



Health  
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# HIV/AIDS

## LESSONS LEARNED: REFRAMING THE RESPONSE

### Canada's Report on HIV/AIDS 2002



Canadian Strategy on  
HIV/AIDS  
La Stratégie canadienne  
sur le VIH/sida



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Our mission is to help the people of Canada  
maintain and improve their health.

*Health Canada*

## ACKNOWLEDGEMENTS

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Albert McNutt

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# MESSAGE FROM THE MINISTER

It is not only on World AIDS Day 2002 that we should reflect on the state of the HIV/AIDS epidemic, both in Canada and internationally, but certainly this day calls to our attention the need to continue to do more, to contemplate the challenges that lie ahead and evaluate our successes.

As described in this annual report, progress is being made. We have a solid infrastructure for addressing the epidemic in Canada and for cooperating with partners abroad. Much good work has already been done, but the challenges ahead are significant.

The HIV/AIDS epidemic in Canada grows more complex each day. At-risk populations are difficult to reach and continue to face stigma, marginalization, prejudice and discrimination. These populations include individuals who inject drugs, sex trade workers, prisoners, gay men, as well as women and children from HIV-endemic countries. As well, there are complicated links between HIV, other sexually transmitted infections and hepatitis C. HIV/AIDS treatments that showed promise some years ago are now failing, and we are not achieving a sustained reduction in HIV transmission. Even with the knowledge and resources we have at hand in Canada, about 4 200 new HIV infections occur in this country each year.

The Government of Canada's commitment to combat HIV/AIDS is steadfast. The Canadian Strategy on HIV/AIDS (CSHA) is a comprehensive, pan-Canadian response to the epidemic that respects the values of social justice. Working with CSHA partners here and abroad, the Government of Canada is more resolved than ever to reducing the spread of HIV, ensuring care, treatment and support for people living with HIV/AIDS, finding a cure for AIDS, and ensuring that government policy takes into account the importance of protecting human rights.

We have learned much during the first five years of implementing the CSHA – lessons that will help galvanize future efforts. These efforts include those required for the United Nations General Assembly Special Session on HIV/AIDS Declaration of Commitment on HIV/AIDS. Also, a strategic plan is being developed collectively by all CSHA partners that will carry us forward and enable Canada to more effectively respond to the challenges that lie ahead. As Minister of Health, I remain committed to strengthening Canada's response to this epidemic.

Canadians need to be part of the solution, and I hope that reading this report will encourage you to join these efforts. One individual at a time, one community at a time, across the country, we can make a difference.



**A. Anne McLellan**  
*Minister of Health*  
November 2002



# MESSAGE FROM THE MINISTERIAL COUNCIL ON HIV/AIDS

**H**IV/AIDS is a devastating disease that affects all Canadians and all sectors of society. The Ministerial Council on HIV/AIDS endorses a pan-Canadian response and is working to broaden the engagement of federal government departments, to enhance links with provincial/territorial counterparts, and to ensure the active participation of those living with or at risk of HIV/AIDS.

Like many other Canadians, the Ministerial Council is aware of the frightening magnitude of the global epidemic. Equally disturbing is recent evidence about changing Canadian perceptions of the disease. AIDS is no longer widely viewed as an urgent public policy or health issue. This in spite of the fact that the epidemic continues to take a heavy toll on men who have sex with men and injection drug users and is increasingly spreading to include those infected through heterosexual transmission.

The Ministerial Council is well positioned to advise the federal Minister of Health on pan-Canadian aspects of HIV/AIDS. Its membership encompasses all aspects of the epidemic, including people living with HIV/AIDS, front-line workers, health care providers, researchers and human rights experts.

Over the past year, Council has helped to increase the knowledge and awareness of determinants of health issues among federal departments. It has also advised the Minister on the legal and human rights questions raised by the proposed *Blood Samples Act*, the medical use of marijuana and issues related to women, gay men, injection drug users, Aboriginal people, and African and Caribbean people from HIV-endemic countries. As well, it continued to highlight the urgent and growing need for increased funding for the CSHA.

We fully endorse the UNAIDS slogan for World AIDS Day – “*Live and let live.*” This slogan focusses on stigma and discrimination, which are contributing to the spread of HIV/AIDS in Canada and around the world. It brings home the fact that all Canadians are affected by HIV/AIDS, and we all need to be part of a strengthened response. To this end, the Ministerial Council will continue to work with the Minister of Health to increase awareness and understanding of HIV/AIDS and to more fully engage political leaders, government departments, non-governmental organizations, the private sector and individual Canadians in a human rights-based response to this epidemic.

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# LIST OF ACRONYMS

AIDS	Acquired immune deficiency syndrome
ASO	AIDS service organization
CAAN	Canadian Aboriginal AIDS Network
CAHR	Canadian Association for HIV Research
CANFAR	Canadian Foundation for AIDS Research
CANVAC	Canadian Network for Vaccines and Immunotherapeutics
CARE	Cooperative for American Remittances to Everywhere, Inc.
CAS	Canadian AIDS Society
CATIE	Canadian AIDS Treatment Information Exchange
CIDA	Canadian International Development Agency
CIDPC	Centre for Infectious Disease Prevention and Control (Health Canada)
CIHR	Canadian Institutes of Health Research
CPHA	Canadian Public Health Association
CSC	Correctional Service Canada
CSHA	Canadian Strategy on HIV/AIDS
CTAC	Canadian Treatment Action Council
CTN	Canadian HIV Trials Network
DPED	Departmental Program Evaluation Division (Health Canada)
FNIHB	First Nations and Inuit Health Branch (Health Canada)
FPT AIDS	Federal/Provincial/Territorial Advisory Committee on AIDS
HAART	Highly active antiretroviral therapy
HIV	Human immunodeficiency virus
IAD	International Affairs Directorate (Health Canada)
IAVI	International AIDS Vaccine Initiative
ICAD	Interagency Coalition on AIDS and Development
ICASO	International Council of AIDS Service Organizations
IDU	Injection drug use
MSM	Men who have sex with men
NACHA	National Aboriginal Council on HIV/AIDS
NAS	National AIDS Strategy
NGO	Non-governmental organization
PASAN	Prisoners' HIV/AIDS Support Action Network
PHA	People Living with HIV/AIDS
RTA	Research technical assistant
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNGASS	United Nations General Assembly Special Session on HIV/AIDS

# FOREWORD

This report is intended to inform the HIV/AIDS community, the Canadian public and parliamentarians about the current realities of HIV/AIDS, about progress that has been made in Canada in responding to the epidemic, and about the challenges that lie ahead. This report will also help inform international audiences about Canada's domestic and global response to HIV/AIDS. Finally, it meets Health Canada's obligation to report annually on the CSHA.

*Canada's Report on HIV/AIDS 2002* covers the period from April 2001 to March 2002. Information on significant events that have taken place since March 2002 is also contained in the report, including the G8 Summit (June 2002) and the XIV International AIDS Conference (July 2002). As well, although the majority of activities described in the report are funded through federal resources under the CSHA, efforts have been made to provide additional information on HIV/AIDS-related activities funded by other sources.

To better represent the reality of HIV/AIDS in Canada, Health Canada interviewed four Canadians involved in the domestic response. Their personal experiences and perceptions are presented in short feature articles to put a face to a disease that continues to affect thousands of Canadians. By their very nature, these vignettes are intended to give readers a glimpse of the realities faced by Canadians and are not intended to make broad or definitive statements about any particular vulnerable group or about those working in the field.





# REJUVENATING CANADA'S HIV/AIDS RESPONSE

The HIV/AIDS epidemic is growing rapidly and changing in Canada and around the world. Although the disease has been with us for more than two decades, the Joint United Nations Programme on HIV/AIDS (UNAIDS) has stated that the epidemic is still in its early stages and is spreading quickly. This section of the report presents an overview of the current realities of the HIV/AIDS epidemic and future directions for rejuvenating Canada's domestic response and support for the international response.

## **The Global Epidemic**

As each year passes, the reality of the global HIV/AIDS epidemic becomes more appalling. According to UNAIDS, some 40 million people worldwide are infected with HIV or have AIDS. An estimated 15 000 new HIV infections occur each day, and UNAIDS has predicted a total of 45 million new infections by 2010. Other data from UNAIDS are equally distressing:

- In 2001 alone, an estimated five million people became newly infected with HIV, almost half of whom were women and 800 000 of whom were children.
- An estimated 12 million of those already infected with HIV are youth.
- Three million people died of AIDS-related illnesses in 2001.
- Between 2000 and 2020, an estimated 68 million people will die of AIDS in the 45 most affected countries in the world.

HIV/AIDS continues to be a serious global health issue affecting development, human rights and human security issues. HIV/AIDS has now reached every corner of the world. More than 90 per cent of those living with HIV/AIDS live in the developing world, where in some countries prevention efforts are weak or absent, infection rates are exploding, health care infrastructure is deteriorating and access to drugs and treatment is severely limited or non-existent.

Families, communities, economies and entire countries in the most affected regions of the world are being ravaged by AIDS. The devastation has been particularly brutal in sub-Saharan Africa and the Caribbean. While prevalence rates remain relatively low overall in China and India, small pockets of high HIV incidence and prevalence indicate that these countries may be on the brink of much larger epidemics. In recent years, countries of the former Soviet Union have experienced the most rapid increase in new infections, mostly through injection drug use.

### **The Epidemic in Canada**

In developed countries such as Canada, 20 years of response from community stakeholders and governments have helped slow the epidemic's initial decimation. The availability of funding for HIV/AIDS research and prevention projects, access to care and treatment, well-organized support networks, human rights advances and the use of new information technologies to raise awareness of HIV/AIDS and disseminate relevant information have all contributed to a more balanced, coordinated response in the western world.

Yet the epidemic in Canada remains severe and deeply troublesome. According to Health Canada's Centre for Infectious Disease Prevention and Control (CIDPC), at the end of 1999 an estimated 49 800 people in Canada were living with HIV or AIDS – a small number compared to the global situation but significant for Canada's population.<sup>1</sup> Many infected individuals are living longer, healthier lives, and the rate of deaths from AIDS and AIDS-related illnesses (including drug toxicity that can cause life-threatening side effects) has declined. Nevertheless, Canada's HIV/AIDS epidemic has evolved in unforeseen and frightening ways. We still have a long way to go.

One of the most alarming aspects of the domestic epidemic is an apparent change in public perceptions about HIV/AIDS. A recent survey by Decima Research entitled "Public Attitudes Towards HIV/AIDS in Canada," revealed that Canadians have lost their sense of urgency about HIV/AIDS and do not view the epidemic as either a personal threat or a significant public policy or health issue. Treatment advances, while prolonging and improving the quality of life of those living with HIV/AIDS, have contributed to the notion that HIV/AIDS is no longer the killer it was 20 years ago.

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<sup>1</sup> Unless otherwise noted, all domestic epidemiological and surveillance data presented in this report have been provided by CIDPC.

## AIDS in A Small Town

**M**any people in small towns believe that AIDS is something that only happens in large municipal centres. Albert McNutt knows differently. A board member of the Canadian AIDS Society who lives in the small town of Truro, Nova Scotia, Mr. McNutt was diagnosed with HIV in 1986.

At one time, Mr. McNutt faced a combination of "homophobia and fear of the unknown." Today, however, after years of education and awareness activities, the community has come around. "People are stopping me all the time to ask about my health," says Mr. McNutt. "They will stop me, touch me. You didn't see that five years ago."

For many in the community, AIDS is still a disease that happens to other people, whether they be gay men, injection drug users or sex trade workers. Even today, the perception that people with AIDS come from these high-risk groups causes more stigmatization than does the disease itself.

Ironically, advances in medicine sometimes complicate Mr. McNutt's awareness work. "You talk to 16-year-olds and they learn I have been HIV-positive for 17 years, and they hear 'non-detectable levels.' They think to themselves, 16 plus 17 is almost 40, and that seems like a lifetime to them."

In other words, the threat of AIDS no longer strikes some people with the same fear they might have experienced five or ten years ago. Mr. McNutt feels that, due to media coverage about new treatments and the fact that people with HIV are living longer, more productive lives, HIV/AIDS is now viewed by many as a manageable disease.

Still, he has clearly gotten through to many people. "I hear students say to me, 'What you told me had an impact on me. I don't want to get HIV.'" People often approach Mr. McNutt on the street and tell him that, because of his presentations, they have taken measures to protect themselves.

Mr. McNutt does more than education and awareness work, however. The organization he established – the Northern AIDS Connexion Society – also helps people living with HIV/AIDS find medical equipment, delivers groceries and offers a friendly source of support and advice, particularly when it comes to treatment issues. The only money the organization provides is to help people get to Halifax.

"When you're in a rural community and you have HIV, it means going into the city to see specialists and to pick up medications."

The lack of financial resources is a source of worry for Mr. McNutt. Aside from an annual AIDS walk and an art auction, his group has no other revenues. Finding and retaining volunteers is also difficult with such stressful work.

