



# Changing the Landscape for People Living with Metastatic Breast Cancer

Metastatic Breast Cancer

**MBC**alliance>

*together we are stronger than the disease*

**Metastatic Breast Cancer  
Landscape Analysis:  
Research Report**  
October 2014

**Second Edition**



## MBC Alliance members:

From bottom right: Katherine Crawford-Gray, MBC Alliance Project Director; Christine Benjamin, SHARE; Elly Cohen, BreastCancerTrials.org; Jo Dulay, Genentech; Janine Guglielmino, Living Beyond Breast Cancer; Jane Levy, CancerCare; Elyse Spatz Caplan, Novartis Oncology; Michael Zincone, Pfizer; Musa Mayer, AdvancedBC.org; Julissa Viana, Cara Thompson, Celgene Corporation; Margaret (Peg) Mastrianni, Breast Cancer Research Foundation; Christine Wilson, Triple Negative Breast Cancer Foundation; Shirley Mertz, Metastatic Breast Cancer Network; Stacy Lewis, Young Survival Coalition; Katherine O'Brien, Virginia (Ginny) Knackmuhs, Metastatic Breast Cancer Network; Megan McCann, Young Survival Coalition; Catherine Ormerod, Living Beyond Breast Cancer; Lisa Schlager, Facing Our Risk of Cancer Empowered (FORCE); Kimberly Sabelko, Susan G. Komen; Marc Hurlbert, Avon Foundation for Women; Virginia (Ginny) Mason, Inflammatory Breast Cancer Research Foundation; Hayley Dinerman, Triple Negative Breast Cancer Foundation; Diane Rose, FORCE; Susan Brown, Susan G. Komen; Allison Harvey, Cancer Support Community; Stephanie Reffey, Susan G. Komen; Kerry Gruninger, SHARE; Jane Perlmutter, Consultant; Amy Bonoff, Dr. Susan Love Research Foundation

Photographer: Yasmeen Anderson Photography

Members absent from photo as of March 2014:

Christine Verini, Eisai; Kelly P. Hodges, Sisters Network® Inc.; Hope Wohl, Breastcancer.org; Elda Railey, Mary Lou Smith, Research Advocacy Network

Metastatic Breast Cancer



*together we are stronger than the disease*

#### **Our Vision**

**MBC Alliance members are driven by a vision to transform and improve the lives of people living with metastatic breast cancer.**

#### **Our Mission**

**The MBC Alliance unifies the efforts of its members to improve the lives of and outcomes for those living with metastatic breast cancer and their families through increasing awareness and education about the disease and advancing policy and strategic coordination of research funding specifically focused on metastasis that has the potential to extend life, enhance quality of life, and ultimately to cure.**

Metastatic Breast Cancer

# MBCalliance>

*together we are stronger than the disease*

BreastCancerTrials.org  
Genentech

Dr. Susan Love Research Foundation  
Triple Step Toward the Cure

Research Advocacy  
Network  
Susan G. Komen

Sisters® Network Inc.

AdvancedBC.org







# MBC Alliance

**Nov 2012**

Breast cancer nonprofits join MBC advocates to discuss how to increase MBC awareness and improve the lives of people living with MBC; all agree that through collaboration, far more can be achieved than by individual organizations; MBC Alliance is formed with support from Celgene Corporation

**Jun 2013**

Mission and goals are adopted; governance approaches are considered; landscape analysis is identified as first initiative; Breastcancer.org, Breast Cancer Research Foundation, Genentech, and Pfizer join

2013

**Feb 2013**

Early members are AdvancedBC.org, Cancer Support Community, FORCE, Living Beyond Breast Cancer, Metastatic Breast Cancer Network, Research Advocacy Network, SHARE, Susan G. Komen, Triple Negative Breast Cancer Foundation, and Young Survival Coalition

**Aug 2013**

Avon Foundation for Women becomes the Alliance's administrative home with Dr. Marc Hurlbert as project leader

