ESSENTIAL NEWS FOR CANADIANS AFFECTED BY BREAST CANCER

networknews

SPRING 2014, Vol. 18, No. 1

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Modifiable risk factors:

Reduce your risk of recurrence

NUTRITION PAGE 10-

EXERCISE PAGE 11
EMOTIONAL
WELLBEING PAGE 12

MEDICATION PAGE 14

Cancer among the Inuit PAGE 5

Building a united voice for metastatic breast cancer in Canada PAGE 17

Survivor Story: My life after breast cancer PAGE 8

CBCN Canadian Breast Cancer Network

of Partnership, Advocacy and Suppor



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LETTER FROM THE CHAIR OF THE BOARD OF DIRECTORS

Dear readers:

CBCN is celebrating! We're pleased and proud to have reached 20 years of being the voice of breast cancer patients and survivors in Canada, building partnerships, and providing educational resources. Thanks to all our supporters who have allowed us to work towards fulfilling our mission: we couldn't have done it without you, and we look forward to your continued support.

This issue of Network News brings you strategies around modifiable risk factors that breast cancer survivors can use to help reduce the risk of recurrence. You'll find the latest science-based information on exercise, nutrition, medication, stress, and depression, just to mention a few of the feature topics. We also present the first-person story of a triple-negative breast cancer survivor as well as a special report on breast cancer among the Inuit.

There have been several new metastatic breast cancer drugs that are now available and you'll find more information about these in Research Roundup. There's lots of food for thought in this issue. We're encouraging you to be the healthiest you can be, so you can live life to the fullest. Enjoy!



Warm regards,

Cathy Ammendolea, CBCN Board Chair

Carry annector

Inside this issue

- 04 YOUR TURN: How do you deal with stress and breast cancer?
- **05** FEATURE: Kaggutiq Inuit Cancer Glossary
- 06 SURVIVOR STORY: An Inuit woman's fight with breast cancer - Sophie Keelan
- **08** SURVIVOR STORY: My life after breast cancer - Tamara Levine
- $10\,$ HEALTHY LIVING: Can food reduce your risk of breast cancer?

- 11 HEALTHY LIVING: Exercise improves health, quality of life, and survival rates after breast cancer
- 12 EMOTIONAL WELLBEING: Soothing facts about stress and breast cancer
- 14 TREATMENT TALK: Do medication benefits outweigh side-effects?
- 15 TREATMENT TALK: Cancer drug review process Q&A
- $16\,$ CBCN IN ACTION: Focus on metastatic breast cancer

- 17 CBCN IN ACTION: Building a united voice for metastatic breast cancer in Canada
- 18 RESEARCH ROUNDUP: Your update on the latest breast cancer research
- 19 RESEARCH ROUNDUP: Update on new breast cancer drugs
- 20 RESEARCH ROUNDUP: Metastatic breast cancer clinical trials that are currently open in Canada
- **21** RESOURCE DIRECTORY
- 23 CALENDAR



How do you deal with stress and breast cancer?



Taking one day at a time

I found a few things that helped when I was going through chemo.

- Going for walks outside, no matter how short or long.
- When time stood still or seemed to turn backwards, I prayed, as I believe in God. One time I was very distraught and thought God had abandoned me. The next day I remembered one of my favorite poems, "Footprints in the Sand." Then I realized God had not abandoned me at all; he carried me while I couldn't walk. He had actually made it bearable for me to get through the day and night.
- Remembering to breathe. Sounds silly, but remembering to take deep breaths allowed me to bring a sense of calm to my body.
- Trying to appreciate the things I could do rather than focusing on the things I could previously do. One day I was so weak but wanted to go outside. I could not physically open my front door. I was extremely upset. My husband said not to worry about it. We did go for a walk that day, and I was happy that I could at least manage that.
- I taught myself to take one day at a time, one hour by hour, or moment by moment when things were really bad. I now live in the moment instead of always wishing ahead.
- I realize these are not easy things to accomplish. I learned a lot of these things after six rounds of breast cancer chemo, and lots of it after radiation along my journey.

Suzanne Paintin Winnipeg, Manitoba

Visualization and prayers worked

Agreeing to have chemotherapy was the hardest part of my breast cancer treatment journey. How was I going to let someone stick a needle in my arm and give me poison, like a criminal being put to death by lethal injection? I was terrified. I had never been sick before and feared the nausea and fatigue that would accompany the chemo....Before every treatment, my boyfriend and I would pray over the bag of chemo drugs that they would do their magic and cleanse me of the cancer without making me dreadfully ill. I visualized cleansing waves of pure, clean water washing out the cancer cells, followed by Pac Man gobbling up any leftover cancer crumb cells. My visualization and our prayers worked. I have been dismissed from the cancer center and have celebrated six years of healthy living. And, wonders of wonders, I was never sick!

Carolynn Ouellette Sault Ste. Marie, Ontario

Support from family is key

The major factor for dealing with stress was to turn to the love and support given by family, especially my fiancé, who became the love of my life and my husband.

Gail Stewart Westville, Nova Scotia

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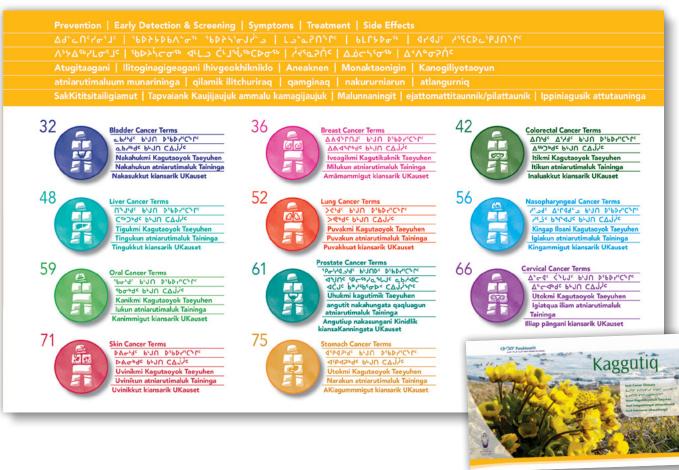
Kaggutiq Inuit Cancer Glossary

Cancer is the second most common cause of death among Inuit living in Canada; the rate is nearly twice as high as the rest of the country. There is a need to provide Inuit with more information about the disease in the Inuktitut language. In 2012, Pauktuutit Inuit Women of Canada began a two-year project to increase Inuit knowledge about cancer, to increase health literacy, and to promote the importance of cancer screening and early detection.

With the support from the Public Health Agency of Canada, Pauktuutit worked with a variety of stakeholders—linguistic experts, elders, educators, community health and social service providers, including the Canadian Breast Cancer Network—to develop an Inuit cancer glossary. The Inuit Cancer Terminology Forum was held in Inuvik, NWT in July 2013 and resulted in the translation of 250 cancer terms into five Inuit dialects. As a result of this project, Pauktuutit launched "Kaggutiq Inuit Cancer Glossary" in March 2014.

