



1999 – 2000 A Landmark Year for CATIE

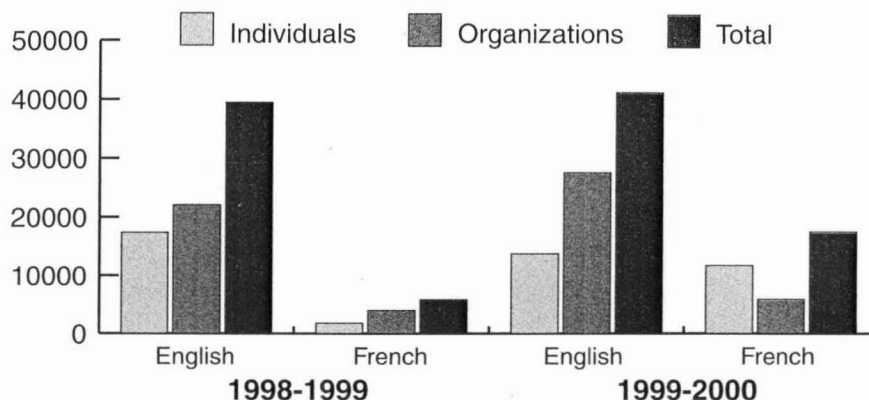
This past year CATIE achieved a number of milestones in our drive to serve all facets of the HIV/AIDS community across Canada more effectively.

We made significant management changes to enable CATIE to fulfill its national mandate and to meet the challenges of the future. Our new national board will ensure a national and regional perspective for the organization. We've developed a new strategic planning framework that includes extensive external stakeholder and complete staff participation in the planning process. We've initiated a new level of proactive national outreach that is already achieving impressive results.

Last year we experienced unprecedented demand for information with increases in both print and electronic formats. More people and organizations requested CATIE's publications and visited our Web site than ever before.

In 1999–2000, CATIE distributed 58,587 English and French language print publications, a 30% increase over the 1998–1999 total of 45,192. (All figures based on April – March fiscal year.)

Print Publication Distribution



English language materials make up almost 75% of the publications distributed with French language materials accounting for the rest.

Web site

There was a 66 per cent increase in the use of CATIE's award winning Web site (www.catie.ca) compared to the previous year. Almost as many pages were viewed in 1999 – 2000 as in the previous two years combined.

The original 29 pages that opened the Web site in 1996 have increased to more than 10,000. By May 31, 2000 a cumulative total of 2,669,921 pages had been viewed by visitors since the opening of the site. In 1999 – 2000 an average of 81,751 pages were viewed every month.

In addition, the site is now very well connected. There are currently 24 treatment information links from the French portion of the site and 100 links from the English portion.

Telephone Service

Last year CATIE responded to 2,861 treatment information telephone requests from across Canada. When you include e-mail and drop-in requests, this number rose to 3,059. Approximately 25% of these requests were French language calls and 75% English. Nearly 40% of callers were women, 55% were men, and 5% did not specify their gender.

Workshops

The number of workshops given across Canada increased from 45 in 1998 – 1999 to 57 in 1999 – 2000, as well as 15 CATIE exhibits at national and regional conferences. Particular attention was given to complementary and alternative therapies, nutrition, women & HIV and Internet skills building. Along with PHAs (People living with HIV/AIDS) and their partners, friends and families, audiences were increasingly made up of AIDS Service

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Organizations, Health Care Professionals, Aboriginal people and Women. The number of workshops given in Correctional Institutions has also increased.

Volunteer Hours

Our dedicated volunteers play an important role in our success at meeting the increased demand for information. Last year our volunteers gave a total of 2,181 hours of their time, the equivalent of 1.6 full-time staff. Volunteers fulfill a number of vital administrative functions, including: preparing membership packages and mailings, including Treatment Update subscriptions, preparing treatment information kits for conferences as well as filling in at reception here at CATIE. At conferences they sometimes staff the CATIE booth and take care of event logistics. In our National Reference Library for HIV/AIDS Treatment, their activities include indexing materials into the library database, organizing the filing of new treatment information and conducting research into new sources of treatment information.

