

# Metastatic Breast Cancer



## A Day of Metastatic Awareness

BY JOSH FERNANDEZ

Every October, items on shelves and in the aisles of retail stores abound with pink ribbon logos. Charities host events and programs to fundraise and raise awareness. For these 31 days, the spotlight shines on women and their experiences with breast cancer.

Though Breast Cancer Awareness Month draws public attention to the disease, **Dikla Benzeevi**, 43, of Los Angeles, Calif., feels the pink ribbon-saturated month slants toward bringing awareness to early-stage breast cancer and detection. She has lived with metastatic disease for more than 10 years.

"Events, promotions and commercials in October act as if we've overcome breast cancer, but we haven't," **Dikla** says. "It makes anyone with metastatic breast cancer feel like a failure of the campaign."

**Debra Strauss**, 61, of Melrose Park, Pa., who has lived with metastatic breast cancer for 21 years, shares similar frustrations.

"Breast cancer awareness is wonderful and we are living longer, but we're still getting it and still dying from it," **Debra** says.

To help women like **Dikla** and **Debra** feel included in Breast Cancer Awareness Month, and to bring much needed awareness to metastatic disease, advocates campaigned to establish October 13 as Metastatic Breast Cancer Awareness Day.

### AWARENESS DAY BEGINNINGS

According to the American Cancer Society, nearly 40,000 Americans will die from breast cancer in 2013. Experts estimate that up to 30 percent of early-stage breast cancers will metastasize but the range of risk is wide and varies with the amount and extent of disease at diagnosis, as well as the tumor subtype. While the average life expectancy is 3–5 years, there is a very wide range in typical outcomes depending on a large number of tumor and treatment factors.

**Kelly Lange**, president of METAvivor, an organization that raises funds for metastatic breast cancer research, thinks more education is needed throughout the month.

"Everyone is aware of breast cancer," **Kelly** says. "What people don't know, or choose not to know, are the uncomfortable facts about breast cancer."

Metastatic Breast Cancer Network (MBCN), an advocacy organization for those affected by the disease, spearheaded Metastatic Breast Cancer Awareness Day to shed light on these facts.

In 2007, MBCN asked its supporters to contact their local government officials to request they dedicate October 13 Metastatic Breast Cancer Awareness Day.

By 2008, officials in 25 cities and seven states signed proclamations designating Metastatic Breast Cancer Awareness Day.

Living Beyond Breast Cancer made sure Philadelphia, Pa., was among those cities.

"We saw the importance of acknowledging metastatic breast cancer during Breast Cancer Awareness Month so that would bring more visibility to those diagnosed and living with metastatic disease," says **Elyse Spatz Caplan, MA**, LBBC's director of programs and partnerships.

DIKLA BENZEEVI



DEBRA STRAUSS



"We thought it made sense to appeal to Mayor Michael Nutter, so we did and he signed the proclamation."

In 2009, The number of cities and states designating MBC Awareness Day grew, but the major development that year was the national proclamation introduced by Rep. Rosa DeLauro (D-Connecticut) and Sen. Evan Bayh (D-Indiana). Both congresspersons were approached by MBCN leaders, such as **Shirley Mertz**, the organization's president.

"We had a significant number of supporters in both chambers until finally, in October, we received notice that both the Senate and the House had unanimously passed the resolutions," Shirley says. "We felt like we accomplished a lot."

PAT BIEDERMANN



CARYN KAPLAN

## SILENT VOICES AND BEYOND

Long before Metastatic Breast Cancer Awareness Day, LBBC offered an annual October webinar series, conference workshops and a helpline matching service for women with metastatic disease. In 2005, LBBC created a 64-question needs assessment survey with the goal of expanding our resources for women with metastatic breast cancer.

"LBBC feels it is important to raise public awareness that not all breast cancers are alike, and stage 4 breast cancer is a serious diagnosis that requires tailored information and support," Elyse says.

The survey results were published in *Silent Voices*, a report written by LBBC consultants **Musa Mayer, MS, MFA** and **Susan E. Grober, PhD**. The data obtained from the 618 respondents covered topics ranging from the role of information and support in the lives of women living with metastatic disease to the availability of services and resources.

Musa, an author, breast cancer advocate and founder of the website [AdvancedBC.org](http://AdvancedBC.org), says it was the first ever large-scale needs assessment of the metastatic breast cancer population.