This unique resource intends to provide Inuit patients and caregivers, as well as health care professionals, plain language information in English and five major dialects of Inuktitut. Pauktuutit encourages Inuit and health service providers to use this glossary of terms to improve communication and understanding of cancer terms.

To request hard copies of this glossary, please contact the health department at Pauktuutit, 1-800-667-0749 or info@pauktuutit.ca. The glossary is also available online at www.pauktuutit.ca.





An Inuit woman's fight with breast cancer

In November 2006, Sophie Keelan of Kangigsualujjuag, Nunavik, in nothern Quebec, felt a pain in her breast; while checking her breast, she felt something hard, like a rock. She went to the local clinic and consulted a nurse. who arranged for her to travel to Kuujjuac for a mammogram at Ungava Tulattavik Health Centre. The result was abnormal.

In December 2006, after spending Christmas at home, Sophie travelled to far-off Montreal to consult a doctor at the Jewish General Hospital. "I was all alone. No one from my family was there," she says.

When the doctor told her she had breast cancer, she was shocked. "I didn't expect the news. I was so shocked that I lost everything. My surroundings weren't there anymore. My family was so far away. I ran out in the hallway looking for the phone. I called my husband. Luckily he was home. Only then was I able to cry."

The doctor prescribed surgery, which took place in February 2007, and chemotherapy followed by Herceptin. The Herceptin was a shock to Sophie's system. "My body was shaking. I felt so cold. My teeth were chattering."

She ended up in the emergency ward with an infection. She fell asleep and woke up later that evening to see her husband in the hallway outside her hospital room. She asked him, "Why weren't you around me when I needed you the most?" He answered, "The nurses and doctors said I was to be farther away from you because you weren't feeling too good."

The Herceptin was stopped, but Sophie went through eight more chemotherapy treatments. "It was awful because I lost all my hair. All my nails got black. And the palms of my hands



and the bottom of my feet turned brown. And the sides of my tongue got black.

"I was like an old woman. I wasn't able to walk properly. Five steps and I was out of breath. That's how bad my system was."

Eating was also extremely difficult. Everything tasted like metal. So Sophie's friend sent her seaweed and Arctic char, good natural food that Sophie was able to tolerate.

In the hospital in Montreal, Sophie participated in a support group at Hope and Cope; she wishes that there were support groups in communities in the North. She also urges the health system to make sure that patients from the north have a friend or family member to accompany them to the big, unfamiliar city and hospital. This is especially important for patients who don't know the language or their diagnosis.

When Sophie's treatments ended, she returned to Kangigsualujjuag cancer-free. In July 2013, Sophie was pronounced a five-year cancer survivor. Sophie is a member of the advisory committee for the Inuit Cancer Project. She feels an Inuktitut cancer glossary will help others understand their diagnosis and treatment.

It was the support of her friends and family and her faith in God that got Sophie through this ordeal. Even people that she didn't know sent her get-well cards, which she appreciated very much.

"I thank all the people that were helping me out, encouraging me. I'm very thankful to be alive," she says.







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By Tamara Levine

After breast cancer and treatment, how do we deal with the fear it might come back?

In 2009, I was a seemingly healthy 58-year old wife, mother and adult educator living in Ottawa when I found a lump in my armpit ten months after a clear mammogram. I was devastated to be diagnosed a few weeks later with Stage III breast cancer that had spread to my lymph nodes.

Soon afterward. I attended the funeral of a friend who had died of metastatic breast cancer. "I wondered how I dared hope to beat my cancer when Martha hadn't," I wrote in But Hope is Longer: Navigating the Country of Breast Cancer.

Following chemotherapy, surgery, radiation and complications from radiation and working with a naturopathic doctor throughout, my husband and I celebrated the end of our "year from hell" with a trip to the Greek islands. Now cancer-free for three years, I find that the fear of recurrence still lingers.

At the end of eight rounds of chemo, a lumpectomy and a lymph node dissection, I was ecstatic when my pathology report showed the cancer was gone. I also learned it was triple negative, a particularly aggressive marker with a higher rate of recurrence (one in four) for which no preventive drugs are available.

I told my oncologist I wanted my portacath¹ removed. He wanted me to leave in place the device that had safely

1 A portacath is an implanted venous access device placed completely under the skin of the chest. It is used for patients who require frequent or continuous chemotherapy administradelivered chemo to my vein "just in case". He also suggested that I pay attention to otherwise regular things that could indicate a recurrence, such as headaches, coughs or pain.

He didn't say it, but I knew he didn't want me to have to have a new portacath surgically inserted if my cancer came back. For me, the portacath was symbolic. Taking it out was an act of faith that would have gone a long way toward quelling my fears. A year later, it felt like a victory when he finally agreed to have the portacath removed.

The good news is that I am well. I continue to be monitored closely. I see my oncologist every four months and have regular mammograms, CT scans and ultrasounds. I also work closely with my naturopath on prevention with vitamins and natural supplements.

But living beyond cancer presents a paradox: How do I live in a hopeful way without obsessing about a possible recurrence?

A while ago, a routine mammogram showed a shadow on my lung. It was scary to imagine that the cancer might be back.

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.





Would I have to go through treatment again? Would I make it this time? My fear exploded and hit me full-blast. It felt like an eternity before the test results came back negative.

My mantra "Carpe diem", seize the day, means I try to live as fully as possible. I swim, work out and eat lots of vegetables, grains, fruit, nuts, and small amounts of chicken and fish. I enjoy walking, cycling, yoga, singing with the women's community choir Shout Sister and chairing the board of Inter Pares, a social justice organization. I cherish my time with family and friends.

I try to hold on to the unexpected gifts cancer brought. One was that if I could accept dying before my time as a possible outcome, I could be less afraid and embrace and fight for my life more fully. It helped me to live in the present when the future was murky and unpredictable.

I also try to keep some of the "letting go" I learned during treatment: if I was getting the best of what mainstream and complementary medicine had to offer and doing all I could to heal myself with food and exercise, I'd have to accept that the rest is a mystery.

My friends and family supported me through treatment and recovery. I wrote, "While going through cancer was the loneliest time in my life, it was also when I felt the most loved and cared for." Breast Friends, the feisty breast cancer support group I joined after my diagnosis, still meets for breakfast once a month.

Another gift was finding my "winter", a time to focus on being rather than doing. I had been working flat out for decades with little time for reflection and contemplation. When cancer made me slow down, new possibilities emerged.

