

The OHTN **ex**CHANGE

Autumn 2005
Volume 1, Issue 1

A newsletter for consumers, providers, researchers & policymakers

OHTN Research Conference 2005

Whether you are a person living with HIV/AIDS (PHA), an AIDS service organization (ASO) provider, a researcher or health care professional—anyone with an interest in HIV/AIDS research, care and treatment should plan on attending this unique event hosted by the Ontario HIV Treatment Network.

Program Highlights

Learn from the experts.

Researchers will share their findings on leading-edge topics in Oral and Poster Presentations.

Stay with the tour.

Knowledgeable experts will provide guided tours of thematically organized Poster Presentations.

Talk amongst yourselves.

Join one of our lunchtime round-table discussion groups (on Friday, November 25) to meet and network with others. Discuss compelling issues such as HIV and crystal meth, complementary/alternative therapies, women living with HIV, and access to social benefits. A complete list of topics is available on the conference website.

Join the party.

Our annual conference reception promises to be the best yet, with superb food and drink. Plus, the networking opportunities don't get much better.

Make a bid.

At the reception, choose from many great items at the silent auction and support the Positive Action Fund, which provides emergency financial assistance to PHAs in Ontario.

Featured Keynote Speaker: Jon D. Kaiser, MD, author of *Healing HIV: How to Rebuild Your Immune System*, on **Micronutrient Therapy as Part of a Comprehensive Treatment Program for HIV**. Dr. Kaiser has been treating patients with HIV and other immune system disorders for the past 15 years. He is a Clinical Instructor at the University of California, San Francisco Medical School. His interests include nutrition, vitamin therapy, hormone balancing and stress reduction.

Susan King Lecture: This annual lecture—bestowed in recognition of the achievements of Dr. Susan King, well known in the HIV research community for her research in paediatric AIDS—will be presented by **Steffanie Strathdee, PhD**. Dr. Strathdee's lecture is entitled **Inspiring Stories: Women at the Forefront of HIV/AIDS Research in Canada**.

The OHTN
Research Conference
2005

A Network of Knowledge

November 24-25, 2005

The Hilton Toronto

145 Richmond Street West

An alumnus of the University of Toronto, Dr. Strathdee holds faculty positions at The Johns Hopkins School of Public Health in Baltimore and the School of Medicine at the University of California, San Diego, Department of Family and Preventive Medicine.

Register and view the full program online at www.ohtn.on.ca or call 416.642.6486 for more information.

Financial Assistance for travel and accommodation is available for those who require it—check the conference website for details.

Message from the Scientific and Executive Director



Welcome to the first issue of *exCHANGE*, the OHTN newsletter for HIV community members, health care providers, researchers and policymakers. Along with our research conference, website, articles and papers, this newsletter is part of the OHTN's new *knowledge transfer and exchange* strategy. The newsletter's name captures our intent: By exchanging and sharing information with our stakeholders, we can help develop new knowledge that will change policy and practice—and improve life for people with HIV.

Since its inception in 1997, the OHTN has been dedicated to funding and encouraging AIDS research. However, we have not been as effective as we could be in sharing research findings and helping our partners use those findings to shape and influence policy and practice. That is something we intend to change. It's not enough just to generate knowledge; we must get that knowledge into the hands of people who can put it into action. Future issues of *exCHANGE* will highlight our research findings and other projects

and describe how research-based knowledge can be used by people with HIV, by community-based organizations, by providers, by researchers and by government to enhance their work.

“Never doubt that a small group of thoughtful, committed people can change the world. Indeed, it is the only thing that ever has.”

The OHTN is committed to an ongoing active exchange of knowledge and ideas. We will continue to build our network, bringing our partners and stakeholders together to identify the issues facing people with HIV and those at risk as well as strategies to enhance their lives. By listening to all of our stakeholders and learning from their experience, we will find better ways to use our strengths and resources—our research funding, our expertise in technology and systems, our databases, our network—to anticipate and respond to emerging trends and needs. It is these stakeholders that will drive our work.

Pioneering anthropologist Margaret Mead once said: “Never doubt that a small group of thoughtful, committed people can change the world. Indeed, it is the only thing that ever has.” By continually exchanging ideas and information—by working more closely together—we believe we *can* change our world.

A handwritten signature in black ink, appearing to read 'Sean B. Rourke'.