## Oct 2013

MBC Alliance launches on National Metastatic Breast Cancer Awareness Day; members now include CancerCare, Dr. Susan Love Research Foundation, Sisters Network Inc., Eisai and Novartis

## Jun - Aug 2014

American Cancer Society Cancer Action Network, Patient Advocacy Foundation, and Eli Lilly join the MBC Alliance; all current 29 members meet to consider draft key recommendations for the Alliance and next steps; governance model is formalized

## Dec 12, 2013

San Antonio Breast Cancer Symposium  
Alliance members meet to review the landscape analysis methodology; working groups are formed

2014

## Jan - May 2014

Landscape analysis work continues; membership reaches 26 with the addition of BreastCancerTrials.org, Inflammatory Breast Cancer Research Foundation, Nueva Vida, Sharsheret, and Triple Step Toward the Cure

## Oct 2014

Results of the landscape analysis are released along with actions for the MBC Alliance through 2016

## Nov 2013

MBC Alliance project director is appointed; work begins on the landscape analysis; all members meet for the first time

The background is a solid yellow color. Overlaid on this are several sets of thin, white, curved lines that create a sense of motion and depth. These lines form concentric, overlapping shapes that resemble stylized, elongated triangles or teardrops, pointing towards the corners of the page. The lines are most dense in the center and become more sparse towards the edges.

## **Acronyms and Other Terms**



advanced breast cancer	includes both metastatic breast cancer and locally advanced breast cancer (stage III) and locally recurrent breast cancer
Akt	a serine/threonine-specific protein kinase
BRCA mutation	mutation in the tumor-suppressor gene <i>BRCA1</i> or <i>BRCA2</i> , associated with hereditary breast cancer
CSO	Common Scientific Outline ( <a href="http://www.icrpartnership.org/CSO.cfm">www.icrpartnership.org/CSO.cfm</a> )
de novo MBC	breast cancer that is metastatic at the time of <i>first</i> diagnosis
ER–	estrogen receptor negative/hormone insensitive breast cancer
ER+	estrogen receptor positive/hormone sensitive breast cancer
ErbB	epidermal growth factor receptor (protein family)
gHRAsp	Grants in the Health Research Alliance Shared Portfolio ( <a href="http://www.ghrasp.org">www.ghrasp.org</a> ),
HCPs	HCPs
HER2	human epidermal growth factor receptor 2
hormone-sensitive MBC	MBC where tumor growth is promoted by estrogen and/or progesterone
HRA	Health Research Alliance
ICRP	International Cancer Research Partnership
incidence	Rate of occurrence of new cases in the population (measure risk of developing a disease)
IOM	Institute of Medicine
KOL	key opinion leader
MBC	metastatic breast cancer
MBC Alliance	Metastatic Breast Cancer Alliance (also called the Alliance)
mTOR	mechanistic target of rapamycin (serine/threonine protein kinase)
NCI	National Cancer Institute
PDQ	Physician Data Query
PI3K	phosphatidylinositide 3-kinase
prevalence	proportion of cases in the population (measures how widespread the disease is)
RECIST	Response Evaluation Criteria in Solid Tumors
SEER	Surveillance, Epidemiology, and End Results program of the National Cancer Institute (NCI)
stage IV breast cancer	another term for metastatic breast cancer
TBCRC	Translational Breast Cancer Research Consortium
TN MBC	triple-negative (hormone insensitive and HER2-negative) metastatic breast cancer
TNBC	triple-negative (hormone insensitive) breast cancer
US	United States

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# Chapter 6: Public Education: Building Awareness of MBC