I started writing. My letters to friends and family about my breast cancer journey became the basis for my book, along with reflections and interviews with my oncologists, surgeon, naturopath and life coach.

Now retired, I share my experience to help other breast cancer patients. I speak to support groups for newly diagnosed women and with nursing students. I give readings and workshops based on the book.

There is too much breast cancer. With the number of women diagnosed rising each year, we need to advocate for prevention, better treatment and support for complementary care.

When asked for advice, I say, "Be captain of your own ship. Stand up for yourself. Ask questions. Join a support group. Allow yourself to receive, so difficult for women used to taking







care of everyone else. It's in being able to accept support and love that we find our strength."



My book is available from secondstorypress.ca, chapters.ca, and independent bookstores.





HEALTHY LIVING

Can food reduce your risk of breast cancer?



No food or diet can prevent you from getting breast cancer. But some foods can make your body the healthiest it can be, boost your immune system, and help keep your risk for breast cancer as low as possible. No food or diet can cure cancer, though some of them may help control treatment side effects or help your body get well after treatment. Some food choices may help cancer treatment work more effectively. Others can be dangerous and can interfere with treatment and recovery.

Healthy weight reduces risk of first-time breast cancer and recurrence

Maintaining a healthy weight may help reduce the risk of breast cancer coming back. In a 2005 study, researchers found that women who gained weight after their breast cancer diagnosis had an increased risk of recurrence¹.

A healthy eating plan should include some physical activity. Aim for three to four hours of walking per week to start. If you're having treatment right now, you may need to start slowly and work up to this.

Low-fat diet may reduce risk of recurrence

Sticking to a low-fat diet may help reduce the risk of breast cancer coming back, according to a study by the Department of Medicine at the Los Angeles Biomedical Research Institute². It will take more than this one study to know who is most likely to get the biggest benefit from specific dietary changes. But no matter what kind of cancer you've had, you might get significant benefit from lowering the amount of fat in your diet. Plus, other healthy choices are more likely to come with a low-fat diet, such as eating more fruits and vegetables and losing weight. All these changes together may help lower your risk of recurrence.

Research on diet and breast cancer is ongoing

Studies are looking at the relationship between diet and breast cancer risk and the risk of recurrence. The Women's Health Initiative Trial suggested that a diet very low in fat may reduce the risk of breast cancer. More research is needed in this

important area for women who are interested in eating well to reduce their risk of ever getting breast cancer.

Doctors and dietitians are eagerly waiting for the results of the Women's Healthy Eating and Living (WHEL) study. WHEL is looking at whether a diet rich in fruit and vegetables and low in fat can help reduce breast cancer recurrence. But the results won't be ready for a few more years.

In the meantime, here's what dietitians suggest:

- Keep your body weight in a healthy range for your height and frame. Body mass index, though not a perfect measurement, can help you estimate your healthy weight. (Calculate your body mass index at http://www.dietitians.ca/Your-Health/ Assess-Yourself/Assess-Your-BMI/BMI-Adult.aspx.)
- Eat plenty of vegetables and fruit (more than five cups a day).
- Try to limit your fat intake to less than 20 percent of your total calories per day. This is an extremely small amount of fat to eat (an average amount is about 30 to 35 percent of total calories per day). Start by eliminating some foods with the highest fat content (like fried foods and margarine) and gradually lower the amount of fat you eat.
- Eat foods high in omega-3 fatty acids.
- Avoid trans fats, red meats, and charred or smoked foods.

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Exercise improves health, quality of life, and survival rates after breast cancer

According to a review article by researchers in Greece, "several epidemiological studies have shown an inverse relationship between the risk of breast cancer and physical activity levels, whereas exercise training has been recognized as a significant means in the rehabilitation process of breast cancer survivors. The relative risk reduction of breast cancer for women who engaged in moderate to vigorous physical activity for three to five days per week ranged between 20 to 40 percent. Furthermore, several studies demonstrated a 24 to 67 percent reduction in the risk of total deaths and a 50 to 53 percent reduction in the risk of breast cancer deaths in women who are physically active after breast cancer diagnosis compared with women who lead a sedentary lifestyle. Breast cancer survivors should be encouraged to participate in rehabilitation programs in order to obtain numerous physiological and psychological benefits. These include reductions in fatigue and improvements in immune function, physical functioning, body composition, and quality of life. Based on recent scientific evidence, a complete rehabilitation program for patients with breast cancer should combine both strength and aerobic exercise in order to maximize the expected benefits¹."

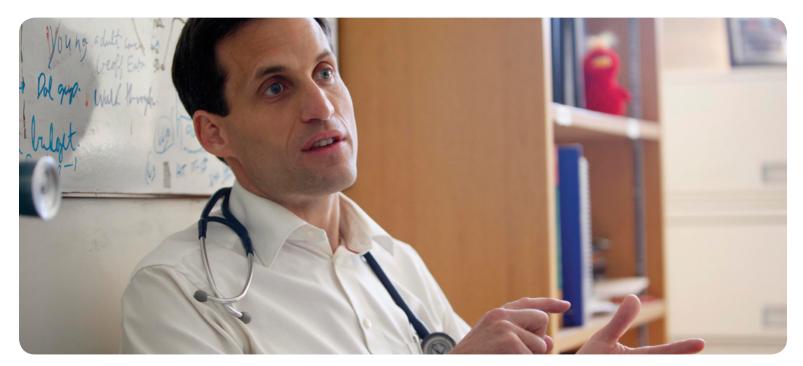
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EMOTIONAL WELLBEING



Soothing facts about stress and breast cancer

By Dr. Rob Rutledge

Radiation Oncologist and Associate Professor, Faculty of Medicine, Dalhousie University

Disclaimer: I am not trying to change your mind if you believe that stress or emotional repression was a significant cause of your breast cancer. As an oncologist interested in complementary medicine and truly trying to understand the conditions that facilitate healing. I honestly don't know what causes cancer in any one person. Cancer may well be a manifestation of psychological dis-ease for you as an individual. If your belief encourages you to work on healing your personality or relationships, I'm all for it because I believe deeper psychological and spiritual healing manifest as health and energy in the body. However, if you are feeling guilty about the past or stressed about the future because you think your attitude is compromising your chances, please read on.

Does stress cause breast cancer?

Not to any measurable extent. A recent study in the British Medical Journal¹ about work-related stress further supports this view. The authors combined 12 high-quality European studies that assessed stress levels in 116,000 healthy workers at the start of the studies. After 12 years of follow-up, 5700 people had a cancer diagnosis but their level of job strain was not related to the chance of developing breast, colorectal, lung or prostate cancer. Even those feeling high stress and low levels of control at work were at no greater risk.

