

# breast cancer *info exchange*

SHARING INFORMATION ABOUT BREAST CANCER ACTIVITIES IN ONTARIO

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*Breast Cancer Info Exchange* is the semi-annual newsletter of the Ontario Breast Cancer Information Exchange Partnership (OBCIEP). The OBCIEP is a coalition of organizations committed to ensuring that information about breast cancer is available to all people in Ontario.

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## Winter/Spring 2005

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# OBCIEP Breast Cancer Information Dissemination Study

## *Final Report Summary*

The idea for the breast cancer information study was created at an OBCIEP Coalition meeting in 2002 when OBCIEP Coalition partners reported that women were still saying "no information" was given to them at the time of their diagnosis and/or treatment for breast cancer. The purpose of the study was to learn the difference between what women say is happening and what information providers believe should be happening. The study also planned to identify the most effective method(s) of making appropriate information available to those who need it, when they need it.

Between November 2003 and August 2004 OBCIEP interviewed 28 breast cancer survivors and two information providers and held focus groups with 127 breast cancer survivors and 24 information providers. The themes arising from the preliminary interviews provided the springboard for discussions in the focus groups that were held in Kingston, Ottawa, St. Catharines, Burlington, Sarnia, Woodstock, Windsor, Dryden, Thunder Bay and Toronto. The main themes that emerged from the conversations are discussed below.



### Shock of Diagnosis

It was clear from our discussions in the focus groups that cancer still has the power to terrify people. The fear and panic it triggers has a profound impact on how women respond to information about their disease, if at all. Many who had received information brochures or books at the time of diagnosis admitted they did not read the material as the challenge of accepting their diagnosis was in itself overwhelming.

### Good and Bad Experiences in the Health Care System

Another issue that arose in these discussions that linked all themes was the positive and negative experiences women reported in the health care system. The positive experiences reflected the time, patience and care taken by some health professionals to explain the disease, treatment options and follow-up care. Women were particularly appreciative of the time doctors and nurses spent talking with them about their cancer. By contrast, the bad experiences exposed the fragmentation in cancer care, described like a series of disjointed procedures rather than a proper "system". There were a variety of unfortunate experiences with members of the medical team from significant breaches of protocol (receiving test results of another patient) to rude and insensitive behaviour by medical or administrative staff.

### Being Your Own Advocate

Most participants reported that the onus was on them as a cancer patient to identify resolve their own information needs and learn about and understand their own medical treatments. Many found that they were left to decipher the information they were given and had to search out the more detailed information of interest only to them about their particular disease.

Discussions with health care providers mirrored this finding. Many working in cancer care conceded that one of their greatest challenges is appropriate screening to identify those who need additional support and information. The pressures in cancer care presently do not allow time to counsel every patient appropriately.

### Different Types of Information Women Want



Participants acknowledged that each woman's interest in obtaining information is as distinct as her particular disease. Some want to know everything, others nothing and many reported that their information needs changed during their treatment. It was agreed that general information on breast cancer is available but information specific to the individual woman's disease and interest was a challenge to find. A variety of formats should be offered at different times—written, audio or video tapes, telephone contact, interactive online chat rooms or message boards, and one-on-one or group interaction with medical professionals or breast cancer survivors. Women are receptive to information at different times in treatment so a "one size fits all" approach was not recommended for breast cancer information.

Information providers talked about the challenges of providing appropriate information resources for women and keeping aware of everything available. They also acknowledged the administrative difficulties and costs of providing information resources at many points on the cancer continuum and in many languages other than English. Both survivors and information providers discussed the enormous challenges of providing information and support services for those in remote and rural communities and suggested that innovative methods may be needed to reach those women.

