Changing the Landscape for People Living with Metastatic Breast Cancer

Metastatic Breast Cancer Landscape Analysis:

Executive Summary, October 2014

Metastatic Breast Cancer
MBCalliance>
together we are stronger than the disease

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Photographer: Yasmeen Anderson Photography

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Metastatic Breast Cancer

MBCalliance

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.

Acknowledgments

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

Steering Committee

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Executive Summary

Why present another report about breast cancer? Few would dispute that breast cancer has a higher profile than other types of cancer. Since the establishment of National Breast Cancer Awareness Month in the mid 1980s, a tremendous effort has been invested in messaging aimed at screening for early stage breast cancer while celebrating those who survive diagnosis and treatment.

The dominance of the "breast cancer survivor" identity masks the reality that patients treated for early stage breast cancer can experience metastatic recurrence. The focus on survivorship obscures the fact that, in spite of decades of breast cancer awareness and research funding, **40,000 women and men *still* die of breast cancer every year in the United States (US)**[1] **with metastasis the cause of virtually all deaths from breast cancer.**

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

While some progress with research and new treatments has been made in reducing mortality rates from breast cancer, median survival after an MBC diagnosis is 3 years—and this has not increased meaningfully in more than 20 years[2]. Despite these statistics, research funding for MBC accounts for only 7% of the total breast cancer research investment.

Currently, data are not collected on how many people experience a recurrence of breast cancer as MBC or the number of people living with the disease. We have only estimates of how many women diagnosed with early stage breast cancer will experience a recurrence. For unknown reasons, their breast cancer returns after a few months or as long as up to 20 years or more after initial diagnosis. It is also *estimated* that at least 150,000 people of all ages and all racial and ethnic groups are living with MBC in the US[3].

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. With breast cancer organizations' main focus on detection and screening of early stage breast cancer, MBC patients and their caregivers face real challenges in finding MBC-specific support and information from these organizations. Further, many MBC patients persist in believing a cure is likely, and health care professionals do not always have the time and skill to discuss treatment options when the prognosis is poor.

A lack of awareness about MBC and how it differs from early stage breast cancer; little research funding to combat this unique and deadly disease; a lack of accurate statistics on incidence, prevalence, and survival; and difficulty in finding information and support services essential for people living with MBC—these are the issues that have defined the work of the MBC Alliance over the past year.

The MBC Alliance

Many patient advocate groups have been working to change the landscape of MBC. In 2012, representatives of breast cancer organizations joined with MBC patient advocates to discuss ways to change the persistent lack of understanding about MBC and how organizations could work together to provide better information and support services to people living with MBC. All agreed that more could be achieved through working together than could be achieved by working alone. Assistance for these early steps was provided by Celgene Corporation.

On October 13, 2013 (National Metastatic Breast Cancer Awareness Day), the MBC Alliance of 16 nonprofits and 5 pharmaceutical corporations was launched. Over the past year, the Alliance has experienced growth in its membership as new advocates and industry partners realized the Alliance's potential to create positive change and impact individual lives. Currently, there are 29 member organizations.

Recognizing the valuable current and future contributions of each member to the MBC field, the Alliance is committed in its approach not to duplicate efforts of its members. Collaboration and learning from others is vital if the Alliance is to have real impact in improving the lives of people living with MBC.

Landscape Analysis of MBC

As its first initiative, the Alliance undertook a landscape analysis 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 Alliance members could work together to meet the unique needs of those living with MBC.

Aspects of the MBC landscape examined by advocates and experts with knowledge and experience specific to the area of investigation were:

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

Methods

The Alliance collected and reviewed multiple sources of data and information for the landscape analysis:

- Scientific research—a first time effort to analyze information on breast cancer treatment trials recruiting MBC patients in the US and information on breast cancer and MBC research grants awarded by most of the major cancer and biomedical research funding organizations. Interviews were conducted with 59 key opinion leaders with scientific expertise relevant to MBC research.
- Quality of life for MBC patients, and their families and caregivers—more than 150 published, peer reviewed articles relevant to the experience and needs of people living with the disease and 13 MBC surveys from 2006–2014 were analyzed.
- Information and support services specific to MBC—Alliance members were interviewed about their efforts in research, patient advocacy, patient education and support, and community awareness. Collateral materials, including surveys and research reports and information about services and support relevant to MBC, were collected from Alliance members. Member organizations' print and web-based materials were analyzed, and a short survey on telephone information/helplines was conducted.
- Epidemiology—the literature was reviewed to identify shortcomings in currently available population-based statistics relating to MBC.
- Public awareness of MBC—Over the course of work of the landscape analysis, discussions among advocates, patients, and industry members at MBC Alliance meetings highlighted the need to educate the public about MBC. Members helped to compile information on common misconceptions around MBC and brainstormed actions for the Alliance to increase understanding.