In another seminal paper², author Bert Garssen looked at all kinds of stress like life events, bereavement and loss, social relations, or distress and depression. None of these kinds of stress could be shown to increase the risk of getting cancer. (Dr. Linda Carlson points out that the studies are more nuanced than I have presented here³. For instance, seven out of 14 studies showed that depression increased the risk of recurrence of cancer—and seven studies did not).





EMOTIONAL WELLBEING

My interpretation is that the chemicals released in a stress reaction don't seem to cause normal cells to change into cancer cells, and that the immune problems caused by chronic stress don't play an important role in eliminating newly created cancer cells. (See disclaimer above).

Does stress increase the risk of relapse of breast cancer?

If it does, it plays a very small role. The same long-term studies seem to show that high levels of stress don't increase risk, with a few exceptions. Montreal researcher Elizabeth Maunsell⁴ measured social support in 224 women diagnosed with breast cancer and followed them to see how they did. Those women with at least one confidant (spouse, child, friend) in their lives had a 72 percent survival rate versus only 56 percent in the women who claimed to have no close supporters in their lives.

The only other scientifically proven psychological factors (partially) predictive of how women will do after a breast cancer diagnosis are whether they a) take a helpless or hopeless or pessimistic approach to their situation or b) use emotional suppression or repression in dealing with the difficulties in their lives. Just over half of the high-quality studies show these emotional strategies put them at risk—while the remaining studies don't show a difference in survival.

So does this mean that dealing with stress is not important?

Absolutely not. Learning to work with stress in the moment and finding ways to keep life in balance to counteract chronic stress can be two of the most powerful ways of improving your health. The chemicals released during a stress reaction literally eat away at your tissue – from your stomach lining, to your joints and bones, to your brain and the chromosomes in your every cell. (I'm not trying to stress you out with this info.) But you really reduce your risk of all sorts of health problems by teaching yourself to settle down when you're suddenly stressed, and by practicing a relaxation exercise that will reset your brain for a more peaceful way of being in the world. Women who take this proactive approach can more easily get through the huge physical and psychological stresses of getting through surgery, chemotherapy and radiation. Lastly, and perhaps most importantly, learning to let go of inappropriate 'fight or flight' reactions allows us to make better decisions, draw on our inherent resilience, and appreciate more fully the beauty of living.



For tips from readers on managing stress, see page 4 of this newsletter. I recommend that you learn a relaxation technique from a specialist: a social worker, psychologist, qualified Yoga teacher, Tai Chi master, or someone trained in mindfulnessbased stress reduction. For more information, visit the Healing and Cancer Foundation website at http://www. healingandcancer.org/healing-program.

Depression and longevity in breast cancer

Though stress may not decrease your chance of cure or increase your longevity, depression definitely can compromise a woman's chances. In a randomized trial looking at whether support groups improve survival in women with metastatic breast cancer, the women whose mood improved during the first year had an average survival of 54 months while those women who became more depressed at one year had an average survival of 25 months⁵. I believe we should all take this study to heart regardless of your stage of cancer: if you are suffering from prolonged depression, get some professional help. It appears cognitive therapy is a good start.

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TREATMENT TALK

Do medication benefits outweigh side-effects?

Let's face it, no one is thrilled with the idea of having to take medication on a daily basis, especially if there are unpleasant side-effects, which is sometimes the case with medication that breast cancer survivors are prescribed. However, if taking this medication significantly reduces your risk of recurrence, are the side-effects worth it? We'll let you decide, but let's look at the research so that you can make an informed decision.

According to a 2009 survey by Leger Marketing, only one in five patients said they followed their physician's instructions most of the time. The most common reason for not following a physician's instructions was forgetting to take the medication, followed by the fact that some side-effects are too severe.

One in four breast cancer patients who are candidates for adjuvant endocrine therapy either do not complete the recommended five-year course of treatment or skip the drugs altogether, according to a study published in Breast Cancer Research and Treatment¹. Stopping medication early can decrease the effectiveness of the drug, which can negatively affect long-term health. Non-adherence is associated with increased physician visits, higher hospitalization rates, and longer hospital stays.

Five years of daily tamoxifen or aromatase inhibitors have well-established benefits in reducing recurrence and improving survival in women with invasive breast tumors that express estrogen and/or progesterone. "With two recent studies documenting increased efficacy when endocrine therapy was extended to ten years, these findings have major implications," said lead author Christopher Friese, PhD, RN, assistant professor at the University of Michigan School of Nursing².

According to a meta-analysis of 37,000 women with breast cancer, the recurrence rate among patients who did not receive adjuvant hormonal therapy was nearly 50 percent in node-positive patients and 32.4 percent in node-negative patients throughout the first ten years after diagnosis³. These data showed that some years of adjuvant tamoxifen treatment substantially improved the ten-year survival of women with estrogen receptor-positive (ER+) tumors and of women whose tumors are of unknown ER status, even in women who had node-negative disease.

Taking your medication as prescribed is important for your long-term health and has been shown to reduce your risk of recurrence. So what can you do to overcome some of the challenges that may prevent you from adhering to what your doctor has prescribed? Here are some tips and ideas that will hopefully help!

Tips for managing common side-effects

If you are experiencing side-effects, don't stop taking your medication. Talk to your doctor about alternatives. It may be possible to switch to another medication with fewer side-effects. There are also several ways to manage the side-effects.

For joint symptoms

- Use pain medications like aspirin, acetaminophen, or ibuprofen.
- Use heating pads and warm baths or showers.
- Remember that there is a correlation between joint pain during the first three months of treatment and a beneficial response to treatment.

For weakness and fatigue

- Eat nutritious meals
- Stay hydrated
- Stay moderately active
- Make time for rest
- Pace yourself
- Speak to your doctor about fatigue if symptoms continue

For hot flashes

- Keep records of your hot flashes: when, what you were eating, doing and feeling
- Speak to your doctor about adjusting the timing of your treatment.
- Stress is the most common trigger of hot flashes; try to reduce stress as much as possible.
- Talk to your doctor about medical options to reduce hot-flash triggers.







TREATMENT TALK



Tips for remembering your medication

- Ask your doctor to put a medication plan in writing.
- Create a medication diary.
- Always take your medication at the same time.
- Remind yourself with a watch or other alarm.
- Sign up for automatic refills.
- Be a buddy with someone in your support group.

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Cancer drug review process Q&A

By the pan-Canadian Oncology Drug Review Process (pCODR)

What is pCODR?

The pan-Canadian Oncology Drug Review Process (pCODR) was created in 2011 by the provinces in order to establish a clear and consistent process for reviewing cancer drugs in Canada. Previously, every province and territory had its own process and timelines for evaluating cancer drugs. For patients and oncologists, it was difficult to determine if a particular drug was under review, its current status, and which province provided coverage. With the new pCODR process in place, every province can benefit from having the same set of evidence-based recommendations to guide their funding decisions.

