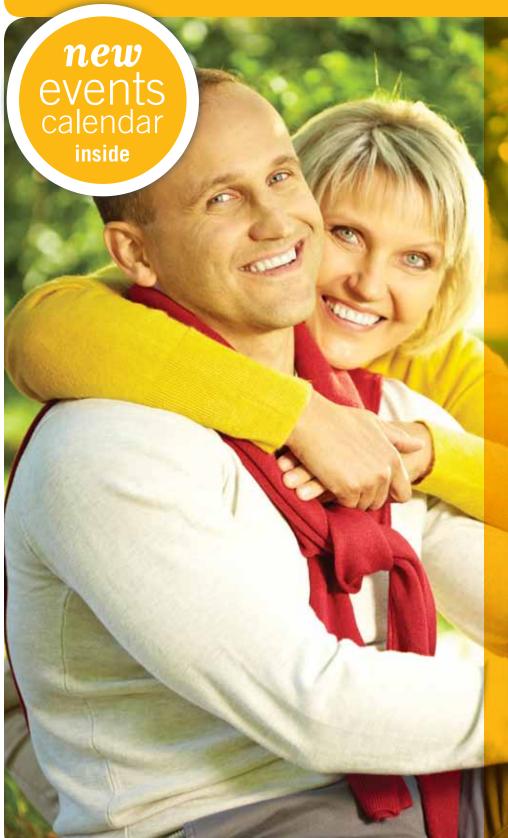


# network news

**ESSENTIAL NEWS FOR CANADIANS AFFECTED BY BREAST CANCER** 



04: Survivor Story
Linda's breast cancer
journey

O7: Emotional Wellbeing:
Meditation and exercise
help in coping with breast
cancer

10: Healthy Living:
Dragon boating an escape
for breast cancer patients

12: Advocacy:
Why share your breast cancer story?

14: Treatment Talk:
Oncotype DX: A test to
help breast cancer patients
personalize their treatment

16: Research Roundup:
Research of interest to breast cancer survivors

Recruiting participants for studies of exercise, art therapy and counselling for breast cancer

21: Resource Directory:
Services, seminars, books
for breast cancer survivors

# **NETWORKNEWS**

Volume 16, Number 3, Fall 2012

Network News is published by the Canadian Breast Cancer Network (CBCN) to provide the breast cancer community with up-todate and understandable information on issues at the national level, to promote education and awareness, and to highlight the concerns of Canadians affected by breast cancer.

We would like to thank the individuals who wrote articles and the breast cancer support groups that provided information. We welcome your ideas, contributions and letters, subject to editing and available space. The articles in this issue do not necessarily represent the views of CBCN but are the opinions of the authors. CBCN gives permission to copy with attribution.

"Production of this issue of *Network* News has been made possible through a financial contribution from the Public Health Agency of Canada. The views expressed herein do not necessarily represent the view of the Public Health Agency of Canada."

# **Canadian Breast Cancer Network.**

331 Cooper Street, Suite 602, Ottawa, ON K2P 0G5. Tel.: (613) 230-3044. 1-800-685-8820. Fax: (613) 230-4424. E-mail: cbcn@cbcn.ca. Website: www.cbcn.ca.

### **Editors:**

Jenn McNeil, Wendy Hall

### **Staff and Volunteers:**

Jenn McNeil,

Operations Manager, jmcneil@cbcn.ca

Rebecca Wilson,

Administrative and Communications Assistant, rwilson@cbcn.ca

Wendy Hall,

Publications and Office Assistant, whall@cbcn.ca

Lea Castro.

In Memoriam Coordinator Volunteer. In-memoriam@cbcn.ca

Contributors: Cathy Ammendolea, Cancer Care Nova Scotia, Oren Cheifetz, Sara Chenault, Sheila Dong, Linda Edgar, Thandi Fletcher, Genomic Health, Shawna Ginsberg, Kate Laux, Rethink Breast Cancer, Adina Rojubally, Linda Schneidereit, Victoria Steiner, Willow Breast Cancer Support Canada, Young Adult Cancer Canada

**Translation:** Martin Dufresne

### **Board of Directors**

Cathy Ammendolea, Chair, Quebec Beatrice Bernhardt, Nunavut

Mary Chaffey. Newfoundland

Diana Ermel, Past-Chair, Saskatchewan

Juliette Inglis, Alberta

Beverley Jacobs, Ontario

Suzanne LeBlanc, New Brunswick

Janis Murray, Secretary, British Columbia

Wendy Panagopolous, Nova Scotia

Judy Donovan Whitty, Prince Edward Island

Sharon Young, Vice-Chair, Manitoba

ISSN: 1481-0999 Circulation: 3600 **PUBLICATIONS MAIL AGREEMENT** NO. 40028655

Return undeliverable canadian addresses to CANADIAN BREAST CANCER NETWORK 331 COOPER ST, SUITE 602 OTTAWA ON K2P 0G5

E-mail: cbcn@cbcn.ca



# Subscribe to our e-letter, Outreach!

Outreach is the Canadian Breast Cancer Network's free e-letter, which contains action alerts, info about our activities, programs and projects. You can find out about opportunities to join panels, do surveys, order reports, and much more! It is only available by e-mail. To subscribe, send an e-mail to cbcn@cbcn.ca or call 1-800-685-8820 to sign up.





# LETTER FROM THE CHAIR OF THE BOARD OF DIRECTORS

# Dear readers:

Welcome to the new and hopefully improved Network News. We have been busy reviewing all the great feedback that we received from you in our spring survey, and we would like to share the results with you.

Overall, the feedback was very positive. The vast majority of respondents agreed that they look forward to receiving Network News, and you share it with friends and family. You indicated that you also prefer a print version, which we will continue to produce. Here are some of your comments:

"Very inspiring stories. Nice to learn about what's happening in other parts of the country."

"I understand the language used—it's not over my head."

"It is helpful for support group/community contact."

"We don't always know the questions to ask doctors; your publication addresses a lot of unanswered questions."

"Good overview of Canadian initiatives."

"The articles have given me hope and encouragement."

Here are some of the changes that readers asked for and that we have made, starting with the current issue. First, you wanted us to update the design to make the newsletter more like a magazine. Second, you wanted to see regular features on a range of topics, especially treatments and survivors' stories. We have responded by freshening up the design, adding more photographs and instituting different departments on the topics you asked for. Beginning with this issue, look for Treatment Talk, Research Roundup, Healthy Living, Emotional Wellbeing, Advocacy, and Survivor's Story.

We hope you enjoy the new look and content. Write to us with your comments on the newsletter, or send a letter to the editor for publication in the next issue. Let's keep the dialogue going with views from across Canada!

Cathy Ammendolea, CBCN Board Chair

Carry annextor

# **SURVIVOR STORY** Linda's breas cancer journe LINDA IN ROME, OCTOBER 2011

When Linda S. was diagnosed with Stage III infiltrating duct carcinoma breast cancer in 1999, at age 39, she was totally unprepared. Her reaction? "Shock!" she exclaims. Linda couldn't understand how this could have happened to her. After all, she felt she had taken good care of herself. So, before beginning any treatments, and with her surgeon's blessing, she sought a second opinion. Several days later, the diagnosis was confirmed.

Linda went from thinking of herself as a healthy woman to becoming a patient with a double mastectomy within just 16 days of her initial diagnosis. "It was really hard," she says. "The first day after they took off my bandages, I was taking a bath, and I looked down and thought, 'I look like a plucked chicken'." What was even harder for her was that she was initially given an approximately 90 percent chance the cancer would recur within two years.

Then came six rounds of chemotherapy over four months. All Linda's blond hair fell out, and her blood count was way down. The chemotherapy left her so tired that all she could do was lie on the sofa for the first week to ten days after each treatment. "I was flat on my back," she says. "I couldn't do anything." And her nausea was so bad she couldn't even stand the smell of cooking, so she was very grateful that friends pitched in to provide her family with home-cooked meals.

Also during chemotherapy, Linda developed lymphedema. Her left arm was very sore and swollen. But her surgeon's assistant told her it couldn't possibly be lymphedema because "that

never happens to our patients." Linda says that, looking back now, she is annoyed they didn't offer any support. "The fact that the surgeon was denying that it could be a problem was very arrogant," she says.

