, there is a 15% chance of eliminating the virus. This means that 85% of people infected will develop chronic hepatitis (persistent viremia). Of these 85%, 30 to 40% will continue to have normal liver enzymes with a very slow progression rate. However, 60 to 70% will have high enzymes, with progressive chronic liver disease. Among the latter, 20% of cases will progress to cirrhosis in 20 years. And among the cirrhosis cases, 1 to 4% per year will have early liver cancer.

## Progression Cofactors

The impact of HIV on HCV is well known. There is an accelerated progression of liver fibrosis, and therefore an increased risk of cirrhosis and liver cancer. Although a person beginning HIV treatment may experience an improved immune system, liver damage may be pronounced if the person is co-infected with HCV. Many of the drugs used to treat HIV or related ailments may be toxic to the liver.

The presence of a pre-existing liver disease, such as hepatitis B, immunosuppression (CD4<200), obesity, being male, and being infected at a later age (>40 years), may accelerate the progression of HCV as does the active consumption of alcohol (> 3.5 drinks per day).

## Treatment of Hepatitis C

The recognized treatment for HCV is interferon-ribavirin combination therapy from 6 to 12 months, depending upon genotype.

Response to treatment varies. Genotype 1 HCV does not respond well to classic treatment. There is little information available on the efficacy of interferon and ribavirin in patients co-infected with HIV and HCV. It does, however, seem quite clear that treatment is much less effective.

Peg-interferon appears to be more practical and promising because injections can be administered only once per week, compared to 3 times with interferon.

Unfortunately, these treatments have numerous side effects. Interferon may cause flu-like symptoms, mood swings, irritability, depression, some hair loss, diarrhea, flare-up of psoriasis or of a pre-existing auto-immune disease, diabetes, or it may affect bone marrow function (anemia, etc.). The possible side effects of ribavirin are hemolysis, dry cough, skin rash, itching and insomnia.

The contraindications for this treatment are active or planned pregnancy (may cause birth defects), depression, psychosis or, if there is a history, suicidal tendency, liver failure, hemolytic disorder, ischemic vascular disorder, cardiac arrhythmia and kidney failure.

AZT, D4T and DDC may have an antagonist effect on ribavirin, while DDI may have a potentiator effect. The clinical meaning of these drug interactions is not well known.

## Active Addiction

The problem of active addiction raises several questions regarding HCV treatment. Active alcohol consumption may accelerate the progression of hepatitis to cirrhosis and is contraindicated. Should we treat someone who continues to drink? All aspects, such as the ability to comply with treatment and the risk of re-infection, must be taken into account. Curbing the damaging effects should be a very important issue among this group.

## Conclusion

HCV is quite prevalent among people infected with HIV. Unfortunately, it often affects a marginalized and difficult to treat population. Moreover, the treatment currently used has limited efficacy with very significant side effects. For certain co-infected people, the risk of dying from HCV may be greater than the risk of dying from HIV. ■



Glen Hillson, Dr. Pierre Coté, Christian LaForce, James Kreppner and Daryn Bond present on Hepatitis C Co-infection at CTAC's skills building session in Montreal.

**Issues in***by Daryn Bond***HIV and Hepatitis C Co-infection**

To the HIV activist, hepatitis C may seem like someone else's problem. And, indeed, many agencies exist solely to respond to the needs of those infected with hepatitis C. Yet to the growing number of people living with both HIV and hepatitis C co-infection presents many challenges that are not adequately addressed by any group.

Of the estimated 13,000 co-infected individuals in Canada<sup>1</sup>, the majority come from society's disenfranchised populations. Injection drug users (71%), men who have sex with men and inject drugs (15%), aboriginal populations (14%), and inmates (5%) are at the greatest risk. The voice of the co-infected individual is often not present and rarely valued.

Active drug users are often entirely excluded from treatment for hepatitis C. Some medical professionals argue that drug users are less adherent to medications. However, studies have shown that drug users, given proper information and training, are no less adherent to HIV medications than control groups. Nothing suggests adherence to HCV treatment would be different<sup>2</sup>. Prejudicial attitudes are not valid reasons to exclude individuals from treatment. Another reason active drug users are excluded is the risk of re-infection following treatment. HIV and hepatitis are preventable, and given adequate resources, such as needle

exchange and harm reduction training, people can protect themselves from re-infection<sup>3</sup>.