How will patients benefit from the creation of pCODR? Every Canadian benefits from having a consistent, transparent and timely process for assessing cancer drugs and from the knowledge that leading experts are involved in decisions about the treatment value and cost-effectiveness of cancer drugs. The pCODR process also ensures that scarce health care resources are used to fund only the most effective cancer drugs.

How long does it take for pCODR to complete each submission review?

pCODR works closely with the manufacturer, patient advocacy groups and other partners to ensure that each review is high-quality, rigorous, consistent and based on evidence. On average, the process takes between five to eight months to complete. In exceptional cases, it may take longer. In order to have more timely recommendations, pCODR encourages manufacturers to start the review process before Health Canada approves a new drug for sale.

How can patients or patient groups get involved in the review process?

During a review, patient groups can prepare a submission that captures the experiences facing patients affected by a specific type of cancer and with the drug under review (i.e. side-effects, impact on quality of life, access). To strengthen the patient perspective further, three patient representatives sit on the pCODR Expert Review Committee to ensure that the patient voice is understood and heard during its deliberations.

How can I find information about a specific drug review?

On the pCODR website, anyone can access information about each drug under review and the rationale behind pCODR's recommendations. In addition, any change to the timelines for a specific review (e.g., need to gather additional information) are listed on the website, along with the rationale for the change.

How can I find out if my province or territory is funding a specific cancer drug?

As part of its commitment to transparency, pCODR publicly posts all funding decisions made by each province (excluding Quebec) for cancer drugs that have completed the pCODR review process. This information, referred to as the "Provincial Funding Summary," is updated monthly.

To learn more about pCODR, visit www.pcodr.ca.





Focus on metastatic breast cancer

The Canadian Breast Cancer Network has been actively working to build greater awareness and understanding around metastatic breast cancer among decision-makers, health service providers, and the general public.

Providing the patient perspective

CBCN has provided patient input submissions to the pan-Canadian oncology drug review (pCODR) for four new drugs (Afinitor, Halavan, Kadcyla and Perjeta) intended to improve treatment outcomes for patients with metastatic breast cancer. CBCN hopes that through our patient evidence submissions to pCODR we can raise awareness about the challenges associated with treating metastatic breast cancer, and ensure that the experiences of patients are being leveraged towards more informed decision-making.









Engaging decision-makers

In September, CBCN will hold a lobby day on Parliament Hill to raise the issue of metastatic breast cancer among key parliamentarians. The event will build on a 2013 lobby day, when CBCN Board members Cathy Ammendolea and Wendy Panagopoulos met with 13 Members of Parliament, including Leader of the Liberal Party, Justin Trudeau, Conservative Member of Parliament Roxanne James, and New Democratic Party Member of Parliament Peter Stoffer. The meetings were very successful, and CBCN was able to establish all-party support for actions to raise national awareness and understanding of metastatic breast cancer. This year CBCN will continue to engage parliamentarians around metastatic breast cancer and build momentum towards ensuring that the needs and concerns of metastatic breast cancer survivors are addressed.

Highlighting the patient journey

In 2013, CBCN, in partnership with ReThink Breast Cancer, released Metastatic Breast Cancer in Canada: The lived experience of patients and caregivers, a novel report highlighting the patient journey by examining the realities and lived experiences of metastatic breast cancer survivors and their caregivers. The report detailed the specific challenges associated with a metastatic breast cancer diagnosis and emphasized the impact on survivors' quality of life, focusing on both the physical and psychosocial aspects of the disease. For more information and to access the report, please visit www.cbcn.ca.

Promoting the patient voice

In April, CBCN hosted an advocacy training session for breast cancer survivors in Calgary. The training focused on the issue of metastatic breast cancer and offered participants the opportunity to enhance their communication skills and effectively deliver strong advocacy messages to a wide variety of audiences. A similar event was held in 2013 in Halifax. If you are interested in participating in future advocacy training sessions, please connect with Niya Chari at nchari@cbcn.ca or 1-800-685-8820 x231.





Building a united voice for metastatic breast cancer in Canada

Each year, an estimated 10 percent of women newly diagnosed with breast cancer will receive an initial diagnosis of metastatic breast cancer¹ and approximately 30 percent of women diagnosed originally with earlier stages of breast cancer will go on to develop the disease.2 Yet there continues to be a lack of awareness and understanding of the distinct challenges affecting Canadians living with metastatic breast cancer.

The Canadian Breast Cancer Network (CBCN) is committed towards breaking this silence. Our objective is to build a community dedicated to raising the overall profile of this disease in Canada and addressing the treatment, support and healthcare needs of Canadians living with metastatic breast cancer.

We are working with decision-makers, health care providers and the general public to build national awareness of the distinct and complex challenges faced by Canadians living with metastatic breast cancer. Our key efforts include working with parliamentarians to designate October 13 as a national day of awareness for metastatic breast cancer, promoting the "In My Own Words" social media campaign to get people talking about the disease, and presenting at health conferences to promote improved services that will meet the needs of Canadians living with metastatic breast cancer.

CBCN also champions the voices and perspectives of metastatic breast cancer patients by ensuring that patient input informs the decision-making processes of key health bodies, including the pan-Canadian Oncology Drug Review



and L'Institut national d'excellence en santé et en services sociaux. CBCN is also expanding opportunities to increase the knowledge and capacity of Canadians living with metastatic breast cancer through our advocacy skills training workshops. educational programming and information sharing.

Beyond our educational and awareness raising efforts, CBCN also helms active advocacy campaigns to promote equitable and timely access to new treatments for metastatic breast cancer, increased investments in metastatic breast cancer research and improved surveillance and statistical data of metastatic breast cancer in Canada. We also act as a resource for patients to get connected to information and services and navigate through the drug access system.

Through this combination of education, information-sharing and targeted advocacy activities, CBCN hopes to build a united voice committed to promoting the best quality of care for all Canadians living with metastatic breast cancer. Please visit cbcn.ca or call us at 1-800-685-8820 for more information on metastatic breast cancer and how you can lend your voice to this issue.

² O'Shaughnessy, J. (2005). Extending Survival with Chemotherapy in Metastatic Breast Cancer. The Oncologist, Vol.. 10 (supp13): 20-29.





¹ Bernard-Marty, C. (2004). Facts and Controversies in Systemic Treatment of Metastatic Breast Cancer. The Oncologist, Vol. 9: 617-632.