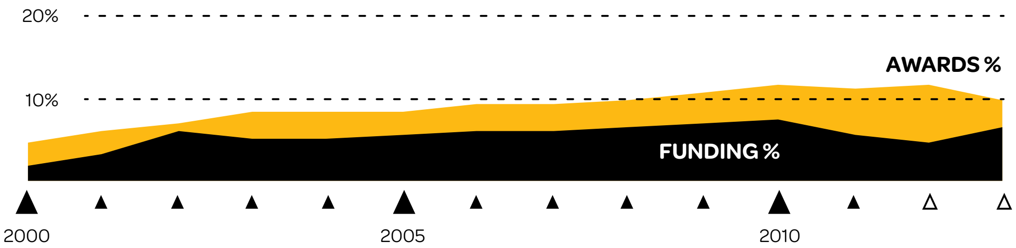
Key Findings

MBC Scientific Research

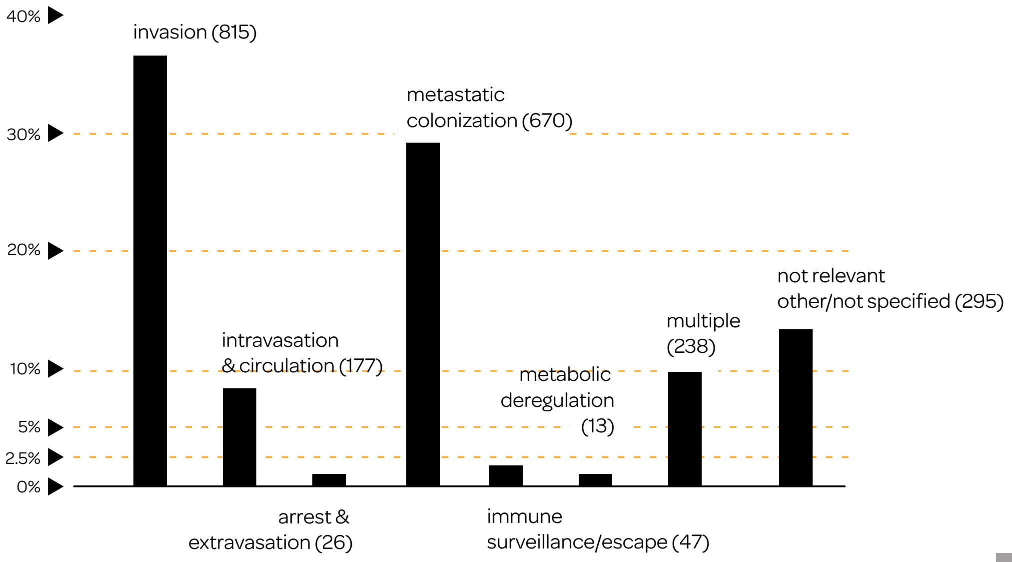
More funds need to be directed to MBC research. MBC-focused research made up only 7% of the $15-billion invested in breast cancer research from 2000 to 2013 by the major governmental and nonprofit funders from North America and the United Kingdom. Specific scientific areas are under studied. The field of MBC research is relatively small.

- MBC research grants are focused on the metastasis steps of invasion and metastatic colonization, with far fewer studying intravasation and circulation, arrest and extravasation, or metabolic deregulation. Why these gaps exist in funding and research focused on these areas of the biology of metastasis need further exploration.
- The distribution of funding across stages of MBC research (basic, translational, clinical, and cancer control) has not changed over the past decade, with most funding going to support basic research. There is a paucity of research in MBC cancer control, outcomes, and survivorship.
- Research on mechanisms of disease in cell lines and animal models is usually focused on tissue taken from early stage, primary breast cancer, and not metastatic tumors. In addition, clinical trial endpoints such as tumor shrinkage may not have relevance to tumor spread or metastasis.
- More research is needed to understand all the steps of metastasis to develop new treatments for the multiple types of MBC and to understand how best to improve the quality and duration of the lives of women and men in whom breast cancer becomes metastatic.
- Barriers to clinical trials include too many "me-too" trials in industry and the academic "reward" system for single investigators conducting single-institution phase II trials. To accelerate MBC clinical research, these barriers must be broken down by the conduct of multi-institution, multi-investigator trials.