There is a lack of information about treating co-infection. For example, doctors are uncertain whether it is better to treat HIV or HCV first. Some HIV medications are harmful to the liver, but combination therapy makes it difficult to be certain which medication is the culprit. The effect of street drugs on the liver and interactions with HIV and HCV medications are largely unknown. Research is needed, but few projects are designed to address these problems. Often HCV studies exclude HIV+ individuals from participating, and the few studies designed for the co-infected include other prohibitive restrictions. Most studies require the participant be on a stable HIV treatment regimen, or HIV treatment naive (at which point the researcher introduces anti-retrovirals). This contradicts current treatment wisdom that would postpone the use of anti-HIV medications. Doctors are reluctant to treat co-infected patients, especially if they are not taking HIV medications.

Action needs to be taken to improve treatment options, further research efforts, and establish equitable access to treatment for co-infected individuals. Most importantly, the injection drug use community and others at risk of co-infection need to participate in this work and ensure their needs are being met. Treatment activists have a major role to play in addressing the complexities of HIV/HCV co-infection. Fortunately, the battle against HIV has given activists the tools and experience to effectively tackle these issues. ■

1. Hepatitis C Division, Population and Public Health Branch, Health Canada, *Final Report - Estimating the number of persons co-infected with Hepatitis C virus and HIV in Canada*, March 31, 2001.

2. G. L. Davis and J. R. Rodrigue, "Treatment of Chronic Hepatitis C in Active Drug Users," *New England Journal of Medicine*, July 19, 2001.

3. *ibid*

# HIV, Hepatitis and Transplants

by James Kreppner

## Treatment has been discussed

elsewhere here, and I would only add that some additional drugs under consideration include Sciclone Pharmaceutical's Thymosin alfa product (Zadaxin) (thought to enhance interferon treatment) which is in Phase II trials, and antiviral drugs such as Amantadine (a flu antiviral), and Heptazyme (a ribozyme which cleaves viral genetic material) both of which are thought to disable the hepatitis C virus. If these drugs

have some efficacy, it is possible that future HCV therapy may involve broader multi-drug combinations much like HIV.

Another area to be explored involves the concept of "maintenance therapy." This is the concept that even where it fails to eliminate the virus, perhaps anti-HCV therapy can have a positive effect on the liver (if the patient

can tolerate the treatment). The American National Institutes of Health (NIH) is currently undertaking a large scale study of whether continued treatment is helpful and if the results of this study mirror the results of some smaller studies, this may become an accepted treatment alternative.

When treatment fails and the liver itself is failing, the final fallback is liver transplantation. This is a treatment that has been denied to those co-infected with both HIV and HCV. With an initial expectation of low life expectancy, and given the fact that livers are in short supply, it was thought to be a waste to transplant one for a patient in this situation. Data collected from early transplants seemed to support this fear, as the survival rate was not a good one. There was also a fear

that the post transplant immunosuppression would be problematic for those individuals already having an immunosuppressive disease (namely, HIV).

These concerns are not valid, however. As we are all aware, individuals living with HIV no longer have obviously foreclosed life expectancies, and some recent data also suggests that HIV+ transplant recipients can do just as well post transplant as those who are HIV-. With respect to immunosuppressive therapy, Dr. John J. Fung of the University of Pittsburgh program noted that "there is some evidence that immunosuppressive agents actually have a beneficial effect on HIV-infected patients."

There are a number of centers in the U.S. that are doing transplants in the co-infected population, with perhaps the best known being the University of Pittsburgh. Since 1997, the University of Pittsburgh has performed ten liver transplants on HIV/HCV co-infected individuals, and eight of these recipients are still alive and doing well. Other centers, such as University of California at San Francisco (UCSF) and Kings College in London, UK, have reported more mixed results, and the UCSF experience was that there was a rapid reoccurrence of HCV disease after transplantation. Of the five liver transplants done at these latter two centers, all died within 3 to 25 months after transplant surgery. In comparison, three other HIV+ patients who were transplanted with new livers because of a hepatitis B co-infection were all doing well post transplant. This dataset is extremely limited, but it poses the question of whether liver transplants are more effective in hepatitis B co-infection, than in hepatitis C co-infection.

