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Promoting quality of life through research, education and cross-sector partnerships

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*Community Naturopathic
Clinic at the Sherbourne
Health Centre*

*Our Partners, Sponsors
and Members*

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A Message from CWGHR's Founding Co-chair

By Stephanie Nixon

November 1st and 2nd, 2002, marked the end of a wonderful era for me. It was at this semi-annual meeting of the Canadian Working Group on HIV and Rehabilitation (CWGHR) that I stepped down as Co-chair, a role that I had held since we first invented the job back in 1998. As expected, it was a bittersweet experience.

CWGHR has provided me with unprecedented opportunities to learn about HIV and the depth of the communities that have responded, about organizational development and the challenges that go along with work in the non-profit sector, and about the value of partnership-building at all levels.

CWGHR has been a family, with all of the diversity and dynamics that one would expect from such a wonderful collection of sisters and brothers. And I've had the magical opportunity to watch this family grow into an effective, productive organization with integrity and reach.

This meeting, in particular, saw the CWGHR membership, in a healthy combination of old and new, come together to tackle tough questions. For instance, we developed strategies to address the sophisticated area of disability insurance. This comprehensive dialogue saw CWGHR members from AIDS Service Organizations (ASOs), government, and the insurance industry, to name a few, meaningfully engage with each other in an honest and productive way on this complex topic.

Yes, CWGHR is healthy and vibrant, exactly what we've been working towards since 1998. And this makes it a perfect time to step down and make room for fresh ideas and new directions. Thank you CWGHR - it's been wonderful!

Stephanie Nixon is a PhD candidate at the University of Toronto. Stephanie was CWGHR's Co-chair from 1998-2002.

CWGHR WOULD LIKE TO THANK
STEPHANIE FOR ALL HER WORK AS
CWGHR CO-CHAIR SINCE 1998.

HER VISION AND HER
COMMITMENT TO CWGHR, AND
TO REHABILITATION IN THE
CONTEXT OF HIV, HAVE BEEN AN
INSPIRATION TO EVERYONE
INVOLVED IN CWGHR'S WORK.



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A Message from CWGHR's New Co-chair

By Louis-Marie Gagnon

This year the Canadian Working Group on HIV and Rehabilitation (CWGHR) reached a new level by becoming a non-governmental, non-profit corporation - an important step in its growth since its launch in 1998. The annual meeting held on November 1 and 2, 2002, in Toronto, greatly reflected this change.

I succeed Stephanie Nixon as Co-chair, but would like to point out that although I succeed her, I will not be able to replace her! Her enthusiasm and joie de vivre, her sense of humour and, above all, her unfailing devotion will not soon be forgotten. I cannot overlook the contribution of Francisco, Co-chair, without whom CWGHR could not have evolved. Elisse's abilities no longer need to be proven; without her and those around her, we would not be able to accomplish everything we have planned for today and the future.

As for my modest contribution, I hope that you will not be disappointed. I am bringing to this position my management skills as co-founder and Executive Director of a Montreal community AIDS agency closely involved with rehabilitation and part of the Quebec landscape since 1991. But I bring, above all, a personal experience with AIDS, which I have been fighting since 1983.

Together, with everyone's contribution, CWGHR is destined to have a bright future thanks to the undying commitment and activism of all those people living with HIV/AIDS. Together we will overcome it!

Louis-Marie is the Executive Director of Maison Plein Cœur in Montreal. In November 2002, he became, along with Francisco Ibáñez-Carrasco, Co-chair of CWGHR.

CWGHR WOULD LIKE TO WELCOME LOUIS MARIE AS CWGHR'S NEW CO-CHAIR WITH FRANCISCO IBÁÑEZ-CARRASCO, OUR OTHER CO-CHAIR SINCE 2001. CWGHR IS SURE TO BENEFIT FROM THEIR COMBINED EXPERTISE AND EXPERIENCE IN THE FIELD OF REHABILITATION IN THE CONTEXT OF HIV.



Stephanie Nixon, CWGHR's founding Co-chair

The "CWGHR Roadshow" Continues

By Kate Reeve

"I am pleased workshops continue to take place. This gives me hope."