### Components of a Successful Dissemination Strategy

Both groups made recommendations to women and to information providers to improve the current situation. These recommendations will be explored in detail in the final report. From the discussions a series of components of a "good" breast cancer information dissemination strategy were identified:

- information or links to information early on in the process, even prior to diagnosis
- time for news of a cancer diagnosis to sink in and contact with a health professional for support
- a consistent health professional contact or information provider to answer questions pertinent to a woman's particular disease
- a road map or critical pathway to spell out steps in treatment, let women know what to expect
- consistent medical team to coordinate treatment
- encouragement, optimism and honesty from medical staff
- share information about existing services in the community
- referrals to credible information sources.

The report will focus on two programs that received positive comments, one in Ottawa and one in Oxford County (Woodstock) at two different points in the treatment continuum. A summary of the major themes with perspectives from survivors and information providers appear in Table 1.

The final report is posted on OBCIEP's web site at [OBCIEP Activities](#). For more information contact Irene Nicoll, OBCIEP at [irene.nicoll@sw.ca](mailto:irene.nicoll@sw.ca) or by telephone at 416-351-3815.

**Table 1****Breast Cancer Information Dissemination Study - Summary of Findings**

Theme	Breast Cancer Survivors	Information Providers
<b>Shock of Diagnosis</b>	Find impact of diagnosis overwhelming — emotional toll has profound effect on how, when and if women seek or take up information about their disease.	Observe high levels of stress in those having breast abnormalities investigated or those recently diagnosed. Recognize that women need support and guidance at these stages.
<b>Onus on the Patient</b>	Report that women are left to find and decipher information on their own.	Face challenges in meeting this need and recognize that women are becoming increasingly specific about the information they want.
<b>Experiences in Medical System</b>	Report well known problems in the health care system —waiting times, fragmented services, time delays, funding constraints, staffing shortages— and examples of truly exemplary but also inexcusable behaviour by some health professionals.	Acknowledge that services are not standardized (rural and remote areas face special challenges) and that screening and providing service for those who need additional support are not meeting current needs.
<b>Different Types of Information Women Want</b>	Recommend all types of resources in many different formats be available at different points along treatment continuum, i.e. everyone seeks information and learns differently.	Note barriers to providing appropriate information in many languages, appropriate for different cultures and in multiple formats (usually due to funding constraints), and in reaching women rural and remote areas.
<b>Recommendations to Women</b>	<ul style="list-style-type: none"> <li>• Become educated about your disease, information needs and different options for support</li> <li>• Recognize that your information needs may change over time and leave yourself open to the many forms and ways different types of information can reach you</li> </ul>	<ul style="list-style-type: none"> <li>• Confirm that information is power. Encourage women and their families to seek information about to breast cancer</li> <li>• Advise women that there may not be specific answers to every question they may ask</li> </ul>
<b>Recommendations to Information Providers</b>	<ul style="list-style-type: none"> <li>• Recognize support as essential particularly at diagnosis</li> <li>• Be aware of existing services in the community to refer patients</li> <li>• Encourage family physicians to play a larger role in providing information and support</li> <li>• Develop a "road map" for patients, teach them the steps of cancer care, what to expect</li> <li>• Coordinate care, provide consistency in medical team/ patient contact</li> <li>• Help patients understand medical information and implications of treatment choices</li> <li>• Address issues for those in rural and remote areas</li> <li>• Treat patients with respect</li> </ul>	<ul style="list-style-type: none"> <li>• Maximize existing information and support services in the community</li> <li>• Develop a critical pathway or road-map for breast cancer patients</li> <li>• Focus resources on support services</li> <li>• Investigate nurse or patient navigator models of support</li> <li>• Work together to avoid duplication</li> <li>• Develop template/resource keep information providers up-to-date on new and locally relevant resources and how to obtain existing ones</li> <li>• Use existing networks in remote communities to improve communication and monitoring among health care and support agencies</li> <li>• Look for unique opportunities to work together</li> </ul>

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# Breast Cancer Information and Support - Preferences and Resource Development