As noted, the hepatitis C co-infected transplant data is

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**"There is some evidence that immunosuppressive agents actually have a beneficial effect on HIV-infected patients"**

## HIV, HEPATITIS AND TRANSPLANTS

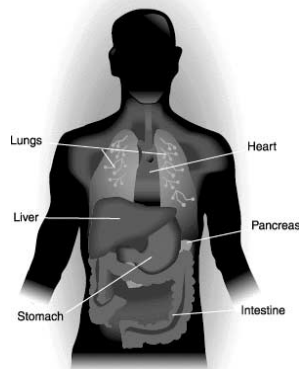
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contradictory, and the American NIH has funded a national study involving ten participating centers (the University of Pittsburgh being one of them) to study the outcomes of liver and kidney transplants in HIV infected individuals. At the recent national Canadian Hepatitis C Conference, it was announced that a similar study would be conducted in Canada as well, but there has been no obvious movement on this issue here, and HIV+ Canadians are still finding the doors closed to similar transplants.

With respect to the shortage of donor organs, one of the promising developments involves "living donor" organs. The liver has an amazing ability to regenerate,

and there was a recent transplant in Tokyo involving a co-infected 41 year old hemophiliac who received part of his 48 year old brother's liver in an operation that lasted about 20 hours. Both men have done well since the operation, which was conducted in April of last year.

CTAC's role should be to advocate for better HCV treatments with fewer side effects, and to monitor and promote new positive developments in treatments. As well, if drug treatment fails, co-infected individuals should have the option of a liver transplant, an option they have currently had difficulty accessing in this country. ■



# Hepatitis C Detection

*by Glen Hillson*

## Liver malfunction

is a common problem for people living with HIV/AIDS. Evidence that the liver is not working well comes in various forms, including elevated enzymes noticed during routine blood monitoring, clinical symptoms like loss of appetite, nausea, bloating and jaundice, or by more sophisticated diagnostic procedures such as ultrasound or liver biopsy. Liver illness is always potentially very serious and even life threatening.

One of the most difficult challenges is to determine the underlying reason(s) for liver problems. HIV itself impacts on many body systems, including organs such as the liver. Combination drug therapies can also affect liver function. Different drugs can adversely affect the liver through different biological processes that are not

medically well defined. Nucleoside drugs can interfere with cell mitochondria and cause a condition called lactic acidosis leading to terminal liver failure. Non-nucleosides and protease inhibitors can also add to liver stress, either through rapid adverse reactions or by adding to other compound stresses. Viral illnesses such as hepatitis A, B and C are well known causes of liver disease and damage.

Because HCV is transmitted through blood, medical practice has generally viewed blood transfusion recipients and injection drug users as the only populations at risk for infection. Consequently, the HCV blood test is frequently only administered to persons in those categories.

The diagnosis of hepatitis C has proven unreliable for people with HIV/AIDS and for gay men, for several reasons:

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## HEPATITIS C DETECTION

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1. People with diminished immune capacity may be HCV infected but not have developed antibodies to the virus producing false negative results.
2. Recent research suggests people with HIV disease may be biologically more vulnerable to HCV through sexual transmission.
3. While experts generally report that the risk of sexual transmission is low, they also acknowledge that risk is greater for individuals with multiple sex partners.
4. Canadian research suggests that men who have sex with men and those who practice rimming and fisting may be at greater risk.

Last year, the BC Centre for Excellence in HIV/AIDS advised HIV treating physicians not to rely solely on HCV antibody testing in people with HIV who have unexplained liver illness. They suggest qualitative polymer chain reaction (PCR) testing, designed to identify HCV itself rather than antibodies.