During this ordeal, Linda was glad to have a good friend to talk to. Her husband wasn't as helpful. "He would say, 'Let's go to the movies to get your mind off things.' He couldn't handle hearing what I was going through," she says. She also wished that her husband could have been more supportive in telling their son, age 8, and their daughter, age 10, about their mother's illness. "Breaking the news to them was one of the hardest things," says Linda. "My greatest fear was that I wasn't going to live to see them grow up."

Linda completed her treatment at Calgary's Tom Baker Cancer Centre in November 1999 and then, in August 2000, she moved with her husband and two children to Ontario so he could accept a promotion in his company. "That was just one life stressor on top of another," she now says.





# **SURVIVOR STORY**

"I wish doctors would develop a technique that allows women to retain more sensation, because right now it's just for aesthetics."

Linda's initial prognosis had given her two years to live cancer-free. But, in 2009, after ten years of checkups, the doctor told her she didn't have to see him again. She was cancer-free.

Around that time, Linda decided to finally do something about the self-image she had been struggling with since her double mastectomy. For ten years, Linda had been trying to accept her post-mastectomy body the way it was. At first, she had tried wearing loose-fitting shirts and lots of vests. Later, she tried prostheses, but they weren't very comfortable, and it made wearing 'feminine' clothes a challenge. She says, "I felt my appearance was a barrier to communication with people I didn't know well. I never knew if they were looking at the real me, or if were just thinking, 'Oh, poor woman, she had breast cancer'." She said her husband had reassured her that she was still beautiful with her new shape, but she didn't believe him.

So, when she was 49, Linda began to research reconstructive surgery. She was advised by two surgeons that, because of her slim body type, implants were her only option. She found an excellent surgeon at the Princess Margaret Hospital in Toronto, and had the three-part procedure (tissue expanders, permanent implants, and nipple reconstruction) in 2009 and 2010. "But I made a mistake when I agreed to allow the surgeon to do the nipple tattoos," Linda admits. Although excellent at surgery, her doctor was by no means a professional tattoo artist. A year later, Linda ended up having to pay to have the colour removed, and then the tattoos applied properly by a paramedical tattoo artist.

Asked about her one wish for improvements in reconstructive surgery, Linda says, "I wish doctors would develop a technique that allows women to retain more sensation, because right now it's just for aesthetics."

Linda says that her experience with cancer, and its aftermath, was one of the causes of her eventual marriage breakdown in 2011, when she left her husband to start a new life on her own. She sees this as a positive move, though, because it enabled her to find a new partner who is better suited to her and who accepts her as she is. "We weren't giving each other what we needed," she says of her former husband. "Who knows, without the cancer, we might have just kept on living day to day, not wanting to admit to ourselves, or each other, how far we'd grown apart, and how much we were missing out on in our lives."



Linda counsels other breast cancer patients to ask a lot of questions of healthcare professionals, at all stages of treatment, and to persevere until they get good answers. She says not all healthcare practitioners are equally skilled, so patients need to do research to find the best care. Self-advocacy can be difficult when you're ill, but it's vital—your health and even your life depend on it, she says.

Linda also recommends seeking psychological counselling during the early stages of the breast cancer journey, and later as well if you need it. "I didn't do that, but in retrospect, it would have helped me, and my children, a lot," she says.

Linda's experience with breast cancer made her realize that she has to take chances in life, and do what she wants because no one knows what's going to happen tomorrow. She also speaks her mind so people know what she's thinking. "Cancer has changed the way some people think about me," she says. "I get

more respect. For right or wrong, people look at me and think I'm a strong woman."

Now living in London, Ontario, Linda recently turned 52. She says that, despite some very mild lymphedema, "I'm feeling better than I have ever felt before in my life."

Note to breast cancer survivors: Inspire others! Tell your story in the next edition of Network News. Contact editor Wendy Hall at whall@cbcn.ca.for details



# POWERFUL

**Breast Fest 2012** 

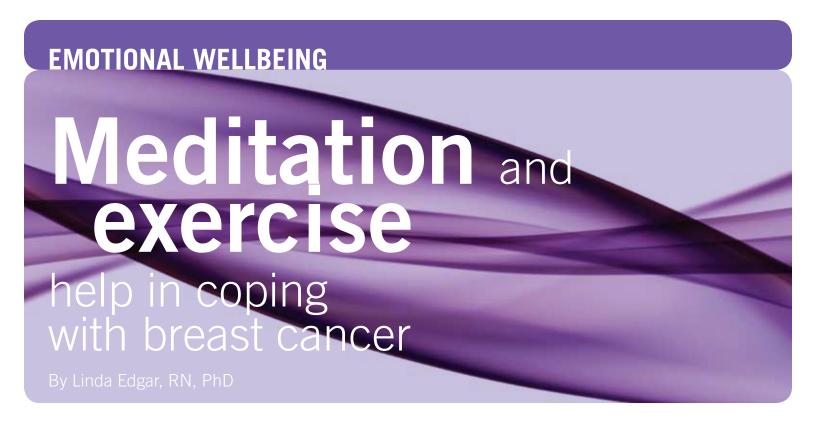
**NOVEMBER 2 - 4, 2012 • BLOOR HOT DOCS CINEMA** 

www.breastfestfilmfest.com









If a pharmaceutical company owned the wonderful discovery of mindfulness for cancer patients, there would be shouting from the rooftops, and headlines in print and on the web. There would be drug representatives reaching out to doctors in their offices and hospitals all across the country. But since mindfulness and exercise aren't owned by drug companies, not enough people know about them. I hope that this article will help you get started in understanding, practicing, and making exercise and mindfulness part of your own life plan. Perhaps you'll become an educator and advocate in spreading the word.

Let's start with exercise. Long gone are the days when rest was seen as more important than exercise in healing; when exercise was to be done lightly if at all, and with great caution. Today science has learned that those who are active see their risk of developing breast cancer drop by about 30 percent, and those with breast cancer can lower their risk of recurrence by 50 percent<sup>1</sup>.

Andre Picard, The *Globe and Mail's* expert on medical matters, said that exercise is one of the cheapest and most effective methods we have for preventing and treating breast and many other cancers. Exercise can be anything from grocery shopping and housework to moderately brisk walking to strenuous workouts in a gym. Plus, whatever you do is cumulative. That is, you can do 10 minutes here, 10 minutes later, etc. It all adds up. The aim is to work up to a mere 30 minutes of moderate exercise, five days a week.

Good health habits are also cumulative – if you don't smoke or drink to excess, as well as exercise, your risk of getting breast cancer can drop by 70 percent<sup>2</sup>. Besides helping to prevent and treat breast cancer, exercise also makes you happier, sleep better, be more energetic, have better resistance to infection, and look and feel better, among other great benefits.

Before you stop reading to go for a walk around the house or the block, it's time to introduce mindfulness, sometimes referred to as mindful meditation. Mindfulness is defined by Jon Kabat-Zinn as "paying attention in a particular way, on purpose, non-judgmentally in the present moment... Just being in the now." Everyone has experienced being mindful from time to time and paying attention to the present moment, but it takes practice to strengthen being mindful to reap the benefits. Since only the present moment is real, we have a limited awareness of the larger picture of life around and inside us, so that connecting with our

2 McCullough LE et al. (2012) Cancer, Fat or fit: the joint effect of physical activity, weight gain, and body size on breast cancer risk. DOI: 10.1002/ cncr.27433.

1 Anna L. Schwartz and L. Armstrong, (2004) Cancer Fitness. New York: Fireside Press. Available through amazon.com.



# **EMOTIONAL WELLBEING**

true self is both awesome and powerful.

There is scientific evidence that being mindful and able to regulate our attention can cause positive changes in the brain. Such changes help us control the primitive parts of the brain, manage emotions better, strengthen intuition, develop healthier and happier bodies, and be at peace. And the really amazing thing is that being mindful is easy. Try it right now by simply bringing your attention to your breath and how it feels to be breathing – inhaling and exhaling.

If your mind wanders away from paying attention to your breathing, gently bring it back to your breath. Continue this way for about five breaths. Another easy way to practice is to hold a small object in the palm of your hand, like a raisin or a small pebble, and pay attention to it, examining it closely and focusing your mind on it.

According to Chade-Meng Tan, the author of a great new book called Search Inside Yourself, mindfulness is the mind just being. It does, however, take lots of practice to be able to deepen and sustain being aware only of the present moment. When we practice being mindful we are actually meditating and doing some mental training. You are training your mind to focus on the present. Meditation helps the mind become relaxed and at peace, but at the same time, be alert, focused and stable.