Number and Amount of MBC Awards as a Function of Overall Breast Cancer Funding



Grants Categorized by Steps in Metastatic Process



LEFT TO RIGHT: Heather, Linda, Kristin

Finding joy in every day

Linda Roy

I am 63 years old, and for the last 6½ years I have been living with metastatic breast cancer. I would like to share my story so other women can see that metastatic breast cancer can be treated and that life can go on despite this diagnosis.

I was originally diagnosed with breast cancer in 1990 when I was just 39. At that time I was a wife, a mother, an elementary school teacher, and a doctoral student. My tumor was a hard lump the size of a pencil eraser, but it never showed up on a mammogram. Because I opted for a complete mastectomy, and no cancer cells were found in my lymph nodes, chemotherapy was not recommended. But to be extra careful, I had 4 months of chemotherapy and then had breast reconstruction. I was ready to put breast cancer behind me, and I moved on with my life. I got my school administrator certification, became an elementary-school principal, and watched both my children graduate from college. In 2005, I was 54 and attended my daughter's wedding, which was a joyous event.

In my 50s, however, I had frequent back pain and was diagnosed with a bulging disc. Despite massage, chiropractic adjustments, scans, medical examinations, and physical therapy, the pain continued. I had no stamina and I didn't feel well much of the time. Finally, in 2007, at 56, I began to suffer spinal fractures. I was shocked to learn that the original breast cancer had remained in my body and was now in my bones and ribs. I was sure my life was over.

Since then, I have taken hormone blocking medications, different types of infused chemotherapies, and oral chemotherapy. I have also had frequent doses of bone strengthening drugs and a course of radiation on my spinal tumors. Each type of treatment lowered my tumor marker levels and slowed the progression of the cancer for a while. When one medication stopped being effective we moved on to another, and fortunately so far the cancer has not spread beyond my bones.

I am living with metastatic breast cancer and yet I find joy in every day. I enjoy life with my husband, my children, my grandchildren, and my friends. I am able to garden, volunteer in the community, teach knitting, take short trips, and cook. I am sometimes tired, I walk with a cane, and my back is not strong enough to lift anything heavy—but I gain lots of strength from family, friends, and the other women with metastatic breast cancer whom I've befriended through local support groups. I consider myself blessed.

Characteristics of Linda's breast cancer: HR+, PR-, HER2-

Key Findings

Quality of Life for MBC Patients and their Families

Patients with MBC have unique emotional, physical, and psychosocial needs, and these have not changed over the last decade of academic research and patient surveys. The needs of minority and poor populations living with MBC have not been fully addressed in research or patient surveys.

- Emotional distress, experienced by a majority of MBC patients, is associated with increasing physical symptoms. Depression and anxiety are common, yet patients receiving mental health services are a minority; many methods exist for addressing psychosocial distress, most of which are underutilized.
- Most patients initially report adequate emotional support from friends, family, and community, but many feel isolated by the experience of the disease; social stigma is felt by half of MBC patients, especially within the breast cancer community.
- Individualized information about MBC is a critical factor for informed participation in treatment decision making. Information also plays an important role in coping by reducing uncertainty, lack of control, and distress.
- However, many MBC patients do not receive adequate information from HCPs to enable them to understand the disease and its treatments so they can make informed decisions. Patients' understanding of the nature of the disease and goals of treatment is often poor; many believe they will be cured. Limitations of time and resources in busy oncology practices may result in poor patient–doctor dialogue, including one-way "doctor-knows-best" communication. MBC patients also report confusion about reliable sources of information.
- Most MBC patients suffer multiple symptoms of disease and side effects of treatment that disrupt their lives—most common are fatigue, pain, and sleep problems. Despite this, half of patients say they are not routinely asked about their symptoms and express concern about "bothering" their doctors.
- Financial hardship is a common issue for families dealing with MBC, and many patients do not realize they will likely qualify for Social Security Disability benefits or Medicare. However, if eligible, the 2-year waiting period for Medicare represents a financially vulnerable time; many file for bankruptcy and face lower standards of living. Other practical needs may include transportation to treatment, home, shopping and child care, disability and insurance applications, and work-related issues, among others.
- A significant number of MBC patients report they are not receiving the help they need to address their physical symptoms, side effects from treatment, and emotional distress. Better communication among patients, caregivers and providers and better access to supportive and palliative care are clearly needed.
- Action and initiatives based on the findings from surveys of patients' needs, and other research, are lacking.