SEAN B. ROURKE, PhD
Scientific and Executive Director
Associate Professor of Psychiatry, University of Toronto
Adjunct Professor of Psychology, University of Windsor


New Thinking, New Directions: It's All Part of the Plan

Over the past year, there's been a shift in direction at the OHTN.

"The OHTN had been in operation for about seven years, and it was time to take a critical look at what we were doing," explains Bill Flanagan, President of the Board of Directors. "We had made a lot of progress, but the world was shifting around us. We had been focusing all our efforts on one way to gather clinical data and one type of clinical management system, but the technology was changing, the environment was changing and the needs of our stakeholders were changing. What we were doing was expensive, and it wasn't having enough impact, so we needed to rethink our approach."

The OHTN's new thinking and new directions are set out in its Strategic Plan to 2010. The new directions focus less on developing software and more on working with stakeholders—people with HIV, community-based agencies, clinicians, researchers and policymakers—to find, gather and share information and to advance HIV policy and practice in Ontario.

Flanagan is confident that the OHTN's new directions will lead to very tangible, practical results. "As a result of what we're doing now, Ontario soon will have more doctors providing care for people with HIV, better networking among health care providers, better and more flexible tools to improve the quality and consistency of HIV care across the province, better data that is easier for researchers to access and use, more research and—when we start to apply that research knowledge—better quality of life for people with HIV."

"The OHTN is part of a larger network of HIV programs and services in Ontario and in Canada," added Sean Rourke, Scientific and Executive Director. "When we were developing our plan, we looked at both the Ontario and the pan-Canadian strategies to see how we could use our skills and resources to achieve common goals. The emphasis on the broader determinants of health and social justice issues in those strategies gives us the opportunity to be bolder and more innovative. For example, we are now building strong community/academic/policy partnerships to address issues such as housing and mental health for people with HIV. We're going to continue to try to bring people together to solve some very difficult problems faced by people with HIV. At the OHTN, we believe that together we are stronger and we can make a difference." 

The 7 Objectives of the OHTN Strategic Plan

1. To increase the number and capacity of health care providers caring for people with HIV.
2. To support efforts to provide integrated care, treatment, support and prevention services that address all the determinants of health.
3. To strategically invest in high-quality research that has a direct impact on HIV care, treatment, support, policy and prevention in Ontario.
4. To support effective and innovative health information technologies.
5. To support and collect data on a sufficiently large and clinically meaningful cohort of people with HIV in Ontario that will lead to research results that will improve HIV policies and care.
6. To support knowledge transfer and exchange expertise to consolidate and synthesize HIV research findings that will lead to improved HIV care, treatment and prevention policies and practice.
7. To monitor and evaluate the activities of the OHTN and to communicate these results to all of our stakeholders.

The 4 Goals of the OHTN Strategic Plan

1. To improve the health and well being of people with HIV in Ontario.
2. To contribute to HIV prevention efforts in Ontario.
3. To promote knowledge transfer and exchange among all HIV stakeholders.
4. To ensure value for resources.

Progress Report

- ✓ More than 20 HIV physicians have implemented Clinical Management Systems to improve care.
- ✓ The launch of a Housing and Health initiative exploring the impact of stable housing on health and quality of life for PHAs.
- ✓ PHAs, community agencies, researchers and policymakers participate in Think Tank on HIV, Mental Health and Addiction to improve policy and practice.

Meet the Chairs

New committees at the OHTN

In the spring of 2005, in tandem with the evolution of the OHTN Strategic Plan to 2010, the OHTN created four new Committees. Taken together, these groups are intended to provide advice in their respective areas of expertise to the OHTN Board of Directors, paying particular attention to the implementation of the Strategic Plan and the achievement of its seven objectives.

Research Network Advisory Committee

Chair: Dr. John Lavis



We can't always predict what type of research will yield the greatest improvements in quality of life for people with HIV or the greatest impacts in preventing new infections. But in a research landscape where many funding agencies support discovery-oriented research, I am delighted to support the OHTN's efforts to become more strategic in its approach to its research investments. Our committee's role is to assist the OHTN by providing advice and broad perspective to the OHTN Board of Directors on the prioritization and support of high-quality, locally applicable research—research that truly makes a difference in HIV prevention, care and support. This will mean striving for a balance in the types of research and capacity enhancements that the OHTN supports and making sure that this balancing act responds dynamically to current and emerging needs. In addition, this committee will provide advice regarding ways to ensure that OHTN research dollars are having an impact.

