

breast cancer *Info Exchange*

Winter/Spring 2006; Volume 10, Issue 1

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The Fizzle and the Sizzle ... thoughts on the Internet

by Sue Keller-Olaman

Increasingly people are turning to the Internet to find information, activities, services and products. On the other hand, as many of you will be aware, some judicious browsing is often needed to find exactly what you are looking for. OBCIEP has heard these comments from those affected by cancer--that the Internet is a natural home of specialized information but also a source of exasperation at times. OBCIEP is developing an accessible user-friendly Internet 'hub' resource where people can obtain cancer-related information and support when they need it. As a first step, we completed a needs assessment, based on nine focus groups in the Greater Toronto Area and in Northern Ontario. A total of 64 people participated in the discussions. In the past issue we presented some of the findings on how the Internet stacked up as a resource compared to more traditional resources (such as books and videos). In this issue we again draw from the needs assessment, this time looking at frustrations encountered with the Internet as well as features that make a website 'work'. Here we present an overview of focus group participants' comments.

The Fizzle

The participants reported their frustrations and reasons for giving up on a website when searching for health and cancer-related information:

- **Information gaps.** Some would get frustrated because they could not find what they were looking for. For example, inadequate information regarding drug therapies; alternative therapies; a dearth of information for lung and ovarian cancer patients relative to breast cancer information; few resources in languages other than English; not many in French, or Spanish.

Please see *Internet* on page 2

Internet . . . cont'd

The Internet and Coping

"I learned that (breast cancer) doesn't mean a death sentence and that the survivor rate is excellent."

Sites You Like

www.breastcancer.org

USA site

www.bcans.ca

Canadian, Breast
Cancer Action Nova
Scotia

www.bclist.org

Canadian, The Breast
Cancer Mailing List
listserv

www.susanlovemd.com

USA, Dr. Susan Love

- **Clarity of information.** Many of the other frustrations were related to the way the information was presented. Most were looking for very clear and brief explanations. Frustrations therefore arose with: too much information (overload); unclear explanations; explanations that are too long; terminology that is too "medical" - not easy to understand; information that is out of date.
- **Credibility/ relevance.** Further frustrations included not knowing which sites to trust. Some would first check who sponsored the website before reading the content. They were suspicious of sites sponsored by drug companies. Some were also turned away by doubting the credibility of the information source. Websites presenting alternative therapies were given as an example where they believed there was a lack of credible sources. Frustrations were also linked to the greater number of American websites, when more relevant Canadian content was sought and preferred.
- **Visual features.** Objects that move on the screen were seen as distracting and upsetting to people who are already not feeling well. Exiting a website was also more likely if the site had annoying pop-up windows; graphics that zoom about the screen, a font size that is too small to read; any pulsing images, neon-bright colours; text that is too crowded or has too many highlighted words (too "busy" looking).
- **Too slow/ 'getting lost'.** People familiar with the Internet are accustomed to rapidly delivered information. Websites with many features (e.g., video, flash displays) that take too long to load led to frustration and quitting a website. Similarly, if a site takes many seconds to switch from screen to screen, the participants give up. One further frustration was not being able to track back to where a search began.

Interactive Features

The participants did find discussion boards useful; a place to find everyday information not often mentioned by health professionals (e.g., problems with fingernails due to chemotherapy). Having said this, while most were happy to read replies, they were less likely to post a question themselves. Discussion boards were viewed as useful but frustrations were linked to sorting through, and deciding between, great versus unhelpful or incorrect information. It was also a 'turn off' if the discussion board went off topic.

The Sizzle

Keys to “good” cancer information and support websites (see some “favourite” sites reported by focus group participants):

- **Easy-to-remember** domain names, short URLs that relate to site (no abbreviations), e.g., www.breastselfexam.ca.
- **Clarity/ accuracy.** Easy to understand, up-to-date information is key. A glossary of terms or dictionary was mentioned as a “plus” for any site. Short sentences and brief descriptions were also favoured. Canadian websites were desired and preferred to those created in other countries.
- **Specialized topics/ resources.** The participants wanted less generic and more specific information available online such as: financial concerns; alternative therapies; what clinical trials typically involve, etc., plus different information/links for younger women versus post-menopausal women versus Aboriginal women who face different issues and/or may be on different treatment therapies.
- **Search and link features.** When searching for information, the participants prefer sites where it is clear which level they are on. This makes it easier to know where they have been and where they are within the site map. In terms of search options, they prefer search tips, and engines that are built within the site they are browsing.
- **Positive.** Positive tone, positive messages (e.g., preference for survivor data versus mortality data). The participants enjoy websites where there are humorous or inspirational poems/ pictures/ stories sprinkled throughout (uplifting).
- **Presentation.** The participants prefer sites that are bright, bold, in large font, with limited text/written content on the screen. Navigation tips should be clear and graphics used, where possible, to describe, explain or demonstrate things.
- **Options.** Participants have a preference for: print-friendly pages; a place to post questions (e.g., ‘Ask the expert’); if they register with a site, the option NOT to receive e-mail updates; the use of audio and visual aids (video) (acknowledging that not all have a system to successfully use different media).

