


ESSENTIAL NEWS FOR CANADIANS AFFECTED BY BREAST CANCER

networknews

Fall 2015, Vol. 19, No. 2

 Canadian Breast Cancer Network  @CBCN

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LETTER FROM THE CHAIR OF THE BOARD OF DIRECTORS

Dear readers:

Welcome to a special edition of Network News that's all about metastatic breast cancer. Patients with this disease often feel their issues are ignored and misunderstood, so we're shining the spotlight on them.

Metastatic breast cancer occurs when breast cancer cells move from the breast to a vital organ and that is what threatens life. Breast cancer primarily metastasizes to the bone, lungs, regional lymph nodes, liver, and brain, with the most common site being the bone.

Metastatic breast cancer is not an automatic death sentence. Although most people will ultimately die of their disease, some will live for many years. There are no definitive prognostic statistics for metastatic breast cancer. Every patient and their disease is unique.

Of the 25,000 women diagnosed with breast cancer in Canada in 2015, it is estimated that 5 percent will have an initial diagnosis of metastatic breast cancer, and approximately 30 percent of women diagnosed initially with earlier stages of breast cancer will go on to develop metastatic breast cancer.

Treatment for metastatic breast cancer is lifelong and focuses on control of the disease and quality of life.

This issue of Network News addresses these and other issues. In these pages, you will find articles on the new targeted therapies for breast cancer, tips for dealing with insomnia and the difficult emotions that metastatic breast cancer brings, and a first-person story of a patient with this disease. You'll also learn about our campaigns to champion the voice and honour the lives of Canadians living with metastatic breast cancer.

CBCN is proud to stand in solidarity with individuals across Canada affected by metastatic breast cancer, to raise awareness about this disease, and to promote a community of support for all Canadians affected by metastatic breast cancer.

Warm regards,



Cathy Ammendolea, CBCN Board Chair

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Targeted therapy for breast cancer



As researchers have learned more about the gene changes in cells that cause cancer, they have been able to develop newer drugs that specifically target these changes. These targeted drugs work differently from standard chemotherapy drugs. They often have different (and less severe) side effects.

DRUGS THAT TARGET THE HER2/NEU PROTEIN

In about one in five patients with breast cancer, the cancer cells have too much of a growth-promoting protein known as HER2/neu (or just HER2) on their surface. Breast cancers with too much of this protein tend to grow and spread more aggressively without special treatment. A number of drugs have been developed that target this protein:

- Trastuzumab (Herceptin)
- Pertuzumab (Perjeta®)
- Ado-trastuzumab emtansine (Kadcyla™)
- Lapatinib (Tykerb)

Trastuzumab and pertuzumab are monoclonal antibodies — man-made versions of a very specific immune system protein. They are given into a vein (IV).

Ado-trastuzumab emtansine is a monoclonal antibody attached to a chemotherapy drug. It is also given IV.

Lapatinib is a targeted drug that is not an antibody. It is given as a pill.

When are these drugs used

Trastuzumab can be used to treat both early- and late-stage breast cancer. When used to treat early breast cancer, this drug is usually given for a year. For advanced breast cancer, treatment doesn't stop after a year and can last a long time.

Pertuzumab can be given with trastuzumab and chemotherapy to treat advanced breast cancer. This combination is also used to treat early breast cancer before surgery.

Ado-trastuzumab emtansine is used to treat advanced breast cancer in women who have already been treated with trastuzumab.

Lapatinib is used to treat advanced breast cancer. It is most often used if the doctor thinks that trastuzumab is no longer working.

Side-effects

The side-effects of these drugs are often mild. Discuss what you can expect with your doctor.

TREATMENT TALK

Some women do develop heart damage during or after treatment with the antibody drugs (trastuzumab, pertuzumab, and ado-trastuzumab emtansine). This can lead to a problem called congestive heart failure. For most (but not all) women, this effect lasts a short time and gets better when the drug is stopped. The risk of heart problems is higher when these drugs are given with certain chemo drugs that also can cause heart damage, such as doxorubicin (Adriamycin) and epirubicin (Ellence). Because these drugs can cause heart damage, doctors often check your heart function (with an echocardiogram or a MUGA scan) before treatment, and check it again every few months while you are taking the drug. Major symptoms of congestive heart failure are shortness of breath, leg swelling, and severe fatigue. Let your doctor know if you develop any of these symptoms.

Lapatinib can cause severe diarrhea, so it is very important to let your health care team know about any changes in bowel habits as soon as they happen. It can also cause something called hand-foot syndrome, in which the hands and feet become sore and red, and may blister and peel.

None of these drugs should be given to women who are pregnant because they can harm and even cause death to the fetus. Women who could become pregnant need to use effective birth control during treatment.

A DRUG THAT HELPS HORMONE THERAPY DRUGS WORK BETTER

Everolimus (Afinitor®) is a drug that can be used along with a hormone therapy drug to treat women with advanced hormone receptor positive breast cancer. This targeted therapy drug

blocks mTOR, a protein in cells that normally promotes their growth and division. By blocking this protein, everolimus can help stop cancer cells from growing. Everolimus may also stop tumors from developing new blood vessels, which can help limit their growth. In treating breast cancer, this drug seems to help hormone therapy drugs work better.

Everolimus is a pill taken once a day.

This drug is approved to treat advanced hormone receptor–positive, HER2–negative, breast cancer in women who have gone through menopause. It is meant to be used with exemestane (Aromasin) in these women if their cancers have grown while they were being treated with either letrozole or anastrozole (or the cancer started growing shortly after treatment with these drugs was stopped). This approval was based on a study that showed that giving everolimus with exemestane was better than exemestane alone in shrinking tumors and stopping their growth in post-menopausal women with hormone receptor–positive, HER2–negative breast cancer that had stopped responding to letrozole or anastrozole.

Common side effects of this drug include mouth sores, diarrhea, nausea, fatigue, feeling weak or tired, low blood counts, shortness of breath, and cough. Everolimus can also increase blood lipids (cholesterol and triglycerides) and blood sugars, so your doctor will check your blood work periodically while you are on this drug. It can also increase your risk of serious infections, so your doctor will watch you closely for infection while you are on treatment.

