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# Bridging Gaps, Expanding Outreach

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## *Metastatic Breast Cancer Advocacy Working Group Consensus Report*

On January 25, 2008, we – the Metastatic Breast Cancer (MBC) Advocacy Working Group comprised of 16 patient advocates from seven countries – convened at a Pfizer-sponsored meeting, held in New York City, to share insights on the current obstacles and discuss potential solutions for better addressing unmet needs of women with MBC.

Now is a critical time to have this conversation. Here's why:

- Breast cancer is the leading cause of cancer death among women worldwide. Globally, there are an estimated 4.4 million women alive who have been diagnosed with breast cancer within the last five years.<sup>i</sup> In developed countries, 30 percent of women with earlier stages of breast cancer will eventually be diagnosed with metastatic disease.<sup>ii</sup> In developing countries, the majority of women with breast cancer are diagnosed with advanced stage disease.<sup>iii</sup>
  - The exact proportion of those living with MBC is unknown as these data are not collected. Data collection of MBC prevalence and survival rates are essential to assess recent advances in treatment, and determine areas where additional research is needed.
- Women living with MBC report feelings of isolation in regards to the attention, support and care they receive, compared to women with earlier stage breast cancer.
  - Awareness initiatives that educate the public and dispel misconceptions are essential in decreasing the marginalization of the MBC community.
- As women are living with MBC for longer periods of time, the need for programs and services specific to MBC is becoming increasingly important.
  - Women with MBC have unique characteristics and needs that differ from those in the broader breast cancer community, and the same resources are often not appropriate for them. Further, within the MBC community, women often have varied experiences.
  - According to women with MBC, there are not enough information and support services specific to advanced disease, and some find it difficult to locate and access existing materials.
- Given the need for additional treatment options for MBC, clinical trial information and services are critical but largely underutilized. Further, women with MBC who are eager to participate in clinical trials may face enrollment barriers due to restrictive design protocols.
  - While a majority of cancer patients report being receptive to enrollment, accrual to breast cancer clinical trials remains low.<sup>iv</sup> While there are likely many reasons for this, major contributors include negative misconceptions, lack of access to appropriate information and difficulty in understanding clinical trial materials.
  - Clinical trials that exclude previously treated patients or certain metastases may decrease the chances for women with MBC to be eligible for enrollment.

### **Given this situation, we are prioritizing the following three areas for immediate action:**

1. Improve access to tailored information, resources and support for women with MBC.
2. Heighten attention to the MBC community – create a unified voice and platform that speaks to their unique needs.
3. Increase understanding of and access to clinical trials.

This report is a call to action for advocacy groups, industry, healthcare professionals, government, academia, community/religious organizations, and all other relevant breast cancer stakeholders to begin implementation of the following strategies as appropriate in each country setting.

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## Improve Access to Information, Resources and Support Services

- Solicit registries, government, academia and industry to collect data on the prevalence, incidence and current survival rates of MBC to understand the proportion of those living with the disease and to investigate changes in prognosis in this patient group.
- Create tailored support and information resources that are relevant to the diverse experiences of women within the MBC community.
  - Offer online, telephone and/or in-person support groups and information resources that are specific to different subsets of women with MBC, for example, by age, race, site of metastases, hormone status, and timing of advanced disease diagnosis (e.g., initial versus recurrent). Offer culturally relevant materials.
  - Provide information on existing and emerging treatment options, including clinical trial data and clinical practice guidelines, as well as symptom and side effect management.
  - Prepare women for what to expect following treatment for MBC; offer materials that focus on topics such as “chemo brain”, post-treatment fatigue, and the role of nutrition and exercise in disease management.
- Increase collaboration and information sharing of resources for women with MBC in an effort to provide greater access to information.
  - Create centralized Web-based and off-line venues that house information on MBC to help organize and streamline the information gathering experience.
- Coordinate interactive research-focused conferences and workshops that provide women with MBC access to other patients as well as thought leading physicians who can provide updates on the latest research and treatment options. Ensure MBC-specific information is integrated into the agendas of existing general breast cancer conferences/forums.
- Create an infrastructure for healthcare professionals to provide accurate clinical information, psychological and practical support, including financial, legal and end of life guidance, from the point of diagnosis onwards and throughout the duration of the illness.
  - Encourage healthcare institutions to initiate MBC patient support programs (e.g. patient navigator or case management programs; key worker services) to improve a patient’s experience in the healthcare system upon diagnosis and throughout treatment.
  - Educate women completing treatment for primary breast cancer about the signs and symptoms of MBC. Ensure that healthcare providers are properly trained to recognize the signs of disease progression.

