

# breast cancer *Info Exchange*

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## Telephone Support Help Over the Wires

*by Sue Keller-Olaman*

Breast cancer support groups have been instrumental in helping many women cope with their diagnosis, learn about cancer and treatment, reduce depression and enhance their relationships with their family members. A typical group may gather at a local community centre, a Canadian Cancer Society office, or even someone's home. One-on-one telephone support provided by CancerConnection and Willow helps link survivors who otherwise cannot or choose not to attend face-to-face group meetings.

What about other ways to "meet" as a group? In our busy, wired world there are different opportunities for individuals to connect that do not require in-person appearances. OBCIEP's current Community Capacity Building project, Preferences and Resource Development, is examining some innovative alternatives.

A key objective of the project is to develop, pilot and evaluate a user-friendly website, enabling women with breast cancer to tailor information and support that is right for them at the time. A main feature of the website and a critical component of the study is a link to telephone and online peer-led support groups. The groups meet with a facilitator either using the telephone or meet online using secure live chat rooms that operate like MSN Messenger.

Two breast cancer telephone support groups were trialed in the summer 2006. Each group was facilitated by an experienced peer support group facilitator trained by Willow Breast Cancer Support Canada. Three to four survivors were in each group and they were located in all parts of the province. A conference telephone number and pass code were provided and each participant dialed in to the conference at a specific day and time each week for six

Please see *Help Over the Wires*, page 2

### *Help Over the Wires . . . cont*

weeks. The study coordinator contacted each participant via e-mail after every session for feedback and overall evaluations were conducted by interview at the end of the six weeks. Some comments are below—any names used are pseudonyms.

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*“I feel better . . . I preferred the phone, I talked about things in the back of my mind, issues I hadn’t really thought of.”*

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#### *What do you like about the telephone support group?*

Overall, the women expressed very positive experiences and talked about the benefits of a phone support group.

- “I was looking forward to it each week...having a connection with women in other areas...supportive to call in and catch up, compare notes...always felt uplifted, better each week”.
- “A lifeline for rural women”.
- “I do feel a connection with these ladies even though we haven’t formally met. I think the phone idea works just fine”.

#### *What is working (facilitators’ comments)?*

The facilitators have also identified appealing aspects of this type of group:

- the phone group is ideal for people that are shy
- the smaller group size (compared to face-to-face) means that all women are more likely to talk
- the phone group works well for discussion of certain topics (e.g. sexual relationships)
- the flow of the group works well, people listen to each other
- “I think that they (participants) have learned.”

#### *What do you not like/ what is not working?*

The main challenge was linked to the use of the telephone and not being able to see the group. “Compared to face-to-face (where we exchanged phone numbers), I just couldn’t call Mary and talk as we didn’t have that connection,” commented one participant.

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*“The anonymity provided by the large range of locations is a bonus, especially for women living in small towns. They can talk more freely about their situation without concern about being identified.”*

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The lack of eye contact and not being able to read body language was also a challenge for the facilitators. "When (a participant) paused, was she thinking of something else to say; was she formulating her next comments; was she tearing up.....without being in the same room with her and having the visual clues, it was difficult to make a judgment about what was an appropriate response," said one facilitator.

### *Suggestions for the future?*

The facilitators and participants were invited to offer suggestions on how we could improve the groups for the future. Some comments included:

- decide on a topic among the group members to discuss for the following week, therefore offering participants the chance to think about questions and their own situation
- enroll a minimum of six women for each group, ensuring adequate numbers each week if someone can not take part
- do not offer the groups during the summer as there are many disruptions with vacations and other activities
- do not add new women to the group once a six-week group has started as the dynamics may be disrupted
- run the groups for eight weeks instead of six
- one meeting per week was considered appropriate
- phone or e-mail participants to remind them about the group each week

The project is scheduled to be completed in March 2008. For more information and feedback about the teleconference and online pilot studies see future issues of *Info Exchange*.

