



## Breast Cancer Network of WNY

### Metastatic Breast Cancer: Facts to Know

- **What is Metastatic Breast Cancer?** (pronounced as Met-a-STA-tic) MBC also known as Stage IV is cancer that has spread outside of the breast to other organs such as bones, liver, lung or brain. This process is called metastasis. (pronounced as Me-TAS-ta-sis)
- **What happens when breast cancer spreads?**  
Breast cancer that spreads to another organ, such as bones, lung, or liver, is still breast cancer and does not become bone cancer or liver cancer or lung cancer. Under a microscope, the tumor cells will still look and act like breast cancer and will be treated as breast cancer.
- **Who gets metastatic breast cancer?**  
No one brings metastatic disease on themselves. The sad truth is that anyone who has had an earlier stage of breast cancer can experience a metastatic recurrence and some women have metastatic disease on their initial diagnosis of cancer—despite mammograms and early detection!
- **Why does breast cancer metastasize?** (pronounced as Me-TAS-ta-size)  
Researchers at this time can't explain why metastatic disease occurs, but they're working on finding answers. Early detection is a detection tool, but it does not a cure or prevent an early cancer from coming back in the future as metastatic disease.
- **What are the statistics on incidence of metastatic breast cancer?**  
There are estimates that 20-30% of patients with an early stage cancer will have their cancer return as metastatic, even if they were told their early stage cancer had been "cured." Another 8% of new breast cancer cases are found to be metastatic at their initial diagnosis.
- **What is the main difference between early stage breast cancer and metastatic breast cancer?**  
Metastatic Breast Cancer (MBC) is treatable but no longer curable. Treatment is lifelong and focuses on preventing further spread of the disease and managing symptoms. The goal is for patients to live a good quality of life for as long as possible.
- **How is metastatic breast cancer treated?**  
Depending primarily on the kind or subtype of MBC, patients may be on either targeted therapies or systemic chemotherapy. Radiation and surgery are also sometimes used.
- **What are the different kinds (subtypes) of metastatic breast cancer?**  
Subtypes for early stage and metastatic breast cancer are the same: An estimated 65% of patients have Hormonal (estrogen or progesterone driven), also called ER+/PR+; 20% have Her2+(fueled by a protein identified as Her2 neu) and 15% have Triple Negative Breast Cancer (TNBC- which does not have any of the 3 above known biomarkers: ER, PR or HER2). These numbers are approximate, because some people have more than one subtype (HER2+ and ER+) or their subtype may change over time.
- **How many women and men die of breast cancer each year?**  
Approximately 43,250 die of breast cancer each year—a number that essentially is unchanged over the last 20 years. All deaths from breast cancer are caused by metastatic breast cancer.
- **How many people are living with MBC in the US?**  
Although the National Cancer Institute collects statistics of patients who have an initial diagnosis of MBC, the NCI does not count metastatic breast cancer recurrences. Studies estimate that there are over 168,000 women and men living with metastatic breast cancer in the US—and doing our best to live well!

- Is metastatic breast cancer a chronic disease?**  
Not yet, but that is an important goal. As researchers identify more and better treatments, MBC could become a chronic disease like diabetes or HIV/AIDS, where patients can be stable on medications for 20 or more years.
- How much is spent on research funding for metastatic breast cancer?**  
Several years ago, the Metastatic Breast Cancer Alliance did a study that found that of all research grants, funded by major public and private sources from 2006-2013, only 7% of funds studied metastatic breast cancer, even though metastasis is what causes breast cancer to become a deadly disease.
- What is National Metastatic Breast Cancer Awareness Day?**  
October 13 was sent aside by unanimous House and Senate resolutions in 2009, establishing that one day in October should recognize and bring awareness to metastatic breast cancer. One day is not enough but it's a start for year round awareness of what MBC is and why it's important for all of us.
- Do men get breast cancer?**  
Yes, men do get breast cancer and they are often misdiagnosed initially. They represent about 1% of the new cases of breast cancer and 1% of the deaths from metastatic breast cancer. In 2022, about 530 men will die from breast cancer.
- Do young women get metastatic breast cancer?**  
YES. For young women under 40: 5% of the new cases of breast cancer and 3% of the deaths. Metastatic breast cancer is the leading cause of cancer deaths in this age group. For young women under 50: 27% of the new cases of breast cancer and 16% of the deaths.
- How is metastatic breast cancer monitored?**  
Usually MBC is monitored by periodic imaging tests (CT, PET or bone scans or MRIs), blood tests measuring tumor markers and assessment of how the patient is feeling.
- How often are patients living with metastatic breast cancer scanned?**  
Usually we are scanned every 3 months; if metastases remain stable or shrink, scans may be done less frequently (eg. every 6 months).
- What is scanxiety?**  
Scanxiety refers to patient anxiety over scans and occurs as their scan date approaches. Good test results refer to stable disease (mets are not growing or spreading) or NED (no evidence of disease) on scans.
- What is NED (no evidence of disease) and how does it differ from being 'in remission' or being 'cancer free'?**  
No Evidence of Disease means that the metastases are no longer detectable on an imaging scan. This is great news, but because breast cancer cells are still circulating in the body, treatment continues. 'In remission' is an older term and not usually used in metastatic breast cancer. Once you are metastatic, you are never 'cancer-free,' but being NED or being stable are still wonderful words to hear from your oncologist.
- Why does treatment for metastatic disease seem 'less aggressive' than treatment for early stage disease? Why does everything feel less urgent, despite a much more serious prognosis?**  
Treatment of early stage disease focuses on curing the cancer and therefore is immediate and aggressive. Because there is no cure for MBC at this time, treatment focuses on controlling the disease and permits a more measured, long-term approach to therapy, with hopefully more attention directed to long term quality of life and reducing or preventing adverse side effects of treatments.
- People often ask 'Why do you look so good, if you have an incurable cancer?'**  
Metastatic breast cancer has its ups and downs. Sometimes, we may be feeling relatively good and are living with stable disease. Other times we may be experiencing a lot of side effects. If hair loss isn't one of them, people may not notice. Even when the disease is progressing, we may still look ok, up to a certain point.

