FORCE Resources and Programs for People with Metastatic Breast Cancer

Dr. Kelly Owens, PhD
Director of Education and Research
RESEARCH
Addressing barriers to hereditary metastatic breast cancer research

“I just learned about a clinical trial but my doctor says we have treatment options and research is a last resort.”

“My friend’s doctor told her clinical trials were only for patients with no other options and put her on ineffectual chemotherapies. When her breast cancer recurred to her brain, she was ready for a clinical trial, but too sick to qualify.”

“I wanted to start a clinical trial but my doctor just started me back on chemo last week.”

Poor physician and nurse engagement driving low patient recruitment
Less than 0.2% of patients seen annually are referred into clinical trials
Hereditary MBC Research Matching Tool

- Recruited for hereditary MBC registration trials
  - OLYMPIAD
  - EMBRACA

- Recruiting now for hereditary MBC studies
  - PARP inhibitors for people with non-BRCA mutations
  - Immuno-oncology Agents
  - Metastatic Breast Cancer Project
Peer Navigation Program

Matches people with peer volunteers and information based on:

- personal situation
- age
- mutation
- diagnosis
- geographic location
EDUCATION
Media coverage of cancer news can be misleading.

XRAYS was developed to help young women understand breast cancer research in the news.
**XRAYS**: eXamining the Relevance of Articles for Young Survivors

- Summarizes science in plain language
- Rates relevance for research
- Rates accuracy of media coverage

Help not hype
XRAY:MBC  **eXamining the Relevance of Articles for You: Metastatic Breast Cancer**

- Summarizes science in plain language
- Rates relevance of research
- Rates accuracy of media coverage
- **Focus:** Metastatic breast cancer in women and men of any age
- **Information and enrollment status of clinical trials**
XRAY: Metastatic Breast Cancer Approach

- Summary of research in plain language
- Relevance meter for people with MBC
- Strength of science meter
- Timeline meter: when in clinic
- Links to open clinical

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This study in mice looked at how wound healing after surgery affects metastasis. Researchers found that wound healing caused changes in the mouse immune system that allowed some cancer cells to grow, but that treatment with a non-steroidal anti-inflammatory drug (NSAID) reduced inflammation and frequency of metastases. This research is being studied in clinical trials in humans. If results are positive, it could change clinical care.
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Connect with us

Website: FacingOurRisk.org
XRAYS: FacingOurRisk.org/XRAYS
Helpline: 866-288-RISK (7475)
Email: info@FacingOurRisk.Org
Get Social: FacingOurRisk
SHARE Resources and Programs for People with Ovarian Cancer

Ivis Sampayo
Our Mission

To create and sustain a supportive network and community of women affected by breast or ovarian cancer.
SHARE’s Vision

- Our trained survivors will continue to educate and support people and their loved ones throughout their diagnosis, treatment, and beyond.

- We will empower women to make more informed decisions about their care.

- We will be on the cutting edge of technology to disseminate information and support to as wide an audience as possible.
Our Services Include:

- Peer support helplines, available 7 days a week
- Peer-facilitated support groups, in person and via teleconference
- Educational programs and webinars
- Online community of peer support
- Outreach in underserved communities
- Workplace seminars
Helplines: 844-ASK-SHARE

- Callers talk to trained peer volunteers to get a viewpoint that can only come from someone who’s been there.

Support Groups

- People facing breast and ovarian cancers share experiences and support one another with the help of a trained facilitator.
LatinaSHARE

- Spanish-speakers have access to support groups, educational programs, outreach initiatives, and helplines in Spanish.
- Dedicated support and education for MBC
Educational Programs & Webinars for Breast, Ovarian, MBC

- Patients, Family, Friends and the public learn what’s happening in breast and ovarian cancers from the experts, either in person or online.
SHARE Ambassadors

- Latina and African-American survivors educate medically underserved NYC communities about ovarian cancer risks, screening, and what to do if they encounter symptoms.
- 31,675 people were reached by SHARE Ambassadors in 2016.
Metastatic Support Services

- 11 Peer Led Support Group Sessions Monthly
- Topic Driven Discussions Specific to Sub-Type
- On-line MBC Community
- Educational Programs
- Dedicated MBC Helpline Coming Soon
- Trained Metastatic Peers
- Participating Member of the MBCA
Patient Advocacy & Collaborations

- SHARE works with ovarian cancer researchers to amplify patient voices as they develop new treatments.
- SHARE is also a leading collaborator with a range of ovarian cancer organizations, including FORCE, OCRFA, Foundation for Women’s Cancer, and NOCC.
Focus on Clinical Trial Education

Every Tuesday, SHARE’S Social Media feed is filled with information about clinical trials. Programs featuring patients who have participated in clinical trials are offered regularly. Patient Videos explain the different ways clinical trials are used in treatment of MBC today. Dedicated MBC Clinical Trials Search Engine (Metastatic Trial Search)
Metastatic Novela

First of its kind educational story of Anna, who together with her family faces a metastatic recurrence.