Katherine Crawford-Gray<sup>1</sup>

<sup>1</sup>*Metastatic Breast Cancer Alliance*

## Abstract

Breast cancer campaigns have heightened public awareness yet have propagated unexpected misinformation. **Methods:** We informally explored various aspects of misinformation around MBC. **Results:** The most persistent myths relate to the breast cancer “survivor,” which masks the reality that a proportion of women who have had early breast cancer will eventually develop metastatic disease. Further, the promotion of the “survivor” can stigmatize patients whose breast cancer progresses. The majority of adults in a recent survey reported they know little to nothing about MBC, that breast cancer in the advanced stages is curable, and that breast cancer progresses because patients did not take the right medicines or preventative measures. **Conclusions:** There is an opportunity for the Alliance to help ensure the facts about MBC are brought into the public awareness; to do so, a broad communication strategy should be informed by MBC patient advocates and developed drawing on Alliance member’s collective experience, resources and spheres of influence.

## Discussion

The Alliance aims to build an understanding of MBC, and how it differs from early stage breast cancer, among those diagnosed, their families, HCPs, researchers, and health policy experts.

The past 30 years of breast cancer campaigns have been successful in shining the light on the disease, the importance of early detection, and the methods of screening. And yet with this heightened public awareness of “survivorship” has come unexpected misinformation. A 2014 Pfizer-sponsored study of more than 2000 adults in the general public found that 72% believed breast cancer in the advanced stages is curable if diagnosed early; 50% believe that breast cancer progresses because patients did not take the right medicine or preventative measures, and more than 60% said they knew little to nothing about MBC<sup>[111]</sup>.

The focus on fighting and beating breast cancer has led to the creation and dominance of the breast cancer “survivor”—an identity central to various public fundraising events, celebrity endorsements, and calls to action. This “survivor” identity masks the reality that 20-30% of women who have had early breast cancer will eventually develop metastatic disease<sup>[112]</sup>.

Campaigns with a focus on “the cure” distract from a research agenda to increase the quality and quantity of life for MBC patients. Drives based on “beating cancer” and survivorship also deny the fact that women who have early breast cancer can develop metastatic disease. Further, the promotion of the survivor stigmatizes patients whose breast cancer progresses; they are seen or may even see themselves at fault for the cancer’s progression, and ultimately failing to win the battle for survival.

“We did nothing wrong. Our medical team did nothing wrong. Metastatic breast cancer happens...at any time...regardless of your age, whether you did chemo[therapy], radiation, had a mastectomy, had a bilateral mastectomy, ate well, took vitamins, exercised regularly, prayed, had positive thoughts, had negative thoughts, got regular mammograms, did self exams religiously, had a tiny stage 1 primary tumor, or a stage 0 primary tumor, or a stage 3 primary tumor, or never even had primary breast cancer. It doesn’t matter.” — MBCN website [www.mbcn.org](http://www.mbcn.org)

Nearly half of surveyed MBC patients report a sense of stigma, of feeling like outcasts or feeling isolated, especially within the larger social context of the breast cancer community.

Effects of stigmas and myths cannot be overstated. A global survey on perspectives about cancer determined that myths and stigma present significant challenges to cancer control, have a silencing effect, and affect individuals' behavior in seeking out support and making treatment and quality of life decisions<sup>[113]</sup>. According to researchers, key aspects of stigma are secrecy, myths and misinformation, social rejection and isolation, and shame, self-blame and low self-esteem<sup>[114]</sup>. These key elements are hallmarks of the MBC experience, within the breast cancer community and in the community at large. "When misfortune strikes, it is a natural human tendency to search for a reason," wrote psycho-oncologist Jimmie Holland. "The ready explanation is often 'he must have brought it on himself.' By blaming the victim, we get a false sense of security that we can prevent events that are beyond our control"<sup>[115]</sup>.