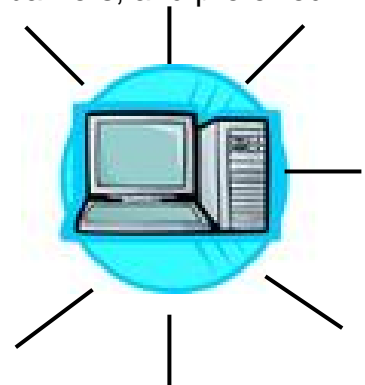
OBCIEP has received funding for a new four-year breast cancer information and support study. The impetus for the project proposal was an awareness noted in previous OBCIEP studies and information shared by OBCIEP Coalition and network partners that women are still not receiving breast cancer information and support when they need it and how they need it. Recent research has demonstrated uses of the Internet to provide professional online support. This led to the idea of an online menu of options for those dealing with cancer to select different types of information and support tailored to their individual needs. The options could include medical information on the disease, telephone support, peer group support, professional online support, etc.

OBCIEP's project partners are the Canadian Cancer Society - Ontario Division, Lung Cancer Canada, National Ovarian Cancer Association, and Willow Breast Cancer Support & Resource Services.

The aim of this four-year project is to enhance the information and support of women living with a breast cancer diagnosis. The results of the breast cancer information indicate that women often report a lack of options at specific times and do not always know what information and support various services offer and how they may be helpful. The three-phase project includes a needs assessment, the development, pilot and evaluation of an online resource.

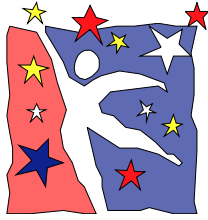
The objectives are to:

- Identify preferred means for accessing breast cancer information, barriers, and preferred types of information and support.
- Learn about critical times during the cancer experience for specific information and support requirements.
- Examine preferences and expectations when provided with a comprehensive menu of information and support options, including online emotional support.
- Develop and pilot an Internet resource (complimenting existing services with new) that serves as an accessible "hub", enabling women with breast cancer to tailor information and support that is right for them at the time.
- Evaluate the usability and effectiveness of the resource.



Expected results include an innovative Internet resource that can offer reliable and tailored information and support options, accessed in at least three Ontario regions in two different languages (English and French or Aboriginal or other). The site will link to sites in Canada and elsewhere to existing services and resources. Focus groups and interviews will be conducted in and around the Greater Toronto Area as well as in northern Ontario.

For more information on the study please contact Sue Keller-Olaman at [sue.keller-olaman@sw.ca](mailto:sue.keller-olaman@sw.ca) or by telephone at 416-351-3808.



# Ontario Breast Cancer Community Research Initiative Update Spring 2005

## Spirituality and Breast Cancer

~ Judy Gould and Pam Grassau

*Researchers at the OBC CRI are conducting a research study on how women understand, define and practice spirituality when dealing with breast cancer.*

Judy Gould and Pamela Grassau from the Ontario Breast Cancer Community Research Initiative and Sue Wilson of Ryerson University have interviewed 28 women with breast cancer regarding the role of spirituality in their lives. These researchers initiated the study because they wanted to better understand:

- ❖ how women define and experience 'spirituality';
- ❖ how women experience of spirituality in the context of a breast cancer diagnosis;
- ❖ how women describe their relationship with God or a 'higher power' (if their spirituality included 'God' or a 'higher power'); and,
- ❖ what, if any, spiritual resources they would like made available at community-based cancer agencies and cancer treatment centres.

Participants were recruited from breast cancer support groups and newsletters, cancer treatment centres and clinics and with the aid of health care providers.

Twenty-eight women from across Canada volunteered to be interviewed for the study and 18 of those women identified as being affiliated with a religious organization. These women ranged in age from 37 to 64 years, most had post-secondary education, and half had a household income of below \$60,000/year. The women identified themselves from the following ethno-cultural groups: Caucasian/European, Jewish, African American, First Nations, and Filipino.

The women defined spirituality in unique ways as is exemplified in the following quotes and perceived their spirituality as either a part of, or separate from, formal religious organizations. Here are examples of the way two women defined spirituality:

*"It's caring about the environment, people, animals, plants, respecting and loving. (That), to me, is spirituality."*

*"There was an awakening... spirituality started to emerge...out of the religion...I think the container for me needs to be religion...spirituality is grounded in religion."*

Themes (in bold) emerging from the interviews include experiences of **meaning and transformation, and relationship with deity, resting spaces and layers of support (or resources)**.