Available in English and Spanish

Dispersed widely in NYC and Beyond
Metastatic Information and Support in Spanish

- Blended Support Groups
- Caregiver Services
- Education
- Social Media
- Clinical Trial Awareness
CONTACT US

sharecancersupport.org
844-ASK-SHARE

lsampayo@sharecancersupport.org
Komen

Dr. Krissa Smith, PhD
Susan G. Komen MBC Resources

- kosher.org
  - Living with Metastatic Breast Cancer page
  - Metastatic Trial Search
  - Komen educational materials/videos
  - MBC Progress

- Komen Treatment Assistance Program

- Komen MBC events

- Susan G. Komen Breast Care Helpline

- Susan G. Komen Clinical Trial Information Helpline
Living Beyond Breast Cancer

Arin Ahlum Hanson
From Silent Voices to Hear My Voice:
LBBC’s Information and Support Programs for People Living with Metastatic Breast Cancer
Mission: To connect people with trusted breast cancer information and a community of support.
LBBC Overview

• National nonprofit founded in 1991.
  ▪ Among the first to fulfill the need for breast cancer-related information, connection and support after treatment.
• Today LBBC reaches 560,000 people per year.
• As the need for specialized services increased, LBBC expanded to assist people at all stages of diagnosis, treatment and survivorship.
• Tailored programs and resources for young women, those living with metastatic breast cancer, people with different types of breast cancer, among others.
In 2005, LBBC conducted the first nationwide assessment of the psychosocial needs of women living with metastatic breast cancer. LBBC report from this project, Silent Voices, revealed that women living with MBC felt isolated and shut out from the majority, early-stage community. The study also found that information specific to people living with Stage IV disease was difficult to find, if available at all.

LBBC used this information to plan our first Metastatic Breast Cancer Conference in July 2007, which continues today and a rich variety of other metastatic program offerings.
LBBC Programs

Programs and services available in different formats to accommodate individual preferences

Online  In print  By phone  In person
Today LBBC’s Conference on Metastatic Breast Cancer has become a national meeting place for individuals and organizations seeking community, high quality information and a platform to raise their voices.

“I had an absolutely incredible weekend at LBBC’s conference. It was truly life-changing, and I left feeling so energized, informed, and encouraged about the state of MBC and my diagnosis as well.”

Join us!

- April 5-7, 2019, Philadelphia, PA
- Registration launches in January 2019. Travel grants available!
In Person: Hear My Voice Outreach Volunteer Program

• The Hear My Voice Program trains volunteer advocates with metastatic breast cancer to educate the public about MBC and connect others living with the disease to information and resources.

• 135 volunteers have been trained to date, through 5 trainings.

• Our Hear My Voice Volunteers have efforts have connected more than 100,000 people in their physical and digital communities to educate them about MBC.
In Print: Metastatic Publications

Guide for the Newly Diagnosed
Managing Stress and Anxiety
Treatment Options for Today and Tomorrow

All LBBC Guides are medically and consumer reviewed.

To order: LBBC.ORG/GUIDES
Online: Metastatic Programs

- LBBC.ORG/METS
- Webinars
- Twitter Chats
- Breast Cancer 360s
- Videos
By Phone: Breast Cancer Helpline

• Connects callers to a trained volunteer who has been diagnosed with breast cancer for emotional support, guidance and hope.

• Callers will be matched with a trained volunteer who has a similar experience to you whether that be age, diagnosis type, stage, or concern.

• 27% of our Helpline volunteers are living with MBC

• LBBC.ORG/Helpline
MBC Alliance Support for the MBC Patient Community

Laurie Campbell
Executive Director
Introducing the Metastatic Breast Cancer Alliance (MBCA)

- Largest coalition of organizations in the U.S. with ongoing collaboration and focus on metastatic breast cancer
- More than 100 volunteers from 43 member organizations plus 18 individual members - many of whom are living with MBC
- Three areas of focus
  - Advancing research
  - Improving knowledge
  - Increasing understanding of metastatic breast cancer
Our members are driven by a vision to transform and improve the lives of people living with metastatic breast cancer.

