

Canadian Treatment Action Council

Annual Report
2007-2008



For more information, contact us at:

Canadian Treatment Action Council (CTAC)

P.O. Box 203, Suite 1109B

555 Richmond Street West

Toronto, Ontario M5V 3B1

Phone and Fax: (416) 410-6538

Email: ctac@ctac.ca

For an electronic version of this
report or for more information
on CTAC's current work,
please visit our website at:

www.ctac.ca



BOARD OF DIRECTORS (MARCH 31ST 2008)

CHAIR Louise Binder
VICE-CHAIR Ron Rosenes
TREASURER Patrick Cupido
SECRETARY Brian Finch
Richard Baker
Colleen Price
Sandy Lambert

STAFF (MARCH 31ST 2008)

Sarah Benn – Administrative Assistant
Béatrice Cardin – Coordinator,
Communications and Organizational
Development
Ross Chapman – Manager of Finance
Sonika Lal – Project Coordinator
Ruth Pritchard – Senior Policy Analyst
Leah Stephenson – Executive Committee
Advisor

COUNCIL (MARCH 31ST 2008)

Mark Randall Alberta
Sam Friedman British Columbia
Myles Legacy New Brunswick
John Baker
Newfoundland & Labrador
Michael Sangster
Nova Scotia
Harlon Davey Ontario
Troy Perrot Prince Edward Island
Jean-Pierre Bélisle Québec
Ron Rosenes AIDS Action Now! (AAN!)
Ken Buchanan British Columbia
Persons with AIDS Society (BCPWA)
Christal Capostinsky
Canadian AIDS Society (CAS)
Terry Pigeon Canadian AIDS
Treatment Information Exchange
(CATIE)
James Kreppner
Canadian Hemophilia Society
Richard Elliott
Canadian HIV/AIDS Legal Network
Ken Monteith Coalition des
organismes communautaires
québécois de lutte contre le sida
(COCQ-sida)
Louise Binder Toronto People
with AIDS Foundation (TPWAF)
Angel Parks
National Women's Representative
Marco Gomes
National Youth Representative
Sandy Lambert
Aboriginal Representative
Jeanne Nzyeimana
Representative of Black Canadian,
African and Caribbean Communities
Karen Dennis
Representative of current and former
substance users
Greg Simmons
Representative of prisoners/ex-prisoners

Primary Sources of Revenue

Public Health Agency of Canada (PHAC)
PHAC - Volunteer Sector
Response Fund
PHAC - National HIV/AIDS
Capacity Building Fund
Boehringer Ingelheim Canada Inc.
Bristol-Myers Squibb Pharmaceutical
Group
Gilead Sciences
GlaxoSmithKline in partnership
with Shire BioChem
Hoffmann-La Roche
Merck Frost
Pfizer Canada, Agouron Pharmaceuticals
Inc.
Sanofi Aventis
Tibotec



Chair's Report

Laurie Bender



In 2007–2008, CTAC continued to inform public policy in support of access to all necessary therapies and treatments throughout Canada, participated in international advocacy efforts, and contributed to the initiative to improve public health policy and research directions affecting people living with HIV/AIDS in Canada and internationally.



Access to Treatment, Drug Pricing, and Cost Containment

Changes in Federal Funding for AIDS Service Organizations

In the spring of 2007 the federal government announced a financial commitment of \$111 million over 5 years to HIV vaccine research initiatives. However, this money is to be obtained by diverting resources previously allocated to the Federal Initiative on HIV/AIDS. This represents a betrayal of the federal government's commitment to deliver \$84.4 million dollars in 2008-09 to HIV/AIDS care, treatment, and support initiatives. CTAC issued a press release in November 2007

urging that the need for adequate funding for prevention, treatment, and other necessary services for people who have contracted or are at risk of contracting HIV be recognized and met by the federal government. In December 2007, CTAC joined other national HIV/AIDS NGOs in attending a meeting with the Minister of Health and added its voice to those urging that any and all funds for vaccine research be dispensed in addition to current Federal Initiative funding levels.

