IMPACT THROUGH
COLLABORATION

Metastatic Breast Cancer
MBCalliance

LISTENING
LEARNING
LEADING

2024 PROGRESS REPORT

DEAR FRIENDS,

Your support this year has been essential to keep our mission moving forward, as we continue to work as the largest coalition in the U.S. to improve outcomes for people living with metastatic breast cancer.

In 2024, the Metastatic Breast Cancer Alliance embarked on a journey of **listening, learning, and leading.** Over the summer, we conducted thoughtful listening sessions with all stakeholder groups that gave our collaborative leadership team valuable insights into the needs and aspirations of our community.

These conversations enabled us to **learn** from the perspectives of patient advocates, nonprofits and industry leaders about how we can transform the way we work together to better include all voices, and ensure we achieve the priorities and direction set out in the Alliance's strategic plan.

Inspired by the possibilities of what we can do together, we are determined to collectively **lead** the way toward a future where metastatic breast cancer is no longer a threat. By harnessing the power of our diverse voices, resources, and knowledge, we believe we can make a difference for thousands of people navigating this disease.

We are grateful to the support of members that empower our ongoing strategic initiatives and propel our work forward. We invite you to explore this annual report to learn more about our achievements this year, and see how our shared resources are put to work for the MBC community.

In partnership,

Beth Burnett,
Chair, MBC Alliance

Laurie Campbell
Executive Director

2024 YEAR IN REVIEW

ENGAGING OUR COMMUNITY

91 **Alliance Members**

37 Individual Patient/Advocates: +5
13 Pharma/Industry: +1
41 Nonprofits: +3

4 **All Member Meetings**
Organized

2 **In-person**
2 **Virtual**

8 **Active Working Groups**

Engaging **67 Members** and **5 Consultants**

19 Listening Sessions and
3 Leadership Retreats Hosted
Engaging **88 Members**

EXPANDING OUR REACH

$22,500 **Awarded in Travel Scholarships**
to support Patient Advocates Attendance at Conferences

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19 **Blog Posts Published**

36K Website Visits For an Audience of
+18K Website Visitors

NEW! Quarterly Member E-Newsletter
Launched in January 2024

+74% Monthly Website Users
+67% LinkedIn Channel Followers
+10% Overall Digital Reach

Website: Average monthly users: 3,000, +74% YoY
Average monthly pageviews is flat YoY, meaning we have more users coming and reading the same number of pages.

Followers	**Digital Reach**
Facebook: 9,602 followers, +2% YoY	2024: 17,923 (+10% from 2023)
Twitter / X: 4,976 followers, +3% YoY	2023: 16,248 (+5% from 2022)
LinkedIn: 344 followers, +67% YoY	2022: 15,459

EXCHANGING KNOWLEDGE

4 **Webinars Hosted with a Focus On:**

—Palliative Care
—Access to Care for Black Patients With MBC
—Patient Navigation

Policy Landscape Initiative of MBCA Members

22 **One-on-one Interviews**

54 **Desktop research on organizations**

ADVANCING RESEARCH

9 **Speakers Hosted**
by BCBM WORKING Group and Quarterly Update Meetings Hosted for Nonprofit & Industry

Key Sponsor
of the 2024 ABTA/MBTC Brain Mets Survey Initiative and partnered with ACCC to share best practices for HR+, HER- MBC

HOW WE WORK

As a coalition we continue our work to amplify our collective efforts through collaboration and innovation to improve the lives of people living with metastatic breast cancer. Our main initiatives, which ladder up to four areas of strategic focus, are planned and carried out by Working Groups.

OUR STRATEGIC FOCUS AREAS

Research	Clinical Trials	Standard of Care	Quality of Life
Advocate to prioritize critical **research** to improve outcomes for all MBC patients.	Advocate that **clinical trials become more patient-centric** by implementing patient-driven designs and procedures, removing barriers to participation, ensuring equity and diversity in recruitment, and supporting Alliance member clinical trial initiatives and materials.	Ensure that all patients—regardless of race, ethnicity, age, gender, geographical location, sexual orientation, education level or ability to pay—have **equitable access to quality standard of care** including an appropriate clinical trial.	Integrate **quality of life** services and care (i.e., palliative care, financial toxicity, shared decision making) into all treatment planning from initial diagnosis.