*“...it's a primary relationship in my life because I was conscious of that when I was lying on the stretcher waiting to go in for the mastectomy and there's nobody else around...certain things in life you face on your own and it's good to have a sense that you're not alone...” (Relationship with deity)*

*“it's not about doing, it's about being who I am and just being here, accepting who I am and not trying to change things...” (Resting Spaces)*

Many women mentioned the following **spiritual resources** as particularly helpful in the first year following diagnosis: books, spiritual/religious organizational support, religious leader support, psychotherapy, yoga, Qigong, massage, hospital chaplains, retreats, and talking to other people who had experienced cancer.

The research team is interested in learning how these meanings and experiences might change over time. To that end the team plans to talk to these women again at three and five years post-diagnosis. Watch this newsletter for details for more information or contact [judy.gould@sw.ca](mailto:judy.gould@sw.ca) or [pam.grassau@sw.ca](mailto:pam.grassau@sw.ca).

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## Femmes francophones atteintes du cancer du sein – Mise à jour

~ Stephanie Austin

Depuis le lancement du livret résumant la recherche auprès des femmes francophones de l'Ontario en 2004 ([Femmes francophones atteintes due cancer due sein: Qu'est-ce qu'elles ont à dire? Qu'est-ce qu'elles à faire?](#)) un groupe de personnes engagées à mieux servir les femmes francophones atteintes du cancer du sein se rencontre régulièrement pour parler d'activités de recherche action. Sur ce comité de travail, nous avons des survivantes du cancer du sein, des chercheurs et intervenants communautaires, et des représentants d'organismes de soutien pour les gens affectés par le cancer. Les membres du groupe proviennent de milieux divers et reflètent aussi la diversité culturelle et ethnique des femmes francophones atteintes du cancer du sein en Ontario.

Nous espérons organiser des groupes de discussion pour déterminer quelles formes de soutien seraient les plus utiles pour les femmes francophones. Pour le moment, nos activités visent particulièrement les femmes francophones atteintes du cancer du sein qui vivent à Toronto.

Si vous aimeriez en savoir plus, n'hésitez pas à communiquer avec Stephanie Austin ([stephanie.austin@sw.ca](mailto:stephanie.austin@sw.ca)), Lucie Chauvette ([lucie.chauvette@sympatico.ca](mailto:lucie.chauvette@sympatico.ca)) ou Candice Nguema ([candice@cmsctoronto.org](mailto:candice@cmsctoronto.org)).

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# Francophone Women Living with Breast Cancer - An Update

~ Stephanie Austin

Since the production of the booklet summarizing the research conducted with Francophone women living with breast cancer in 2004 ([\*Femmes francophones atteintes due cancer due sein: Qu'est-ce qu'elles ont à dire? Qu'est-ce qu'elles à faire?\*](#)) a group of people committed to better meeting the needs of Francophone women living with breast cancer in Ontario has been meeting regularly to discuss action research activities. In this working group, there are breast cancer survivors, community researchers and developers, and people working in cancer support agencies. The members of the group come from diverse backgrounds and reflect the ethnic and cultural diversity of Francophone women affected by breast cancer in Ontario.

We hope to organize discussion groups to determine what forms of support would be the most useful for Francophone women. For the moment, our activities have been focused on meeting the needs of francophone women living with breast cancer in Toronto.

If you would like more information, do not hesitate to contact Stephanie Austin ([stephanie.austin@sw.ca](mailto:stephanie.austin@sw.ca)), Lucie Chauvette ([lucie.chauvette@sympatico.ca](mailto:lucie.chauvette@sympatico.ca)) or Candice Nguema ([candice@cmsctoronto.org](mailto:candice@cmsctoronto.org)).