Many other theoretical risk factors for HCV transmission need to be researched. Timely detection of HCV is one of many issues for people who are co-infected. Optimal strategies for the concurrent medical management of HIV and hepatitis C are also highly experimental as are many of the combinations of compounds that are used to treat each disease separately. ■

## CANADIAN TREATMENT ACTION COUNCIL (CTAC) 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.

# CO-INFECTION and Complementary Medicine

by Ron Rosenes

**Co-infection with HIV and HCV** has the potential to double the stress on the liver. As if it were not enough to assault the liver with fatty foods, alcohol, and HIV meds, hepatitis C can lead to fibrosis (early scarring of tissue), cirrhosis (advanced scarring), and possibly cancer. For many years people have used natural approaches including herbs, vitamins and systems such as Traditional Chinese Medicine (TCM) to slow or reduce damage to this vital organ. Unfortunately, it's what we don't know that can cause us the most harm.

TCM practitioner David Bray works with co-infected patients using acupuncture and traditional Chinese medicinal herbs to promote the liver in its TCM function, which is to ensure the smooth unhindered circulation of Qi and blood in the body. Treatment is individualized. The research and the practice which date back thousands of years suggest there is benefit to be derived from keeping an energy balance in the body and from the use of herbs.

The herb glycyrrhizin, the active ingredient in the licorice plant, has been studied in clinical trials and shown to reduce alanine aminotransferase (ALT). But don't rush out to buy glycyrrhizin. These trials were conducted using an IV formulation of the herb, so more research is needed before informed decisions can be made about its use. Licorice may cause problems with blood sugar levels and possibly cause a dramatic rise in blood pressure. The use of DGL (de-glycyrrhized licorice) may be preferred.

The herb we know the most about is milk thistle (MT). The active ingredient silymarin appears to have desirable anti-inflammatory, anti-fibrotic and



anticarcinogenic properties. It has been shown to inhibit viral replication in HCV. Many practitioners would recommend it, but need more research regarding interactions with HIV meds. According to Health Canada researcher Brian Foster, there is evidence that MT, used occasionally, may inhibit some of the pathways used to clear HIV drugs. Studies are ongoing to determine if repeated use leads to increased blood levels and toxicities of these drugs.

Herb-drug interactions are difficult to evaluate because the active ingredient and dose are often not known. Herb-drug interactions may take longer to appear. Studies that determine the appropriate dose and potential to interact with drugs are needed. It is important to find knowledgeable practitioners and tell them about everything you are taking.

Treatment action efforts must remind industry of its responsibilities, including funding relevant trials and encouraging government leadership in promoting research. ■

## FEATURED ADVOCATE: **Art Zoccole**

by Darren Greer



**Art Zoccole** says that it is a shared sense of isolation that motivates him to work with Aboriginal people on the issues of HIV and AIDS. Zoccole, a 2-spirit Ojibway man, grew up on a country lane in Northern Ontario. The disconnect and loneliness he felt then he now likens to the feelings of isolation and despair an Aboriginal person can feel when he or she is diagnosed with HIV.

Art first began to think seriously about Aboriginal AIDS and 2-spirit issues in 1989, when Cree writer Tomson Highway approached him on Church Street in Toronto and asked him to form a support group for downtown 2-Spirit Aboriginal men and women. Art eventually took Highway's advice, which resulted in the creation of 2-Spirited People of the First Nations, Ontario's first Aboriginal AIDS service organization, which Art helped co-found in 1991. Eleven years later, in 2000, Art became the Executive Director of the Canadian Aboriginal AIDS Network, and is now recognized as one of the foremost leaders of the Aboriginal AIDS movement in Canada. But it is still talking and identifying with Aboriginal people living with HIV, he says, that makes his work worthwhile.

These days, however, Art does far more than talk, or even listen. The Canadian Aboriginal AIDS Network has its organizational fingers in many pies, from international indigenous issues, policy discussions with Health Canada and meetings with Aboriginal health and political organizations to decide how best to deal with issues of AIDS and HIV. One of the biggest ongoing challenges, Art says, is coping with the stigma of the disease in many Aboriginal communities, where HIV is still seen as a gay, white man's disease. "We need to change these attitudes,"

he says, "and that's what a lot of our work is about."

On the other hand, Art talks about the need for non-Aboriginal communities to recognize Aboriginal autonomy in the area of HIV/AIDS and other health arenas. Art spends much of his time at public forums, trying to convince governments and non-Aboriginal organizations of this, while at the same time advocating for the training and resources necessary for Aboriginal people to undertake HIV/AIDS work in their own communities.