*The Breast Cancer Information and Support—Preferences to Guide Service Development* project is funded by the Community Capacity Building Component of the Canadian Breast Cancer Initiative, Public Health Agency of Canada. OBCIEP's project partners are the Canadian Cancer Society - Ontario Division; Lung Cancer Canada; the National Ovarian Cancer Association; and Willow Breast Cancer Support Canada.

Project personnel include Dr. Margaret Fitch, Director OBCIEP; Dr. Sue Keller-Olaman, Project Researcher; Kathy Thompson, Project Coordinator, Thunder Bay; Irene Nicoll, OBCIEP Coordinator. If you have questions about the project or would like to share comments or suggestions, please contact Irene Nicoll at OBCIEP by telephone at 416-351-3815 or by e-mail at [irene.nicoll@sunnybrook.ca](mailto:irene.nicoll@sunnybrook.ca).

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*"I am still feeling a little awkward because I can't see people's faces. I might need a more visual connection than some people."*

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## Greening Your Cleaning

### What's Under the Kitchen Sink?

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#### **"Green" Ingredients**

Pure Soap, Vinegar,  
Cornstarch, Eucalyptus Oil,  
Washing Soda ((Sodium  
Carbonate), Baking Soda  
(Bicarbonate of Soda)~

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#### **All Purpose Cleaner**

##### Mild Mixture

1 gallon (4 L) hot water  
1/4 C (50 ml) sudsy  
ammonia  
1/4 C (50 ml) vinegar  
1 T (5ml) baking soda

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For a stronger cleaner or  
wax stripper, double the  
amounts of all ingredients  
except water.~

~ [www.greenpeace.ca](http://www.greenpeace.ca)

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In our zeal to have clean, germ free homes we may have become too focused on what has been dubbed the "chemical warfare against dirt". The Environmental Association of Nova Scotia states that indoor air in the home is often eight to ten times more polluted than outdoor air, and that cleaning products, personal care products and chemical pest controls are the main culprits. A wide variety of specialty cleaners for windows, counters, sinks, ovens, toilets, floors and drains lurk under the kitchen sinks of many homes.

If you use commercially prepared cleaning solutions recognize that manufacturers are not required to disclose ingredients in their products. Also, be aware of products that claim to be environmentally friendly but do not provide a list of ingredients on the label. Know the four warning labels most frequently found on cleaning products that indicate that the product can be corrosive; reactive; flammable; and/or, poisonous. Use and store all products carefully. It is recommended that all cleaned surfaces be rinsed with plain water.

Alternative or "green" cleaning solutions require basic household ingredients like baking soda, vinegar, salt and "elbow grease" as they often need more time and scrubbing than commercial products to work. While the recipes are simple and inexpensive some may still prefer to purchase cleaning products for convenience. Three Canadian producers of green products are Pure Source, F.T. Ross and Fruits and Passion.\* Many grocery stores chains in Ontario now offer their own name brand green cleaning products (e.g. Loblaws "PC Green" line).\*

In choosing alternative cleaning solutions you can create a healthier living space by reducing harmful chemicals in your home and in the environment. You also do not need a different product for every task. Try "going green" the next time you clean!

*"Are household cleaning products hazardous to my health?" Frequently Asked Health Questions, Canadian Health Network, Health Canada, [www.canadianhealthnetwork.ca](http://www.canadianhealthnetwork.ca)*

*"Guide to Less Toxic Products". The Environmental Association of Nova Scotia, [www.lesstoxicguide.ca](http://www.lesstoxicguide.ca)*

*"What does clean really mean?" ToxicSmart Information Guides, Georgia Strait Alliance, [www.georgiastrait.org/TScleaners.pdf](http://www.georgiastrait.org/TScleaners.pdf)*

\*OBCIEP does not endorse any product; producers listed for information only.

Quality of Cancer Services Report

## CCO Studies New Strategies to Improve Cancer Care for Women

In May 2006 Cancer Care Ontario (CCO) released the report “The Quality of Cancer Services for Women in Ontario”, an initiative of the Ontario Women’s Health Council in partnership with CCO and the Cancer Quality Council of Ontario. The report attempted to address five key questions about cancer services for women about the measurement of services, accessibility of services, use of best practices, outcomes, and efficiency.