- Workshop participant who volunteers for an AIDS service organization (ASO)

As outlined in the last issue of the newsletter, CWGHR holds workshops in communities across Canada on rehabilitation in the context of HIV. We've been busy in recent months. Some highlights include:

- ▶ At a workshop at an Opening Doors conference in Sudbury, health care providers as well as staff and volunteers from ASOs in North Bay and Sudbury discussed the wide range of barriers faced by people living with HIV trying to access rehabilitation services, including a lack of knowledge among service providers. Nursing students expressed frustration at the lack of formal training provided by their college on HIV and/or rehabilitation issues. One nursing student talked about how he has taken initiative to learn about HIV by volunteering with an ASO and coming to workshops like this one. Similarly, students in other CWGHR workshops have appreciated hearing from PHAs and health provider practicing in their community. A massage therapy student remarked that the workshop "gave [her] some insight into the field that [she is] hoping to work in." See the article about Dr. Patty Solomon and Dr. Dale Guenter's research project for more information about work on curriculum issues.

► CWGHR presented at the National Aboriginal Health Conference, in partnership with the Toronto organization, 2-Spirited People of the 1st Nations. LaVerne Monette linked the Aboriginal concept of holistic healing and CWGHR's concept of rehabilitation. Duane Morrisseau, a CWGHR member shared his own experiences as an Aboriginal person living with HIV as a way to better understand these links.

► At two full-day workshops in Toronto, held in partnership with Casey House Hospice, a number of amazing speakers outlined the complexities of rehabilitation from various perspectives. Particularly powerful was Kim Johnson of Voices of Positive Women sharing her story as a service provider and a woman living with HIV. One participant commented that: "Presentations and individuals like her keep me involved, active and encouraging others to do the same."

Check the CWGHR website, www.backtolife.ca, for more information about our workshops.

Kate Reeve is CWGHR's Education Co-ordinator.

HRDC - Canada Pension Plan (CPP) has recently undertaken a consultation process regarding their income support program for people with disabilities, Canada Pension Plan Disability, CPP (D). In response, CWGHR worked with the Canadian AIDS Society (CAS) to produce a brief outlining the issues relating to CPP (D) in the context of HIV, and highlighting issues related to the unpredictable and episodic nature of HIV. Representatives from CAS then presented the brief to the Parliamentary Sub-Committee on the Status of Persons with Disabilities. Check CWGHR's website, www.backtolife.ca, for a copy of the brief and CPP (D) Consultations website at www.parl.gc.ca/disability

The Role of CWGHR at the "Positive Gathering" for People Living With HIV in BC

By Glen Bradford

In October, BC Persons With AIDS Society (BCPWA) co-sponsored the first Positive Gathering for people living with HIV (PWAs) in BC. Over 200 people attended 20 different workshops. CWGHR presented a workshop in which we discussed the need for a national organization, such as CWGHR, to advocate on back to work issues.

The workshops that attracted the most participants were the ones on relationships, sex, new drugs, living with side effects, spiritual perspectives, alternative therapies and the interaction between party drugs and HIV antiretrovirals. It was clear that

people living with this episodic disability have a need for "back to life" issues to be addressed. For a while, many of us who are living with this illness have been asking the question: "What does living look like for us now?" Clearly, the message from PWAs at the Gathering was that we are living longer and we want a life to go with it.

For many of us, we are past the "survivalist" mentality. Whether we are going back to the bars, or seeking out spiritual guidance, long-term relationships or back to work options, we are seeking new strategies to live with this disease. We want our life back and CWGHR is in a position to help make some of this a reality.

Glen Bradford represents BCPWA as a CWGHR member and was the Co-chair of the Positive Gathering.

Note: Acronyms to describe people living with HIV vary from community to community (PWAs, PHAs, PLHAs, etc). Wherever possible, we have kept these regional variations and used the acronym suggested by the author.

Rehabilitation Education Activities in Winnipeg

By Ron Bowie and Dick Smith

Education activities related to rehabilitation in the context of HIV began in Winnipeg in response to one fundamental question: How much is really understood in the field of health care concerning HIV disease, the people living with this now chronic illness and the diversity of their needs relating to rehabilitation?

With fewer than 500 Manitobans currently identified with HIV disease, health care providers see few people living with HIV/AIDS (PLHAs). As a result, education activities provide an important opportunity to create links between health care providers, community groups and PLHAs and to improve awareness of and access to rehabilitation services.