Tan writes that meditation leads to happiness, meaning that when the mind is relaxed and alert at the same time, it returns to its default position, which is happiness. Happiness trumps pain every time. Thus, happiness is just being. Imagine that - happiness as an added benefit to preventing and treating breast cancer!

# Motivation

If everyone reading this article accepts that exercise and mindfulness will make them healthier, happier and help prevent recurrences of breast cancer, do you think that everyone is going to exercise more and learn to be mindful? You are right: the answer is no!

We have just run up against a pervasive, tricky human condition called, "I'll start tomorrow" or "It won't work for me" or Procrastinationitis. It's the exact opposite of motivation. Right now, how motivated are you to exercise and to practice mindfulness? Here are six stages involved in the process of taking on a new skill or making a change in your daily life. Which stage describes you now?

- 1. Precontemplation. You really haven't begun to think seriously about the possibility of making a change.
- 2. Contemplation. You are considering that it would actually be good for you to make such a change.
- 3. Preparation. You make a time and a place to practice, and set some small reasonable goals for yourself. If you are planning to walk more, you may buy a new pair of walking shoes.
- 4. Action. You start! There will be setbacks from time to time but you don't let that stop you and you return to your practice as soon as possible each time.
- 5. Maintenance. After about 30 times of practice you will find that you look forward to your new activity and fit it in to your schedule without much thought. It's on the way to becoming a habit. Good habits are great - we don't have to work to keep them, they keep us! Habits only come with practice.... 30 to 60 times of practice.
- 6. Relapse. Life has a way of upsetting our plans. Should you for whatever reason stop your practice, accept that it's part of the change process and start back at stage 2. If you give up after only a few sessions, research has shown that you haven't actually had enough practice to experience the results. You have merely observed yourself, and cannot know whether it's for you or not.

# Coping with new ideas

To cope well with life and whatever life brings means that you actively problem solve through life's challenges and take full advantage of the newest findings for health and well-being. Even though you may believe that learning new skills can be critical to your health, it isn't easy to change old patterns. And that's not surprising as we've learned our ways of thinking and behaving extremely well from childhood. To become motivated even to learn a simple new skill that has enormous potential for you isn't as simple as we'd like.

Eleanor Roosevelt said that a human life is like a candle ... sometimes it has to struggle for brightness. Our struggle for brightness is made easier as we understand more today about how the brain works and the part we play in determining our thoughts.

In my book on coping, I explain how most of life consists of facts over which we have little or no control; that every fact





# **EMOTIONAL WELLBEING**

leads to a thought; and that it is our thoughts that lead to our feelings. We can't change the facts of our lives but we do have complete control over our thoughts. As our brain hears less negative thoughts that we substitute for the ones that make us feel bad, it responds to the better thoughts and overrides the negative ones.

Don't resist or fight negative thoughts, accept and change them. Realize what your first pessimistic thought is, and gently put a positive thought in its place. The secret to this astonishing turn of events is that the brain responds to whatever messages we give it, whether we believe them or not.

# More on motivation

Now let's return to motivation. Motivation needs three particular kinds of thinking. First, believe that whatever new change you are making is one that you can enjoy and feel completely involved with.

Second, imagine what you want to achieve. Research has found that even before events happen, the brain begins to turn our thoughts and feelings into actions to make that event more likely to take place. As Marc Lesser writes in his book, Less: Accomplishing More by Doing Less, "In a sense, we learn from the past what to predict for the future and then we live the future we expect." So imagining or visualizing what we want to happen in learning a new habit can help make it happen, just as athletes visualize themselves scoring, winning, and playing well.

Third, rely on your ability to be resilient, to bounce back from setbacks and find ways to overcome obstacles along the way. We all fail and fail often at things large and small. We forget that failure is an essential part of success. However, if you usually doubt your ability to follow through and reach your goal, you may be a closet pessimist. If that is you, don't feel badly, because as you read in the above paragraph it's not your first negative thought but your second less negative thought that counts. You don't even have to believe your positive thought – your brain feels it and will act on it. Hard to believe but true!

One last point to emphasize over and over is that trying—just a few times - is not enough, and certainly not grounds for deciding change isn't for you. Practice at least 30 times before you pass judgment, and by then you will be convinced of the advantages. What if a new habit could revolutionize your life and you'd never know because you didn't practice enough!

To sum up, exercise and mindful meditation are two welltested ways to become healthier and happier. Why not practice them both? Recognize how motivated you are and how to get closer to actually taking action by using your coping skills. You have already taken steps along your journey by reading this article. Remember the present is what we have and as it turns out it's also what we need. Remember too that the brain responds to the thoughts we give it – so go ahead and put in some hopeful, optimistic, determined and practical thoughts. Do your job by practicing and the brain will follow.

The books mentioned in the article are suggested for further reading:

Linda Edgar (2011, 2012) Mastering the Art of Coping in Good times and Bad. www.artofcoping.com, available in English and French.

Jon Kabat –Zinn (1990) Full Catastrophe Living: Using the Wisdom of Your Body and Mind to Face Stress, Pain, and Illness. New York: Delacorte Press.

Marc Lesser. (2009) Less: Accomplishing More by Doing Less. Novata, Ca: New World Library.

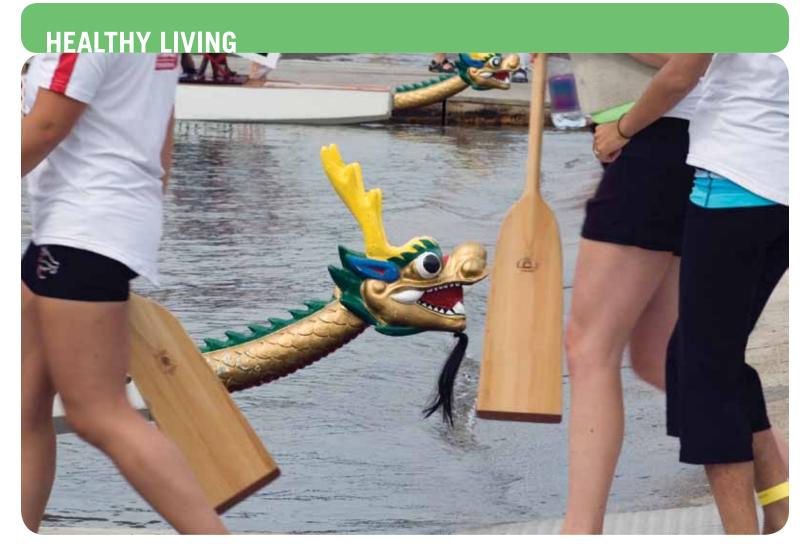
Cheng-Meng Tan (2012) Search Inside Yourself. New York: Harper One.

# Wehinar series:

# Coping skills for breast cancer patients

The Canadian Breast Cancer Network will be hosting a threepart webinar series that will feature Dr. Linda Edgar and will focus on developing and improving coping skills for breast cancer patients. These one-hour webinars will be free of charge and will provide participants from across Canada with the opportunity to learn practical tips on how to improve their coping skills. These sessions will take place at 7:30 p.m. Eastern Time on October 23, November 6 and November 20, 2012. To participate in these webinars, you will need access to a computer with an internet connection and a phone. All calls will be toll-free. For more information or to register, e-mail Rebecca at rwilson@cbcn.ca.





# Dragon boating an escape for breast cancer patients

Breast cancer may be the common link between paddlers in Calgary's Sistership dragon boat team, but it's not something they talk about much.

"I'd say cancer brought us together," said paddler Deidre Palik, "but for the most part, it's just about getting on with dragon boating."

Founded in 1998, Sistership is a competitive dragon boat team made up of breast cancer survivors in Calgary.

Dragon boating is a popular sport among women with a history of breast cancer. The movement was sparked in 1996 when Vancouver sports medicine specialist Dr. Don McKenzie brought together 24 breast cancer patients to form a dragon boat team. At the time, doctors recommended breast cancer patients limit exercising their upper bodies to prevent lymphedema, a painful condition that can develop after breast

surgery that causes swelling of the arm and chest.

But McKenzie wanted to test that theory and see whether the repetitive, upper body exercise of paddling could actually prevent lymphedema. None of the women developed the condition from paddling.

