



MBC Alliance Breast Cancer Brain Metastasis (BCBM) Initiatives: *The Marina Kaplan Project & Living Beyond Breast Cancer*

Medha Deoras-Sutliff, Consultant

medha@mbcalliance.org

International Patient Advocacy Symposium on Brain Metastases
Vienna, Austria






































June 25, 2023

Who is the Metastatic Breast Cancer Alliance?

- Established on October 13, 2014, and currently the largest US-based coalition of **cancer nonprofits (37)**, pharmaceutical **industry members (11)** and individual **patient advocates (34)**.
- Leading the way for collaborative action to transform and improve the quality and quantity of life for people living with metastatic breast cancer.
- Focus on **4 Strategic Goals**
 1. Prioritize critical **Research** to improve outcomes
 2. Advocate for patient-centric **Clinical Trials**
 3. Ensure all MBC patients have equitable access to quality **Standard of Care**
 4. Integrate **Quality of Life** services and care into all treatment planning



Alliance Nonprofit Organization Members



LIVING BEYOND
BREAST CANCER®

Trusted Information



Conference



ASK THE EXPERT:
Metastatic breast cancer

Claudine Isaacs, MD
Lombardi Comprehensive Cancer
Center at Georgetown University

Wednesday, December 14 | 7:00 – 8:15 p.m. (ET)

Webinars



Online content

www.lbbc.org

www.lbbc.org



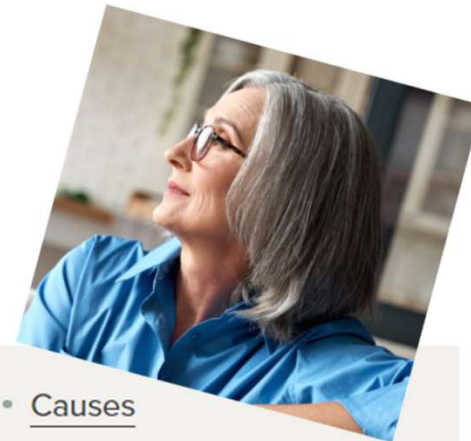
LIVING BEYOND
BREAST CANCER®

[ABOUT BREAST CANCER](#) > [TYPES OF BREAST CANCER](#) > [METASTATIC](#) > [METASTATIC BREAST CANCER TO THE BRAIN](#)

Metastatic breast cancer to the brain

Metastatic breast cancer to the brain is one of the most common locations breast cancer can spread to.

13 MIN. READ | MEDICAL REVIEW: [NANCY U. LIN, MD](#)



On This Page

- [What are brain metastases?](#)
- [Who gets brain metastases?](#)
- [How is it diagnosed?](#)
- [Prognosis](#)
- [Additional resources](#)
- [Causes](#)
- [Symptoms](#)
- [Treatments](#)
- [Support groups](#)

For more information, please contact:
Janine Guglielmino
Vice President, Mission Delivery
janine@lbcc.org