The Research Network Advisory Committee is made up of researchers from all research disciplinary areas (basic science, clinical science, epidemiology, socio-behavioural science and community-based research) as well as community members.

Dr. John Lavis is the Canada Research Chair in Knowledge Transfer and Uptake, Associate Professor in the Department of Clinical Epidemiology and Biostatistics, Member of the Centre for Health Economics and Policy Analysis, and Associate Member of the Department of Political Science at McMaster University. He currently chairs the Board of Directors at the AIDS Committee of Toronto.

Community Network Advisory Committee

Co-Chairs: Ron Rosenes, Ruthann Tucker



We are very excited to have an opportunity to make a meaningful contribution that we believe will improve health outcomes and quality of life for people with HIV in Ontario. We have assembled a group that brings together a wealth of community and research experience to determine what is needed to create a fertile environment that will ultimately lead to better services and supports in our communities. Our committee will look for innovative models that bring researchers and community agencies together in the quest for persuasive data that will lead to better public policy.

This committee will advise the OHTN on issues related to people who are disproportionately affected by HIV: women at risk, ethno-racial men who have sex with men, and people from the Aboriginal, African and Caribbean communities. The committee will draw on its network of individuals and organizations to identify the issues that matter to people with HIV, seek ways to build research literacy within our communities and use that strength to turn research into meaningful improvements in life and health.

The Community Network Advisory Committee is made up of a variety of people working in research, advocacy, housing and ASOs. Several members are self-disclosed as living with HIV. New members will be sought on an ongoing basis.

Ron Rosenes is Vice-Chair of the Canadian Treatment Action Council (CTAC) and Board Secretary of AIDS2006 Toronto Local Host. He has long been interested in building community research connections.

Ruthann Tucker is the Executive Director of Fife House in Toronto, which provides secure and affordable housing and support services to people living with HIV/AIDS. Ruthann has worked in the community-based HIV/AIDS movement for more than 16 years.

The 4 New Committees:

1. Research Network Advisory Committee
2. Community Network Advisory Committee
3. Health Care Provider Network Advisory Committee
4. OHTN Cohort Study Governance Committee

Health Care Provider Network Advisory Committee

Chair: Dr. Brian Cornelson



The OHTN works to promote the well being of people living with HIV, and one of the best ways to do this is to promote excellence in care by their health care providers. Hence the recent establishment of the Health Care Provider Network Advisory Committee, whose purpose is to promote and support the health care providers who provide care to people with HIV.

HIV has become a complex, chronic health care challenge, and the needs of people with HIV can no longer (if ever!) be met by physicians alone. The many challenges faced by people with HIV are optimally managed by an interdisciplinary approach which can include physicians, nurses, pharmacists, social workers and dietitians—to mention only a few. This committee was formed with representatives of HIV-treating physicians, nurses, pharmacists and social workers as well as people living with HIV. The challenges it will address include

encouraging students in the health care professions to consider a career that includes care for people with HIV; supporting those already providing care through measures such as continuing education, accreditation and practice aids (for example, guidelines and electronic medical record systems); and advocating for the needs of health care providers and their patients. The committee's first initiative will be the establishment of the Ontario Society of Physicians in HIV Care. Work is already underway to make this a reality.

Dr. Brian Cornelson has been an HIV primary care physician for 13 years and works in a multidisciplinary family practice teaching clinic that is part of St. Michael's Hospital and affiliated with the University of Toronto. This past summer he worked in an AIDS clinic in Lesotho in southern Africa.

OHTN Cohort Study Governance Committee

Chair: Darien Taylor



I am thrilled to be the Chair of the OHTN Cohort Study Governance Committee. It is a perfect fit for me. This committee is charged with the governance of the third generation of HOOD (HIV Ontario Observational Database), a research project that brings together people living with HIV, researchers and care providers to find answers to important questions about HIV care and treatment. For me it represents the essence of the OHTN—all the stakeholders working together to improve the quality of life for people with HIV. We have a lot of work to do to transform the original HOOD and HIIP (HIV Information Infrastructure Project) research programs into a single OHTN Cohort Study, to reinvigorate the research community and ensure that data is accessible to answer diverse research questions, to review research protocols and to make sure that the research findings have an impact on HIV policies and clinical practice. In addition, we have an exciting opportunity to develop and make

available software tools that will help people with HIV manage their own health.