The study acknowledged that CCO is working to improve the quality of service for women but noted there are gaps in information which limit what can be measured. For example, because of lack of information it is not possible to assess the quality of care of subgroups of women who may be underserved because of income, education, culture, language and other factors; it is not possible to detect differences in waiting times for treatment between men and women; and, although women outnumber men in the population and there are sex differences in drug metabolism, side effects, and toxicity, historically women have not participated in clinical trials as frequently as men. As there is no gender analysis of data collected on clinical trials it is difficult to find information on how women fare relative to men on particular trials.

While the report acknowledged the positive influence of women’s health promotion programs aimed to reduce smoking and obesity, it also noted the limitations of such programs that do not take into account the impact of factors such as gender, age, socio-economic status and geography. For example, the report noted that there are significant barriers to maintaining healthy body weight and physical activity for those living on low incomes or for those living in remote areas. These barriers include the lack of recreation programs and/or facilities; the lack of availability and affordability of healthy foods; and the lack of education and transportation.

Some of the key recommendations to CCO are to improve data collection methods and to create specifically tailored prevention and health promotion programs. In particular the report recommends targeted efforts to increase cancer screening and health promotion to reach out to underserved women.

The report is available on the Cancer Care Ontario website at [www.cancercare.on.ca](http://www.cancercare.on.ca).

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*Encouraging more women to participate in clinical trials and collecting and reporting sex-specific trial data can improve cancer care for women.*

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# Couples and Cancer: Rebuilding the Ship at Sea

## What makes couples vulnerable at times of illness

by Karen Fergus

Why is that some couples are drawn closer together because of a breast cancer diagnosis and other couples are pulled apart?

Breast cancer is a major event for both the breast cancer patient and her life partner. It is often challenging for couples to assimilate the crisis of the illness into their everyday relationship. In order to deal with the illness, they find they must develop new coping skills, both as individuals and as a couple. It is not unlike having to rebuild the ship while it's at sea because not only is there the stress of the illness but there is also the stress of retooling and reorganizing the relationship as well. Many factors come into play: the couple's prior history with serious illness and crisis; practical constraints such as caring for children or aging parents; and the added financial burden associated with breast cancer. Because of the illness, the relationship is suddenly in flux.

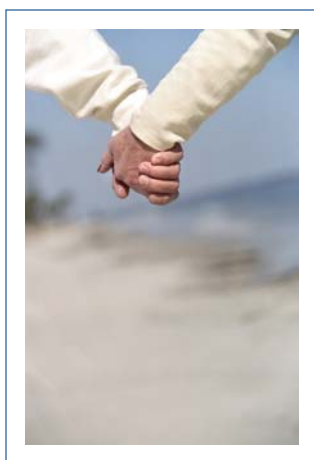
A recently completed two-year study explored couples' experiences with breast cancer. A goal of the project was to learn strategies and lessons about what bonds suffer and what can be strengthened at this vulnerable time. Experiencing breast cancer can magnify or exacerbate pre-existing marital tensions but even close couples experience periods of distress and disconnection. What accounts for these vulnerable points in the relationship while a woman is going through breast cancer?

Thirty individuals took part in the study that included one-on-one interviews as well as couple interviews and a focus group. The average age of the participants was 54 years for females, 51 years for males, and the couples had been together between seven and 40 years. The time since diagnosis was between three and 12 years, and five of the men taking part in the study had also experienced serious health conditions such as cancer and heart disease.

A few prominent themes concerning relationship vulnerability emerged from the analysis:

***Fish out of water:*** Many men indicated that they felt unprepared for the demands they faced in supporting their partners.

***"Under burdening":*** Although cancer patients often are concerned about being a burden to their partners and their families, the study revealed that *under* burdening was often more of a problem. Women



*"Nothing in how I've been raised as a man has prepared me for what I would face with my wife's illness," stated one spouse.*

## Info Exchange

are used to being the primary caregivers in the family and may have trouble asking for and accepting help when it is offered. Some react by becoming overly independent which can create distance in a relationship, or they may not ask directly for what they want, leading to feelings of resentment when the spouse does not respond to unstated needs or desires. "I just wouldn't even admit to myself that I needed help. Because I wanted to be . . . I wanted things to be OK," said one woman. In addition, many women try to hide their fears from their spouses and children in order to protect them.