Yet many organizations, even governmental ones, ask Mr. McNutt to provide education and awareness services for little or no compensation. He often heads to the penitentiary in Springhill to work free of charge with prisoners, even though the institution is several hours from his home.

The lack of government funding gnaws at Mr. McNutt in other ways, too. "When I die, what happens if they can't find somebody with the same drive I have? What happens to this program when I'm no longer here to carry out my work?"

Mr. McNutt certainly has drive. He makes 200 presentations a year and is politically active on a national level. "I thought to myself, before I die, I want to contribute to my community."

He certainly has.

The reality, as those who work in this area know, is quite the opposite. We still have much to learn. Some treatments that once held great promise are now failing in the face of drug resistance and new HIV strains. Research has also shown that long-term use of antiretroviral therapies can cause organ damage, heart disease, diabetes and other health consequences. Although the disease may progress more slowly, HIV/AIDS still kills.

What makes the domestic epidemic particularly disturbing is that, despite evidence that Canadians generally have a good understanding of modes of HIV transmission, risk factors and prevention options, the virus continues to spread. About 4 200 new infections are occurring each year across a broadening range of population subgroups. For example, an estimated 370 Aboriginal people are becoming infected with HIV each year – an average of more than one per day.

Although men who have sex with men and injection drug users still account for the largest number of positive HIV tests and AIDS case reports, surveillance data on new HIV-positive test reports for 2001 show that the epidemic is gradually spreading to increasingly include those affected through heterosexual transmission. Of particular concern is the rising proportion of women aged 15 to 29 among both positive HIV tests and reported AIDS diagnoses. As well, CIDPC estimates that about one third of HIV-positive Canadians – some 15 000 people – are not aware that they are infected. These individuals represent a significant challenge for prevention, care and treatment efforts.

### **A Call to Action**

Recapturing a sense of urgency and maintaining HIV/AIDS as an important health and public policy issue in Canada is now a challenge for all governments, organizations and individuals working in this field. Canada's HIV/AIDS response needs greater vigour and more engagement on all fronts.

Key stakeholders in the HIV/AIDS community have renewed their commitment to rejuvenate Canada's HIV/AIDS response in the face of growing public complacency and the increasing complexity of the epidemic. But the challenges are many. For example:

- Many of those most at risk face multiple barriers to accessing services, tend to be on the margins of society and are difficult to reach with prevention messages.
- Stigma, marginalization, prejudice and discrimination continue to be associated with HIV/AIDS.



## Understanding the Epidemic

In the early days of HIV/AIDS, Dr. Liviana Calzavara's research helped us understand which behaviours carried the greatest risk. She still does this work. But now Dr. Calzavara also studies the social and psychological forces that drive people to engage in behaviours they sometimes know will place them at greater risk, such as unsafe sex and injection drug practices.

Dr. Calzavara brings a unique scientific perspective to her work. "My original field of research was not health, it was sociology," she notes, "but I graduated at the time when HIV/AIDS came into being. Here was a new disease that nobody knew much about and no one knew how devastating it would be."

Shortly after graduating from the University of Toronto with a degree in sociology, Dr. Calzavara saw a posting for someone to direct an epidemiological study that would identify risk factors for HIV and follow its natural history. Although her academic supervisors urged her to stay in sociology, her curiosity had been piqued. She signed on and broadened the study's scope to include tracking the sexual behaviour of people who had been infected with HIV.

The project had begun under Dr. Randall Coates, who himself had the virus and who introduced Dr. Calzavara both to epidemiology and to the gay community. Dr. Coates died three days before his protégée was awarded a scholar grant to fund her research, and his passing became a major motivation to keep going.

As an epidemiologist, she has come to recognize that a broad range of social, psychological and other factors are at work that have an impact on HIV infection rates. Her goal is to help the world better understand these factors so that appropriate actions can be taken to stop the spread of a virus that is devastating populations around the globe.

Today, through the work of Dr. Calzavara and others, HIV/AIDS risk behaviours are well known. Yet, for many Canadians, this success has led to the belief that HIV is under control and that it is time to shift our attention to other potential health threats, such as cancer or heart disease.

"The passion is not there anymore, either negative passion or positive passion, even within the communities most affected," says Dr. Calzavara, noting that people with HIV/AIDS are living longer and many see AIDS as a chronic, manageable disease. She believes that "the fear is gone," in contrast to the epidemic's early days, when some people were attending funerals every few days.

Dr. Calzavara compares the development of the disease and the fight to find a cure to a marathon. "As the race continues, we realize this is a marathon, not a sprint." Because of this marathon, Dr. Calzavara thinks that some Canadian researchers are finding it difficult to keep running in part because they spend too much of their valuable time struggling for research funding and career support.

Yet, when Dr. Calzavara compares HIV research funding in Canada to that in other industrialized countries, she is amazed at what researchers have been able to accomplish. "Much of the achievement has been driven by our dedication and commitment to our work, our strong desire to beat this disease," she says.

- Unfounded optimism about treatments and a cure may be contributing to increased levels of unsafe behaviour.
- HIV/AIDS is “competing” with other diseases for public attention, research funding and political commitment.
- HIV/AIDS is more than a health issue. It has significant socio-economic contributing factors and implications, as well as political, cultural, legal, ethical and human rights considerations.
- New strains of HIV and ongoing shifts in the epidemic continue to present challenges for researchers, policy makers and practitioners.
- Canada needs to continue to play a significant role in addressing the global epidemic while simultaneously strengthening its domestic response.

### **Renewing the Vision**

A renewed vision is now being developed for the CSHA. CSHA partners and other stakeholders are reviewing past experiences and current realities, with the goal of developing a strategic plan that will enable Canada to respond effectively to the challenges presented by the domestic and global epidemics. Specifically, CSHA partners are exploring ways to:

- put HIV/AIDS back on the public agenda
- respect, protect and promote the human rights of people living with HIV/AIDS (PHAs) and those vulnerable to HIV
- strengthen the pan-Canadian approach through key strategic partnerships
- revitalize HIV prevention efforts and integrate prevention, care, treatment and support programming
- improve surveillance work and establish better linkages between surveillance and programming efforts
- incorporate the commitments of the United Nations General Assembly Special Session on HIV/AIDS (UNGASS) Declaration of Commitment into Canada's response to HIV/AIDS
- redefine, in the future, the federal role and funding levels

## Injection Drug User Finds Hope

**B**onnie Hebert thought she was safe. Although she used injection drugs, the Surrey, B.C., woman never shared her needles, and she was sexually abstinent. But in December 1996, Ms. Hebert began to feel very ill. Six months later, she was diagnosed with HIV.

"I was devastated," she recalls. "Believing myself to be totally safe, and having been tested every six months, I didn't think past my own responsibilities and put myself in a situation where I was vulnerable. Once you have HIV, that's it. You can't 'un-have' it."

At first, the bad news worsened a lifelong problem with drugs. "I thought I had a death sentence. Knowing I had this dreadful disease, I wasn't doing anything positive with my life and was rapidly going downhill."

Part of the problem was that Ms. Hebert felt isolated and alone in her community. At the time, there was little in the way of support or services for HIV-positive people in Surrey (things have since improved). But thankfully, someone directed her to AIDS Vancouver.

Today, Ms. Hebert is on a methadone program and lives in an apartment across from the Dr. Peter Centre, where she gets her medication every day and attends therapeutic sessions. After a lifetime of feeling judged and found wanting because of her drug habit, Ms. Hebert is now in a supportive environment.

This human compassion has made an incredible difference. Ms. Hebert is feeling healthier and better about herself. "Instead of spending my life on drugs and feeling sorry for myself, I'm making an effort to make my life better."

## Tackling HIV/AIDS in Vancouver's Downtown Eastside

**W**hen Ojibway nurse Viola Antoine first started dealing with HIV/AIDS in 1995, she knew almost nothing about the disease. But working for the Vancouver Native Health Society in the city's rugged Downtown Eastside, her education came fast.

Most of the people Ms. Antoine sees who have HIV/AIDS use injection drugs, and many have had the virus for as long as 15 years. Some have been on the same treatment regimen for years and are stable, but others continuously fail, no matter what treatment is tried.

The Vancouver Native Health Society's Positive Outlook Program

serves about 1 400 people, 60% of whom are Aboriginal. At one time, Ms. Antoine found that many Aboriginal people with HIV/AIDS were rejecting modern medicine in favour of traditional treatments. "But that was only in the beginning," she notes. "They don't do that anymore."

Among the other changes Ms. Antoine notes is more openness about HIV/AIDS, a development that is due at least in part to the Society's street outreach efforts. "The public is more open to AIDS now and people are more willing to talk with us," she says. "It's not hidden anymore."

Still, the challenges on Vancouver's Downtown Eastside remain enormous.

There is never enough money for the work that needs to be done, and Ms. Antoine worries that cuts in social spending will lead to increased crime and violence in her neighbourhood, further complicating a difficult job.

But this also can be said: after seven years on the job, Viola Antoine's commitment to being part of Canada's HIV/AIDS response is stronger than ever. On almost any given day, she can be found on the streets of Vancouver's Downtown Eastside, helping those who need it most. Despite the challenges they face, hundreds of others like her are doing the same in communities across Canada.





# CANADA'S RESPONSE IS EVOLVING

In 1990, the federal government established the National AIDS Strategy (NAS) to help coordinate the various players involved in Canada's HIV/AIDS response. In 1993, NAS was renewed for five years, with an increase in annual funding from \$37.3 million to \$42.2 million.

Following extensive stakeholder consultations in the summer of 1997, the CSHA was launched in 1998 with annual ongoing federal funding of \$42.2 million. The CSHA provides a framework for unprecedented cooperation and innovation in addressing the epidemic. It is a work in progress that continues to evolve through collaborative planning processes that involve the full spectrum of HIV/AIDS stakeholders.

## **The Canadian Strategy on HIV/AIDS**

The CSHA represents a shift from a disease-oriented approach to one that looks at the root causes, determinants of health and other dimensions of the HIV epidemic. Its goals are to:

- prevent the spread of HIV infection in Canada
- find a cure
- find and provide effective vaccines, drugs and therapies
- ensure care, treatment and support for Canadians living with HIV/AIDS, their families, friends and caregivers

- minimize the adverse impact of HIV/AIDS on individuals and communities
- minimize the impact of social and economic factors that increase individual and collective risk for HIV

In pursuing these goals, three policy directions guide the implementation of the CSHA:

- enhanced sustainability and integration – New approaches and mechanisms will be put in place to consolidate and coordinate sustained national action in the long term.
- increased focus on those most at risk – Innovative strategies will be devised to target high-risk behaviours in hard-to-reach populations that are often socially and economically marginalized.
- increased public accountability – Increased evidence-based decision making and ongoing performance review and monitoring will ensure that the CSHA continues to be relevant and responsive to the changing realities of HIV/AIDS.

People living with HIV/AIDS and those at risk of HIV infection are the focus and centre of CSHA efforts. Funding allocations for the CSHA are shown in Table 1.

*Table 1: CSHA Annual Funding Allocations (millions of dollars)*

Prevention	\$ 3.90
Community Development and Support to National NGOs	\$ 10.00
Care, Treatment and Support	\$ 4.75
Legal, Ethical and Human Rights	\$ 0.70
Aboriginal Communities	\$ 2.60
Correctional Service Canada	\$ 0.60
Research	\$ 13.15
Surveillance	\$ 4.30
International Collaboration	\$ 0.30
Consultation, Evaluation, Monitoring and Reporting	\$ 1.90

## **A Pan-Canadian Approach**

The CSHA is a national approach that enables the engagement of voluntary organizations, communities, the private sector and all levels of government.

Health Canada, the lead federal department for issues related to HIV/AIDS, coordinates the CSHA. Several responsibility centres within Health Canada contribute to this work, including CIDPC, the Departmental Program Evaluation Division (DPED), the First Nations and Inuit Health Branch (FNIHB), regional offices and the International Affairs Directorate (IAD). As well, Correctional Service Canada (CSC) and the Canadian Institutes of Health Research (CIHR) are the other federal government partners.

Major non-governmental stakeholders are also considered full partners in the CSHA. These include:

- the Canadian Aboriginal AIDS Network (CAAN)
- the Canadian AIDS Society (CAS)
- the Canadian AIDS Treatment Information Exchange (CATIE)
- the Canadian Association for HIV Research (CAHR)
- the Canadian Foundation for AIDS Research (CANFAR)
- the Canadian HIV/AIDS Clearinghouse, Canadian Public Health Association (CPHA)
- the Canadian HIV/AIDS Legal Network
- the Canadian HIV Trials Network (CTN)
- the Canadian Treatment Action Council (CTAC)
- the Interagency Coalition on AIDS and Development (ICAD)
- the International Council of AIDS Service Organizations (ICASO)

Several federal departments and agencies provide supplemental funding to address HIV/AIDS. CSC invests \$3 million annually in HIV/AIDS programming in federal penitentiaries. Similarly, FNIHB invests \$2.5 million annually to provide HIV/AIDS education, prevention and related health care services to Inuit and on-reserve First Nations people. The CIHR is also committed to contributing at least \$3.5 million per annum to HIV/AIDS extramural research, and in 2001-2002 invested a total of \$5.1 million.