## Heighten Attention to the MBC Community

- Educate the public and the larger breast cancer community about MBC and the need for increased attention and resources through

the implementation of programs, such as the designation of a specific day or week to MBC awareness.

- Assist and support women with MBC interested in speaking out and sharing their personal experiences within their communities. Seek publicity and promotional opportunities to raise the profiles of these women, as appropriate. Identify and work with public figures who can help raise awareness on a national level and give a much needed voice to women with MBC.
- Shift the dialogue to be more positive when speaking about MBC.
  - Begin talking about metastatic disease as a long-term illness that can be managed in some cases.
  - Sensitize healthcare professionals to use language that avoids contributing to MBC women’s feelings of guilt, anxiety and fear that they failed or should have done things differently.

## Increase Understanding of and Access to Clinical Trials

- Initiate guidelines requiring healthcare providers to communicate the option of clinical trials at time of first diagnosis, when most women with MBC actively seek information.
  - Assist women with the decision making process to ensure they are making an informed choice by discussing the benefits and potential risks, while dispelling common misconceptions.
- Create an up-to-date, user-friendly listing of all available clinical trials for MBC.
- Develop materials that will help women better understand the terminology associated with clinical trials. For example, extend access to a clinical trial glossary of terms and frequently asked questions/answers. Trial sponsors should create easy-to-read clinical trial cards that clearly communicate quality of life endpoints and trial locations.
- Provide one-on-one support for women throughout the enrollment process, including assistance with informed consent documents, transfer of medical records and follow-up correspondence. Implement support systems for patients enrolled in clinical trials, including trial support groups and check-in calls from nurses and/or social workers.
- Increase communication about compassionate use/expanded access programs to women who are not eligible for a MBC clinical trial.
- Design clinical trials that include underserved segments of the MBC community, such as heavily pretreated women and women with certain metastases.

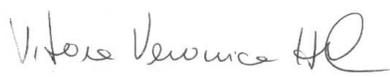
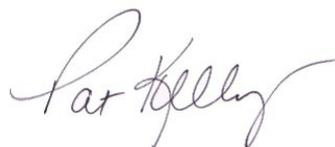
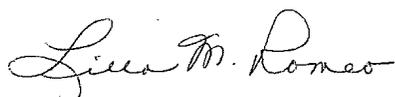
As an increasing number of women live with MBC for longer periods of time, many more people are in need of support and information on MBC. Unique information and support services are critical and we as breast cancer advocates need to strategically address the development and position of future initiatives.

## MBC Advocacy Working Group

The MBC Advocacy Working Group was established with sponsorship from Pfizer Oncology and includes the following individuals, among others.

- Elyse S. Caplan, MA, Living Beyond Breast Cancer (U.S.)
- Linda Englander, SPHR, Breast Cancer Network of Strength (U.S.)
- Ednin Hamzah, MD, Breast Cancer Welfare Association (Malaysia)
- Vitoria Herzberg, ABCANCER (Brazil)
- Carla Howery, MA, Patient Advocate (U.S.)
- Pat Kelly, MA, Campaign 2 Control Cancer (Canada)
- Susan Knox, Europa Donna – The European Breast Cancer Coalition (Head Office, Italy)
- Stacy Lewis, Young Survival Coalition (U.S.)
- Jackie Manthorne, Canadian Breast Cancer Network (Canada)
- Alejandra Mijares de Capín, Grupo Reto (Mexico)
- Jennifer Paradis, Breastcancer.org (U.S.)
- Lilla Romeo, Metastatic Breast Cancer Network (U.S.)
- Donna Sheehan, Willow Breast Cancer Support (Canada)
- Pat Spicer, MSW, CancerCare (U.S.)
- Marisa Weiss, MD, Breastcancer.org (U.S.)

This Report represents the opinions of more than 30 women living with metastatic breast cancer who participated in reviews of the statements and strategies put forth in this Report.



<sup>i</sup> Parkin M, Bray F, et al. Global Cancer Statistics, 2002. CA Cancer J Clin. 2005; 55:74-108.

<sup>ii</sup> O'Shaughnessy J. Extending Survival With Chemotherapy in Metastatic Breast Cancer. The Oncologist. 2005;10(suppl 3):20-29.

<sup>iii</sup> Anderson B, Eniu A, et al. Breast Cancer in Limited-Resource Countries: Health Care Systems and Public Policy. Breast J. 2006;12(suppl 1):S4-S15.

<sup>iv</sup> Simon M, Du W, et al. Factors Associated With Breast Cancer Clinical Trials Participation and Enrollment at a Large Academic Medical Center. J Clin Oncol. 2004; 22:2046-2052.