Six Aspects of Living with MBC

Some estimates are that as many as one third of MBC patients suffer from mood disorders such as major depression and anxiety, and one quarter experience mild depression.

Fatigue is by far the most common physical symptom reported by MBC patients, occurring in 80% or more of those undergoing treatment.

Key Findings

Information and support are not distinct from one another. MBC patients find information to be supportive and seek information from their support systems; thus, services for MBC patients should refer to both.

Nearly half of MBC patients surveyed say they find the information they need difficult to locate and confusing, and that what they do find doesn't fully address their needs.

MBC Patient Information and Support Services

Alliance members, and others, need to improve consistency of information about MBC across agencies; better quantify the numbers of people living with MBC they are serving; understand what services are most often accessed; and expand reach into all communities regardless of socioeconomic status, gender, race, culture or geography.

- Quantitative data on the demographics and numbers of MBC patients accessing programs and services are not consistently collected. As a result, it is not known how patients use the tools, how the programs and services can be optimized, and which patients are not being reached.
- The majority of organizations report that their programs and services are underutilized, surmising that patients don't know about them, do not consider the programs to be suited to their needs, or are seeking information and support in other places.
- Many Alliance members provide high-quality information and support services to MBC patients and their families. However, the information provided requires that patients have relatively high health literacy and be Internet savvy. Organizations must consider how to reach other subgroups of the MBC patient population. Because Alliance members offer so much general information, it is difficult for individual patients to find what they need.
- Persistent gaps in MBC information on members' sites and in print include detailed information on the latest treatments; monitoring of treatment, including for side effects and quality of life; palliation; and advanced directives and end-of-life care. Information on how MBC is diagnosed could be improved, and there is a dearth of information on new drugs in clinical research.
- Alliance member websites do not address MBC facts sufficiently to inform the MBC patient populations or even caregivers and early stage breast cancer patients. More content and community can be created by enhancing current information, using a modern design, and adding tools for social networking.

Stable after participating in a clinical trial

Fran Kamin

I am currently a doctoral student working on my dissertation: *Women with metastatic breast cancer and their perceptions of their journeys.* I am also a single mom with a 15-year old son who started high school this year.

My first diagnosis was in January 2007 with IIIb breast cancer. I was HER2+, ER-, PR- with 8 out of 9 lymph nodes positive. My son was 7 years old and in first grade. I had a lumpectomy, a mastectomy, and 8 rounds of chemo along with 5 ½ weeks of treatment.

The first time I was diagnosed, I did not feel like the breast cancer was going to kill me. I pretty much sailed through treatment (as much as one can!) and I was going along thinking everything was fine.

Then in February 2011, I was diagnosed with metastatic breast cancer, with liver and bone mets. This time I was HER2+,ER+,PR-. I found being diagnosed a second time around a lot more difficult. As soon as my oncologist gave me the diagnosis, I knew it was bad. It was as if my life lost its color. With early stage breast cancer, I was out and about; now I had anxiety about leaving my house.

Very early on, probably my second visit, my doctor told me there was a phase III clinical trial he thought I would be perfect for. When he asked me if I had any interest in participating, I said OK without hesitation! I have a great medical team and I trust my oncologist. I really saw it as an opportunity for me to live.

As part of the trial I was assigned a study nurse. She became my liaison and she treated me like a VIP. She made all of my appointments, and made sure I knew when they were all going to be. She checked up on me and made sure I had my medication. If I needed anything I called her. It was so nice to have that extra assistance, and to have a person alongside me while I went through the treatment. It's almost as if I had a partner - I did not have to go through this alone.

I was in the trial for at least a year and a half. The treatment was a pill; there was no travelling and I could be in the clinical trial in my hometown. The medical team really takes care of you. I had an echocardiogram every 2 months to check that my heart was functioning OK. I also had a CAT scan every 2 months. It was a really positive experience to be assured every 2 months that everything was shrinking and everything was stable. At the end of the trial period, the lesions were completely gone from my chest; one of the lesions on my liver was also completely gone, and the other had shrunk by 70%.

One of the things I found out from being in the trial is that the treatment affects everyone differently and it is important to understand that not everyone is going to have the same side effects. It is important to weigh up the pros and cons, but I think it is always worth giving a clinical trial a shot. There is nothing to lose. When my doctor thanked me for being in the trial and helping patients in the future, it felt pretty good! I am pretty sure being in this trial saved my life. I have been stable since August of 2011.