Community Therapy Services (CTS), providing therapy for individuals restricted to the home, received only nine clients with HIV in 2001 as referrals for physiotherapy and occupational therapy. These clients were all in the end stages of the disease, suggesting a need for earlier intervention. This may also suggest that, when people living with HIV in Manitoba are receiving treatment for specific neurological or musculoskeletal conditions, they are doing so without the benefit of an interdisciplinary, integrated and co-ordinated approach that tries to address all their needs.

It then becomes critical that health providers in the field of rehabilitation are aware of the network of community services established to support people living with HIV and, as well, that people in community-based organizations are aware of rehabilitation services. Education activities, then, should involve an exchange of information between PLHAs, staff and volunteers in the community and health care professionals. This is being tackled from a number of angles, including:

- ▶ Multi-sector workshops:
 - ▶ A presentation to Nine Circles Community Health Centre (NCCHC) staff and staff of ASOs (AIDS Service Organizations) about home care services available through CTS
 - ▶ An overview of HIV to CTS therapists presented by CWGHR members, the NCCHC interdisciplinary team, and PLHAs, including a tour of NCCHC to acquaint therapists with the city's ASOs and resources for PLHAs
 - ▶ A workshop with the Manitoba AIDS Co-operative with participants from all disciplines involved in HIV care and rehabilitation, PLHAs, community workers and caregivers.
- ▶ Presentations to:
 - ▶ academic and clinical leaders in physiotherapy and occupational therapy at the University of Manitoba's School of Medical Rehabilitation (SMR)
 - ▶ the interdisciplinary Association of Rehabilitation Medicine of Manitoba
 - ▶ the 2002 annual meeting of the Canadian Association of Physical Medicine and Rehabilitation.
- ▶ Training programs for students, including a component on rehabilitation in the context of HIV in the program for specialists in physical medicine and rehabilitation, and possibly for undergraduates.

"There is a need for earlier intervention, co-ordinated care and more links between community groups and health providers."

While there is no specific rehabilitation program for people living with HIV in Manitoba, there is a need for earlier intervention, co-ordinated care and more links between community groups and health providers. Key players in the field of rehabilitation in the context of HIV have begun to come together and will continue to address these issues.

Dr. Ron Bowie and Dr. Dick Smith are physicians and CWGHR members who represent the Canadian Association of Physical Medicine and Rehabilitation, and the College of Family Physicians of Canada, respectively. Both live in Winnipeg, MB.

Persons with HIV/AIDS (PHAs) as Educators in the Health Sciences: Impact of a Training Program on Learners and PHAs

By Dr. Patty Solomon and Dr. Dale Guenter

CWGHR has funded a number of re-search projects in communities across Canada on rehabilitation in the context of HIV. The article below is taken from the executive summary of one of these projects, a project carried out by Dr. Patty Solomon and Dr. Dale Guenter at McMaster University. For the complete report, see the research section of CWGHR's website, www.backtolife.ca.

The purpose of this project was to develop and evaluate an innovative model of education for health professionals. The model involved persons living with HIV/AIDS (PHAs) being trained to participate in a variety of educational roles in the Faculty of Health Sciences at McMaster University. Our goals were to help health professional learners to achieve a deeper understanding of the lived experience of PHAs; and, to enhance the quality of life and sense of meaning among PHAs.

Planning, recruitment and training were carried out collaboratively by the two partner organizations, McMaster University and Hamilton AIDS Network. Seven PHAs participated in interactive educational group sessions to prepare them for a variety of educational roles. Learner target groups included physiotherapy and occupational therapy students and family medicine residents. Educational events that PHAs participated in included small group tutorial sessions, role playing and being interviewed.

Learners completed an evaluation form at the completion of each educational event. PHAs were asked to keep a journal following each of their educational experiences outlining their reactions and challenges. In addition the PHAs were interviewed at the end of the project. A

qualitative analysis of the students' evaluations and the PHAs' journals and interviews was undertaken.

Feedback from the learners indicated that the students valued the personal interaction with the PHAs and that they were able to provide perspectives that gave the students insights into the experience of living with HIV.

Learners also appreciated hearing the PHAs' stories and experience of living with HIV. Learners also appreciated hearing the PHAs' stories and experiences of dealing with other health professionals. Students also had to confront their own values and assumptions about PHAs and were surprised at the continued stigma surrounding HIV/AIDS. Their feedback also indicated that there needs to be strategies to best incorporate the PHAs into the educational events.

