

C T A C



Annual Report  
2009-2010

**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](mailto: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](http://www.ctac.ca)**





## COUNCIL (MARCH 31ST 2010)

### BOARD OF DIRECTORS (MARCH 31ST 2010)

CHAIR Louise Binder  
VICE-CHAIR Ron Rosenes  
TREASURER Patrick Cupido  
SECRETARY Richard Baker  
Brian Finch  
Sandy Lambert  
Bruno Lemay  
Devan Nambiar  
Colleen Price  
Mark Randall

Brent Lewandoski Alberta  
Sam Friedman British Columbia  
John Baker Newfoundland & Labrador  
Michael Sangster Nova Scotia  
Harlon Davey Ontario  
José Sousa Québec  
Ron Rosenes AIDS Action Now! (AAN!)  
Ken Buchanan British Columbia  
Persons with AIDS Society (BCPWA)  
Mark Lapierre Canadian AIDS Society (CAS)  
Terry Pigeon CATIE (Canadian AIDS  
Treatment Information Exchange)  
Curtis Brandell  
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  
Sandy Lambert  
Aboriginal Representative  
Devan Nambiar Representative  
of Black Canadian, African  
and Caribbean Communities  
Karen Dennis Representative of current  
and former substance users  
Brian Finch Representative of gay men/men  
who have sex with men (MSM)

### Primary Sources of Revenue

Public Health Agency of Canada  
(PHAC)

Abbott Laboratories  
Bristol-Myers Squibb  
Gilead Sciences  
Glaxo-SmithKline in partnership  
with Shire BioChem  
Merck Frosst Canada Ltd.  
Pfizer Canada  
Sanofi-Aventis  
Schering Canada  
Tibotec, a division  
of Janssen-Ortho Inc.  
Theratechnologies  
ViiV Healthcare

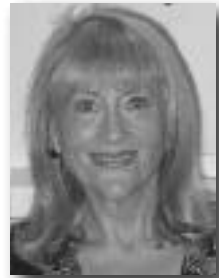
### STAFF (MARCH 31ST 2010)

Rakiba Amin Administrative Assistant  
Béatrice Cardin Communications and  
Organizational Development Manager  
Shahla Defileh Manager of Finance  
Fiona Knight Policy Manager  
Leah Stephenson  
Executive Committee Advisor  
Mary Gilbert Administrative Support



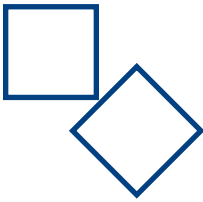
# A Message from the Chair

*Sandra Bender*



In 2009-2010, CTAC continued to be a strong voice calling for greater access to treatments, and for more and better treatment options. We worked with policy-makers, with AIDS service organizations, NGOs, community groups, researchers, health care providers, the private sector and people living with HIV and hepatitis across Canada and abroad.

Together, we made great strides on important issues.



CTAC officially added co-infection to its mandate. It developed and presented a workshop, and began planning the [1<sup>st</sup> Canadian HIV/HBV/HCV Co-Infection Research Summit](#).

The community mobilized and supported our action to provide solid organ transplants to people with HIV and co-infection. Now we look forward to having a Centre of Excellence for Solid Organ Transplantation for People with HIV once the Ministry of Health signs off on the Centre – the last hurdle.

Even as we celebrate the successes, we see serious challenges ahead.

We see infection rates increasing.

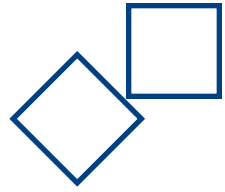
It has become difficult to implement prevention programs that include science-based drug policy because the current federal drug strategy conflicts with these proven approaches.

Funding is increasingly directed to prevention efforts at the expense of programs for care, treatment and support.

Experience taught us that we must invest in the full continuum of prevention, diagnosis, care, treatment, research and support. Prevention efforts must meet the needs of the communities in which they are implemented, and they don't work in isolation. Without access to good treatment, people will not get tested. When people aren't tested and don't know their HIV status they are less likely to take precautions to prevent transmission.