Drug Pricing, Regulation and Availability

This year, CTAC worked towards the resolution of a wide range of issues relating to access to pharmaceutical drugs and therapies. CTAC continued to monitor the development of cross-border internet pharmacies and urged its members to pressure their Members of Parliament to respond to the proposed American *Pharmaceutical Market Access and*

Drug Safety Act of 2007, which would legalize the importation of prescription drugs from Canada by patients, pharmacists, and wholesalers. CTAC also contributed to policy research in this field by commissioning a policy paper on *Generic Drug Pricing in Canada*, which recommended convening a multi-stakeholder focus group meeting which would provide

policy recommendations to the federal government to alleviate high generic drug costs in Canada. Responding to the proposed drug tendering system in British Columbia, CTAC has been active in meeting with community stake-

holders throughout the year to discuss possible impacts and ways of resisting this detrimental policy. CTAC has also lent its support to other advocacy organizations, including the Canadian Society of Intestinal Research, involved in negotiating drug pricing procedures with the government in British Columbia. In addition to these efforts, CTAC is currently preparing a policy paper on National Formulary and Catastrophic Drug Coverage policies, complementing the province-by-province series of Formulary Review articles published throughout the year in its newsletter.



Liver Transplants for HIV+ Patients

At least a third of HIV+ individuals are co-infected with Hepatitis C. In addition, many HIV therapies have hepatic consequences. However, people with HIV/AIDS continue to be denied access to life-saving liver transplants. Throughout the year, CTAC supported the work of individuals in the community seeking liver transplants and taking the lead on the issue.

Lipodystrophy

CTAC continues to urge that lipodystrophy treatments be reclassified as a necessary reconstructive rather than elective or cosmetic intervention. In British Columbia, CTAC joined other HIV/AIDS organizations in negotiating to make facial lipodystrophy treatments eligible for coverage under the Medical Services Plan.



Common Drug Review

CTAC, in collaboration with the Best Medicines Coalition, spoke before the federal Standing Committee on Health on May 9, 2007, to deliver its analysis of the performance of the Common Drug Review. CTAC presented essential standards for a drug review process not currently met by the CDR's protocol. The recommendations outlined a broad approach to cost-containment, including:

- comprehensive and progressive data analysis models to take into account the costs of hospitalization, surgeries, and universal health care
- a flexible model that incorporates novel and innovative medicines (treatment for previously unmet needs or rare disorders and those which offer significant therapeutic advance)

- an expedited review process, with improved consultation of national and international experts in each therapeutic area
- meaningful consultation of patients and stakeholders
- transparency
- a formal, fair appeal process for drugs not approved by the CDR

CTAC's contribution was taken into consideration by the Standing Committee, whose report was presented to the House of Commons on December 12, 2007.



Community Workshops & Skills Building

CTAC hosted and participated in several information exchanges this year. These included the Community-Campus Partnership in Health Conference in April, the Nova Scotia Skills Building Ceilidh in June and the Newfoundland PHA Skills Building Symposium in August.

In February, CTAC traveled to Vancouver to present the *Access Denied: Are PWAs in British Columbia getting what their doctor ordered to treat HIV/AIDS and related conditions* and *Walking the Western Medicine Road: HIV/AIDS Treatment Access for Aboriginal People* workshop and panel discussions. The *Access Denied* workshop welcomed community members, advocates and clinical practitioners to discuss barriers to treatment in British Columbia. The *Walking the Western Medicine Road* workshop

recognized the specific needs of Aboriginal people living with HIV/AIDS and conducted workshops which generated several recommendations. These workshops provided valuable information to community members while identifying new and emerging issues including:

- rural access to HIV/AIDS care
- access to dental care
- disclosure issues raised by new medical technologies
- barriers to treatment encountered by people newly arrived in Canada.

