



In October 2013, the Metastatic Breast Cancer Alliance was founded by fifteen nonprofit organizations and three pharmaceutical/biotech members. In less than a decade, the Alliance has grown into the largest coalition in the U.S. dedicated to working collaboratively to improve outcomes for patients living with metastatic breast cancer.

Today, we are honored to serve as an amplifying force for a robust membership that includes thirty-three nonprofit organizations, twelve pharmaceutical/biotech members, and twenty-eight individual patient/advocate members. This year alone, we were delighted to expand the breadth of our membership

by welcoming six new members: **Stemline Therapeutics/Menarini Group, the Male Breast Cancer Global Alliance, and patient advocates Janice Cowden, Gwen Manchion, Danielle File and Ellen Landsberger.**

An important part of our organizational growth and momentum can be attributed to the guidance and support of our industry members. In 2022, thanks to your support, the Alliance was able to successfully pursue a number of initiatives that improve the lives of people with metastatic breast cancer. The initiatives included in this annual Progress Report were designed, planned, and implemented by the Alliance's various Task Forces, and reflect our four strategic goals.

We hope you will be inspired, as we are, by the progress made possible when a group of passionate and skilled people come together around a shared vision. As we look to the future, we are honored to serve as your partner in leveraging our collective talents and resources to make a greater impact.

PROGRESS >>

TOWARD STRATEGIC GOALS

As an Alliance, our common mission is to extend life, enhance quality of life, and end suffering and death from MBC. Throughout the year, our task forces worked to realize this mission through initiatives that ladder up to four strategic goals.

STRATEGIC GOAL I

RESEARCH

Advocate to prioritize critical research to improve outcomes for all MBC patients.

RESEARCH TASK FORCE INITIATIVE



Thought Leader Update to Landscape Analysis

In April 2022, the Alliance released a Thought Leader Update to our prior 2014 landscape analysis report. To inform this effort,

the Alliance interviewed 20 thought leaders in the MBC community to develop a survey that was sent out to a larger pool of participants. With 119 responses gathered across the academic, research, industry, government and nonprofit sectors, the resulting data offers a snapshot of recent progress and future directions for MBC research, as well as key areas of need related to clinical trials.

In Summer 2022, the Alliance conducted a focus group of stakeholders to get their feedback on priorities that have informed the Alliance's strategic planning, based on findings gathered in the Thought Leader Update. These recommendations will be included in the forthcoming MBCA Priority Statement paper.

> Learn more: MBCAlliance.org/ThoughtLeader22

RESEARCH TASK FORCE INITIATIVE

MBC Alliance Priority Statement Paper

Drawing on findings gathered through the Thought Leader Update, the Alliance has developed a priority statement paper that will

be finalized and presented to membership in early 2023. Key priorities identified in the paper include accelerating clinical trial innovations, increasing clinical trial enrollment of people who have been historically excluded from MBC treatment trials, educating people living with MBC and healthcare providers about innovative and emerging testing options to inform personalized treatments, addressing financial toxicity in all aspects of living with MBC, providing timely access to expanded use of investigational medications, accelerating research in key areas, and enhancing education and communication between patients and healthcare providers.



> Stay tuned to learn more: MBCAlliance.org/News

RESEARCH TASK FORCE INITIATIVE

Research Funding Analysis Tool & Update to Landscape Report

In collaboration with ICRP (International Cancer Research Partnership) and the CCRA (Canadian Cancer Research Alliance), the Alliance continued work this year on development of a software tool that identifies metastatic grants and houses them in a database that supports search and analysis by categories such as metastatic stage, subtype and sites of metastasis.

The tool can be used to follow progress in research and trends over time; and to provide evidence-based data to support continued investment in MBC research and identify collaboration opportunities between Alliance members, constituents and donors. Data gathered through this project will also inform an MBC Research Funding Update to the Alliance's 2014 Landscape Analysis Report, which is expected to be released in 2023.

› Learn more: MBCAlliance.org/ResearchFunding22



RESEARCH TASK FORCE INITIATIVE

Alliance Expands Resources and Foster Relationships

The Alliance is committed to thought leadership in the field of patient-focused MBC

research, with the goal of influencing progress for the community we serve. One significant example is in the area of breast cancer brain metastasis. The BCBM (Breast Cancer Brain Metastasis) subcommittee met biweekly in 2022 to identify and address gaps in BCBM research. The subcommittee is also holding regular meetings with top researchers in the field to expand resources and foster relationships. They recently joined a collaborative effort led by the American Brain Tumor Association that brings together nonprofits working in this area, across multiple cancer types, to share learnings and leverage knowledge and resources.

The Marina Kaplan Project also served as a catalyst and partner for a new website launched in January 2022 that is the first one-stop resource hub for metastatic breast cancer patients living with brain metastasis or leptomeningeal disease. Funded by Seagen, SHARE Cancer Support hosted the creation and launch of the site, which offers education on diagnosis and treatment options for specific subtypes; and connects patients to clinical trials and a directory of experts in the field.

› Learn more: MBCBrainMets.org



STRATEGIC GOAL II

CLINICAL TRIALS

Advocate for clinical trials to 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.