CTAC will continue working to ensure public policy for effective, accessible treatment even as funding priorities shift. It will advocate for programs that meet the specific needs of all groups including gay, lesbian, bisexual, transgendered people, Aboriginal people, substance users, prisoners, women and

## A MESSAGE FROM THE CHAIR

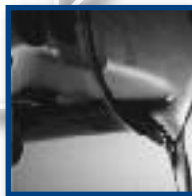


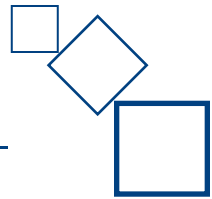
youth so that treatment is accessible for all Canadians.

As CTAC does this, young people interested in joining advocacy initiatives and being mentored by established community leaders are reaching out to us. As young people step forward, CTAC is ready to work with and mentor them. CTAC's environmental scan of treatment barriers for youth was an important step in the process of hearing and including future leaders.

Moving forward, CTAC will remember those who came before us and build on their efforts. People who are most affected by the epidemic and yet are often excluded from the decision-making will be at the forefront of our work.

CTAC will not become complacent. Sustained and inclusive community action is the only way to bring about the change we seek.





## HIV/HCV Co-infection

Remarkable progress has been made regarding the care, treatment and support of people living with hepatitis and HIV. In 2009, CTAC broadened its mandate to include HIV/HBV/HCV co-infection.

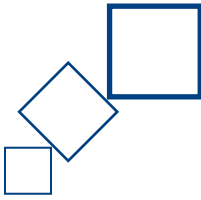
CTAC refined and presented a new *Tools for Action* workshop on hepatitis C/HIV co-infection. In 2009-2010, the workshop was presented in Nova Scotia, Newfoundland, and in Ottawa and Toronto. Information about housing, youth, and solid organ transplants was added.

Work on co-infection included a poster presentation at the 6th Canadian HIV/AIDS Skills Building Symposium in March 2010. The poster was entitled "Responding to HIV/HCV Co-infection through Advocacy & Social Policy Development through PLHIV/HCV Co-infected." CTAC also launched a



co-infection e-newsletter and the first issue can be downloaded from the CTAC website.

Another major milestone is the [1<sup>st</sup> Canadian HIV/HBV/HCV Co-Infection Research Summit](#). By the end of the fiscal year the organization of the Summit was well under way. It will bring together people living with HIV co-infection, frontline workers, clinical specialists and researchers from across Canada in autumn 2010.



## Dental Coverage

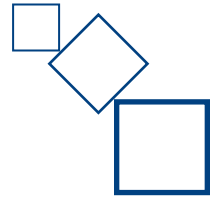
Although dental care is important to physical health and emotional well-being, it is poorly covered by publicly funded health care plans. Throughout 2009 and 2010, a CTAC whitepaper on dental coverage was prepared. The draft paper is entitled *Oral Health, Privilege or Necessity?* It includes an environmental scan of current programs and gaps in Canada and looks at models in nations with comparable wealth. The paper focuses specifically on economic barriers to accessing dental care. It offers recommendations for the development of a national oral health program in Canada.

Using the draft paper as a basis for discussion, CTAC is continuing consultation with people living with HIV, government funders of public health care plans, and provincial and national dental associations.

As part of this work, CTAC Vice-Chair Ron Rosenes led a consultation and workshop at the 6<sup>th</sup> Canadian HIV/AIDS Skill Building Symposium in March 2010. The workshop was entitled *Are Dental Costs Giving You a Tooth Ache?*

CTAC's goal is to improve publicly funded coverage of dental care through national discussions with federal, provincial, and territorial governments and other stakeholders including dental associations.





## Solid Organ Transplantation

Throughout 2009 CTAC worked to end the discriminatory and life-threatening practice of refusing to provide solid organ transplants to people with HIV.

The situation had become urgent for several people in need of a transplant and community members, including Gregory Robinson and the late James Kreppner, requested that CTAC take on leadership. CTAC organized an online petition and public meetings. The meetings included a session on solid organ transplants held in conjunction with a meeting of the CTAC Board of Directors in April 2009. CTAC built a business case for solid organ transplants. CTAC showed there were surgeons willing and able to perform the transplants in Canada and that surgeons in the United States had already established guidelines for successful transplants in people living with HIV.

