



**Changing the  
Landscape for  
People Living  
with Metastatic  
Breast Cancer**

Metastatic Breast Cancer

**MBCalliance** >

*together we are stronger than the disease*

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

**Second Edition**

## Foreword

The slogan of the Metastatic Breast Cancer Alliance (MBC Alliance)—*together we are stronger than the disease*—is not an empty claim. Each year approximately 40,000 women and men will die of metastatic breast cancer (MBC) in the United States. This number has remained unchanged for over a decade. Given the devastating toll this disease takes, the MBC Alliance members—29 cancer, breast cancer, and MBC advocacy organizations, individuals, and industry partners—have come together to transform and improve the lives of people living with MBC. This collaboration is truly the “first of its kind” for breast cancer, with all advocate and industry members committed to working together, openly sharing resources and information.

Since the MBC Alliance’s public launch on October 13, 2013, we have been conducting a comprehensive landscape analysis of the needs of people living with MBC and the available information and support services. We have also been looking at funding of MBC research, the analysis of which will help to identify the needs and gaps for future funding.

This is exciting work! In inquiring whether the psychosocial and quality of life needs of MBC patients are being met, we have looked at what gaps exist in information and support available to those living with MBC today and how we can improve our own organizations and programs. We have also conducted a comprehensive assessment of MBC research that has been funded since the year 2000, spanning basic research, clinical trials, epidemiology, and quality of life and psychosocial research.

The purpose of the analysis is to learn from recent patient surveys, comprehensive research-gap analysis, and our own new analysis of the literature, clinical trials, and grant funding in order to develop actions that MBC Alliance members and others can implement to improve outcomes for people with MBC.

It is an honor for me to lead the MBC Alliance as it launches. The Avon Foundation for Women is able to provide a much-needed “neutral place” for the Alliance’s early work. I am delighted that the Avon Foundation will be working alongside MBC Alliance members to begin tackling some of the challenges and implementing the critical actions highlighted in this report.



Marc Hurlbert, PhD  
Project Leader, MBC Alliance Landscape Analysis  
Executive Director, Breast Cancer Crusade, Avon Foundation for Women



# Acknowledgments

The MBC Alliance is grateful to the many organizations and individuals who volunteered their time, particularly the women and men living with MBC who shared their personal experiences and advice.

The landscape analysis in Chapter 2 reflects the contributions of key opinion leaders including scientists, medical teams, advocates, journalists, policy makers, other stakeholders, and various consultants.

Special thanks to Elly Cohen and Susan Colen for analyzing currently active MBC clinical trials and to Lynne Davies and the International Cancer Research Partnership (ICRP) for helping with the funded grants analysis.

Special thanks also to Musa Mayer for her work in researching quality of life and epidemiology.

Sincere thanks to Celgene Corporation, Genentech, Eisai, Eli Lilly, Novartis Oncology, and Pfizer for providing financial support for the Alliance in 2013 and 2014. Also, thank you to the Avon Foundation for Women—the administrative home for the Alliance.

The landscape analysis was overseen by a steering committee and working group structure comprised of representatives of member organizations.

## Steering Committee

Musa Mayer, AdvancedBC.org; Marc Hurlbert, Avon Foundation for Women; Cara Thompson, Celgene Corporation; Virginia (Ginny) Knackmuhs, Shirley Mertz, Metastatic Breast Cancer Network; Kelly P. Hodges, Sisters Network Inc.; Kimberly Sabelko (replacing Stephanie Reffey), Susan G. Komen

## Working Groups

### Information and Services

Jane Levy, CancerCare; Allison Harvey, Cancer Support Community; Jo Dulay, Genentech; Janine Guglielmino, Catherine Ormerod, Living Beyond Breast Cancer; Ginny Knackmuhs, Shirley Mertz, Metastatic Breast Cancer Network; Christine Benjamin, SHARE; Kelly P. Hodges, Sisters Network® Inc.; Susan Brown, Jeremy Patch, Susan G. Komen; Jean Rowe, Young Survival Coalition

### Research

Musa Mayer, AdvancedBC.org; Marc Hurlbert, Avon Foundation for Women; Elly Cohen, BreastCancerTrials.org; Lisa Schlager, FORCE; Ginny Mason, Inflammatory Breast Cancer Research Foundation; Mary Lou Smith, Elda Railey, Research Advocacy Network; Stephanie Reffey, Kari Wojtanik, Susan G. Komen; Michelle Esser, Young Survival Coalition

### Governance

Julissa Viana, Celgene Corporation; Amy Bonoff, Heather Ortner, Dr. Susan Love Research Foundation; Jean Sachs, Living Beyond Breast Cancer; Rochelle Shoretz, Sharsheret