RESEARCH TASK FORCE INITIATIVE

MBC Connect™ Patient Experience Registry

Launched by the Alliance in 2018, MBC Connect is a patient-powered registry designed to help researchers access powerful patient experience data, while connecting participants to potential matches for clinical trials and notifying them of important news, events and resources.



As of November 22, 2022 a total of 1,104 patients and 186 caregivers have registered and an average of 73-79% have completed the five core surveys. Of the registered users, 56% have entered treatment data with an average of 5.5 treatments per user. Participants come from 48 states, the District of Columbia, and Puerto Rico. Over 400 clinical trials are currently in the database, 83 of which are focused on specific mutations, with 282 engaged users. Of the

trial matches delivered to those patients, 1,823 have been viewed and 732 have been saved for future reference. Patients can easily share potential trial matches with their healthcare providers.

The findings from a cross-sectional study conducted through MBC Connect that surveyed patients on their experiences during the COVID-19 pandemic will also be submitted for publication in early 2023. The two-part REACT (REthink Access to Care & Treatment) Survey collected data from 341 validated participants to assess and modify patient management strategies to clinical protocols in oncology care, with the goal of optimizing these protocols for future public health emergencies.

› Learn more: MBCconnect.org

STRATEGIC GOAL III

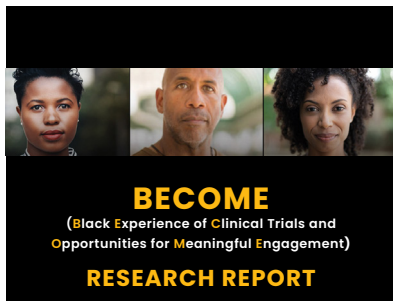
REMOVING BARRIERS TO STANDARD OF CARE

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.

INFORMATION TASK FORCE INITIATIVE

BECOME Research Report

In May 2022, the Alliance released an Executive Summary of its BECOME (Black Experience Of Clinical Trials And Opportunities For Meaningful Engagement) Research Project. Using real-life patient input, the project aimed to inform practical and actionable methods to make it easier for Black people living with MBC to learn about and participate in clinical trials.



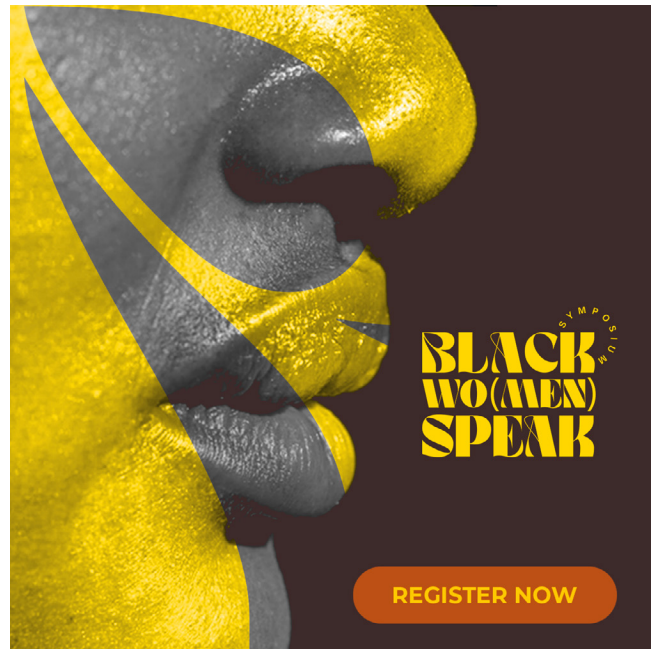
Interest in the project has been high, with the Alliance's patient-led research poster for BECOME featured in a discussion

session at the American Society of Clinical Oncology (ASCO) Annual Meeting in June 2022, reaching about 40,000 oncology professionals from around the world.

In October, the Alliance released the full research report, with detailed findings from 102 respondents who self-identified as Black along with some comparison metrics from a full pool of 424 respondents. Through this work, four areas of focus have been identified for healthcare professionals, nonprofits and advocates to begin making change: by better informing Black patients, by inspiring trust, by ensuring access to clinical trials and by addressing concerns.

› Learn more: MBCAlliance.org//BECOMEreport

INFORMATION TASK FORCE INITIATIVE



Black Wo(Men) Speak Symposium

On December 5, 2022, the Alliance co-hosted the Black Wo(Men) Speak Symposium in conjunction with the San Antonio Breast Cancer Symposium. The event drew 118 in-person and 115 virtual attendees to learn about the urgent need for greater diversity in clinical trials by exploring data gathered in four recent surveys by breast cancer organizations, including findings from the Alliance's BECOME project. The goal of the event was to empower healthcare providers, pharmaceutical companies, researchers, advocates and patients with information and best practices for reducing disparities in clinical trial enrollment.

› Learn More: MBCAlliance.org/Black-Women-Speak

STRATEGIC GOAL IV

QUALITY OF LIFE

Integrate Quality of Life services and care (i.e., palliative care, financial toxicity, shared decision making) into all treatment planning from initial diagnosis.