As part of the global response, the Canadian International Development Agency (CIDA) provided \$36 million in funding for HIV/AIDS initiatives in 2001-2002. This is part of a five-year investment totalling \$270 million, with incremental increases from \$22 million in 2000-2001 to \$80 million in 2004-2005. The Government of Canada has also announced a \$150 million contribution to the Global Fund to Fight AIDS, Tuberculosis and Malaria, a public/private partnership that will disburse funds to countries in need to help reduce the burden of these diseases. Canada's initial contribution, in 2001-2002, was \$80 million.

Provincial and territorial governments provide major support through contributions to the delivery of HIV/AIDS-related health care services, research and prevention activities.





# REPORTING ON PROGRESS

As was the case last year, *Canada's Report on HIV/AIDS 2002* describes the activities and progress of CSHA partners in five key areas:

- coordinating HIV/AIDS policy and programming
- increasing Canadian involvement, participation and partnership in the HIV/AIDS response
- advancing the science of HIV/AIDS
- increasing the use of reliable information
- building Canada's capacity to address HIV/AIDS

Most of the information presented in this section of the report is directly related to activities funded through federal resources under the CSHA. However, efforts have been made to also include non-CSHA achievements involving federal departments and agencies that supplement the work of the CSHA.

Additional information on the CSHA, and specifically on Health Canada's HIV/AIDS policies and programs, can be found on the Health Canada website at [www.hc-sc.gc.ca](http://www.hc-sc.gc.ca). Similarly, information on other CSHA partners' programs and initiatives can be found on their respective websites, which are listed in Section 4 of this document (see page 53).





# COORDINATING HIV/AIDS POLICY AND PROGRAMMING

Developing effective responses to HIV/AIDS requires coordination across the spectrum of public policy issues, from health care and housing to poverty and security. The CSHA is encouraging a pan-Canadian response that not only involves all levels of government and all sectors of society, but also spans the full range of policy issues that can contribute to reducing the spread of HIV, respecting the human rights of people living with HIV/AIDS and improving their quality of life.

CSHA partners have confirmed the need to move towards a social justice framework and specifically to include vulnerable populations in policy and program development, implementation and evaluation. Among CSHA partners and stakeholders, there is a heightened awareness of the need to think and act strategically in order to address more effectively the epidemic in Canada and around the world.

### **Greater Policy Coordination Leads to Strategic Actions**

CSHA stakeholders convened in April 2002 to further the implementation of the 10 directions established at the first CSHA direction-setting meeting.

This follow-up meeting, held in Montréal, was organized by Health Canada and coordinated with representatives of CSHA partners. Some 180 people attended, representing a broad cross section of HIV/AIDS organizations, coalitions and networks; Aboriginal organizations; health care organizations and health care providers; professional associations; researchers and research organizations; government departments; and key CSHA committees.

Participants in the Montréal meeting collectively proposed 20 far-reaching initiatives intended to turn the 10 strategic directions identified at Gray Rocks into actions. Concrete steps have been taken to further develop and follow up on these proposed recommended actions. Regular updates on this work have been given to participants and are posted on the CSHA website.<sup>2</sup>

### **National Committees Fulfill a Crucial Advisory Role**

A number of national advisory groups are providing government with valued advice on HIV/AIDS issues. These committees bring a broad range of perspectives to bear on CSHA policy and programming, including the views of people living with HIV/AIDS.

The Ministerial Council on HIV/AIDS, for example, provides advice directly to the federal Minister of Health on pan-Canadian aspects of HIV/AIDS. During 2001-2002, the Ministerial Council and the Federal/Provincial/Territorial Advisory Committee on AIDS (FPT AIDS) jointly undertook a study of HIV and health determinants entitled “HIV/AIDS and Health Determinants: Lessons for Coordinating Policy and Action.” The study has increased the knowledge base of linkages between HIV/AIDS and determinants-of-health issues. The Ministerial Council also advised the Minister of Health on such matters as the need to enhance harm reduction approaches and HIV prevention programs in prisons; the legal and human rights questions raised by Bill C-217 (the proposed Blood Samples Act); and issues related to women, gay men, injection drug users, Aboriginal people, African and Caribbean people from HIV-endemic countries, and the medical use of marijuana. As well, the Ministerial Council continued to express concern about Canada’s policy regarding the mandatory testing of immigrants for HIV.

FPT AIDS provides policy advice to the Conference of Deputy Ministers of Health. In addition to working with the Ministerial Council on the determinants-of-health study, during 2001-2002 FPT AIDS developed “Guidelines for the Testing of Women During Pregnancy.” This involved a literature review to determine what guidelines were already in place in various provinces and territories. The Conference of Deputy Ministers of Health subsequently approved the release of the guidelines.

The Federal/Provincial/Territorial Heads of Corrections Working Group on Infectious Diseases, which advises the federal and provincial governments on a wide range of issues related to infectious diseases in correctional facilities, began to explore the need for a more integrated strategy on blood-borne pathogens and tuberculosis. Another significant issue explored by the Working Group in 2001-2002 was how to respect an HIV-positive inmate’s right to confidentiality

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<sup>2</sup> More information on the Montréal follow-up meeting is available at [http://www.hc-sc.gc.ca/hppb/hiv\\_aids/can\\_strat/strat\\_admin/gray\\_rocks.html](http://www.hc-sc.gc.ca/hppb/hiv_aids/can_strat/strat_admin/gray_rocks.html)

while taking into account the rights, needs or fears of his/her spouse or partner, corrections staff and other inmates.

A new national advisory committee – the National Aboriginal Council on HIV/AIDS (NACHA) – was created in May 2001 to address concerns about the escalating vulnerability of the Aboriginal population to HIV infection. NACHA will provide advice and direction to Health Canada on HIV/AIDS issues that affect Aboriginal peoples and examine the impact of the disease on Aboriginal communities. NACHA includes representatives from all three Aboriginal groups in Canada – First Nations, Inuit and Métis – as well as Aboriginal AIDS service organizations (ASOs) and Aboriginal people living with HIV/AIDS. NACHA has established subcommittees to address key issues, such as HIV/AIDS epidemiology and surveillance, and plans to build linkages with other HIV/AIDS advisory bodies to further the work of the CSHA.

Also during 2001-2002, IAD's Working Group on International HIV/AIDS Issues continued to provide advice and direction on international issues to the federal government as part of Canada's response to the global HIV/AIDS epidemic. The Working Group includes representatives from Health Canada, the Department of Foreign Affairs and International Trade, CIDA, CAS, CPHA, ICAD, ICASO and the Canadian HIV/AIDS Legal Network.

### **Developing Policy Positions**

CSHA partners play an important role in policy development, both through collaborative processes and by undertaking work that feeds into broader policy initiatives.

The need to develop a comprehensive policy on issues related to HIV vaccine preparedness and implementation has emerged as a priority for the near future. During 2001-2002, the Canadian HIV/AIDS Legal Network examined the legal and ethical issues associated with developing vaccines and planning for their delivery. The Legal Network's final report, entitled *HIV Vaccines in Canada: Legal and Ethical Issues*, concludes that Canada needs a formal HIV vaccine plan and should substantially increase its investment in HIV vaccine research and development. The report is supported by a 400-page background document and a series of information sheets. This body of work constitutes a major contribution to the development of policy and guidance on vaccine preparedness and implementation. Also in this regard, the Legal Network organized an international expert meeting entitled "HIV Vaccines for Developing Countries – Advancing Research and Access." The meeting, which was funded in part by IAD, UNAIDS and CIDA, examined policy issues for vaccine development and access in developing countries.

The Legal Network also developed a discussion paper on safe injection sites. The paper was adapted from an article on the need for safe injection facilities in Australia that appeared in the *Melbourne University Law Review*.<sup>3</sup> The release of this paper was coordinated with ASOs in various Canadian cities to ensure wider regional coverage of issues related to injection drug use. Both the City of Montréal and the Royal Canadian Mounted Police are using the paper to develop policy positions on safe injection sites.

Senior Health Canada officials at the International Conference on HIV/AIDS in Barcelona indicated that the Department will begin a formal dialogue with key stakeholders to develop a plan that will support the global vaccine effort and focus on vaccine production and equitable distribution.

In collaboration with FPT AIDS, CIDPC established a working group to study the issue of multi-drug-resistant HIV. The working group comprised experts from Health Canada; the HIV testing and counselling communities; the legal, ethical and human rights field; HIV/AIDS clinical care; and ASOs. Its report concludes that multi-drug-resistant HIV is adding another layer of complexity to the HIV/AIDS epidemic in Canada and around the world. Although extraordinary responses are not currently required, the working group suggests that this added complexity compels all sectors and jurisdictions to consider the impact of multi-drug-resistant HIV on their policies and programs.

In January 2002, CIDA held a round table entitled "Dialogue on Antiretroviral Therapies." A number of issues were addressed, including the need for concise and accessible information on appropriate care, treatment and support initiatives for people living with HIV/AIDS in resource-limited settings; concerns about antiretroviral therapy in resource-limited settings; requirements for the safe and effective implementation of antiretroviral therapy; and the ways in which these issues should fit into CIDA's current programming priorities. After further consultations with NGOs, a draft discussion paper was developed entitled *Building Comprehensive Approaches to HIV/AIDS Care, Treatment and Support in Resource Limited Settings*. This document was the basis for discussions at a two-day meeting in June 2002 that brought together 40 international and Canadian representatives of United Nations agencies, civil society groups, universities and government departments. The final version of the paper will be published in late 2002 and will provide the framework for CIDA's operational guidelines for comprehensive HIV/AIDS care, treatment and support programming.

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3 Malkin, Ian. "Establishing supervised injecting facilities: a responsible way to minimize harm." 2001.

Following the transfer of most of the CSHA's health research funding to the CIHR, Health Canada undertook a process to find a new administrative location for its Community-Based Research Program and its Aboriginal Research Program. This exercise provided an opportunity to conduct national consultations on the design and future of the Community-Based Research Program. Health Canada is now developing a plan to address options identified through the consultations to make the program more responsive to the needs of communities. The Department is also working with Aboriginal stakeholders on a similar process to renew and relocate the Aboriginal Research Program.

### **Contributing to Global Policy and Programming Initiatives**

CIDA continues to strengthen its commitment to HIV/AIDS policy development and programming at the global level. CIDA provides core funding for HIV/AIDS initiatives to multilateral organizations such as UNAIDS, the United Nations Children's Fund and the United Nations Development Programme. Bilateral funding is provided for programs in several countries and regions of the world where CIDA is working with governments and civil society to mitigate the impact of HIV/AIDS. CIDA also provides funding to numerous Canadian partners/stakeholders working internationally in the field of HIV/AIDS.

CIDA and IAD are represented on the UNAIDS Programme Coordinating Board and the UNAIDS Contact Group to Accelerate Access to HIV/AIDS Care. Both of these bodies contribute to global HIV/AIDS policy efforts. Also during the year, IAD funded the Canadian HIV/AIDS Legal Network to develop a paper exploring legal, ethical and human rights issues associated with global access to HIV/AIDS treatment and trade and intellectual property rights.

HIV/AIDS is increasingly on the agenda of international organizations. For example, the G8 Summit hosted by Canada in Kananaskis, Alberta, in June 2002, provided an opportunity for a wide variety of NGOs and community organizations to contribute to Canada's understanding of HIV/AIDS issues and to promote increased political commitment from G8 leaders to fight the HIV/AIDS epidemic in Africa. The G8 Action Plan for Africa, which was released at the Summit, included a strong commitment to address HIV/AIDS and reflected a number of recommendations put forth by the Global Treatment Action Group. This is an umbrella network of more than 30 Canadian NGOs, including the HIV/AIDS Legal Network, ICAD, Doctors Without Borders and the Canadian Labour Congress.

### **Including Persons Infected With and Affected by HIV/AIDS in the Response**

People living with HIV/AIDS, and those at risk, are at the centre of the CSHA and are increasingly involved in all aspects of its work. Including these individuals in the response leads to better policies and programs, both in Canada and abroad.

For example, the involvement of people living with HIV/AIDS in various policy forums has drawn attention to the fact that individuals who are already HIV-positive continue to have prevention needs (for example, they need to participate in preventing transmission, thereby reducing rates of infection, and to avoid being reinfected with different strains). This is contributing to a shift toward more integrated programming in which HIV/AIDS prevention and care, treatment and support strategies are inextricably linked. CIDPC is supporting this shift by coordinating the development of a strategic national framework for HIV prevention, care, treatment and support. As part of this process, linkages will be established between HIV/AIDS initiatives and activities in areas such as sexual health, hepatitis C and substance use.

CAS is also providing opportunities for infected and affected individuals to engage in policy and program development. The “People Living with HIV/AIDS Forum,” held once a year in conjunction with CAS’s annual general meeting, allows people living with HIV/AIDS to direct CAS’s work plan and activities. Recommendations from the meeting are also forwarded to other organizations when appropriate.

