

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

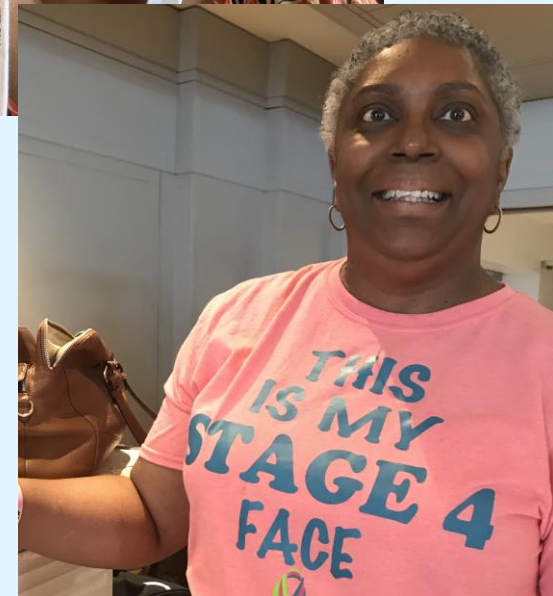


**Christine Hodgdon,
M.S.**



**Stephanie Walker,
R.N.**

From Patient to Patient Advocate



San Antonio Breast Cancer Symposium®, December 6-10, 2022

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

Support

Emotional

Medical

Financial

Legal

Education

Advocacy organizations offer educational resources to help patients navigate a cancer diagnosis

Policy

Patients influence government officials to increase funding for cancer research & quality healthcare

Research

Patients use their own personal experiences to inform scientific researchers and research processes

Health Disparities & Racial Inequities



Tigerlily
Foundation

Beauty. Strength. Transformation.

Maimah Karmo
Founder



CANCER IN THE KNOW

Keeping patient advocacy at the forefront

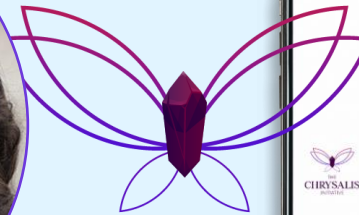
Roberta Albany
Founder & CEO



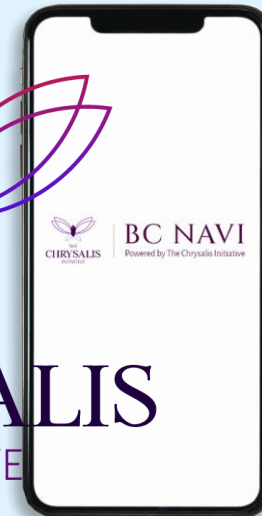
Valencia Robinson
Founder



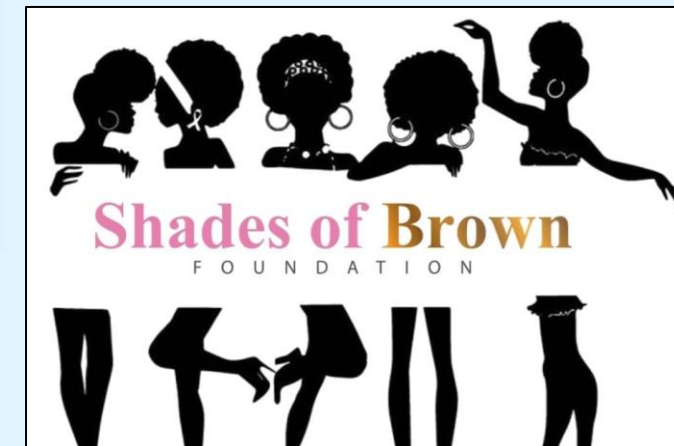
Jamil Rivers
Founder



THE
CHRYsalis
INITIATIVE



WOMEN OF COLOR
Wellness Alliance



Health Disparities & Racial Inequities



Jasmine Souers
President & CEO



My Style Matters

Get Tied to the Cause!