We are working to build on past successes during 2000 – 2001. One of our biggest challenges will be to develop information that communicates effectively to specific groups in the HIV/AIDS community, for example, women, Aboriginal people,

families, youth, and people who have lower literacy levels.

This past year has been one of enormous change here at CATIE. As a treatment information provider in an age where information changes on an hourly basis, we will continue to strive to be at the forefront of the latest in HIV/AIDS treatments. We will expand awareness and understanding of treatment-related innovations and new health issues, continuing to communicate effectively in the rapidly evolving field of HIV-related health care.

I'm proud of our accomplishments this year and look forward to your input, at our Annual General Meeting on November 18 and through many other venues, as to how we can continue to improve our services in order to meet your needs.



Anne Swarbrick
Executive Director



Development of new board structure continues – become a CATIE member and have your say!

The creation of CATIE's national Board of Directors at last year's Annual General Meeting (AGM) set the ball in motion for the development of a new board structure. At the February strategic planning session, the board established the National Board Development Committee to do just that.

"Our mandate is to ensure that the principle of fair and balanced representation of the HIV-positive community across Canada is embedded in the structure of CATIE's national Board of Directors," said Rob MacKay of Thunder Bay, CATIE board member and Chair of the National Board Development Committee. "We want to create a forum that embodies regional representation and the representation of diverse perspectives." The latter includes New Brunswick's Grace Getty, Montreal's Daniel Levac, Vancouver Island's Ruthann Tucker and Toronto's Brian Robinson.

The Committee spent considerable time this spring consulting with other national community-based healthcare organizations to determine which governance structures will work best for CATIE.

"We're looking at a number of options, including creating five

regions across Canada that reflect the HIV-positive and general population base and not simply geographic size. In this scenario, some board members would represent specific regions. Others would be members at large," Rob said.

Other recommendations being considered are limiting the size of the board to approximately 15 members and the number of terms served as well as creating rotating terms of office.

Once the National Board Development Committee's recommendations have been approved in September by CATIE's Board, they'll be drafted as new or revised by-laws and voted on by the membership at or prior to this year's Annual General Meeting on November 18. A copy of the proposed by-laws will be distributed to all members prior to the AGM.

This is an important time for CATIE. If you would like to have a vote in CATIE's future, consider becoming a member. To receive information on membership, call Andrew Boxer, Memberships Coordinator at 1-888-66-CATIE, ext. 289 or e-mail aboxer@catie.ca.

2000 National Conference on Women and HIV/AIDS



Networking, discussion and sharing experiences were the order of the day throughout the 2000 National Conference on Women and HIV/AIDS. The three-day conference held in May was the largest gathering ever in Canada of HIV positive women, healthcare and policy professionals and others working with women in the HIV/AIDS field.

As one of the host organizations of the conference, along with the Canadian Aboriginal AIDS Network, the Canadian AIDS Society and the Canadian Treatment Advocates Council, CATIE was active in planning and managing the event and program delivery. CATIE distributed kits including fact sheets specific to women's health issues.

"The agenda examined all aspects of HIV/AIDS as it relates to women individually and to the community at large," said Jane Oliver, CATIE Workshop Coordinator, and member of the conference organizing committee.

CATIE staff delivered four workshops. Deirdre Maclean, Senior Writer, presented two workshops: "Managing the Medical Muddle" and "Gynecological Issues for HIV Positive Women". Sean Hosein, Treatment Editor, presented "A Strategy for Survival: Dealing with HIV/AIDS". Patrick Soje, Treatment Service Representative, facilitated a workshop entitled "Herbal Remedies for Managing HIV Treatment Side Effects".