When asked about Aboriginal HIV/AIDS treatment issues, Art painfully recalls the early days of the disease, when he anonymously dropped off a desperately sick friend at a hospital emergency room in Toronto and ran away before the nurses could refuse to admit a patient with AIDS. On a lighter note, he also remembers when the protease inhibitor Saquinavir first came out, and a lot of the Aboriginal clients at 2-Spirit People Of The First Nations in Toronto used to, only half jokingly, refer to it as 'Gwenavere', because they couldn't pronounce the name of the drug. Using this example, Art points out that making sure information is relevant, culturally and linguistically appropriate is the #1 priority of treatment advocacy aimed at Aboriginal people.

But still, despite all the work that is being done, and as busy as Art and other Aboriginal AIDS activists are, Art's motivation remains unchanged. He has been touched personally by the disease. "The most important connection to make with somebody in this life," Art says, "is to understand them, love them and to accept them for who they are." It is the only thing, he believes, that can end our sense of isolation, from wherever that source of isolation may come. ■

# SMALL BUT MIGHTY: Canadian Treatment Activists and Educators at NATAF 2001

by Paula Braitstein



Louise Binder, CTAC's Chair, and Charles Roy, Executive Director of AIDS Committee of Toronto, presented as part of a Leadership Panel.

December 2-5, 2001, saw the first gathering of over 500 HIV/AIDS treatment advocates, activists, and educators from across North America, including Mexico and the Caribbean, and even from eastern Europe. NATAF, or the North American Treatment Action Forum, was, until 2001, previously known as National AIDS Treatment Advocates Forum. This was a U.S.-based conference for AIDS treatment activists that began in 1992, and which Canadian treatment educators and activists have always supported and attended.

Vancouver was the city of choice for this first venture outside the United States, both because of the weather and the favorable dollar exchange (their favour, of course...). But be prepared, because I think eyes are set on Montreal for 2003. Of the organizations originally approached, CTAC, the Canadian AIDS Society, and the British Columbia Persons with AIDS Society stepped up to the plate. Having attended NATAF a few times before, I was excited - and hugely intimidated - about working with activists from the US on such an important conference.

We determined at the outset that we would have Canadian representation in every workshop, in the planning of the program, and in plenaries. When the National Minority AIDS Council (NMAC), the organization that brings together the coalition of groups who put the conference together, first approached us, they were very respectful of the "local" scene (i.e. Canada in general, and Vancouver in particular). It was clear they were looking for meaningful partnerships. Early in the process, when I was still intimidated about working with these folks, Glen Hillson said to me, "It isn't what they think of you now that matters; it's what they think when it's all over." I am quite certain that, almost without exception, the US and international delegates walked away thinking that they had underestimated Canadians.

Small but mighty, we showed incredible leadership and expertise in all sorts of areas - including Glen's standup comedy, and Louise Binder's fierce telling of truths that so much need to be heard. And, while Glen and Louise, as the leading Canadian treatment activists, did do several presentations each, there were many other presentations by many other Canadians which essentially strutted our Canadian stuff. Our strengths showed themselves to include mental health, nutrition issues, complementary therapies, prison work, models of self-empowerment and peer support, materials and mechanisms for people of low literacy to access HIV treatment information, women's issues, immigration issues, pregnancy, and of course antiretrovirals - to mention a few.

I realized during the process of organizing this conference that the number of people doing this work even in the United States is small, and in Canada it is even smaller. While there are more people involved in doing treatment education in both countries, the number of individuals doing collective advocacy and activism is relatively small. I don't think our approaches differ very much (though we may be more polite, in general!). The major advocacy issues facing us are similar to the major issues facing activists in the US: spiraling drug costs, inadequate health care systems, and poverty and marginalization leading to extreme vulnerability. As Canadian treatment advocates, activists, and educators at NATAF, I think we showed the breadth of our experience and capacity. However, to face these major advocacy issues into the future will require us to show our depth - depth of commitment, of passion, and of creativity. Most importantly, they will require all of us to work more collaboratively together. And although we have a great deal in common with our southern neighbors, be prepared, when the time comes for collaboration, to be engaged in a cross-cultural experience! ■