More Sites You Like

www.breastselfexam.ca

Canadian, Thunder Bay
Breast Cancer Coalition

www.breastcancercare.org.uk

United Kingdom

www.mayclinic.com

USA, Mayo Clinic

www.oncolink.upenn.edu

USA, University of
Pennsylvania

www.komen.org

USA, Susan G. Koman

OBCIEP is in the process of building and piloting a new Internet ‘hub’. We will provide updates to let you know how this interesting project is progressing. If you have questions about the project or would like to share your own comments or suggestions, please contact Irene Nicoll at OBCIEP at 416-351-3815 or by e-mail at irene.nicoll@sw.ca.

Turning UP the Volume on Ovarian Cancer

by Annie Atkinson

Canadian women know alarmingly little about ovarian cancer, according to a poll conducted by Decima Research for the National Ovarian Cancer Association (NOCA). Of the almost 1,400 women surveyed, 96% could not identify a combination of the most common symptoms of the disease. Ovarian cancer is the most fatal of gynecologic cancers and a disease that kills over 60% of those diagnosed.

Early detection of Ovarian Cancer increases the survival rate from 15% to 80%.

Other findings include:

- 12% of women claim to have never heard of ovarian cancer;
- One in three women believe a Pap test screens for ovarian cancer, which is untrue;
- Women at higher risk for ovarian cancer due to age (50+) are significantly less likely to be aware of ovarian cancer than younger women.

These findings are worrisome because there is no screening test for ovarian cancer, and women and their physicians must rely on symptoms to bring the disease to their attention. Common symptoms include abdominal pain, swelling of the abdomen or bloating, changes in urinary frequency, weight loss or gain, and nausea.

NOCA has launched a campaign called *Turn UP the Volume!* to increase awareness about ovarian cancer. For further information, visit www.ovariancanada.org or call NOCA toll free at 1-877-413-7970.



Ovarian Cancer

- Affects 1 in 70 Canadian women
 - Is diagnosed in 2,300 - 2,600 Canadian women each year
 - Claims 1,500 lives a year across the country
-

Web Resources on Ovarian Cancer

National Ovarian Cancer Association www.ovariancanada.org

Ovarian Cancer Canada www.ocac.ca

American Cancer Society www.cancer.org

Online article: *Sexuality for Women and their Partners*

Association of Cancer Online Resources www.acor.org

Listserve specifically for women with ovarian cancer

The Wellness Community www.thewellnesscommunity.org

Online guide: *The Patient Active Guide to Living with Ovarian Cancer.*

The Ontario Breast Cancer Community Research Initiative

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

by Jennifer Nelson

Very little research has been done in Canada to examine the breast cancer education and information needs of women of colour. While many breast cancer information resources exist, women of colour often report that these do not answer their questions and do not address them in ways relevant to their cultures. This study, through the Ontario Breast Cancer Community Research Initiative*, and funded by a grant from the Canadian Breast Cancer Research Alliance, set out to explore the needs of women of colour from their own perspectives.

Principal investigator Jennifer Nelson and research assistant Leslie Norville recruited 38 women from a number of immigrant and racial minority communities in the Greater Toronto Area, including Caribbean, Chinese, Filipino, Korean, Latin American, South Asian, African and West Asian. They ranged in age from 35 to 75 years and all had experienced a breast cancer diagnosis. The research process was guided by a consulting advisory committee made up of community group members, women's health researchers and facilitators.

The participants engaged in small, facilitated focus group discussions over a half-day session in which lunch and honoraria were provided; in a few cases, according to their preferences, they were interviewed one-on-one. In all cases, they were given samples of several information materials about breast cancer to read and discuss. Samples included informational brochures, pamphlets, and articles from magazines. During the group discussion, they were asked to assess the relevance, quality, format and accessibility of the materials from their own perspectives. They were also asked to comment on the images in magazines relating to breast cancer and those used in patient education materials.