Feedback from PHAs indicated that there was a marked positive impact on them in terms of their teaching skills, self-awareness, personal understanding of HIV, confidence in teaching and everyday life. There were specific challenges related to their educational roles; these

included difficulty with role playing, interacting with large groups, difficulty with following discussion when medical discussion was used, knowing how to challenge the students and difficulty with some of the values and assumptions of health professionals.

The results of this study point to several areas for further development of the model. These include providing the PHAs with strategies for introducing themselves and clarifying that the role of the PHAs is not one of being the content expert but rather the expert on living with HIV. In addition, some PHAs had greater difficulty assuming specific roles and may be more suited to educational events that do not require facilitation skills.

Dr. Patty Solomon is the Assistant Dean of the Physiotherapy Program of the School of Rehabilitation Science, and Dr. Dale Guenter is a professor with the Department of Family Medicine at McMaster University.

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"Students valued the personal interaction with the PHAs and that they were able to provide perspectives that gave the students insights into the experience of living with HIV."

Research on Lifelong Episodic Disability: Phase II of CWGHR's Research

By Kate Reeve

CWGHR is currently undertaking a research project on unpredictable episodes of illness in the experiences of persons living with HIV. This is the second phase of a three-phase project. Looking Beyond the Silos (2002), Phase I of the project, explored disability issues from a cross-disability perspective and is available on CWGHR's website. The purpose of Phase II of the project is to examine the experience of living with HIV, particularly the uncertain, unpredictable, episodic and fluctuating nature of the disease, and to articulate this experience in order to provide recommendations for rehabilitation programs and policies.

To gather this information, we have conducted a literature review and have held focus groups across the country with people living with HIV. The knowledge gained from this research will provide an important foundation for exploring disability issues for people living with other life-long episodic illnesses and disabilities. Check our website, www.backtolife.ca, for more information.

Who do you tell when you experience side effects from your HIV/AIDS meds? PASS Them Along to the Canadian Treatment Action Council (CTAC)

By Francisco Ibáñez-Carrasco

Treatment issues are inextricably linked to rehabilitation, as medications play a critical role in extending the lives of people living with HIV. Some rehabilitation services, such as physiotherapy and complementary therapies, can help improve quality of life by addressing the range of side effects that people can experience from medications. Learning from other people living with HIV about medications, their interactions, and side effects is an important part of this process. This article outlines a CTAC research project to identify strategies for collecting and sharing information about medications.

The Post Approval Surveillance System (PASS) tracks side-effects and drug interactions for medications approved for sale and use in Canada. Unfortunately, Canada does not have an active consumer-centred post approval system to allow consumers to provide this information to a central source. Each of us living with HIV and using these drugs has valuable information about our experiences which can help others. We have no convenient ways to give our information to a central group that collects and *passes* it on to relevant stakeholders. As a result, people living with HIV miss vital information when we make our treatment-related decisions. CTAC research project will find out how different community-based ways of reporting information on side-effects and drug-interactions work for people living with HIV.

We encourage all people living with HIV currently on any antiretroviral/prophylactic treatment to choose a way to participate. Your experience will help those who have treatment decisions to make and/or need treatment information. Once completed, CTAC will have gathered information about which methods of sharing information were successful. CTAC will then make the results public and advocate that policy makers provide these reporting methods for all PWAs on an ongoing basis.

For more information about the PASS Study, contact us at PASS@ctac.ca, call the toll-free survey line 1-866-253-7277, or visit the CTAC web-site at www.ctac.ca.

Francisco Ibáñez-Carrasco, the PASS Study Coordinator, works as a social researcher, in the areas of health, sexuality, and multiculturalism. He is an HIV-positive CWGHR member and Co-chair.



Francisco Ibáñez-Carrasco unveils CWGHR's new website, www.backtolife.ca.

Community Naturopathic Clinic at the Sherbourne Health Centre

By Bill Merryweather

The Community Naturopathic Clinic is a joint project of Sherbourne Health Centre, The Canadian College of Naturopathic Medicine, The Toronto People with AIDS Foundation (PWA) and The AIDS Committee of Toronto. Founded four years ago at PWA, the clinic provides naturopathic care free of charge to people living with HIV/AIDS. Under the supervision of a licensed doctor, eight interns from the Naturopathic College offer a holistic approach to health management and a variety of services including acupuncture, homeopathy, botanical medicine, massage and clinical nutrition.

