

Learning and Sharing > 15 Years of Knowledge Exchange

Réseau canadien d'info-traitements sida



Canadian AIDS Treatment Information Exchange

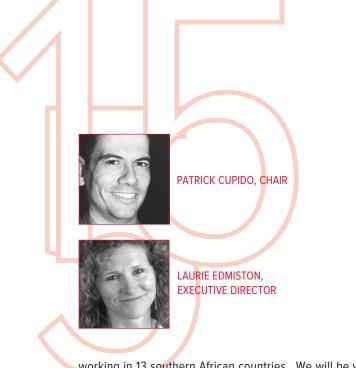
learning and sharing > 15 years of knowledge exchange

Knowledge exchange is the heart and soul of CATIE's work, central to our mission, vision and values. Although enthusiasm for the art and science of what is now called "knowledge exchange" is guite recent, CATIE's practice of learning and sharing has been the essence of our work since our inception over 15 years ago. "Exchange" has been part of CATIE's name since before this idea was fashionable.

CATIE sprang from the activist group AIDS ACTION NOW! Well known for their direct action and their advocacy efforts demanding access to treatments, this collective of activist leaders and visionaries also practiced knowledge exchanges educating themselves and others about the immune system and the viral replication cycle; sharing evidence-based knowledge, research and anecdotal observations gleaned from their own experiences with HIV, opportunistic infections, AZT and complementary therapies; and offering insight into the best ways to effectively navigate the health care system.

This commitment to share knowledge with other people living with HIV (PHAs) spawned the birth of Canada's first treatment information publication, TreatmentUpdate. Conceived as a way to share evidence-based research on treatment options, the goal was to inform and empower people living with HIV as well as the individuals and organizations that supported them. Since TU's first edition was mailed out 17 years ago, each and every one of its subsequent 152 issues have been written by Sean Hosein, one of the original AIDS ACTION NOW! activists and since then, CATIE's Science and Medicine Editor.

We have built upon this tradition of collective learning and sharing (aka knowledge exchange) in many ways over the years, including our recent capacity-building project. Working with seven communities across Canada, we have assisted staff and volunteers from AIDS service organizations (ASOs) and related services to develop community-specific means to integrate treatment information into existing prevention and support services. Innovative activities have been developed from this initiative, such as the impressive peer-led collaborative treatment information wall in the PHA lounge at Positive Living North.



As we are all acutely aware, the AIDS epidemic is harsh in many parts of the world, often worse than our experience here in Canada. CATIE's board and staff feel compelled to contribute to an international response to AIDS through what we do best-knowledge exchange. To that end, in the past year we have worked in partnership with local ethno-specific ASOs to adapt our highly regarded treatment fact sheets, so that they are now available in multiple languages and are being accessed daily all over the world through our Web site. And just recently, in the second half of 2006, we received funding from the Canadian International Development Agency (CIDA) to partner with an ASO working in 13 southern African countries. We will be working with HIV-positive women in Zambia and Tanzania, learning their technique of body mapping and sharing our knowledge of treatment information to better enable HIV-positive women to be informed and feel empowered when negotiating treatment options with their health care providers.

CATIE humbly continues to learn from PHAs and to proudly share treatment information with those who need it most—PHAs in their communities, in Canada and around the world. Knowledge is power. Knowledge exchange therefore, is empowerment. And that is—and always has been—our task.

1988 > AIDS ACTION NOW! is founded in Toronto and publishes a broadsheet for Pride Day on possible treatments.

January 1989 > AAN! publishes the first issue of AIDS UPDATE by Sean Hosein. In subsequent issues the publication becomes bilingual and is renamed TreatmentUpdate/TraitementSida.

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WWW >internet services



ELIZABETH GRABER, PROJECT MANAGER INTERNET SERVICES



LIN AI, MANAGER OF INFORMATION TECHNOLOGY

With the Internet becoming the tool of choice of Canadians looking for information on HIV, CATIE's Web site www.catie.ca has continued to grow rapidly in size and reach. This year, there were over 900,000 visits to our site, which represents a 41% increase over the previous year. This extraordinary growth occurred in all areas as people accessed our full range of services, from downloading an electronic copy of one of our Practical Guide Series to requesting to be added to the e-Bulletin subscriber list.

