Changing the Landscape for People Living with Metastatic Breast Cancer
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.

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Acknowledgments

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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.

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

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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 is a serine/threonine-specific protein kinase.

BRCA mutation is a mutation in the tumor-suppressor gene BRCA1 or BRCA2, associated with hereditary breast cancer.

CSO is Common Scientific Outline (www.icrpartnership.org/CSO.cfm).

de novo MBC is breast cancer that is metastatic at the time of first diagnosis.

ER- is estrogen receptor negative/hormone insensitive breast cancer.

ER+ is estrogen receptor positive/hormone sensitive breast cancer.

ErbB is epidermal growth factor receptor (protein family).

gHRAsp is Grants in the Health Research Alliance Shared Portfolio (www.ghrasp.org).

HCPs is human epidermal growth factor receptor 2.

HER2 is human epidermal growth factor receptor 2.

hormone-sensitive MBC is MBC where tumor growth is promoted by estrogen and/or progesterone.

HRA is Health Research Alliance.

ICRP is International Cancer Research Partnership.

incidence is Rate of occurrence of new cases in the population (measure risk of developing a disease).

IOM is Institute of Medicine.

KOL is key opinion leader.

MBC is metastatic breast cancer.

MBC Alliance is Metastatic Breast Cancer Alliance (also called the Alliance).

mTOR is mechanistic target of rapamycin (serine/threonine protein kinase).

NCI is National Cancer Institute.

PDQ is Physician Data Query.

PI3K is phosphatidylinositol 3-kinase.

prevalence is proportion of cases in the population (measures how widespread the disease is).

RECIST is Response Evaluation Criteria in Solid Tumors.

SEER is Surveillance, Epidemiology, and End Results program of the National Cancer Institute (NCI).

stage IV breast cancer is another term for metastatic breast cancer.

TBCRC is Translational Breast Cancer Research Consortium.

TN MBC is triple-negative (hormone insensitive and HER2-negative) metastatic breast cancer.

TNBC is triple-negative (hormone insensitive) breast cancer.

US is United States.
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[^4]. 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.
People living with metastatic breast cancer and patient advocates at the Metastatic Breast Cancer Network 2013 Annual Conference.