RESEARCH ROUNDUP

YOUR UPDATE ON THE LATEST BREAST CANCER RESEARCH

Yoga reduces insomnia in breast cancer patients treated with Hormone Therapy

Having trouble sleeping? If you're on hormonal therapy, such as aromatase inhibitors or tamoxifen, you may want to try yoga to help reduce your symptoms of insomnia and also improve your quality of life. Research by Dr. Peppone of the University of Rochester Medical Centre demonstrated that women on hormonal therapies who participated in a four-week yoga program, consisting of two 75-minute sessions each week, significantly reduced insomnia. In addition, these patients were also able to reduce the use of prescription sleep medications. For additional information on the results of this trial, visit www.cancernetwork.com



Aromatase inhibitors reduce breast cancer risk by over 50 percent for postmenopausal women at high risk A recent study, the International Breast Cancer Intervention Study II (IBIS-II), demonstrated that the aromatase inhibitor, anastrozole, reduced the risk for breast cancer by 53 percent among postmenopausal women at high risk for the disease. Based on these results, the head of the Cancer Research UK Centre for Cancer Prevention said that anastrozole should be the treatment of first choice for these patients compared with other preventative therapies; however, he also added that long-term follow-up would be essential in understanding the full risks and benefits. For more information on this study, visit www.cancernetwork.com.

Bisphosphonates show benefits in reducing the risk of breast cancer recurrence

Bisphosphonates have been used for many years in the management of osteoporosis and studies are now demonstrating that they show a significant benefit for women who are postmenopausal in reducing the risk of breast cancer recurrence and improving overall survival. Several studies demonstrated that postmenopausal women with breast cancer benefit from a reduction of recurrence of bone metastasis as well as a reduction in breast cancer related mortality. For more information, visit www.medpagetoday.com



Exercise improves quality of life, reduces risk of recurrence, and improves bone health Evidence continues to show that there are significant benefits for breast cancer survivors from regular exercise. Dr. Roanne Segal, from the Ottawa Hospital, has shared at several conferences that evidence shows that regular exercise is safe for breast cancer survivors and demonstrated several benefits, which include an improved quality of life; decreased fatigue and depression; improvement in bone health, which is compromised by many of the drugs that are used to treat breast cancer; and a decrease in recurrence rates as well as deaths as a result of breast cancer. So take advantage of the days of spring and summer and head out for a walk, bike ride, hike or perhaps try something new like an aquafit or yoga class!





UPDATE ON NEW BREAST CANCER DRUGS FOR CANADIANS LIVING WITH METASTATIC BREAST CANCER

In the past couple of years, several promising new metastatic breast cancer drugs have received Health Canada approval and are have either been added to provincial formularies or are at various stages of the drug approval process. Below is a brief overview of each one and what it's indicated for. Some of these have already been added to the provincial formularies and others are still in the approval process. For more information on whether these treatments are right for you or are currently covered by your province, speak with your oncologist.

Afinitor (everolimus) is used to treat advanced hormone receptor-positive, HER2-negative breast cancer along with exemestane in postmenopausal women.

Halaven (eribulin) is a chemotherapy for metastatic breast cancer that is currently approved for use after the cancer has progressed on at least two types of metastatic breast cancer therapy.

Perjeta (pertuzumab) is approved for use in combination with Herceptin (trastuzumab) and docetaxel for HER2-positive metastatic breast cancer in patients who have not received anti-HER2 therapy or chemotherapy for metastatic breast cancer.

Kadcyla (ado-trastuzumab emtansine) is approved to treat HER2-

to treat HER2positive metastatic breast cancer after prior treatment with Herceptin (trastuzumab) and a taxane. 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

How can patients access new breast cancer drugs that are in the approval process or haven't been listed on the provincial formularies?

We often receive inquiries from Canadians asking how they can access a new drug that they might benefit from if it hasn't yet been added to the provincial formulary. Here are some options to consider:

Enroll in a clinical trial: Some therapies have clinical trial sites open across Canada; speak to your oncologist to see if there is one in your area that you might be able to enroll in.

Compassionate access programs: The manufacturers often have compassionate access programs that certain patients may qualify for; your oncologist will need to submit the appropriate documentation to the manufacturer for consideration.

Private health insurance: If you have private health insurance, check with your insurer to see if these are now covered under your drug plan.

Special access programs: Ask your oncologist if there is a special access program through the provincial healthcare system that may allow you to access new drugs that haven't yet been added to the formulary.

Connect with CBCN: If you are still having trouble accessing a new therapy after discussing these options with your oncologist, contact CBCN! We connect with provincial and territorial decision making bodies and ministries of health to ensure that the patient experience and needs are considered when funding for new breast cancer therapies are being decided. We want to ensure that your concerns, challenges and needs are being voiced and that breast cancer patients across Canada are able to access the drugs that they need to manage their disease. Call us toll free at 1-800-685-8820 or email Niya Chari at nchari@cbcn.ca.



METASTATIC BREAST CANCER CLINICAL TRIALS THAT ARE CURRENTLY OPEN IN CANADA

There are several clinical trials in Canada, specifically for metastatic breast cancer, that are currently open and recruiting participants. Below is a list of some of these trials; a comprehensive list of trials for both metastatic breast cancer and early stage breast cancer can be found on CBCN's website www.cbcn.ca in the sub-site "Research & Clinical Trials". If you are interested in participating in one of these trials, speak with your primary physician for more information.

Title: A Phase III Randomized, Double Blind Placebo Controlled Study of BKM120 with Fulvestrant, in Postmenopausal Women with Hormone Receptor-positive HER2-negative Locally Advanced or Metastatic Breast Cancer Which Progressed on or After Aromatase Inhibitor Treatment (**BELLE-2**)

Patient Population: Postmenopausal women with HR+HER2-breast cancer with progression on or after aromatase inhibitor treatment without symptomatic brain metastases

Cities / Centres: Calgary, Edmonton, Kelowna, Vancouver, Halifax, Cambridge, London, Newmarket, Ottawa, Toronto, Montreal, Laval, and Quebec City

Title: A Phase III Randomized, Double Blind, Placebo Controlled Study of BKM120 With Fulvestrant, in Postmenopausal Women With Hormone Receptor-positive HER2-negative AI Treated, Locally Advanced or Metastatic Breast Cancer Who Progressed on or After mTOR Inhibitor Based Treatment (**BELLE-3**)

Patient Population: Postmenopausal women with locally advanced or metastatic breast cancer (HR+HER2-)

Cities / Centres: Montreal

Title: A Randomized Double-blind, Placebo-controlled Study of LEE011 in Combination With Letrozole for the Treatment of Postmenopausal Women With Hormone Receptor Positive, HER2 Negative, Advanced Breast Cancer Who Received no Prior Therapy for Advanced Disease (**MONALEESA-2**)

Patient Population: Postmenopausal women with advanced (recurrent or metastatic) breast cancer who received no prior therapy for advanced disease

Cities / Centres: Hamilton, Ottawa, Toronto, Burnaby, Montreal, and Quebec City

Title: Palbociclib (PD-0332991) Combined with Fulvestrant in Hormone Receptor+ HER2-Negative Metastatic Breast Cancer After Endocrine Failure (**PALOMA-3**)

