



A PATIENT ADVOCACY KIT

USE YOUR VOICE AND STORY

FOR CHANGE IN

METASTATIC BREAST CANCER

The Metastatic Breast Cancer Network www.mbcn.org

METASTATIC BREAST CANCER AWARENESS DAY

October 13

Until 2009, metastatic breast cancer was rarely mentioned during October, the month of Breast Cancer Awareness. The leaders of The Metastatic Breast Cancer Network knew what is kept hidden and not discussed will never be changed.

Nine determined metastatic breast cancer patients, all members of the Metastatic Breast Cancer Network, traveled to Washington, D.C. in the summer of 2009 to change that reality. The 9 patients, with friends and family, lobbied Senators and House members to designate one day in October--October 13-- as National Metastatic Breast Cancer Awareness Day. Back home, many, many metastatic patients called their Senators and Representatives to ask them to support the requested resolutions.

On October 13, 2009, the Metastatic Breast Cancer Network received word that our efforts had been successful. Each house of Congress, the Senate and the House of Representatives, passed a unanimous resolution declaring October 13 as OUR DAY to put metastatic breast cancer patients and their needs in front of the public and stakeholders within the breast cancer community.

Now it is up to every metastatic breast cancer patient and those who love and support them to find ways to make use of this day (and throughout the year) to further our cause to support those living with the disease and demand focused research to find treatments to extend our lives.

YOU can make a difference by using your voice to tell your story and the realities of metastatic breast cancer to others.

13 FACTS ABOUT METASTATIC BREAST CANCER

1. No one dies from breast cancer that remains in the breast. When cancer cells travel to a vital organ (known as metastatic disease), the cancer threatens life. Typically breast cancer cells travel to the bones, lungs, liver and/or brain.
2. An estimated 155,000 Americans, young and old, females and males, are living with metastatic breast cancer. The exact number is unknown because the NCI SEER Data only count those who have a first diagnosis of metastatic breast cancer.
3. Metastatic breast cancer causes nearly 40,000 deaths annually in the United States. The number of deaths has not changed significantly over the past twenty years.
4. Although at this time, clinicians cannot cure metastatic breast cancer, the disease is treatable. Treatment is life-long and focuses on control of the disease while maintaining quality of life.
5. Metastatic (Stage IV) breast cancer is the initial diagnosis for about 5-10% of people living with metastatic disease. Other patients receive a metastatic diagnosis years after successful treatment for an early stage breast cancer.
6. Early detection and successful treatment of early stage breast cancer does not guarantee that a patient will not develop metastatic disease years later or not die of breast cancer.
7. Little is known about the causes of breast cancer metastasis or why cancer cells travel to specific organs in the body.
8. Among people initially diagnosed with early stage breast cancer, approximately 30% will go on to develop invasive or metastatic breast cancer 5, 10, 15 or 20 years later. Researchers do not know yet how to prevent this from happening.
9. Just as there are different types of primary breast cancer, there are different types of metastatic breast cancer and they are treated differently. Cures are needed for each type.
10. Little is known about the causes of breast cancer metastasis. Regrettably, only 5% of all breast cancer research dollars are spent on metastatic breast cancer, yet 95% of deaths from breast cancer occur among those who have advanced or metastatic disease.
11. The Metastatic Breast Cancer Network (www.mbcn.org) is a nationwide patient-led organization that provides information and education to people with metastatic breast cancer and their loved ones while advocating for improved outcomes in the clinic.
12. The Metastatic Breast Cancer Network successfully lobbied the U.S. Senate and House of Representatives to designate October 13 as National Metastatic Breast Cancer Awareness Day to bring attention to the disease and seek support for more focused research to find treatments to extend lives until a cure can be found.
13. Every breast cancer patient can use their voice to speak out about the unique needs of metastatic patients, while demanding focused research to end patient suffering and death

HOW TO GET STARTED TO CREATE AWARENESS AND BRING ABOUT CHANGE

We know there is a lot of misinformation about breast cancer, particularly because of the media and the fundraising campaigns of many breast cancer organizations. Where do we start to change things? It's really 4 easy steps:

- [Step 1: Get Educated](#)

You can't expect to change minds and dispel myths without knowing what you're talking about! So spend some time reviewing the MBCN website, particularly the Education and Awareness Sections. Read the 13 Facts several times.

- [Step2: Pick an Activity](#)

There are a range of activities you can do –including writing a letter, posting comments to a blog or article, writing your story, being interviewed, organizing a program or support group, hosting a fundraiser or being a patient reviewer of research grants.

It all begins with your very own story. Think about it. Write about it from your heart. You have a unique perspective on being diagnosed with metastatic disease and learning to live with that reality. You don't have to tell every detail of your disease and life. Think in terms of a few paragraphs, 500 words or less, a 5 minute speech. We can help you.