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Make a slider for lymphedema management

By Leda Raptis

Compression therapy is central to lymphedema management. However, putting a compression garment on can be difficult. This may lead to poor adherence to treatment, which is likely to negate any benefit achieved via months of laborious bandaging. A solution to this difficulty is a slider.

A slider is a tube made out of slippery cloth such as nylon. It goes on your arm first, followed by the compression garment, and is then removed.

Sliders are commercially available and can be purchased over the Web (www.lymphedemaproducts.com) or from your local fitter. But these sliders can be expensive. A cheaper alternative is to sew one yourself. Here are some simple instructions on how to make an arm slider.

MATERIALS

- Choice of cloth (1.2 m):
 - nylon, as used for the outer shell of windbreaker coats, or
 - nylon taffeta, or
 - spinnaker sail cloth (available from sailmakers). This cloth's advantage is that it does not fray, which makes it easier to sew, since it does not need hemming.
- thread, in matching colour
- paper, 1.1 m in length (newspaper is suitable, or you can tape pieces together)
- ruler
- pen
- scissors
- pins
- sewing machine

CUTTING INSTRUCTIONS

1. Using the ruler and pen, draw the pattern in Figure 1A on a sheet of paper; then cut out the shape.
2. Test the nylon to find out which direction is most slippery (spinnaker cloth is equally slippery in both directions.) Wet

the thumb and index fingers, pinch the nylon and slide back and forth in one direction, then at a 90 degree angle. It is important to sew the nylon so as to take advantage of its most slippery direction. Usually this is along the length of the bolt. That is why you need to buy 1.2 m, not 0.5 m. The width is usually 1.5 m, so that you can make three sliders with the 1.2 m.

3. Spread the material on a cutting table so that the most slippery direction is lengthwise as shown by the arrow (Figure 1A). Pin the pattern on top.
4. Cut out the shape shown in Figure 1A. The size shown fits most arms but it can be made bigger if necessary.
5. Cut a strip of 34x5 cm and a strip of 30x6 cm for the stirrup (Figure 1B).

SEWING INSTRUCTIONS

1. Fold along the dotted lines (see Figure 1A), placing the two less slippery sides together, and sew the three sides (b,c,d) in straight stitch; then hem in zig-zag.
2. Turn the tube inside out and sew the three sides (b,c,d) with a straight stitch at 2 mm from the edge.
3. Fold the edges of the strips and sew to make sturdy strips of 34x1.5 cm and 30x2 cm.
4. Sew the 34 cm strip (e) along the wider end of the slider (a). Then insert the 30 cm strip (f) as shown, fold (e) over it and sew it to the 34 cm strip. Do several passes to ensure strength.

USING THE SLIDER

1. Fold the narrower end of the slider (c,d) inside the wider one as shown in Figure 1C.
2. Pass the arm inside.
3. Pull the compression sleeve on top of the slider. It should slide easily.
4. Remove the slider: Hold the sleeve and pull from the stirrup, by passing a door handle or a foot through the loop (Figure 2).

TREATMENT TALK

FIGURE 1

Measurements are in centimetres.

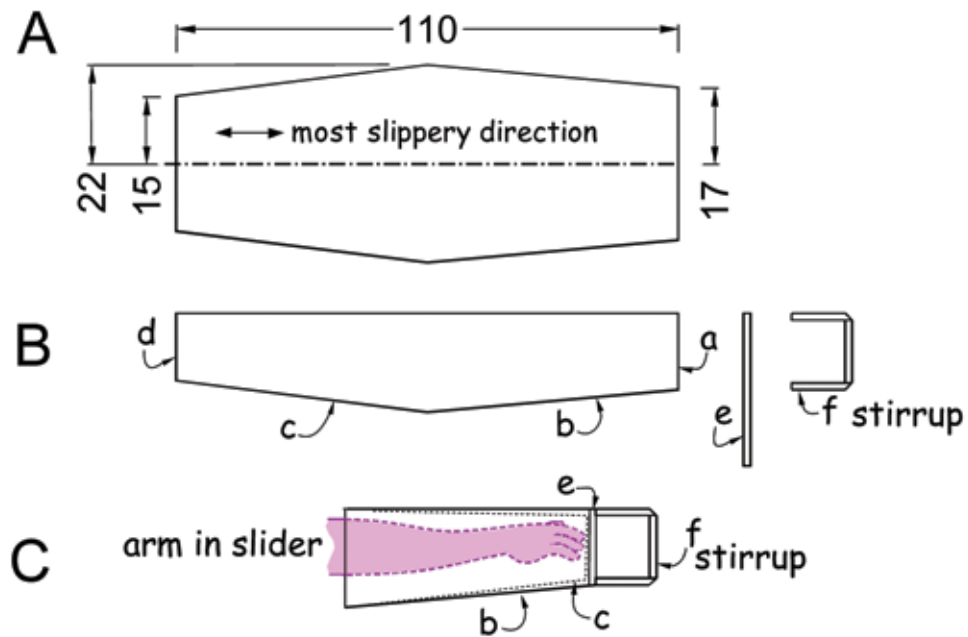


FIGURE 2





Drug-free ways to cure insomnia

Are you tossing and turning all night and fatigued during the day? If so, you're not alone. According to a survey of metastatic breast cancer patients conducted by the Canadian Breast Cancer Network, insomnia and fatigue are the symptoms that most affect metastatic patients' quality of life. These symptoms are very common: one study found that 61 percent of breast cancer patients had significant sleep issues¹.

Medications are one treatment for insomnia. However, they are recommended only for short-term use, and they do not address the underlying causes of insomnia.

A non-drug alternative that is just as effective as drugs is Cognitive Behavioural Therapy for Insomnia, or CBT-I. This therapy teaches better sleep habits.

The cognitive part of CBT-I teaches you to recognize and change beliefs that affect your ability to sleep. For instance,

this may include learning how to control or eliminate negative thoughts and worries that keep you awake. The behavioral part of CBT-I helps you develop good sleep habits and avoid behaviors that keep you from sleeping well.