Working with partners ranging from Toronto’s Hospital for Sick Children to TeenNet, CATIE initiated research to develop model interventions to assist youth living with HIV/AIDS. Also during 2001-2002, CATIE held focus groups with injection drug users and their service providers, as well as with representatives of Inuit communities and Prisoners’ HIV/AIDS Support Action Network (PASAN) to inform the design of program initiatives.

CTAC is primarily a volunteer-driven organization, run by and for people living with HIV/AIDS. CTAC is engaging HIV-positive hemophiliacs and those co-infected with hepatitis C by working with the Canadian Hemophilia Society, the Hepatitis C Society of Canada and others on issues related to drug review processes. Specifically, these groups are involved in an ongoing dialogue with Health Canada on the need for a more efficient drug review process and an effective post-approval surveillance system. CTAC also requests expeditious access to provincial formulary coverage.



CAAN has launched its Aboriginal PHA Coordination Program, whose goal is to identify and coordinate a response to issues of care, treatment and support for Aboriginal people living with HIV/AIDS. As part of this effort, CAAN will develop and disseminate a position paper as well as community bulletins and articles for its newsletter. Program staff will also assist in coordinating information for CAAN's national committees, explore the potential for an online discussion forum for Aboriginal people living with HIV/AIDS, post relevant information and help prepare Aboriginal AIDS Awareness Day materials.

Inmates at several CSC institutions participated in World AIDS Day activities in December 2001, including HIV/AIDS knowledge contests, information booths and "guess the number of condoms in the jar" contests. They also assembled red ribbons and promoted HIV/AIDS testing.

### **Challenges and Opportunities**

Policy development is by its very nature a slow-moving process, and the complexities of the HIV/AIDS epidemic, combined with the need to engage partners from many disciplines and jurisdictions as the CSHA moves toward a social justice framework, only add to this challenge. Underlying these dynamics is the inherent difficulty of developing effective tools and providing appropriate information and education that will enable individuals to protect themselves.

Nevertheless, coordinated policy and program development has many benefits. It ensures a more strategic approach, results in better-targeted initiatives, reduces duplication of effort and minimizes the impact of limited human and financial resources. Partners in the CSHA will continue to be challenged to work together and with others to achieve these benefits in the face of a changing epidemic.





# INCREASING CANADIAN INVOLVEMENT, PARTICIPATION AND PARTNERSHIP IN THE HIV/AIDS RESPONSE

**I**ncreased involvement, participation and partnership are core values of the CSHA. Stronger relationships between government partners, NGOs, community-based and regional organizations, individuals living with HIV/AIDS, researchers, the private sector and others are needed to develop policies and programs that foster a more flexible, compassionate and effective response to the epidemic.

CSHA partners are increasingly working together to achieve the CSHA's goals and are reaching out to others to broaden and deepen Canadians' involvement with HIV/AIDS through skills-, knowledge- and experience-sharing opportunities. Many Canadian organizations are also strengthening their international activities and partnerships, recognizing that Canada needs to be vigorously involved in global efforts to arrest the spread of HIV/AIDS and to improve access to care and treatment for those already infected.

## **Extending the Scope of the HIV/AIDS Response**

The changing face of the HIV/AIDS epidemic in Canada requires CSHA partners to continually expand the scope of their activities to engage new target groups and organizations.

For example, CATIE has taken steps to involve a broader range of participants in developing its consumer-driven services. Regular dialogue sessions between service users and CATIE are helping the organization respond to changing realities. As well, CATIE is attracting a larger and more diverse group of individuals to its annual general meetings.

CIDPC, IAD and the Women's Health Bureau of Health Canada, along with the CIHR and CIDA, provided funding to the Maritime Centre for Excellence in Women's Health to help ensure that gender issues are considered in HIV/AIDS programming. Among other activities, the Centre sponsors research on women and HIV/AIDS and contributes to the development of gender-appropriate training on HIV/AIDS.

CIDPC now invites representatives of national and community-based organizations and persons living with HIV/AIDS to its national epidemiological meetings, which traditionally have attracted mainly researchers and federal/provincial health officials. The CIHR also reached out to communities in 2001-2002, primarily through the Institute of Aboriginal People's Health and requests for applications that aimed to increase the direct involvement of communities in the development and implementation of research projects.

Increased collaboration is occurring among HIV/AIDS researchers. A survey recently commissioned by the CIHR indicates that almost all CIHR-funded HIV/AIDS researchers collaborated with others during 2001-2002 in the formulation and design and/or conduct of their research.<sup>4</sup> Most collaborations in the formulation and design of research occur between researchers (90 per cent reported collaborating with biomedical researchers and 66 per cent with clinical researchers), but a significant number of researchers also extended their scope and collaborated with community groups (47 per cent), health practitioners (50 per cent), people living with or at risk of HIV/AIDS (36 per cent), and health policy makers (17 per cent). More than 30 per cent of researchers have involved, or plan to involve, potential users of their research in its funding, implementation, analysis and design. As well, more than 50 per cent of CIHR-funded researchers have or will involve potential users in the dissemination of their research results. Almost half of the surveyed researchers (45 per cent) are collaborating more today than they did a year ago, and almost one third report that their collaborations involve greater interaction with other disciplines.

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<sup>4</sup> The CIHR survey was distributed to 64 funded HIV/AIDS researchers, and 58 responses were received (90 per cent).

A major priority for the Canadian Network for Vaccines and Immunotherapeutics (CANVAC) is to rapidly move its findings into human clinical trials of HIV prophylactic and therapeutic vaccines. In order to facilitate this, CANVAC has formed a Clinical Trial Planning and Protocol Development Committee and partnered with the CTN. With the CTN, CANVAC has developed and received approval for Canada's first therapeutic HIV vaccine trial. There are also concerted efforts under way to partner with international HIV vaccine organizations, especially in Africa, and to lay the groundwork for future prophylactic vaccine trials in Africa.

CAS is also increasing its collaboration with non-traditional partners, such as cancer and hepatitis C agencies, to draw attention to the linkages between HIV and these diseases and develop more effective awareness and prevention campaigns. Similarly, CAS is working with non-HIV/AIDS youth groups to develop and deliver more effective prevention messages to young people.

CSC continues to collaborate with provincial correctional facilities by participating in anonymous testing pilot projects. An evaluation of a pilot project in Prince Albert Provincial Correctional Centre has been completed, and a pilot project is currently under way at Saskatchewan Penitentiary (a federal facility). Further projects are expected in three New Brunswick facilities.

### **Canadians Are Getting Involved**

Canadians are becoming involved in the fight against HIV/AIDS in a number of ways.

In 2002, more than 52 000 Canadians in 125 communities participated in the eighth annual AIDS Walk Canada, the country's largest single event for raising awareness and funds for HIV/AIDS. Held in September 2002, AIDS Walk Canada raised \$2.2 million to assist local AIDS organizations in every province and territory (money pledged to walkers remains in the communities where it was raised). AIDS Walk Canada is coordinated nationally by CAS and depends on hundreds of volunteers from coast to coast to coast.

Volunteers are also integral to the activities of CSHA partners and ASOs throughout the year. For example, some CAS member organizations are completely volunteer-based, while other ASOs integrate volunteers into their daily work. In 2001-2002, volunteers donated more than 10 000 hours of service to CATIE, compared to 7 400 hours the previous year.

FNIHB and other branches of Health Canada worked with Pauktuutit (Inuit Women's Association) on several initiatives to engage Inuit youth in HIV/AIDS prevention initiatives. In one highly successful project, Grade 6 students from Aqarniit Middle School in Iqaluit produced an enormous (2.5 metre by 1 metre) AIDS puzzle depicting personal HIV/AIDS-related messages. The puzzle is intended to provide an opportunity for Canadians to gain a deeper understanding of the importance of compassionate community responses to HIV/AIDS. The puzzle, which was judged by elders and other community leaders, became a winning entry in the Iqaluit Arctic Youth HIV/AIDS Fair. By engaging both youth and adults, this project has helped to destigmatize HIV/AIDS across the North, underlined the need to talk about HIV/AIDS issues and raised awareness of the role that individuals can play in prevention, care, treatment and support. The puzzle has since been reduced in size and sent to every seniors' facility, school and community health centre in the 53 Inuit communities, as well as to individuals and organizations who requested copies. More than 500 puzzles have been distributed to date.

### **Engaging in the Global Response**

Through UNGASS (held in June 2001) and other fora, the world has witnessed an unprecedented mobilization of political leadership on HIV/AIDS. Global issues associated with HIV/AIDS have also been more broadly embraced by Canadian NGOs and ASOs, resulting in greater levels of international collaboration.

The Government of Canada's first annual report on implementation of the UNGASS Declaration of Commitment was submitted to UNAIDS in the spring of 2002.<sup>5</sup> The report, which was based on a UNAIDS questionnaire, was coordinated by IAD and included input from all federal government partners involved in the CSHA or other HIV/AIDS-related efforts. The draft report was forwarded to FPT AIDS and to the NGO members of IAD's Working Group on International HIV/AIDS Issues for input before it was finalized. IAD subsequently funded CAS to promote the distribution and use of the UNGASS report as well as IAD's *Case for Canadians to Act Globally Against HIV/AIDS* and ICASO's *Advocacy Guide to the UNGASS Declaration of Commitment on HIV/AIDS*.

Also in relation to UNGASS, ICASO collaborated with community-based organizations, UNAIDS and governments to devise a monitoring and evaluation strategy to hold governments accountable for the commitments they made when signing the Declaration of Commitment. For its part, ICAD has been promoting the Declaration among its members and encouraging them to integrate it into their operational and programming strategies, both in Canada and abroad.

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5 The report can be accessed online at [http://www.hc-sc.gc.ca/datapcb/iad/ih\\_ungass-e.htm](http://www.hc-sc.gc.ca/datapcb/iad/ih_ungass-e.htm).

The Declaration of Commitment presents a unique opportunity to find common ground among groups that do not normally work together and can serve as a unifying force on HIV/AIDS issues.

The XIV International AIDS Conference in Barcelona, Spain (July 7 – 12, 2002) brought together more than 15 000 scientists, health care workers, heads of state, policy makers, NGOs and people living with HIV/AIDS from around the world. It was a unique opportunity for these individuals and organizations to share knowledge and information, broaden the involvement of different sectors in the global response to HIV/AIDS, and forge new partnerships for the work that lies ahead. More than 250 Canadians attended the conference and were involved in some 120 presentations. Health Canada was a Cooperating Institute of the conference and sponsored satellite sessions on legal, ethical and human rights issues; vaccines; HIV prevention in drug-using populations; gender; and citizen-engaged HIV/AIDS policy. CIDA, also a Cooperating Institute, hosted a satellite symposium organized by ICAD on international twinning. Other NGOs also sponsored satellite sessions. ICASO continued in its role as a conference co-organizer, as it has done for all international AIDS conferences since 1992. A clear message arising from the Barcelona conference was that developed countries need to devote additional attention and increased funding to the global epidemic. The conference also confirmed that HIV/AIDS prevention and treatment are not mutually exclusive and should be pursued in tandem in order to secure an effective response to HIV/AIDS.

ICASO played a key role in ensuring that the voice of community-based organizations was heard during the design of the Global Fund to Fight HIV/AIDS, Tuberculosis and Malaria. ICASO's executive director was appointed to the transitional working group that developed the Global Fund's governance system and processes. Although this work was completed by the end of 2001, ICASO continues to serve in an advisory role to the Global Fund.

Many smaller activities were also undertaken in 2001-2002 to strengthen international participation and partnerships. For example, ICAD and other organizations commissioned journalists to write articles about how communities in Canada, Zambia, Mozambique and Trinidad are coping with the HIV/AIDS epidemic. Clinicians associated with the CTN enriched the professional capacity of physicians in the Caribbean through education and training. Canadians also participated in the 10<sup>th</sup> International Conference for People Living with HIV/AIDS (held in Trinidad in October 2001) and other activities of the Global Network of People Living with HIV/AIDS.

IAD was invited by the Government of St. Kitts and Nevis to help this Caribbean country further develop its HIV/AIDS policies and programming. To this end, IAD facilitated linkages between appropriate Canadian groups and professional organizations and St. Kitts and Nevis health officials and other stakeholders. CIDPC also helped St. Kitts and Nevis strengthen its HIV/AIDS epidemiological and surveillance work.

### **Challenges and Opportunities**

Significant progress has been made in broadening the participation of individuals and organizations, at the local, national and international levels, in Canada's response to the HIV/AIDS epidemic. As well, valuable lessons have been learned about when and how partnerships add value to a project and which types of partners should be involved. Still, more needs to be done.

CSHA partners must continue to strengthen their efforts to engage vulnerable populations by creating supportive environments. New linkages need to be created between stakeholders who have little history of cooperation. CSHA partners also need to invite AIDS coalitions and volunteers to further strengthen the response.