You can start slowly with advocacy: write your story, write a letter to the editor of your local newspaper. As you get more involved you may find yourself trying other activities in this kit or creating your own. We've included details and tips on various activities to help you along.

- [Step 3: Use MBCN resources](#)

MBCN offers a brochure for the newly diagnosed and one for the general public to explain what mbc is and what MBCN does. We have pdf files, suitable for posting where mbc patients will see them. We offer in pdf file and by mail a comprehensive Guide to Metastatic Breast Cancer which is great to share with newly diagnosed patients or to use for information.

We can help you publicize a program or event in your area by listing it on our website, Facebook, Twitter and sending an email blast to members in your local area.

We have included tips and guidelines for various activities in this kit. Remember you can always call or email us and one of us will be happy to discuss your questions and plans and help you edit your story.

- [Step 4: Report Back](#)

We'd love to know what you're doing, so don't forget to take pictures of your event or program, or send us links to news articles or letters. We will publicize these on our website, Facebook, Twitter and our email newsletter to thank you for your efforts and to inspire others to follow your lead to get the message out.

ACTIONS YOU CAN CHOOSE

- [Write your story](#)

Use your powerful voice to write and/or speak about your story and issues pertaining to metastatic breast cancer.

Submit your story to our website. And our story editor can help you edit it and focus your ideas.

Read others stories on our website:

<http://mbcn.org/get-involved/category/inspirational-stories/>

Begin your story with a general introduction of who you are, your breast cancer history and a general description of mbc. Follow this by sharing your particular struggles (coping with side effects, raising children, making job changes, relationship issues) Conclude with how you are managing to move forward with the disease. Readers tend to respond to a balance of realism and hopefulness in a story.

The act of writing your story will focus you on what your personal message is from your experience and becomes the basis for writing letters to the editor or being interviewed. Here's an example that uses some of the 13 Facts and whose personal message is: the shock of recurrence after 17 years and confronting breast cancer misinformation.

I have a Confession to Make by Ginny Knackmuhs

<http://mbcnbuzz.wordpress.com/2012/06/26/i-have-a-confession-to-make/>

I have a confession to make. Before I was diagnosed with metastatic breast cancer, I would hear that someone in my community had died from breast cancer and I would think: "It's too bad they didn't get annual mammograms. It's too bad they ignored early detection practices. It's too bad they died, but it's really their own fault."

I was diagnosed in 1992 with early stage cancer—stage 0 or DCIS—the earliest you can have. I had a simple mastectomy, which was considered a 100% cure, and breast reconstruction. I continued on with my life, without worrying too much about breast cancer.

I continued for 17 years with annual mammograms, 17 years of breast self exams, 17 years of annual checkups and then I was diagnosed with advanced breast cancer with metastases to the bone—stage IV—treatable but no longer curable. I was no longer the poster girl for early detection, because this time early detection had failed me.

Like many in our pink-drenched communities, I had accepted the message that early detection was the cure and that mammograms were a fail-proof screening test. My education in breast cancer began the day I was diagnosed with metastatic disease.

The message promoted by many breast cancer organizations is one of positivity, survivorship and fighting and winning. So the actual capabilities of a screening tool have been exaggerated and early detection has become synonymous with "the cure".

But I'd like to believe that I have stage IV metastatic breast cancer for a reason: to speak out about it, to educate people, to fill in the missing gaps in the breast cancer awareness messages, to dispel the "guilt" myth, that this cancer is my own fault, that I failed to eat right, think positively, live well.

October 13 is Metastatic Breast Cancer Awareness Day—one day in Pinktober that Metastatic Breast Cancer Network lobbied Congress for in 2009. One day to talk about the ugliness and deadliness of breast cancer, but also the promise and hope of 155,000 or more living with the disease in the US, struggling to live every day well, waiting for the next treatment to extend our lives a few months longer, hoping for a cure to finally stop metastases from occurring.

I have a confession to make. I have metastatic breast cancer. I think 40,000 women and men who die every year from breast cancer is unacceptable. It's too bad that the breast cancer message has been

skewed. It's too bad that few know that an estimated 25-30% of survivors will become metastatic. It's too bad that there is not enough money going to coordinated, effective research on metastases.

It's not too early to start thinking about October. I'll be writing letters, lobbying the media, working to get the message out. What will you be doing?

- [Write a letter to the editor](#)

A letter to the editor of your newspaper is the opportunity for a strong opinion piece in response to a news story previously published in that paper or a current event. That is why October is such fertile ground for us to write letters and respond to the onslaught of awareness stories (that most often leave the metastatic community out!)

Letters can express strong sentiments about a relevant issue. It is important to get your facts right and make your letter concise. Check out the 13 Facts for a few talking points or our statistics page: <http://mbcn.org/education/category/statistics/>

Here's an example of a letter to the editor, based on the above story:

Dear Editor

Does anyone NOT know that October is Breast Cancer Awareness Month? But do they realize that despite massive pink publicity and programming in October, the whole story of breast cancer is not being told?