We have a brilliant group around the table, a blend of those with HOOD and HIIP experiences as well as several newcomers with a fresh perspective. The OHTN Cohort Study Governance Committee is the only OHTN Committee with 50%-plus-one PHA membership.

I am firmly committed to guiding the OHTN Cohort Study to new achievements and to ensuring that it continues to make significant and unique contributions to our knowledge of HIV care and treatment. 🍌

Darien Taylor is the Director of Treatment Information at the Canadian AIDS Treatment Information Exchange (CATIE). She has been living with HIV for more than 15 years and has worked in the field of HIV/AIDS for most of that time, with organizations such as the AIDS Committee of Toronto, AIDS ACTION NOW! and Voices of Positive Women.

A Living Legacy

A conversation with Carol Major about the history of the OHTN Cohort Study

How was the OHTN Cohort Study born?

The Cohort Study has its origins in a project called HOOD—the HIV Ontario Observational Database. HOOD was intended as a large-scale observational database—a repository of anonymous clinical information drawn from the medical records of people living with HIV in Ontario—that could be used for research purposes. HOOD was born in the early days of HIV. There was a lot of tension between those affected by HIV and policymakers. AIDS activists (most prominently AIDS Action Now!) were pressuring for some very important rights, including access to treatment. The HIV Project Centre, led by Dr. Anita Rachlis, had been established at Sunnybrook Hospital to distribute desperately needed antiretrovirals free of charge.

We realized from the beginning that research was as necessary as the treatments. The real hero behind HOOD was James Thatcher. James was the quintessential activist—very ill himself, yet very smart, driven and politically well connected. James prepared a compelling video that challenged community, bureaucrats and researchers to create a database to study the clinical aspects of HIV—in essence, to create HOOD. The video was shown at his memorial service—it was a very powerful moment. Many of the people most involved in HIV in Ontario were there. Jay Browne, the coordinator of the recently formed AIDS Bureau, and Anita Rachlis accepted the challenge.

What were some of the early challenges in getting this project up and running?

Obviously, funding was one necessity. Jay managed a complex set of negotiations to have Burroughs-Wellcome donate 25% of provincial AZT profits, which resulted in \$500,000/year allocated to supporting the



study. Anita began the development of a protocol to create a province-wide observational cohort study. She brought Jim Lavery and Greg Robinson on board, two individuals with great community credibility.

But it was not an easy ride from there. Community groups and clinics had a lot of anxiety regarding confidentiality of data. We instituted a policy of “community ownership,” and established the HOOD Executive Committee with 50%-plus-one community/PHA membership. We believe this was a Canadian first—the governance of an academic research project in the hands of a community-majority committee.

So this was really the birth of HOOD. What did it do first?

Peggy Millson joined as a researcher. To ensure security and confidentiality, HOOD was built as a stand-alone database complete with a “kill” command. Ethics approval was received and the sites were selected. Enrollment began shortly after, and in 1996-97, data began to accrue.

The first article, “HIV Ontario Observational Database: A Foundation for Growth in HIV/AIDS Research,” was published in July 1995 in the *Ontario Medical Review*, authored by Drs. Millson, Rachlis & Robinson and Ms. Alice Peter. By 1997, 3,200 people were enrolled and data was being analyzed. Several important presentations at the 1998 International AIDS Conference were drawn from HOOD, regarding HIV health costs, TB screening, long-term progressors, complementary therapy and treatment patterns. However, some practical realities became apparent. Manual data

collection was cumbersome and expensive, with long lag times to have data ready to analyze. PHAs and clinics saw no real incentive to participate. Again, with the assistance of the AIDS Bureau and Frank McGee, Don Kilby and Greg Robinson led a task force to consider a new approach.

So, then, it was recognized that the original concept had to be expanded further.

Yes. In 1997, the Ontario HIV Treatment Network (OHTN) was established. At that time, the concept of electronic Clinical Management Systems (CMS) was emerging—on-site computer systems to collect and manage patient data. Part of the OHTN's original mandate was to create the next generation of HOOD, incorporating this new technology. That was how HIIP—the HIV Information Infrastructure Project—was created.