"In the years since, *Silent Voices* served as a basis and inspiration for much subsequent research, which is very gratifying," Musa says. "The information it gave LBBC about the kinds of services women were interested in and could benefit from was extremely useful."

*Silent Voices* generated such high interest that it was selected as one of two best abstract oral presentations for the first Advanced Breast Cancer International Consensus Conference (ABC1), in Lisbon, Portugal in 2011.

It was also instrumental in the development of several programs and resources at LBBC, among them the Metastatic Breast Cancer Series *Guides to Understanding Breast Cancer* and the Annual Conference for Women Living With Metastatic Breast Cancer.

Held in Philadelphia, Pa., each spring, the conference is one of two annual conferences for metastatic breast cancer in the United States.

Since its inception, **Pat Biedermann**, 56, of Warminster, Pa., thinks LBBC's conference has built more awareness and helped women with metastatic disease find a sense of community and hope.

"At this past conference, the audience members were asked how long we've been living with metastatic disease," says Pat, who has had metastatic breast cancer since 2006. "One woman said she'd been living with her metastases for about 20 years. Everyone in the room was in awe."

**Caryn Kaplan**, 53, of Holland, Pa., diagnosed with advanced disease in 2004, shared similar feelings.

"When you go to those conferences and look around, you see yourself in everybody," Caryn says.

Dikla, whose first LBBC event was the 2004 Conference for Young Women (C4YW), is so impressed with LBBC's programming that she promotes content and organizes large groups of 20–40 women from California to go together to C4YW and LBBC's conference for women living with metastatic breast cancer.

"The organization is warm and inviting and takes a well-rounded approach to providing support and awareness for the metastatic breast cancer community," Dikla says.

*"When you go to those conferences and look around, you see yourself in everybody,"*

## FURTHERING AWARENESS: OCTOBER 13 AND YEAR-ROUND

**Dian (CJ) Corneliusen-James**, founder and director of advocacy at METAvivor, says the organization observes and celebrates MBC Awareness Day through blog and social media promotion, and by getting media coverage in the Annapolis, Md. area.

LBBC has no formal program for the day, but it does promote October 13 and awareness of metastatic disease through its online channels, in addition to offering a two-part metastatic breast cancer webinar series that month.

Shirley says MBCN offers resources for supporting MBC Awareness Day activities and events on [mbcn.org](http://mbcn.org). Their goal is to bring national broadcast and print media attention to this day. She says people can participate in MBC Awareness Day by contacting their local government leaders about proclamations and encouraging their local breast cancer centers and organizations to hold events.

Though many women with metastatic disease see Metastatic Breast Cancer Awareness Day favorably, some women either don't know about the day or think awareness must go beyond one day.

"There's still a big void in awareness, resources and support for metastatic breast cancer," Caryn says. "I searched for a support group for years until I discovered LBBC."

The purpose of MBC Awareness Day is to include the experiences of women with metastatic disease in Breast Cancer Awareness Month, but metastasis needs to be discussed every day, Shirley stresses. "We still don't know what causes metastasis to occur and until we answer that

question, we're not going to be able to prevent it or keep women from dying of the disease."

Dikla points out that women with metastatic breast cancer have come a long way in making their voices heard since she was first diagnosed. This is partially due to increased awareness of the disease through the observance of October 13 and through other messaging and programs.

"I'm very happy with all the increased resources out there for women with metastatic disease, and I just want the nation as a whole to know that although it's still a serious illness, it can still be lived well," Dikla says. "We must continue to show that we are also survivors, thrivers and doing our best to live a full life."

*Get more information and resources on metastatic breast cancer. Visit [lbbc.org/events](http://lbbc.org/events) to sign up for our October webinar series and download our Metastatic Breast Cancer Series guides at [lbbc.org/guides](http://lbbc.org/guides).*

## FEATURED CLINICAL TRIAL

### Observational Study Seeks Women With HER2-Positive Metastatic Breast Cancer

*New registry created to monitor treatments and outcomes*

*Trial Started: June 2012 | Trial Ends: December 2020*

WRITTEN BY NICOLE KATZE, MA

REVIEWED BY LARRY WICKERHAM, MD

The SystHERs (Systematic Therapies for HER2-Positive Metastatic Breast Cancer Study) Registry seeks to enroll 1,000 people with HER2-positive metastatic breast cancer to analyze treatment patterns and outcomes.

#### About the Study

*Observational cohort studies* follow a group of people over a long period of time to identify common practices in treatment, risk factors for—and the develop of—side effects, and whether treatments work and for how long.