Focus groups in this project have recently wrapped up and the data analysis is just beginning. While the final report will not be available for a few months, we are able to note some preliminary, general observations. For example, the majority of participants felt they had not received enough information at their time of





"I graduated from university, but for cancer, I didn't know anything. With these brochures I knew ... something...but some of the words were very difficult... and I couldn't find anybody to ask what that means."

diagnosis. Many participants liked the materials discussed and found them helpful, but they had various suggestions that would make information less ethnocentric and more user-friendly for women from non-white and immigrant communities. Some of these suggestions included: more racial diversity in references to food choices, the use of simpler, less technical language, and the depiction of different cultures and races in images. Many participants noted that most breast cancer images depicted upper middle class women, whether white or women of colour. This did not reflect the realities of patients who experienced financial difficulty or could not participate in the kinds of activities portrayed in the literature, e.g. sports and leisure, gardening. Women also commented that most images were of white or lighter-skinned black women, and that even where effort was made to show diversity, many cultures were still absent.

Several women suggested that educational materials should involve different "levels" of explanation about cancer, including added references to medical terms for those who were interested in understanding more, but simpler language for those who might have problems with English or were not scientifically trained. Many participants did report that they had been pleased with the health care they received, but that more information would have been helpful, especially about treatment decisions and physical changes with treatment, such as early menopause. Overall, the research points to the fact that breast cancer information and services remain largely geared toward a "model" patient who is white, middle aged, middle class, and well educated.

For further details of the study results, stay tuned to the Ontario Breast Cancer Community Research Initiative web site (<http://www.crwh.org/programs/obccri.php>) in the summer, 2006. Following the final report, recommendations from this research will be shared widely with healthcare workers and breast cancer community groups with a view to improving information provision for a wider range of communities.

**The Ontario Breast Cancer Community Research Initiative is a partnership of Sunnybrook & Women's College Health Sciences Centre, the University of Toronto, and The Centre for Research in Women's Health, and is funded by the Canadian Breast Cancer Foundation, Ontario Chapter.*

Good Food for Life

Participants Needed!

by Judy Gould

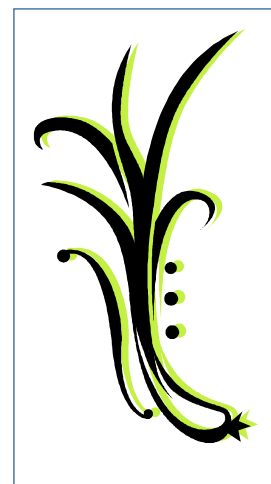
An eight-week, plant-based cooking program entitled **Good Food for Life: Supporting Dietary Change in Young Survivors of Breast Cancer** is the latest offering by FoodShare and funded by the Canadian Breast Cancer Foundation, Ontario Chapter. FoodShare is a food organization dedicated to increasing access to affordable and healthy food in Toronto. This currently offered food support program is intended to support lifelong dietary changes in young survivors of breast cancer, especially by increasing fruit and vegetable intake. The course will also focus on the fact that food has meaning in our lives that goes far beyond its function in keeping our bodies healthy. The program will offer social and interactive hands-on food skills; personal reflection and mindful eating; the opportunity to be connected to local food sources; and, interactive discussions about key issues related to food and the environment. Participants will be supported to make and sustain self-directed changes to their diet that are motivated from within.

Ontario Breast Cancer Community Research Initiative (OBC CRI) researchers will be assessing participants' expectations of the program, their experience of the program and their thoughts regarding changes or improvements to the program. In other words, folks who participate in this program this spring will also participate in three focus groups. The first will be held prior to the first class, the second prior to the last of the eight classes, and the third 12 weeks following the last class. During these focus groups you will be asked questions such as:

- how is the program supporting you to make or sustain healthy food choices?, and
- how could the program improve to assist you to make or sustain healthy food choices?

If you are interested in participating in the Good Food for Life program in the Greater Toronto Area and its evaluation and we would love to hear from you if you:

- were pre-menopausal at diagnosis
- are finished the treatment for breast cancer
- are not more than three years post-diagnosis, and
- are interested in helping us learn about your experience in this program



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We anticipate that the first evaluation of the Good Food for Life program will commence in the spring 2006. An honorarium for your participation in the evaluation will be provided.

Please call Judie Benyei at 416-363-6441 ext 230 or e-mail judie@foodshare.net to find out how to participate or to get more information. If you would like more information about the content and process of the evaluation please e-mail Judy.Gould@sw.ca.