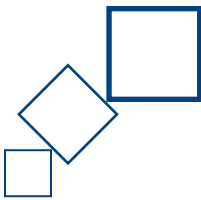
CTAC met and worked with representatives from the University of Toronto Health Network and Toronto

General Hospital, including transplant surgeon Dr. Ian McGilvray. The University Health Network submitted a proposal to Ontario's Ministry of Health and Long-Term Care to form a Centre of Excellence for Solid Organ Transplantation for People with HIV. The Ontario Health Technologies Assessment Community approved it. We wait for the Ministry of Health approval for a full Centre of Excellence. The proposed Centre will be multi-disciplinary and bring together surgeons, endocrinologists, and nurses to provide optimal care.



CTAC presented the Glen Hillson award posthumously to James Kreppner, a leading HIV and hemophilia activist who died of liver failure. He had been unable to obtain a liver transplant.

Dr. Ian McGilvray was also presented with the award in recognition of his work to support solid organ transplants for people with HIV.

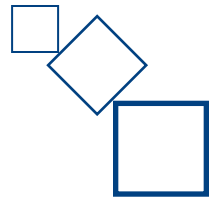


## HIV and Aging

Throughout 2009-2010 a CTAC working group explored issues related to aging with HIV. This included organ failure, cardio-vascular health, bone fragility, depression and physiological changes in the brain as a result of the virus and length of time on medications. CTAC also recognized the need to move beyond research that simply confirms signs of premature aging. New ways to manage accelerated aging and improve health outcomes are needed. Specifically CTAC advocates for research to find new and better medications



with fewer side effects, and to develop strategies to care financially and socially for people who need adequate housing, mental health services and social support. A draft paper was prepared and further work is being undertaken, including a review of new literature on the subject.



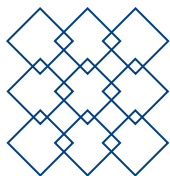
## Direct-to-Consumer Advertising

CTAC continued working with a number of concerned AIDS service organizations and members of the pharmaceutical industry to discuss and better define the boundary between disease awareness and direct-to-consumer advertising campaigns. CTAC demands an approach that would lead consumers to community-based sources of information such as CATIE and Le Portail VIH/SIDA du Québec. CTAC's position is that neutral third-party treatment information is helpful. Pharmaceutical companies should direct their

marketing and communication dollars to community organizations that specialize in providing unbiased, patient-focused information about a variety of treatment options.

In contrast, the creation of proprietary campaigns promoting treatment simplification or other specific treatment options can be confusing for consumers. Given the complexity of individual treatment needs and options, an advertising campaign with a one-size-fits-all approach will rarely provide enough information for informed decision-making. A number of pharmaceutical companies have agreed to dialogue with CTAC and AIDS Service Organizations (ASOs). Some advertising campaigns have been modified as a result.





# REMOVING BARRIERS TO TREATMENT

---

## Catastrophic Drug Coverage

CTAC continued consulting with people living with HIV and cross-disability groups to refine a paper on catastrophic drug coverage and produce a second draft. The paper will be used to promote dialogue. The long-term goal is to convene a summit of all relevant public and private representatives and to present, in the form of a final paper, a formula to implement the needed coverage. An overview of this work was published in an article in the Spring 2009 newsletter. The newsletter and slides from the consultations are available on the CTAC website.



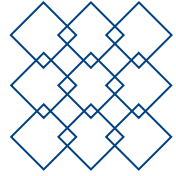
## Access to Complementary and Alternative Medicine

CTAC participates in the Program Advisory Committee for the Natural Health Products Directorate (NHPD) at Health Canada. Through participation in the committee, CTAC provides advice on the regulation of natural health products.

Canada is playing a leadership role in regulating natural health products as their own distinct category – not as food, nor as drugs. The challenge has been to create a framework for approximately 30,000 natural health products. The framework must ensure safety, efficacy and quality while maintaining individual choice and access.