The first step in the therapy is to keep a sleep journal for a week or two. The journal should show patterns in your sleep routines. You can download one from <http://sleepfoundation.org/sleep-diary/SleepDiaryv6.pdf>. Continue to keep a journal throughout the therapy to record your progress.

A second technique is Stimulus Control Therapy. The object of this technique is to make your bedroom a stimulus for sleep, and to eliminate factors that condition the mind to resist sleep. For example, you might set a consistent bedtime and wake time and avoid naps, use the bed only for sleep and sex, and leave the bedroom if you can't go to sleep within 20 minutes, only returning when you're sleepy.

A third technique is Sleep Restriction. Lying in bed when you're awake can become a habit that leads to poor sleep. This treatment decreases the time you spend in bed, causing partial sleep deprivation, which makes you more tired the next night. Once your sleep has improved, your time in bed is gradually increased.

A fourth technique is Sleep Hygiene. This method involves changing basic lifestyle habits that influence sleep, such as smoking or drinking too much caffeine late in the day, drinking too much alcohol, or not getting regular exercise. It also includes introducing calming rituals at bedtime, such as taking a hot bath or listening to peaceful music.

A fifth technique is Sleep Environment Improvement. This offers ways that you can create a comfortable sleep environment, such as keeping your bedroom quiet, dark, and cool, and not having a TV in the bedroom. Also, since watching the clock can increase your distress about not falling asleep and can thus keep you awake, you should hide it from view.

A sixth technique is Relaxation Training. This method helps you calm your mind and body. Approaches include meditation, imagery, muscle relaxation, and others.

A seventh technique is to remain passively awake. Also called paradoxical intention, this involves avoiding any effort to fall asleep. Paradoxically, worrying that you can't sleep can actually keep you awake. Letting go of this worry can help you relax and make it easier to fall asleep.

If you find that using these techniques on your own are not sufficient to help you sleep, you may wish to work with a sleep specialist. Ask your doctor for a referral.

CBT-I requires steady practice, and some approaches may cause you to lose sleep at first. But stick with it, and you'll likely see lasting results.

Sleep-inducing tips

- Exercise can promote good sleep. Vigorous exercise should be taken in the morning or late afternoon. A relaxing exercise, like yoga, can be done before bed to help initiate a restful night's sleep.
- Food can be disruptive right before sleep. Stay away from large meals close to bedtime. Also, dietary changes can cause sleep problems: if you are struggling with a sleep problem, it's not a good time to experiment with spicy dishes. And, remember, chocolate has caffeine.
- Ensure adequate exposure to natural light. This is particularly important for older people who may not venture outside as frequently as children and adults. Light exposure helps maintain a healthy sleep-wake cycle.
- Establish a regular relaxing bedtime routine. Try to avoid emotionally upsetting conversations and activities before trying to go to sleep. Don't dwell on, or bring your problems to bed.
- Save your worries for daytime. If concerns come to mind in bed, write them down in a "worry book," then close the book until morning.
- Associate your bed with sleep. It's not a good idea to use your bed to watch TV, listen to the radio, use a computer or tablet, or read.

REFERENCES

¹ Fortier et al. (2002, November 24). Sleep and quality of life in breast cancer patients. *Journal of Pain and Symptom Management*, pp. 471-480.

SOURCES

- Reprinted from the MayoClinic.com article "Insomnia treatment: Cognitive behavioral therapy instead of sleeping pills" (<http://www.mayoclinic.org/diseases-conditions/insomnia/in-depth/insomnia-treatment/art-20046677>.) © Mayo Foundation for Medical Education and Research. All rights reserved.
- National Sleep Foundation, sleepfoundation.org

Facing your emotions as you near the end of life

For women living with metastatic breast cancer, theirs is a chronic illness for which they will always be undergoing treatment. If you have this illness, you may face many difficult emotions, such as fear, anger, guilt and regret, grief, feeling alone, and seeking meaning.

Knowing that metastatic breast cancer can eventually lead to death takes an emotional toll on the person with cancer and their loved ones. This is an emotional time and it's hard to talk about it; still, these issues must be addressed. Knowing these feelings are normal and expected may help you cope with what's happening. Some of the emotions you can expect to have are discussed below.

FEAR

People may feel afraid to die, but it can help to pinpoint what part of death they are afraid of. Are they afraid of dying alone? Are they afraid of suffering or pain? Are they afraid that they will die and there will be nothing beyond earthly life? Is there a fear that their lives had no purpose or meaning? These are some of the more common reasons that people fear death.

Your fears may be either concrete, like pain, or abstract, like your life's purpose. Either way they're very real.

Trying to figure out what you fear can help you face it and manage it. It will also help others support and care for you better. For example, if you're afraid of being alone, share this with your family and loved ones so they can plan to have someone with you. Sharing with loved ones and your health care team gives them a chance to help you find ways to cope with and ease some of your fears. It gives them a chance to correct any wrong ideas you may have, too. It can also give you a chance to look at and deal with some of your fears in new ways.

ANGER

Anger is sometimes hard to identify, but ignoring it won't work. Very few people actually feel ready to die. It's perfectly normal to feel angry about your life being cut short – it's unfair and you have a right to be mad! Unfortunately, anger often gets directed at those

closest to us, the ones we love the most. We feel safest with these people and know they will probably accept our anger and forgive us for it. But it may help to try to direct your anger at the disease and not your loved ones. Also, you can try to channel your anger as a source of energy to help you take action where it's needed. You can use it as fuel to solve problems, to become assertive, or to get your needs met. You can sing at the top of your lungs, give a speech with vigor, or tell your family some things you really want them to know. Try to re-channel your anger to do meaningful, positive things.

GUILT AND REGRET

In their last few months of life, a person might regret or feel guilty about many things. We feel regret when we think that we should have done something differently. Or maybe there's something we wish we had not done at all. We may feel guilty when we don't meet our own or someone else's expectations. But how does it help anyone if you hold onto guilt or regret? Worrying endlessly about these things won't make you feel better about them. It won't improve your relationships with family members. It won't ease the burden they're carrying. It won't make you feel better. It won't make you live longer. It will only make you feel bad.