Before I was diagnosed with metastatic breast cancer, I would hear that someone in my community had died from breast cancer and I would think: "It's too bad they didn't get annual mammograms. It's too bad they ignored early detection practices. It's too bad they died, but it's really their own fault."

I was diagnosed in 1992 with early stage cancer—stage 0 or DCIS—the earliest you can have. I was treated and continued for 17 years with annual mammograms, 17 years of breast self exams, 17 years of annual checkups. Then I was diagnosed with advanced or metastatic breast cancer where cancer cells spread to vital organs like bones, liver, lungs or brain. This is also called Stage IV and is treatable but no longer curable. I had a terminal diagnosis and would be in treatment for the rest of my life. I was no longer the poster girl for early detection, because this time early detection had failed me.

Like many in our pink-drenched communities, I had accepted the message that early detection was the cure and that mammograms were a fail-proof screening test. My education in breast cancer began the day I was diagnosed with metastatic disease

There are an estimated 155,000 of us in the US living with metastatic disease, fighting for more treatments to extend our lives. I urge everyone to find out more about breast cancer, visit our website: Metastatic Breast Cancer Network (mbcn.org) and support October 13, Metastatic Breast Cancer Awareness Day--one day out of the whole month that tells the whole story.

- [Hold a Fund Raising Event](#)

Ask local bar, restaurant, hair salon, store, bowling alley, sports team or café to donate a percentage of proceeds of sales on October 13. Have MBCN brochures available for distribution.

Host a bake sale, garage sale, or raffle. Have a neighborhood garage sale.

Invite friends, family, colleagues to a party at a local pub or café. Charge a small admission in exchange for a drink ticket or a chance on a raffle.

Solicit donations of raffle prizes from local merchants.

MBCN can provide 501c(3) and tax letter for proof of charitable status.

Read what others have done at: <http://mbcn.org/get-involved/category/fundraisers/>

- [Organize an Educational Program](#)

Reach out to a local hospital or breast cancer non-profit and discuss partnering with them on an educational program, talk or panel discussion to raise awareness. (Or, look in your community for existing October programs that may not include the metastatic voice and ask to be part of the program.)

The program can be geared to people living with mbc, members of their support systems, the breast cancer community, the general public and/or medical professionals. The partner organization can assist with providing space for a program, publicizing the program and contacting patients of their particular center.

Possible formats include:

- a meet and greet for people living with mbc and/or their families
- a presentation by a medical professional on understanding mbc and its treatment
- a talk by a social worker or psychologist about the emotional effects of living and coping with mbc.. A patient panel could also be included.
- a panel of an early stage and a metastatic stage patient along with a caregiver to give the full range of what breast cancer means. Patients can tell their inspiring stories and a social worker can facilitate the Q&A session.

Provide refreshments if possible to attendees, using donations from local merchants or the hospital/clinic/support organization that is hosting the event.

- [Be the metastatic voice at existing breast cancer events](#)

Look in your community for local events during October for breast cancer. It can be a walk, fundraiser, program, health fair. Ask if you can be involved as a voice for metastatic breast cancer. Maybe you could speak and tell your story, distribute MBC Facts pamphlets, and share how metastatic breast cancer differs from early stage breast cancer. Make a difference!

- [Start an email campaign](#)

We know there will be programs and positive pink survivor stories during October. Contact the talk shows and news programs you watch and ask them to include your story of living and coping with metastatic breast cancer.

Katie Couric's new show, Ellen, The View, all 3 morning network news/talk shows.

Urge them to include a discussion of metastatic breast cancer on their show.

Example:

Please do not include a segment on breast cancer during Pinktober WITHOUT including those of with metastatic breast cancer, also known as advanced or Stage IV cancer. Metastatic Breast Cancer is treatable but no longer curable and we are fighting for treatments to extend our lives. We are NOT expendable in the war on cancer and there are an estimated 155,000 of us living every day to the fullest with this deadly disease. We got our mammograms, did breast self exams, but the cancer still came back. Hear our inspiring stories. Go to mbcn.org for more information at the Metastatic Breast Cancer Network, an all volunteer national patient advocacy group for mbc.

- [Do outreach to hospitals and treatment centers in your locality](#)

Distribute materials on metastatic breast cancer to local hospitals and clinics. Talk to the social workers or nurse navigators who interact with mbc patients. Ask them to post our flyer: "Are you living with Metastatic Breast Cancer? We can help"

Show them these brochures to see if they can be added to their information center or given to nurses and social workers who could distribute them:

Diagnosis: Metastatic Breast Cancer: What it means for you

Get the facts: metastatic breast cancer

Leave a few brochures, but tell them these brochures can be ordered online for free. Tell them to sign up for our MBCN email list to receive our monthly newsletter.