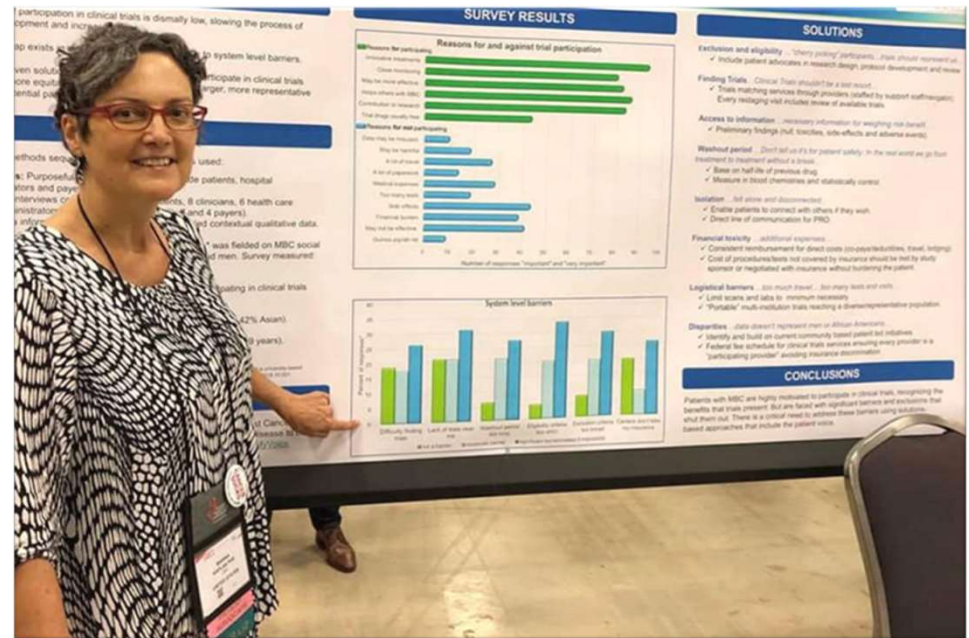


LIVING BEYOND
BREAST CANCER®

MBC Alliance

Breast Cancer Brain Metastasis: *The Marina Kaplan Project*

The **BCBM Marina Kaplan Project** is a patient-led initiative of the MBC Alliance that aims to accelerate urgently-needed research on breast cancer brain metastasis through increased funding and influencing key stakeholders.



Goals of the BCBM Marina Kaplan Project

Ensure an inclusive clinical trial design with less restrictive eligibility criteria

Increase the quality of basic science research

Increase the number of clinical trials testing a variety of interventions

Incorporate clinically meaningful trial endpoints to measure QoL AND survival

Increase access to information on treatment and support for patients

BCBM Subcommittee



BCBM Subcommittee – Methods

Engagement

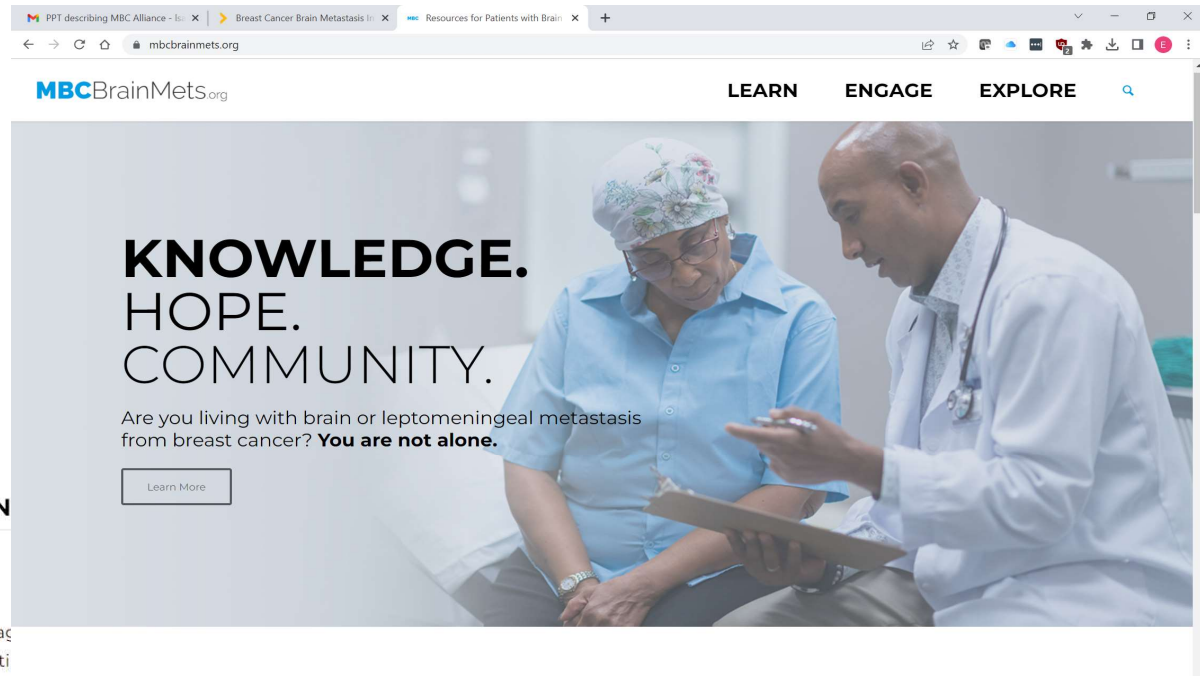
- **Meet monthly with translational investigators** for discussion and provide a patient perspective at least once per month
- **Meet with clinical trial PIs and sponsors** to ensure that trials ask questions that are important to patients, include both stable and active brain mets, include diverse populations, include PRO's and are designed to maximize benefits and minimize harms
- **Quarterly update meetings with Alliance pharma** representatives to encourage funding research that will benefit ALL patients with CNS metastasis