In 1998, McKenzie wrote an article about the team that was published in the Canadian Medical Association Journal. Since then, dragon boating for breast cancer patients has grown into a worldwide movement, with more than 150 teams sprouting up in the United States, Great Britain, Australia, and many other countries.





# HEALTHY LIVING

That same year, Sistership started in Calgary, inspired by the original Vancouver group. Since then, more than 200 breast cancer patients have signed up to try their hand at the sport.

"I felt like it was the reason that I had been presented with breast cancer," Palik said.

"Honestly, it was like the gate to a whole new piece of my life."

But Palik is quick to say Sistership is not a cancer support group. While teammates will lend an ear if someone is going through a difficult time, she said the mandate is "more about healthy living and getting on with it." Once the team pushes off from the dock, padding is their escape from breast cancer, she said.

"A lot of these girls have never been on a sports team before," she said. "When they get on the boat, not only do they find a way to survive, they find a way to thrive."

Palik, who has been paddling for six years, said the sport transformed her life. From the moment she attended her first meeting, she felt connected to the sport.

"I felt like it was the reason that I had been presented with breast cancer," Palik said. "Honestly, it was like the gate to a whole new piece of my life."

As soon as the ice melts on Calgary's Glenmore Reservoir, Palik said the paddlers and their coach are on the water. The team competes in about four festivals a year, and has raced in cities across Canada, from Victoria, B.C., to Sydney, N.S. They don't always win, but Palik said winning for them "is the mere fact that we're in a boat, too."

Since they began, Palik said the team has lost more than a boat load of its members to the disease. "It can be difficult," she said, her voice breaking with emotion. "A couple of years ago, we lost a very dear member. But she was so competitive, truly to honour her, you get back in that boat and you keep fighting."

Before racing against other breast cancer dragon boat teams, Sistership releases 22 doves, signifying the number of seats in a dragon boat, to honour paddlers whose lives were claimed by the disease. The ceremony is emotional, Palik said, but it also helps send a message that a breast cancer diagnosis isn't a death sentence.

"They can see that despite the fact that we're all very emotional at this moment, that there's strength in us, that there's a day after breast cancer and a life after breast cancer," she said. "What we want to give out and express is hope."

Danny Ng, co-chair of Calgary Dragon Boat Society, said he was touched the first time he saw the dove ceremony.

"It hits you in the heart to see something like that, knowing where they came from," said Ng. "Through all the hardship, they bond together through the sport of dragon boating."

Source: Thandi Fletcher, The Calgary Herald, http://www.calgaryherald.com/health/Dragon+boating+escape+breast+cancer+patients/7130568/story.html#ixzz24xTEu6dt , August 23, 2012. Reprinted with permission of The Calgary Herald.

# Yes!

# I want to support the Canadian Breast Cancer Network! The voice and advocate for survivors!

As a <b>Member</b> Annual Membership Fee: \$25 – individuals and organizations	As a <b>Friend</b> of the n	etwork \$100 or Add my donation for \$
Cheque enclosed VISA MasterCard Total Amount:	\$	_
CARD NUMBER:	EXPIRY DATE	_ SIGNATURE
NAME:	_ ADDRESS	
CITY	PROV	_ POSTAL CODE
TELEPHONE	EMAIL(Receive C	Outreach alerts and news by email)

# Why share your breast cancer story

Why survivor advocacy is important - and not as intimidating as it sounds





By Jenn McNeil

Everyone has a story, and every breast cancer patient and survivor has a story about their journey and the impact that this disease has had on their life. Each survivor brings a unique voice to the breast cancer experience based on many variable factors. Over the past few years working with the Canadian Breast Cancer Network, I have had the privilege of listening to many breast cancer

survivors share their very powerful stories and I am always amazed at the strength, courage and determination that they all show. Each journey is unique; however, there are often similarities experienced by patients and survivors.

When asked about their breast cancer experience, most survivors can identify positive aspects of their journey, such as meeting new people, realizing their own strength and experiencing the love and support of others. Everyone I've spoken with can also identify challenges and obstacles that they experienced as they went through their journey, such as the impact that the disease and treatment had on their daily life, adjusting to a new normal, the psychosocial and physical effects of the disease and the financial burden of a breast cancer diagnosis.

As the voice of breast cancer survivors across Canada, the Canadian Breast Cancer Network (CBCN) aims to engage breast cancer survivors and patients to provide them with the opportunity and platform to share their experiences and help affect change to improve the lives of both breast cancer survivors and patients across Canada. CBCN seeks to support breast cancer survivors by empowering them to advocate for themselves and on behalf of other survivors. We strive to do this by providing survivors with advocacy training, support, education and the opportunity to meet decision makers.

Oftentimes when people hear the word advocacy they are intimidated. The idea of meeting with decision makers or

speaking with the media can seem like an overwhelming task that might be better suited so someone who has more experience working with governments or media; however, CBCN believes that the people who are the most appropriate to speak about challenges and improvements needed for breast cancer patients and survivors are those who have lived through or are living with this disease. The patients and survivors are the experts on knowing the direct impact of this disease and therefore are the ones who should be dictating where the gaps are and what needs to be done in order to improve the lives of themselves and others.

CBCN holds survivor advocate training workshops throughout the year at a provincial and national level to help provide breast cancer survivors with the confidence to effectively share their story with decision makers and help affect change across the country. We are always looking for additional participants to help continue to raise awareness around the needs of breast cancer survivors and patients. If you would like to find out more information on how you can become involved and share your story to affect change please contact Jenn McNeil at jmcneil@cbcn.ca or at our offices 1-800-685-8820.







16th Annual

Empowering patients and professionals

Register before

September 14

for best pricing and

workshop selection

Saturday • October 27, 2012 Courtyard Marriott • Toronto

# **Plenary Sessions and Workshops**

- The Chronic Care Model
- The Science of Compression
- Lymphedema Basics-101
- Self-Care Management
- Challenging Case Studies
- Creating Your Own Case Studies
- Additional Treatment Options
- Hospital Program Clinicians Session
- Exercise and Lymphedema
- Ethnodrama-Theatrical Presentation
- Ask the Expert Panel

Become a member today to receive reduced conference rates and a subscription to **Pathways** 

Special CBCF luncheon guest speaker **Professor Miles Johnston** Advances in Lymphatic Research

# **Featuring International Experts**

- Anna Towers
   David Keast
- Robert Harris Margie McNeely
- Andreas and Hildegard Wittlinger of the Vodder Akademie in Austria plus additional workshop facilitators

# **NEW this year**

You can now register online through our website www.lymphontario.ca

Take advantage of the SPECIAL LAO CONFERENCE RATE of \$119 when booking your stay at the Courtyard Downtown Marriott

With such a low hotel price, why not make a weekend out of it!

Book your reservation by calling 416-924-0611 before **September 25, 2012** as rooms are subject to availability









For more information and to register online visit www.lymphontario.ca







Have you recently been newly diagnosed with early-stage breast cancer? Are you struggling to make treatment choices? More than 23,000 Canadian women will be diagnosed with breast cancer this year, but for some women, chemotherapy may not add any significant medical advantage.

Cancer is an extremely complex disease: each patient's cancer contains different gene expression profiles which make up the unique biology of the patient's tumour. As a result, certain patients may be more likely than others to have aggressive disease or to respond to certain therapies. Currently, traditional clinical and pathological measures like patient's age or tumour size and grade offer limited insight into the underlying biology of your cancer, which makes tailoring your treatment difficult. This is where Oncotype DX comes in.

Oncotype DX is a diagnostic test that helps identify which women with early-stage, estrogen receptor-positive breast cancer are more likely to benefit from adding chemotherapy to their hormonal therapy. This test also helps an individual woman understand the likelihood of having her breast cancer return. Oncotype DX provides important information that you and your doctor may use when making decisions about treatment.

After a breast cancer diagnosis, doctors and patients work together to plan an appropriate course of treatment following surgery; the goal is to keep breast cancer from coming back. One key step in treatment planning is to determine how beneficial certain types of treatment, such as chemotherapy, may be for an individual patient. Another step is to understand the individual likelihood of having your cancer return.

Therefore, learning as much as you can about your breast cancer tumour right now can help you and your healthcare team develop a more informed treatment plan.