The men on the other hand, try to minimize the stress on their spouses by not revealing very much about their own worries and apprehensions.

During the illness, many women gave themselves permission, often for the first time, to focus primarily on themselves and to become the object of *their own* caregiving. At times, this redirection of attention from others unto themselves was interpreted as a lack of consideration. In relation to her husband one woman said "I didn't have one more ounce of space to give."

***When to declare the illness is "over"***: Once active treatment for the disease is over the relationship is particularly vulnerable. For the spouse there may be an urge to return to the welcome pre-illness life. For the woman who has had breast cancer it is a period of renewed uncertainty--she often feels more fragile because she is no longer being monitored by a health care team. Women often describe the feeling as though they've been cut adrift. They also have to recuperate both physically and mentally from the treatment and contend with the implications of having had cancer and the changes, some permanent: premature menopause, loss of fertility, physical changes, change in sexuality, etc. Women say they often do not feel like the same person any more and their spouses are not immediately prepared to deal with the emotionally difficult work of supporting their partner into survivorship.

When couples are able to hold sight of the loving bond between them it can override some of the losses and disappointments experienced in the relationship when cancer is diagnosed. One of the objectives of the study is to develop booklets and couples' seminars outlining common relationships traps and tensions and how to problem solve in relation to them. With these resources, couples will be better able to anticipate the types of challenges that may lie ahead in facing the illness and post-treatment periods and learn ways to work through or circumvent them.

*Karen Fergus, PhD, CPsych, psychologist consultant to the cancer program of Toronto's Sunnybrook Health Sciences Centre recently completed a post-doctoral fellowship with the Canadian Breast Cancer Foundation - Ontario Chapter, focusing on the impact of breast cancer on spousal relationships.*

*"I'm not sure how many times I gave (my wife) the full sense of my state of burden because I didn't want that to distract her from what she was trying to do."*



## Canadian Dietitians help you to Eat Well, Live Well

### **DC Tips**

*For added fibre eat skins and peels, and have the fruit or vegetable more often than its juice.*

~ ~ ~

*Forget the dieting and get on with living. Adopt an eating pattern you can live with.*



The Dietitians of Canada (DC) serve over 5,400 dietitians across the country. DC's bilingual website provides information for its member dietitians and health professionals but also has many helpful, user-friendly online consumer tools and resources.

A special feature in the Eat Well, Live Well section is the Eat/Activity Tracker or "EATracker" that assesses food choices and provides personalized feedback on your total intake of calories and essential nutrients. An online eating and activity log form is provided and generates a daily assessment with tips to help improve eating and/or activity patterns. A history is also provided so participants can follow their progress.

In the "Virtual Grocery Store" you can learn how to use the nutrition information on the labels of packaged foods to make healthy choices. "One Day at a Time" offers helpful hints and recipes to continue healthy eating throughout your day. You can locate a dietitian in your area using the "Find a Dietitian" database.

The interactive website is fun and easy to use. Visit the site at [www.dietitians.ca](http://www.dietitians.ca).

### **Make-Ahead Banana Berry Wake-Up Shakes**

Make this calcium-packed shake the night before and you'll be ready for a quick morning meal to go. People who are allergic to milk or who are lactose intolerant can substitute a calcium-fortified soy beverage and soy yogurt. Makes 2 servings.

- 1 banana
- 1 cup frozen berries (any combination)
- 1 cup milk or vanilla-flavoured soy beverage
- $\frac{3}{4}$  cup lower-fat yogurt (vanilla or other flavour that complements berries)

In a blender liquefy fruit with a small amount of the milk. Add remaining milk and yogurt; blend until smooth. If shake is too thick, add extra milk or soy beverage to achieve desired consistency.