Use It or Lose It: Preparing to Focus on Knowledge Translation/Knowledge Exchange

The Canadian Institutes of Health Research (2005) defines knowledge translation as "the exchange, synthesis and ethically-sound application of knowledge - within a complex system of interactions among researchers and users - to accelerate the capture of the benefits of research for Canadians through improved health, more effective services and products, and a strengthened health care system".

Knowledge exchange highlights the importance of two-way communication between researchers and those who are going to apply the research.

The goal of the Ontario Breast Cancer Community Research Initiative (OBC CRI) is to make a difference in the lives of women with breast cancer. Since 2001, OBC CRI researchers have generated knowledge about the lived experience or the social, psychological, emotional and spiritual impacts of breast cancer. Equipped with this knowledge we have worked with the breast cancer community to improve health services and support.

Though we make knowledge exchange part and parcel of our individual research projects, we now have the opportunity to extend our research mandate to focus intensely on knowledge exchange on consolidated projects.

The Canadian Breast Cancer Foundation, Ontario Chapter awarded the OBC CRI one year of funding, beginning April 2006, to consolidate, translate research results and evaluate knowledge exchange activities. You will be hearing more about our knowledge exchange strategies, activities and findings over the course of the next year.

~ Judy Gould

Ontario Breast Cancer Community Research Initiative

Women diagnosed with breast cancer know that it strikes more than their bodies--they are looking for insight into the social, psychological, emotional and spiritual impacts of breast cancer. The OBC CRI is creating and sharing this knowledge.

*See list of research studies and publications on **The Centre for Research in Women's Health** website at*

www.crwh.org/programs/obccri.php

New OBC CRI Study

Social and Psychological Determinants of Delayed Presentation in Locally-Advanced Breast Cancer

OBC CRI researcher Judy Gould has been working with Barbara Fitzgerald, an advanced practice nurse, psychologist Karen Fergus and oncologist Mark Clemons of the Toronto Sunnybrook Regional Cancer Centre to understand the circumstances associated with delay between discovery of breast symptom and diagnosis by a health professional in the medical system. Some of the questions being studied are: what are women's reactions to the discovery of a breast symptom or abnormality? What brings women to seek medical attention when they do? What other issues (work, family, concern about possible diagnosis, medical system delays, etc.)---if any---may influence women's behaviours?



Late in 2005, Fauzia Baig joined the team as the research coordinator of this quantitative and qualitative project that was funded by the Canadian Breast Cancer Foundation, Ontario Chapter. We have just begun to consult with women who receive treatment in the Locally Advanced Breast Cancer Clinic at the Toronto Sunnybrook Regional Cancer Centre. We will apprise you of the findings as they become available in the Fall, 2006. For more information, please contact Judy.Gould@sw.ca.

Information on Ontario Clinical Trials

New cancer therapies are tested in clinical trials and many patients may wish to consider participation in a clinical trial when deciding on the best option for the treatment of their cancer.

The Ontario Cancer Research Network(OCRN), with funding from the Ontario Government, has created this site to help you learn about clinical trials for cancer, where they are taking place and whether or not you might be eligible to participate. You can search through the database of all cancer trials in Ontario to find trials that may be suitable for you. The site includes tips, "frequently asked questions" and links to information on the Canadian Cancer Society's Cancer Encyclopedia, and a glossary to guide information searches on the database. Visit the site at www.ontariocancertrials.ca.

The OCRN is a not-for-profit corporation working to accelerate the development and testing of promising new cancer therapies. OCRN programs support research to develop promising scientific discoveries into new cancer therapies and promote clinical trials of new cancer therapies so that innovative treatments can be brought to patients sooner.

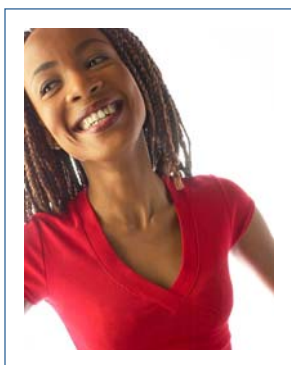
New Breast Cancer Support Program

Peer Navigation for Young Women

Young women often feel separate from their peers, and also find themselves isolated among the broader cancer population because of their stage of life and relatively young age. In response to these realities, a new program is being piloted in Toronto in the fall of 2005 to provide psychosocial and informational peer support for women in this population.

