

The OHTN *ex*CHANGE

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A newsletter for consumers, providers, researchers & policymakers



How a community-driven study will lead to better housing and health for people with HIV/AIDS

IT ALL STARTED IN 2002. People with HIV/AIDS (PHAs) and community-based AIDS organizations—surveyed for the provincial HIV/AIDS strategy—identified housing as a serious problem for PHAs. According to the community, the lack of appropriate, affordable housing was putting people at risk of HIV and contributing to disease progression.

That same year, at an Ontario AIDS Network (OAN) retreat, the executive directors of the province's community-based AIDS organizations decided to tackle the housing issue. "We knew from our day-to-day work that housing was one of the greatest unmet needs of PHAs," says Ruthann Tucker, executive director of Fife House in Toronto, "but we didn't have the information to really understand the problem. We needed to know more about where PHAs are living now—what type of housing—and how much they spend on housing."

The group worked with Saara Greene, the OAN's research assistant, to develop a proposal. They received funding from the OHTN, the Wellesley Corporation and the AIDS Bureau of the Ontario Ministry of Health and Long-Term Care to conduct a study to assess the current state of PHA housing.

The Right Place at the Right Time

Around the same time, the OHTN was reviewing its funding priorities. "We've always done a good job of funding basic science and clinical research that will lead to better treatment," says OHTN Scientific and Executive Director Sean Rourke, "but we weren't paying as much attention to the issues that affect quality of life for PHAs. The provincial strategy highlighted the need to pay more attention to the broader social determinants of health, like housing, employment and income. That was a challenge. We had to look at our priorities and see what we could do differently."

"Housing is one of the greatest unmet needs of people living with HIV/AIDS."

In October 2004, the OHTN's Priority Initiatives Program (PIP)—designed to support work in areas identified as emerging priorities—invited representatives of vulnerable populations to discuss the best way to use PIP funds. "Every single group identified housing as a challenge," Tucker says. "It was one issue that crossed all populations, and we realized we needed to do more than just our baseline study to make a difference."

(continued on page 6)



(from left) Ruthann Tucker, research coordinator Amrita Ahluwalia and Jay Koornstra at CAHR in May 2006



Message from the Scientific and Executive Director Our Commitment to Community

As an academic researcher working in the fields of mental health and HIV, I thought I had a pretty good understanding of what it meant to work with the community. But, since coming to the OHTN, I have gained a real appreciation of how community involvement can strengthen an organization and have an impact on policy-relevant research.

A commitment to community involvement means more than the number of people with HIV on our committees. The true test is: Does the community feel listened to and respected? Are we funding projects that address their issues? Is the community actively engaged in our projects? Do researchers seek their advice and expertise? Do we help broker useful partnerships that can lead to better care and service delivery? Are we having an impact that is important to the community?

Community involvement means more than the number of PHAs on our committees.

In this issue of the *exCHANGE*, we focus on how our unique structure and approach give the HIV/AIDS community a strong voice in shaping our broad research agenda. As an organization, the OHTN benefits every day from its close working relationship with the community. For example, in our housing and health initiative, we're learning how to support community-based research at its best, and I hope that will lead to many more collaborative initiatives on the social determinants of health.

Being a network of four stakeholders—community, health care providers, researchers and policymakers—isn't always easy. Sometimes we disagree on the best way to achieve our mission, but because we all share the same commitment to stopping HIV, it works. In fact, it brings out the best in all of us. Personally, I have learned a great deal from working so closely with the community and I've grown in the process. I look forward to continue working together to tackle issues that have the potential to improve health outcomes and quality of life of people living with and affected by HIV/AIDS in Ontario.