A number of CATIE volunteers also played an important role at the conference. Acting as reporters in the Treatment, Legal, Ethical and Public Policy and Support streams, they recorded the recommendations made in the various sessions. The recommendations were compiled daily and presented on the last day. The recommendations will also form part of a final report currently being prepared by the Canadian AIDS Society (CAS). This report will be available from CAS in September and copies can be obtained by calling Lilja Jonsdottir at 1-800-499-1986, ext. 116.

The conference was a valuable networking opportunity for CATIE to engage in dialogue with women across Canada about their issues and concerns as well as their views on CATIE's services.

At an Open Mike session hosted by Anne Swarbrick, Executive Director, CATIE was praised for its accessibility, cooperation and support in its work with the Union of Ontario Indians. CATIE's French-language resources, the quality of translation and success at providing bilingual services were also commended. Several women from rural areas expressed appreciation for CATIE's publications which are "like a lifeline". CATIE was asked to develop more plain language publications at various literacy levels and provide more in-depth information about complementary and alternative therapies.

Later this year CATIE will be publishing *A Practical Guide for Women Living with HIV*. The 2000 National Conference on Women and HIV/AIDS provided an ideal forum to survey women about their treatment information needs. Our thanks to the many women who stopped at our booth to complete the questionnaire. Results of the survey, which are currently being tabulated, will be used to shape the editorial content of the Guide.

Congratulations to Liz Branham, of Midland, Ontario, a Board member of the AIDS Committee of Simcoe County, who won a Body Shop gift certificate in the draw held at CATIE's booth.

For more information on HIV treatment issues concerning women or to receive one of our FACT Sheets on a variety of topics specific to women's issues call 1-800-263-1638, ext. 291 or visit our Web site at www.catie.ca.

Canada AIDS Russia Project: CIDA Funding in Action

Slava Loukachenkov, Technical Director for the Canada AIDS Russia Project in St. Petersburg, Russia spent a week in May meeting with CATIE staff to learn more about treatment information delivery, computer systems, library management, CATIE's Web site and fundraising.

"We are currently experiencing many problems in Russia related to disseminating good treatment information. I was particularly interested in exploring ways that we can provide our services at a more specialized level. Given the rapid spread of AIDS in my home country, accessible treatment information is critically important," Slava said.

CATIE's award-winning Web site was of great interest. "One of Slava's primary goals is to create a highly organized Web site with excellent search capabilities," said Susan MacLean, Web Publisher. "Slava was keen to learn as much as he could about what we're doing at CATIE so that he could apply it to his own work."

"During my week at CATIE, I received practical training on how to collect and access information, Web site construction and database management. I also learned some rudimentary skills in fundraising for non-profit organizations," Slava said.

"I was very impressed by the quality of teamwork and supportive working environment at CATIE."

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New Collaborations

The National HIV/AIDS Network for Children, Youth & Families

CATIE is collaborating with the National Network for Children, Youth and Families Affected by HIV/AIDS on a research study to identify service and treatment information gaps for families who are affected by or infected with AIDS.

"This research, together with a recent study by the Canadian AIDS Society to determine service gaps for youth, provides a comprehensive picture of what's available and what needs to be developed across Canada," said Barbara Zuppinger, Coordinator of the National Network on Children and Families Affected by HIV/AIDS. "The study will form the basis of the Network's advocacy agenda in the coming year."

The report will be available this fall through the National Network's Web site at www.resnat.ca/e/research.html.

Hemophilia Ontario

Approximately 90 per cent of HIV-positive hemophiliacs are also co-infected with hepatitis C (HCV). Because HIV can affect the progression of chronic hepatitis, many co-infected hemophiliacs are living with serious liver disease. Transplantation is the only

effective treatment for end-stage liver disease. CATIE staff have recently collaborated with Hemophilia Ontario to produce a literature search and annotated bibliography on liver transplantation in HIV/HCV hemophiliacs. This work will be available by the end of the year from Hemophilia Ontario and can be ordered by calling Richard Yampolsky at 1-888-838-8846 or by visiting their Web site at www.hemophilia.on.ca.