# PROVINCIAL UPDATES

## ALBERTA

*by Bob Mills*

Our World AIDS Day campaign went very well this year. On Friday November 30th I was a guest on the Edmonton A Channel Morning Breakfast Show. Following the television interview I, representing CTAC, along with Kevin Midbo (ACCH), Maggie McGinn (Living Positive Society), Dr. Barb Romanowski (HIV Clinician), and many activists from around Alberta held a very successful press conference raising awareness of the need to increase the funding to the Canadian Strategy on HIV/AIDS. On World AIDS Day, an information fair was held in Old Strathcona where CTAC had a table sharing newsletters and position papers as well as its mandate and contact information, followed by a candlelight vigil. ACCH held its first meeting of 2002 from February 5-8 where an update was presented on CTAC's workplan for 2002 and interested ACCH members were invited to participate on the many CTAC committees.

## PRINCE EDWARD ISLAND

*by George Clark-Dunning*

Over the past year, Atlantic Canada has watched as the Ministers of Health in each province discuss their drug formularies. Originally, the idea was to buy drugs in bulk, thus lowering the purchasing price. As well, the process to approve new drugs was to be sped up, and instead of four committees meeting quarterly to review new drugs and drug requests, one committee would meet to make these decisions for all of Atlantic Canada.

In reality, what is happening is that some drugs will be dropped from some formularies. In the last calendar year, prescriptions for drugs that improve quality of life for people living with HIV/AIDS, from human growth hormone to anti-fungal cream, have not been covered in PEI. While PEI covers all of the combination chemotherapy drugs, others drugs are being dropped.

If this trend is not addressed, there is a real fear that other provinces will follow this precedent set by Atlantic Canada. CTAC will continue to monitor this situation and take action where needed.

## ONTARIO

*by Enrico Mandarino*

A total of 58 participants took part in the skills building day held in Toronto in November 2001. CTAC and The Ontario AIDS Network continue to collaborate in the area of access to treatments by holding skills building opportunities and discussing and working on treatment issues in Ontario.

The day included a brainstorming session on current access to HIV treatment issues in Ontario. The group re-affirmed its commitment to working via committees to inform public policy on these issues for the province. The committees are: The Ontario AIDS Strategy Committee, The Formularies Committee, Care Shortage Committee and Dental Care Committee, in addition to the new Resistance Testing in Ontario Committee. Please visit CTAC's website or contact the CTAC office for more information on how to get involved.

### **The Ontario AIDS Strategy Committee**

The Ontario AIDS Strategy expired in 2000. Last year, this committee filled out a questionnaire on the Strategy which was designed to help develop a new strategy for Ontario. Since then, The AIDS Bureau of The Ministry of Health and Ontario Advisory Committee on HIV/AIDS(OACHA) have created a document entitled "Status Report: HIV/AIDS in Ontario." I participated in a working group that evaluated the discussion paper and offered advice on strategic directions that will help shape the next provincial HIV/AIDS strategy. The working group focused on: the key challenges facing HIV in Ontario, the

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## PROVINCIAL UPDATES

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creative recommendations or solutions that can be developed in response to the identified challenges, and obstacles to the solutions. A final report will be made available via CTAC's website.

### NEWFOUNDLAND AND LABRADOR

*by Philip Lundrigan*

The Newfoundland and Labrador PWA Network (NLPWAN) - CTAC Nfld. & Lab. held its 3rd annual face-to-face meeting in October 2001. Twenty-one people attended, of which eighteen were living with HIV/AIDS. The meeting took place in St. John's, however, all regions of the province were represented.

The agenda for the weekend event included a day of skills building on a wide variety of treatment-related issues, including treatment side-effects, drug interactions, and the long-term complications of antiretroviral therapy. A discussion regarding alcohol, recreational/street drugs, and HIV treatments proved especially timely for some members, and was generally well received by the network. Adherence, resistance, new options and structured treatment interruptions (STIs) also received considerable attention.

Two half-day sessions were devoted to discussions on issues related to access to treatment. The Executive Director at the AIDS Committee of Nfld. & Lab. (ACNL), Bill Downer, discussed the ACNL operational funding proposal. The discussion focused primarily on areas where the ACNL provides direct services to people living with HIV/AIDS.