While it is upsetting to receive a diagnosis of breast cancer, it is important to gather as much information as possible to determine a treatment plan that is right for you. Because every patient's

breast cancer is unique, your doctor will analyze your cancer to design a plan based on the specific characteristics of your breast tumour. To help your doctor understand your tumour, many factors will be assessed. These factors include your age, the size of your invasive tumour, whether your tumour has spread and whether there are estrogen receptors and HER2 receptors on the cells of your tumour.

In addition to these factors, the Oncotype DX test provides more information about what is happening inside your tumour. The test measures the activity of 21 different genes, 16 of which relate to both benefit from chemotherapy and the chance of cancer coming back.

Oncotype DX gives you and your doctor a better understanding of how your tumour behaves. This important information helps determine which treatment to use. As Oncotype DX provides individualized information about your tumour, it enables the treatment to be tailored specifically for you.

The Oncotype DX test is appropriate for women who are newly diagnosed with early-stage, lymph node-negative and estrogen receptor-positive breast cancer. Additionally, certain women with estrogen receptor-positive, lymph node-positive breast cancer may wish to discuss with their doctor if the Oncotype DX test would be of benefit to their care.

Your doctor will receive a report with the results of your Oncotype DX test. The report contains the Recurrence Score result, which is a number between 0 and 100.

Women with lower Recurrence Score values have a lower risk that their cancer will return. These women also have a cancer that





# TREATMENT TALK

is less likely to respond to chemotherapy, so their doctors may recommend treatment with hormone therapy alone.

Women with higher Recurrence Score values have a stronger change that their breast cancer will return. While, this can be distressing, the good news is that women with higher Recurrence Score values are more likely to gain a large benefit from chemotherapy. For these women, having chemotherapy (in addition to hormonal therapy) may help reduce the chance that their cancer will come back in the future.

It is important to understand that a lower Recurrence Score result does not mean that there is no chance that a woman's breast cancer will return. Also, a higher Recurrence Score does not mean that a woman's breast cancer will definitely return.

The Oncotype DX test results also provide additional information, such as the activity levels of the estrogen and progesterone receptors in your tumour, to help further guide your treatment.

Oncotype DX is performed on a small amount of your tumour tissue that was removed during your original surgery (lumpectomy, mastectomy or core biopsy). This tissue is routinely saved and stored at the hospital where you had your surgery. When your doctor orders the Oncotype DX test, the hospital will send a sample of your tissue to Genomic Health, the laboratory that performs the Oncotype DX test. You will not have to go through any additional surgery or procedure to get the Oncotype DX test.

It is important for your doctor to request the Oncotype DX test before starting any treatment with chemotherapy, since the Oncotype DX test is intended to help determine whether or not you are likely to benefit from chemotherapy in addition to your hormonal therapy. If you do not know the stage of your breast tumour or the estrogen receptor or nodal status, please check with your doctor.

It will typically take 10 to 14 days from the date the tumour sample is received by Genomic Health for the results to be available. The Oncotype DX test results are sent to your doctor so that he or she can discuss the results with you and answer your questions.

The test can only be ordered by a licensed healthcare professional, such as your doctor.

The Oncotype DX test is reimbursed publicly for qualified patients in Ontario, Quebec, and Saskatchewan, with a number of provinces considering public funding for qualified breast cancer patients.

"As cancer specialists, we would like to offer each patient a risk assessment and treatment plan that is based on the best possible information and is specific for her," said Sandy Sehdev, M.D., oncologist in the William Osler Health Centre's Oncology Clinic

in Brampton, Ontario. "This will allow chemotherapy to be used where it will be most beneficial to women and spare some women from having chemotherapy, when it is not needed."

The Oncotype DX test is based on genomics--the study of complex sets of genes, their functions, and how they interact with one another. Another way to think about it is as a small network of genes and how they work together to influence the tumour biology and behavior.

Multiple studies, including a recent study from British Columbia, have shown that the knowledge of the Oncotype DX test result changes treatment recommendations in patients with ER+ invasive early-stage breast cancer by 30 percent on average.

Today, more than 5,000 women from across Canada and over 300,000 patients worldwide have benefited from the information provided by this test.

The Oncotype DX test is based on genomics--the study of complex sets of genes, their functions, and how they interact with one another. Another way to think about it is as a small network of genes and how they work together to influence the tumour biology and behavior.

The key to effectively using genomics to make decisions to improve cancer treatment lies in better understanding which sets of genes and gene interactions affect different subsets of cancers. Genomic Health, as well as other companies and academic research centers continue to carry out studies in an effort to better understand which patterns of gene expression within a tumour are linked to cancer therapy response. In breast cancer, studies are in progress to develop clinical tests to guide selection of specific drugs and/or drug classes, such as taxanes, anthracyclines. angiogenesis inhibitors, and PARP inhibitors to provide patients with more targeted therapies.

The field of genomics is a dynamic area of research--growing and evolving very quickly as more and more researchers grasp the potential of this exciting branch of science.

To learn about patients who have used genomic testing to personalize their breast cancer treatment, visit: www. mybreastcancertreatment.org or call 1-866-662-6897.



# RESEARCH ROUNDUP

A DIGEST OF CANADIAN AND INTERNATIONAL RESEARCH OF INTER

# BREAST CANCER STUDIES LOOK AT A ROBOT, DIET, THE LGBT EXPERIENCE, HEART HEALTH AND **BREAST-CONSERVING SURGERY**

# Protecting the hearts of cancer patients

Dr. Sean Virani, director of heart failure at Vancouver General Hospital, has been looking at the impact of cancer therapies on the heart, trying to find a way to better support the heart through the chemotherapy and radiation treatment process, and beyond.

Dr. Virani is co-leading a research trial to specifically look at breast cancer patients who are receiving specific types of chemotherapy which are known to be toxic to the heart. The trial has just received three years of funding from the Canadian Cancer Society totaling \$172,000.

Women battling breast cancer are at risk for developing microscopic scar tissue in the heart, leading to abnormal contraction and other symptoms of heart failure because of a common family of drugs used during chemotherapy: anthracyclines. While effective, anthracyclines are known to have a negative impact on the heart.

In addition, many women are being diagnosed and treated for breast cancer later in life and may already be suffering from

common heart problems such as hypertension. Pre-existing heart problems make the likelihood of experiencing cardiotoxicity from anthracyclines even greater.

In September, Dr. Virani was to enroll 78 women in the sixmonth, placebo-controlled trial. He will examine how eplerenone, a common medication used for preventing or reversing heart damage in heart attack patients, can impact the quality of life, and ultimately scar tissue formation on the heart, for breast cancer patients when used in tandem with anthracycline.

The funding for Dr. Virani's research is one of 28 new innovation grants provided by the Canadian Cancer Society to researchers across the country. The goal of the grant program is to support unconventional concepts, approaches or methodologies to address problems in cancer research.

For more information, please contact Dr. Virani at 604-875-5092.

Source: Sheila Dong, Canadian Cancer Society

# UBC project examines the LGBT experience with breast and gynecological cancers

Researchers at the University of British Columbia are leading the first nationwide project on how sexual and gender minorities experience cancer. Led by Prof. Mary Bryson, Director of the Institute for Gender, Race, Sexuality and Social Justice, and funded by the Canadian Institutes for Health Research, the three-year Cancer's Margins project will look at how lesbian, gay, bisexual and transgender cancer patients and members of their support networks in British Columbia, Manitoba, Ontario, Quebec, and Nova Scotia experience breast and gynecological cancers from screening and diagnosis to care, treatment and support networks. Researchers want to understand what individuals value about their care and support networks, how

they educate themselves, and what they consider culturally competent care. "People try to look for health information in communities that reflect themselves," said Bryson, also a professor in the Faculty of Education. "We've found that these groups don't have access to cancer health care, or cancer support communities that map onto their own support networks and community values." For more information, visit the Cancer's

Margins website at www.queercancer.org.

Source: University of British Columbia news release, "UBC project examines the LGBT experience with breast and gynecological cancers", http://www.publicaffairs.ubc.ca/2012/08/02/ubc-project-examines-the-Igbt-experience-with-breast-and-gynecological-cancers/, August 2, 2012.



# RESEARCH ROUNDUP

# High-carb diet tied to breast cancer for some

Older women who eat a lot of starchy and sweet carbohydrates may be at increased risk of a less common but deadlier form of breast cancer, according to a European study.