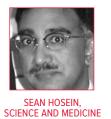
Responding to the ever-changing needs of our users, CATIE's Internet team was busy with a significant Web site redesign, preparing for launch in Summer 2006. The new interface brings a fresh experience to visitors and relevant treatment information is much easier to find. Several new sections provide ready access to specific information needs in a logical, easy-to-follow structure. These include: Living with HIV; Information for Health Care Providers; and Information for Service Providers. The site continues to be highly accessible, with fast download times and easy navigation. Much of the progress attained in this project is thanks to scores of volunteers across Canada who have been guiding us in this redesign.

We have also been working on several new Internet projects. Our holistic healthy positive lifestyle magazine The Positive Side received a new interactive presence with its own site,

www.positiveside.ca. We launched an extensively revised Web site for youth living with HIV, www.livepositive.ca, in partnership with the Toronto Hospital for Sick Children, Positive Youth Outreach and other organizations across Canada serving youth. This site, designed by youth, includes many interactive features such as games, guizzes, posted artwork and a discussion group. Working with the Toronto Ethnoracial Treatment Support Network, we launched a new multilingual Web portal called www.treatHIVglobally.ca at AIDS 2006, which provides treatment information in Chinese, French, Punjabi, Swahili, Tagalog, Tamil, Vietnamese and other languages, as well as a multilingual glossary to facilitate translation and interpretation both domestically and abroad.

This year CATIE completed a national needs and readiness assessment on the use of e-learning tools to build HIV treatment knowledge among PHAs and their communities. As a result, next year we will be embarking on a number of exciting new initiatives, such as Webcasts on key treatment topics, videoconferencing at our newly expanded annual general meeting and, pending funding, the creation of low-literacy multimedia learning modules for PHAs, based on content from Managing Your Health.





EDITOR

TIM ROGERS, DIRECTOR, PUBLICATIONS &

INTERNET

TreatmentUpdate celebrated its 150th issue in Summer 2005. marking 17 years of providing cutting-edge treatment information. CATIE-News continued to provide bite-size news bulletins, from the arrival of LGV in Canada to the continuing challenges faced by HIV-positive substance users.

HIV treatment continues to advance quickly, and CATIE has kept abreast, making revisions to several key publications, including our Practical Guide to HAART and Practical Guide to Side Effects. Spring and summer 2006 saw the creation and launch of a new series of brochures for use in clinics, ASOs, and doctors' offices. The first one is HIV and Hepatitis C Co-infection, with a new and simplified publications order brochure and a pamphlet on Viral Load Testing to follow.

The Positive Side continued to bring a holistic view to living with HIV/AIDS with stories about staying fit, staying sexual, and staying adherent. A special edition for distribution at the AIDS 2006 conference provided a look at international issues and the Canadian experience, including an interview with Stephen Lewis, a retrospective of AIDS treatment activism in Canada, and a profile involving Insite-Vancouver's supervised injection drug site.

June 1989 > AIDS activists seize the stage at the International AIDS Conference in Montreal. AAN! demands that the Federal government establish a national treatment registry.

1990 > AAN! establishes the Treatment Information Exchange, and Health Minister Perrin Beatty announces funding for a national treatment registry as part of the National AIDS Strategy. > The Emergency Drug Release Program opens up to allow access to unapproved treatments for AIDS-related conditions. 5

CATIE's publications, whether in print or online, are reaching out to people looking for solid HIV treatment information. In the past year, we distributed:

> 56,830 printed publications 32,097 bulletins through e-mail over 2.1 million pages through the Web

These numbers do not include the reprinting and dissemination of CATIE's information by our partner organizations. We will continue to work closely with other ASOs to provide publications tailored to their needs.

The Publications team added capacity through the hiring of a new staff writer/editor, providing the needed resources to start updating some of its core publications. A new edition of A Practical Guide to Nutrition is planned for this year. The new edition will cover the basics of healthy eating for PHAs, along with advances in our understanding of how important nutrition has become in managing HIV. And we continue the process of revising our flagship book on living with HIV, Managing Your Health. A new edition is projected for 2007.

services > 1-800 support





DEVAN NAMBIAR,

FDUCATOR

TREATMENT INFORMATION

Of a total of 2,542 treatment information requests CATIE received in 2005/2006, 2,350 of these were for treatment information through our toll-free phone line. While treatment information consumers continue to explore and employ our new electronic access options, overall use of toll-free phone line as a method of accessing confidential, accurate HIV treatment information is nonetheless up by 24%.



