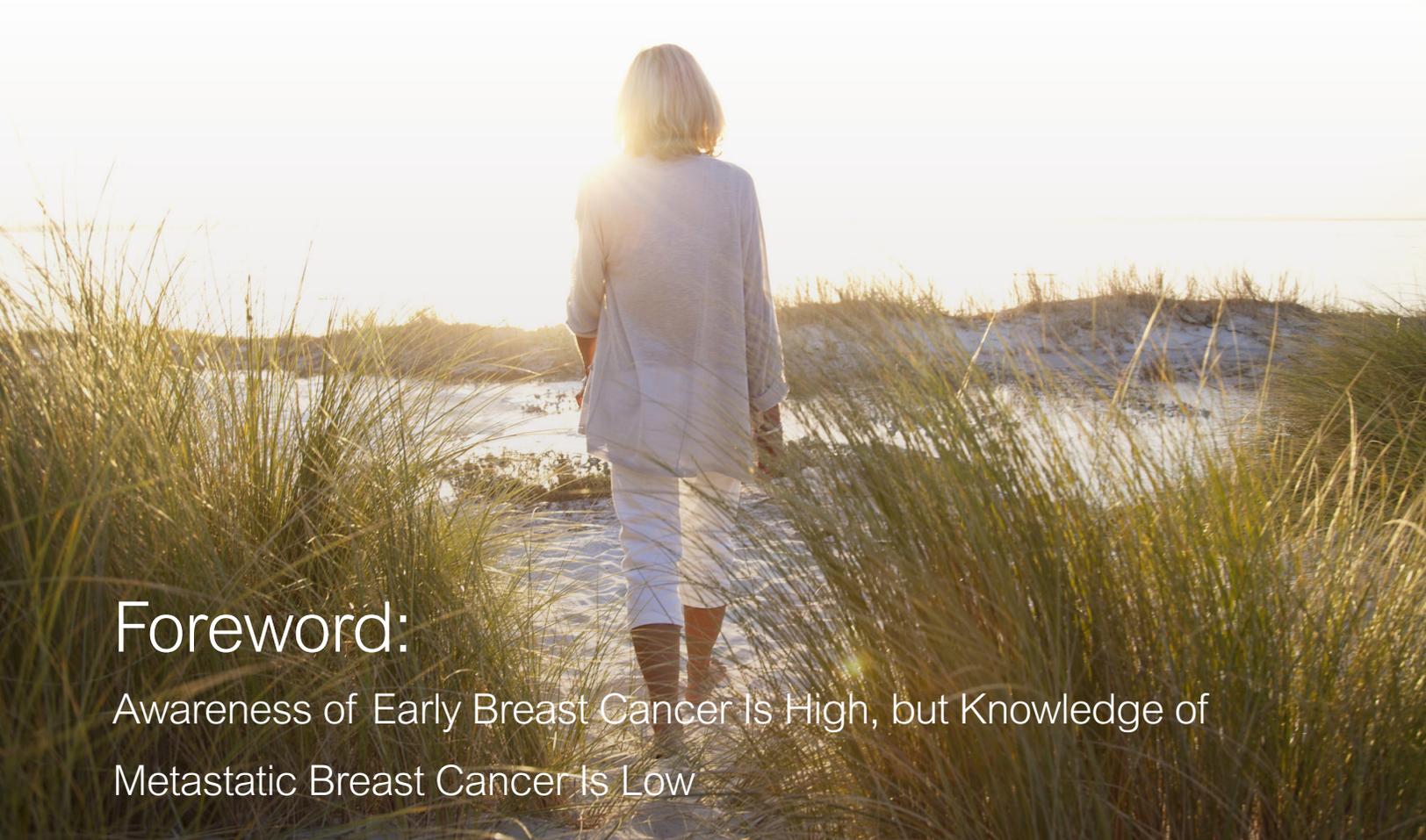


BREAST CANCER:
A STORY
HALF
TOLD

A Focus On Metastatic Disease



This document was first published October 2014, and updated in November 2017. Any research advancements made, or statistics updated after November 2017 are not reflected within the material.