My first mammogram was also my last mammogram

Katherine O’Brien

I got my first—and last— mammogram in July 2009; I was 43 years old. I chose that date and time because layoffs were imminent at my company, so, although I had no health complaints, I was catching up on overdue appointments. All was going well with my general physical. But then the nurse practitioner felt a hard spot on my breast. She gave me a prescription for a diagnostic mammogram, which is different from a routine screening mammogram. Anyone who is told to get a diagnostic mammogram should most definitely do so!

The day I had my diagnostic mammogram was the day I found out I definitely had breast cancer. “This is NOT a cyst,” the radiologist told me. “You have to see a surgeon.” In preparation for a mastectomy, the surgeon ordered a round of imaging tests (PET/CT [positron-emission tomography–computed tomography], MRI [magnetic resonance imaging], and bone scan). I then learned I had metastatic, or stage IV, breast cancer. My breast cancer had already spread to my spine when it was found.

Because of the characteristics of my breast cancer(ER/PR+ and HER2– [estrogen- and progesterone-receptor positive, HER2 negative], the most common type), I was able to start on the very lowest end of the toxic-drug spectrum. Eventually I will have to have chemo (and again, I will always be in treatment) but hopefully that won’t be soon.

Had I to do things over, I would have been proactive about getting a mammogram at age 40—and possibly sooner if my doctor had recommended it. My mom died of metastatic breast cancer at age 53. I am also of Ashkenazi Jewish descent—people of Eastern European Jewish heritage have an increased risk for breast and ovarian cancers.

Early detection is not a breast cancer cure. Most of the 155,000 people in the US currently living with metastatic breast cancer were originally treated for early stage breast cancer—their cancer came back 5, 10, 15, and even 17 years later—even though they took excellent care of themselves and had regular mammograms. It is very unusual for someone to be like me–diagnosed with metastatic breast cancer from the very start—this only happens 10% of the time.

No one dies from early stage breast cancer—a lump in the breast is not what kills. When cancer spreads beyond the breast—to bone, liver, lung, brain, or some combination thereof, it can no longer be cured. Obviously, it is better to find breast cancer before it can spread. We don’t know which cancers seen on a mammogram would go on to spread and which would never do anything. So everything that is seen on a mammogram must be treated. It would be wrong to say that mammography doesn’t save lives. But, as one prominent oncologist put it, we need to use mammography with caution, explain its limitations, and realize that we need a better test.

Key Findings

Epidemiology of MBC

Better epidemiologic data are needed on the numbers of early breast cancer patients who experience a recurrence and metastasis and on outcomes and length of survival after a metastatic diagnosis. Only modest improvements in survival after a metastatic diagnosis have been observed, and not in all populations.

- Over the past few decades, the duration of survival after metastatic diagnosis has increased modestly—by a matter of months, not years. Hospital-based studies generally report a larger survival benefit than population-based studies.
- The modest increase in survival has been observed mainly in ER+ (estrogen receptor positive/hormone sensitive) MBC and/or HER2+ (human epidermal growth factor receptor 2–positive) MBC and is attributable to the wide use of targeted therapies. No survival benefit has been found in triple-negative MBC.
- The disparity in survival between black women with MBC and non-Hispanic white women with MBC appears to be increasing. It is unclear how much of the observed disparity in outcome is related to access to care and socioeconomic concerns and how much is related to the greater incidence of triple-negative MBC among black women.
- The prevalence and incidence of patients with MBC is unknown. Also unknown is whether the number of relapsed MBC patients is increasing, decreasing, or staying the same. Without this information, we cannot accurately and effectively demonstrate the need for services or plan and fund the application of services.
- Disease trajectories, outcomes, and patient experiences for the different subtypes of MBC have not been well characterized.
- Many critical questions regarding the optimal treatment of MBC remain unresolved. It is imperative that the use, effectiveness, and impact of MBC treatments on the overall MBC population be understood.
- Despite existing research, we have no accurate estimate of how long MBC patients are likely to live. The factors underlying observed variability in median survival across studies are unknown. Among the potential factors are differences in access to newer drugs (especially targeted therapies) and multiple lines of treatment, access to careful follow-up and expert palliative care to preserve optimal quality of life, and the presence of co-morbidities.
- Despite research demonstrating poorer outcomes for disadvantaged, underinsured populations overall, the true impact is unknown of socioeconomic factors on what treatments and care are available for MBC patients and, in turn, how this may affect duration of survival and quality of life.

Data are not collected on how many people experience a recurrence of breast cancer as MBC, as well as the number of people living with the disease.

Today, an estimated 3.1 million women living in the US have a history of breast cancer, but we have no way of knowing how many of these people are actually living with MBC.