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

Progress Report on the Strategic Plan: Highlights

- The OHTN got an "A" rating from the Board for our accomplishments in the first year of the Strategic Plan.
- The OHTN has received a record 37 applications in the Studentship and Fellowship competition of the Investigator-Driven Research Program.
- We hosted two Think Tanks in June: "Best Practices in Needle Exchange and Harm Reduction" and "Immigration and Mental Health."
- The OHTN is collaborating with CAHR to develop a Pan-Canadian Database of HIV research.
- We held six consultation meetings with researchers across the province to raise the profile of the OHTN Cohort Study.
- The OHTN supported a meeting of the Global Coalition for Women and AIDS Leadership Council in June.
- We're helping the Ontario Science Centre develop an educational exhibit promoting and highlighting HIV research as a lead-up to AIDS 2006.
- We hosted the inaugural meeting of the Ontario Society of Physicians in HIV Care on June 10.

Fifty Percent + One

How the community guides the OHTN

Community involvement has been a guiding principle for all HIV/AIDS initiatives in Ontario since the 1980s. Community members were at the table in the government's first advisory groups and have been contributing their knowledge and expertise ever since.

When the OHTN was formed, the key role of the community was captured in the Board structure: seven of the 13 voting members of the Board of Directors—a 50% + 1 majority—are community representatives elected through the Ontario AIDS Network. Four of the seven must be people living with HIV/AIDS (PHAs).

The OHTN's commitment to community helps connect the real world and the ivory tower.

The community also plays a key role on other OHTN governing and decision-making bodies. The governance committee of the OHTN Cohort Study—the project that collects information on the care and treatment of PHAs in Ontario—also includes 50% + 1 PHAs (see back cover). This ensures that PHAs have a strong, effective voice in how their information is used in research.

Community members also sit on committees involved in other OHTN initiatives, including the scientific review

committee for the OHTN's Investigator-Driven Research Program (IDRP). "The direct involvement of the community in reviewing research proposals and guiding our funding decisions breaks new ground in the research world," says OHTN Scientific and Executive Director Sean Rourke. "Research proposals are typically judged only by other researchers. Our review process looks not only at the scientific rigour of each proposal but also its value to the community, linking everything back to our mandate—improving the lives of PHAs."

Board President Bill Flanagan adds: "As Board and committee members, it is up to us to ensure that resources are used wisely to achieve our goals. We are fortunate to have a wide range of committed community members who bring a diverse set of skills to the OHTN along with an intimate knowledge and understanding of the various communities affected by HIV/AIDS."

Board composition is just part of the story. "It's possible for an organization to have a community-inclusive board and still not have a community culture," Rourke says. "Our job is to make sure the intent of the '50% + 1 rule'—meeting the needs of the HIV community—is reflected in all we do."

This commitment is reflected in the types of projects the OHTN funds, in its recent push to explore the determinants of health, and in its Board-Directed Funds (see page 4). It has also led to the requirement that all OHTN-funded researchers have links with the community and build community collaboration into their proposals—helping connect the real world and the ivory tower. 🌍

The OHTN at AIDS 2006

Promoting community-based research



In August, AIDS 2006—the XVI International AIDS Conference—will be held in Toronto. At past conferences, community-based organizations were involved in only a small proportion of the papers and posters presented; this year, organizers want the community to have a stronger voice. The OHTN has been working hard behind the scenes to encourage greater community participation.

AIDS 2006

In January and February, we collaborated with the AIDS 2006 Local Host Secretariat to offer a series of workshops on abstract writing for people working and volunteering in community-based organizations. To reach as many people and organizations as possible, five workshops were held in Toronto, two in other Ontario communities, and three outside Ontario.

With the Canadian Institutes of Health Research (CIHR) and the Canadian Aboriginal AIDS Network, the OHTN will co-host a satellite meeting on August 16 from 6-8 pm to showcase community-based research initiatives in Canada.

Look for us

The OHTN will have a booth in the NGO section of the exhibit hall. OHTN staff will be on hand to answer questions and provide updated information on OHTN-funded research presented at the conference. Be sure to drop by and say hello.

For more info on OHTN research being presented at the conference, watch for the next issue of the exCHANGE.

Board-Directed Funds

Taking action on urgent issues



LGV: A “New” Sexually Transmitted Infection

Bill Flanagan, president of the OHTN Board and Dean and Professor of Law at Queen's University, championed a research project on LGV 9 (lymphogranuloma venereum), a sexually transmitted infection common in other parts of the world which is now appearing in North America. Most Canadian cases have occurred in gay men in Ontario, but there is little research on this new infection and little awareness about it in the gay community.