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## Examining Breast Cancer Information from Racially Marginalized Perspectives: A Community-based Analysis

~Jennifer Nelson

Dr. Jennifer Nelson (Principal Investigator) and Leslie Norville (Research Assistant) have begun recruiting participants for a study that is investigating racially marginalized women's responses to breast cancer educational materials. We will ask women from African Canadian, South Asian, Chinese, Filipino and Arab communities, who have experienced a breast cancer diagnosis, to participate in facilitated group discussions in which they will analyze several examples of breast cancer information. The results will be made available to breast cancer community groups and treatment facilities, to help them determine how to develop new materials or to improve existing resources for diverse groups of women. For more information about this study contact [leslie.norville@sw.ca](mailto:leslie.norville@sw.ca), or [jennifer.nelson@sw.ca](mailto:jennifer.nelson@sw.ca).

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# Generating Dialogue with Health and Income Security Professionals about the Experiences of Low-income Women with Breast Cancer

~Judy Gould

This study was funded by the Canadian Institutes of Health Research<sup>1</sup> to better understand the barriers and strategies associated with connecting low-income women with breast cancer to financial resources.

Researchers with the OBC CRI have now summarized all of the information provided to us in interviews and focus groups with 27 surgical, medical and radiation oncologists, pharmacists, pharmaceutical representatives, community-based cancer professionals and public insurance representatives.

During the interviews and focus groups participants were asked to comment upon:

- personal experiences working with low-income women with breast cancer;
- barriers for connecting women with financial resources;
- strategies for linking women to financial resources; and,
- recommendations to better link women to financial resources.

The findings have been grouped into three main areas: 1) perceived barriers that exist in the cancer system, 2) strategies to alleviate barriers; and, 3) recommendations for resources.

## **BARRIERS**

### **Identification of Need**

*“If you don’t ask and the patient doesn’t say, nobody knows.” (Oncologist)*

Cancer centre professionals mentioned only one direct mechanism to identify the financial needs of breast cancer patients. This mechanism appears on an intake/registration sheet in the form of the question, ‘do you have any financial needs?’. Health professionals were concerned that while this form might be a helpful mechanism for identifying financial need, it is presented to patients at a time when patients don’t know that cancer treatments will cost them out-of-pocket or that they might suffer loss of/reduced income.

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<sup>1</sup> This study was guided by an advisory committee: Pamela Bowes, Cathy Cameron, Lucie Chauvette, Barbara Fitzgerald, Margot Lettner, Irene Nicoll and Kate Sigurdson.

This project is one of three projects funded within the same grant by the Canadian Institutes of Health Research (2003). The grant is entitled: “Intersecting Vulnerabilities: Gender, Poverty, Age and Aboriginal Identity in Women’s Lived Experience of Breast and Gynecological Cancers” (Co-PI’s: Mitchell, T., Gould, J., Sinding, C., & Fitch, M. and Co-Applicants: Aronson, J., Burhansstipanov, L., Gustafson, D., McGillicuddy, P., & Peng, I.).

Because this mechanism for identifying financial concerns is hit-and-miss, participants also discussed how they informally identify patients' financial concerns. These indirect mechanisms include conversations with breast cancer patients. This mode of identification is inconsistent among health care professionals.

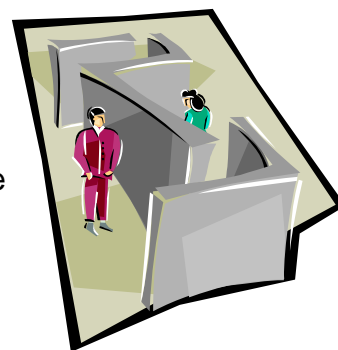
Health professionals noted that they and their colleagues expect patients to identify and express financial need. As one nurse stated, *"it's like the onus is on (the patient) to ask the question to get the information rather than it being given..."*. The health professionals felt that self-advocacy was an unrealistic expectation for patients who are often new to the cancer system.