Patient Population: Women (any menopausal status) with metastatic or locally advanced HR+/HER2- breast cancer

Cities / Centres: Kingston, Oshawa, Toronto, Barrie, St. Catharines and Ottawa

Title: A Study of Palbociclib (PD-0332991) + Letrozole vs. Letrozole for 1st Line Treatment of Postmenopausal Women with ER+/HER2- Advanced Breast Cancer (**PALOMA-2**)

Patient Population: Postmenopausal women with metastatic or locally advanced ER+ breast cancer with no prior systemic anticancer therapy for advanced ER+ breast cancer

Cities / Centres: Vancouver, London, Sudbury, Toronto, Newmarket, Quebec City, Montreal

Title: A Study of Pertuzumab in Combination with Herceptin (Trastuzumab) and A Taxane in First-Line Treatment in Patients with HER2-Positive Advanced Breast Cancer (**PERUSE**)

Patient Population: Enrolling male or female patients with HER2+ advanced breast cancer not previously treated with systemic non-hormonal anticancer therapy in the metastatic setting

Cities / Centres: Edmonton, Victoria, Halifax, Kitchener, Toronto, Brampton, Montreal, Greenfield Park

Title: A Study Evaluating Efficacy and Tolerability of Veliparib in Combination with Temozolomide or in Combination with Carboplatin and Paclitaxel Versus Placebo in Subjects with BRCA1 and BRCA2 Mutation and Metastatic Breast Cancer

Patient Population: Women with a locally recurrent or metastatic breast cancer with a deleterious breast cancer gene BRCA1 or BRCA2 germline mutation.

Cities / Centres: Toronto, Quebec City, Montreal



RESOURCE DIRECTORY



Maplesoft Centre in Ottawa offers cancer coaching

The Ottawa Regional Cancer Foundation's Maplesoft Centre is currently offering cancer coaching –a new concept in cancer care that focuses on an individual's needs – physical. informational, emotional, and spiritual- to help them meet the challenges of cancer, live well, and be their healthiest. The cancer coach serves as a partner, working with the cancer survivor to enhance his or her overall quality of life. Together, cancer survivors and their coaches work to establish health goals, and work to achieve a balance of mental, physical, spiritual and emotional well-being. Empowerment is key; each person is active and responsible for the decisions regarding their care and managing their own goals and well-being. Cancer coaching is offered privately or in a group setting. In addition, wellness programs and healing therapies focus on disease management, fitness/exercise, nutrition/cooking and mind-body-spirit balance. The wellness programs and healing therapies are available to help participants meet their health goals. The Maplesoft Centre is located at 1500 Alta Vista Drive in Ottawa. For more information, telephone 613-247-3527 or visit https://survivorship.ottawacancer.ca/main.jsf.

Nanny Angel Network provides free relief childcare to mothers with breast cancer

The Nanny Angel Network is a group of women comprised of professional care providers and board members who generously volunteer their time to provide quality,

compassionate relief childcare, at no cost, to mothers diagnosed with breast cancer, in treatment or in the early stages of recovery. All Angels are pre-screened, professional, experienced child care providers who volunteer their time providing mothers with the security that their children are being well looked after while they get some much needed rest, go to appointments or simply have time for themselves. Angels are currently available in Metro Toronto, Ottawa, Calgary, and Vancouver. For more information, call 416-730-8963 or visit www.nannyangelnetwork.com.

CancerBridges Survivor Network advocates for better care

The CancerBridges Survivor Network (CBSN) is a group of Albertans who have been affected by cancer and want to be part of making the cancer system better. The Survivor Network will help Alberta Health Services tap into the valuable insight, feedback and advice that patients, survivors and family members have on how to improve the cancer care system in Alberta. The CancerBridges Survivor Network is also a direct link between cancer survivors and programs dedicated to encouraging survivorship within both Alberta Health Services and community-based organizations. It is dedicated to getting cancer survivors into programs that will help them thrive in the turbulent post-treatment/chronic care phase of a cancer journey. For more information, visit http://www.cancerbridges. ca/2011/10/survivor-network/.





RESOURCE DIRECTORY



Wellwood supports cancer patients in Hamilton, Ontario

Everyone who is connected with CBCN knows how difficult the cancer journey can be. No one should have to do it alone. Wellwood, in Hamilton, Ontario, is committed to helping people to live well with cancer. While some services are delivered at the Juravinski Hospital and Cancer Centre,

most programming takes place in a beautiful, safe, fully accessible "home" located at 501 Sanatorium Road, providing an escape from the clinical environment. Programs are driven by client input, based on the self-help model, and are free of charge to everyone affected by cancer. "It is YOUR journey, YOU are in control, YOU make the decisions, and WE are simply there to walk with you on your path," says Executive Director Jane George. Programming embraces the themes of: peer mentoring and support; movement and exercise; creative expression; coping strategies; and information and navigation. The wide range of services includes everything from meditation, yoga and tai chi, to art, Native beadwork and touch therapies. In addition to one-on-one peer support, Wellwood hosts a group for people diagnosed with breast cancer. For more information, visit www.wellwood.on.ca, call 905-667-8870 or e-mail wellwood@hhsc.ca.

Rosanna Bechtel Memorial Library offers breast cancer resources

In Bedford, Nova Scotia, if you're looking for information or services on breast cancer or breast health, the Rosanna Bechtel Memorial Library is your place to start. The library offers a comprehensive collection of books, videos, audio tapes, reports, studies, and publications in a cozy setting. You can browse the collection, borrow resources, have a cup of tea, search the Internet, or privately talk with someone who has been through breast cancer. You will leave feeling more informed and empowered. Hours are 10 a.m. to 4 p.m. weekdays or Saturday by appointment. The library is located at Mill Cove Plaza, 967 Bedford Highway, Suite 205, Bedford. Call 902-465-2685 for more information.

Exercise guide for breast cancer survivors

Researchers from the University of Alberta and Athabasca University have joined together to produce a science-based exercise guide for breast cancer survivors. Exercise for Health: A Guide for Breast Cancer Survivors tells you all you need to know to get started with an exercise program, which the authors say is "especially important" for breast cancer survivors, who are at an increased risk of heart disease, breast cancer recurrence, memory problems, osteoporosis and lymphedema. The good news is that by exercising regularly you can reduce your risk, and even prevent some of these problems. Download the guide for free from http://www. behaviouralmedlab.ualberta.ca/ForCancerSurvivors.aspx.