“I thought the OHTN had an opportunity to be proactive on this emerging issue,” Flanagan says, “so last September I supported a proposal to the OHTN Board to fund some groundbreaking research in this area.” The Board approved a cross-sectional study of HIV positive and negative men who have sex with men. The study will evaluate the prevalence of LGV in

Ontario, determine the sensitivity and specificity of LGV serology in the study population, and explore possible risk factors for LGV infection (including HIV serostatus). The principal investigator is Dr. Jill Timmouth at Sunnybrook & Women's College Health Sciences.

“This research builds on the unique strengths of the OHTN. Our deep links to communities affected by HIV help us identify emerging issues quickly, and the Board-Directed Funds permit us to move rapidly to fund research that can have a direct impact on public policy,” Flanagan says. “The project demonstrates the productive collaboration that we have nurtured at the OHTN between community, researchers and public policymakers.”



Fighting Facial Lipoatrophy

The facial wasting that often results from otherwise successful highly active antiretroviral therapy (HAART) can be psychologically devastating. Expensive, difficult-to-access surgical treatments are the only available options for reversing the disfiguring effects of facial lipoatrophy (FLA). These treatments are poorly publicized and understood within the community—and few can afford them. “We were very fortunate to be able to collaborate with investigators who have a real investment in this issue and empathy with the people affected,” says **Tony Di Pede**, OHTN Board member and long-standing community advocate. In September 2005, Di Pede championed a proposal by Drs. Colin Kovacs and Mona Loutfy of the Canadian Immunodeficiency Research Collaborative (CIRC), based in Toronto's Maple Leaf Medical Clinic.

The lipoatrophy project—guided by a stakeholder group including PHAs, OHTN members, HIV physicians and plastic surgeons—incorporates research, education and advocacy. Through a literature review and CIRC's own clinical trials, the group will compile comprehensive data on the different interventions now available. This information will be made easily available to PHAs contemplating treatment, via the Internet and a specially-designed consultation program. Finally, “This project will play a crucial role in advocating for treatment coverage,” Di Pede says. Because FLA treatments are currently considered “cosmetic,” the cost is not covered by provincial health ministries—a policy this project hopes to change. “By assessing the clinical and psychological ramifications, we hope to convince the Ontario government that these interventions are necessary reconstructive techniques for a debilitating condition—not cosmetic niceties.”

For more info on the facial lipoatrophy project, go to www.mapleleafmedical.com

One of the most direct ways for community members to shape the OHTN's work is through our Board-Directed Funds. Each year, the OHTN Board of Directors sets aside funds for urgent or emerging HIV issues in Ontario. Any of our stakeholders—community, health care providers, researchers and policy-makers—may submit a request for board-directed funding on an issue they see as a priority. A designated OHTN Board member must then support the proposal, present it at a Board meeting and argue the case for funding. The Directors evaluate these proposals on a case-by-case basis. Here are the Board members who successfully championed four recent Board-directed initiatives.



Micronutrients: A Way to Delay HAART?

"There was a lot of excitement at the 2005 OHTN Research Conference when Dr. Jon Kaiser presented data showing the potential for micronutrients to boost the immune system of PHAs," says **Ron Rosenes**, Vice-Chair of the Canadian Treatment Action Council and of the AIDS 2006 Toronto Host Board of Directors. PHAs are major consumers of complementary and alternative medicine, and, as Rosenes says, "the community has always supported research that would answer questions about the value of various supplements. One question that still remains is whether appropriate micronutrients might make it possible to delay the initiation of HAART."

At a round-table networking session the day after Kaiser's presentation, researchers and community members began to envision studies that might address this question. "We learned that Dr. Bill Cameron in Ottawa and Dr. Joanne Allard in Toronto were studying the value of micronutrients for people with HIV," says **Gloria Aykroyd**, OHTN Board member and program coordinator with the Infectious Diseases Care Program at St. Joseph's Health Care in London. "With the active support of OHTN staff, we developed a proposal for a Board-Directed Fund project to support and build on their work."