Foreword:

Awareness of Early Breast Cancer Is High, but Knowledge of Metastatic Breast Cancer Is Low

The cultural collective of breast cancer advocacy and awareness activities, and an abundance of education efforts, information and news coverage have made breast cancer a familiar disease. Thanks to the significant strides made in early detection, research, treatment and patient empowerment over the past 30 years, there is much progress to celebrate. Indeed, the prognosis of early stage breast cancer has transformed as survival rates have steadily increased.

For late stage breast cancer, however, the narrative is markedly different.

In the United States, it is estimated that more than 150,000 women in the U.S. are living with metastatic breast cancer.¹ Metastatic disease – the most advanced stage of breast cancer in which cancer has spread beyond the breast to other organs in the body – remains an incurable condition and is the second leading cause of cancer death among women today.^{2,3,4,5} Even when diagnosed at an early stage, approximately 30 percent of women with early breast cancer will eventually progress to metastatic disease and face a five-year survival rate of 28 percent following an initial diagnosis of metastatic disease.^{1,6,7,8,9,10}

Rather than a single disease with uniform characteristics, breast cancer embodies many diseases, each with different biological and clinical traits.

Metastatic breast cancer is clinically complicated. Further, the emotional toll of metastatic disease can be profound, and can transcend into the ways people feel about themselves, communicate with others and live their lives.^{11,12}

Language is vital to the way that we connect, process and explain our worlds. While the breast cancer conversation is vast, it has been dominated by messages of early detection, routine diagnosis and survivorship. Understanding the language of the metastatic breast cancer patient is new territory. Research has shown that people with metastatic breast cancer can feel isolated and under represented in the larger breast cancer dialogue.^{11,12}

There is an unyielding consensus among healthcare professionals, patients, the advocacy community and Pfizer that women living with metastatic breast cancer should be part of the larger breast cancer dialogue, and receive the support and information they need. Pfizer has united with advocates, patients, and healthcare professionals under the common goal of expanding the conversation to be more inclusive of metastatic disease.

To accomplish our goal, we have undertaken the *Breast Cancer: A Story Half Told* initiative to understand and address gaps in breast cancer dialogue across audiences. As part of this initiative, we enlisted a multi-disciplinary steering committee comprised of breast cancer patient advocates, healthcare professionals and academic linguists, and conducted two complementary studies which helped us understand various aspects of the breast cancer conversation. The initial approach was a first-of-its-kind study to measure the general public's understanding of early breast cancer as well as advanced disease, which encompasses both Stage III (locally advanced) and IV (metastatic) breast cancer.¹³ The second study analyzed the real-life conversations between physicians and patients after a metastatic breast cancer diagnosis.¹⁴ Taken together, these studies yielded surprising and thought provoking results that not only help us understand the current gaps within the breast cancer conversation as it relates to metastatic breast cancer, but also suggest a number of important actions that need to be taken by multiple parties to improve patient experiences and outcomes.

Hand-in-hand with the steering committee, we have made recommendations which we believe are meaningful and actionable. Ultimately, our objective is clear. We aim to expand the breast cancer conversation to heighten understanding and knowledge of metastatic disease within society at large, while empowering patients to have a clear voice within conversations about their breast cancer experience.

It will take commitment, attention and resources from multiple parties to change the environment. Though the task is challenging, the time is now to begin the next phase of the breast cancer movement, where all people living with breast cancer – the early, the advanced and the metastatic – feel equally embraced.



Freda C. Lewis-Hall, MD, DFAPA
Senior Medical Advisor, Pfizer Inc.



Mace L. Rothenberg, MD
Chief Medical Officer, Pfizer Inc.

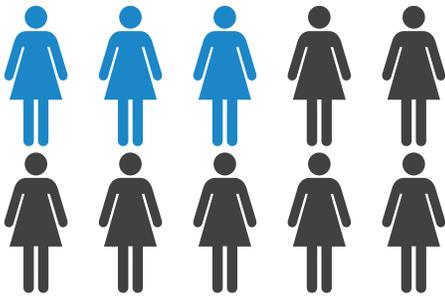
and the ***Breast Cancer: A Story Half Told* Steering Committee***



* Please see page 16 for full list of Steering Committee members.