The findings from a study of nearly 335,000 European women, published in the American Journal of Clinical Nutrition, do not prove that sweets, French fries and white bread contribute to breast cancer-- but they do hint at a potential factor in a little understood form of breast cancer.

Specifically, the study found a link between high "glycemic load" and breast cancers that lack receptors for the female sex hormone estrogen, so-called "ER-negative" breast cancers.

A high glycemic load essentially means a diet heavy in foods that cause a rapid spike in blood sugar, such as processed foods made from white flour, potatoes and sweets.

The study, conducted by Isabelle Romieu of the International Agency for Research on Cancer in Lyon, France, looked at nearly 335,000 women who took part in a long-running European study on nutrition factors and cancer risk.

Of these, 11,576 developed breast cancer over a dozen years. Overall, there was no link between breast cancer risk and glycemic load, as estimated from diet questionnaires the women completed at the study's start.

But the picture changed when the researchers focused on postmenopausal women with ER-negative cancer. Among women in the top 20 percent for glycemic load, there were 158 cases of breast cancer, versus 11 cases in the bottom 20 percent - a 36 percent higher risk.

ER-negative tumours account for about one-quarter of breast cancers. They typically have a poorer prognosis than ER-positive cancers because they tend to grow faster and are not sensitive to hormone-based therapies.

Sources: 1. Isabelle Romieu et al (2012), Dietary glycemic index and glycemic load and breast cancer risk in the European Prospective Investigation into Cancer and Nutrition (EPIC). Am J Clin Nutr August 2012 vol. 96 no. 2 345-355, http://www.ajcn.org/content/96/2/345. abstract 2.http://www.vancouversun.com/health/women/High+carb+diet+tied+breast+cancer+risk+some/7000055/story.html, July 27, 2012

# Canadian robot can detect and treat breast cancer

A Canadian robot that could transform the early detection and treatment of breast cancer is within months of being tested on patients. The main advantages of the robot are its accuracy and the ability to scan, test and remove a lump all at once instead of patients having separate appointments for each step. The spiderlike robot attaches to any magnetic resonance imaging (MRI) machine. If a lump is found, the doctor gives the co-ordinates to the robot, which instantly performs a precise

biopsy to determine if the lump is benign or a cancerous tumour. Called IGAR, the robot was developed by the Centre of Surgical Invention and Innovation, which is housed at McMaster University and St. Joseph's Healthcare in Hamilton, Ontario. The robot will be tested on up to 120 patients in Hamilton, Toronto, Quebec and the United States by early 2013.

Source: http://www.thespec.com/news/local/article/757402--hamilton-robot-can-detect-and-treat-breast-cance, August 1, 2012

# One in five women with breast cancer has a reoperation after breast conserving surgery

One in five women with breast cancer who opt for breast conserving surgery rather than a mastectomy have a reoperation, according to a British national study of 55,297 women published on bmj.com. This increases to one in three of those women who have carcinoma in-situ disease. This information on the risk of reoperation should help women in making the decision about whether to undergo breast conserving surgery or mastectomy.

When combined with radiotherapy, breast conserving surgery produces similar survival rates to those achieved with mastectomy alone. But because some tumours are difficult to detect, breast conserving surgery may result in their inadequate removal and lead to another operation. This reoperation may involve another breast conserving operation or a mastectomy.

Lead author, Dr David Cromwell, Senior Lecturer in Health Services Research at the London School of Hygiene and Tropical Medicine, said: "Breast conserving surgery with radiotherapy is as effective as mastectomy but if women choose conserving surgery, there is a risk of having another operation. Before this study, it was unclear what that risk was but now women can be better informed."

Source: R. Jeevan et al (2012) Reoperation rates after breast conserving surgery for breast cancer among women in England: retrospective study of hospital episode statistics.

BMJ2012;345:e4505, http://www.bmj.com/content/345/bmj.e4505, http://www.bmj.com/press-releases/2012/07/12/one-five-women-breast-cancer-has-reoperation-after-breast-conserving-surge, July 12, 2012.

Note to researchers:

To share your research

results with Canadian breast
cancer survivors, e-mail a notice

to Wendy Hall at

whall@cbcn.ca for publication

in Network News.



# PICKA FIGHT THE FRIGHT





# Recruiting participants for studies of exercise, art therapy and counselling for breast cancer

Participating in clinical trials can be a good way for breast cancer survivors to gain access to novel treatments to which they might not otherwise have access. Clinical trial participants also help researchers make new discoveries that benefit future breast cancer patients. This article presents four clinical trials that are recruiting participants across Canada.

# **Community-based exercise** program for well cancer survivors

Hamilton Health Sciences has teamed up with the YMCA of Hamilton/Burlington/Brantford and McMaster University to conduct a clinical trial of a community-based exercise program for well cancer survivors (CanWell) at any stage of their cancer care or disease. The goal of CanWell (www.canwellprogram. ca) is to provide a community-based exercise and education program that is based on the best available evidence. Another goal is to train YMCA fitness staff in providing safe and effective exercise for people with cancer.

CanWell is a 12-week supervised exercise and education program located at Les Chater YMCA in Hamilton, Ontario. Participants in the program learn how to exercise safely based on their unique needs related to their cancer, cancer treatment, exercise interests, and personal goals. Each exercise program consists of strength and endurance exercises with participants having access to a pool and all other facilities at the YMCA.

As CanWell is an on-going program, participants have the choice to participate in research evaluating the effectiveness of the program or not. Those who do not participate in the research component have similar access to supervision and the exercise programs and will also benefit from the effects of exercise.

If you are interested in participating, download the CanWell referral form (at http://www.canwellprogram.ca/canwellfiles/ ymca hhs referral form.pdf) and talk to your doctor. For more information, please e-mail Oren Cheifetz, Physiotherapist, Hamilton Health Sciences, at research@canwellprogram.ca or call the Hamilton YMCA at 905-529-7102.

# **Art Therapy Intervention for Breast Cancer Patients**

The Cedars Breast Clinic and Cedars CanSupport based in the McGill University Health Centre are conducting a clinical pilot study on group art therapy for breast cancer patients. As studies continue to debate the effects of quality of life on survival, increased attention is being focused on investigating complementary therapies to boost overall total health in cancer patients. Art therapy is an interesting growing field, which has shown promise to positively influence quality of life in the pediatric and adult oncology population alike. As there is a paucity of well controlled studies in this field, the investigators propose to study the impact of art therapy sessions for women living with breast cancer with quantitative and qualitative analysis of emotional health and physical symptoms. The results of the investigators' study will have widespread applicability to oncology programs that wish to offer/implement such sessions to their palliative and non-palliative outpatients in an effort to address the important concept of whole person care.

If you are interested in participating, please contact Kate Laux, Art Therapist/Cedars CanSupport (MA, ATPQ) at artcanheal@gmail. com or 514-934-1934 x35315.

Note to researchers:

If you are looking for breast cancer survivors to participate in a clinical trial, why not submit a notice for publication in Network News? For details, contact Wendy Hall at whall@cbcn.ca.



# **CLINICAL TRIALS**

# **Moving Forward After Breast Cancer**

# A STUDY OF ONLINE SUPPORT AND EDUCATION FOR YOUNG **BREAST CANCER SURVIVORS**

"I was hoping to learn, to know how others are doing who are going through what I am. I received more than I was expecting - very good friends, supporting, encouraging, understanding me."

Moving Forward After Breast Cancer is a study that connects young women survivors of breast cancer in a ten-week online support group led by a professional counselor or a peer facilitator. This study tests the effectiveness of coping skills education and professional or peer-led online support groups. The study provides women with an opportunity to learn about effective coping strategies and to connect with other young breast cancer survivors.

The study will also look at whether the online support group can:

- reduce cancer-related distress.
- change perceptions of how much breast cancer interferes with physical well-being
- increase confidence in coping with future challenges

"I was able to talk about important things. I felt a lot better - I couldn't talk with others in my life outside of the group."

CancerChatCanada is currently recruiting eligible participants through the spring 2013. Women with a home computer and internet access will be able to participate entirely from the comfort of their own home. Everyone who takes part in this study will receive a free workbook that gives information about coping after cancer and a relaxation CD.

To be eligible, you must be:

- 45 years of age, or younger
- Not more than 3 years past diagnosis
- Able to speak and write in English

For more information or to register, please visit http:// cancerchatcanada.ca. The principal investigator for this study is Dr. Joanne Stephen (1-800-663-3333 x 4960) at the BC Cancer Agency. The study is funded by the Canadian Breast Cancer Research Alliance.