Sometimes the best thing to do is to decide to "let yourself off the hook" and spend your last days and months not feeling guilty about things that are out of your control. Simply let it go. You can't change the past, but there are things you might be able to do today. Apologize for the things you regret and ask for forgiveness. Be willing to forgive others and yourself. Fix what can be fixed and try to let go of the things that can't be changed.

This is a good time to talk with your children about the important things you want them to know. It's also good to talk to them about how to handle their feelings and the loss they will soon go through. You may want to write letters to the people you love, record messages for them, make videos they can watch – give them things they can keep to remember their time with you. Tell

EMOTIONAL WELLBEING

your kids who they can talk with when you're gone and encourage them to be open when they are hurting. Spend your time focusing on your children's future, not feeling guilty about the past. Strengthen your relationships with loved ones. Live your life the best you can, and use your time for what's most important to you.

GRIEF

It's natural to feel intense grief during the last months of your life. You are grieving the loss of the life you have planned and expected. You can no longer look ahead to a seemingly "endless" future. And you may have lost many things already, such as the strength to walk or get around like you used to, or the interest in eating the things you enjoy, or maybe the ability to get together with friends. You may feel distanced from friends who cannot handle the fact you are going to die soon. This is another loss that can cause sadness and grief. Many physical and emotional losses come before the loss of life itself.

The people you love are grieving too. They know they're about to lose you. How can you and those who love you find meaning in what's happening? Try to talk to your loved ones about the grief and loss of dreams you're all going through. Being able to rise above the grief and connect spiritually to something greater than one's self might help your loved ones heal after you are gone.

Talking with someone about these feelings – a partner, a dear friend, a spiritual advisor, someone you trust – can help you process these feelings so that they no longer weigh you down. It may take many tries, but once you have done this you will feel a burden has been lifted and you can move on to the other physical and emotional tasks that make up the end of life. There are many important tasks at the end of life, but coming to terms with the losses is one of the most painful.

ANXIETY AND DEPRESSION

What does anxiety feel like? Anxiety has been described as having a nervous stomach, a shaky feeling all over, being short-tempered, a sense of dread or worry, or a fear of the unknown. It can be quite unpleasant.

Some anxiety is expected, but if it's severe it can be treated through counseling or with medicine – the goal is to make you more comfortable and help you better cope with the changes that are taking place. Anti-anxiety medicines or even anti-depressants can help. Counseling can be especially helpful in changing how you think about things so that you can focus on the present and not worry about tomorrow. Breaking problems into smaller, easier-

to-manage pieces can be a good way to handle some kinds of anxiety.

Depression is more than just feeling sad. Depression includes feeling hopeless or helpless, feeling useless, feeling sad for weeks at a time, and having no joy in any activity. These feelings are not normal, not even when life is ending. Depression can sometimes be helped with anti-depressants, counseling, or a combination of both. Managing anxiety and depression well can make a big difference in how much joy or pleasure you can find in your last few months of life.

FEELING ALONE

Very few people know what it feels like to know for sure they are facing their last months of life. There can be a loneliness that's different from any other. It's a loneliness of the heart, even when you have people around you. Frankly, there may be very few people who can really talk with you in a way that helps you feel less lonely. Some of them may be experts who are comfortable talking with people at the end of life, such as hospice social workers, nurses, or other end-of-life caregivers. They may have that special gift for silence or listening when you need it. Finding a few people that you can truly connect with is critical to ease this sense of intense loneliness. Your health care team may end up being one of your greatest resources in this area.

SEEKING MEANING

Almost everyone wants to feel their life had purpose – that there was some reason for their being on earth. Some people find meaning in their work. Others find that raising a family has brought them the greatest sense of joy and accomplishment. It's helpful to go through a process of reviewing your life and figuring out for yourself what your purpose in life has been. What was your special contribution to the world? What have you done to make the world a better place? How would you like the world or your children, family, and friends to remember you? What were the things that you thought were really important and want your children to know about for their future? It doesn't have to be something huge or earth-shaking – look for those things that have been important to you and those around you. The end of life experience is full of meaning that can be uncovered using personal reflection. Sharing your thoughts, experiences, and wisdom is a gift that your friends and family can cherish for years to come.

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CATHY AND HER HUSBAND, STEPHEN SPENCER

My never-ending story of hope

By Cathy Spencer

Because I have no family history of breast cancer, the reality of it hits home hard. On September 19, 2007, I am diagnosed with Stage IIb breast cancer and I am HER2-positive. How can I feel so healthy and be so sick?

I start treatment: eight rounds of chemotherapy and later radiation. The chemo is working: after the third cycle, I am scanned, and I show no signs of active disease. I am relieved, but I still need to complete the last five rounds of treatment.

After the seventh cycle, I can't remember simple things. I'm confused and can't focus on conversations.

On February 15, 2008, I am diagnosed with a 2.5 cm brain metastasis. I am in disbelief. How can cancer in the breast spread

to the brain? I find out that chemotherapy can't pass through the brain because it is protected by a blood barrier. I am now metastatic.

I am so confused and afraid that my life is over. Surgery is recommended. My husband and I take a huge leap of faith. I am nervous. What if I don't wake up? I can't die; I have small kids and they need me.

My parents arrive on March 15. On March 17, I go for surgery.

SHARE YOUR STORY

Possible side-effects include stroke, paralysis, loss of hearing, and blindness. I want to throw up; this is just too much to process. At this point, I do not have any choice. As I am wheeled into surgery, I feel like this is the end; I can't survive.

The surgery is four hours and the surgeon will be using a new MRI technique. When I wake up, I am told that the surgery was a success. It appears that they got everything. I am so relieved.

I am released from the hospital two days later. I'm alive and this is my second chance. My side-effects are problems with balance, short-term memory loss, and fatigue. I have six weeks to recover before radiation, and I am not allowed to drive. My parents stay to help out with my children, driving, groceries, cooking, and loving support. I am very grateful.

My next challenge is radiation, starting in April 2008: 10 rounds of whole brain radiation and 25 rounds of breast radiation. The radiologist explains that I have three to six months to live. I am told my case is textbook—check the Internet.

I am given a list of things that might happen in the next few weeks. I stand up to leave and ask, "Did you even read my chart?"