How can we, as an alliance of individual members, begin to challenge the myths and stigmas that cause fear in the breast cancer community and the larger public, resulting in financial, social, and emotional distress for people living with MBC? How do we reduce the isolation that many people with MBC feel? How can the Alliance focus its resources on educating different groups about MBC and the importance of helping those with MBC to live longer and better?" To address the lack of understanding of MBC, the Alliance will draw on our collective experience, resources, and spheres of influence. The following principles will guide our future efforts to build understanding across all spheres of MBC, including scientific and quality of life research, epidemiology, and information and support services:

- Our actions must be led by advocates and informed by research and evaluation if we are to change the landscape for people living with MBC.
- The Alliance will not duplicate efforts of individual member organizations of the Alliance.
- We value learning from other cancers and other diseases, so we can apply best practices to our work.
- People living with MBC come from diverse backgrounds; differing cultural values and belief systems must inform the provision of information and support services, as well as public education about the disease, treatments, and quality of life.
- Collaboration is essential. Advocate organizations and industry members of the Alliance will work together to learn from each other's experience and research.
- As our work is resource intensive and time consuming, we will be thoughtful in how we commit our assets to future campaigns.
- Developing an evaluation framework that goes beyond counting pamphlets, banners, press releases, radio announcements, and Facebook posts is an exciting challenge for the Alliance and one that will be a major part of our planning for 2015–2016.

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## Chapter 7: Analysis to Action

The analysis undertaken by the MBC Alliance over the past year has prepared a solid foundation of shared knowledge across the MBC landscape. Collectively, Alliance members are now better informed about the areas of scientific research needing further exploration, gaps in information and support services that require resources, the need to accelerate improvement in quality of life, and increasing evidence-based public education about MBC.

Actions for the next phase of work for the Alliance have been prepared based on the research from this landscape analysis and the many discussions with patient advocates and breast cancer organizations.

We have identified a series of actions for our next phase of work over 2015 and 2016. These actions are aligned with our goals of advancing research, increasing understanding, and improving knowledge and awareness of MBC. They require sustained commitment of multiple stakeholders and MBC Alliance members stand ready to contribute time and energy to this work.

**We look forward to reporting on our progress in 2015.**



# GOALS, ACTIONS



## advance research

### GOAL 1

Advance research focused on extending life, enhancing quality of life, and ultimately ending death from MBC

#### MBC Alliance Think Tanks (2015)

Convene small think tanks of experts and advocates to investigate the data from the landscape analysis and prioritize research gaps.

#### MBC Summit (2016)

Convene summit of scientists and medical experts from the private and public sectors, along with patients to identify collaborative approaches for metastatic research.

#### Clinical Trials

Advocate for new trial designs incorporating new end points.

Assess feasibility of establishing a national tissue registry of paired primary and MBC tissue and blood for use by all researchers.



## improve knowledge + access

### GOAL 2

Improve knowledge by ensuring all patients and their caregivers know how to and can access the care and services they need from a responsive and well-informed health care system

#### Knowledge and Information Sharing

Facilitate stronger collaboration and sharing amongst Alliance members and other stakeholders with webinars, town halls, and newsletters to improve and extend services for people living with MBC.

#### MBC Information Project

Investigate with partners the potential to create an independent, up-to-date collection of evidence-based and trusted MBC information.

#### Empower Project

Building on the work of Alliance members, investigate how to better address information gaps for patients and caregivers, with a focus on underserved communities, as well as physicians.

Potentially pilot new decision-making tools with small groups of health professionals and patients with the aim of strengthening communication between patients and HCPs.



## increase understanding

### GOAL 3

Increase understanding of MBC and how it differs from early stage breast cancer among those diagnosed, their families, HCPs, researchers, and health policy experts

#### Public Awareness

Develop with communications researchers main messages that educate people about MBC and how it differs from early stage breast cancer.

Explore how to best leverage the communication capacity of Alliance members to implement a MBC public awareness campaign.

#### Epidemiology Pilot Project

Collaborating with other agencies and registries, initiate a pilot study designed to achieve more accurate data about the prevalence and disease course of MBC.

#### Abbreviations:

HCPs = Health Care Providers

MBC = metastatic breast cancer

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People living with metastatic breast cancer and patient advocates at the Metastatic Breast Cancer Network 2013 Annual Conference

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