"Research that achieves economies of scale with a variety of partners and funders has real potential to improve outcomes for PHAs," Rosenes says. "We dream of the day when supplements might be made available through the provincial formulary, offering less-costly and possibly easier-to-take alternatives to antiretrovirals."




African & Caribbean Communities: Confronting Stigma and Discrimination

Virtually all workers who provide HIV prevention and support services to the African and Caribbean communities cite stigma and discrimination as key challenges for their clients. A proposal to investigate these issues, submitted to the OHTN's Priority Initiatives Program in 2002, was not funded at that time. But, with the persistence of the researchers, the AIDS Bureau and OHTN staff, the proposal was resubmitted to the Board-Directed Funds and approved last year.

"This project was motivated by our lack of information on HIV among Ontarians of African and Caribbean descent," says **Frank McGee**, coordinator of the AIDS Bureau, Ontario Ministry of Health and Long-Term Care, and ex-officio member of the OHTN Board. "The African and Caribbean Council on

HIV/AIDS in Ontario (ACCHO) was established to address HIV prevention and support issues in these communities, but it was crucial to build evidence and information from which ACCHO could develop its work."

The study's principal goal is to understand the role of stigma, denial, discrimination and fear associated with HIV/AIDS among Ontarians from the Caribbean and sub-Saharan Africa. "The OHTN provided an ideal means by which we could bring together researchers and members of the African and Caribbean HIV communities," McGee says. Lead investigator Liviana Calzavara of the University of Toronto heads up the research team, along with co-investigators from key service organizations including Women's Health in Women's Hands, ACCHO and the AIDS Committee of Toronto.

The ACCHO project will be featured in the next issue of the exCHANGE. 

Through PIP, the OHTN provided additional funding for the initiative and connected the housing and health project working group with academic researchers—experts in the field of housing and homelessness—who could help refine the research questions. The OHTN also hosted a Think Tank on Housing and Health, where experts identified the type of information that could influence policy, as well as ways to use and share that information.

With the OHTN's assistance, the group developed a funding proposal to the Canadian Institutes for Health Research (CIHR), which led to \$100,000 a year for three years for *Positive Spaces, Healthy Places*—a longitudinal study on HIV, housing and health. Six hundred PHAs— from across the province and across all groups (gay men, injection drug users, women, Aboriginal people, people from countries where HIV is endemic)—will be interviewed initially and then again six and 12 months later to monitor changes in their housing and health. The survey delves into a wide range of issues, including physical and mental health, discrimination, and alcohol and drug use.

"This study will help us understand the relationship between quality of housing and people's physical and

The Research Teams

Positive Spaces, Healthy Places

Principal Investigators:

Ruthann Tucker, Fife House
Dr. Dale Guenter, McMaster University
Dr. Saara Greene, York University

Co-Investigators:

LaVerne Monette, Ontario Aboriginal
HIV/AIDS Strategy
Lea Narciso, Ontario AIDS Network
Jay Koornstra, Bruce House
Steve Byers, AIDS Niagara
Michael Sobota, AIDS Thunder Bay
Dr. James R. Dunn, Centre for Research on Inner
City Health (CRICH), St. Michael's Hospital;
University of Toronto
Dr. Stephen Hwang, CRICH; Univ. of Toronto
Dr. Sean Rourke, OHTN; CRICH; Univ. of Toronto

Housing Solutions

Dale Butterill, Centre for Addiction and Mental
Health (CAMH)
Rick Kennedy, Ontario AIDS Network
Dianne Macfarlane, CAMH
John Sylvestre, Centre for Research and
Community Services, University of Ottawa

Research Builds PHA Skills

Positive Spaces, Healthy Places looks for every opportunity to involve and benefit PHAs. The study has hired PHAs as peer research assistants responsible for recruiting and interviewing participants.

"There are real advantages to using peer interviewers," says Dave, a peer research assistant in Ottawa. "We can identify with what people are saying, which makes the person being interviewed more comfortable, and I think we get more open, honest responses."