How did HOOD translate into the new HIIP/CMS? How were the values that had guided the HOOD project incorporated into this new entity?

HOOD moved from Sunnybrook to the OHTN, at first administratively and then physically. The HOOD governance body became the HIIP Advisory Committee (HAC)—this time with 50%-plus-one PHA representation (formerly 50%-plus-one community participation). HIIP's governance mandate included the development of the CMS, as well as the data ownership and governance of research activities.

It was originally thought that HOOD would be replaced by a new Central Research Database (CRD) that receives data from electronic medical records. (In fact, this did not come to pass.) Dr. Ahmed Bayoumi assumed leadership of HIIP/HOOD research. A significant body of important HIV research was produced during this period.

As with any major software project, CMS implementation took longer than planned. In the meantime, "HOOD2" was developed, using data input directly into laptops rather than via paper forms. This was not only easier and more efficient but more secure.


By 2004, CMS implementation was underway and data was beginning to flow to the CRD. However, it was becoming clear that CMS data extraction would not replace the HOOD model of data collection. HOOD2 works efficiently in specific settings, and both data collection mechanisms need to be maintained in order to collect data from hospital and primary care settings.

How did the OHTN move into what is now called the Cohort Study?

In March 2005, the OHTN Board of Directors approved a new Strategic Plan that emphasizes the research aspects of HOOD and CRD. Sean Rourke, the Scientific and Executive Director of the OHTN, has now assumed leadership of this project and we have recognized a need to consolidate and strengthen the observational database/cohort study into a single entity: The OHTN Cohort Study.

The OHTN Cohort Study Governance Committee still retains the original 50%-plus-one PHA representation and assumes all the responsibilities of the previous governance committees. The future includes a single merged OHTN Cohort Study that will build on the foundation established by HOOD and become an international leader in database research.

Would you say that the original vision of the community members and researchers who founded HOOD has been realized?

There are currently more than 4,000 enrollees in the OHTN Cohort Study and it is expected that by 2006 there will be nearly 6,000. This is more than one-third of the estimated 15,000 people diagnosed with HIV in Ontario. The future is bright and exciting, as the database holds the key to many unanswered questions about HIV care and treatment. We are expecting many important research findings that will impact on the care and treatment of people living with HIV in Ontario. Most importantly, this project is built on community/academic/care provider/policymaker alliances, collaboration and trust. 



Carol Major is the Expert Adviser on Special Projects at the OHTN.

Milestones

Congratulations are in order!



The OHTN is pleased to acknowledge the appointment of our Board President, **Bill Flanagan**, to the position of Dean of the Faculty of Law at Queen's University for a five-year term that began July 1, 2005.

Bill's academic achievements include a JD from the University of Toronto Faculty of Law (1985), a DEA in international economic law from the University of Paris (1986), and an LLM from Columbia University (1989). He began teaching at Queen's University in 1991.

Bill has published extensively on legal issues related to HIV/AIDS and has been strongly committed to HIV community volunteerism and activism since the early years of the epidemic.

He has served on the OHTN Board since July 2003 and became President in March 2004. The OHTN is privileged to have a volunteer of Bill's skill and stature on board and we offer our sincere congratulations on this important career milestone.



Robert (Bob) Duck, former Director of the OHTN's HIV Information Infrastructure Project (HIIP), has accepted a secondment position with the Toronto Local Host Secretariat of the XVI International AIDS Conference, which will be held in Toronto August 13-18, 2006.

Bob joined the Toronto Local Host Secretariat Staff Team in August 2005 and has assumed a leadership role with the Local Host Team. Bob's skills as an excellent manager, communicator and organizer will be invaluable in this challenging new position.

As Senior Manager of Special Projects, Bob will have the lead role in a variety of responsibilities throughout the coming year, including Security, Health and Safety, medical services, first aid services and coordination with community health services. The OHTN is

delighted that Bob has accepted this exciting challenge and we are pleased to support the International AIDS Conference in this important way.

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Mission

To optimize the quality of life of people living with HIV in Ontario and to promote excellence and innovation in treatment, research, education and prevention through a collaborative network of excellence representing consumers, providers, researchers and other stakeholders.