Naturopathic medicine is an obvious component of the complementary therapies approach evident in the AIDS movement from the beginning. It provides an alternative to conventional drug therapy for those who are unable to tolerate its side effects or who wish to independently pursue a more natural form of treatment. Interns work with the clients to ensure that programs are individual and effective and that there are no undesirable reactions between treatment types as certain substances have been shown to decrease the body's ability to maintain adequate levels of anti-viral drugs in the blood stream.

Many of the clinic's clients are on fixed incomes. As such, naturopathic treatments and supplements are often inaccessible. The clinic allows access to these services and provides the opportunity for greater choice and determination. Naturopathic treatments are an important part of the rehabilitation process by controlling debilitating conditions such as diarrhea, nausea and peripheral neuropathy, allowing the client to function in their day-to-day life with as little interruption as possible.

A four-year grant from the Trillium Foundation enabled the clinic to move from the Toronto People with AIDS Foundation offices to a larger, purpose-built location at Sherbourne Health Centre in September of 2002. In addition, it has made possible the hiring of a coordinator to manage operations, fundraise to add a second day of service and increase the core supply of treatments, and liaise with AIDS service organizations in the community

effort to increase the diversity of the client base. For further information about the Community Naturopathic Clinic, please call the Clinic Coordinator at 416-324-4164 or check out the Sherbourne Health Centre website at www.sherbourne.on.ca.

Bill Merryweather is the Co-ordinator of the Naturopathic Clinic.

Our Partners

By Suzanne Boggild



Sherbourne Health Centre is a community-based health care organization dedicated to providing primary care that enhances the quality of life in South East Toronto. The Centre is located at 333 Sherbourne Street across from Allen Gardens.

We currently provide general primary care services, primary care for the lesbian, gay, bisexual, transgendered and two-spirited (LGBT) communities, mental health services, mobile health services including the Health Bus, and complementary and alternative medical services that include the chiropractic and naturopathic clinics. Over the next year we will renovate our building to accommodate an extended hours general primary care centre and an infirmary for the homeless or underhoused.

A key component of the Centre's approach to providing health services is the development of partnerships with existing health providers in the community. This happens in a number of ways including co-location on our site, mutually supportive relationships and service partnerships. Our goal is to provide seamless, integrated and convenient access to care for the community by recognizing the strengths of current health care agencies and finding the best ways of working together.

Given the Centre is particularly committed to partnerships and collaboration we look forward to an ongoing and rewarding relationship with CWGHR.

Suzanne Boggild is the Chief Executive Officer of the Sherbourne Health Centre, where CWGHR's offices are located.

Upcoming Events

Below is a list of key events coming up in the next few months.

Working Positive Summit Conference: Developing Evidence- and Experience-Based Best Practices in Employment Supports for People Living with HIV/AIDS
Philadelphia, PA, USA www.matrixresearch.org
April 9-11, 2003

Making the Connections: 12th Annual Conference on HIV/AIDS Research (CAHR)
Halifax, NS www.cahr-acrv.ca
April 10-13, 2003

The Tapestry of HIV Care: 11th Annual Conference of the Canadian Association of Nurses in AIDS Care (CANAC)
Halifax, NS www.aciis.org
April 13-15, 2003

Stemming the Tide of STDs and HIV: Fifteenth Biennial Congress of the International Society for Sexually Transmitted Disease Research (ISSTD)
Ottawa, ON www.isstdr.org
July 27-30, 2003

4th Canadian HIV/AIDS Skills Building Symposium
Calgary, AB www.cdn aids.ca
November 20-23, 2003

CWGHR IS EXCITED TO ANNOUNCE THAT THERE WILL BE A WORKSHOP STREAM DEDICATED TO REHABILITATION ISSUES AT THIS YEAR'S CANADIAN SKILLS BUILDING SYMPOSIUM. CHECK OUT CWGHR'S WEBSITE FOR INFORMATION ABOUT HOW TO SUBMIT AN ABSTRACT.

CWGHR workshops

Check out www.backtolife.ca for upcoming CWGHR workshops!

Disclaimer: While the content of these articles is, to the best of our knowledge, current and reliable, information is not a substitute for actual health care and treatment. Articles do not necessarily reflect the official policy of CWGHR or any sponsoring organizations.

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