The Current Breast Cancer Landscape



Approximately

THIRTY PERCENT

of women who have had early breast cancer will eventually develop metastatic breast cancer^{6,7,8,9,10}

Let's start with a well-known fact. Breast cancer awareness has come a long way, in large part due to the valiant efforts of advocacy organizations and dedicated healthcare professionals, and the courage of patients, family, friends and caregivers. Funding for research, breast cancer screening and public education have all increased tremendously over the past three decades.¹⁵ Concurrently, public awareness of the disease has risen steeply and society's perception of the breast cancer narrative morphed from a potential death sentence into a path of strength and survivorship.¹⁵

Amidst all of this progress, however, it is estimated that more than 150,000 women in the U.S. are living with metastatic breast cancer, the most advanced stage of breast cancer.¹ Also known as Stage IV breast cancer, this condition is incurable, with fewer treatment options available compared to early breast cancer.^{2,3,5} Far from a rare condition, approximately 30 percent of women diagnosed with early breast cancer will eventually progress to metastatic disease.^{6,7,8,9,10} However, women with metastatic breast cancer continue to express feelings of isolation as their stories and struggles do not align with the public image and understanding of breast cancer.

“The mental demands facing metastatic patients are significant. Our need for support and encouragement never ends because we will always be in treatment.”

Shirley Mertz, JD

President, Metastatic Breast Cancer Network & metastatic breast cancer patient

Distinctly different needs and challenges separate women living with metastatic breast cancer from those with early breast cancer. Without a cure, they undergo treatment as long as they live, and carry the emotional weight that comes along with it.^{5,11,12} Without a strong voice, their experiences are lost amidst messages of early detection and prevention.

Indeed, previous research has confirmed the isolation that metastatic breast cancer patients may experience.^{11,12} In a study conducted by Pfizer in 2009, 53 percent of surveyed women with metastatic breast cancer reported that their condition receives too little public attention. Furthermore, 38 percent of respondents reported being afraid to talk openly about metastatic breast cancer, and 48 percent said their friends and family were uneasy talking about the disease.¹¹ Other organizations have also studied this issue and reached similar conclusions – that there is an undeniable problem within the breast cancer community.

Women with metastatic disease feel isolated, alone and ignored and they demand more attention.¹²
Action needs to be taken.

While poignant, these findings raise questions – what are the external factors that contribute to the isolation, emotional burden and unmet needs in the metastatic population? What in the patient’s broader environment contributes to this phenomenon? Our goal was to find out.

General Public Survey: Testing Society's Breast Cancer IQ

This survey was administered online to more than 2,000 adults, representative of the U.S. population across various socioeconomic, geographic, educational and ethnic backgrounds. The study was fielded in April 2014.**

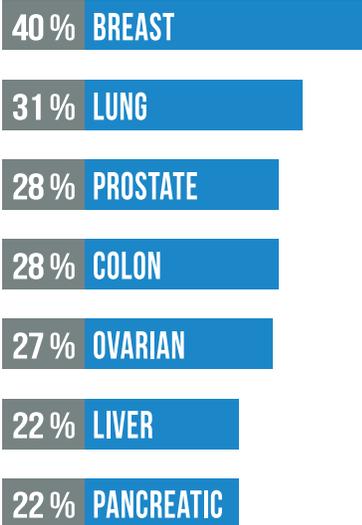
In order to understand metastatic breast cancer patients' broader environment, a national study was conducted to examine the general public's perception and understanding of all stages of breast cancer. While previous studies have investigated the perceptions of metastatic breast cancer (MBC) patients, no other study has examined the general public's perspective on MBC in the U.S., making this study the first of its kind.

Findings from this study showed that there is high awareness and personal connection to breast cancer, but metastatic breast cancer is less well known. Indeed, 40 percent of respondents reported that they know a good amount about breast cancer, with fewer saying this about other types of cancer, such as lung (31%), prostate (28%), colon (28%), ovarian (27%), liver (22%) and pancreatic (22%). Most surveyed (51%) said that someone close to them has or has had breast cancer and five percent of respondents have or have had breast cancer themselves.¹³

Not surprisingly, the research showed that the majority of people associate breast cancer with the color pink (75%), walks (68%) and fundraisers (57%). Most people (60%) reported that they know little to nothing when it comes to metastatic breast cancer. Lack of awareness of metastatic breast cancer is particularly acute among people earning less than \$35,000/year, as a great majority of them (71%) said they know little or nothing about metastatic breast cancer, whereas 57 percent of people earning more than \$35,000 responded similarly.¹³

HOW MUCH DO YOU KNOW about the FOLLOWING TYPES OF CANCER?