*"When you're just diagnosed with something it's so overwhelming to deal with that, so unrealistic to have to then go out and navigate through all these systems and programs that you never even thought you'd ever have to use before..."(Community Organization Professional)*

## Service Barriers

Participants identified several service barriers:

- 1) Fragmented services: Services provided both within the cancer centre and between different organizations that provide support to cancer patients are often fragmented. Health professionals told us that a few financial resources do exist but a mechanism to 'connect the dots' is lacking.
- 2) Unmet expectations: Study participants mentioned a number of expectations (their own and those expressed by patients) associated with relieving financial distress. These mostly unmet expectations were communicated in three ways: what financially stressed patients expect that institutions or services cannot provide; what institutions expect from financially concerned patients that patients cannot always provide; and, what institutions expect from services that services cannot or are not providing.



For example, though many health professionals in the cancer system believe that social workers will facilitate access to financial resources for patients requiring assistance, the social workers felt that there was little they could offer some cancer patients because of the lack of social programs and/or patient's ineligibility for existing programs.

*"so I think sometimes the people are sent to us with the idea that we can somehow make things happen...that we have access to money...and because it's a social worker calling another social worker, it's (access to resources) going to happen" (Social Worker)*

- 3) Cost-shifting: A final barrier discussed by the health professionals concerns the payer of prescription drugs. As the costs for these drugs escalate, governments, insurance industries and hospitals are required to examine ways to offset or contain costs for these drugs by shifting the payer from the hospital to another institution, such as public or private insurance, or to the breast cancer patient.

## ACCESS STRATEGIES

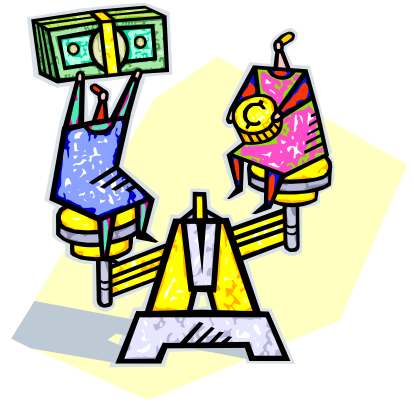
Once financial need has been identified, patients with breast cancer can and do access a few services from cancer organizations and treatment centres. These resources include the Canadian Cancer Society transportation service, a food delivery program (Good Food at Home

offered by FoodShare), emotional support programs (such as those offered by Willow and Wellspring), and public insurance programs such as, Trillium Drug Program. These programs address barriers frequently encountered by those with financial need by offering their services free of charge.

Still, community organization professionals advocate for more instrumental support programs such as food, housekeeping and childcare services.

In the cancer treatment centres, health professionals (usually social workers) also assist patients to alleviate financial concerns. Participants relayed to us that they:

- organize and refer patients to compassionate-use prescription programs;
- refer patients to community-based services such as Community Care Access Centres home care and Interlink;
- assist patients to complete myriad forms associated with private and public insurance programs and provide individualized service to assuage patients' financial concerns; and,
- organize information sessions about issues related to treatment and aftercare.



## RECOMMENDATIONS

The research participants made the following recommendations to better assist financially-concerned women with breast cancer:

### Instrumental Support in the Community

Financial Resource Manager/Navigator: to provide practical and individualized support to financially-stressed patients. The participants felt that this service would be best located in the community and not in the cancer centre.

*“having somebody who can help you navigate the system is a really helpful thing because there’s so much information and so much to think about and if you’re not linked up...you’re just kind of lost”* (Community Organization Professional)

This financial manager might:

- follow-up on applications to income security or drug benefit programs;
- discuss the treatment costs with patients at intake and throughout the treatment trajectory to ascertain financial need;
- provide financial counseling to assess how patients might get back on their feet financially following treatment; and,
- provide information about community and institutional services.

### Institutional Resources

#### 1) Screening Procedures: Revisiting Identification of Financial Need

- all patients should be asked about their financial need at intake and asked several times over the treatment trajectory.
- develop a high-risk screening tool to identify individuals requiring financial assistance.