---

# REMOVING BARRIERS TO TREATMENT



The CTAC position is that regulation should follow a risk-based approach. CTAC advocates for greater levels of clinical evidence before approving higher risk products.

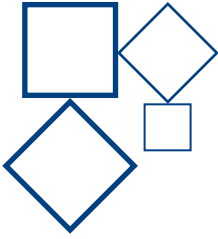
CTAC Vice-Chair Ron Rosenes is a community researcher with the MAINTAIN study. This exciting study seeks to find out if a proprietary high-dose formula of vitamins, minerals, and antioxidants can slow disease progression for people living with HIV or delay the start of anti-retrovirals in adults without symptoms. It is a randomized, placebo controlled, clinical study.

If the study demonstrates a successful role for the formula in improving health and delaying the start of treatment, CTAC would advocate for coverage under the health system. More information is available in the Spring 2010 CTAC newsletter.

## Lipodystrophy

CTAC has advocated for health care coverage to help reverse lipodystrophy. In particular, CTAC is working to secure coverage for fillers to help reverse facial wasting, known as lipoatrophy. There are very few products available and approved for market in Canada, and the situation has been complicated by problems that recently came to light with one of the products, Bio-Alcamid. Work to advocate for increased coverage of fillers will continue when the results of a case-by-case analysis of people treated with Bio-Alcamid is completed and product safety has been confirmed.

CTAC is currently working with a Canadian Biotech company, Theratechnologies to advise on the review processes to approve a novel human growth hormone analogue that has shown the ability to reduce abdominal fat, for those suffering from lipodystrophy.



# WORKING WITH AND ADVOCATING FOR SPECIFIC POPULATIONS

---

## Engaging Youth Living with HIV

CTAC conducted an environmental scan of barriers to treatment access faced by youth with HIV in Canada. The scan was conducted with the help of organizations that are led by or serve youth. Focus groups were held in Toronto, Vancouver, and Montreal. Youth who couldn't attend were able to participate in an online survey.

The consultations showed that youth living with HIV in Canada experience feelings of alienation,

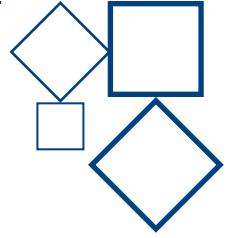
underrepresentation, and disengagement. Many youth feel that they are not heard within systems led by adults. To involve youth and ensure effective services for them, communities across Canada must understand that leadership can come from the youth themselves. CTAC thanks the youth who participated in the environmental scan, and looks forward to the ongoing participation of young people living with HIV.

In addition to the environmental scan, CTAC worked with Positive Youth Outreach, YouthCO AIDS Society in Vancouver, CATIE, and the Canadian AIDS Society (CAS) to hold a satellite session for HIV-positive youth and youth service providers at the 6<sup>th</sup> Canadian HIV/AIDS Skills Building Symposium.



---

# WORKING WITH AND ADVOCATING FOR SPECIFIC POPULATIONS



## Policy and Outreach for Prisoners and Ex-Prisoners

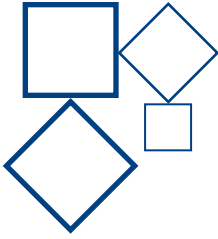
In June 2009, the Federal Minister of Public Safety introduced proposed amendments to the Corrections and Conditional Release Act. CTAC worked with The Canadian HIV/AIDS Legal Network, PASAN (Prisoners' HIV/AIDS Support Action Network), and the John Howard Society to raise awareness of the proposed amendments. CTAC and partners are concerned that the amendments would erode prisoners' rights, result in harsher conditions in prisons, and make it more difficult for prisoners to reduce HIV transmission and to access HIV treatment.

CTAC also participated in the development of The Canadian Prison Advocacy and Outreach Coalition. The coalition will advocate for incarcerated and formerly incarcerated people. Members aim to improve the quality of life for all



incarcerated people, especially those living with and affected by hepatitis C and HIV.