# ADVANCING THE SCIENCE OF HIV/AIDS

Researchers in Canada and around the world continue to advance the science of HIV/AIDS. On the biomedical/clinical front, promising developments in HIV vaccine and microbicide research were announced at the XIV International AIDS Conference in Barcelona, a venue that provided Canadian scientists with opportunities to both share their work with others and to learn from international colleagues. Innovative social science research is also helping us to better understand risk behaviours among the most vulnerable populations and to develop appropriate prevention responses.

Canadians are involved in all aspects of HIV/AIDS research, with many recognized as world leaders in specific areas of study. In collaboration with the pharmaceuticals industry, the health care system and governments, Canadian researchers are striving to develop new knowledge, new technologies and new approaches that will help stop the spread of HIV infection and contribute to the development of effective vaccines and therapies and a cure for AIDS.

### **Canadian HIV/AIDS Research Partners**

The CSHA provides annual funding of approximately \$13 million for HIV/AIDS research. Of this amount, about \$1 million supports epidemiological research within Health Canada. The remainder is dedicated to extramural research at universities, hospitals and other institutions (see Table 2 for a breakdown of extramural research funding streams). In addition, the CIHR, which administers the CSHA's extramural research program, is committed to contributing at least \$3.5 million per annum to HIV/AIDS research from its own budget. In 2001-2002,

the CIHR invested a total of \$5.1 million in this work. During the year, 25 new HIV/AIDS research projects were approved by the CIHR, bringing the total to 91 funded projects.<sup>6</sup>

*Table 2: Federal HIV/AIDS Extramural Research Funding Streams (\$M)*

	CSHA	CIHR
Community-Based Research	1	
Aboriginal Community-Based Research	0.8	
Biomedical/Clinical*	4.5	5.1
Health Services/Population Health**	2.37	
Canadian HIV Trials Network**	3.13	

\* CSHA funds administered by the CIHR

\*\* CSHA funds administered by the CIHR as of July 1, 2001

Canadian HIV/AIDS researchers also receive significant funding from sources other than the CIHR and the CSHA. In fact, approximately \$0.61 of every dollar received by Canadian researchers for HIV/AIDS research came from national and international sources other than the CIHR and the CSHA.

For example, in 2001-2002 the Canada Foundation for Innovation, a non-profit corporation established by the federal government to strengthen Canada's capacity to carry out world class research and development activities, invested approximately \$1.9 million in HIV/AIDS research infrastructure at universities and not-for-profit institutions across Canada. CANVAC, which brings together leading Canadian scientists specializing in the fields of immunology, virology and molecular biology, spent approximately \$1.3 million on HIV/AIDS projects. Genome Canada, the primary funding and information organization for genomics and proteomics in Canada, has invested \$11.5 million over three years in three large-scale research projects related to HIV/AIDS. These projects will increase our understanding of the role of genetics in immune-based diseases such as HIV and in opportunistic infections that pose a threat to people with weakened immune systems.

Funding from sources outside Canada also helped Canadian researchers develop new knowledge in 2001-2002. The 2001-2002 CIHR Survey of HIV/AIDS Researchers indicated that approximately \$0.24 of every dollar received by Canadian researchers for HIV/AIDS research, or \$5.4 million, came from international sources.

<sup>6</sup> Details on recently funded and ongoing HIV/AIDS research projects can be found on the CIHR website at [www.cihr.gc.ca](http://www.cihr.gc.ca).

These various sources of research funding have enabled Canadian scientists to contribute substantial new knowledge to the fight against HIV/AIDS. Funding provided through the CIHR enabled HIV/AIDS researchers to publish an estimated 307 articles in peer-reviewed journals. These researchers also made an estimated 517 presentations at scientific congresses and conferences in Canada and internationally.<sup>7</sup>

### **Developing a Strategic Approach**

Currently, most of the HIV/AIDS research funded through the CIHR is investigator-initiated; research grants are awarded to meritorious proposals submitted to competitions that are open to all health research disciplines. However, new research opportunities and emerging health threats can be overlooked when too much emphasis is placed on investigator-initiated research programs. With this in mind, the CIHR is now developing a more strategic, targeted approach that will allow Canada to identify and fund research priorities in HIV/AIDS and other fields and encourage researchers to move into new areas.

To this end, over the past year the CIHR's Institute of Infection and Immunity has been working with key stakeholders to develop a framework for determining research priorities for HIV/AIDS. This framework envisions the establishment of a research advisory committee that will include representatives of CIHR institutes, Health Canada, HIV/AIDS researchers, community organizations and others involved in HIV/AIDS research. This committee will be tasked with regularly identifying research priorities for HIV/AIDS.

### **Treatments**

Clinical trials are an important element of the scientific response to HIV/AIDS, particularly for people living with HIV/AIDS. For example, clinical trials have led to the development and use of antiretroviral therapies that have allowed many HIV-infected people to live longer, healthier lives than in the past. At the same time, clinical trials involve some personal risk for the volunteers who participate in them, since the goal is to test the safety and effectiveness of new drugs and treatments. Clinical trials are typically lengthy, can require changes in lifestyle and may result in negative side effects for some participants.

The CTN, which receives \$3.2 million in CSHA funding each year through the CIHR, is the principal organization conducting HIV/AIDS clinical trials in Canada. The CTN is a partnership of researchers and research institutes committed to developing treatments, vaccines and a cure for HIV/AIDS. In 2001-2002, the CTN worked at full capacity with no fewer than 19 clinical trials – four of them new – involving 1 106 Canadians with HIV/AIDS.

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<sup>7</sup> Estimates of the number of publications and presentations are based on an average of 4.8 publications and 8.1 presentations per respondent to the CIHR Survey of HIV/AIDS Researchers. The response rate for the survey was 90 per cent.

CTN trials under way include two innovative, Canadian-designed and led, CIHR-funded trials:

- CTN 161, the Simplified Protease Inhibitor Trial (SPRINT), is recruiting at clinical sites in Canada, Argentina and the United States. The study addresses the urgent need to develop drug regimens that are easy to follow by testing the effectiveness and safety of simplified dosing schedules for a class of drugs known as protease inhibitors.
- CTN 164 (STI) is one of the first major prospective studies of structured treatment interruptions in people who have experienced the failure of two lines of antiretroviral therapy.

Clinical trials continue to achieve positive results, both in Canada and abroad. At the XIV International AIDS Conference in Barcelona, for example, researchers announced promising results from clinical trials for a new drug called T-20, a fusion inhibitor that prevents the virus from binding to target cells. T-20 can work in people for whom other drugs are no longer effective and may be on the market within the next 12 months.

While new treatments offer hope for people living with HIV/AIDS, some antiretroviral treatments that had proven effective in arresting the progression of the disease are showing signs of failure. New strains of HIV have emerged that are resistant to traditional drug treatments, and other strains have grown drug-resistant over time. Although antiretrovirals can prolong life, they can also cause organ damage (for example, to the liver and kidneys) as well as heart disease, diabetes and other health consequences. Perhaps most alarming, the availability of antiretroviral therapies appears to have resulted in the false perception among certain populations that HIV/AIDS is not a serious health threat, which may be contributing to increased levels of unsafe behaviour.

Due to the growing number of people with HIV/AIDS who are no longer benefiting from antiretroviral therapies, there is a significant need for additional research on effective HIV treatments. The OPTIMA trial (Options in Management with Antiretrovirals) is designed to evaluate the best treatment strategies for HIV-positive people for whom highly active antiretroviral therapy (HAART) has failed. The CIHR is contributing \$3.7 million over four years as Canada's share of this \$20 million, tri-national clinical trial. Other national partners in the study are the Department of Veterans Affairs in the United States and the Medical Research Council in the United Kingdom. The OPTIMA trial has begun recruitment of the targeted 1 700 treatment experienced participants. The CTN is coordinating the Canadian component of the trial and aims to recruit 400 participants from the 22 participating hospitals in Canada (CTN 167).

One of the most important treatment questions facing clinicians and HIV-positive people is when to start HAART. A research team from British Columbia recently published an article that has influenced clinical practice guidelines internationally. Their research indicates that the effectiveness of antiretroviral therapy is determined by the level of CD4 cells (cells that orchestrate the immune response) in HIV-positive people.

### **HIV Vaccines and Microbicides**

The search for AIDS vaccines has become a key focus of research worldwide, and Canada's participation has become integral to the success of this work. At the G8 Summit in Kananaskis, the Prime Minister announced that, through the Canada Fund for Africa, \$50 million would be contributed over three years toward the development of an AIDS vaccine for Africa. This contribution will go to the International AIDS Vaccine Initiative (IAVI) – making Canada the largest government donor to IAVI – and the African AIDS Vaccine Program.

IAVI researchers have made encouraging progress. For example:

- Two vaccines – an MVA vector vaccine and a DNA vaccine, both containing genetic fragments of HIV – have successfully completed Phase I safety trials in the UK and Kenya. IAVI is proceeding to test both vaccines in a combined approach and hopes to proceed to Phase III efficacy trials within the next three years. IAVI is collaborating with the University of Nairobi and Oxford University to develop this vaccine, which is geared specifically to target Clade A of the virus (predominant in East Africa).

In other vaccine news:

- AIDSVAX, developed by VaxGen Inc., is currently in Phase III trials in North America, the Netherlands and Thailand. Results of these studies should be made available in 2003.
- A second Phase III AIDS vaccine trial will begin enrolling volunteers in 2003 in at-risk heterosexual men and women in Thailand. This trial involves a combined vaccine approach, using AIDSVAX and a cellular immunity-generating canarypox vector called ALVAC.

Canadian researchers have been instrumental in identifying populations with natural resistance to HIV and potential mechanisms for protective immunity. For example, researchers from the University of Manitoba have been studying a small minority of female commercial sex workers in Nairobi, Kenya who are repeatedly exposed to HIV but remain uninfected with the virus. Another group of researchers at McGill University Health Centre compared two groups of intravenous drug users who were exposed to HIV through needle sharing with partners known to be HIV-positive. One group became HIV-positive after a year of exposure; the other remained negative. The work of the Manitoba group has led to the development of a vaccine that is currently being tested in a clinical trial conducted by researchers in Oxford and Kenya. The findings from the McGill University study support the current trend in HIV vaccine design, which is to find vaccines that elicit an HIV-specific cellular immune response (an increase in HIV-specific cytotoxic T lymphocyte activity).

CIDPC has struck an internal working group on HIV Vaccine Development and Equitable Distribution. A range of stakeholders from within and outside government will be included in the working group's consultations.

UNAIDS, CIDA and IAD also supported vaccine work by funding the Canadian HIV/AIDS Legal Network to host an international meeting of vaccine experts. The meeting explored obstacles to the development and distribution of HIV vaccines suitable for use in developing countries.

CANVAC has also been very active in the international search for vaccines. A CANVAC research team recently discovered that mice immunized in the nose with inactivated HIV particles plus a novel immune stimulator are protected from genital infection with a model virus expressing one of the HIV proteins. This discovery, which suggests that an HIV vaccine administered through a mucosal surface (the nose, for example) may protect from infection at another distant mucosal surface (such as the genital tract), is the key to CANVAC's HIV vaccine development program. This model will be used to test vaccine preparations in mice, with the most effective preparations then proceeding to human trials.

As well, CIDPC is currently involved in a major collaboration with leading Canadian immunologists to investigate vaccine constructs. Vaccine work needs to be done in collaboration with external researchers, and CIDPC is facilitating a network that brings in some of the best talent in Canada.

Work is also continuing on the development of effective microbicides to prevent the transmission of HIV. Microbicides are chemical or biological compounds that destroy disease-producing microbes, such as HIV. About 60 microbicides are now being tested in Canada and abroad, with 11 in early human trials. While some products offer hope, progress is slow. Some experts believe that a first generation microbicide for vaginal use only could be available in 2007. CAS is the lead Canadian partner for the global microbicide campaign, and has formed a national working group of stakeholders to encourage microbicide research in Canada.

### **Prevention**

On the social science front, a team of researchers in Montréal is investigating the social dimensions of HIV/AIDS prevention in populations that are particularly vulnerable to HIV/AIDS and hepatitis. The team has discovered that even in the most marginalized populations, subgroups of people are taking maximal care to protect themselves. It appears that the way individuals view their place in society has a greater impact on prevention behaviour than does their knowledge of HIV/AIDS and means of transmission or personal/behavioural characteristics such as age, education, prostitution, injection drug use, etc. This information is now being used by public health authorities and community organizations in their work with marginalized groups.

### **Testing Technologies**

Advances are being made in HIV testing technologies. These advances support research and improve our understanding of new HIV strains and issues such as drug resistance.

CIDPC is playing a lead role in this regard. For example, CIDPC has a state-of-the-art flow cytometry laboratory equipped with sophisticated machinery that can analyse blood samples (count CD4 cells) to determine whether people are responding to therapy. Over the past year, Health Canada researchers have been building a smaller, more affordable version of this expensive machinery that can be powered by a car battery. Although this modified machine will not be able to support much of the sophisticated research being done by the Health Canada laboratories, it is proficient at counting CD4 cells and may eventually be a useful diagnostic tool in resource-poor settings and remote Canadian communities.