OUR 2024 WORKING GROUPS

Advocacy Slide Deck Refresh

Breast Cancer Brain Metastasis

Dandelion Project

Insider's Guide to MBC

Policy Steering

Research Grants

Speaker Series

NEW TO THE ALLIANCE

We welcomed the following members to the MBC Alliance in 2024.

Individual Advocate Members
Jamie Carroll
Jo Lynn Collins
Melanie Sisk
Jill Tirabassi

Industry Member
Arvinas

Nonprofit Members
LYTE Foundation
Sisters Network®, Inc.
SurvivingBreastCancer.org

LISTENING & LEARNING

In 2024, we worked to refine the culture of the MBC Alliance by developing a **"Who We Are, Who We Are Not"** statement. This guided our leadership team in listening, learning and refining our organizational framework for working effectively as a diverse and democratic coalition.

› ***Learn more: MBCAlliance.org/Culture***

Transforming Our Work to Reflect All Member Voices

This summer, our leadership team engaged in stakeholder listening sessions facilitated by Executive Coach Ife Lenard. We heard candid feedback from nonprofit, individual advocates and industry members on what's going well; and how we can better support the MBC community and one another as a coalition of allies working together to drive impactful change.

Then, the Alliance hosted a three-day leadership retreat to engage in collaborative work focused on themes that emerged from the listening sessions. Through collective brainstorming, actions were identified to evolve our organizational framework and processes for working effectively as a diverse and democratic coalition. These included expanding our Senior Leadership Team and reallocating our Executive Group structure to increase patient participation; and adding a Membership & Finance Committee. The Alliance's mission statement was also revised to reflect the focus on increased patient participation at every level of decision making.

› ***Learn more: MBCAlliance.org/Transform***

Bringing Members Together to Learn & Share

This year, the Alliance held four all-member meetings that offered opportunities to learn from experts about new developments in the field of metastatic breast cancer; explore new programs and activities for members; and get updates on collaborative work.

Our virtual meetings in February and November featured keynotes on how research on tumor dormancy could help prevent breast cancer brain metastases; and the state of Black breast cancer research, including work in translational genomic medicine. At our in-person meeting at ASCO in June, we shared survey findings on members' policy priorities and a structure that could be used to amplify their advocacy efforts. And at our in-person meeting at SABCS in December, we met for a Year in Review, celebrated our efforts and successes, and hosted an interactive session around Allyship which reinforced key member programs that support the MBC community.

› ***Meet our members: MBCAlliance.org/Members***

PROGRESS TOWARDS STRATEGIC GOALS

The Alliance pursued a number of initiatives in 2024 laddering up to our four strategic goals, advancing our mission to transform and improve the lives of people living with metastatic breast cancer.

ICON KEY

RESEARCH
CLINICAL TRIALS
STANDARD OF CARE
QUALITY OF LIFE

MAKING ADVANCES FOR BREAST CANCER BRAIN METASTASIS

RESEARCH

As part of The Marina Kaplan Project, our Breast Cancer Brain Metastasis Working Group is focused on identifying and addressing research and care gaps for people living with CNS metastasis or leptomeningeal disease from breast cancer. The Working Group hosts a speaker series where researchers and clinicians present their work directly to patient advocates, and receive feedback. The Working Group also shares its progress with pharma members at quarterly update meetings, and continues to build out the **MBCBrainMets.org** site as a one-stop resource hub.

Additionally, the Alliance is a key partner for a survey initiative led by the ABTA Metastatic Brain Tumor Collaborative (MBTC). Targeted to launch in 2025, surveys for brain mets patients, caregivers, and physicians aim to leverage the collective power of all partners working together to gather data that can help improve prognoses, treatments, and disease/symptom management.

› *Learn more: MBCAlliance.org/BCBM*

ANALYZING RESEARCH GRANTS & NEEDS

RESEARCH

In 2023, we unveiled a database and query tool developed with the International Cancer Research Partnership, the Health Research Alliance and the Canadian Cancer Research Alliance that allows for analysis of metastatic breast cancer research grants. This tool serves as a starting point to analyze ongoing funding and identify gaps, with a focus on research areas that are a high priority for people living with MBC.

This year, the Research Grants Analysis Working Group focused on updating the database with data from BCTrials.org, and querying the research funding status for two top patient priorities. These were to 1) define subsets of MBC and appropriate treatments for these subsets, and 2) identify better treatments for brain metastases and central nervous system metastases. The Alliance plans to submit the results to be shared with the wider MBC community at a future scientific meeting.