# **Couplelinks: Online workshop for** young breast cancer survivors and their male partners

Dr. Joanne Stephen is also a co-investigator in a study relating to female breast cancer survivors and their male partners. The purpose of this project is to test an online educational program geared to the practical and emotional needs of young couples coping with breast cancer (e.g., communication and intimacy, fertility concerns, communication with young children). The program entails reading the web-based materials and participating in six weekly relationship enhancement exercises with your partner. The course is facilitated by a mental health professional.

Eighty couples from across Canada will participate but only half will receive the workshop during the study, and the other half will be wait-listed. The two groups will then be compared on the same questionnaires to determine if Couplelinks.ca was helpful.

Participants will be asked to complete questionnaires at the start of their participation, and then at two-month and five-month time points. Total maximum time commitment is approximately 10 hours over a five-month period. Enrollment began in the spring of 2011 and will continue for approximately three years.

For a couple to be eligible for the study:

- The woman must be 45 years of age or younger at the time of diagnosis (there is no restriction on the age of the male partner);
- She must have a diagnosis of breast cancer without metastases:
- She must be involved in a committed relationship with a male partner;
- She must be within 36 months of her original diagnosis;
- She can be at any stage of treatment or recovery from treatment; however, it can be easier to participate once active treatment has been completed.

For more information, visit www.couplelinks.ca. If you would like to participate in this program, please contact the facilitators at cancerchatcanada@bccancer.bc.ca or at 1-800-663.3333 x 4960 or 4966.

The principal investigator for this study is Dr. Karen Fergus at Sunnybrook Odette Cancer Centre. The study is funded by the Canadian Breast Cancer Research Alliance/Canadian Breast Cancer Foundation.







# **Nova Scotia seminar: Living Beyond Cancer**

Capital Health and Cancer Care Nova Scotia have teamed up to bring the community a new class called "Living Beyond Cancer: What Happens Now". The class will provide you with information about what to expect after your cancer treatment. Topics include: long and short-term side effects of cancer treatment, physical activity, nutrition, coping and adjustment, services available and sexual health concerns. This education session is also a great place to connect and network with other cancer survivors, as well as members of the health community. To register, please call 902-473-6567 (The Sunshine Room, Victoria General Building of the Queen Elizabeth II Hospital) and 'press 2' to leave a message on the Education Session Registration line. A member of The Sunshine Room staff will call you back to complete the registration process. For more information, visit http://abcn.ca/wpcontent/uploads/2012/07/Living-Beyond-Cancer-poster.pdf.

# Peer support for young women with breast cancer

Sometimes it helps to talk to someone who's been there. Let Rethink Breast Cancer connect you with a young woman who experienced breast cancer at a similar age and stage of life as you. Peer support volunteers are ready to listen, offer skilled emotional support and share their experiences and understanding. One-to-one support is available over the phone or by e-mail, as you need it. This service is free and confidential to women anywhere across Canada. For more information, or to become a peer support volunteer, e-mail Shawna at support@rethinkbreastcancer.com or call 416-920-0980 (toll-free 1-866-738-4465) x 228.

# **Getting Back on Track: Life After Breast Cancer Treatment**

This informative, 211-page book, published by the Canadian Breast Cancer Foundation—Ontario and the Princess Margaret Hospital, addresses some of the normal concerns that breast

cancer survivors have during the transition from active care to the rest of their lives. During this time, you may have many mixed feelings. One moment you may be thrilled that your active treatment is over. The next moment you may feel abandoned, or anxious that your cancer may recur. This book will give you some remedies and coping skills that may help you get back on track. Included are chapters on your health care needs now; the residual side effects of breast cancer; the importance of a healthy lifestyle; your emotional, spiritual and social needs; relationships and finances. An appendix lists Ontario resources for breast cancer survivors. To order a copy, contact resourcesON@cbcf.org or call 416-815-1313 or toll-free 1-866-373-6313.



# Support Saturdays - Toronto program registration opens for January 2013 session

Rethink Breast Cancer created Support Saturdays to bring together families raising babies and young children while also recovering from breast cancer, because we know that connection and

camaraderie are key to living well and helping your family cope with this life-changing experience. With the program now in its sixth year, registration is open for a January 2013 start. The program takes place in the mornings over eight consecutive Saturdays.

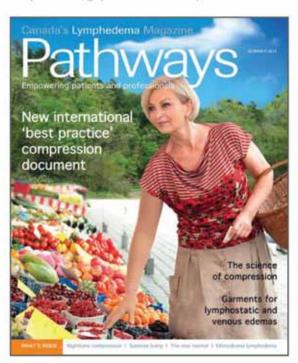
Need support, but you're not in Toronto? Rethink offers home support in both Toronto and Calgary, and a number of other resources and programs that can be accessed nationally - including two books to help you talk to your kids. For more information or to register for family support, please contact Shawna Ginsberg: 416-920-0980 x 228 or Shawna@ rethinkbreastcancer.com.

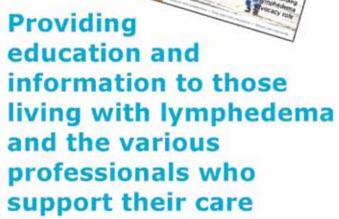


Canada's Lymphedema Magazine

# Pathways

Empowering patients and professionals





Written by leading Canadian and International lymphedema experts and reviewed by a strong Editorial Board

Published by the **Canadian Lymphedema Framework**, an academic and patient collaboration, working to improve the management of lymphedema in Canada

For a subscription to Pathways, visit our website at:

# www.lymphedemapathways.ca

# Regular Features Include

- Research and Medical Advances
- Ask the Expert
- Patient Perspectives
- Clinical Perspectives
- Case Studies
- National Advocacy
- Helpful Suggestions
- International Conference Reviews





To receive regular notification of upcoming events, try CBCN's monthly e-mail newsletter, Outreach. To subscribe, e-mail your name and e-mail address to Wendy Hall at whall@cbcn.ca.

OCTOBER 9, NOVEMBER 13, DECEMBER 11: METASTATIC SUPPORT GROUP CALL. Join other young women with metastatic breast cancer for a telephone networking and support session - a support group without leaving home! These interactive sessions are designed to address your specific concerns. Topics include, but are not limited to: hopes and fears, work, children, communicating with friends and family and living with ongoing and changing treatment. These calls are facilitated by Susan Glaser, MSW, Evelyn Lauder Breast Center at Memorial Sloan-Kettering Cancer Center in New York and are open to new and previous participants. Calls are FREE and can be accessed both nationally and internationally. Calls take place at 8 p.m. ET on the dates above. The national call-in number is 800-804-6968. The international call-in number is 647-723-7260. The access code is 0284559. For information, contact the Young Survivor Coalition at 646-257-3000 or 877-972-1011.

OCTOBER 13, CHICAGO: "MOVING FORWARD WITH BREAST CANCER," THE SIXTH NATIONAL CONFERENCE OF THE METASTATIC BREAST CANCER NETWORK (MBCN), takes place at Northwestern University, Robert H. Lurie Medical Research Center, 303 E. Superior St. The agenda includes talks by medical experts from Robert H. Lurie Comprehensive Cancer Center and other Chicago institutions. Topics include: current treatment for metastatic breast cancer; clinical trials vs. standard of care; future research; bone metastases; surgical/radiation therapies for lung and liver metastases; complementary therapies such as acupuncture, Chinese herbology and supplements; and a panel of those living with metastatic breast cancer. For more information, or to register, telephone MBCN at 1-888-500-0370.

OCTOBER 23, NOVEMBER 6, NOVEMBER 20: A THREE-PART WEBINAR SERIES ON COPING WITH BREAST CANCER. Sponsored by the Canadian Breast Cancer Network, the webinars will feature Dr. Linda Edgar talking about developing and improving coping skills. These one-hour webinars will be free of charge and will provide participants from across Canada with the opportunity to learn practical tips on how to improve their coping skills. These sessions will take place at 7:30 p.m. Eastern Time. To participate in these webinars, you will need access to a computer with an internet connection and a phone. All calls will be toll-free. For more information or to register, e-mail Rebecca at rwilson@cbcn.ca.