My husband and I are in shock because we were told by the surgeon that I was cancer-free. I was told that radiation will help catch any cancer that is microscopic. We leave in disbelief. We have come so far and now we have lost all hope.

I call Tom Melvin, the minister at my church, to update him on my news. He asks me to call my surgeon and get clarification. He says to be direct and ask why I should do radiation if I only have three to six months to live.

First thing Monday morning, I call and ask to speak to my surgeon. I am told the surgeon does not accept calls; I need to book an appointment. I am crying on the phone, saying "If he will not take my call, I will not complete the radiation and I will die." I am put on hold.

Minutes later the surgeon is on the phone. I can barely speak, I am wiping tears, shaking, and I am so scared. I ask him about my prognosis. He tells me that the radiologist has made a mistake because I have not developed the symptoms they see with brain metastases. He asks me to complete the radiation. He tells me I have minimum one year and many more. I am told to go and live my life.

My side effects for the brain radiation are hair loss, a wicked sunburn, and fatigue. The breast radiation makes the skin under my breast peel and become infected. The only treatment is a

cream to apply twice daily. Fatigue and vomiting are taking over my life. I am told that the radiation may have clipped a section of my stomach.

It takes three months for both areas to heal. I am depressed. My hair doesn't completely grow back, and I now wear a wig.

In 2010, I join a support group for Stage IV breast cancer. My first day, I'm uncomfortable and my brain is swimming with so much information. Many participants have progression and I cannot find anyone who has brain metastases. I am worried that I do not fit in, and I must be in the wrong group. They are all talking and sharing about treatments and different drugs/chemo. Everything is just going right over my head.

The next week I return. I notice people are talking about their experiences with family, friends, and their medical team. Travel outside of Canada is a huge topic. I am relieved that it isn't just about the drugs/chemo. We don't need to give up everything. We all have similar hopes and dreams. We meet weekly, same time, same place.



I make this group my priority, because the support is good for me. I am bonding with these women. I do not have to pretend that I am okay and I don't have to make excuses for my cancer. I feel whole and I want to share, laugh, and cry all at the same time.

The hardest part of being in the group is that my friends pass away. It is not that they have lost the fight; it is just that they have run out of treatment options. We all process death differently. I go to the funerals; afterward I raise a glass of wine to honour my friends.

People wonder why I attend a group where people struggle with progression and die. I tell friends and family my group is where I can openly talk about my cancer and how it affects me without guilt about how my cancer affects others. Like every other group member, I'm not ready to leave. I'm living for my family.

SHARE YOUR STORY



In July 2012, I start seriously thinking about my five-year anniversary of being metastatic, and I feel like I should plan my final resting place. I want to be part of the decision of where my remains will end up. I know that I want to be cremated. I walk through the cemetery and I see all the memorial benches. I like what I see. That day my husband and I purchase our spot. One more thing off my list.

In October 2012, I attend my first Living Beyond Breast Cancer (LBBC) conference in the USA. This is where I meet other women with brain metastases. I am excited because I ask them how they cope. I meet about 20 women who are still here after five to ten years. The conference gives me hope. At this conference, my friends and I are interviewed for The Atlantic magazine and our picture is published. I can't believe that we were selected to be interviewed.

In September 2013, I attend a CBCN Survivor Advocacy Training in Halifax. I never thought that patients needed to advocate for clinical trials, treatment, and patient care across Canada. After that conference, I have found my voice. I am not the same girl anymore. I need to share my experience that I am not fighting to the end; I am actually living through it.

The next few months I start sharing my story at different events in my home town of Calgary. I speak on a panel to survivors regarding survivorship. This is a huge success. As people leave, they shake our hands. Maybe sharing my story means something. I thank the organizer and say I would love to help out more, if needed.

My name is passed on to many groups. I speak to nurses who are about to graduate and to new doctors as well. I am over the moon to share my story. At the end of my talk, I ask the new doctors to please take five minutes and read their patients' files before they come in to see them. This was a powerful moment for me because of my brain radiation experience.

In October 2013, I submit my story and a poem to the Metastatic Breast Cancer Network, A huge surprise: I am on the cover of *Insights in Metastatic Breast Cancer* magazine. I am so proud of the article.

In October 2014, I am invited to the LBBC conference to share my story and my poem becomes a video. When the video is played, I get my first standing ovation. I fly back to Calgary on Cloud Nine.

In October 2014, I join Cancer Connections to offer telephone support for breast cancer patients newly diagnosed with brain metastases. This is a rewarding experience to offer hope and support over the telephone.

Also in October 2014, I participate in a media campaign about HER2-positive breast cancer.

In January 2015, I participate in my first rally. Three times the Alberta government has promised Calgary a new cancer centre, and three times that promise has been broken. My chant is "BUILD IT NOW!" I am the loudest. People chant back. It is very powerful for me. My T-shirt gets the reporters' attention: it reads, "Stage IV needs more. Treat. Scan. Repeat." I'm not sure what the outcome of the rally will be, but I am standing up to the province to build our cancer centre now! Life is good.

Advocacy gives me energy. I am still in active treatment eight years later, and sometimes it's hard to breathe when I have just completed another scan. I openly talk about my life experience with metastatic breast cancer. I think awareness is important.

The sad truth is we have no cure. We can still participate in clinical trials, get new treatments, and advocate for more. We can live our lives to the fullest.

I still want to travel and grow old. I look forward to retirement and grandbabies one day. Am I worried? Yes, at the fifth year I wanted to prepare my funeral and do things that settled my anxiety. I still go crazy because I am in the cycle of treat/scan/repeat.

Each one of us has a story to tell. Don't let cancer silence you. Use your voice and feel good about how far you have come. It's not easy, this roller coaster ride of life, but right now I am so glad to be alive!

The views expressed in this article are those of the author and not necessarily those of the Canadian Breast Cancer Network.

Raising awareness about metastatic breast cancer with the Living Legacy campaign

CBCN is excited to announce that we are continuing our “Living Legacy” campaign to raise awareness about metastatic breast cancer. Initially launched in October 2014, the “Living Legacy” campaign aims to celebrate Canadians living with metastatic breast cancer and reinforce the message that a metastatic breast cancer diagnosis does not define you.