Percent of respondents who reported that they know a good amount:



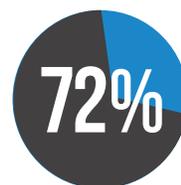
MORE THAN 60% SAY THEY KNOW LITTLE TO NOTHING about METASTATIC BREAST CANCER

**The general public survey assessed breast cancer knowledge in 2,090 men and women in the U.S., aged 18 or older, who were representative of the U.S. population across various socioeconomic, geographic, educational and ethnic backgrounds. Pfizer commissioned Kelton to conduct the online survey and responses were collected in April 2014. The findings from the study were analyzed on a national level.

This lack of knowledge around metastatic breast cancer became apparent through additional findings from the study, which revealed that the following truths were not well understood:¹³

1 **There is No Cure for Breast Cancer in the Advanced Stages:**

Nearly three-quarters of those surveyed thought that if diagnosed early, advanced breast cancer can be cured.¹³ However, the truth is that advanced or metastatic breast cancer cannot be cured.³



**BELIEVE THAT
BREAST CANCER**
in the
ADVANCED STAGES
IS CURABLE
IF DIAGNOSED EARLY

2 **Breast Cancer Progression Can Occur Regardless of Treatment or Preventative Measures Taken:**

Fifty percent of people surveyed said that breast cancer progresses because either patients did not take the right treatments or preventative measures.¹³ In reality, the women who later progress to metastatic disease do so even if they took treatment or preventative steps, such as mastectomies and mammograms.⁵ This misperception is particularly problematic, as it potentially leads to the stigmatization of people with metastatic breast cancer.



**BELIEVE BREAST CANCER
PROGRESSES**
BECAUSE PATIENTS
either did not take the
RIGHT TREATMENT
or
PREVENTATIVE MEASURES

3 **Prognosis of Advanced Disease Remains Poor and Treatment Options May Be Limited:**

Half of the respondents from the study reported that advanced breast cancer has a significant number of treatments. About 4 in 10 people also believed that people with advanced breast cancer may live a long time.¹³ While some people with advanced breast cancer live for many years, there is still a large unmet need to improve patient outcomes, as the five-year survival rate following a diagnosis of distant (metastatic) breast cancer is 28 percent.¹⁶

“I know from personal experience as a patient and professional experience as a nurse that a breast cancer diagnosis is shocking and feels as though it comes out of nowhere. Further, progression to metastatic disease can happen quickly and inexplicably. Though no one can predict when a diagnosis will happen and what the disease will do, there are two things that I know for sure: 1) a diagnosis is no one’s fault and 2) people living with the disease are not alone.”

Hollye Jacobs, RN, MS, MSW
New York Times bestselling author of *The Silver Lining: A Supportive & Insightful Guide to Breast Cancer* and *TheSilverPen.com*, speaker and clinician

“When asked about the meaning of metastatic breast cancer, most people will likely shrug their shoulders in confusion. There is a clear need to demystify the term ‘metastatic breast cancer’ among the public.”

Arif Kamal, MD Fellow
American Society of Clinical Oncology (ASCO)

Most people believed breast cancer death rates are the same across various ethnic groups.¹³ The reality is that while death rates are decreasing across ethnicities, five-year survival is much lower in certain ethnic groups than in the Caucasian population.^{17,18} African-American women with breast cancer are on average 40 percent more likely to die of the disease than white women with breast cancer.¹⁸ For Hispanic women, breast cancer is the leading cause of cancer death.¹⁹

Lastly, one of the most striking findings from this study is that those who have had breast cancer or know someone close to them affected by the disease seem to be no more informed about metastatic breast cancer than people without this background. In fact, in some cases, these individuals are even less informed than those with no personal experience.

IN ONE EXAMPLE, STUDY FINDINGS INDICATED THAT:



Clearly, there are vast societal misperceptions around all stages of breast cancer, and the deepest misunderstandings cluster around late stage disease.* More needs to be done to demystify metastatic breast cancer and elevate awareness to incite change.

