

#### Canadian Treatment Action Council

# Canadian Treatment Action Council Annual Report 2003-2004

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Sauce Burdin

he CTAC Board of Directors is pleased to provide this annual report for the 2003/2004 fiscal year. In keeping with its usual pace, the past year was an extremely busy one for CTAC. The

organization continued to work on many treatment access issues, some of which have been a part of CTAC's work since its inception while others are newly emerging issues. As things change in the medical, political and economic environments, so too must CTAC change and adapt. The following report does not capture all of the details of CTAC's work during the year but rather is intended to mark highlights, milestones and other noteworthy happenings.

# **Drug Review Process and Prescription Drug Pricing**

During the past year, CTAC continued to work collaboratively with other stake-holders on the federal drug review process, pre and post-approval. CTAC has partnered with the Best Medicines Coalition and other disease/disability groups in coordinating meetings with high-level officials at Health Canada and the Therapeutic Products Directorate (TPD) to provide advice regarding policies and practices leading to effective, efficient review of drugs for sale in Canada. CTAC participated in numerous consultations and public policy fora hosted by the TPD related to both drug review issues as well as internal operations at the TPD. CTAC also participated in TPD's Advisory Committee on Management.

Post-approval surveillance (PAS) of prescription drugs on the Canadian market continues to be part of CTAC's work. Many of you know that as part of its advocacy regarding the review process for prescription drugs, CTAC has also been a strong proponent of PAS of prescription drugs. Over the past several years CTAC has developed and implemented a research protocol on various methods of collecting adverse event data in a consumer-reporting environment. During the past year the research study was completed and data analysis began. Preliminary findings were presented at the Ontario HIV Treatment Network Research Day and also at the Canadian Association for HIV Research Conference.

During the past year, the Common Drug Review (CDR) process went into effect. The CDR, which is operated from the Canadian Coordinating Office for Health Technology Assessment (CCOHTA), is intended to serve as a means of streamlining provincial formulary reviews in order to ensure improved review times by provincial formularies. It is also to afford more consistency in terms of drug availability across provinces. In collaboration with other stakeholders, CTAC has been successful in 1) identifying issues of concern for consumers and 2) communicating this information

to the officials at CCHOTA and to appropriate provincial/territorial government and formulary officials. CTAC has made numerous presentations on this issue and continues to closely monitor review times and outcomes for HIV treatments.

Prescription drug pricing is another long-standing issue for CTAC. Dialogue continues with pharmaceutical industry representatives, politicians, and Canada's drug price regulator, the Patented Medicine Prices Review Board (PMPRB). CTAC also participated in consultations including the Federal Legislative Renewal Process and public hearings hosted by the Standing Committee on Health. At these consultations, CTAC presented its concerns related to access and reiterated the need for drug price controls to ensure that rising prices do not cripple our health care system. Other key points made during CTAC's presentations included the need for mechanisms for: reviewing and controlling prices of all prescription drugs and introducing them onto the market while at the same time continuing to monitor their therapeutic value, side effects and interactions with other drugs. At these events, CTAC also presented its position on the need for monitoring of adverse effects and prescribing practices, and direct-to-consumer advertising (DTCA). In 2003/2004 CTAC participated in a boycott against Abbott Laboratories for increasing the price of ritonavir (Norvir) in the U.S. by 400%. CTAC also developed an online petition and letter campaign.

Recent events in the US have given new cause for concern with regard to prescription drug prices. Cross-border sales of prescription drugs, and in particular sales by internet pharmacies, has raised concerns in the HIV community as well as in other stakeholder groups. CTAC has played a lead role in identifying and addressing this very important treatment access issue. CTAC has developed, with other stakeholder groups, a position statement on cross-border internet pharmacies (CBIP). CTAC hosted skills building sessions on this issue at its inperson Board meetings in Calgary, Toronto and Vancouver as well as at the Canadian HIV/AIDS Skills Building Symposium.

# **Hepatitis C Co-infection**

Hepatitis C co-infection continued to hold a prominent position on CTAC's agenda during the past year. Dialogue continued with partners, government officials, researchers and other stakeholders. In the 2002/2003 year CTAC began

hosting regional co-infection public fora and some were completed that year. In the past year (2003/2004) CTAC completed the last two events and followed-up with a National Consensus Building Meeting involving researchers. These events proved to be very productive in terms of identifying issues and stimulating stakeholder discussions.

#### **Alternative Treatments**

CTAC has always considered the term "treatment" to encompass a wide array of products and practices which includes, in addition to western allopathic medicine, other treatment modalities. While CTAC does not endorse any particular product or practice, it does advocate for informed choice. CTAC has provided input to the Natural Health Products Directorate, the Stakeholders Advisory Committee on Medicinal Marijuana, Steering Committee for Canadian HIV Vaccine Plan Development and various microbicide initiatives.

#### Women's Issues

CTAC has, since its inception, believed in the need for a discreet focus on women's issues. In its structure CTAC has a provision for a National Women's Representative and has a Committee on Policy Issues Specific to Women. CTAC has been fortunate to have strong leadership with regard to women's issues and as a result has developed some valuable partnerships. Throughout the past year CTAC representatives have presented workshops and hosted various community events. Of particular note are collaborations with other national partners regarding International Women's Day in collaboration with Stephen Lewis, media interviews by CTAC's Chair on this topic, and partnerships with Canadian AIDS Society and Microbicides Advocacy Group Network (MAG-Net) on the microbicides issue.