My male breast cancer story

William (Bill) Becker

My initial diagnosis of stage III male breast cancer was in May, 2011. In June I had surgery, a full mastectomy of my left pectoral. Chemotherapy followed at the end of July and ran in 2 phases which ended in December of 2011. I was a hot mess at the end of it, very tired, and I just couldn't take much more. However, therapy wasn't finished; my oncologist asked me to see a radiologist about bettering my chances of survivorship with radiation therapy. Unwillingly, I continued on with radiation into February of 2012—the worst sunburn of my life is the best way to describe my radiation burns, even after applying all the ointments they recommended. I was prescribed tamoxifen to help combat the cancer.

The fact that I'm a man plays into the possibilities of not being able to handle the side effects of tamoxifen. In reality, it was more like everyone around me not being able to tolerate me because of the side effects. My normal, easy, outgoing self turned into a raging lunatic with a very short fuse—to the point that I was wrecking my home life and stirring up a hornet's nest at work. Shortly after being taken off the tamoxifen, I began to feel some pain in my hip. It was time for a bone scan to get an idea of what might be going on.

Suspicious spots were found on my hip and lower spine, and a biopsy revealed my new, stage IV metastatic breast cancer. We spent the spring of 2013 attacking the new spots with more radiation and hormone therapy. More bone scans showed that the spots were not sitting still and we needed to go back to chemotherapy—not to mention that the spot on my hip now had a fracture. The summer brought on new chemotherapy that included a stay at the hospital for acute congestive heart failure. Bone scans in early autumn found new spots and more movement of the original ones. We weren't getting very far with stopping the cancer. A trip to Memorial Sloan Kettering Cancer Center for a biopsy and a better understanding of the now-spread cancer gave us a new direction for treatment. The new chemotherapy and some radiation to combat some pain were on my plate all through the winter of 2013–2014. This has continued through spring and summer, with more radiation and new chemotherapy to combat the still-moving cancer. This battle of mine with breast cancer continues....

So what have I done with the cards I've been dealt? Surrounded myself with amazing people. My family has not wavered in their support of me. I've received excellent medical treatment and have been given tremendous support from other male breast cancer survivors.

I have created a foundation - *Breastcancerbrothers.org* -to raise awareness of male breast cancer and funding for research for men like me and them. The treatment of male breast cancer is based on knowledge of treatment for women. Although our tissue is very similar, men are a little different in how we are able to tolerate some of the treatments.

We need to keep more men alive by raising awareness and funding research, because **men get breast cancer too!**

Postscript: Bill Becker offered his story for this publication in August 2014. Sadly Bill died from male metastatic breast cancer on September 17, 2014. He was 46 years old. He donated his body to Harvard Medical School so they can research male breast cancer and save others.