Dave applied for the position because it doesn't affect his disability coverage and is flexible enough to not interfere with his medical appointments (an issue for many PHAs trying to re-enter the workforce). Overall, he says, it's been a positive experience: "I've had HIV for 22 years, and doing the interviews reinforces that I am not alone. It also gives me a chance to provide support for others. I'm a recovering addict, so when I'm interviewing someone in recovery, there's an opportunity for mutual support. I'm also in a position to help direct people to services."

"Many of the peer research assistants have been off work for a number of years, so they're dusting off old skills and developing new ones," says Jay Koornstra, executive director of Bruce House. "It's having a positive effect on their confidence and self-esteem—something you can lose when you're out of the workforce. Another residual benefit of the research is that it's helping us get hands-on experience with back-to-work issues—one of the other social determinants of health that we need to address."

mental health and their ability to access care, treatment and other services," Tucker says. "We'll also examine how housing may change over the course of HIV disease. We're going to try to untangle the cause-and-effect relationship between housing and health."

"If it wasn't for the OHTN," Tucker adds, "we never would have approached the CIHR. The OHTN provided the expertise we needed to develop the larger study—and the CIHR funding means our results will be taken more seriously."

"This project is an excellent example of research that is built on identified needs and fully engages the community," says Jennifer Gunning, team lead for the CIHR HIV/AIDS Research Initiative. "It is also based on sound research principles and involves a team with the broad range of expertise to help ensure its success."

According to Gunning, the community-based research program is an important component of the CIHR HIV/AIDS initiative, which is part of the larger Federal Initiative to Address HIV/AIDS in Canada. When reviewing community-based research proposals, CIHR looks for "a clear link to the community, relevance and the potential to improve the situation for PHAs and people at risk," Gunning says. "Projects also have to meet the same standard for

methodological rigour and ethics review as other research. This project clearly brings all of that together.”

The Right Partners, the Right Questions

The response to the *Positive Spaces, Healthy Places* study has been extremely positive. More than 400 participants have been recruited, and work is well ahead of targets and timelines. “Many people in the community understand the value of research and how to use knowledge to influence decision-making,” Rourke says. “Ruthann and others on the research team have been incredible leaders, pulling people together to work on this issue, and I think we’re seeing the benefit of a truly community-driven project in the response rates.”

Tucker, no stranger to community-based research, says, “This is the first time I feel that all the people who are going to use the information—policymakers, researchers and community—are at the table from the beginning.” Gunning agrees that this is key: “By engaging PHAs and community organizations upfront and involving the AIDS Bureau, it’s more likely that the project’s findings will influence policies and programs, which is CIHR’s bigger goal. We want to fund research that, with the right transfer of knowledge, will lead to improved health. Though the project is focused in Ontario, the results have the potential to be applied more broadly across the country and used to improve the lives of other populations as well as PHAs.”

“What I like about this collaboration is that the community was there when the first question was asked,” says project co-investigator Jay Koornstra, executive director of Bruce House in Ottawa. “No one has lost sight of that. We are in control of the project, and the academic researchers are helping us find the information we need. It’s been a real sharing of expertise to achieve common goals.”

According to Koornstra, involvement in community-based research requires a lot of time, but if the project is well thought out, it’s worth it. “I went into the project scared,” he says. “Research is out of my realm of comfort. But with the right partners, it’s not that overwhelming. I believe this project will give us important information that will strengthen our agency and show us how we can make a difference.”

“Supporting research on the social determinants of health should be part of the OHTN’s role,” says Ron Rosenes, co-chair of the Community Network Advisory Committee. “As a person living long-term with HIV, I can tell you that people aren’t talking about the virus, they’re talking about the problems they’re having with very basic needs, such as housing, income and eating well. This research will give us the information we need to advocate for meaningful policy changes.”

For more info on HIV, housing and health, go to www.healthyhousing.ca 

Brick by Brick

The *Positive Spaces, Healthy Places* study is only one part of the larger housing and health research initiative. Several other pieces are also helping to build the knowledge and understanding needed to improve housing and health for PHAs.