The SystHERs Registry aims to collect and record data on therapies used for the treatment of people with HER2-positive metastatic breast cancer, as well as on the cycle and order of treatments given.

Additional goals of the study include assessing the safety of treatments; *progression-free survival*, the length of time after starting treatment during which cancer does not grow; *overall survival*, the time from the start of treatment until death from any cause; *post-progression survival*, the time from cancer progression until death; and *time-to-treatment failure*, the length of time a treatment works effectively.

Genentech, the sponsor of this clinical trial, manufactures medicines used in treating HER2-positive metastatic breast cancer, including trastuzumab (Herceptin) and pertuzumab (Perjeta).

#### Who Is Eligible?

You may be eligible to participate if you

- are 18 years old or older
- have HER2-positive metastatic breast cancer
- were diagnosed within the last 6 months

#### Study Locations

This study is being held in 95 locations throughout the United States. For a full listing of locations and local contact information, see trial NCT01615086 on [ClinicalTrials.gov](http://ClinicalTrials.gov).



## Surviving and Thriving With Metastatic Breast Cancer

BY SHARON FOSTER, FOR LBBC

**I**n 2002, at the age of 35, I was diagnosed with an aggressive, stage III breast cancer that was estrogen and progesterone receptor-positive, as well as HER2-positive. After going through chemo, a mastectomy of my left breast and radiation therapy, I thought my life would again get back to normal—that I would no longer have to worry about cancer and its treatments.

Seven years later, in 2009, my world turned upside down again when I was diagnosed with a metastasis to my liver. I had to face my worst fear and find some way of dealing with it. I set out on a journey to cope with this dreaded disease and have managed, through a series of lifestyle choices, to be not just surviving with it, but thriving.

I found out quickly that the old saying “misery loves company” really does have some truth to it. I never wanted anyone to be in my shoes, but I certainly did want to connect with and draw strength from people who were. For 11 years, I’ve been part of a support group in my community for women with all stages of breast cancer. Realizing how much strength it gave me, my fellow survivor and friend, Sherry, and I started a small but powerful support group specifically for women with metastatic breast cancer called Sharing, Hoping and Empowering. The name summed up exactly what we wanted to impart. Being able to share our fears, joys, tips and support helps ease the feelings of isolation and loneliness that only someone with advanced breast cancer may understand completely.

Staying informed and knowledgeable about my disease has also helped me cope. I was a pediatric oncology nurse for 25 years, so I instinctively want to know everything about my illness. Not everybody feels this way of course, but knowledge gives me a sense of empowerment and helps me keep feelings of helplessness at bay. As a subscriber to LBBC’s email list, I stay updated on the latest research and clinical trial information, join in on their webinars and listen to their podcasts. In April 2012, I attended the LBBC Annual Conference for Women Living with Metastatic Breast Cancer in Philadelphia, Pa.

The information gained and the opportunity to be together with hundreds of women with MBC was a powerful experience. I also plan to attend the Metastatic Breast Cancer Network’s annual conference this fall and, hopefully, the World Conference on Breast Cancer next June.

A significant coping strategy for me has been to do what is in my power to improve my overall health. I, alone, can make choices that make me feel better on a daily basis as well as strengthen my body’s natural defenses to battle my cancer. I have done some reading and research on integrative therapies over the past few years. I have chosen to add yoga and guided meditation to my daily life, which bring me a sense of peace and relaxation. I’ve also increased my exercise. In addition to practicing yoga, I walk often and paddle with the local dragon boat team.

The biggest change I made to my lifestyle pertains to my diet.

Over the past couple of years, I slowly but steadily implemented nutritional changes such as cutting down on sugar intake and increasing the amount and variety of fruits and vegetables I consume daily, to name a few. It feels wonderful to know I am doing my part to contribute what I can to my own health.

Addressing the psychological and spiritual aspects of my well-being has been just as important as maintaining my physical health. I surround myself with positive relationships and try to distance myself from the negative ones; I try to stay focused on the present and not dwell too much on the future or the past; and I try to find goodness in the things that, and people who, surround me. I begin and end each day with gratitude—gratitude for my supportive husband, children, family and friends, my healthcare team and my support groups.

My liver metastasis has been stable since 2010, and there has been no further progression of my disease. I feel wonderful. Putting all of these strategies in place for myself is how I am coping with metastatic breast cancer. I am not just living or surviving, I am thriving!

*“Staying informed and knowledgeable about my disease has also helped me cope.”*