CTAC also presented the *Tools for Advocacy Level 1 Workshop* at the Open Doors Event in Burlington, Ontario on November 14.





Regulatory Issues

Clinical Trials

CTAC has initiated a Clinical Trial Working Group in order to identify and resolve the vulnerabilities of people participating in clinical trials of newly developed pharmaceutical therapies. CTAC continues to advocate for a 50/50 gender split in pharmaceutical trials. As part of its continuing involvement in this matter, CTAC has been participating on a committee of the Canadian General Standards Board which is developing standards for research ethics boards reviewing clinical trials.

Natural Health Products (NHP)

CTAC has been monitoring the effect of Bill C-51 on access to treatment and has been preparing materials to present information on issues surrounding this legislation. In addition, CTAC Board member Ron Rosenes has participated in a number of consultations to ensure the new legislation treats natural health products fairly within the new *Food and Drug Act* (Bill C-51). He has also been an active member of the Management Advisory Committee, seeking to reduce the backlog in NHP reviews and the Expert Advisory Committee as well.



Post-Approval Surveillance and the Progressive Licensing Framework Projects



Throughout the year, CTAC continued its efforts towards developing a consumer-oriented surveillance of therapies through its Post-Approval Surveillance System (PASS) working group, and continued to advocate for an implementation of this system. CTAC submitted an abstract of its findings to the Canadian Agency for Drugs and Technologies in Health conference, held in Ottawa on April 23-24.

Responding to calls to modernize out-of-date legislation and approaches to the licensing of therapeutic products, the federal government has initiated a policy shift towards a “life-cycle” approach to drug regulation. It is being undertaken by the Health Products and Food Branch of Health Canada and includes proposals for proactive planning in advance of new product submissions, provisional licensing, and continual reassessment of safety and effectiveness data once a therapeutic product is on the market.

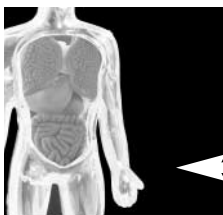
As a leader in PASS research and as the author of a published community based study which analyzes the best methods of post-approval data collection, CTAC has proposed that the HIV/AIDS community is an ideal place to begin researching the implementation and effects of progressive licensing. CTAC is continuing to move the development of the Progressive Licensing Framework (PLF) project forward by developing a protocol for such a pilot project.

CTAC has reached out to community stakeholders to seek feedback regarding the proposed changes. Consultations have been taken with numerous stakeholders. Information and input was solicited from the Bureau for Women’s Health and Gender, AIDS service organizations, people living with HIV/AIDS, Aboriginal people living with HIV/AIDS, prisoners, HIV/AIDS researchers and clinicians, pharmaceutical manufacturers, and representatives of the Common Drug

Review, the Patented Medicine Prices Review Board, and provincial ministries of health. This feedback will be compiled in a written report and submitted to the CTAC Board, who will then draft the recommendations to be made to Health Canada.

Approach to Canada's Progressive Licensing Framework which included a presentation by David Lee, Director of the Progressive Licensing Project at Health Canada.

In order to prepare for this initiative, CTAC presented a skills-building session on October 13, 2007 entitled *AIDS Community Leads the Way: A Consumer-centered*



HIV/HCV CO-INFECTION

On April 16, 2007, CTAC partnered with the Ontario HIV Treatment Network in co-sponsoring *Toward Greater Integration: A Think Tank on Hepatitis C and HIV Co-infection in Ontario*. This event gathered people living with HIV/HCV co-infection, federal and provincial government officials, physicians, researchers, and front-line support workers, who together

selected representatives to form the Ontario HIV/HCV Task Force. CTAC sits on this committee, which has compiled and publicized the recommendations that emerged from the conference, as well as reviewed these recommendations and developed an action plan to address the identified issues. Also as a result of the Think Tank, CTAC formed its own Working Group on this issue.