ΓΡΙΓΙΔ SMITH PROJECT MANAGER, TREATMENT INFORMATION

Our call-tracking database allows CATIE to compile information about incoming treatment information calls. An analysis of this database shows that we are reaching out broadly across Canada, supporting a diversity of PHAs and their care providers. We are accessible to women who make up approximately 32% of our requests for treatment information, to Francophones who make up approximately 19% of treatment information requests, and to Canadians living with HIV, who represent more than 40% of our callers.

In January 2006, CATIE welcomed Tricia Smith as Project Manager, Treatment Information. Tricia has begun a comprehensive evaluation of CATIE's 1-800 treatment information phone line with the aim of helping us better understand the role of our phone service in a world of rapidly changing information technology.

CATIE continues to respond enthusiastically to requests for HIV treatment-related workshops on a wide variety of topics. Treatment Information Educators Devan Nambiar, Michael Bailey, Bruno Lemay, Susan Massarella and Annika Ollner presented a total of 79 workshops in 2005/2006 to 3,619 diverse participants across the country.

We presented workshops on topics as varied as pain management and kidney health to a diversity of audiences: PHAs in Gatineau, Quebec; social service workers in Campbell River, BC; health care providers in Igaluit, Nunavut; people co-infected with HIV and hepatitis C, prisoners, pharmacists, social workers and researchers—to cite a sampling. We also participated in numerous forums and exhibits, on panels, in consultations and in meetings. We continue to revise our workshops so that they are current, interactive, and cover the topics in which our clients are most interested. We have also improved our Workshop Request Form on the CATIE Web site, so that those interested can browse a complete annotated list of our workshops and submit their requests online.

Participants consistently rate CATIE workshops very highly. Evaluations tell us that:

- 94% of attendees felt more empowered as a result of a CATIE workshop to make decisions about managing their health;
- 95% were satisfied or very satisfied with our workshops;
- 98% would recommend our workshops to colleagues or friends.



PROGRAM ASSISTANT

SUSAN MASSARELLA

INFORMATION SPECIALIST

Through our toll-free 1-800 line and increasingly by e-mail, our library staff and volunteers help PHAs and their health care providers find the treatment resources they need, responding to over 250 individualized requests for treatment information research in the past year.

In order to ensure that both CATIE staff and service users have access to the most comprehensive and current resources, we added over 1,500 articles to the library's treatment information databank, and the subject headings on the Web documents page were updated to reflect current treatment practices, making it easier for individuals to find the information they need. Among the new HIV treatment-related resources added to our National Reference Library were 80 books, 912 articles and 85 Web resources (including 17 in French). The entire library catalogue is available at www.catie.ca/e/library/index.html and items from it are available upon request.

Supporting our mandate to empower PHAs through the provision of treatment information, we assisted CATIE service users to strengthen their Internet research skills by offering our popular workshop, "An Introduction to Researching Your Own HIV/AIDS Treatment Information," in a number of venues across the country.

1991 > The Canadian HIV Trials Network establishes a Community Advisory Committee to vet all its trials. > AAN!'s Treatment Information Exchange project becomes an independent organization, the Community AIDS Treatment Information Exchange (CATIE).

1993 > CATIE publishes the first edition of Managing Your Health. 1995 > After years of false starts, the national treatment registry project is taken over by CATIE, assuming a national role. 1996 > CATIE begins full-time phone service and launches its Web site. > The International AIDS Conference is held in Vancouver.

services > library

6

Drawing on the expertise of our Information Specialist, Susan Massarella, we are in the process of developing this workshop into an e-learning module in order to increase its accessibility.

CATIE's Library-in-a-Box program, which assisted organizations in enhancing their capacity to provide HIV treatment information, evolved in the past year into the Library-without-Borders project, and was presented at the Canadian Association for HIV Research (CAHR) conference in May 2006. Evaluation of the Library-in-a-Box project revealed a need for CATIE training to build the capacity of participants to research their own resources, and for CATIE's assistance in creating bibliographies on treatment topics. An interesting result of the Library-without-Borders project has been a request for CATIE's Information Specialist to visit two participating ASOs to work with staff to organize and assess their resource collections.