Working closely with our Metastatic Breast Cancer Advisory Committee and representatives of the metastatic breast cancer community, the campaign aims to share and champion the voices of Canadians living with metastatic breast cancer in their own words. Through these powerful stories, recorded on video, we hope to raise awareness about the need to facilitate greater information, support, and connection to a wide network of

Canadians who are facing similar challenges when it comes to understanding their diagnosis and accessing treatment options.

The Living Legacy campaign recognizes that there is so much more to each and every person living with metastatic breast cancer than just their disease. Through this campaign, we want to help replace feelings of isolation and fear with connection and hope.

The Living Legacy campaign is a collaboration with one of Canada’s leading research-based pharmaceutical companies.

To learn more about the campaign and become part of the Living Legacy, please visit www.cbcn.ca.

CBCN releases new report, *Waiting for Treatment: Timely, Equitable Access to Drugs for Metastatic Breast Cancer*

Through our work with the metastatic breast cancer community, CBCN is aware that timely access to new treatments is essential for Canadian patients. As drugs often lose their effectiveness over time, many metastatic patients must switch their treatment to other drugs or combinations of drugs to keep ahead of disease progression.

The treatment landscape for metastatic breast cancer varies greatly depending on the type of breast cancer you have and where you live in Canada. Each province and territory has its own list of cancer drugs (the formulary) for which it will cover part or all of the cost through publicly-funded drug plans. Unfortunately, not all provinces and territories choose to include new drugs on their formularies. If a drug is not listed on the formulary, the patient must cover the drug cost out of pocket or through private insurance, which creates a situation of unequal access and affordability across Canada.

In order to address the vastly differential coverage for metastatic treatments in provinces and territories across the country, the Canadian Breast Cancer Network has released a report on access to new metastatic breast cancer treatments in Canada. *Waiting for Treatment: Timely, Equitable Access to Drugs for Metastatic Breast Cancer* provides a detailed overview of the present drug approval and funding processes in Canada and explores the discrepancies in wait times to access new treatments between provinces and territories. The report also shares a detailed portrait of the experiences and realities of women living with metastatic breast cancer concerning access to new drugs.

To read the report and learn more about metastatic drug access in Canada, please visit www.cbcn.ca

THE LATEST IN RESEARCH: UPDATES FROM ASCO

The 2015 American Society of Clinical Oncology (ASCO) Annual Meeting was held May 29 to June 2 in Chicago. ASCO represents an opportunity for researchers from around the world to present the latest in cancer treatment and research. We were excited to hear that there have been many significant developments in breast cancer research. Here are some of the highlights from the conference.

Perjeta paired with Herceptin and docetaxel shows improvement in the neoadjuvant setting

The addition of Perjeta and Herceptin with docetaxel in the neoadjuvant setting offers significant improvement over other options for patients with HER2-positive breast cancer. The results showed that Perjeta, Herceptin, and docetaxel had improved pathologic complete response over Herceptin plus docetaxel, Perjeta and Herceptin, and Perjeta and docetaxel.

The Perjeta, Herceptin, and docetaxel combination also had greater progression-free and disease-free survival than the other combinations that were studied. These results show that the combination of Perjeta Herceptin, and docetaxel offers the most promising options for women affected with HER2-positive breast cancer in the neoadjuvant setting.

Kadcyla provides better results than Herceptin

The WSG-ADAPT Phase 2 trial showed that Kadcyla offered in the neoadjuvant setting is more effective in treating HER2-positive, hormone receptor-positive breast cancer, with or without endocrine therapy, in comparison with Herceptin and endocrine therapy. The pathologic complete response was 40.5 percent with Kadcyla alone, 45.8 percent with Kadcyla and endocrine therapy, and only 6.7 percent with Herceptin and endocrine therapy.

Shanu Modi, MD, of Memorial Sloan Kettering Cancer Center, who presented the results, called the results “striking.” There was a difference in the results with Kadcyla depending on menopausal status. Significantly more postmenopausal women benefited from Kadcyla alone compared with premenopausal women. There was no difference in results when endocrine therapy was included.

Encouraging results for Xtandi (enzalutamide) in triple-negative breast cancer

The results of the Phase 2 single-arm trial show that the prostate cancer drug Xtandi has shown some promise in women with advanced triple-negative breast cancer whose tumors express the androgen receptor (AR). The trial enrolled women with AR-positive triple-negative breast cancer. Patients received Xtandi as either a first or second-line therapy for their metastatic disease. Patients who were AR-positive had a median progression-free survival of 16 weeks compared with 8 weeks in patients whose tumors were AR-negative. Overall the median progression-free survival was 14.7 weeks.

The androgen receptor is present in many cases of triple-negative breast cancer. About 20 percent to 40 percent of triple-negative breast tumors express the androgen receptor. Currently triple-negative breast cancer is treated with cytotoxic chemotherapies because so far there have not been any targeted therapies that have been proven effective in treating the many forms of triple-negative breast cancer.

Creating an “Inhospitable” environment for breast cancer

Results from a Phase 2 single-arm trial show that using tetrathiomolybdate to target the tumor’s microenvironment creates an inhospitable environment for tumor progression in patients with breast cancer. The effect is most striking in triple-negative breast cancer. “Copper alters the tumor microenvironment, and (tetrathiomolybdate) depletes this microenvironment of factors that are critical for tumor progression,” said study author Linda T. Vahdat, MD, of the Weill Cornell Breast Center in New York.

The trial enrolled patients with moderate to high-risk Stage II breast cancer with at least four positive lymph nodes, or patients with Stage III or IV breast cancer in remission. Patients took tetrathiomolybdate pills for 2 years to test whether the drug could help prevent recurrence. After a median follow-up of 5.6 years, the progression-free survival was 81 percent for all patients, and 94 percent for patients with Stage II or III triple-negative disease. Copper depletion was most efficient in patients with triple-negative breast cancer, who comprised 48 percent of the study group. Due to the promising results, study investigators are currently developing a Phase III randomized study of tetrathiomolybdate in breast cancer patients.