- from *Great Food Fast*, Callaghan & Roblin, Dietitians of Canada, 2000



## South Asian Women's Centre Breast Health Education Project

*by Anamika Mujoo Girotee*

The South Asian Women's Centre (SAWC) in Toronto was founded in 1982 and offers services to women and their families in settlement, employment, domestic violence prevention, supportive counseling, advocacy, research and wellness education. The Centre's two-year Breast Health Education Project, funded by Canadian Breast Cancer Foundation, was a real success story. The program provided much needed education and awareness in breast health often ignored by women in the community because of caring for families, looking for work, working long hours, and non-availability of suitable times to visit a physician. This project was unique because community volunteers were trained to become peer educators in the hope of empowering women and letting them take charge of their own health. Two of the volunteer educators contributed their views on the project.

### *Time to take responsibility of our own health*

Bhakti Parekh

*When I was a student from high school through college, "breast cancer" was just words. I would read in newspapers and magazines with an occasional mention on television. It seemed like something that happened to "other" people. But the last few years have been an eye-opener, after two of my aunts were diagnosed with the disease and both passed away trying to fight it. Ever since, reality has struck me, and even I can become a victim to breast cancer. I have noticed that Indian women in general tend to think they are "Superwoman". They worry about their husbands, children, parents, in-laws and their homes...but tend to ignore their own health. This attitude actually led to the death of both my aunts. Both of them were diagnosed at a very late stage of the disease. They ignored the symptoms at the beginning, and when it got worse; they were too scared and didn't want to worry their families. I never really thought about all this, until last year when my friend, who works for the South Asian Women's Centre in Toronto got involved in a project relating to breast cancer. She approached me to be part of the Gujarati women's group and undergo a training session and then conduct workshops for women in the Gujarati community.*



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## SAWC Breast Health Education Project

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*“Most of these women seemed to be so involved in their families that they had never given a thought about going for regular mammograms, or even discussing it with their family doctors.”*

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*The training session was extremely informative and I think it would be great if all women knew even half of what these sessions have taught me about breast cancer. We went to Swaminarayan Temple complex in Toronto to conduct a session for Gujarati women. We were surprised to see the number of women who turned up to attend the workshop. There were close to 100 women from different socio-economic backgrounds—women who spoke and understood English and women who only spoke and understood Gujarati. We showed them a video of how to do breast self-examination and gave them a brief explanation about breast cancer. We encouraged women to ask questions. It was a fulfilling experience to be able to do this workshop and I hope it triggered at least some, if not all of the women to be more aware of changes in their bodies as they grow older and detect any abnormalities before it is too late.*

### *Mammograms—an effective measure*

Anuradha Sinha

*In the course of my own volunteer outreach activities with this program what I observed was that there is eagerness among the participants to acquire all the breast health-related knowledge as well as about the measures to be adopted to improve the quality of their breast health. It was also good to know through the interactive discussions in the workshops that a few already had some knowledge and experiences about breast cancer through their own family histories or from the experiences of others. A few had mammograms at the recommendation of their family doctors. Many had very little information about breast health issues. This project provided participants a clear explanation with visual details of screening for the first time.*

*Though the awareness was welcomed and appreciated, only a few women agreed to sign up for mammograms right away, which is completely understandable. To expect lifestyle changes and changes in perceptions after one education session is too much to ask for. There is a strong need to have this education and awareness program conducted more frequently in order to reach out to women of all age-groups but especially to women over 50 to encourage them to be aware and to take care of themselves.*

Anamika Mujoo-Girottee is the Breast Health Education Coordinator at the South Asian Women’s Centre, [www.sawc.org](http://www.sawc.org), e-mail [amujoo@sawc.org](mailto:amujoo@sawc.org).

The SAWC Breast Health Education program was offered in partnership with the Canadian Breast Cancer Foundation.



## Breast Cancer Awareness Month Events

### National

#### October 1, Run for the Cure

The Canadian Breast Cancer Foundation CIBC Run for the Cure fund-raising event. To register or for information see [www.cibcrunfortheure.com](http://www.cibcrunfortheure.com).