Greg Simmons, CTAC's prisoners and ex-prisoners representative, wrote about the importance of involving prisoners in policy-making in his article for the Spring 2009 CTAC newsletter. At the 6<sup>th</sup> Canadian HIV/AIDS Skills Building Symposium, he facilitated a workshop on advocating for prisoners living with HIV or hepatitis.



---

## WORKING WITH AND ADVOCATING FOR SPECIFIC POPULATIONS

### Breaking Down Systemic Barriers for Aboriginal People

CTAC provides support for an Aboriginal Working Group as part of the organization's efforts to understand and break down systemic barriers. The working group coordinates CTAC efforts with organizations specifically mandated to serve Aboriginal people.

One of the major barriers was the need for clear information about the Non-Insured Health Benefits program offered by Health Canada for First Nations and Inuit. Clear information is needed about what is covered and how to access benefits. The working group has been reviewing the list of antiretroviral treatments and other medications available through the program to identify gaps, and to initiate dialogue with Health Canada about possible additions to the list.

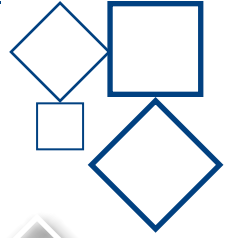
### Empowering Women at Home and Abroad

CTAC continues to be active on issues that effect access to treatment for women in Canada and around the world. CTAC Chair Louise Binder was a guest lecturer for the Social Work Program at the University of Toronto. Her lecture on gender and power focused on women as leaders in dealing with the HIV epidemic, and the importance of microfinance for empowering women to lead positive change. Louise also continued to serve as a co-investigator and member of the research team for a number of studies related to women and HIV. In 2009, she served on a research panel about women and lypodystrophy for Dr. Mona Loutfy of the Women's College Hospital.

CTAC also participated in the Ontario AIDS Bureau working group to develop a discrete strategy for prevention, treatment and care of women, and a working

---

# WORKING WITH AND ADVOCATING FOR SPECIFIC POPULATIONS



group to explore opportunities for a second HIV-positive women's conference.



As a founding member of the National Coalition for a Blueprint for Action on Women and Girls and HIV/AIDS, CTAC has continued on the steering committee and assisted with work to update important documents, such as a Canadian Report Card on Women and Girls and HIV, and the Coalition's Manifesto. The committee consulted with stakeholders about the updated Manifesto at the 6th Canadian HIV/AIDS Skills Building Symposium in March. The consultation was conducted in preparation to launch the 2010 version of the Manifesto at the International AIDS Conference in Vienna.

At the 18<sup>th</sup> Annual Canadian Conference on HIV/AIDS Research (CAHR), Louise Binder made a pres-

entation about the community's role in microbicides. She also participated in the panel leading the discussion of Women in HIV: Implications for Research, Policy and Practice in Canada. Both of these sessions at CAHR are available at the Ontario HIV Treatment Network (OHTN) website.

CTAC also participated in the ATHENA partnership. This group of women from America, Asia and Africa came together to take a position on policy issues that affect women and to advance gender equity within the global response to HIV. The group advises on issues such as HIV and women's reproductive rights, and HIV testing of pregnant women.



# MEDIA EVENTS

---

CTAC and partners continued building awareness of major issues that limit access to treatment or health care.

On June 9, 2009 CTAC and the AIDS Committee of Newfoundland and Labrador (ACNL) held a press conference about the shortage of infectious disease specialists in Canada. In Newfoundland and Labrador in particular, this shortage constituted a health crisis. There were no permanent infectious disease specialists serving the province. John Baker, the CTAC Newfoundland and Labrador Provincial Representative, described the situation in an article published in the Summer 2009 CTAC newsletter.



On World AIDS Day, CTAC issued a media release highlighting the urgent need in Canada for a Centre of Excellence for Solid Organ Transplantation for People with HIV and co-infected with hepatitis. (See the Solid Organ Transplantation section on page 5 for more details.)