A collaborative initiative between Wellspring, Willow Breast Cancer Support and Resource Services, and the Toronto Sunnybrook Regional Cancer Centre, this program will allow young women to share their concerns about breast cancer in a confidential manner with an experienced trained peer volunteer. The program features:

- client and peer matching to suit individual circumstances
- highly trained peer navigation volunteers
- face-to-face and/or phone support within a supportive community
- information and direction to relevant resources
- continuing education for volunteers and users of the service
- quality control, monitoring and supervision



Young women with breast cancer face unique challenges in terms of loss of fertility, premature menopause, major disruptions to early careers and relationships, and concerns for their young children.

For more information as a user of this program, please call Wellspring at 416-480-4440 or 416-961-1928, www.wellspring.ca, or Willow Breast Cancer Support & Resource Services at 416-778-5000, www.willow.org.

This initiative is being funded by **Rethink Breast Cancer**, a charity helping young people who are concerned about and affected by breast cancer through innovative breast cancer education, research and support programs. Contact Rethink Breast Cancer at 416-920-0980 or visit their web site at www.rethinkbreastcancer.com.

Links to Resources for Young Women

For resources and links to sites specifically designed for young women dealing with breast cancer, see the Canadian Breast Cancer Network's site for young women at www.cbcn.ca/youngwomen. The site includes news, resources, bulletin boards, support groups, communities, and links to other resources in English and French.

Up Front: New Perspectives in Breast Cancer

by Cathy Dandy

The Ontario Chapter of the Canadian Breast Cancer Foundation has been working in partnership with several other breast cancer organizations on an initiative called Breast Care in Ontario. Updates on the progress of this initiative have been reported regularly in the Chapter's *In the News* newsletter. Ultimately, the goal of the initiative is to recommend strategies for change so the breast cancer/breast health system can be improved to better respond to the needs of women in the province.



Over the past year, we have learned about Ontario women's experiences within the breast cancer and breast health system through interviews and focus groups with breast cancer survivors, a public opinion survey of women across Ontario about their knowledge and understanding of breast health, and other research methods. As a next step, we are preparing to launch the project publicly under the name "Up Front: New Perspectives in Breast Cancer." This phase will see us connecting with communities across the province in order to report and validate our research findings and ensure they reflect the experiences of a broader population of women beyond those who were involved in the research directly. This work will be done through a series of consultations to take place in selected communities in March and April - Ottawa, London, Toronto, Sudbury and Timmins. The consultations will report the findings, listen to women and also begin the process of collectively formulating effective strategies to improve the breast care system in Ontario.

*Creating a future without
breast cancer*

www.cbcf.org/ontario

Partners involved in the Breast Care in Ontario initiative are the Canadian Breast Cancer Foundation - Ontario Chapter, the Canadian Breast Cancer Network, Princess Margaret Hospital Foundation - Breast Centre Women's Committee, the Ontario Breast Screening Program and Willow Breast Cancer Support & Resource Services.

If you have any questions, you can call 1-866-373-6313, ext. 680, or e-mail **Up Front** at info@cbcf.org. You can sign up for the Up Front newsletter at

<http://postsnet.com/app/campaigner/services/optinlist/processoptinrequest.jsp?oilb=86681822>.

News from OBCIEP Partners

Canadian Cancer Society Introduces New Website

The Canadian Cancer Society recently revamped its website at www.cancer.ca.

The website is organized in six major sections--About Cancer, Prevention, Cancer Research, Support/Services, How You Can Help, and Publications--all accessible from every page. Once you have selected one of the six main sections you will find the navigation menu for that section on the left panel. The health information on the site has been developed from credible sources and reviewed by experts. All pages include the date of the last review. The site is not sponsored by any outside organizations or corporations, and is maintained by Canadian Cancer Society staff.

The site include excerpts from the Cancer Information Service Cancer Encyclopedia, a national community services directory, latest research, links to clinical trials, and information on upcoming events.

Navigating Your Path

Navigating Your Path, a guide for people with advanced breast cancer is now available online on the Canadian Breast Cancer Network's website at www.cbcn.ca in "Tips and Tools for Women with Advanced or Metastatic Breast Cancer" of the Resources section. It is also on OBCIEP's site, Breast Cancer Information, at www.obciep.on.ca.

The French language version of the guide, *Vivre au jour le jour, un guide pour les personnes atteintes de cancer du sein à un stade avancé* is available from the CBCN. To obtain a copy please e-mail CBCN at cbcncn@cbcncn.ca or call in Ottawa local 613-230-3044, or, toll free at 1-800-685-8820.

CBCN's "Tips and Tools" resource list includes links to articles, guides, books, other publications, research, transcripts and videos of interest to people dealing with advanced or metastatic disease.