Jim Dunn and Stephen Hwang, researchers with the Centre for Research on Inner City Health (CRICH) at St. Michael’s Hospital in Toronto, have already completed a systematic review of existing studies on the impact of housing on PHAs.

“We found about 20 studies of reasonable quality,” says Hwang, one of Canada’s top researchers on homelessness and the author of several studies that have demonstrated the impact of housing on health. “Most compared people who were homeless with those who had stable housing, and most found that people with unstable housing had problems adhering to treatment and poorer health outcomes. The new Ontario study has the advantage of being able to look at people in a full range of housing situations over time and assess how different types of housing and changes in housing affect health. This will be an important addition to the literature.”

When asked about his experience with the community-driven project, Hwang said it was a different way of working for him: “In this study, the academic research partners are not in the driver’s seat; the community organizations are taking the lead. I think this approach can lead to very meaningful research that will resonate with the community and with policymakers.”

Building Bridges

The final piece of the puzzle is a separate study, *Housing Solutions*, which looks at how the housing system works for PHAs in Ontario. The study team, led by Dale Butterill of the Health Systems Research and Consulting Unit at the Centre for Addictions and Mental Health (CAMH), is talking to community-based AIDS organizations, mental health housing providers, social housing service providers, and the larger housing system in Ontario about the current housing system’s capacity to provide stable, affordable, appropriate housing for PHAs.

“We want to identify the range and type of housing and housing support services available to PHAs in Ontario,” says Rick Kennedy, executive director of the Ontario AIDS Network (OAN) and a member of the project team. “We also want to find out how other sectors, such as mental health, have handled similar problems so we can learn from each other and advocate with the larger system to help us meet HIV needs.”

Team members bring extensive experience in housing and mental health issues to the project. Butterill, who started working in housing support for people with mental health problems 30 years ago, understands that “housing is a complex issue for PHAs, particularly if they also have mental health or substance use issues. We can’t just think housing; we also have to look at the housing support services that will help people maintain their health.”

Working closely with the team is the project’s Provincial Knowledge Exchange Group, which has a broad membership including the AIDS Bureau, Bruce House, AIDS Niagara, Ontario Non-Profit Housing Association and members of the PHA community.

The Thatcher REPORT

The OHTN Cohort Study: A model for community involvement for North America

In April 2006, the Ontario Cohort Study (OCS) became part of the North American AIDS Cohort Collaboration on Research and Design (NA-ACCORD), which brings together more than 60 single and multi-site cohorts—from both academic medical centres and community-based HIV care facilities—representing more than 60,000 people with HIV/AIDS (PHAs) and HIV-negative controls from the United States and Canada. In the next year, the NA-ACCORD will focus its research powers on the failure of highly active antiretroviral therapy (HAART), with a special concentration on multi-drug-resistant virus and its consequences and management.



The NA-ACCORD is one of several international groups of HIV cohorts funded by the U.S. National Institutes of Health (NIH). “The advantage of becoming part of the NA-ACCORD is that researchers will have access to data on a much larger group of PHAs than the 4,000 OCS participants in Ontario,” says Darien Taylor, chair of the OCS Governance Committee. “This allows us to address research questions that cannot be explored through smaller cohorts.” Furthermore, she says, “The diversity of Ontario’s PHA population will provide important information that the NA-ACCORD would not be able to obtain from other participating cohorts.”

To ensure that the OCS reflects the priorities of the HIV community in Ontario, all research proposals are reviewed and approved by the OCS Governance Committee, which includes 50% + 1 representation of PHAs. Regarding the community’s role in research, “The OCS model of PHA governance is unique and one of our great strengths,” Taylor says. “It leads to more informed research initiatives and better use of research findings. One of the roles that we plan to play in the NA-ACCORD is to promote greater community involvement in more centres.”

The Thatcher Report is the regular update on the OHTN Cohort Study: a community-governed research project that uses health data provided by PHAs in Ontario to improve care, treatment and health services.

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.

The OHTN
exCHANGE

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