**An analysis of the research on the state level showed results were similar to national findings and support the need for more regional/demographic initiatives to increase awareness and change behavior.*



In-Office Study: Exploring Physician/Patient Conversations in the Real World

In addition to understanding societal perceptions of breast cancer, we knew that it was crucial to understand the conversation in its truest form – the patient and physician dialogue. From March to May 2014, we commissioned a study which observed the interactions between metastatic breast cancer patients and their community-based oncologists in the physician’s office, following a Stage IV (metastatic) breast cancer diagnosis. After the office visit, both parties were interviewed separately to evaluate what was understood from the conversation, and the intended and experienced effects of the communication. All conversations and follow-up interviews were videotaped with consent from all parties.

In total, the study included 22 women with metastatic breast cancer from across the U.S. and their oncologists. The seven oncologists who participated in the study practiced in private, community-based settings with an average of 27 years in practice (range 19 – 35) and saw an average of 413 patients per month (127 patients with breast cancer).



Analysis of their conversations revealed three primary findings:¹⁴

1 Patients Do Not Have a High Level of Engagement During In-Office Conversations:

The research revealed that conversations in the physician's office were largely driven by the oncologist. Generally, patients in the study offered minimal input and asked few questions, allowing their physicians to control the office visit and conversation. This was particularly true in discussions around treatment options, as decisions were often presented unilaterally by the oncologist, with general acquiescence from the patient.¹⁴

While patients in general did not actively participate in the treatment discussion, we learned in the follow-up interviews that half believe they have a voice in treatment and half see it as the oncologist's responsibility.¹⁴

Physician:

"The other reason for telling you that we may want to put you on a medication is because of the fact that on your X-rays we did notice some **changes in the bone**, and there's a drug that is currently being used to reduce the risk of fractures. When **cancer of the breast attacks the bones**, your bones become very brittle."

2 Within These Conversations, Oncologists Use Vague or Overly Technical Language:

The study revealed that some oncologists used imprecise language to describe disease progression, for example, using a phrase such as “changes in the bone.”¹⁴

When talking about treatments, physicians who were studied used vague terms, often without any explanatory context, to describe what was happening. These vague terms included those such as “work” (for example, “the treatment is working”) and “respond” (for example, “the cancer is responding”), in contrast to more descriptive language, such as “the treatment is working, which we can see from tests that show the tumor is shrinking/not getting bigger” or “the treatment does not work, as tests show the tumor continues to grow.”¹⁴

Interestingly, when describing the disease itself, some oncologists in the study switched to highly technical jargon, using words such as “locally advanced disease” and “antibodies.”¹⁴

Physician:

“We measured the tumor marker, which showed that the amount of the breast cancer antibody was very high—about 3,500...

So, we knew the cancer came back.”

3 The Severity of Metastatic Disease Tends to Be Minimized by Physicians:

In conversations studied, metastatic disease was conveyed as a chronic, livable disease, which minimized the actual severity of metastatic breast cancer.¹⁴ With prognostic information unclear, patients are not provided the maximum opportunity to plan accordingly.

Physician:

“You have an excellent prognosis.

You’re going to live for a long, long time and probably never die of breast cancer.”

ONCOLOGIST RARELY USE...	AND INSTEAD USE... ¹⁴
METASTATIC	ADVANCED
PROGRESSION	ACTIVITY
INCURABLE	CHRONIC
DECLINE	RESPONSE
IMPROVEMENT	



Call to Action: Expanding Breast Cancer Conversations

Based on our research findings, our goal is clear: we must expand the current breast cancer conversation to address the gaps between early and metastatic disease both on a societal and physician/patient level. To make this change, we all need to take action:

AUDIENCE	RECOMMENDATION
 PHYSICIANS, ONCOLOGY HEALTHCARE PROFESSIONALS AND ADVOCATES	EMPOWER PATIENTS AND THEIR CAREGIVERS TO ENGAGE MORE ACTIVELY IN DISEASE MANAGEMENT AND TREATMENT DECISIONS AND GENERATE MORE PRODUCTIVE DISCUSSIONS
 PATIENTS AND CAREGIVERS	<p>VOICE QUESTIONS AND CONCERNS ALLOWING THEMSELVES TO PLAY AN ACTIVE ROLE IN CONVERSATIONS WITH THEIR HEALTHCARE PROVIDERS AND ENSURE THEIR NEEDS ARE ADDRESSED</p> <p>SHARE THEIR EXPERIENCE WITH OTHERS TO INCREASE UNDERSTANDING OF THE DISEASE</p>
 MEDIA, PATIENT SUPPORT NETWORKS, THE PHARMA INDUSTRY AND HEALTHCARE PROFESSIONALS	UNITE AROUND THE COMMON GOAL OF INCREASING THE SOCIETAL KNOWLEDGE OF METASTATIC BREAST CANCER AND THE UNIQUE NEEDS OF PATIENTS

“Change will not happen overnight, but with the commitment of these parties we will amplify the voice of metastatic breast cancer patients under a united, common approach.”