Our Mission
Membership

Nonprofit Members

Canadian Cancer Survivor Network  The Cancer Couch Foundation

Industry Members

AstraZeneca  Celgene  Eisai  Genentech  Lilly  Novartis  Pfizer

Supporting

Genomic Health  MacroGenics  Seattle Genetics  Syndax
Alliance Members’ Info & Support Services

Online resources are available across a number of categories via [mbcalliance.org](http://mbcalliance.org). You can learn more about the information and support services Alliance members offer for people living with metastatic breast cancer and their caregivers.
Activity Highlights

- Published **Changing the Landscape for People Living with Metastatic Breast Cancer**, one of the most comprehensive analyses of metastatic breast cancer research, clinical trials, epidemiology, quality of life, and information and support services. (Landscape Analysis)

- Collaborated in the development of "The Dandelion Project" - a first-of-its-kind research initiative designing a set of visual tools to help healthcare teams communicate with patients about their diagnosis and treatment options. (Epidemiology Research)

- Published three research papers:
  - "Estimation of the Number of Women Living with Metastatic Breast Cancer in the United States" in *Cancer Epidemiology, Biomarkers & Prevention*
  - "Differential presentation and survival of de novo and recurrent metastatic breast cancer over time: 1990-2010" in *Breast Cancer Research and Treatment*
  - "Moonshots and metastatic disease: the need for a multi-faceted approach when studying atypical responders" in *npj Breast Cancer*

- Ongoing, collaborative initiatives in the area of clinical trials - Metastatic Trial Search/Metastatic Trial Talk, the "Bubble Charts" visualization tool, and our Clinical Trials "Road Show"
Metastatic Trial Search and Trial Talk

- Designed for online searching
- Nearest research sites appear on a map
- High-level study purpose and eligibility
- Option to filter results by geography, phase, treatment, new trials
- Ways to share trial information

- Companion portal to the re-designed MTS
- Curates the best info on MBC research
- View meetings from across the U.S.
- Read about new trials
- Hear from the experts
- Share personal stories

POWERED BY BreastCancerTrials.org
The Right Track Framework

together we are stronger than the disease

Welcome to the Precision Medicine Revolution

RIGHT TRACK
Your path to precision resources and treatment

Right Team
Access experts and centers that have extensive experience treating your specific type of cancer

Right Tests
Get the information, test, and precise diagnosis to make the right treatment decisions

Right Treatment
Work with your team to decide on the best treatment plan and/or to identify clinical trials

Share at Every Step
You can help yourself while helping others
The MBCA Patient Registry

- **Goal:** To advance research into MBC by creating a platform that serves as a link between patients and clinical researchers.

- **Highlights**
  - Information is de-identified, encrypted and HIPAA/locally compliant.
  - MBC patients or their caregivers will enter and update their own data which will populate an open access database available via the researcher portal.
  - Patients will receive “Insights” and can be linked to appropriate clinical trials.
  - Currently available in English and Spanish in the U.S.
MBC Connect™ App Screenshots
Upcoming Alliance Member Events

**METASTATIC BREAST CANCER FORUM 2018** – Dana Farber Cancer Institute | October 20 | Boston, MA

**NW Metastatic Breast Cancer Conference 3.0** | Susan G. Komen Puget Sound | October 26-27 | Seattle, WA

**SOUTH CENTRAL METASTATIC BREAST CANCER CONFERENCE** | Susan G. Komen Houston | October 27 | Houston, TX

**TRIAGE CANCER CONFERENCE** | Saturday, October 27 | Lewiston, ME

**NEW YORK METASTATIC BREAST CANCER CONFERENCE** | Susan G. Komen Greater NYC | October 27-28 | New York, NY

**5TH ANNUAL METASTATIC BREAST CANCER CONFERENCE** | Theresa’s Research et al | November 15-16 | Baltimore, MD

**YSC SUMMIT 2019** | Young Survival Coalition | March 8-10, 2019 | Austin, TX

**ABC5: BRIDGING THE GAP** | ABC Global Alliance | November 14-16, 2019 | Lisbon, Portugal
If you are interested in learning more, please stop by the Alliance booth or contact me at Laurie@MBCAlliance.org

www.mbcalliance.org  facebook mbcalliance  twitter @mbcalliance

www.mbcconnect.org  www.keepmeinthepicture.org