Corrections Canada

Patrick Soje and Clément Chabot, two of CATIE's Treatment Information Service Representatives, recently conducted a two-day Peer Counselling training session at Fenbrook Penitentiary, a medium security facility in Gravenhurst. Both inmates and staff attended the workshop which focused on prevention and treatment information and included a train-the-trainer component.

The Corrections Canada program focuses on transferring skills to inmates so that they may counsel their peers. CATIE is working towards creating a collaboration with Corrections Canada in order to broaden our delivery of treatment education workshops to both staff and inmates in prisons across the country.

Community News

Report on Rapid HIV Testing Available

The Canadian HIV/AIDS Legal Network has recently published *Rapid HIV Screening at the Point of Care: Legal and Ethical and Questions*, an in-depth analysis of the potential benefits and concerns about point-of-care testing. The report includes over 20 recommendations to maximize the potential benefits and minimize the potential harms of rapid point-of-care testing. It also includes a commentary on ethical issues.

Copies of the report are available in English and French through the Canadian HIV/AIDS Legal Network's Web site at <http://www.aidslaw.ca>. Click on "Added in March 2000" on the home page.

You can also order a copy of the report by contacting the Canadian AIDS Clearinghouse, 1565 Carling Avenue, Suite 400, Ottawa, ON, K1Z 9R1. Tel: (877) 999-7740 (toll free) or (613) 725-3434. Fax: (613) 725-1205. E-mail: aids/sida@cpha.ca.

International HIV/AIDS Conference



Anne Swarbrick, Executive Director of CATIE (right), joins the Honourable Maria Minna, Minister for International Cooperation (left) and the Honourable Allan Rock, Minister of Health (centre) at the International HIV/AIDS Conference held in Toronto in June. Minister Minna announced that the Canadian International Development Agency (CIDA) will spend \$120 million over the next three years to fight HIV/AIDS in developing countries and in countries in transition.

For more information, visit CIDA's Web site at www.acdi-cida.gc.ca.

New Complementary Therapy Guide for People Living with HIV Now Available

CATIE has recently published *A Practical Guide to Complementary Therapies for People Living with HIV* to provide HIV patients and their caregivers with reliable, easy-to-understand, relevant information about the many alternative and complementary therapies available today. Medical professionals from a broad spectrum of health disciplines contributed the information and recommendations presented in the guide.

The 32-page booklet includes a brief overview of alternative medicine specialties such as homeopathy, naturopathy, North American Aboriginal healing traditions, Indian Ayurvedic and Chinese medicine and acupuncture. The guide also looks at wellness strategies such as aroma and herbal therapies, juicing, touch therapies and various types of massage and mind-body medicine. In addition, readers can find information on unconventional treatments such as DNCB, melatonin and oxygen therapies.

Making an informed decision about therapies that often fall outside of Western medicine can be difficult. *A Practical Guide to Complementary Therapies* offers suggestions to help people gather the information they need, including questions to ask about a potential therapy and how to choose a therapist.

To order *A Practical Guide to Complementary Therapies for People Living with HIV* call 1-800-263-1638, ext. 291 or send your request to info@catie.ca. The guide is also available on our Web site at www.catie.ca.

East Coast Workshops

CATIE strengthened its presence in Atlantic Canada by participating in three regional AIDS conferences held in June in Nova Scotia, New Brunswick and Labrador.

Treatment Service Representative Patrick Soje's tour of the East Coast began by leading three workshops at the Nova Scotia Rural Development Conference III hosted by the AIDS Coalition of Nova Scotia, followed by presentations at a conference held by the AIDS New Brunswick Health and Welfare Committee and the AIDS Retreat organized by the Newfoundland and Labrador AIDS Committee.