# **Health Care Reform and Treatment Access Issues**

Since 2001, CTAC has been following with keen interest the debate over health care reform in Canada. In 2002, CTAC was represented at the Romanow Commission hearings and struck a committee to follow the issues. After Commissioner Romanow's report was released, there was a period of low activity, however, in 2003/2004, the issue re-emerged during

the federal election campaign. CTAC has continued to monitor developments and has written to high level government officials including the Prime Minister's Office as well as offices of the Ministers of Health, Industry and Finance regarding the need for a continued publically supported and accessible heath care plan.

During the 2003/2004 year CTAC began a dialogue with its membership on a national survey of treatment access issues and health care services for people living with HIV/AIDS. At its 2003 AGM the membership endorsed the idea and CTAC's Board is continuing to move forward with development of the survey and a request for proposals to fund the work.

# **Organizational Administration**

CTAC's structure continues to be developed and refined to ensure that the organization is responsive to the needs of its members. In addition to a wide variety of public events, CTAC continues to communicate with its membership and others interested in its work through its newsletter, brochure, website and e-mail lists. During the 2002/2003 fiscal year, CTAC undertook to develop and implement an Evaluation Plan. During that year a macro evaluation was completed and in the 2003/2004 fiscal year the Board responded to recommendations in the macro evaluation. A number of measures were undertaken including by-law changes, policy development and the initiation of a strategic planning process. In the past year CTAC also undertook to expand its evaluation process to include specific areas. In 2003/2004 evaluations were completed for CTAC's financial management processes as well as human resources and communications.

Work is ongoing in a number of organizational committees including finance, fund development, organizational development and membership. Please see CTAC's audited Financial Statements for more information about fiscal management.

CTAC has been built on a foundation of dedicated and determined volunteers, a willingness to collaborate and a recognition of the strength of partnerships. CTAC has continued to develop its partnerships across the HIV/AIDS community and with other disease and disability groups. Many of CTAC's most active members have broad ranging affiliations and CTAC has used these affiliations to build sound, long-lasting and productive partnerships.

# **Canadian Strategy on HIV/AIDS**

CTAC has worked closely with its national partners towards improving the Canadian Strategy on HIV/AIDS (CSHA) and has collaborated on letters to, and meetings with, government officials to call for at least an immediate \$100 million increase, as recommended by the Federal Standing Committee on Health.

#### **Conclusion**

The 2003/2004 fiscal year for CTAC was vibrant and exciting. Progress was made on many key issues, however, as is usually the case with systemic treatment access issues, the progress is short of our goals. CTAC will continue to work on the important treatment access issues that are still unresolved and will continue to watch for, and respond to, emerging issues. As an organization, CTAC has changed and evolved and has overcome many hurdles. CTAC has superb staff and highly motivated volunteers and is well positioned to continue to address the issues that are important to people living with HIV/AIDS.

The continued growth of CTAC's membership has also been vital to the success of this organization. With over 85 new members in 2003/2004 we continue to see our numbers increase in Canada and in many other countries around the world. We thank all of our members for their involvement and support and we look forward to the upcoming year.

In conclusion, it should be noted that a significant portion of CTAC's success is attributable to the many people who participate in the organization and its activities. You are encouraged and invited to be a part of that success.

For an electronic version of this report or more information on CTAC's current work, please visit our website at www.ctac.ca.

#### For more information, contact us at:

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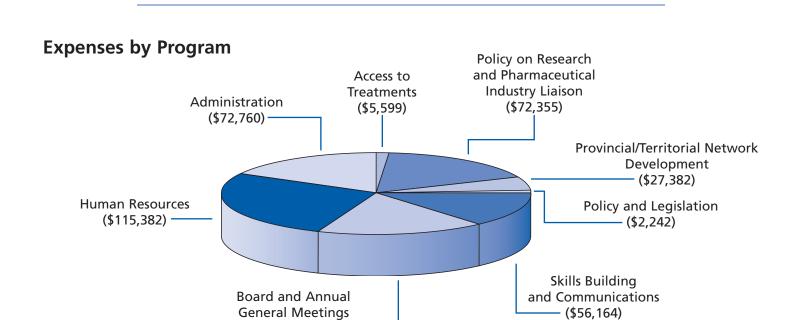
# **Financial Statements**

PASS Research Project (\$28,683) —

The following is a summary of selected financial information from CTAC's audited financial statements for the year ending March 31, 2004. Full statements are available upon request, through the CTAC office.

Davisson	¢	2004		<u>2003</u>		Primary Sources of Revenue
Revenue	Þ	480,971		479,068		
Expenses		428,408		523,221		Health Canada
Excess (deficiency) of revenue over expenses		52,563		(44,153)	_	Abbott Laboratories Limited Bristol-Myers Squibb
Fund balances, beginning of year		109,638		153,791		Pharmaceutical Group
Fund balances, end of year	\$	162,201	\$	109,638		Boehringer Ingelheim Canada Inc.
						Gilead Sciences
						GlaxoSmithKline in partnership
Revenue						with Shire BioChem
			Interest and other			Hoffmann-La Roche
Industry Operational Funding				project income (\$44,777)		Merck Frosst Canada Inc.
						Pfizer Canada, Agouron Division
(\$188,511) ——						Schering Canada

Health Canada — (\$219,000)



(\$76,524)