## 2) More Social Workers

- more social workers should be hired as part of the breast cancer team in order to meet the needs of those addressed as having financial concerns.

## 3) Information sessions

- information sessions about the financial costs of cancer should be offered at the treatment centre several times a year. Community organization staff could be invited to speak about their services, and social workers could discuss costs associated with cancer treatment/aftercare and inform cancer patients about how to apply for public insurance.

## 4) Advertise that Cancer Costs

- regardless of socioeconomic status, all women and men diagnosed with cancer should be directly informed that cancer will cost them out-of-pocket especially, those men and women who are without adequate private health insurance.

### **Build Coalitions/Advocacy**

Health professionals from community-based organizations identified that the cancer care system lacks the ability to mobilize advocacy efforts. Other participants were more hopeful that cancer organizations are beginning to advocate to policy-makers and governments on behalf of the needs of their constituents and strongly suggested that these organizations continue to do so.

Community-based cancer organizations participants felt that the production and distribution of research studies that underscore the financial need of cancer patients are imperative to “*effect some kind of change to the system*” and to assist health and income security professionals to understand that many individuals with cancer will also suffer financially.

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# **Environment, Health, Quality of Life: Understandings among Women Affected by Breast Cancer**



It is important to know about links between exposures (such as chemicals) and adverse health outcomes. This focus, however, does not provide a complete picture of how the environment matters in a broader sense for people in their everyday lives. Our understandings of environment and health are complex, involving both objective and subjective aspects. There is also not a great deal of information regarding positive aspects of environment, for health and quality of life for those affected by, and recovering from, cancer. This project aims to build a different kind of knowledge, to learn about aspects of the environment that matter for the health and quality of life of women affected by breast cancer.

We plan to talk with at least 15 women that live in an urban setting (such as Hamilton or Toronto) and at least 15 women that live in rural or remote areas (such as Northern Ontario). To date, ethical approval has been sought and the interview schedule has been piloted with several

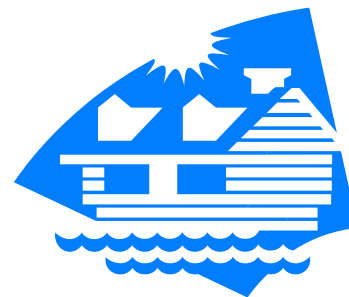
women affected by breast cancer, who live in rural areas. With support from the Centre for Research in Women's Health (CRWH), a student will be employed for the summer (May-August) to work with this project. We expect the interviews with women living in Hamilton or Toronto to be completed during the summer. The interviews with the women living in rural and remote areas will be conducted at the same time or later in the year.

If you want to find out more about this project or if you would like to take part, please contact Dr Sue Keller-Olaman by telephone at 416-351-3808 or by e-mail at [sue.keller-olaman@sw.ca](mailto:sue.keller-olaman@sw.ca).

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## Cottage Dreams

'Cottage Dreams' is a unique initiative, where those that have completed cancer treatment (up to nine months ago) can apply to stay for one week, in a donated cottage, with family or friends. Cottages are available year-round in many communities across Ontario. An evaluation is being conducted to learn about the benefits and challenges of the program, and to build understandings of the extent to which the cottage experience is perceived as a restorative environment for healing and recovery.



This study has mostly involved women recovering from breast cancer treatment. Twenty eight interviews have been completed; twenty with cancer survivors and eight with friends or family members that also stayed at a cottage. The interviews are currently being transcribed. Initial analyses are underway and the final report is expected to be completed before May.

To learn more about Cottage Dreams visit the website at [www.cottagedreams.org](http://www.cottagedreams.org).

If you have any questions about the study, please contact Dr. Sue Keller-Olaman by telephone at 416- 351-3808 or by e-mail at [sue.keller-olaman@sw.ca](mailto:sue.keller-olaman@sw.ca)

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**The Ontario Breast Cancer Community Research Initiative** is a partnership of the Sunnybrook & Women's College Health Sciences Centre, the Centre for Research in Women's Health and is funded by the Canadian Breast Cancer Foundation, Ontario Chapter. For more information contact Angela Sardelis by e-mail at [angela.sardelis@sw.ca](mailto:angela.sardelis@sw.ca) or by telephone at 416-351-3811.