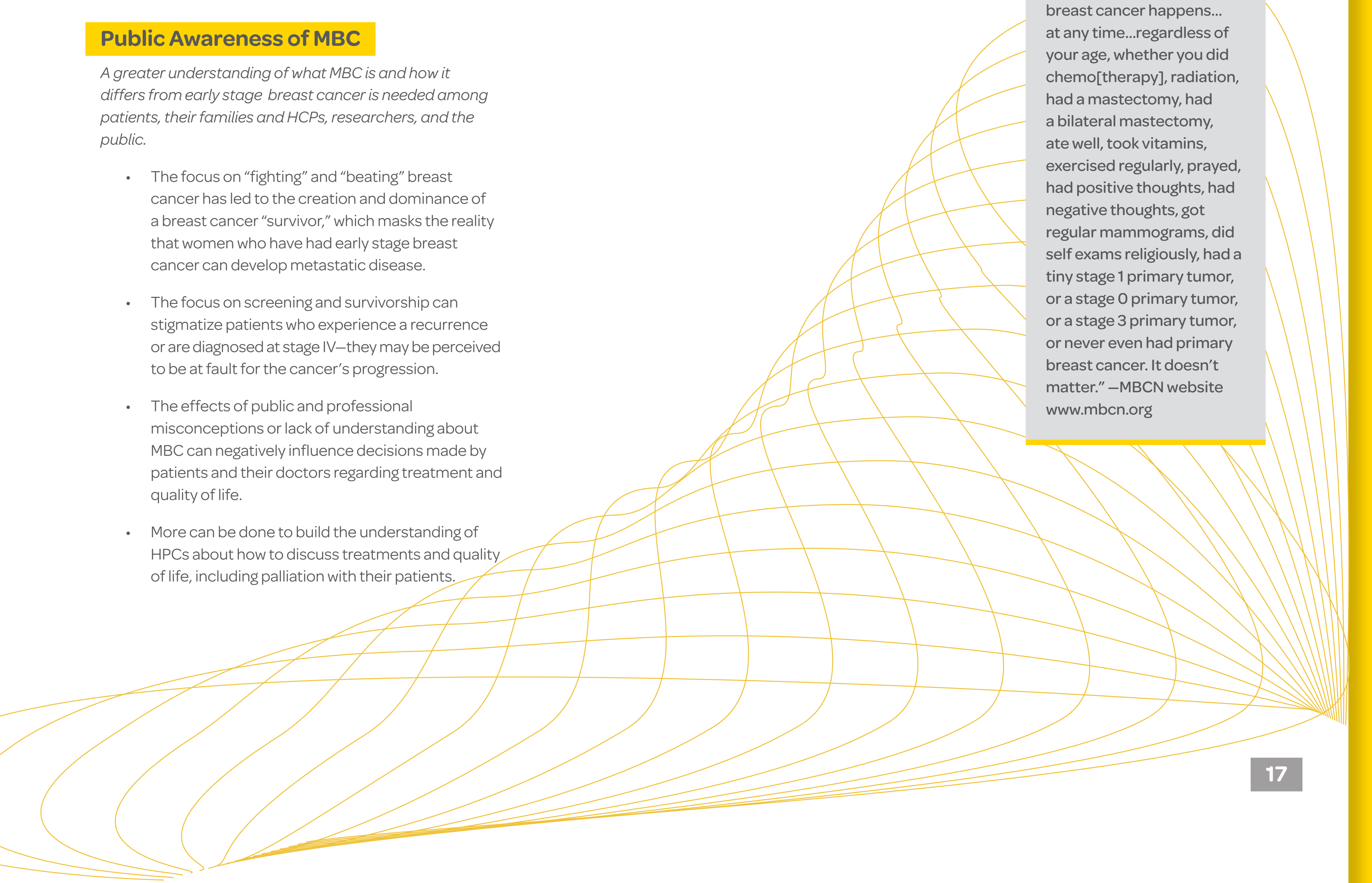
Key Findings

Public Awareness of MBC

A greater understanding of what MBC is and how it differs from early stage breast cancer is needed among patients, their families and HCPs, researchers, and the public.

- The focus on “fighting” and “beating” breast cancer has led to the creation and dominance of a breast cancer “survivor,” which masks the reality that women who have had early stage breast cancer can develop metastatic disease.
- The focus on screening and survivorship can stigmatize patients who experience a recurrence or are diagnosed at stage IV—they may be perceived to be at fault for the cancer’s progression.
- The effects of public and professional misconceptions or lack of understanding about MBC can negatively influence decisions made by patients and their doctors regarding treatment and quality of life.
- More can be done to build the understanding of HPCs about how to discuss treatments and quality of life, including palliation with their patients.

> “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



A stronger voice

Khadijah

I didn't realize how strong my voice really was until I was diagnosed with breast cancer in 2003. I was 28 years old, with lots of dreams to fulfill, and my daughter was a spirited 6-year-old. It felt unfair to have to deal with such a devastating illness at a young age. When I explained to her that I was going to have to take medicine that would make me lose my hair, a single tear fell from her large almond-shaped eyes. This ignited my fire to fight with everything that I had so I could be around to raise her.

After I had a mastectomy and endured chemotherapy for several months, I was deemed "cancer free." I wanted to help other survivors along their journey, so I started working with the Young Survival Coalition as their program manager. In this role, I traveled to various events and conferences to educate the public and the health care community about young women with breast cancer. I also shared my story with various media outlets. In 2007, I recorded an inspirational CD, *This Day*, and gave it away to other survivors to encourage them to stay positive despite the adversity they faced.

I continued living my "new normal" life until I developed a persistent cough in 2010. To my dismay, a chest x-ray showed a blood clot and multiple tumors in my lungs; a biopsy confirmed that the cancer had returned. Unlike when I was first diagnosed and cried profusely, I didn't this time. The doctor tried to gently explain what metastatic breast cancer meant, but I said that I understood: my disease was incurable. I needed to take control of something because my stomach was swirling around and I was wondering how I was going to relay this information to my loved ones. This time around, my daughter was 13, so she understood more about what cancer could mean. When I told her the news, she gave me a hug and said sweetly, "Mom, you beat it before; you'll do it again." My heart wept.