- What are clinical trials and are they a 'last resort' when all other treatments fail?**  
 Not at all. Clinical trials are controlled treatment studies on new drugs and are the method used to obtain FDA approval of new treatments. They should be an option considered right from the beginning of treatment for MBC patients, along with standard treatments. A clinical trial may or may not be right for an individual and should be discussed with the oncologist.
- What are the types of clinical trials and what's the advantage to participating?**  
 Phase 1 and 2 trials involve a relatively small sample size of people (sometimes less than 100) and determine dosage, safety and effectiveness of the new drug. If results are favorable, a phase 3 study is launched which is on a large scale, involving multiple clinical sites across the country (and sometimes worldwide). A trial compares the current standard of care to the new treatment. While there are always risks and benefits, participation, especially in a phase 3 study, can give someone access to the latest promising drug, long before it comes to market.
- What does it take in terms of time, money and research to bring a new drug to market?**  
 On average, it takes 8-10 years and approximately \$1 Billion for a new drug to go from a chemistry model to FDA approval. Overall, only 11% of drugs that start in clinical trials are eventually approved, but 34% of Phase 3 Clinical Trial drugs are approved. "Every advance in breast cancer treatment and care has been the result of a clinical trial."
- Why are people living with MBC seldom acknowledged during breast cancer awareness events?**  
 As a practical matter, someone with metastatic breast cancer will be outnumbered...at awareness walks, at treatments centers, everywhere. Of the 3.5 million US people living with a history of breast cancer (all stages), an estimated 168,000 have Stage IV breast cancer. This means when the average person thinks about breast cancer, they aren't thinking about people with MBC. They are thinking about family and friends who had early-stage disease, were treated and, to their knowledge, are fine. This is certainly understandable—but an ongoing challenge and one we must address if we want to make any meaningful progress in terms of education, awareness and scientific progress. We need early-stage breast cancer patients to help us out—to advocate for more research, encourage greater clinical trial participation and address health inequities.
- What does being BRCA positive mean?**  
 Having an abnormal or mutated BRCA1 or BRCA2 gene means that the risk of developing breast or ovarian cancer dramatically increases, but not everyone with a BRCA mutation will get cancer. Mutations in these genes are rare in the general population and higher in certain ethnic subgroups, such as those of Ashkenazi Jewish descent. Overall, BRCA mutations account for 5% of all breast cancers.
- Is there a difference between palliative care and hospice care?**  
 Yes! Although many people think they are synonymous, palliative care should be part of each person's cancer care right from the beginning. Palliative care is treatment of side effects, stress and pain. Studies have shown that palliative care not only improves quality of life, but also can extend life by several months.
- Why should everyone care about metastatic breast cancer?**  
 Early detection does not guarantee a lifetime cure, and treating early stage breast cancer does not mean the person will never have breast cancer again. Metastatic breast cancer can occur 5, 10 or 15+ years after a person's original diagnosis and successful treatment. An estimated 20-30% of women initially diagnosed with an early stage cancer will go on to be diagnosed with metastatic breast cancer.

Compiled by MBC Alliance