INTERNATIONAL ISSUES

Global Availability of Pharmaceutical Treatments

On July 25, 2007, CTAC member Ron Rosenes attended the International AIDS Society Conference in Sydney, Australia in the capacity of Community Activist Liaison and as a member of the Community Advisory Group. This body co-authored the *Sydney Community Statement* that supported new treatment breakthroughs while stressing the need for these treatments to be made available at globally affordable prices. The statement also emphasized the

role of prevention research, harm reduction strategies and community involvement in comprehensive prevention programs.

CTAC continues to support the efforts of the Canadian HIV/AIDS Legal Network as it works towards ensuring that the federal government's recent legislative commitment to facilitate the export of low cost generic medications to low and middle income countries is fulfilled.





Rwandan Community Mobilization and Leadership Initiatives

In January 2007, CTAC participated in community mobilization and leadership initiatives held in Kigali, Rwanda. Working with other international and local organizations, CTAC contributed to developing a process to create a national report card on HIV/AIDS among women and girls in Rwanda. In addition, CTAC members facilitated a community mobilization and leadership workshop for HIV/AIDS organizations and people living with HIV/AIDS, as well as Living Positive sessions with an orphans' and vulnerable children's support group. CTAC also co-facilitated a gender-based violence workshop with a local fathers' support group.

products of a local income generating program for HIV+ women. Abstracts developed from this work were developed and successfully submitted to the XVII International AIDS Conference in Mexico City, held in August 2008.



Responding to the economic barriers to treatment among Rwandan women, CTAC is assisting with market development for the

POPULATION SPECIFIC ISSUES

Aboriginal Issues

In collaboration with the Canadian Aboriginal AIDS Network and the Positive Women's Network, CTAC hosted a workshop in Vancouver, British Columbia in February that developed recommendations stressing the culturally-specific needs of Aboriginal people living with HIV/AIDS.

These recommendations included:

- providing Aboriginal-specific training relating to HIV/AIDS for doctors, nurses, and other health care professionals
- an all-cultural campaign of story-telling
- aboriginal-specific clinical research
- better and more accessible educational materials
- more research regarding co-infection
- training Aboriginal AIDS educators
- promoting the understanding of traditional medicine, including Medicine Wheel teachings
- improving and ensuring access to physical and mental health

services for people in both urban and remote regions.

CTAC supports the Canadian Aboriginal AIDS Network, Healing our Spirit, the Northern Task Force on HIV/AIDS, and Red Road HIV/AIDS in their efforts on behalf of Aboriginal people living with HIV/AIDS.

Prisoners' Issues

This year, CTAC created a new Council position and successfully recruited a Prisoner/Ex-Prisoner



representative. Partnering with Prisoners HIV/AIDS Support Action Network (PASAN), CTAC has prepared public awareness materials in order to bring attention to this urgent issue and continues to support PASAN and the Canadian HIV/AIDS Legal Network in their important work in the field.



Women's Issues

CTAC has worked tirelessly to raise the profile of women's issues within the HIV/AIDS community. In addition to its advocacy efforts on the Canadian scene, CTAC works internationally with the International Community of Women Living with HIV/AIDS, the Blueprint for Action on Women and Girls and HIV/AIDS, Advancing Gender Equity and Human Rights in the Global Response to HIV/AIDS (ATHENA) and Oxfam Canada to confront the complex issues surrounding the ability of women to access HIV/AIDS treatment globally. In July 2007, CTAC attended the first World YWCA International Women's Summit on HIV/AIDS in Nairobi, Kenya, which developed a *Call to Action and Pledge* that highlighted gender-specific issues faced by women on an international level. Economic oppression was identified as a barrier to women's sexual autonomy and to their access to treatment. CTAC has signed on to this *Call to Action*. At the International AIDS Society Conference in

Sydney, Australia, CTAC joined its other international women's partners through the Blueprint for Action on Women and Girls and HIV/AIDS at a press conference calling for greater involvement of women in AIDS-related research and more research relevant to women.