Bill also gave an update on efforts by the ACNL to reactivate/renew the Provincial AIDS Strategy. It was originally established in 1993 but has been inactive since that time. People living with HIV/AIDS will have an opportunity to participate in all negotiations. ■



#### **Bob Mills receives Medal of Merit**

Bob Mills was nominated by HIV Edmonton for the International Year of the Volunteer Medal of Merit. He was one of 10 recipients of the prestigious award. Member of Parliament Anne McLellan presented the medal during a public ceremony in Edmonton, December 2001.

Our heartfelt congratulations, Bob!

## CTAC Online

CTAC is pleased to announce the launch of its website - [www.ctac.ca](http://www.ctac.ca). Available on the site are current and past issues of our newsletters, position papers, press releases, current activities, information on how to get involved, links to other related sites, and much more. The CTAC website is an excellent resource for anyone looking for information about CTAC. Contact the CTAC representative in your province. Become a CTAC member online! Choose to receive our newsletter electronically instead of by mail. Be sure to check out CTAC online at: [www.ctac.ca](http://www.ctac.ca).

# WOMEN'S ISSUES Update

by Shari Margolese

The North American Treatment Action Forum held in December 2001 provided several opportunities for CTAC to share its knowledge about women's treatment issues with a wide variety of stakeholders.

One of many presentations by CTAC Chair Louise Binder, *Broadening the Agenda, Fighting for Access to Quality Care and Treatment for HIV and Women* communicated the Canadian experience of organizing the First National Women and HIV Conference in May 2000, and the resulting treatment recommendations and efforts to implement them. Ms. Binder also announced that CTAC and its national partners have begun preliminary discussions to plan the Second National Conference on Women and HIV/AIDS in 2003.

The First National Conference on Women and HIV/AIDS included participation by over 500 HIV+ women, health care providers, representatives from ASOs and NGOs, doctors and researchers. Recommendations for action were developed in each of four tracks: prevention, support, treatment and legal, ethical and public policy issues, which were then consolidated into one set of recommendations. Specific organizations will be leading the work areas under their jurisdiction.

CTAC has already begun to disseminate the treatment-related issues through a number of presentations and workshops developed and delivered by its Women's Committee members over the past year.

The treatment access recommendations fit in to five main categories: Access to Treatment, Care and Testing; Research; Post Approval Surveillance System; Complementary and Alternative Medicine; Policy and Program Development and Implementation.

Access to Care, Treatment and Testing recommendations call for revision of the treatment guidelines to reflect gender differences, establishment of optimum antiretroviral dosing for women, access to more tests and to well-informed healthcare professionals.



Microbicide and HIV vaccine research and development are included in the research path as are development of clinical trials that are accessible to and representative of women, together with research specific to women and research that incorporates gender analysis.

Recommendations for a Post Approval Surveillance System focus on inclusion of women's issues, active reporting mechanisms for all stakeholders and a mechanism for the analysis and broad dissemination of information collected.

Paramount to discussions about Complementary and Alternative Medicines (CAM) is how to pay for them. Suggestions include advocating for increased government and community based funding of CAM and tax relief for those using CAM. Women's conference participants also cited a lack of clinical trials on vitamins, herbs, and supplements, including interactions with conventional treatments and the need for educational opportunities, partnerships and networking amongst all relevant stakeholders.

The Policy and Program Development and Implementation stream recognizes the need for individualized adherence plans and for women to be recognized as at risk for HIV infection. It also points out the lack of targeted information resources for women regarding pregnancy, cultural and other issues.

The complete list of recommendations and continued plans for their implementation is available through the CTAC office. ■

## CALENDAR OF EVENTS

SPRING 2002

● **April 11th-13th, 2002**

**3rd International Workshop on Clinical Pharmacology of HIV Therapy**

Washington, DC

Registration Information:

<http://www.virology-education.com/index2.html> or  
+31 30 230 7146

● **April 24th, 2002**

**CTAC Skills Building Event**

Winnipeg, Manitoba

See [www.ctac.ca](http://www.ctac.ca) or contact the CTAC office for more details!