# “Making Us Visible”

## Promoting Access to Breast Health and Breast Cancer Services for Lesbian and Bisexual Women

~Cheryl Dobinson

“Making Us Visible: Promoting Access to Breast Health and Breast Cancer Services for Lesbian and Bisexual Women” is a two-year innovative health promotion project launched in September 2004 at Sherbourne Health Centre in Toronto.

In partnership with the Ontario Breast Cancer Community Research Initiative, Gilda’s Club Greater Toronto, Willow Breast Cancer Support & Resource Services, and the Metropolitan Community Church of Toronto, Sherbourne Health Centre received funding from the Canadian Breast Cancer Foundation - Ontario Chapter, to build on the work of the Lesbians and Breast Cancer Project.

**Making Us Visible** will address lesbian and bisexual women’s breast health through two volunteer programs designed to increase community involvement and understanding. A group of 10 dedicated volunteers is currently engaged in the challenge of developing culturally appropriate educational materials, which will be launched in April. Planning for a series of six volunteer-led breast health events for lesbian and bisexual women began in March.

A second focus of the project is on increasing accessibility of breast cancer services. A support group for lesbian and bisexual women with breast cancer has been set up at Gilda’s Club from March to May. In addition, a training program to increase knowledge and sensitivity when working with lesbian and bisexual women in breast cancer support initiatives will be piloted at Willow.

In the final stage of the project, the team will produce and disseminate a tool kit of the resources, strategies and materials that have been developed and then host a community event to profile the activities of the project over the two years and talk about next steps.

For more information please contact Cheryl Dobinson, Project Coordinator at the Sherbourne Health Centre, 333 Sherbourne Street, Toronto, ON, M5A 2S5 or by telephone at 416-324-5063 or email [cdobinson@sherbourne.on.ca](mailto:cdobinson@sherbourne.on.ca).

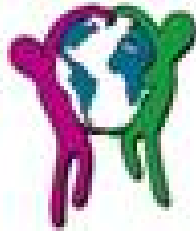
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# Living with Metastatic Disease / Vivre avec une maladie métastatique: brochure d'information à l'intention des femmes atteintes du cancer du sein



A new information booklet for women diagnosed with metastatic breast cancer [Living with Metastatic Disease](#) is now available from Willow Breast Cancer Support & Resource Services. The book discusses diagnosis, treatment options, coping with emotional challenges, communicating with the health care team, and living with metastatic disease. Also available in French ([Vivre avec une maladie métastatique: brochure d'information à l'intention des femmes atteintes du cancer du sein](#)), the information is available online in the "Resources" section of [www.willow.org](http://www.willow.org).

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## THE 4<sup>th</sup> WORLD CONFERENCE ON BREAST CANCER June 8 - 12, 2005, Halifax, Nova Scotia

*Community*

*Connection*

*Culture*

The World Conference on Breast Cancer Foundation is a non-profit organization dedicated to international multi-disciplinary global action on breast cancer through the World Conference on Breast Cancer, held every three years. These conferences are instrumental in raising awareness of breast cancer realities and bringing hope to those affected by this disease. The **Conference** will take place June 8-12, 2005 in Halifax, Nova Scotia, at the World Trade and Convention Centre. Some of the keynotes include: Annie Sasco, Chief, Unit of Epidemiology for Cancer Prevention, International Agency for Research on Cancer and Director of Research, French National Institute of Health and Medical Research, France; Alex Jadad, Director, Centre for Global E-Health, University Health Network, University of Toronto; and, Ranjit Kaur, President, Reach to Recovery International, Malaysia.

For full program details, registration information and/or to purchase a vendor booth, visit the World Conference web site at [www.wbco.ca](http://www.wbco.ca) or call 613-549-1118.