In addition, as a founding member of the Blueprint for Action, CTAC, with its partners Voices of Positive Women, Oxfam Canada, and Business and Professional Women of Canada, co-organized the fourth annual World AIDS Day Breakfast, helping to give voice to the HIV/AIDS issues of women, young women and girls, and to raise funds for Voices of Positive Women and the Blueprint for Action. The event was very successful and featured award-winning author Wayson Choy as the keynote speaker, along with CTAC Chair, Louise Binder, and Toronto Mayor David Miller.





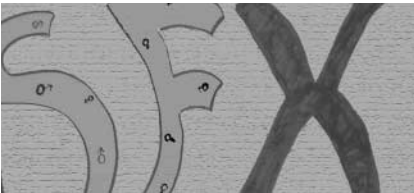
Substance Users' Issues

CTAC successfully recruited its Substance Users representative Council seat and attended the Canadian Centre on Substance Abuse: Issues of Substance conference in November 2007 as well as a forum held by the National Centre for Disease Control to facilitate and exchange knowledge around effective strategies for outreach and HIV/STI service delivery for vulnerable urban populations including substance users. CTAC's profile was raised among this group of service providers and it is hoped that fruitful partnerships will be developed in the coming years.



Youth Issues

CTAC has posted a call to recruit qualified persons to the CTAC Youth Committee which will develop a strategic plan to conduct research and encourage public policy awareness specific to Canadian HIV positive youth. In partnership with Positive Youth Outreach (PYO), CTAC members are drafting terms of reference to guide the work plan of the Youth Committee and provide it a formal structure and place within the larger structure of CTAC.





Organizational Update

This year saw the appointment of two new members to the CTAC Council: Angel Parks was named the National Women's Representative, and Greg Simmons named the Prisoner/Ex-Prisoner's Representative. Marco Gomes resigned from the Board of Directors, and Sandy Lambert joined the Board. Ruth Pritchard was hired to work on the Progressive Licensing Project funded by a grant from PHAC's Specific Populations Fund. In addition, Sarah Benn was hired as CTAC's administrative assistant.

Ron Rosenes, CTAC's Vice-Chair, received the *2007 Leadership Award (Individual Category)* from the Canadian AIDS Society in recognition of his invaluable contribution to the community, including as a member of the XVI International AIDS Conference Local Host.



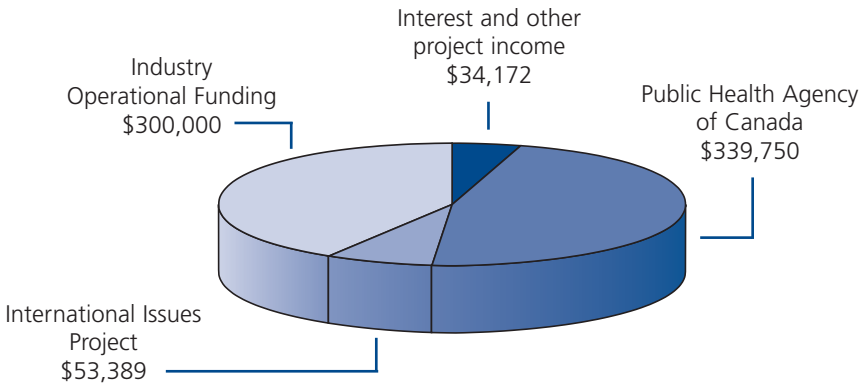
I am pleased to report that as of March 2008, CTAC had 435 full and associate members.

Financial Statements

The following is a summary of selected financial information from CTAC's audited financial statements for the year ending March 31, 2008. Full statements are available upon request, through the CTAC office.

	2008	2007
Revenue	\$ 727,311	\$ 603,787
Expenses	762,674	532,299
Excess (deficiency) of revenue over expenses	(35,363)	71,488
Fund balances, beginning of year	\$ 316,733	\$ 245,245
Fund balances, end of year	\$ 281,370	\$ 316,733

Revenue



Expenses by Program