› *Explore the background: MBCAlliance.org/RFA23*

AMPLIFYING PATIENT-FOCUSED RESOURCES

In March, the Alliance hosted a webinar sharing study results from Susan G. Komen on the navigational needs of people living with MBC, and assessing gaps in the organization's patient navigation training. We also shared the launch of Komen's new course, housed within the Navigation Nation portal, that connects navigators to a supportive community for self-care and ongoing learning. With navigation services reimbursable through Medicare and Medicaid as of January 1, this is a timely resource.

Additionally, the Alliance is collaborating with the Association of Cancer Care Centers™ to provide feedback and help disseminate a co-branded series of three educational videos and a digital publication highlighting best practices in evidence-based treatment strategies, management of toxicities, and optimizing quality of life for patients with HR+, HER- metastatic breast cancer, which account for about 70% of breast cancers. The first two videos were launched in Q4.

› ***Learn more: MBCAlliance.org/Nav24***

UPDATE OF THE INSIDER'S GUIDE TO MBC

A Working Group made up of patient advocates, a science writer, and Alliance leadership is updating ***The Insider's Guide to Metastatic Breast Cancer,*** a book written by patient advocate Anne Loeser, who passed away in 2023. This effort continues Anne's meticulous work of staying abreast of what's new in the MBC landscape and regularly updating this publication to include approved therapies, scientific studies, clinical trials, and management of symptoms and side effects.

In its next edition, this valued and unique resource for those navigating an MBC diagnosis will incorporate science and research presented at SABCS in December 2023, and at ASCO 2024. A final review of the updates will be done by medical oncologist Mark Burkhard, MD, PhD, director of Holden Comprehensive Cancer Center at the University of Iowa. A digital download of *The Insider's Guide* can be accessed through the Alliance website, and can also be purchased from Amazon as an e-book or hard copy.

› ***Learn more: InsidersGuideMBC.com***

ADVOCACY SLIDE DECKS UPDATED

The Alliance offers a series of four slide decks that are freely available on our website for download in both PDF and PowerPoint formats. These can be used by advocates who have been asked to present at events to increase understanding of metastatic breast cancer, knowledge of treatments, and challenges faced by caregivers and people living with the disease. Each deck comes with a “cheat sheet” showing sources and additional details for selected slides. A training video and transcript are also available to show advocates how to use the slide decks to prepare their own presentations.

A team of five patient advocates are reviewing these resources, first released in fall 2022, to ensure all information is current and relevant. As the landscape of diagnosis, treatment, research and legislative action continues to evolve, this effort is key to effectively empower patients and caregivers and to draw attention to challenges that may otherwise receive little attention in public discourse.

› ***Learn more: MBCAlliance.org/AdvocateDecks***

DANDELION TOOLKIT LAUNCHED

Targeted to roll out in early 2025, the Dandelion Toolkit is a new resource designed to empower those newly diagnosed with MBC to more easily understand their unique diagnosis and treatment options; and to communicate more effectively with their healthcare team and family. Developed in partnership with patients, oncologists, nurse navigators and caregivers, the toolkit uses the visual metaphor of a dandelion to explain staging, pathology, subtype, and treatment options.

Packaged in a beautifully designed box, each toolkit contains a conversation card to be filled out with a healthcare team; a navigation notebook to guide personal learning at home, and future discussions with providers; and a colorful sticker affirming “You Can Do This.” Free toolkits will be available in 2025 through the Alliance website for those who have been diagnosed with MBC, and their caregivers, on a first come, first served basis. Bulk orders are also available to our nonprofit members for distribution.

› ***Learn more: MBCAlliance.org/Dandelion***

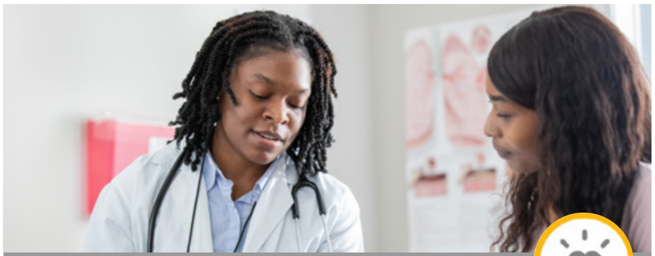
PALLIATIVE CARE SPEAKER SERIES

QUALITY OF LIFE

In 2024, the Alliance hosted a speaker series entitled “Changing the Conversation on Palliative Care.” Featuring guest speakers who are leaders in their fields, this webinar series aimed to make Palliative Care a more approachable topic – one that is not automatically equated with hospice. Each conversation was co-facilitated by a nonprofit member of the Alliance, and a person living with MBC.

