Living with Metastatic Breast Cancer (MBC): The Patient Perspective

Christine Hodgdon, M.S.

Stephanie Walker, R.N.

San Antonio Breast Cancer Symposium®, December 6-10, 2022
From Patient to Patient Advocate

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Objectives for Today’s Talk

1. Discuss the following areas of top concern within the MBC community:
   - Health disparities & racial inequities
   - Clinical trials
   - Quality of life & survivorship
   - Education & support
   - MBC research

2. Showcase how patient advocates are addressing these areas of concern

Who is this talk for?

**Advocates**
- Including patients & caregivers looking for resources and inspiration

**Cancer scientists**
- Including clinicians & researchers interested in learning about the power of patient advocacy
# Addressing the Needs of the MBC Community through Patient Advocacy

<table>
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<tr>
<th>Support</th>
<th>Emotional</th>
<th>Medical</th>
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<td>Education</td>
<td>Advocacy organizations offer educational resources to help patients navigate a cancer diagnosis</td>
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<td>Policy</td>
<td>Patients influence government officials to increase funding for cancer research &amp; quality healthcare</td>
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<td>Research</td>
<td>Patients use their own personal experiences to inform scientific researchers and research processes</td>
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Health Disparities & Racial Inequities

Maimah Karmo
Founder

Jamil Rivers
Founder

Roberta Albany
Founder & CEO

Valencia Robinson
Founder

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Health Disparities & Racial Inequities

Jasmine Souers
President & CEO

Marissa Thomas
Co-Founder & CEO

Tiah Tomlin-Harris
Founder & CEO

FOR THE BREAST OF US
ALL MELANIN. ALL MOXIE. ALL TOGETHER

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Health Disparities & Racial Inequities

**Rev. Dr. Tammie Denyse**
Founder

**Laura Crandon**
President & Founder

**Carla Harvey**
Independent Advocate

**Bridgette Hempstead**
Founder

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Clinical Trials for Underserved Communities

BECOME Research Project
Black Experience of Clinical Trials & Opportunities for Meaningful Engagement

Stephanie Walker
Lead

Ricki Fairley
CEO & Co-Founder

Sharon Rivera Sanchez
Founder

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Quality of Life & Survivorship

Anne Loeser
Founder

Lesley Kailani Glenn
Founder

Shelley Fuld Nasso
CEO

#TheRightDose

A survey of 1,221 patients with MBC found that:
86% had at least one bad treatment-related side effect

National Coalition for Cancer Survivorship (NCCS)

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Awareness & Education

Shirley Mertz
President

Abigail Johnston
Founder

Emily Garnett
Founder

April Stearns
Founder

The Insider’s Guide to Metastatic Breast Cancer
Anne Loeser

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Awareness & Education

Beth Fairchild
Martha Carlson
Janice Cowden
Debbie Denardi
Shonté Drakeford
Roxana Guerra
Deltra James
Felicia Johnson
Teri Pollastro
Kelly Shanahan
Lesley Stephen
Jo Taylor
Stacey Tinianov
Terlisa Sheppard

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Connection & Support

SHARSHERET
Your Jewish Community Facing Breast Cancer

#BCSM
Breast Cancer Social Media

Angelmira’s Center
for women with advanced cancer

LIVING BEYOND BREAST CANCER®

SHARE
sharecancersupport.org

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Support for MBC Patients

LaKesha Gordon
Founder

Jersi Baker
Founder

Shay Sharpe
Founder

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From Patient to Patient Advocate

The Johns Hopkins INSPIRE Breast Cancer Research Advocacy Program is a collaboration among breast cancer survivors, researchers and physicians. Patients who inspire research.

Those Who INSPIRE Us

Christine was diagnosed with stage 4 metastatic breast cancer in 2015 at age 34. She had a complete response to her 26 years old. She has a BRCA1 mutation — that increases the breast and other cancer risks.