Health Canada also collaborates on laboratory research with the Polaris Seroconversion Study, a multi-disciplinary five-year study of people in Ontario who have recently been infected with HIV, and the PRIMO cohort study, which is monitoring HIV incidence among a group of 2 000 gay men in Montréal. Using samples from volunteers in these cohorts, CIDPC is conducting molecular epidemiology research and HIV evolution studies to see how the epidemic is changing over time. The results of this work could contribute to the development of better vaccines for each target group. CIDPC is also examining the persistence of HIV drug resistance mutations among study participants to determine how drug resistance testing should be used in patient care and management, as well as to establish better treatment strategies for individuals infected with drug resistant HIV.

### **Surveillance**

In April 2002, CIDPC released new HIV/AIDS surveillance data for the period up to December 31, 2001.<sup>8</sup>

A total of 50 259 positive HIV tests have been reported to CIDPC since HIV testing began in Canada in November 1985. The number of positive HIV test reports declined by 30 per cent between 1995 and 2000 (from 2 988 to 2 119) and then increased slightly in 2001 (2 172). Since the beginning of the epidemic in the early 1980s, 18 026 AIDS cases have been reported to CIDPC. The annual number of AIDS diagnoses, after adjusting for reporting delays, reached a peak in the mid-1990s and has declined since that time, due in large part to the use of highly effective antiretroviral therapies. However, the overall rate of decline in reported AIDS cases has slowed in recent years, which may be attributable in part to the development of resistance to antiretroviral treatments.

Several trends in the surveillance data are of note. For example, the number of positive HIV test reports among MSM decreased slightly in 2001 after showing an increase in the previous year. Also in 2001, the gradual downward trend continued in the number and proportion of positive HIV test reports and reported AIDS diagnoses among users of injection drugs. However, these two groups still account for the largest number of positive HIV tests and AIDS case reports. The epidemic appears to be shifting slightly toward exposure categories associated with heterosexual transmission; of particular concern is the rising proportion of women aged 15 to 29 among both positive HIV tests and reported AIDS diagnoses. These trends will be examined in further detail in 2002-2003 as more data become available.

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<sup>8</sup> The data in this report represent only those individuals who have sought testing and/or medical care for HIV/AIDS and have been reported to CIDPC. They do not represent the total number of individuals living with HIV/AIDS in Canada.



CIDPC continues to work with other stakeholders to ensure that the most appropriate mathematical and statistical models are used to interpret data and to provide accurate data projections. This work is taking on renewed importance, as the HIV/AIDS epidemiological models developed 10 years ago are starting to break down (people are living longer than projected due to medical advances). Unfortunately, professional interest in this field is waning. To help address this problem, CIDPC is leading an effort to establish an informal international working group to engage statisticians interested in developing new statistical models and methodologies for infectious disease epidemiology, including HIV/AIDS.

Surveillance data for syphilis, another serious sexually transmitted infection, may also foretell changes in the HIV/AIDS epidemic. Although syphilis was rare in Canada only five years ago, infection rates in 2001 were more than double the 1997 rates.<sup>9</sup> Outbreaks have been noted among commercial sex workers in downtown Vancouver, heterosexuals in Yukon, and MSM in Calgary, Ottawa and Montréal. Syphilis infection increases the risk of being infected with HIV by three to five times (the genital sores caused by syphilis make it easier to transmit and acquire HIV). Thus, efforts to control the rate of syphilis in Canada can also help control the HIV epidemic. CIDPC is working with pharmaceutical manufacturers and others to ensure a reliable supply of benzathine penicillin G, the treatment of choice for infectious syphilis.

### **Challenges and Opportunities**

The research community in Canada and around the world is making headway in the fight against HIV/AIDS. Community-based research provides the opportunity to produce excellent results that will help inform effective responses to the epidemic. Promising vaccines and new treatment options are entering clinical trials with humans. Yet even as we welcome progress in these areas, the emergence of drug-resistant HIV strains is resulting in new gaps in our knowledge and capacity to respond quickly.

Attracting and retaining researchers in the HIV/AIDS field is an ongoing challenge. Several individuals who were interviewed for this report noted that, 20 years after the start of the epidemic in North America, HIV/AIDS may be losing its "appeal" as a research field for some researchers. Some new and experienced researchers seem to be moving on to other areas that may have a higher profile. Recruitment is a particular problem for government, where the hiring process is subject to regulation.

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<sup>9</sup> Data on syphilis infection rates are from CIDPC.





# INCREASING THE USE OF RELIABLE INFORMATION

**H**uge amounts of information about HIV/AIDS have been generated in Canada and around the world, and the volume grows daily. People living with HIV/AIDS, policy makers, health care professionals, front-line workers and others engaged in responding to the epidemic need access to this information, as well as confidence in its reliability.

The need to manage the information base was identified as a priority in last year's World AIDS Day report (*Current Realities: Strengthening the Response*) and was discussed at length at the CSHA direction-setting follow-up meeting in Montréal. To support the development of a broad information strategy, participants in the Montréal meeting proposed that a dynamic process be established that will provide CSHA partners with continuous information to support HIV/AIDS programs and research; enable partners to identify information gaps and emerging issues; and provide a mechanism for setting information priorities. CIDPC, the CIHR and the Canadian HIV/AIDS Clearinghouse, CPHA, are now working with a small group of stakeholders to develop this process. In the meantime, CSHA partners continue to generate, disseminate and encourage the use of reliable information in pursuing the CSHA's goals.

## **Information Technologies – A Valuable Distribution Tool**

CSHA partners are embracing the many ways that information technologies can be used to improve access to and broaden the use of reliable information.

The Canadian HIV/AIDS Clearinghouse, CPHA, continues to develop its online capabilities. The Clearinghouse's entire collection – over 20 000 titles – is now searchable on its website. Documents can be ordered online (a new service introduced in 2001- 2002), and the interface for document searching has been improved. Online ordering has allowed for better access to documents and opened the Clearinghouse's collection to a wider audience in Canada and internationally.

CAAN introduced "LinkUp," a new web-based resource for information about Aboriginal people and HIV/AIDS. The LinkUp site includes an online HIV/AIDS resource library with Aboriginal materials; a discussion forum for sharing ideas and information; and information on CAAN member organizations, including links to their websites. Much of the information that can be accessed through the LinkUp site is not available anywhere else.

Both CAS and CATIE have restructured their respective websites to make them more user-friendly and to expand access to information resources. A new website launched by CTAC has received an increasing number of "hits," not only from Canada but from the United States and Europe as well. Visitors regularly download CTAC's newsletters and papers on such issues as drug pricing and direct-to-consumer drug advertising. The Canadian HIV/AIDS Legal Network's website receives over 500 000 hits per month and more than 1 000 different visitors per day, a number that increases significantly following the release of new reports and papers from the Legal Network.

The CIHR shares information on funded HIV/AIDS research projects through a database on its website. Media articles from across Canada that feature Canadian HIV/AIDS researchers supported by the CIHR are also posted on the website.

In addition to maintaining and expanding its web-based fact sheets and discussion fora, ICAD, with financial support from CIDA, is examining the potential use of information and communication technologies to facilitate and enhance twinning partnerships among ASOs around the world. To this end, ICAD has entered into a partnership with the Victoria-based Communications Initiative to develop a website. The project is guided by a steering committee comprising major Canadian and international players with expertise in information and communications technologies and HIV/AIDS.

CIDPC used knowledge acquired at an international research meeting on sexually transmitted diseases, held in San Francisco, to initiate a "cyber-prevention" project with public health officials and gay organizations in Ottawa. As a result of this cooperative approach, HIV/AIDS prevention messages regularly "pop up" on web-sites that cater to the gay community in Ottawa.

The Canadian HIV/AIDS Clearinghouse, CPHA, took advantage of the growing popularity of CD-ROM technology to increase the availability of reliable information. The Clearinghouse worked with Health Canada and the CSHA's national stakeholders to compile information and produce a CD of Canadian resources for distribution at the XIV International AIDS Conference in Barcelona. This project resulted in an electronic inventory of 380 Canadian documents from government and non-governmental partners.

Listsers (electronic discussion groups) continue to be a popular means of linking people working in the same field and providing widespread access to HIV/AIDS information. In April 2001, the Canadian HIV/AIDS Clearinghouse, CPHA, launched Canada's first HIV prevention listserv. More than 185 subscribers now receive regular updates on the latest prevention information and communicate with each other on relevant HIV issues. Similarly, a listserv maintained by the Canadian HIV/AIDS Legal Network is subscribed to by about 250 organizations and individuals.

### **Information Centres Expand Their Reach**

The Canadian HIV/AIDS Clearinghouse, CPHA, and CATIE are world-recognized resource centres on HIV/AIDS prevention, care, treatment and support issues.

As Canada's largest distributor of HIV/AIDS materials, the Clearinghouse provides an invaluable service to HIV/AIDS organizations, individuals working in the field, and people living with or at risk of HIV/AIDS, in Canada and around the world. In 2001-2002, the Clearinghouse's distribution service responded to more than 15 000 requests and shipped 367 560 items (pamphlets, posters, brochures, videos and manuals). The Clearinghouse also distributed more than 28 000 items produced specifically for AIDS Awareness Week in 2001. As well, more than 146 000 pages were downloaded from the Clearinghouse website, which received 193 823 hits in 2001-2002. The Clearinghouse library added 971 new items, bringing the total to more than 20 000 titles. The library has documents in more than 100 languages.

CATIE provides free, current, confidential and bilingual information on HIV/AIDS treatment and related health care issues to people living with HIV/AIDS and their caregivers. In 2001-2002, CATIE experienced a 62 per cent increase in treatment inquiries compared to the previous year. The CATIE website makes about 10 000 documents available online, including a bilingual thesaurus of HIV/AIDS terms, and receives about 180 000 hits per month. CATIE delivered nearly 2.2 million pages of HIV/AIDS treatment information this year through this vehicle alone. CATIE also offers various publications in hard copy and

maintains a bilingual, toll-free phone service. A survey of users shows a high level of satisfaction with CATIE's services: 93 per cent of respondents were satisfied or very satisfied with CATIE products and services.

The Canadian HIV/AIDS Legal Network is also recognized for its unique collection of materials on HIV/AIDS legal, ethical and human rights issues. These materials are used extensively by researchers. Many of the materials in the Legal Network's resource centre are not available anywhere else in Canada, including more than 500 articles on HIV/AIDS in prisons. To improve awareness of this service, the Legal Network is now enabling the electronic database of its holdings to become searchable via its website, thereby vastly increasing access to its holdings.

Finally, ICAD maintains the most extensive resource centre in Canada on HIV/AIDS and development issues. A database of its holdings is currently being developed for posting on the website. Detailed information on twinning projects, as well as numerous fact sheets, backgrounders, bibliographies and other resources, can also be accessed through the ICAD website.

### **New Information Resources Developed**

As new information becomes available about the HIV/AIDS epidemic in Canada and abroad, partners in the CSHA are striving to produce information products that meet the needs of a wide range of stakeholders, including people living with HIV/AIDS.

In addition to disseminating results through the traditional avenues of peer-reviewed journal articles and scientific conferences, HIV/AIDS researchers used alternate means to increase the use of information they generated. Based on data collected through the CIHR Survey of HIV/AIDS Researchers, it is estimated that Canadian HIV/AIDS researchers published 26 books or book chapters, organized 51 seminars or workshops, participated in 150 media interviews, and made 83 presentations to the non-professional public in 2001-2002.<sup>10</sup>

In keeping with its mandate to provide accessible, understandable treatment information, CATIE produced a series of *Plain and Simple Fact Sheets* to help community health representatives and others discuss complex treatment and related HIV/AIDS issues with their clientele. This project built on a series of culturally sensitive fact sheets produced in conjunction with Pauktuutit, the Inuit Women's Association. CATIE also facilitated the publication of materials in Tamil by the Alliance for South Asian AIDS Prevention and contributed to the development of fact sheets in three Asian languages (Mandarin, Cantonese and Vietnamese) by the Asian Community AIDS Services.

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<sup>10</sup> These estimates are based on the average number of activities among the 58 researchers who responded to the CIHR Survey of HIV/AIDS researchers. The response rate for the survey was 90 per cent.

FNIHB provided funding to Circle of Hope in Quebec to develop 10 HIV/AIDS prevention messages geared toward Aboriginal people. The bilingual messages were compiled on a CD and distributed to selected radio stations, which aired them as public service announcements.

In collaboration with CSC, CAAN produced the "Circles of Knowledge Keepers," an infectious disease peer education and counselling program designed specifically for Aboriginal inmates. The program has been distributed to all CSC institutions. CAAN also produced a fact sheet on non-insured health benefits for Aboriginal people.

To encourage the involvement of Canada's private sector in responding to HIV/AIDS at the international level, IAD produced a CD-ROM entitled *Enhancing Canadian Business Involvement in the Global Response to HIV/AIDS*. This new resource explains why businesses should participate in the global response to HIV/AIDS and provides concrete examples of how they can become engaged.