OTHER RESEARCH NEWS

Space robot turned breast cancer detector nets Canadian professor a NASA award

A McMaster University professor won an award for his part in developing an automated robot used for detecting the early stages of breast cancer. Dr. Mehran Anvari, surgical professor and chief executive officer of the Centre for Surgical Invention and Innovation in Hamilton, Ontario, was presented with an award from NASA for innovation in biology and medicine for his work with IGAR, the lesion-detecting robot. IGAR, or image-guided automated robot, originates from the International Space Station, where the technology was used in robotic arms providing space shuttle maintenance. Anvari and his team took the technology and applied it in the field of medicine, using the robot to detect cancerous growths. IGAR is fitted on patient beds and works in combination with MRI scanners to find lesions. The robot simplifies the manoeuvres involved in the MRI process. It will have benefits for the patient (less pain, accuracy, faster treatment), the physician (skill enabler, real-time approach), and the hospital (fewer patients to the operating room, faster biopsy time). For more information, visit <http://www.cbc.ca/news/canada/hamilton/news/space-robot-turned-cancer-detector-nets-mac-prof-a-nasa-award-1.3145029>.

New breast cancer gene found in Poles and French Canadians

A team of researchers from Canada and Poland has uncovered variants in the RECQL gene that are linked to breast cancer susceptibility. A team led by the University of Toronto’s Mohammad Akbari performed whole-exome sequencing on 195 patients with familial breast cancer from Polish and French-Canadian founder populations. From this, the researchers uncovered rare, recurrent RECQL gene mutations in both populations that they then confirmed in some 25,000 additional cases and controls, as they reported in *Nature Genetics* April 27. The researchers note that although these RECQL mutations seem to be rare, the risk of breast cancer among women who have them appears to be very high. In their study, they calculated that around 50 percent of women with a RECQL mutation would develop breast cancer. For more information, visit <http://www.medicalnewstoday.com/articles/293147.php>.

RESOURCE DIRECTORY

GUIDE SUPPORTS PATIENTS LIVING WITH METASTATIC BREAST CANCER

Hearing the words “your breast cancer has spread to other parts of your body” is devastating, whether they come after a period of wellness after initial treatment or as a first diagnosis. The diagnosis brings with it many questions, concerns and unique challenges; however, there have been many advances in available treatments, side effect management, and increased supportive care. Willow Breast & Hereditary Cancer Support, in collaboration with the Canadian Breast Cancer Network and Rethink Breast Cancer, has created a 72-page comprehensive guide for Canadians living with metastatic or advanced breast cancer, caregivers, family, and friends. It provides information and guidance on navigating the physical, emotional, spiritual, and practical aspects of the diagnosis and subsequent journey. This resource was reviewed by women who are living with metastatic breast cancer. Their words of wisdom are included within so that others may benefit from their experiences and insights. To order free print copies, contact Willow at 1-888-778-3100 or info@willow.org. The booklet can also be downloaded from www.willow.org.

NEW ONLINE SERVICE, ACTIVEMATCH, HELPS CANCER PATIENTS FIND PHYSICAL ACTIVITY PARTNERS

Medical professionals are increasingly prescribing physical activity to cancer survivors during their treatment and rehabilitation process because research shows that exercise may help manage negative symptoms, decrease their risk of cancer recurrence, and help individuals live a longer life.

“One of the biggest barriers that women have reported repeatedly is a lack of social support, or ‘no one to exercise with,’” says Dr. Catherine Sabiston, PhD, Canada Research Chair in Physical Activity and Mental Health and Associate Professor at the University of Toronto.

In an attempt to address this barrier, Dr. Sabiston and her colleagues at the University of Toronto have developed ActiveMatch. This free online tool helps match women who have been diagnosed with cancer as exercise partners or groups. You can sign up to create a profile and identify characteristics that you look for in an exercise partner (e.g., similar age, exercise history, cancer history, and preference for type of exercise) and the website will help match you with your ideal exercise partner who lives close to you. Women of any age and any cancer diagnosis are encouraged to sign up online at www.activematch.ca. If you have questions, please email activematchwomen@gmail.com.

UNDERSTANDING THE PATHOLOGY REPORT

If you have recently been diagnosed with breast cancer, and you need help understanding the pathology report, breastcancer.org has a guide for you. *Your Guide to the Breast Cancer*

Pathology Report explains all of the information and terminology you need to know, and gives you questions to ask your doctor. Access the guide at www.breastcancer.org/Images/Pathology_Report_Bro_V14_FINAL_tcm8-333315.pdf.

ART THERAPY HELPS P.E.I. PATIENTS EXPLORE THEIR CANCER JOURNEY

If you are a resident of Prince Edward Island who has been diagnosed with cancer, you may be interested in exploring your experience in monthly two-hour art therapy sessions held by Art PEI. Projects can be personally tailored to suit individual needs and skill levels. Examples of projects include: painting, drawing, music, theatre, writing, sculpture, soap making, and a plethora of crafts of every imaginable kind. Sessions take place on the last Thursday of every month at the Art PEI studio located at 1836 Kinkora Road in North Wiltshire, P.E.I. Classes are free, except for the cost of base supplies. Brushes and all tools are provided for you. For more information, contact Dr. Nancy Yao at nancy.yao@alumni.ubc.ca.

GETTING THE CARE YOU NEED AS A LESBIAN, GAY, OR BISEXUAL PATIENT

Breast Cancer inFocus: Getting the Care You Need as a Lesbian, Gay, or Bisexual Person is a short guide that will help you decide whether you should come out to your care team. The guide gives tips on talking about your orientation or gender identity with healthcare professionals. It also offers personal stories of others who have dealt with coming out while coping with a breast cancer diagnosis, and provides advice on how to determine if your treatment center is accepting. Download or order a copy from Living Beyond Breast Cancer at lbcc.org or 855-807-6386.

FREE CD PRESENTS RELAXATION EXERCISES TO BEAT STRESS

The Canadian Cancer Society has created a CD that presents relaxation exercises for dealing with the stress and anxiety brought on by a cancer diagnosis. These exercises aim to give you a peaceful, calm, and realistic attitude about your situation. To order a free copy, call 514-255-5151.