### Membership

Diane Rose, FORCE; Ginny Knackmuhs, Metastatic Breast Cancer Network; Jacqueline McKnight, Kimberly Sabelko, Susan G. Komen

### Consultants

Lynne Davies and the International Cancer Research Partnership; Kristine De La Torre; Jon Fulton; Pamela Miller; Cynthia Geoghegan, Jane Perlmutter, Patients and Partners, LLC

### Project Director

Katherine Crawford-Gray, MSC, MBA

### Editor

Jenny Lamont, MS, ELS

### Graphic Design

Corrine Ellsworth Beaumont, PhD  
(<http://corrinebeaumont.com>)



## **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

1



# CHAPTER 1:

## INTRODUCTION

Metastatic breast cancer (MBC), also known as stage IV, is an incurable, albeit treatable, progressive cancer that originates in the breast and then spreads or metastasizes to other parts of the body such as bones, liver, lungs, or brain.

**MBC is the cause of virtually all deaths from breast cancer.** For people diagnosed with MBC, managing the disease becomes part of their daily life. Patients change treatments as drugs cease to work and the cancer progresses. Psychologically, the emotional distress of an MBC diagnosis can be worse than that of diagnoses of early stage breast cancer<sup>[4]</sup>. Public messaging about the “cure” and survivorship is so pervasive that people diagnosed at stage IV with MBC can be stigmatized by the perception that they’ve failed to take care of themselves or undergo annual screening. The challenges patients and their caregivers face in finding MBC-specific support and information from the organizations focusing on early stage breast cancer can exacerbate feelings of loneliness and isolation.

Driven by a desire to address the unique needs of those living with MBC, advocate organizations have joined forces as the Metastatic Breast Cancer Alliance (MBC Alliance) to address these challenges. The MBC Alliance brings together some of the most active advocates for patients with breast cancer, the 3 largest private funders of breast cancer research in the US, and 6 pharmaceutical corporations. The Alliance was publicly launched on MBC Awareness Day—October 13, 2013—when it announced its first initiative, a landscape analysis that sought to:

- Assess gaps, duplication, and opportunities in MBC research, patient information and support services, and public awareness to capitalize on identified opportunities, and
- Identify the ways in which Alliance members could work together to meet the unique needs of those living with MBC.

We are pleased to present the following body of work, which is the outcome of research undertaken over the past year by the MBC Alliance. Patient advocates and experts with knowledge and experience specific to the area of investigation examined various aspects of the MBC landscape:

- Scientific research, including clinical trials, focused on MBC
- Quality of life of MBC patients and their families and caregivers
- Information and support services provided by MBC Alliance members
- Epidemiology of MBC: Challenges with population-based statistics
- Public Awareness of MBC.

Chapter 2 reviews the landscape of scientific research with a distillation of data from clinical trials, funded biomedical research grants, and interviews with key opinion leaders (KOLs).

Chapter 3 provides a comprehensive review of the available quality of life literature and psychosocial research of patients living with MBC. This section shares learning about psychological distress, emotional support, and the communication issues with HCPs.

Chapter 4 describes internal research of Alliance members' information and support services to better understand gaps and opportunities for improving the quality of life for people living with MBC.

Chapter 5 investigates the limitations around accurate epidemiologic statistics collected or the lack thereof for patients with MBC, such as National Cancer Institute (NCI) Surveillance, Epidemiology, and End Results (SEER) registries that capture only incidence, initial treatment, and mortality.

Chapter 6 looks at the lack of understanding about MBC, which has very real implications for patients. A greater understanding of what MBC is and how it differs from early stage breast cancer is needed among caregivers and HCPs, insurers, policy makers, researchers, and other key stakeholders, including people living with MBC and those with breast cancer.

The main findings from our research will lay a solid foundation for the Alliance's work over 2015 and 2016. In the final chapter of this report, Chapter 7, we outline actions for 2015–2016 that align with our 3 goals:

1. Advance research focused on extending life, enhancing quality of life, and ultimately ending death from MBC.
2. Improve knowledge and access by ensuring all MBC 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.
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.

We look forward to reporting on our progress in 2015.



Metastatic Breast Cancer

**MBC**alliance>

*together we are stronger than the disease*



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

## **Metastatic Breast Cancer Alliance**

c/o Avon Foundation for Women  
777 Third Avenue  
New York, NY 10017

[mbcalliancesocial@gmail.com](mailto:mbcalliancesocial@gmail.com)  
[www.mbcalliance.org](http://www.mbcalliance.org)  
[www.facebook.com/mbcalliance](https://www.facebook.com/mbcalliance)  
[www.twitter.com/mbcalliance](https://www.twitter.com/mbcalliance)  
[www.pinterest.com/mbcalliance](https://www.pinterest.com/mbcalliance)