Recordings of each event in the series are available for viewing in our speaker series library, following a narrative arc that starts with the definition of palliative care and continues on to share tips for effective communication with loved ones and providers about symptom management and palliative care. Our most recent event, co-hosted with our Black Wo(Men) Speak project team, explored ways to break down barriers to access and address pain management through palliative care.

› ***Learn more: MBCAlliance.org/Speaker-Series***



“DO’S & DON’TS” COMMUNICATION WORKSHOP

QUALITY OF LIFE

The MBC Alliance partnered with the international nonprofit ABC Global Alliance to co-host “The Do’s & Don’ts of Communication on Advanced / Metastatic Breast Cancer,” a workshop held in conjunction with the San Antonio Breast Cancer Symposium. Attended by more than 250 people, this in-person event aimed to help healthcare providers, researchers, industry and nonprofit representatives, patients and advocates from around the world effectively convey complex information, manage emotions, and facilitate open dialogue to help all involved better navigate decisions around treatment, clinical trials and end-of-life care.

Attendees heard from a patient advocate living with MBC and healthcare providers with expertise in patient-provider communication around diagnosis, progression, and clinical trials, who shared tips for effective and compassionate communication. Attendees also participated in an interactive table discussion moderated by healthcare professionals and patient advocates living with MBC.

› ***Learn more: MBCAlliance.org/Communication***

AMPLIFYING ADVOCATE VOICES

The Alliance worked on initiatives this year to explore possibilities for working together to influence policy, and to help ensure that patient voices are considered in research and drug development.

POLICY LANDSCAPE ANALYSIS

Early in 2024, the Alliance embarked on a project to uncover member perspectives on how it could best support members' MBC policy priorities. Cullari Communications was engaged to conduct 22 personal interviews with individual, nonprofit and industry members; and complete a policy mapping of 42 members. Collected data was presented at the Alliance's semi-annual meeting in June, with 82% of interviewees feeling that the Alliance should play an important role in helping its members amplify existing policy efforts.

This work showed that members enthusiastically support the concept of raising their collective voices around policy-related efforts that advance treatment innovation, remove barriers to care, and improve quality of life. While the Alliance will not conduct its own policy initiatives, a collaborative working group has been formed to propose a roadmap for how the Alliance can support the dynamic policy activities of its members. Next steps to be undertaken by this group were shared at the Alliance's semi-annual meeting in December.

› ***Learn more: MBCAlliance.org/Policy24***

PATIENT ADVOCATE CONFERENCE SCHOLARSHIP PROGRAM (PACS)

In February, the Alliance launched a pilot Patient Advocate Conference Scholarships (PACS) Program, which reimburses patient advocates up to $1,500 in expenses to attend a scientific or MBC-related conference where they can learn, network, and share feedback and lived experiences. Fifteen scholarships were awarded this year to individual advocate members, with priority given to actively engaged applicants with diverse identities and life experiences who have never attended a conference; and/or who have a personal connection to the focus of an event, including a specific subtype of MBC.

This program supports the essential goal of ensuring the MBC patient advocate voice is present at key conferences – connecting pharmaceutical companies with patients willing to collaborate, and enabling researchers to hear real world experiences from people enduring lines of treatment. It also empowers advocates to learn about new science, and connect with colleagues to grow their network and impact.

› ***Learn more: MBCAlliance.org/PACS24***

OUR TEAM

By working as a dynamic collective, we are making greater progress together to improve the lives of people living with MBC.