Yet, my faith abounded. I had relied heavily on prayer and reading the Bible during my first diagnosis. I knew that my spirituality would have to anchor me once again because I was literally fighting for my life this time. My doctor recommended that I take oral chemotherapy, which worked for over a year to relieve my symptoms and minimized the coughing. In 2012, my airway was cleared with radiation and with the new chemotherapy regimen that I'm on, and my tumors continue to shrink; so we treat this as a chronic illness. I even had the audacity to get my graduate degree in journalism from Columbia University in 2013 because my dreams are still relevant and attainable.

I have my days when I just get tired of dealing with cancer, but I keep moving forward because it's not over until I stop singing and I don't plan to do that any time soon.

Analysis to Action

This landscape analysis has provided the Alliance with a foundation of shared knowledge of the MBC landscape and pointed us to some critical gaps/needs to be addressed. Collectively, we are now better informed about the areas of scientific research for further exploration, the need to accelerate improvement in quality of life, the gaps in information and support services that require resources, and the current state and limitations of epidemiology of MBC.

One of the forces that drove breast cancer and MBC advocate organizations to join in an Alliance was the need to build understanding about the different types of MBC and how it differs from early stage breast cancer, not just for people living with the disease and their HCPs, but also researchers, policy makers, and the general public.

In moving forward, MBC Alliance members agree that pivotal to resolving gaps/needs is an effort to build greater understanding in all our future endeavors.

The power of the Alliance lies in our collective experience, resources, and spheres of influence. Guiding our approach to future work is a commitment to not duplicate efforts of individual organizations in the Alliance, and collaboration to ensure we learn from each other's experience and research. As our work is resource intensive and time consuming, we will be thoughtful in committing our assets and will develop an evaluation framework as part of our planning for 2015–2016.

We have identified a series of actions for our next phase of work over 2015 and 2016. These actions 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.

MISSION

Unify the efforts of 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 cure.

GOALS + ACTIONS

1

2

3

ADVANCE RESEARCH

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 endpoints.

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

IMPROVE KNOWLEDGE + ACCESS

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

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 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

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

AdvancedBC.org

Cancer Action Network American Cancer Society

AVON Foundation for Women

BREASTCANCER.ORG
REAL. ANSWERS.

BCRF BREAST CANCER RESEARCH FOUNDATION

BreastCancerTrials.org
find a trial that's right for you

CANCERcare®

CANCER SUPPORT COMMUNITY
A Global Network of Education and Hope

Celgene

Dr. Susan Love
RESEARCH FOUNDATION

Eisai

Lilly | ONCOLOGY

FORCE
Facing Our Risk of Cancer
EMPOWERED

Genentech

INFLAMMATORY BREAST CANCER
Research Foundation

LIVING BEYOND BREAST CANCER
LBBC.ORG

mbcn METASTATIC BREAST CANCER NETWORK
EDUCATING • EMPOWERING • ADVOCATING

Eli Lilly
Inflammatory Breast Cancer Research Foundation

Breastcancer.org
Living Beyond Breast Cancer

Celgene Corporation
Eisai
Novartis Oncology
Sharsheret
Triple Negative Breast Cancer Foundation

ACS CAN
Cancer Support Community
Nueva Vida

AdvancedBC.org
Avon Foundation for Women
Breast Cancer Research Foundation
Cancer*Care*
Metastatic Breast Cancer Network
Pfizer
SHARE
Young Survival Coalition

Patient Advocate Foundation

Sisters® Network Inc.

FORCE

NOVARTIS
ONCOLOGY

NUEVA VIDA

PAF Patient Advocate Foundation

Pfizer

Research Advocacy Network
Advancing Patient-Focused Research

SHARE
Dedicated, experienced support for women facing breast and ovarian cancers

SHARSHERET

Sisters

susan G. komen.

TRIPLE NEGATIVE BREAST CANCER FOUNDATION
The Breast Cancer Breakthrough Foundation

TripleStep

YSC YOUNG SURVIVAL COALITION®
Young women facing breast cancer together.

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

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

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

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 Cancer*Care*, Dr. Susan Love Research Foundation, Sisters Network Inc., Eisai and Novartis Oncology

Nov 2013

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

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

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

Oct 2014

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

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3. Mayer, M. and S.E. Grober, *Silent Voices: Women with Advanced (Metastatic) Breast Cancer Share Their Needs and Preferences for Information, Support, and Practical Resources*. 2006: Living Beyond Breast Cancer website.

Metastatic Breast Cancer
MBCalliance

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

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