Heidi Hamilton, PhD
Professor and Chair, Department of Linguistics, Georgetown University

Recommendations:

Let's Talk Metastatic Breast Cancer

Building on our research findings and input from our multi-disciplinary steering committee composed of breast cancer patient advocates, healthcare professionals and academic linguists, we propose the following strategic recommendations, which represent thoughts and ideas generated during several meetings and workshops.

STRATEGY #1:

Empower Patients/Caregivers to Foster Better Engagement during Physician Interactions

“Very often, doctors and patients do not effectively engage on issues that really matter to the patient and impact their care. The ultimate goal is that patients walk away from their conversations with their doctors with an understanding of their treatment options and what they can expect.”

Joanne Buzaglo

*Executive Director, PRO Solutions,
Concerto HealthAI*

Tactically, we recommend:

- **Developing Metastatic Breast Cancer Patient and Caregiver Resources:** Providing communication resources specific to metastatic disease to oncologists' office staff to encourage open lines of communication with patients and their caregivers. These resources can be distributed to patients soon after diagnosis and could include the following:
 - A metastatic breast cancer dictionary including terms commonly used in treatment discussions, defined in patient-friendly language.
 - A visual breast cancer disease backgrounder written for the patient that details the various stages of breast cancer and the unique characteristics of each.
 - A conversation guide patients can share with their physicians to discuss the relative benefits and risks associated with recommended treatments to determine the ideal treatment options.
 - A patient/caregiver empowering guide outlining expectations for their metastatic breast cancer experiences, including goal-setting tips to inform physician interactions and determine the level of involvement they would like to have in treatment discussions.
- **Improving Accessibility to Existing Metastatic Breast Cancer Patient Resources:** Identifying currently available resources for metastatic breast cancer patients and guiding them to these resources. Potentially utilize and build on the work of the Metastatic Breast Cancer Alliance.
- **Enabling Physicians' Staff to Empower Patients:** Training oncologists' office staff to utilize resources that encourage patients and caregivers to actively participate in conversations with their physicians, while also instilling the confidence to proactively bring up questions or concerns.

STRATEGY #2:

Improve Conversations Between Physicians and Patients/Caregivers

“Our goal is to foster an informative and productive, two-way dialogue between physicians that results in mutual understanding. To accomplish this goal, physicians and their office staff need to actively engage their patients as well as caregivers to express their needs. At the same time, they need to be aware of the patient’s and their caregiver’s baseline understanding of the disease and welcome a robust dialogue to increase that knowledge.”

Rich Frankel, PhD

*Professor of Medicine, Senior
Research Scientist, Indiana University
School of Medicine*

Tactically, we recommend:

- **Sharing Patient/Physician Study Data:**
Widely sharing results from the in-office study by presenting the data at an upcoming medical meeting and publishing them in a medical journal. Additionally, identify other studies examining the importance of open patient and physician dialogue to build a database of existing research specific to communication in advanced breast cancer. Physicians and other healthcare staff can leverage these channels to better support metastatic breast cancer patients and communicate with them and their caregivers.
- **Healthcare Professional Language Modules:**
Developing video modules outlining simple ways healthcare providers can enhance the language they use to increase patient and caregiver comprehension and encourage more active participation (for example, don’t take silence for acceptance, ask patients to repeat what they heard). These modules can train physicians on best practices for how to interact with patients and their caregivers.
 - These trainings could potentially be shared with medical students and/or offered as online CME courses.
- **Metastatic Breast Cancer Patient/Caregiver Journal:**
Creating an online or printed tool to help patients and their caregivers prepare for appointments, track diagnosis and source treatment information specific to advanced and metastatic disease. Additional features may include information on goal setting and potential questions for patients and caregivers to ask their physicians.