MAY 9 TO 11, SACKVILLE, NEW BRUNSWICK: SKILLS FOR HEALING **CANCER WEEKEND RETREAT.** Join the Healing and Cancer Foundation and the Canadian Cancer Society for a free weekend retreat open to anyone with a cancer diagnosis of any type or stage. Dr. Rob Rutledge and Timothy Walker will help you learn:

- How to get complete cancer care
- Empowering the body
- Stress reduction and mind-body techniques
- Working with difficult thoughts and emotions
- Meditation and informal discussion

For more information or to register, contact Stephen or Jane at 506-536-4219 or sclaxton@mta.ca, or visit www. healingandcancer.org.

MAY 26 TO 31. TORONTO: WORKSHOP ON THE HEALTHY BREAST PROGRAM AND MIND-BODY APPROACHES TO CANCER AND

HEALTH. Sat Dharam Kaur ND and Dr. Gabor Maté present this workshop designed to give you a comprehensive practical overview of the Healthy Breast Program, created to help women both prevent and recover from breast cancer using yoga, meditation, diet, detoxification, specific supplements, psychological and spiritual exercises and environmental education. On completion of this course, you will:

- understand the biological, social, environmental and spiritual causes of breast and other cancers
- learn how to perform breast self-massage and activate your lymphatic system
- learn health-promoting dietary and nutritional strategies
- learn how to activate your immune system and direct your mind to stimulate a healing response

The program is designed for anyone interested in lifelong health, breast and other cancer survivors, health professionals, and yoga teachers. For more information, call 519-372-9212.

MAY 31 AND JUNE 1, KAMLOOPS, BC: PILATES COURSE.

The Pilates Tree in Kamloops, BC invites Pilates teachers, physiotherapists, occupational therapists, lymphedema treatment specialists and nurses to join Doreen Puglisi and her Pink Ribbon Program on May 31 and June 1. The goal of this interactive two-day course is to provide participants with an in-depth understanding of the stages and recovery process of breast cancer and how to develop an effective rehabilitation and gentle exercise program using a Pilates-based approach. The course costs \$450 plus tax. For more information, call The Pilates Tree at 250-320-2639.

JUNE 5 TO 9, TORONTO: YOUNG ADULT CANCER CANADA SURVIVOR CONFERENCE. The annual Survivor Conference is the biggest reunion of young adult cancer survivors and supporters in Canada. It brings together a group of people who get it to connect and learn things that can help them move forward or beyond the cancer experience. The conference is open to

survivors and their supporters between 18 and 39 years old. For more information, visit www.youngadultcancer.ca or email connect@youngadultcancer.ca.

COMING IN JUNE: The Canadian Breast Cancer Network will host a webinar about familial risk of breast cancer. See our website, cbcn.ca, for the date and time. We usually record our webinars and post them on our website. To access them, visit cbcn.ca and click on "Bulletin Boards." There, you can view a variety of topics, including our April webinar on modifiable risk factors to reduce your risk of recurrence.

SEPTEMBER 19 TO 21, CHAPEL HILL, NORTH CAROLINA: **METASTATIC BREAST CANCER CONFERENCE.** The Metastatic Breast Cancer Network will hold its eighth Annual National Conference in conjunction with the UNC Lineberger Comprehensive Cancer Center. The conference is open to people living with metastatic breast cancer as well as their spouses, partners, friends, and caregivers. For more information, visit http://mbcn.org/.





National Partners

Aboriginal Nurses Association of Canada

Best Medicines Coalition

Canadian Breast Cancer Foundation

Breast Cancer Society of Canada

Canadian Association of Psychosocial Oncology

Canadian Association of Radiologists

Canadian Cancer Action Network

Canadian Cancer Society

Canadian Health Coalition

Canadian Hospice and Palliative Care Association

Canadian Institutes of Health Research

Canadian Lymphedema Framework

Canadian Medical Association

Canadian Nurses Association

Canadian Partnership Against Cancer

Canadian Patient Coalition

Canadian Psychosocial Oncology Partnership

Canadian Working Group on HIV and Rehabilitation

Cancer Advocacy Coalition of Canada

Cancer Fight Club

College of Family Physicians of Canada

CURE Foundation

DisAbled Women's Network of Canada

Episodic Disabilities Network

Fertile Future

HPV and Cervical Health Society

Look Good Feel Better

Ovarian Cancer Canada

Pauktuutit Inuit Women of Canada

Public Health Agency of Canada

Quality End of Life Care Coalition of Canada

Rethink Breast Cancer

Team Shan

Willow Breast Cancer Support Canada

Young Adult Cancer Canada

Provincial Partners

British Columbia Cancer Agency

Breast Cancer Action Manitoba

Breast Cancer Action Nova Scotia

Breast Cancer Action Saskatchewan

Breast Cancer Centre of Hope

Breast Cancer Network Nova Scotia

Cancer Care Manitoba

Cancer Care Ontario

Coalition priorité cancer au Quebec

Hereditary Breast and Ovarian Cancer Society of Alberta

Hereditary Breast and Ovarian Cancer Society of Montreal

Lymphedema Association of Manitoba

Lymphedema Association of Ontario

Manitoba Breast & Women's Cancers Network

New Brunswick Breast and Women's Cancers Partnership

New Brunswick Breast Cancer Network. Inc.

Newfoundland and Labrador Purple Lupin Partnership

NWT Breast Health/Breast Cancer Action Group

PEI Breast Cancer Information Partnership

Quebec Breast Cancer Foundation

Saskatchewan Breast Cancer Connect

Local Partners

Breast Cancer Action Kingston

Breast Cancer Action Montreal

Breast Cancer Action Ottawa

Breast Cancer Support Services Inc.

Cedars Cancer Support

Gilda's Club

Hope and Cope

Manitoba Breast Cancer Survivors Chemo Savvy Dragon

Boat Team

Maplesoft Centre

Nanny Angel Network

Olive Branch of Hope

Ottawa Hospital Cancer Centre — Psychosocial Oncology

Program

Ottawa Integrative Cancer Centre

PYNK Breast cancer Program for Young

Women at Sunnybrook

Wellspring

Hundreds of support groups across Canada

Dozens of Dragon Boat teams across Canada

Dozens of mastectomy boutiques across Canada

CBCN is a member of:

Best Medicines Coalition

Canadian Cancer Action Network

Canadian Breast Cancer Screening Initiative

Coalition priorité cancer au Québec

Episodic Disabilities Network

Quality End-of-Life Care Coalition of Canada



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There are many individuals and organizations that make it possible for CBCN to continue to be the voice of Canadians affected by breast cancer. CBCN gratefully acknowledges the hundreds of individuals and groups across the country who choose to support CBCN with your financial contributions throughout the year and your in-memoriam donations to honour the memory of a loved one. We truly appreciate that you see value in the work that CBCN continues to do and are thankful for your ongoing support.

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Public Health Agency of Canada