CTAC also issued a statement lauding the Honorable Deb Matthews, Ontario Minister of Health and Long-Term Care, for the Ontario Government's provision of \$1.68 million to community-based HIV/AIDS organizations. One million was set aside for the creation of a new women's HIV prevention



---

## MEDIA EVENTS



initiative. The World AIDS Day breakfast was organized by CTAC, the National Coalition for a Blueprint for Action on Women and Girls and HIV/AIDS, Oxfam Canada, Voices of Positive Women and North Toronto Business and Professional Women. The breakfast event emphasized women's HIV/AIDS issues.

On International Women's Day, CTAC, the Canadian Aboriginal AIDS Network, the Canadian HIV/AIDS Legal Network, and the Interagency Coalition on AIDS and Development issued a media release about the brutal impact of HIV/AIDS and poverty on women in Canada and abroad. The media release cited a 2010 report to the United Nations showing that there has been a systematic erosion of human rights for women and girls in Canada. In the release, CTAC and partners

called for urgent action to address endemic poverty and violence against Aboriginal women and girls – factors that contribute to the disproportionately high numbers of Aboriginal women living with HIV.





# COMMUNITY WORKSHOPS AND SKILLS BUILDING

---

## Basic Science

CTAC delivered a Basic Science Community Workshop Series for people living with HIV, service providers, and policy makers. The five-part series included presentations on the adaptive immune response against HIV; the virus life cycle and the role of various proteins; how HIV causes damage to the immune system; co-infections and HIV susceptibility and progression; and approaches to an HIV microbicide.

## Tools for Action

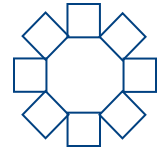
CTAC offers a series of nine established advocacy workshops. In addition to these standard workshops and the Basic Science series described above, CTAC developed and refined presentations and workshops on co-infection, dental coverage, catastrophic drug coverage, advocating for prisoners living with HIV or hepatitis, and participatory leadership principals and strategic planning techniques.

## Presentations at the 6<sup>th</sup> Canadian HIV/AIDS Skills Building Symposium

CTAC members discussed access to treatment for people living with HIV at the following workshops at the Skills Building Symposium in March 2010:

- *Medicines for All: Fixing Canada's Access to Medicines Regime to Scale Up Global Treatment Access*
- *Advocacy for Prisoners Living with HIV/AIDS/HCV*
- *Are Dental Costs Giving You a Tooth Ache?*

CTAC also presented a poster entitled *Responding to HIV/HCV Co-infection through Advocacy and Social Policy Development through PLHIV/HCV Co-infected.*



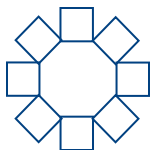
## Partnership with the International Community of Women Living with HIV

The International Community of Women Living with HIV and AIDS (ICW) is a network run for and by HIV-positive women. Members promote and advocate for changes that improve the lives of HIV-positive women. CTAC Chair Louise Binder sits on the ICW international steering committee. She was elected as one of two North American representatives and assisted with recent restructuring. She also helped formalize a North American body consistent with the international coalition. This work included helping develop terms of reference, the mandate, and the membership structure for the North American body. Through the ICW, Louise and CTAC provided input and advice to UNAIDS and other international organizations.

## Community Mobilization and Leadership with Rwandan HIV/AIDS Leaders

CTAC completed a 3-year Community Mobilization and Leadership project with leaders in the Rwandan HIV and AIDS community. The project, funded by Health Canada, included workshops with approximately 30 community members and representatives from service providers in Rwanda. The workshops focused on participatory leadership principals and strategic planning techniques. Participants created four detailed Community Action Plans:

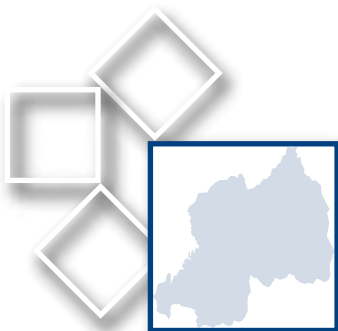
- 1 "Rape prevention through awareness raising and mobilization of the Association of Rwanda's Taxi-Motos (ASSETAMORWA)"
- 2 "Providing access to public primary school for 600 orphans and access to public secondary school for 600 orphans"