- [Get interviewed](#)

Contact your local TV or radio News station and pitch your inspiring story. You may have connections in your community. Let your oncologist know you are an advocate because sometimes they are contacted about a new drug or clinical trial and are asked to suggest a patient who could be interviewed. Use one or two statistics to bolster your story. (see 13 facts or statistics page). Contact us if the station is interested in interviewing several people and we can help you identify others with mbc in your area.

Tips on being interviewed:

Be relaxed and smile. We're not trying to scare people or be depressive. Be confident and be yourself.

Think about the salient parts of your story. Don't go into excessive detail on describing your treatments and drugs. Avoid using names of particular drugs.

Try to concentrate on getting one or two messages of your choosing across: "We are living the best life we can in the face of our diagnosis and there are an estimated 155,000 of us. There are nearly 40,000 deaths a year. essentially unchanged numbers in the last decade. More money for better, coordinated research on what causes breast cancer to spread or metastasize and contain it. Very small percentage (2-5% range) of research dollars for all cancers goes to metastatic research and metastases is what makes cancer deadly.

Think beforehand on how you would answer commonly asked questions, such as:

When and how were you diagnosed?

How is mbc different from early stage cancer?

What has been the hardest part for you?

How have friends and family helped?

How has this diagnosis changed you?

What advice would you give to someone else diagnosed with Stage IV?

What can the public do to help?

Remember that they will edit your interview down to only a few minutes—you have no control of that, so don't be upset if you feel you didn't come through as you wanted. Do the best you can and be confident that your story will make a difference. If there are blatant errors in the reporter's presentation, don't hesitate to contact them afterwards and ask for a correction.

- [Create a local support group](#)

Call those support organizations or treatment facilities that have groups for early stage breast cancer in your area and ask them to add one for those living with metastatic disease. Explain that metastatic patients have different concerns from early stage patients and that it is difficult to have a combined group. Someone grappling with their initial diagnosis of Stage 1, 2, or 3 doesn't want to hear stories about stage 4, because we are their worst nightmare! And, we have unique concerns that are not addressed in a mixed early stage/metastatic group.

Common objections from organizations are that mbc patients don't show up, or that they cannot fund a support session that is open ended.

So, present the idea as a 'pilot' group and then work your hardest to get the word out to other mbc patients.

Offer to help publicize the new group with flyers, a listing in the local newspapers, Facebook postings. MBCN will also send an email blast to all members in your area, if you give us the details of the group.

While we believe the ideal support group is one led by a social worker or professional, you may have to look into a more informal group, and take the lead as the facilitator. You can meet in a coffee shop or see if a non profit will allow you to use their space.

- [Use social media](#)

If you are on Facebook or Twitter, or have your own blog, be sure to post about MBCA Day and other cancer related articles of interest that help inform people about what it's like to live with mbc and what we would like to see as priorities of other bc orgs, and the government in terms of funding and research. Make a video about metastatic breast cancer and share it with friends. Put it on Youtube.

- [Write a guest entry on the MBCNbuzz blog](#)

MBCN has our own blog and we are always looking for guest bloggers. Send us your thoughts on an issue you want to address.

REPORT BACK

- [Tell us what you're doing!](#)

Email us at mbcn@mbcn.org:. Send us pictures of events; links to articles.

DIFFERENCES BETWEEN EARLY AND METASTATIC BREAST CANCER

	EARLY BREAST CANCER	METASTATIC BREAST CANCER
LOCATION	CONFINED TO BREAST	BONES, LIVER, LUNGS, OR BRAIN
NUMBERS	ALL CASES COUNTED	COUNTED ONLY IF 1ST DIAGNOSIS#
STAGE OF DISEASE	I, II, III	IV
THREAT TO LIFE	NOT UNLESS UNTREATED	INCURABLE, BUT TREATABLE
TREATMENT GOAL	CURATIVE	CONTROL METS AND MAINTAIN QOL
TREATMENT LENGTH	HAS AN END	FOR REST OF PATIENT'S LIFE
ANXIETY & FEAR	PRESENT, BUT CAN END	ONGOING, NEVER ENDS
5 YEAR SURVIVAL RATE	88%	15%
SOCIETY'S REFERENCE	"SURVIVORS"	INVISIBLE PATIENTS
STORY'S END	TRIUMPHANT	SAD
RESEARCH DOLLARS	95 % OF ALL DOLLARS	2 to 5 % OF BREAST CANCER RESEARCH
DEATHS	FEW IF TREATED	NEARLY 40,000 ANNUALLY*

#The first diagnosis (whether early or advanced stage) and death from breast cancer are counted in NCI SEER Database. A recurrence of metastatic disease is not counted.

**The yearly number of deaths from breast cancer has remained essentially the same for the last two decades.*