ICAD continued to publish fact sheets on a wide range of HIV/AIDS and development issues, such as *HIV/AIDS and Policies Affecting Children*; *HIV/AIDS: Mother-to-Child Transmission*; and *Best Practices for Care of AIDS Orphans*.

Also on the international front, ICASO, with funding support from IAD, published *International Guidelines on HIV/AIDS: How are they being used and applied?*, which documents violations of the United Nations Human Rights Commission's "International Guidelines on HIV/AIDS and Human Rights." The goal is to encourage the United Nations and its member states to implement and comply with the guidelines.

### **Information Influences Policies, Programs and Decision Making**

CSHA partners and others around the world are using information to develop better HIV/AIDS policies, programs and responses.

For example, CTAC monitors information from researchers and pharmaceutical companies to identify and keep track of potential new HIV/AIDS treatments. This information is also used by CTAC to encourage companies to hold trials in Canada and to strive for early, unrestricted access to treatment.



ICASO's mandate includes sharing crucial scientific, medical and political information and knowledge among community-based organizations around the world, which in turn helps these organizations build their capacity to respond to the HIV/AIDS epidemic. To this end, ICASO routinely publishes reports and guidelines aimed at community groups operating in resource-poor areas of the world where the epidemic is most severe. All of ICASO's publications are provided in at least three languages (typically English, French and Spanish).

In Canada, ASOs and others are using information provided by the CSHA's Community-Based Research Program to develop their capacity to identify local research needs, implement research projects and use the results to develop effective program responses. One example of this was a one-day symposium entitled "Community-Based Research in Motion: The Practice and the Process," which was hosted by Health Canada in conjunction with CAHR's annual meeting in Winnipeg. More than 50 people attended the symposium.

FNIHB funded the Assembly of First Nations to develop the First Nations Action Plan on HIV/AIDS. The Action Plan was sent to 683 First Nation communities and will be used by chiefs and band councils as the basis for building understanding and awareness of HIV/AIDS.

### **Challenges and Opportunities**

The CSHA direction-setting follow-up meeting in Montréal confirmed that the need to manage information is rising to the top of the agenda for many organizations involved in the response to HIV/AIDS. Partners in the CSHA are increasing both the volume and the variety of information they produce and improving its quality. However, there is a general lack of awareness among CSHA partners and end users alike about what information exists. An infrastructure is needed that facilitates "pushing information out," as opposed to the current approach, which relies on potential users "pulling information in."





# BUILDING CANADA'S CAPACITY TO ADDRESS HIV/AIDS

Given the increasing complexity and scope of the HIV/AIDS epidemic, both domestically and abroad, Canada needs to continually renew and enhance the knowledge, skills and abilities of individuals and organizations working in this field. To this end, the CSHA is investing in a wide range of initiatives to strengthen the capacity of service organizations, the research community, front-line workers and, most importantly, individuals infected with and affected by HIV/AIDS. Peer-led, culturally specific training programs and skills-building workshops, support groups and other innovative approaches are helping people to develop and implement prevention projects and provide care, treatment and support to those at risk of or living with HIV.

## **Building Organizational Capacity**

Hundreds of organizations across Canada are engaged in the response to HIV/AIDS, from small community-based ASOs to organizations with national and international mandates and scope. Health Canada invests \$14.8 million each year to help these organizations achieve their objectives and contribute to the goals of the CSHA.

The AIDS Community Action Program (ACAP) administers the largest portion of this funding, providing \$8 million each year to support the operations and projects of more than 100 community-based organizations across Canada (see map on page 46). This funding is administered through Health Canada's regional and national offices. Organizations funded by ACAP may also receive financial support from other sources, including the private sector and municipal/provincial/territorial governments.

# ACAP Project and Operational Funding, by Community

## Northern Secretariat 1 project, 1 op.

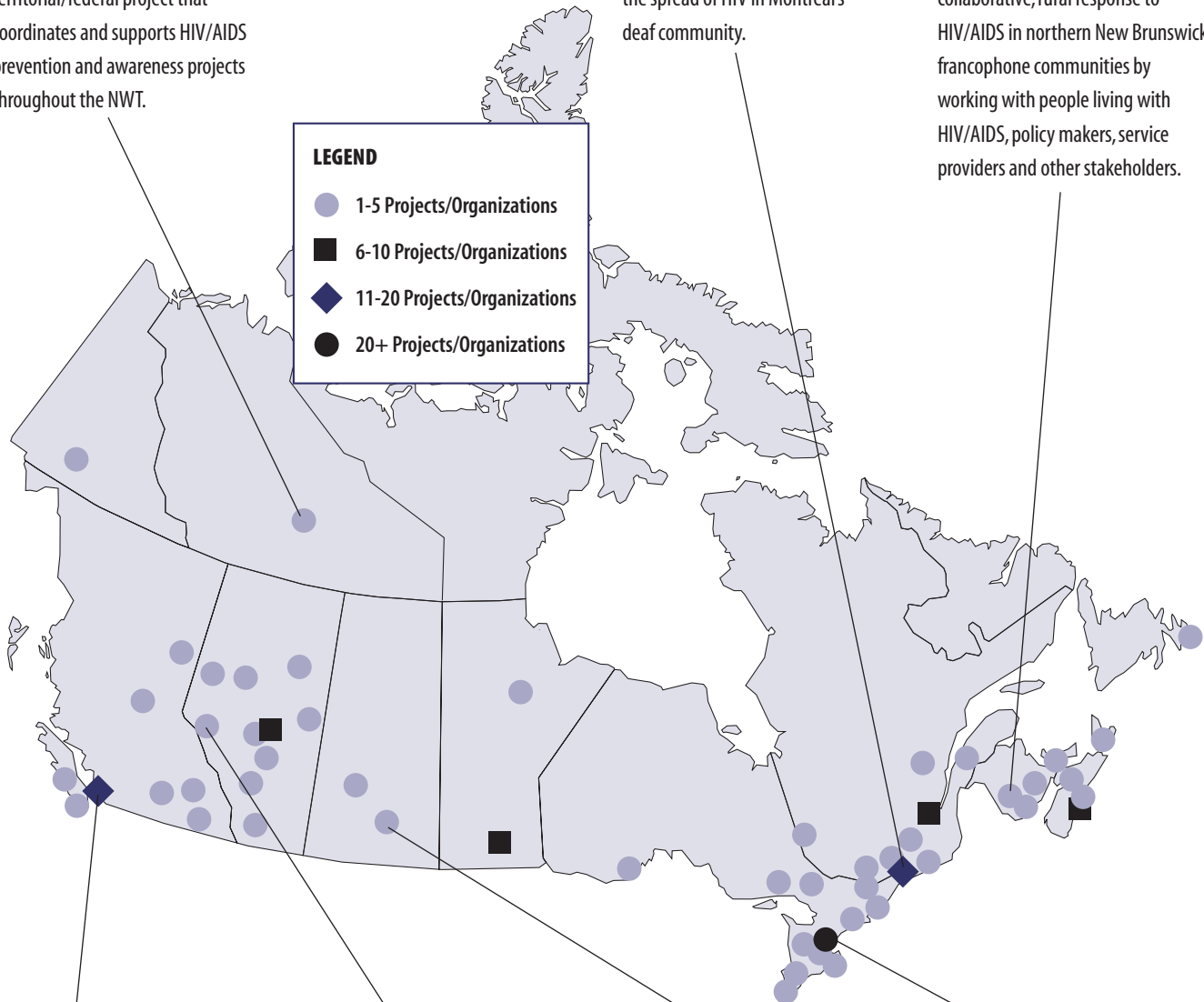
Status of Women Council of the NWT sponsors a joint community/territorial/federal project that coordinates and supports HIV/AIDS prevention and awareness projects throughout the NWT.

## Quebec Region 24 projects, 6 ops.

*La coalition sida des sourds du Québec (CSSQ)* is working to prevent the spread of HIV in Montreal's deaf community.

## Atlantic Region 12 projects, 7 ops.

AIDS New Brunswick/SIDA Nouveau-Brunswick is developing a collaborative, rural response to HIV/AIDS in northern New Brunswick francophone communities by working with people living with HIV/AIDS, policy makers, service providers and other stakeholders.



## BC Region 13 projects, 9 ops.

The PACE Health Network provides sex workers who engage in injection drug use with counselling and education to promote awareness and knowledge relating to HIV/AIDS prevention in Vancouver.

## Alberta Region 17 projects, 7 ops.

AIDS Jasper delivers a peer education program to address high-risk behaviour in transient youth.

## Manitoba/Saskatchewan 6 projects, 3 ops.

All Nations Hope is providing culturally specific services to Aboriginal people living with HIV/AIDS and their caregivers in Regina.

## Ontario Region 13 projects, 22 ops.

The United Caribbean AIDS Network in Toronto is delivering HIV/AIDS education to religious leaders so they can integrate non-judgmental, positive and accurate HIV/AIDS information into their work.

ACAP's approach is to fund initiatives that create supportive environments (access to health care and social services) for people infected with or affected by HIV/AIDS; programs that increase the capacity of people living with HIV/AIDS to manage their condition and to contribute to the response; community-based prevention initiatives that are targeted at populations known to be vulnerable to HIV infection; and activities that strengthen community-based organizations by increasing the skills and abilities of board members, staff and volunteers. To be eligible for funding, projects must also address ACAP's principles, which are as follows:

- A community development approach is critical to the long-term sustainability of any program.
- Health promotion enables people to increase control over, and improve, their health.
- Meaningful partnerships and collaboration help ensure the long-term sustainability of community-based initiatives.
- HIV/AIDS programming needs to work in a broad social context and address the determinants of health (population health approach).
- All organizations that receive ACAP funding are required to develop an evaluation plan to help ensure broad-based learning from community-based initiatives across Canada.

Funding of \$2 million is provided to Health Canada's national NGO partners in the CSHA. This funding ensures that HIV/AIDS issues are addressed in a strategic, multi-sectoral, collaborative way through a strong community infrastructure. Supporting NGOs in the areas of strategic planning, capacity building, local membership development, and creation or enhancement of relationships between national, provincial and local level organizations and governments is essential to a sustained and effective community response. CSHA funding may also be earmarked to subsidize specific staff positions within an organization or for special projects that may be undertaken from time to time.

An additional \$4.8 million from various sources is invested in strengthening the capacity of Aboriginal communities across Canada. Each year, FNIHB invests \$1.1 million of CSHA funding and \$2.5 million of non-CSHA funding to provide HIV/AIDS education, prevention and related health care services to on-reserve First Nations people and Inuit. CIDPC provides \$1.2 million to support HIV/AIDS programming by community-based organizations in non-reserve Aboriginal communities.

Canadian NGOs are also strengthening their ability to engage in the international response to HIV/AIDS. In the spring of 2001, for example, ICAD hosted a series of two-day workshops for NGOs and ASOs on including HIV/AIDS in organizational policies and program planning. In a similar vein, IAD and CIDA co-funded a four-day workshop for 15 ASOs interested in strengthening their capacity to undertake international AIDS work. The course included modules on the results-based management approach, fund raising and cultural sensitivity. IAD also provided funding to the Canadian HIV/AIDS Legal Network, CAS and ICASO to increase their capacity to engage internationally and to develop resources that will help other organizations become involved in the global response.

“Twinning” projects supported by CIDA’s Small Grants Fund also help organizations acquire new skills and expertise. Fourteen new projects received funding of \$75,000 each in 2001-2002, compared to 12 projects that received \$50,000 each the previous fiscal year. Three existing projects were renewed with additional funding of \$25,000 each.

The twinning program, which is co-managed by ICAD and the Canadian Society for International Health, helps organizations implement effective intervention strategies in new locations. For example, Tillicum Haus Native Friendship Centre, a community group that works with Aboriginal youth in Nanaimo, is twinned with an organization in Swaziland to learn how to use puppeteering to bring HIV/AIDS messages to youth. Similarly, the Asian Society for the Intervention of AIDS, which works with Asian communities in British Columbia, collaborated with an agency in the Philippines to develop more effective approaches to targeting Asian sex trade workers in both countries.

### **Professionals Acquire New Skills and Knowledge**

Due to the relatively high rates of HIV infection among inmate populations, nurses employed in correctional facilities are also facing new challenges in the workplace. To help ensure professional, compassionate treatment of people living with HIV/AIDS, CSC has developed palliative care guidelines for correctional settings and will provide training in the implementation of these guidelines. In addition, 50 nurses who work in correctional facilities across Canada attended the annual conference of the Canadian Association of Nurses in AIDS Care, where best practices were shared and new skills learned.

In a project funded by CIDPC, the Association of Canadian Medical Colleges is working with professional dentistry, nursing, psychology and social work organizations to develop options for implementing interdisciplinary HIV/AIDS education. To support this work, pilot projects were initiated in health and social sciences faculties in four Canadian universities. For example, the Memorial University of Newfoundland developed an interdisciplinary teaching model in which a diverse team of health care professionals learned how to work together to provide care for persons living with HIV/AIDS. An evaluation of the project indicated that these educational sessions were extremely beneficial to students.