The Treatment Information Materials and Services Inventory (TIMSI) project identified a broad range of HIV treatment resources that people were using across Canada. The resulting database gives a good overview of what resources organizations knew about-and of which resources people were not aware. TIMSI also identified some "hidden gems" in

services > library



DARIEN TAYLOR.

DIRECTOR, TREATMENT

INFORMATION

NIKA OLLNER

BILINGUAL TREATMENT

INFORMATION EDUCATOR

HIV treatment information, which CATIE was then able to highlight in The Positive Side.

An evaluation of existing library services was conducted this year in order for us to best determine how to ensure that the CATIE library continues to meet the needs of its users. The evaluation is helping in the evolution of the library from a closed print collection to an electronic collection accessible beyond the physical location of CATIE's National Reference Library on HIV/AIDS Treatment Information.

The CONNECT project which united the collections of five HIV libraries across the country (the AIDS Committee of Toronto, AIDS Vancouver, the Canadian HIV/AIDS Information Centre, the Canadian HIV/AIDS Legal Network and CATIE) is well underway. The participating libraries and their librarians collaborated to create a unified database that will serve as the basis for a bilingual Web-based catalogue of their individual HIV/AIDS collections. The union catalogue is the first step to better coordination among the five libraries for purchasing, processing and marketing of resources.

network > t.i.n.

The Treatment Information Network (TIN) is a group of approximately 30 agencies which provide HIV treatment information as part of their service delivery model. In the past year, with CATIE's support, TIN was able to hold a face-to-face in conjunction with our June 2005 AGM. At this meeting, consultant Derek Thaczuk presented the work that he had undertaken (under the direction of TIN) on a national Treatment Information Materials and Services Inventory, which compiled a database of HIV treatment publications and services available across the country. This database was made available on CD-ROM to all TIN members.

In November 2005, with funding secured from the Canadian Institutes for Health Research (CIHR), CATIE held a very productive two-day satellite meeting preceding a Canadian AIDS Society's Skills-Building Symposium, called "Getting In At The Ground Level: Building a National Treatment Information Training Program." TIN members, as well as site representatives from our capacity-building project and others, engaged in action research with community-based researcher San Patten toward the development of a funding proposal to create a national HIV peer-treatment training program.



November 27–30.



MATTHEW CHURCH

DIRECTOR, MARKETING & COMMUNICATIONS

ACOBO RODRIGUEZ

MARKETING & PUBLICA TIONS ASSISTANT

Throughout 2005/2006, we have been working collaboratively Through increased interdepartmental coordination, CATIE with a number of regional, national and international organizations raised our attendance at national and regional conferences to plan conferences. These include: the **Ontario HIV Treatment** where we have been able to disseminate our wide variety of letwork's (OHTN) annual research conference, November CATIE publications, increase CATIE membership, sign people 24–25; "HIV Treatment Access Issues for Women," a treatment up for electronic subscriptions and improve service users' forum which preceded the annual Canadian Association of HIV understanding of the broad range of resources and services Research (CAHR) conference, May 25–28, which we co-sponthat we offer. sored with the Positive Women's Network in Vancouver, and which included participants from local organizations such as YouthCo, the Vancouver Native Health Society and the Oak Tree Clinic; Voices of Positive Women's provincial Dialogue Conference, May 27–29, which saw over 60 diverse HIV positive women and their health care providers come together to discuss HIV treatment and other aspects of living with HIV; and the North American Treatment Action Forum (NATAF) conference, in which CATIE participated, in Oaxaca, Mexico,

1999 > Renamed the Canadian AIDS Treatment Information Exchange, CATIE becomes a partner in the National AIDS Strategy. > CATIE's Web site surpasses the one-million-hit threshold and continues to grow.

2001 > Launch of Plain & Simple Fact Sheets. 2002 > Introduction of The Practical Guide to HAART. 2003 > Creation of The Practical Guide to HIV Drug Side Effects and pre*fix: Harm Reduction for + Users.