Awareness

- Encourage **patient advocate participation** on guideline committees
- **Provide support and education** to patients MBCbrainmets.org

MBCBrainMets.org

Trusted/online source of education and support for patients living with BCBM and LMD.



MBCBrainMets.org

LEARN

PATIENT STORIES



"When I was diagnosed, my provider at the time didn't know statistics. I was blindsided. It ultimately led me to search online, which left me scared and overwhelmed. Having a resource like [MBCBrainMets.org](https://www.mbcbrainmets.org) offers direction, clarity and hope. And it is a site I can return to for information on clinical trials and treatment options."

– Cwen Manchion, MBC Brain Metastasis Patient

[EXPLORE PATIENT STORIES](#)

Clinical Trials Search on MBCBrainMets.org



MBCBrainMets.org

LEARN ENGAGE EXPLORE

Find a trial that is right for you

This patient-friendly trial search will make it easy for you to find a clinical trial and understand what researchers are studying, why, and who can take part. This search engine was developed in partnership with [Metastatic Trial Search](#) and is based on the National Institute of Health's registry of over a quarter of a million clinical trials. In order to filter these trials [MBCBrainMets.org](#) which you may not qualify, you will need to answer a few simple questions about your breast cancer. If you answer, you can still browse trials that might be right for you.

Clinical trials often exclude patients with CNS metastasis. But the status quo is changing, and more often that accommodate patients with CNS disease at different points in their treatment.

The trial search works best on a Desktop computer. We have a brief tutorial to help optimize your search.

[Watch Clinical Trial Search Tutorial](#)

Powered by:  **BreastCancerTrials.org**
find a trial that's right for you

Metastatic Breast Cancer
MBCalliance >

LEARN ENGAGE EXPLORE



Menu

505

trials available in the United States

Find a metastatic breast cancer trial that's right for you.

[LOGIN / REGISTER](#)

[CONTINUE AS GUEST](#)

[How does Metastatic Trial Search work?](#)

MBCA Alliance – Ramping Up Our Focus

- BCBM Marina Kaplan Project
 - Continued participation in external conferences to raise awareness
- MBCBrainMets.org
 - Continue to add new content, graphics and enhanced functionality/site navigation, new patient stories representing all patient populations
 - Develop new research articles and webinars, interviews with experts
 - Highlighting individual trials on website
- Future Collaboration with the ABTA
 - Assist in the development/fielding of 2024 surveys (patient, CG, HCP, Researcher), including specific questions for primary cancers

MBC Alliance *Patient Voice* on Unmet Needs

- ❖ *Being fully included in trials- not just those with stable brain mets but progressing brain mets as well*
- ❖ *A greater focus on brain mets and leptomeningeal disease in trials and drug development*
- ❖ *Further developing imaging tools and means to identify tumor necrosis vs tumor progression*
- ❖ *Sharing of best practices pan-cancer*
- ❖ *Increased screening for brain mets in the breast cancer community*

Thank you!

medha@mbcalliance.org

mbcalliance.org