STRATEGY #3:

Within Society as a Whole, Heighten Understanding and Knowledge of Metastatic Breast Cancer

An urgent need exists to educate all audiences that breast cancer is a multi-dimensional disease with distinct characteristics, patient needs and outcomes. This educational undertaking can become the foundation of a national campaign designed to demystify metastatic breast cancer and address potential patient stigma.

“Metastatic breast cancer patients have unique needs that have to be realized not only by the patient, but by society as a whole, including the patient’s caregiver, family, co-workers, friends and support network.”

Lillie Shockney, RN

*University Distinguished Service
Professor of Breast Cancer, The
Johns Hopkins University School of
Medicine*

Tactically, we recommend:

- **Highlighting That Breast Cancer Is Not One Disease:**
Underscoring that breast cancer is in fact a multitude of diseases – not just one breast cancer – and that each type impacts treatment decisions and outcomes. As part of these efforts we need to educate and provide resources to the public. We also need to empower patients to engage their entire healthcare team – nurses, physicians, social workers – as well as enlist the support of their loved ones.
- **Building the Language of Metastatic Breast Cancer to Expand Societal Conversation:**
Creating a universal “language of metastatic breast cancer” for society. This new language will potentially arm patients, their loved ones and society at large with ways to talk about metastatic breast cancer and understand the patient’s experience, with the ultimate goal of creating a unified voice for the disease and how it is portrayed publicly. Recognizing there may be some existing resources around these topics, there is also an opportunity to enhance, share and leverage those materials to achieve the same goal.
- **Shedding Light on Common Metastatic Breast Cancer Misperceptions:**
Developing a resource to dispel misperceptions, including those around early diagnosis, disease progression and survival rates and misunderstandings caused by common assumptions or vague terms (e.g., patients diagnosed with early stage breast cancer progress to metastatic disease because they didn’t get a mastectomy, definition of recurrent disease). Juxtapose these points with reality to educate the public and help address stigma.

A photograph of three women of diverse ages and ethnicities laughing joyfully on a sandy beach. The woman on the left is older with grey hair, wearing a yellow jacket. The woman in the middle is wearing a straw hat and a light-colored top. The woman on the right is younger with blonde hair, wearing a pink hooded cardigan. The ocean and waves are visible in the background under a bright sky.

Conclusion: Leading Change for All Those Touched by Breast Cancer

Metastatic breast cancer is serious and complex. The toll of the symptoms, treatments and the psychological burden is significant not only for the patient themselves, but for their caregivers, family, friends and support networks.

There is a growing understanding and consensus that the breast cancer conversation needs to change so that people affected by metastatic breast cancer receive the information and support they need. In order to make this happen, we must:

- Elevate and address the needs and challenges of metastatic breast cancer patients so they are not lost amidst the conversation of early breast cancer.
- Empower those living with metastatic breast cancer and their caregivers to play a more active role in understanding their prognosis and in treatment decisions.
- Educate patients, healthcare professionals, caregivers, advocates, family, friends, the pharmaceutical industry, media and society about the current gaps in conversations and what must be done to address them.

While Pfizer plans to initiate programs in support of people with metastatic breast cancer, we trust in the community and healthcare professionals nationwide to join us and/or ignite their own efforts toward elevating the dialogue.

Many steps must be taken to make a significant and lasting impact. Only then can we change the lives of the more than 150,000 women living with metastatic breast cancer in the U.S.¹

Thank you: A United Effort

We thank the following steering committee members for their insights, participation and commitment. Without our esteemed collaborators, this work would not be possible and we are profoundly grateful for their perspectives.

- **Joanne Buzaglo**, Executive Director, PRO Solutions, Concerto HealthAI
- **Rich Frankel**, PhD, Professor of Medicine, Senior Research Scientist, Indiana University School of Medicine
- **Heidi Hamilton**, PhD, Professor and Chair, Department of Linguistics, Georgetown University
- **Hollye Jacobs**, RN, MS, MSW, New York Times bestselling author of *The Silver Lining: A Supportive & Insightful Guide to Breast Cancer* and *TheSilverPen.com*, speaker and clinician
- **Arif Kamal**, MD Fellow, American Society of Clinical Oncology (ASCO)
- **Shirley Mertz**, JD, President, Metastatic Breast Cancer Network
- **Lillie Shockney**, RN, University Distinguished Service Professor of Breast Cancer, The Johns Hopkins University School of Medicine

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