BARRY PLANT

DIRECTOR OF OPERATIONS

AND RESOURCES

CATIE has just completed an 18-month capacity-building project funded through the Public Health Agency of Canada's capacity-building stream with seven ASOs across Canada: Positive Living North in Prince George, British Columbia; HIV Edmonton in Alberta; AIDS Program South Saskatchewan in Regina; Bruce House in Ottawa, Ontario:



MICHAEL BAILEY. BILINGUAL TREATMENT INFORMATION EDUCATOR

MIELS-Quebec in Quebec City; the AIDS Coalition of Nova Scotia in Halifax; and in Iqualuit, Nunavut, the Pauktuutit Inuit Women's Association. The project successfully increased each organization's capacity to integrate the provision of HIV treatment information into its existing continuum of programs and services. A comprehensive process at each site evaluated the organization, its community network and individual stakeholders to assess HIV treatment information capacity. CATIE then worked with each organization to develop a series of workshops targeted to specific community HIV treatment issues. The capacity-building project has allowed CATIE to strengthen partnerships and will serve as a model for communities and their HIV treatment information needs.

network > governance > board of directors

Aboriginal At Large Ken Clement Atlantic Region Atlantic Region National At Large National At Large National At Large National At Large Ontario Region Ontario Region **Ontario Region** Pacific Region



Barb Gibson Dr. Bill Bradley **Bill Downer** Michael Davenport (Secretary) Patrick Cupido (Chair) Peter Coleridae Kevin Hatt Kim Johnson (resigned February 2006) Rob MacKay Daryle Roberts Ed Steele

> Laurette Lévy Terry Pigeon (Vice-Chair) Maggie McGinn (Treasurer) Peetanacoot Nenakawekapo



VAUGHN FITZPATRICK, OUTSTANDING VOLUNTEER 2006



DAVID ONTONOVICH, NATIONAL COORDINATOR VOLUNTEER RESOURCES Abbott Laboratories Ltd. Gilead Sciences Inc.

silver (\$5,000 - \$19,000)

caring > donors

Boehringer Ingelheim Ltd.

Bristol-Myers Squibb Co.

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Ontario HIV Treatment Network

In addition to the above, we had many friends and supporters who generously donated money, products or their services, including the following gifts in kind: Anemia Institute for Research and Education Warren Shepell Consultants Corporation Vandelay Enterprises

government funding

Public Health Agency of Canada Ontario Ministry of Health and Long-Term Care, AIDS Bureau Ontario Ministry of Citizenship and Immigration Human Resources and Skills Development Canada

Spring 2006 > CATIE creates the Learning Institute, an innovative e-learning initiative to enable participants to maximize their time at the XVI International AIDS Conference in Toronto in August 2006.



caring > volunteers

CATIE's work is furthered by the extraordinary support it receives from its volunteers: people from all age groups, backgrounds and sectors across Canada deeply committed to lending their expertise, energy and time. These individuals, groups and businesses are committed to one shared goal that people with HIV/AIDS have access to more treatment options and live healthier lives. Our role in Volunteer Resources is to develop meaningful assignments that engage our current volunteer market and that support CATIE's vision, mission and strategic directions. Whether on-site or "virtual," volunteers play a vital role at CATIE, answering treatment calls, translating, taking part in usability and accessibility testing, conducting research on the Web, attending clinical rounds and being part of CATIE's governance. Our task would be much more difficult-in some cases, impossible—without them.

From all of us at CATIE then, our gratitude and thanks. And for those interested in getting involved or for more information on CATIE's national volunteer program and internship opportunities, please visit www.catie.ca.

Outstanding Volunteer Award 2006

This award was created to celebrate the spirit and energy of volunteerism at CATIE, enabling us to acknowledge each year the efforts of one outstanding volunteer for his or her contributions. All of us at CATIE are pleased to present the 2006 Outstanding Volunteer Award to Vaughn Fitzpatrick of Toronto.

GlaxoSmithKline in partnership with Shire BioChem

caring > partners

At CATIE, partnerships come in various forms. They range in scope from formal working agreements to collaborations on local or regional projects and initiatives. In 2005/2006, we were honored to collaborate on various projects with these and other community partners:

XVI International AIDS Conference ACCESS AIDS Network – Sudbury AEGIS – AIDS Education Global Information System Africans in Partnership Against HIV/AIDS (APAA) AGRO Health Associates AIDS Bereavement Project of Ontario AIDS Coalition of Cape Breton AIDS Coalition of Newfoundland & Labrador AIDS Coalition of Nova Scotia AIDS Committee of Durham AIDS Committee of Guelph & Wellington County AIDS Committee of Ottawa AIDS Committee of Simcoe AIDS Committee of Thunder Bay AIDS Committee of Toronto AIDS Committee of Waterloo & Kitchener AIDS Community Care Montreal AIDS Niagara AIDS/sida New Brunswick AIDS Prince Edward Island AIDS Programs of South Saskatchewan AIDS Saskatoon AIDS Vancouver AIDS Vancouver Island Alberta Community Council on HIV/AIDS Alberta Positive Voices All Nations Hope AIDS Network Alliance for South Asian AIDS Prevention (ASAAP) Anemia Institute of Canada Asian Community AIDS Services (ACAS) Asian Society for the Intervention of AIDS Aspect International Language School Association of Volunteer Administration Association of Translators and Interpreters BC Aboriginal HIV/AIDS Society BC Persons with AIDS Society (BCPWA) Best Medicines Coalition Black-CAP – Black Coalition for AIDS Prevention Blueprint for Action on Women and HIV/AIDS in Canada Coalition British Columbia Children's Hospital Bruce House

Bureau local d'intervention sur la transmission du sida (BLITS) Bureau regional d'action-sida (BRAS) Canada World Youth Canadian Aboriginal AIDS Network (CAAN) Canadian AIDS Society (CAS) Canadian Association of HIV Clinical Laboratory Specialists Canadian Association for HIV Research Canadian Association of Hospital Pharmacists Canadian Association of Nurses in AIDS Care (CANAC) Canadian Administrators of Volunteer Resources Canadian Bar Association – Volunteer Lawyer Service Canadian College of Business & Computers Canadian College of Naturopathic Medicine Canadian Foundation for AIDS Research (CANFAR) Canadian Harm Reduction Network Canadian Health Libraries Association Canadian Health Network Canadian Hemophilia Society Canadian Hepatitis C Network Canadian HIV/AIDS Information Centre Canadian HIV/AIDS Legal Network Canadian HIV Trials Network (CTN) Canadian HIV Vaccines Plan Steering Committee Canadian Hospice and Palliative Care Association Canadian Liver Foundation Canadian Self-Care Tax Reform Coalition Canadian Treatment Action Council (CTAC) Canadian Pharmacists Association Canadian Volunteerism Initiative Casey House Centennial College Central Alberta AIDS Network Centres d'Accueil Héritage Centre des ressources et d'interventions en santé et sexualité (CRISS) Centre for Spanish Speaking People Children's Hospital of Eastern Ontario (CHEO) Coalition des organismes communautaires québécois de lutte contre le sida (COCQ-sida) Code of Good Practice for Non-Governmental Organizations responding to HIV/AIDS Comité des personnes atteintes du VIH (CPAVIH) Comité LIPO-ACTION Conception Bay North AIDS Interest Group Consumer Advocare Network Correctional Services Canada Dignitas International DOCH Program, Faculty of Medicine, University of Toronto Dr. Peter Centre Faculty of Information Studies, University of Toronto Fife House



Georgian College International Internship Program **Global Treatment Action Group** Hamilton AIDS Network - Opening Doors Central West Hepatitis C Society of Canada Heyden Park Secondary School, Toronto HIV Network of Edmonton Society Hospital for Sick Children Humber College Idealist.org (Action Without Borders) IKIT – Institute for Knowledge Innovation and Technology Jeunes adultes seropositifs ensemble Kids Help Phone/Parent Help Line Language Studies Canada Les enfants de Béthanie Living Positive Living Positive Resource Centre Okanagan Maple Leaf Clinic MIELS-Québec National Health Products Directorate Natural Health Products Research Society of Canada Nine Circles Community Health Centre Ontario AIDS Network Ontario HIV/AIDS Treatment Network (OHTN) Ontario Hospital Association Ontario Organizational Development Program Pacific AIDS Network Pauktuutit Inuit Women's Association Peel HIV Network Peterborough AIDS Resource Network Pharmasave Ontario Planned Parenthood Toronto Portugese Speaking HIV Service Providers Network (VIVER) Positive Living North Positive Women's Network Positive Youth Outreach Prisoners with AIDS Support and Action Network (PASAN) Professional Administration of Volunteer Resources Red Roads HIV/AIDS Network Society Regent Park Community Health Centre Ryerson University Salvation Army – Community Service Order Program Seneca College SIDA-AIDS Moncton Somerset West Community Health Centre St. Boniface Hospital St. Clare's Mercy Hospital Streamlogics Two-Spirited People of the First Nations TeenNet at the University of Toronto Department of Public Health Sciences Teresa Group