EXECUTIVE GROUP

SENIOR LEADERSHIP

Beth Burnett, *Independent Advocate, Chair*
Margaret Flowers, *Breast Cancer Research Foundation, Vice Chair*
Christine Benjamin, *SHARE Cancer Support, Past Chair*
Shirley Mertz, *MBC Network, Chair Emerita*

WORKING GROUP LEADS

RESEARCH WORKING GROUP:
Christine Verini, *CancerCare*

CLINICAL CARE WORKING GROUP:
Stephanie Walker, *Independent Advocate*
Sue Weldon, *Unite for HER*

INDUSTRY REPRESENTATIVES

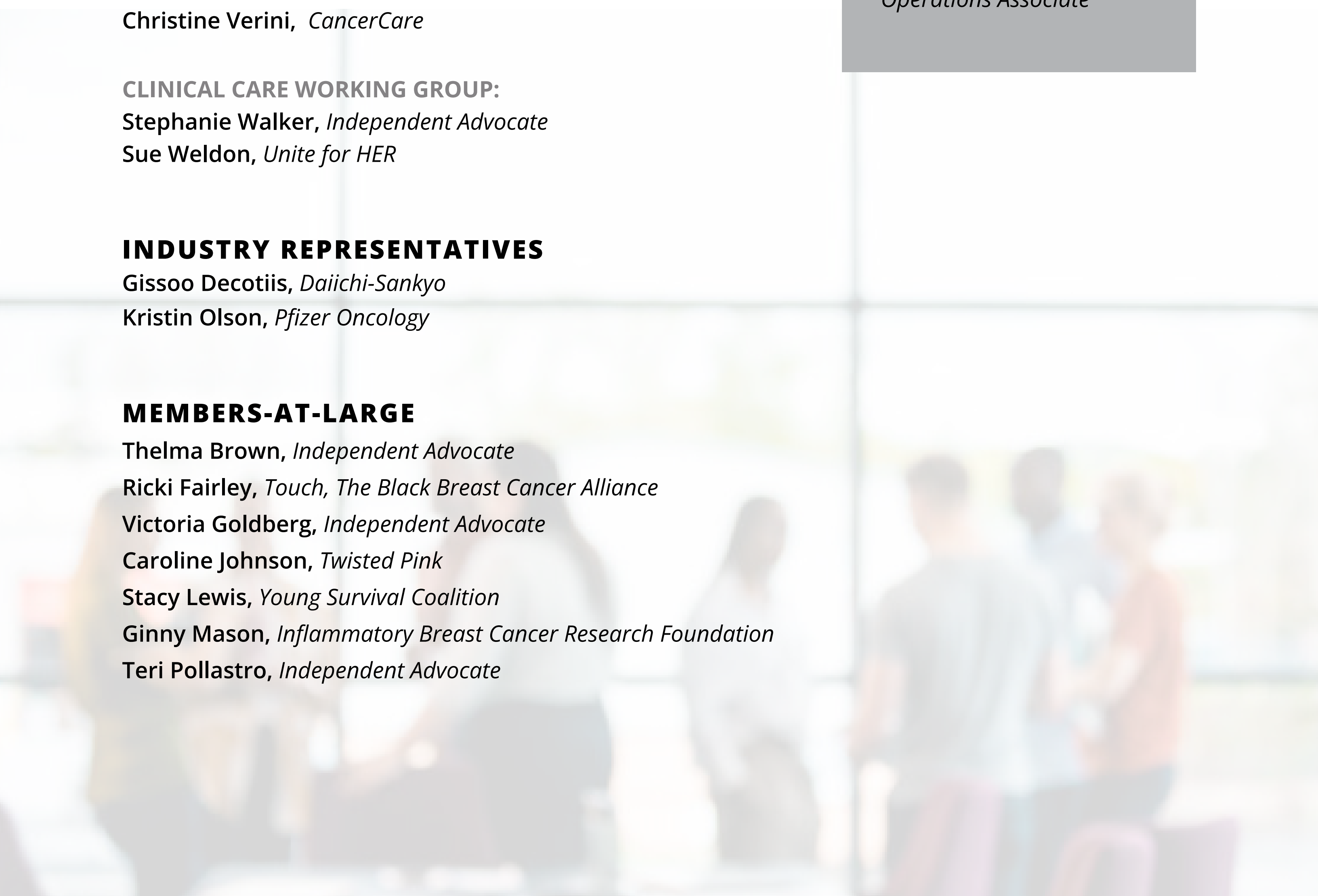
Gissoo Decotiis, *Daiichi-Sankyo*
Kristin Olson, *Pfizer Oncology*

MEMBERS-AT-LARGE

Thelma Brown, *Independent Advocate*
Ricki Fairley, *Touch, The Black Breast Cancer Alliance*
Victoria Goldberg, *Independent Advocate*
Caroline Johnson, *Twisted Pink*
Stacy Lewis, *Young Survival Coalition*
Ginny Mason, *Inflammatory Breast Cancer Research Foundation*
Teri Pollastro, *Independent Advocate*

ALLIANCE STAFF

Laurie Campbell, *Executive Director*
Medha Deoras-Sutliff, *Project Management Consultant*
Jennifer Stanley, *Project Operations Associate*



OUR MEMBERS

We are grateful to our members for their shared commitment to transforming the lives of people living with MBC, and for investing in the Alliance's work of leading collaborative action.