Metastatic Breast Cancer

Know your treatment options

“Four years later, I’m here, I’m hopeful, and I’m happy!”

Advocating for myself and helping others do that, too — says Christine.
Public Policy Advocacy

Beth Caldwell
Founder

Katherine O’Brien
Challenged NCI & CDC to count all people living with MBC

Fran Visco
President

Tori Geib
Changed Ohio legislature to prohibit “fail first” drug coverage policies

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Funding MBC-Specific Research

- Theresa Newby Harpole, Founder, Theresa’s research foundation
- Rebecca Timlin-Scalera, Founder, The Cancer Couch Foundation
- Dian “CJ” Cornelissens-James, Co-Founder, MetaVivor
- Lara MacGregor, Founder, Hope & Scarves
- Kelli Davis & Lisa Quinn, Co-Founders, Metsquerade
- Caroline Johnson, Founder, Twisted Pink

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Funding or Conducting Breast Cancer Research

Dr. Susan Love
Founder

Rick Dunetz
Founder, Executive Director

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Research Advocacy

Bob Riter
Connects cancer survivors with cancer researchers at Cornell University

Elda Railey & Mary Lou Smith
Co-Founders

Research Advocacy Network

Carole Baas
Thelma Brown
Yvonne McLean
Florence
Jane Perlmutter

PROJECT LEAD
An Innovative Science Training Program For Breast Cancer Advocates

25th Year Anniversary

Alamo Breast Cancer Foundation

Susan G. Komen
Advocates in Science

Deborah Collyar
Patient Advocates In Research (PAIR)
Founder & President

Patty Spears
Sandi Spivey
Research Advocacy

Christine Hodgdon  
Co-Founder

Julia Maués  
Co-Founder

Marlena Murphy  
Program Manager

Sandi Stanford

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Rare & Special Breast Cancer Populations

Leigh Pate
Co-Founder

Ginny Mason
President

Claire Turner
Founder & Chair

Cheri Ambrose
Founder & President

Sue Friedman
Executive Director, Founder

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Brain Metastasis Initiatives

Marina Kaplan

Terry Cohen  Elizabeth Frank  Flori Hendron  Christine Hodgdon  Lianne Kraemer

Gwen Manchion  Ginny Mason  Julia Maués  Reilly Starr  Lynda Weatherby

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In memoriam
LaTasha Katris Judson
LaTarsha (Glam) Noland

Theresa Newby Harpole
Monique Headcker-Green
Philipa Hetherington
Grace Evelyn Johnson
Rebecca Timlin-Scalera

Jennifer Alderman
Leila Asoko
Erin Banton
Helen Bacon
Virginia Baskins

Kemisha Brown
Lori Burwell
Beth Caldwell
Laura Campbell
Anne Cargill

Melanie Clark
Angela Davis
Anne Cargill
Ann Donovan
April Grove Doyle
Jennifer Euceda
Augunetta Farr
Elaine Figgins
Amy Foster
Tiffany Kow Fouest
Louise Furneaux

Carolyn Gammon
Emily Garnett
LaKesha Gordon
Monica Hill
Emma Hillier
Dr. Julie Huynh
Bob Holden
Christine Howard
Chongwei Huang
Felicia Irick
Sherone Jones

Eileen Youtie

Dr. Lori Wilson
Division Chief Surgeon, Howard University Hospital

Tori Geib
April Hines
Angela Oliver
Elaine Prejean
Mary Richards
Lindsey Ruland
Carol Sarnese
Barbara Shanahan
Hyneefah Singleton
Danielle Thurston
Tessa Tyler
Laura Wheelock
Sachie Yoshimoto

Crystal Williams-Hunter
Whiteley Littlejohn
Jo Myatt
Leigh Pate
Lisa Quinn
Erin Remme
Beth Roberts
Emily Roberts
Carol Smith
Sandi Spivey
Briana Sykes
Mehret Tesfay
Helga Torres

Nunny Keyla
Reece

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Thank you!

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