**October 1 to 31, CBCN Online Auction**  
Help support the Canadian Breast Cancer Network by participating in the **October 2006 Online Auction!** Bid on hundreds of items. The auction runs from October 1 to October 31 and will be bilingual. Go to [www.cbcn.ca](http://www.cbcn.ca) or call 1-800-685-8820 for more information.

### Ontario

**Taking Steps Against Breast Cancer**  
The Canadian Cancer Society *Taking Steps Against Breast Cancer*, a leisurely 5 to 10 kilometre, non-competitive, pledge-based walk, taking place in communities across Ontario during September and October at various locations. For details of events in your area visit [www.cancer.ca](http://www.cancer.ca).

### Central Ontario

#### September 26

**Eat to the Beat 2006**, Willow Breast Cancer Support Canada's annual fund raising event. Over 60 women chefs participate in Willow's signature fund raising event. At Roy Thomson Hall, Toronto 7:00 p.m. Tickets \$145. Call 416-778-5000 or visit [www.willow.org/eattothebeat](http://www.willow.org/eattothebeat).

#### October 17

**The Role of Hormone Therapy and Herceptin in Early Breast Cancer**, by Dr. Leta Forbes on the effectiveness and side effects of treatment with Tamoxifen and Aromatase Inhibitors and on the rationale and side effects of Herceptin treatment. At Hearth Place, Oshawa, at 7:00 p.m. For more details call 905-579-4833 or visit [www.hearthplace.org](http://www.hearthplace.org).

#### October 20

**Kick Up Your Heels to Support BCSS Party in Pink** is a women only breast cancer fundraiser in support of Breast Cancer Support Services, Burlington. This fun-filled PINK event at the Holiday Inn, Burlington will attract over 750 women. For tickets call Lynn Beechey at 905-331-8182 or visit [www.breastcancersupport.org](http://www.breastcancersupport.org).

### Northwestern Ontario

#### October 27

**Luncheon of Hope**, with guest speaker Wendy Mesley at the Valhalla Inn in Thunder Bay, tickets \$40 available from the Northern Cancer Research Foundation. Call 807-345-4673 for information and tickets.



The Thunder Bay Breast Health Coalition through the Canadian Breast Cancer Foundation - Ontario Chapter Community Education Grant program has created *reNEW*, a women's health magazine. The focus is women's health and breast health and screening, with an emphasis on issues and topics important to women living in Northwestern Ontario. This fall up to 25,000 copies of the publication will be distributed throughout the northwest and it will be posted online at [www.breasthealthnw.ca](http://www.breasthealthnw.ca).



## An Ontario Breast Cancer Community Research Initiative Update

# Putting Knowledge to Work

*by Jennifer Nelson*

It would be difficult to dispute the importance of understanding more about the experiences and needs of breast cancer patients. However, there are many unanswered questions about how this kind of knowledge, gleaned through research, translates into more effective service provision and health care practice.

At the Ontario Breast Cancer Community Research Initiative (OBC CRI) our research involves working very closely with community groups, breast cancer survivors and other stakeholders. We often work with marginalized and under-represented groups of women, and we strive to keep the research relevant to their ideas and concerns. We also try to make sure their recommendations reach people who can make a difference in cancer care. To further this mandate, OBC CRI has received a one-year grant from the Canadian Breast Cancer Foundation - Ontario Chapter, to look more intensively at the ways in which research knowledge is best applied in health care and community settings to assist breast cancer patients. The goal is to learn more about the "knowledge-to-practice" process to

identify the best strategies to facilitate the uptake and use of our research findings.

Since the spring of 2006, we have been analyzing our networks and relationships with health care professionals and community groups to determine the best links and strategies for communicating our findings. We are planning a series of consultations with Ontario cancer service sites and advocacy networks or groups to learn more about the possibilities for future use of our work. These consultations will encompass two general themes that have emerged from our research over the last five years: the **financial burdens** of having cancer and **social inequities** for various groups of women with breast cancer. Each of these themes draws on findings from several different research studies, including work with low income communities, racialized and immigrant women, lesbians, different age groups, and women in various geographic settings. These consultations will occur this fall. We look forward to a positive year of new and enhanced partnerships.