AWARENESS TASK FORCE INITIATIVE

Support of Access to Care Act

In October, the Alliance supported Susan G. Komen Center for Public Policy's campaign to advance the MBC Access to Care Act. During Breast Cancer Awareness Month, member organizations were asked to sign on to a letter to Congress, and individuals were invited to take quick action through an automated process to email their Members of Congress. These emails asked legislators to co-sponsor the Act, which would waive burdensome waiting periods for SSDI and Medicare for people living with MBC so they can maintain vital medical care and support. This collaborative effort boosted the year-round work of dedicated advocates and organizations who continue to share their stories and ask legislators to act now to improve outcomes and quality of life for people living with MBC.

› Learn More: MBCAlliance.org/MBCaccess22



INFORMATION TASK FORCE INITIATIVE



MBC Advocacy Slide Deck Series

In September, the Alliance introduced a series of slide decks to serve as a professional gold-standard resource for advocates presenting at events. Developed by a committee of experienced advocates, this series of four presentations covers important areas of MBC education for various audiences – from basic background about MBC and how it is treated, to current areas of opportunity in MBC research and education for caregivers. Each deck is accompanied by a resource guide linking to facts and statistics used to create these science-based materials, which are freely available to all advocates for download and use and can be accessed by the public for educational purposes.

› Learn more: MBCAlliance.org/AdvocateTools

ADDITIONAL >>

ALLIANCE INITIATIVES

Our work to transform and improve the lives of people living with MBC is informed by real-world knowledge and data that identifies existing needs and opportunities. This strategic approach, made possible with your support, is essential to increasing our impact for the MBC community.

AWARENESS TASK FORCE INITIATIVE

Launch of New MBC Alliance Website

In April 2022, a new MBC Alliance website was launched that optimizes user experience for patients and members and lays a strong foundation for future growth. Created through a collaboration with Dot Think Design, a central feature of the new site is a searchable library of programs and resources that allows members to highlight their organization's offerings designed to support people living with MBC and their caregivers, thereby connecting more people to valuable resources. The site also now includes a password-protected "members-only" section to improve communication and increase transparency across Alliance membership, including the capability to view directories and internal project statuses, download agendas and meeting minutes, and more. Since launch, the website has had more than 17K visitors and has shown a decrease in bounce rates and an increase in the average time a user spends exploring the site.

> Learn more: MBCAlliance.org

ORGANIZATION-WIDE INITIATIVE

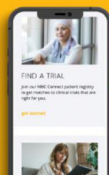
New Strategic Five-Year Goals Identified

Following a survey of our membership and an overview of initial results presented by Praxis Consulting Group, last year a multi-stakeholder Strategic Planning Subcommittee was created to lead the effort of updating the Alliance's five-year strategic plan utilizing the [Achieve System™](#). This year, a final document was presented outlining four strategic goals the Alliance will pursue: prioritization of critical MBC research, more patient-centric clinical trials, improved integration of Quality of Life services and care, and removing barriers to care. Cross-sector working groups are being formed to shape and implement new initiatives in these areas.

> Learn more: MBCAlliance.org/About



NEWLY LAUNCHED!
EXPLORE RESOURCES
MBCALLIANCE.ORG



OUR TEAM >>

EXECUTIVE GROUP

As of December 1, 2022.

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

Senior Leadership

Christine Benjamin, SHARE Cancer Support, Chair

Beth Burnett, Independent Advocate, Vice-Chair

Shirley Mertz, MBC Network, Past-Chair

Task Force Co-Chairs

Research: Margaret Flowers, Breast Cancer Research Foundation & Teri Pollastro, Patient Advisor

Information: Caroline Johnson, Twisted Pink & Martha Carlson, Patient Advisor

Awareness: Christine Verini, CancerCare & Lisa Laudico, Patient Advisor (In Memoriam)

Industry Representatives

Jeanette Meibach, Gilead Sciences

Feyikemi (Kemi) Osundina, Sanofi

Members-At-Large

Deborah Collyar, Independent Advocate

Janine Guglielmino, Living Beyond Breast Cancer

Stacy Lewis, Young Survival Coalition

Stephanie Walker, Patient Advisor

Lynda Weatherby, Patient Advisor

ALLIANCE STAFF

Laurie Campbell, Executive Director

Dana Mooney, Program Associate

Rachel Galione, Project Operations Associate

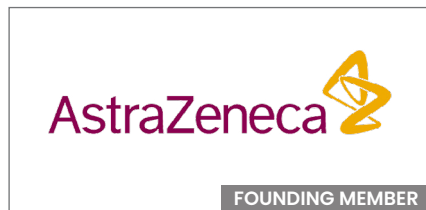
Medha Deoras-Sutliff, Project Management Consultant

Melinda Shaw, Administrative Assistant

OUR INDUSTRY MEMBERS >>

Thank you for your shared commitment to transforming the lives of people living with MBC, and for investing in the Alliance's work of leading collaborative action. Your support is making a difference!

PREMIERE MEMBERS



SUSTAINING MEMBERS



SUPPORTING MEMBERS