CATIE's National Reference Library, accessible through its 1-800 line, supports health care professionals, such as doctors in rural or small communities, by providing them with quick responses to treatment information research inquiries when complex challenges present themselves. CATIE's Innovations and JournalScan subscription services provide physicians, nurses and other health professionals with the latest medical abstracts to keep them up to date on recent advances in HIV/AIDS care.

The Canadian HIV/AIDS Legal Network has taken a lead role, both in Canada and internationally, in exploring and raising awareness of the complex and multi-faceted legal, ethical and human rights issues associated with HIV/AIDS. For example, during 2001-2002, the Legal Network launched a summer internship program to increase awareness of HIV/AIDS issues among law students. Two students were selected from among 70 applicants from across Canada to spend the summer working in the Legal Network's offices. The Legal Network also began to organize regional capacity-building workshops on legal, ethical and human rights issues that are of particular importance in different regions of the country. The first two-day workshop was held in Red Deer, Alberta, and focussed on legal, ethical and policy issues related to injection drug use and issues related to HIV/AIDS and hepatitis C in correctional institutions. About 50 people attended the workshop, including representatives of ASOs, needle exchange programs, offender organizations and corrections facilities.

Canada has also supported professional capacity development abroad. For example, a statistician from the Catalonia region in Spain spent a week working with staff from CIDPC in Ottawa and used the knowledge gained to develop a publication on HIV/AIDS surveillance. CIDPC officials are also working closely with the Centers for Disease Control and Prevention in the United States to develop a methodology for confirming the number of HIV infections in that country.

## **Increasing Research Capacity**

Research is a cornerstone of Canada's response to the HIV/AIDS epidemic. Investments in research capacity contribute directly to better prevention efforts, better treatments, an improved quality of life for people living with HIV/AIDS, the development of HIV vaccines and a cure for AIDS.

One of the primary objectives of the CIHR is to build Canada's research capacity through developmental programs such as research personnel awards.

Training awards and training positions paid from grants increase Canada's future capacity for HIV/AIDS research. In 2001-2002, the CIHR supported 16 new HIV/AIDS training awards, for a total of 40 current training awards. As well, an estimated 160 graduate students and 50 post-doctoral fellows received training as HIV/AIDS researchers through support from research grants and other sources. Research grants also supported more than 250 technical assistants who are helping to conduct HIV/AIDS research and generate new knowledge.

Researcher salary awards increase capacity by allowing HIV/AIDS researchers to devote more of their time to research. In 2001-2002, the CIHR supported three new salary awards, bringing the total to 15.

The Canada Research Chairs Program also strengthens Canada's HIV/AIDS research capacity by attracting and retaining excellent researchers in Canadian institutions. The CIHR supported eight HIV/AIDS researchers through this program in 2001-2002.

Under the CSHA, CIDPC awards scholarships of \$18,000 annually to full-time master's and doctoral students who apply a community-based approach to HIV/AIDS research. To date the program has supported four students under the Community-Based Research Program and one under the Aboriginal Community-Based Research Program. Upon completion of their awards, all five students have remained involved with their chosen community.

Another important element of this program is the Summer Training Awards, which are administered by CAAN and provide support to Aboriginal undergraduate arts and sciences students to participate in community-based research. Recipients of the Summer Training Awards work under the supervision of an academic advisor and an Aboriginal ASO. CAAN also administers the National Aboriginal Community-Based Research Capacity-Building Program, a new program designed to develop and enhance the capacity of Aboriginal community organizations and professional researchers to undertake Aboriginal community-based HIV/AIDS research.

The CSHA's Community-Based Research Program provides funding for research technical assistants (RTAs), who play a key role in developing and enhancing research capacity among community organizations. RTAs work with organizations in their geographical area to identify, plan and deliver initiatives that build capacity for community-based research. Health Canada has funded RTAs for three regional HIV/AIDS coalitions – COCQ-sida in Quebec, the Alberta Community Council on HIV, and the Ontario AIDS Network.

During 2001-2002, CSC, in collaboration with Health Canada, used the services of an epidemiologist to strengthen its surveillance programs and provide more detailed reporting of HIV and other sexually transmitted infections. This will help institutions concentrate on priority areas. CIDPC collaborated with CSC to develop CSC's first surveillance report, which will be released in December 2002.

### **Strengthening Individual and Community Capacity**

People living with HIV/AIDS are increasingly conducting their own research on treatment and information issues. CATIE has become an invaluable capacity-building resource for PHAs, as well as their caregivers and AIDS service organizations. During 2001-2002, CATIE delivered 28 workshops at regional and national conferences for people living with HIV/AIDS, professional and non-professional caregivers, and staff and volunteers of community organizations on a range of HIV/AIDS treatment issues and related topics. CATIE staff and volunteers also responded to a total of 3 905 treatment inquiries, a 62 per cent increase over the previous year.

During 2001-2002, CAS and CIDPC completed work on a plain-language resource entitled *A Guide to HIV/AIDS Epidemiological and Surveillance Terms*. The guide, which builds on a similar publication produced by CIDPC and CAAN in the previous fiscal year, aims to make HIV/AIDS epidemiological and surveillance terminology understandable to people who use this information in their work but have no formal training in epidemiology. CAS has also developed tools to help organizations that do prevention work with youth evaluate projects, write proposals and solicit funding from non-governmental sources.

CIDPC also launched a pilot project with CAS to develop a series of HIV/AIDS *Epi Notes*, which are essentially condensed and simplified versions of CIDPC's *HIV/AIDS Epi Updates*. The goal is to make epidemiological information more understandable to the general public and the media. The first two HIV/AIDS *Epi Notes* were distributed at CAHR's annual meeting in Winnipeg in April 2002.

CIDPC provided support for numerous capacity-building initiatives involving Aboriginal people and communities off-reserve. One initiative, for example, was a train-the-trainer project in Ottawa entitled “Spreading a Good Message.” Similarly, the Department’s Community-Based Research Program hosted skills-building workshops on various topics, including women and HIV/AIDS, and an HIV prevention survey for gay men in British Columbia.

On the international front, CIDA provided support to ICAD to operate an internship program to gather information on effective approaches being used in other countries to engage youth on HIV/AIDS issues. Three interns who linked partners in Canada and abroad were supported in 2001-2002. One travelled to Peru to gather information on an innovative project for condom distribution. The other two projects were in South Africa, where one intern gained knowledge about a successful youth outreach program and another participated in the evaluation of an HIV/AIDS youth project.

### **Challenges and Opportunities**

Building capacity to engage in HIV/AIDS efforts, both domestically and globally, remains a fundamental challenge for the entire HIV/AIDS community in Canada. Government departments, NGOs and ASOs involved in the HIV/AIDS response need to find innovative ways to recruit new staff, to retain existing staff and provide opportunities for high-quality training, and to expand their volunteer base as the epidemic takes root in new population groups and intensifies in developing countries around the world.

While these challenges are significant, there are also many promising opportunities to increase capacity through twinning projects, community-based research and other initiatives. Learning from and building on past successful approaches and programs will be key to sustaining Canada’s capacity to respond to the epidemic.





# KEY CANADIAN PARTNERS

## **Canadian Aboriginal AIDS Network**

A national coalition of Aboriginal people and organizations providing leadership, advocacy and support for Aboriginal people living with and/or affected by HIV/AIDS.

E-mail: [info@caan.ca](mailto:info@caan.ca)

Website: [www.caan.ca](http://www.caan.ca)

## **Canadian AIDS Society**

CAS represents a national coalition of more than 115 community-based AIDS organizations directed by people affected by HIV/AIDS. It speaks as a national voice for a community-based response to HIV infection, advocates for persons affected, and acts as a resource for member organizations.

E-mail: [casinfo@cdnaids.ca](mailto:casinfo@cdnaids.ca)

Website: [www.cdnaids.ca](http://www.cdnaids.ca)

## **Canadian AIDS Treatment Information Exchange**

CATIE is Canada's national bilingual source for HIV/AIDS treatment information. It provides information on HIV/AIDS treatments and related health care issues to people living with HIV/AIDS, their care providers and community-based organizations.

E-mail: [info@catie.ca](mailto:info@catie.ca)

Website: [www.catie.ca](http://www.catie.ca)

## **Canadian Association for HIV Research**

CAHR is an association of Canadian HIV researchers. Members' interests include basic sciences, clinical sciences, epidemiology, public health and social sciences.

E-mail: [info@cahr-acrv.ca](mailto:info@cahr-acrv.ca)

Website: [www.cahr-acrv.ca](http://www.cahr-acrv.ca)

### **Canadian Foundation for AIDS Research**

CANFAR is a national charitable foundation created to raise awareness in order to generate funds for research into all aspects of HIV infection and AIDS.

E-mail: [cure@canfar.com](mailto:cure@canfar.com)

Website: [www.canfar.com](http://www.canfar.com)

### **Canadian HIV/AIDS Clearinghouse, Canadian Public Health Association**

The Canadian HIV/AIDS Clearinghouse is the central Canadian source for information on HIV prevention, care and support for health and education professionals, AIDS service organizations, community organizations, resource centres and others with HIV/AIDS information needs.

E-mail: [aidssida@cpha.ca](mailto:aidssida@cpha.ca)

Website: [www.clearinghouse.cpha.ca](http://www.clearinghouse.cpha.ca)

### **Canadian HIV/AIDS Legal Network**

The Legal Network promotes policy and legal responses to HIV/AIDS that respect the human rights of people with HIV/AIDS and those affected by the disease.

E-mail: [info@aidslaw.ca](mailto:info@aidslaw.ca)

Website: [www.aidslaw.ca](http://www.aidslaw.ca)

### **Canadian HIV Trials Network**

The CTN is a partnership committed to developing treatments, vaccines and a cure for HIV disease and AIDS through the conduct of scientifically sound and ethical clinical trials.

E-mail: [ctn@hivnet.ubc.ca](mailto:ctn@hivnet.ubc.ca)

Website: [www.hivnet.ubc.ca/ctn.html](http://www.hivnet.ubc.ca/ctn.html)

### **Canadian Institutes of Health Research**

The CIHR, Canada's major federal funding agency for health research, administers most of the research funds for the Canadian Strategy on HIV/AIDS. The CIHR supports all aspects of health research, including biomedical, clinical science, health systems and services, and the social, cultural and other factors that affect the health of populations.

E-mail: [info@cihr.gc.ca](mailto:info@cihr.gc.ca)

Website: [www.cihr-irsc.gc.ca](http://www.cihr-irsc.gc.ca)

### **Canadian International Development Agency**

CIDA's goal is to support sustainable development in order to reduce poverty and contribute to a more secure, equitable and prosperous world. HIV/AIDS – a key component of programming for CIDA and its many partners since 1987 – is one of the organization's four social development priorities.

E-mail: [info@acdi-cida.gc.ca](mailto:info@acdi-cida.gc.ca)

Website: [www.acdi-cida.gc.ca](http://www.acdi-cida.gc.ca)

### **Canadian Treatment Action Council**

CTAC is a national organization that promotes better access to treatment on behalf of people living with HIV/AIDS. CTAC works with government, the pharmaceutical industry and other stakeholders to develop policy and systemic responses to treatment access issues.

E-Mail: [ctac@ctac.ca](mailto:ctac@ctac.ca)

Website: [www.ctac.ca](http://www.ctac.ca)

### **Correctional Service Canada**

CSC is a federal government department reporting to the Solicitor General of Canada. CSC plays an important national leadership role and contributes to the prevention, care and treatment of HIV/AIDS in the correctional environment.

E-mail: [suttonna@csc-scc.gc.ca](mailto:suttonna@csc-scc.gc.ca)

Website: [www.csc-scc.gc.ca](http://www.csc-scc.gc.ca)

### **Health Canada**

Health Canada is the lead federal department for issues related to HIV/AIDS in Canada. The Department coordinates the Canadian Strategy on HIV/AIDS, which has an annual budget of \$42.2 million. Several responsibility centres within Health Canada contribute to this work, including the Centre for Infectious Disease Prevention and Control, the First Nations and Inuit Health Branch, the Departmental Program Evaluation Division, the Health Canada regional offices, and the International Affairs Directorate. Health Canada also works closely with the provinces and territories through such mechanisms as the Federal/Provincial/Territorial Advisory Committee on AIDS.

Website: [www.hc-sc.gc.ca](http://www.hc-sc.gc.ca)

### **Interagency Coalition on AIDS and Development**

ICAD aims to lessen the impact of HIV/AIDS in resource-poor communities and countries. It is a coalition of Canadian international development organizations, AIDS service organizations, non-governmental organizations and other interested organizations and individuals.

E-mail: [info@icad-cisd.com](mailto:info@icad-cisd.com)

Website: [www.icad-cisd.com](http://www.icad-cisd.com)

### **International Council of AIDS Service Organizations**

ICASO works to strengthen the community-based response to HIV/AIDS, connecting and representing AIDS service organizations in all regions of the world.

E-mail: [icaso@icaso.org](mailto:icaso@icaso.org)

Website: [www.icaso.org](http://www.icaso.org)