At each of the conferences, Patrick's presentations included an overview of CATIE's services, an update on the latest in treatments and a discussion of complementary therapies. Approximately 100 people living with AIDS, caregivers, AIDS Service Organization staff and related healthcare workers attended the workshops.

For information on a CATIE-led workshop in your region call 1-800-263-1638 ext. 291.

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"I owe CATIE a debt of gratitude for the many practical ideas that I gained from their experience. We are presently making a number of improvements to our Web site based on the models of service delivery that I saw at CATIE and other organizations in Canada."

For more information on Slava's work and the Canada AIDS Russia Project, you can reach Slava in St. Petersburg at +7 (812) 444-6739 or by e-mail at slon@aidssrussia.org. You may also visit their Web site at www.aidssrussia.org. You will also find information at CIDA's Web site, www.acdi-cida.gc.ca, by putting the following title into their search engine: Canada AIDS Russia Project.



Treatment News

Combination treatment for HIV-Hepatitis C patients

A recent study published in the journal AIDS suggests that a combination of interferon alpha (IFN) and ribavirin provides effective and safe treatment for some patients who are co-infected with HIV and hepatitis C (HCV). After six months of therapy, half of the participants had undetectable HCV levels in their blood and the group's average liver enzyme levels had dropped significantly.

More research is needed to determine whether the effects of the therapy can be sustained over the long term. While researchers described the treatment as "well tolerated", alternative therapies are still needed for those patients who experience difficult side effects or who have strains of HCV that do not respond to this treatment.

Adapted from HIV-Hepatitis Study Yields Promising Results for Some, posted at <http://www.catie.ca/aidsinfo.nsf/news>.

L-acetylcarnitine Improves Drug-Related Neuropathy

L-acetylcarnitine (LAC) has recently been found to be helpful in treating peripheral neuropathy (PN), a common side effect of the anti-HIV "d" drugs (ddI, ddC and D4T). Numbness, burning and tingling in the hands and feet are common symptoms of drug-related neuropathy.

Patients experiencing PN often have low levels of L-acetylcarnitine, which is a form of carnitine, an amino acid that plays an important role in providing energy to cells and muscles. After taking LAC orally for six months, researchers observed improvements in PN symptoms and nerve biopsy results in each of the participants.

Researchers noted that LAC is not the same product as many carnitine supplements found in health food stores. Some of these products may not be as effective.

For more information on L-acetylcarnitine and L-carnitine see the CATIE supplement sheet posted at <http://www.catie.ca/supple-e.nsf/supplement+sheets>.

Adapted from L-acetylcarnitine Improves Drug-Related Neuropathy, posted at <http://www.catie.ca/aidsinfo.nsf/news>.

Drug Resistance

According to a British study released last month, drug resistance seems to be occurring at an alarmingly high rate. Researchers who tested 12,000 HIV samples discovered that only 21.8 per cent of the samples were sensitive to all three classes of antiretroviral drugs. Approximately 25 per cent of the samples contained virus that was resistant to all three drug classes.

The high prevalence of drug resistant strains of HIV raises questions about the need for pretherapy resistance testing to enable doctors to determine the status of the virus before they change or adjust therapy.

Drug resistance could pose a substantial problem in the initial clinical management of HIV-1 infected patients. Researchers have reported a higher than expected frequency of drug resistance in a study involving recently infected but untreated HIV-positive subjects. Resistance to non-nucleoside reverse transcriptase inhibitors was most common, although resistance to both nucleoside analogues and protease inhibitors was also detected. Once again, researchers identified the need for pretherapy resistance testing.

Adapted from Prevalence of Drug Resistance High, posted at <http://www.catie.ca/aidsinfo.nsf/news>.

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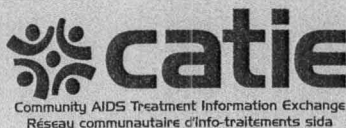
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