OCTOBER 17, CANADA-WIDE: SECOND ANNUAL NATIONAL BREAST RECONSTRUCTION AWARENESS DAY. This is an initiative designed to promote education, awareness and access for women who may wish to consider post-mastectomy breast reconstruction. It is a collaborative effort that includes plastic surgeons specializing in breast surgery, plastic surgery nurse specialists, the Canadian Breast Cancer Foundation, Canadian Society of Plastic Surgeons, medical device industry representatives and breast cancer support organizations. For information about BRA Day events in your area, please go to www.bra-day.com or contact Willow at 1-888-778-3100. The BRA Day website will be updated as information on specific locations becomes available.

# **NOVEMBER 1-5, TORONTO:**

THE YOUNG ADULT CANCER CANADA 6TH ANNUAL SURVIVOR **CONFERENCE.** Meet fellow survivors and supporters, and experience life-changing moments. The conference will include workshops, free time to get to know each other, great speakers to stimulate mind and body, and time to share inspiring stories. The Survivor Conference is free except for travel costs. You just need to make it to the venue; your food, accommodations and program necessities will be provided. There is also a travel assistance program for those who qualify. For information, telephone Beth at 1-877-571-7325 or 709-579-7325.

**NOVEMBER 2-4. TORONTO: RETHINK BREAST CANCER'S BREAST FEST FILM FESTIVAL** takes place at the Bloor Hot Docs Cinema at 506 Bloor St. W. For information, visit www.breastfestfilmfestival.com, or telephone Rethink at 416-920-0980 x225.

**NOVEMBER 9-11, EDMONTON: "EDUCATE AND REJUVENATE,"** A RETREAT, for women living in remote areas who have had a breast cancer diagnosis. Gather with other breast cancer survivors to: Learn new coping techniques and tools for the unique challenges of life after breast cancer, Share your journey and connect with others, and Rejuvenate yourself in your journey with breast cancer. Thanks to funding from the Public Health Agency of Canada, participation in this retreat is free of charge for eligible participants. This funding will cover the cost of travel, accommodations and group meals. The event is presented by the Canadian Breast Cancer Network, in partnership with Willow Breast Cancer Support Canada. To obtain an application, or for more information, please contact Jenn McNeil at: imcneil@cbcn.ca or 1-800-685-8820 x224.

# **National Partners**

- . Breast Cancer Society of Canada
- Canadian Breast Cancer Foundation
- Canadian Lymphedema Framework
- Canadian Cancer Society
- Canadian Cancer Society Research Institute
- Canadian Patient Coalition
- Cancer Advocacy Coalition of Canada (CACC)
- Ovarian Cancer Canada
- ReThink Breast Cancer
- Willow Breast Cancer Support Canada
- World Conference on Breast Cancer

### Provincial/Territorial Networks

- BC/Yukon Breast & Gynecologic Cancer Alliance
- Breast Cancer Network Nova Scotia
- Manitoba Breast and Women's Cancer Network
- New Brunswick Breast Cancer Information Partnership
- Northwest Territories Breast Health/Breast Cancer Action Group
- Nunavut Cancer Network
- Ontario Breast Cancer Exchange Project (OBCEP)
- Prince Edward Island Breast Cancer Information Partnership
- The Newfoundland and Labrador Lupin Partnership

# Provincial/Territorial/Regional/Local Partners

- Amitié Santé 04
- · Association à fleur de sein
- Au Seingulier
- Breast Cancer Action Kingston
- Breast Cancer Action Manitoba
- Breast Cancer Action Montréal
- Breast Cancer Action Nova Scotia (BCANS)
- Breast Cancer Action (Ottawa)
- Breast Cancer Action Saskatchewan
- Breast Cancer Centre of Hope (Winnipeg, Manitoba)
- Breast Cancer InfoLink (Calgary)

- Breast Cancer Support Services Inc. (Burlington, ON)
- Breast Cancer Research and Education Fund
- Breast Health Centre of the Winnipeg Regional Health Authority
- Canadian Breast Cancer Foundation Ontario Chapter
- Cancer Care Manitoba Breast Cancer Centre of Hope
- First Nations Breast Cancer Society
- FLOW
- Hereditary Breast & Ovarian Cancer Society of Alberta
- Lymphedema Association of Ontario
- Manitoba Breast Cancer Survivors Chemo Savvy Dragon Boat Team (Winnipeg)
- Miles to Go Healing Circle Six Nations (Ontario)
- New Brunswick Breast Cancer Network
- Olive Branch of Hope
- Organisation québécoise des personnes atteintes de cancer
- Prince Edward Island Breast Cancer Support Group
- Saskatchewan Breast Cancer Connect
- Sauders-Matthey Cancer Prevention Coalition
- Sentier nouveau Inc.
- Sister to Sister: Black Women's Breast Cancer Support Group (Halifax, NS)
- Soli-Can
- The Young and the Breastless
- Virage, Hôpital Notre-Dame du CHUM

# **Key Partners in Other Sectors**

- Amyotrophic Lateral Sclerosis Society of Canada (ALS)
- Anemia Institute of Canada
- Canadian Health Coalition
- Canadian Health Network
- Canadian Hospice Palliative Care Association
- Canadian Organization for Rare Disorders
- Canadian Prostate Cancer Network/National Association of Prostate Cancer Support Groups
- Canadian Science Writers' Association
- DisAlbed Women's Network Ontario

- Epilepsy Canada
- Early Prostate Cancer Diagnosis Ontario
- HPV and Cervical Health Society
- National Council of Jewish Women of Canada
- National Council of Women of Canada
- Newfoundland and Labrador Women's Institutes
- Ontario Health Promotion Project
- Ottawa Health Coalition
- Parent Action on Drugs
- Quality End-of-Life Care Coalition
- Women's Centre of Montreal
- Women, Health and Environments Network
- Women and Rural Economic Development

### **International Partners**

- National Breast Cancer Coalition (Washington, D.C.)
- Philippine Breast Cancer Network

# **CBCN** is represented on the following groups

- Advocare
- Best Medicines Coalition
- Canadian Cancer Action Network (CCAN)
- Canadian Breast Cancer Screening Initiative
- Coalition priorité cancer au Québec
- Community Capacity Building Committee, Canadian Breast Cancer Initiative, Public Health Agency of Canada
- Episodic Disabilities Network
- Saskatchewan Cancer Advocacy Network

# CBCN · RCCS

CANADIAN BREAST CANCER NETWORK | 331 COOPER STREET, SUITE 602 OTTAWA ON K2P 0G5 | Toll-Free: 1-800-685-8820

cbcn.ca

# Members, Friends, Funding Partners and Corporate Friends

CBCN gratefully acknowledges the following individuals and organizations for their financial contributions for this financial year

# Member (\$25-\$99)

Hundreds of individuals and groups across the country

# Friends of CBCN (\$100-\$499)

Adelphia Floor Surfaces Ltd. Atkinson Schroeter Design Group Inc.

B.J. Normand Ltd.

Capital Tile and Flooring Ltd. Ernesto Cecchetto Cenovus Employee Foundation Club Assist Canada Comfort Mechanical Ltd. Ella Coulthart

Ella Coulthart
Excelcon Steel Co. Ltd.
Exel Contracting Inc.
Florence Graham
Irdeto Canada Corporation
Labarge Weinstein LLP

Patricia Lee Manulife Financial Charlie and Beverly Milbury

Patricia Moore Nation Drywall Limited

Betty Orr Pleora Technologies Inc. R.J. McKee Engineering Ltd. Mary Rogers Tempo Design Studio Ltd. TSMC Design Technology Canada Inc.

Yves Thibeault United Way of Greater Toronto Area

United Way of Peel Region United Way serving St. John's The Winnipeg Foundation Patti Young

# Bronze Level Supporters (\$500-\$4,999)

Gordon Cetkovski Colonel By Child Care Centre Coulthart Family Reason for Hope Society Royal Moving and Storage St. Lucia/Toronto Aid Action Group TELUS Communications Co. United Way Ottawa

# Silver Level Supporters (\$5,000-\$24,999)

Alterna Savings & Credit Union Limited Mark Anthony Group United Awareness Group/ Chocolates for Charity

# Gold Level Supporters (\$25,000-\$99,999)

GlaxoSmithKline Novartis Roche

# Platinum Level Supporters (\$100,000 and over)

Sanofi-aventis

### Government

Public Health Agency of Canada Canada Summer Jobs