NEW CBCN VIDEO EXPLAINS CHEMOTHERAPY SIDE EFFECTS

Do you, or someone you love, need to undergo chemotherapy? Most people are aware of the widely known and visible side effects of chemotherapy like hair loss and nausea. There are also common but less visible side effects of chemotherapy. Febrile neutropenia (FN) is a serious side effect of chemotherapy for breast and other cancers. Learn more about FN by watching a short video at <https://www.youtube.com/watch?v=n3LjpmDMxEI>.

CALENDAR

OCTOBER 27, 12 TO 1 PM EASTERN TIME: WEBINAR ON INTEGRATIVE CARE FOR METASTATIC BREAST CANCER.

Gain a better understanding of integrative care for metastatic breast cancer. During this webinar, speaker Pallav K. Mehta, MD, will help you understand how this form of care can help, ways to find licensed integrative care practitioners, and tips for accessing trusted programs. For more information or to register, visit www.lbbc.org/programs-events. This webinar is presented by Living Beyond Breast Cancer.

OCTOBER 28, 1:30 TO 2:30 PM EASTERN TIME: WEBINAR ON TRIPLE NEGATIVE BREAST CANCER.

Listen in on the telephone or over the Internet. Topics include: overview of triple negative breast cancer; current standard of care; new and emerging treatment approaches; clinical trials: how research contributes to your treatment options; treatment side effects and pain, including neuropathy; follow-up care plan; communicating with your health care team; quality of life concerns; questions for a panel of experts. For more information or to register, visit www.cancercares.org/connect_workshops.

NOVEMBER 4 TO DECEMBER 2, OTTAWA: PROGRAM FOR WOMEN NEWLY DIAGNOSED WITH BREAST CANCER.

Offered free of charge by the Ottawa Integrative Cancer Centre, the Babes4Breasts Head Start Program will help women feel less alone and confused, and better prepared for what lies ahead. Improved quality of life, reduced side effects, reduced anxiety and depression, increased stamina, and better overall health outcomes are explored through the program's combination of support, empowerment, and hands-on lifestyle modifications. For more information or to register, visit www.oicc.ca or call Sarah Young at 613-792-1222 ext. 204.

NOVEMBER 5 TO 7, LISBON, PORTUGAL: THE INTERNATIONAL CONSENSUS CONFERENCE FOR ADVANCED BREAST CANCER.

This major conference aims to develop international consensus guidelines for the management of advanced breast cancer. These guidelines are based on the most up-to-date evidence and can be used to guide treatment decision-making in many different health care settings globally. At the conference, health professionals work closely together with patient advocates and with the strong support of media to raise awareness about the needs and challenges faced by this traditionally underserved and forgotten group of patients. The goal is to identify research priorities based on the most important areas of unmet need, analyse and discuss available data to provide the most accurate management recommendations, but also to influence policy makers and funding bodies and ultimately improve standards of care, survival and quality of life. Research and education, with accurate usage of available knowledge, throughout the world, are key to achieve these goals. For more information, visit www.abc-lisbon.org.

NOVEMBER 9, MONTREAL: COMMUNITY FORUM ON CANCER RESEARCH.

The Canadian Cancer Research Alliance will hold a Community Forum on November 9 from 6:00 to 7:30 p.m. at the Hôtel Montréal Bonaventure at 900 de La Gauchetière West in Montreal. The Community Forum was created to provide a unique opportunity for the public and the cancer research community to engage and interact. The target audience is the lay public, with a focus on cancer patients, survivors, and their families. The forum is open to members of the public and there is no cost to attend the event. Come to hear about the latest research developments from some of Canada's leading cancer researchers. At this forum you will also have an opportunity to meet and ask questions of experts on breast cancer and other cancers. For more information or to register, visit www.ccrca-acrc.ca/index.php/ccrc-community-forum-home.

NOVEMBER 27 TO 29, HALIFAX: SKILLS FOR HEALING CANCER WEEKEND RETREAT.

Presented by the Healing and Cancer Foundation, this retreat is open to anyone who has been given a cancer diagnosis of any type or stage. Learn about how to get complete cancer care, empower the body, reduce stress through mind-body techniques, and work with difficult thoughts and emotions. For more information and to register, contact Alex at alexwhynot@gmail.com or 902-499-5658.

DECEMBER 8 TO 12, SAN ANTONIO, TEXAS: SAN ANTONIO BREAST CANCER SYMPOSIUM.

This annual event showcases state-of-the-art information on breast cancer research. It offers a five-day program attended by a broad international audience of academic and private researchers and physicians from over 90 countries. The symposium aims to achieve a balance of clinical, translational, and basic research, providing a forum for interaction, communication, and education for a broad spectrum of researchers, health professionals, and those with a special interest in breast cancer. For more information, visit www.sabcs.org.

MAY 10 TO 13, 2016, MONTREAL: SIXTH INTERNATIONAL SYMPOSIUM OF HEREDITARY BREAST AND OVARIAN CANCER.

This symposium, to be held at the Mount Royal Centre, represents a unique opportunity to look at all aspects of breast and ovarian cancer, and in particular the susceptibility genes, BRCA1 and BRCA2, which are responsible for a considerable fraction of early-onset breast cancer. This is THE major international conference that covers specific targeted therapies for hereditary cancer. Clinicians and researchers from over 25 countries will gather for the sixth edition of this event, which has come to be recognized as one of the leading international scientific conferences on hereditary breast and ovarian cancer. For more information or to register, visit www.globaleventslist.elsevier.com/events/2016/05/the-sixth-international-symposium-on-hereditary-breast-and-ovarian-cancer.

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 Palliative Care Association
Canadian Institutes of Health Research
Canadian Lymphedema Framework
Canadian Medical Association
Canadian Nurses Association
Canadian Partnership Against Cancer
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
Hereditary Breast and Ovarian Cancer Foundation
Hereditary Breast and Ovarian Cancer 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 & Hereditary Cancer Support
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 Québec
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.
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 Ottawa
Breast Cancer Action Quebec
Breast Cancer Support Services Inc.
Cedars CanSupport
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
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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