---

## INTERNATIONAL ISSUES

- 3 "Prevention of mother-child transmission of HIV-AIDS through mobilization of Nyabugogo cell"
- 4 "Helping reduce the rate of HIV-related stigma and discrimination within the Kiyovu Presbyterian Church and the Nyarutama Christian Life Assembly, which represent 8 places of worship"



### Microfinance

CTAC representatives visited with organizations in Rwanda and the Philippines to see microfinance projects there and to share learning

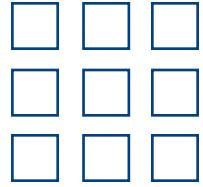
on the topic of microfinance. CTAC Chair Louise Binder is working with the OHTN to develop a study on the potential benefits of microfinance projects for women from Aboriginal and African-Caribbean communities in Ontario. The study aims to find out if results differ for different populations.

### Mentor Program for AIDS 2013 in Norway

Her Royal Highness Mette-Marit, the Crown Princess of Norway and UNAIDS Goodwill Ambassador, invited CTAC Chair Louise Binder to participate in a new UNAIDS program to mentor youth and encourage them to take on leadership roles in the HIV movement. This work follows on CTAC's collaborative work to develop a report card-style analysis of how Canadian and Norwegian national governments are performing with regards to women and girls and HIV/AIDS.

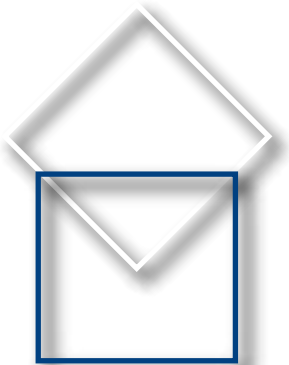
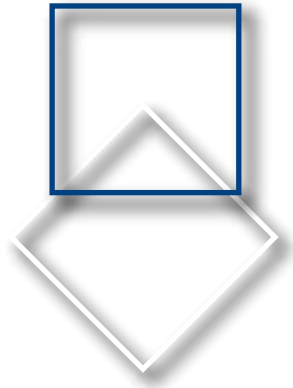
# ORGANIZATIONAL UPDATE

---



In 2009-2010, the following new Board/Council members were selected:

- **Marc Lapierre** replaced **Stephen Hurst** as Canadian AIDS Society representative
- **Curtis Brandell** replaced **James Kreppner** as representative of the Canadian Hemophilia Society
- **Mark Randall** joined the Board
- **Brent Lewandoski** became the new Alberta representative



CTAC welcomed new staff member Fiona Knight as Policy Manager and Mary Gilbert as part-time administrative support consultant to the team. Shahla Defileh replaced Ross Chapman in finance management.

In March 2010, CTAC had a total of 293 full and associate members.

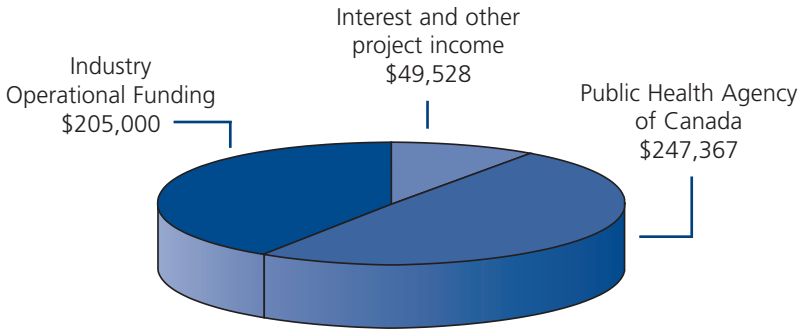


# Financial Statements

The following is a summary of selected financial information from CTAC's financial statements for the year ending March 31, 2010. Full statements are available upon request, through the CTAC office.

	2010	2009
Revenue	\$ 501,895	\$ 731,754
Expenses	657,567	752,276
Excess (deficiency) of revenue over expenses	(155,672)	(20,522)
Fund balances, beginning of year	\$ 260,848	\$ 281,370
Fund balances, end of year	\$ 105,175	\$ 260,848

## Revenue



## Expenses