PATIENT / ADVOCATE MEMBERS


ROBERTA ALBANY


ADIBA BARNEY


AMY BEUMER


BARBARA BIGELOW


THELMA BROWN


BETH BURNETT


MARTHA CARLSON


JAMIE CARROLL


ELISSA CHANDLER


JO LYNN COLLINS


DEBORAH COLLYAR


JANICE COWDEN


KATIE EDICK


DANIELLE FILE


LIZ FRANK


SHEILA GODREAU


VICTORIA GOLDBERG


CHRISTINE HODGDON


LINDA HOLDEN


ANDREA HUTTON


ABIGAIL JOHNSTON


LIANNE KRAEMER


ELLEN LANDSBERGER


Joan Mancuso


JULIA MAUÉS


JANIE METSKER


ALLEN PANNELL


JANE PERLMUTTER


SHEILA PETTIFORD


TERI POLLASTRO


NANCY LEVITAN POORVU


KELLY SHANAHAN


MELANIE SISK


JASMINE DIONNE SOUERS


Jill Tirabassi


STEPHANIE WALKER


LYNDA WEATHERBY

NONPROFIT MEMBERS

ABCD: After Breast Cancer Diagnosis

American Cancer Society Cancer Action Network

Angelmira's Center for Women with Advanced Cancer

Breast Cancer Research Foundation

FOUNDING MEMBER

Breastcancer.org

FOUNDING MEMBER

BreastCancerTrials.org

Cancer Support Community

CancerCare

FOUNDING MEMBER

Chrysalis Initiative

FORCE: Facing Our Risk of Cancer Empowered

FOUNDING MEMBER

Hope Scarves

Infinite Strength

Inflammatory Breast Cancer Research Foundation

Know Your Lemons Foundation

Leslie's Week

Living Beyond Breast Cancer

FOUNDING MEMBER

Lobular Breast Cancer Alliance

LYTE Foundation, Inc.

Male Breast Cancer Global Alliance

Metastatic Breast Cancer Network

FOUNDING MEMBER

METAvivor Research and Support, Inc.

National Coalition for Cancer Survivorship

Nueva Vida

Patient Advocate Foundation

Pink Fund

Research Advocacy Network

FOUNDING MEMBER

SHARE Cancer Support

FOUNDING MEMBER

Sharsheret

Sisters Network Inc.

SurvivingBreastCancer.org

Susan G. Komen

FOUNDING MEMBER

Side-Out Foundation

Theresa's Research Foundation

Tigerlily Foundation

TOUCH, The Black Breast Cancer Alliance

Touch4Life

Triage Cancer

Triple Negative Breast Cancer Foundation

FOUNDING MEMBER

Twisted Pink

Unite for HER

Young Survival Coalition

FOUNDING MEMBER

INDUSTRY MEMBERS

PREMIERE PLUS MEMBER

Pfizer Oncology

PREMIERE MEMBERS

AstraZeneca

Daiichi-Sankyo

GILEAD

Lilly | ONCOLOGY

NOVARTIS

SUSTAINING MEMBERS

Genentech
A Member of the Roche Group

MENARINI group Stemline
A Menarini Group Company

MERCK
INVENTING FOR LIFE

SUPPORTING MEMBERS

ARVINAS

Eisai

MACROGENICS

Sermonix Pharmaceuticals

TOGETHER
WE ARE
STRONGER

ABOUT **THE METASTATIC BREAST CANCER ALLIANCE**

As a collective of cancer nonprofits, pharmaceutical and biotech industry members and individual patient advocates, the Alliance serves as a national leader in collaborative action to transform and improve the lives of people living with metastatic breast cancer. We leverage the resources and knowledge of our dynamic group of trusted experts to increase awareness and education about the disease, and advocate for policy changes and increased funding for research that holds the potential to extend and enhance life – and ultimately end MBC.

› **MBCAlliance.org**

Metastatic Breast Cancer
MBCalliance

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