● **April 25th-28th, 2002**

**Canadian Association for HIV Research 2002**

Winnipeg, Manitoba

Contact: [info@cahr-acrv.ca](mailto:info@cahr-acrv.ca) or (613) 258-5062

● **April 30th-May 3rd, 2002**

**First Annual Aboriginal Hepatitis C Conference**

Edmonton, Alberta

Contact: [anne-halfe@nechi.com](mailto:anne-halfe@nechi.com) or (780) 906-9869

● **May 2nd-5th, 2002**

**Fifth Annual Conference of Infectious Diseases Pharmacotherapy**

Orlando, Florida

Contact: [mad@fusionmdnetwork.com](mailto:mad@fusionmdnetwork.com)  
or 1-888-996-6660

● **May 12th-15, 2002**

**Microbicides Conference, 2002**

Antwerp, Belgium

Contact: [yjacob@itg.be](mailto:yjacob@itg.be) or 32 3 247 65 39

● **July 7th-12th**

**XIV International AIDS Conference**

Barcelona, Spain

Contact: [aids2002@aids2002.com](mailto:aids2002@aids2002.com) or  
(+34) 93 254 0555

## CHAIR'S REPORT

SPRING 2002

*by Louise Binder*

**We are now into a new year.** Many are breathing a sigh of relief since 2001 was certainly filled with some discouraging - even horrifying - events on the world stage. At home there were also some discouraging signs for those of us concerned about health care in this country.

For example, the federal budget focused very little attention on this area. Thus, systemic problems that CTAC and others in the AIDS arena have pointed out repeatedly remain unremedied. There is not enough money in the Canadian Strategy on HIV/AIDS to sustain the gains we have made in the strategic areas covered in it and to deal with emerging issues across the country. Outside of the Strategy there is still not an efficient, effective drug review system for Canada, nor does it have anything approximating an active, consumer-centred post approval surveillance system for drugs sold here. Leadership and creativity at the federal level is sorely lacking on these important issues.

As well, the price of new drugs continues to rise, putting a strain on the entire health care system.

In response to the rising cost of health care and pressure from the provinces to do something about it, the federal government has set up the Romanow Commission to make recommendations about the future of health care in Canada.

As well, the federal/provincial/territorial Ministers of Health met to develop a plan to provide better pharmaceutical management. This led to an agreement that included the establishment of a common review process for coverage of new drugs in Canada. While decisions on benefit coverage and formulary listing will be retained by individual provinces, territories, and the federal government, they agreed to future cooperation wherever desirable. They also agreed to increase collaboration and to enhance the assessment of cost effectiveness in the review process for drug coverage.

While these initiatives may appear benign enough, and even good practice, there are real questions about their practical impact on Canadians' access to universal health care and to treatments. It is unlikely that any of these initiatives will improve access to those who most need it and can often least afford it. It is unlikely even to leave the status quo intact.

CTAC will involve itself in all aspects of this debate that impact access to treatment and treatments for people with HIV/AIDS. As well, it will continue to work on the areas it has already identified for action, including the reform of the drug review process and the development of a post approval surveillance system in Canada.

CTAC will also continue to develop its provincial networks and to provide skills building about these vital issues, for it is only in our collective strength and efforts that we can impact the outcomes of issues of importance to all of us. We trust that you will join us in this work and look forward to a challenging but rewarding period ahead. ■

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### 2001/2002 FUNDERS

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Abbott Laboratories • Boehringer Ingelheim • Bristol-Myers Squibb • Gilead Sciences • GlaxoSmithKline in partnership with Shire BioChem • Hoffmann-La Roche • Merck Frosst • Ontario HIV Treatment Network (OHTN)

## CTAC POSITION PAPERS AND SKILLS BUILDING VIDEOS

### 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.

### Video Tapes

- 2001 - "New Drug Reviews and Research: What's the Rush?" - \$9.00
- 2001 - "Making Room for CAM: Advocacy Issues regarding Complementary and Alternative Medicine (CAM)" and "How to Lobby Politicians and Bureaucrats Effectively" - \$11.00

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Membership applications are available by contacting the CTAC office or by visiting the CTAC web site.

#### 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

### PUBLICATION CREDITS

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