Tiah Tomlin-Harris
Founder & CEO



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

Marissa Thomas
Co-Founder & CEO

Health Disparities & Racial Inequities



Rev. Dr. Tammie Denyse
Founder

**CARRIE'S
TOUCH**



Carla Harvey
Independent Advocate



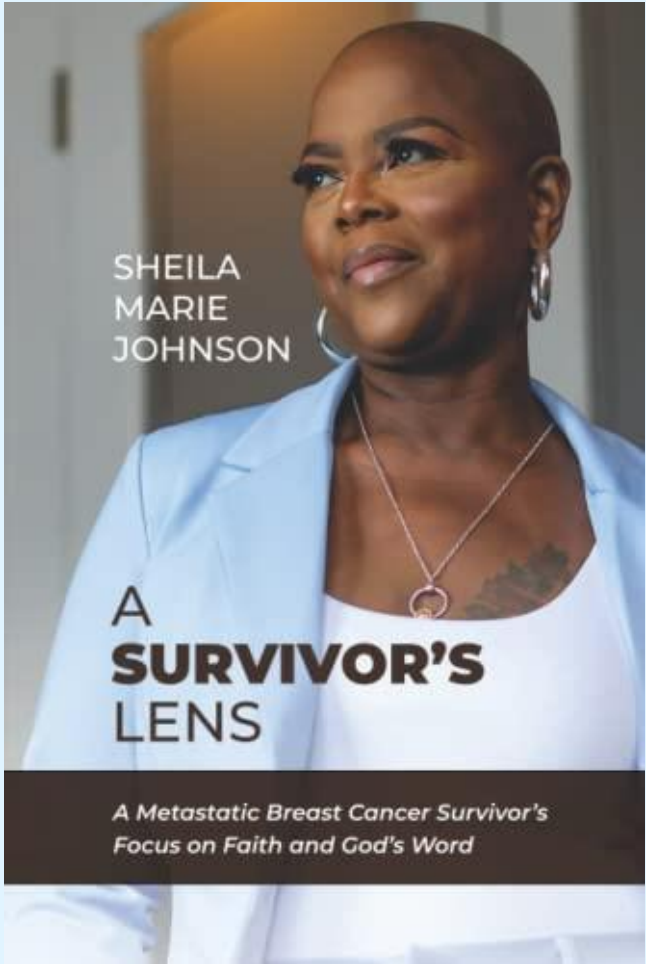
Laura Crandon
President & Founder

TOUCH 4 LIFE



Bridgette Hempstead
Founder

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

Quality of Life & Survivorship



PATIENT
CENTERED
DOSING
INITIATIVE

#TheRightDose



Anne Loeser
Founder



Lesley Kailani Glenn
Founder



A SURVEY¹ OF 1,221 PATIENTS WITH MBC FOUND THAT:

86% HAD AT LEAST ONE BAD TREATMENT-RELATED SIDE EFFECT



NATIONAL COALITION
FOR CANCER SURVIVORSHIP



Shelley Fuld Nasso
CEO

Awareness & Education



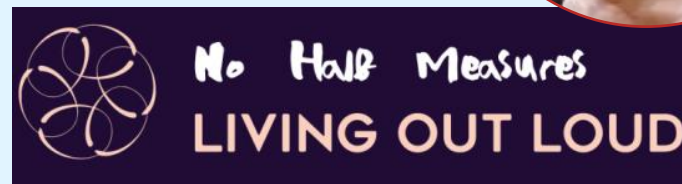
Lisa Laudico
Founder



Abigail Johnston



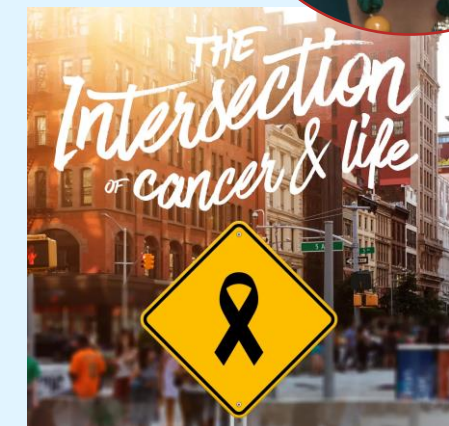
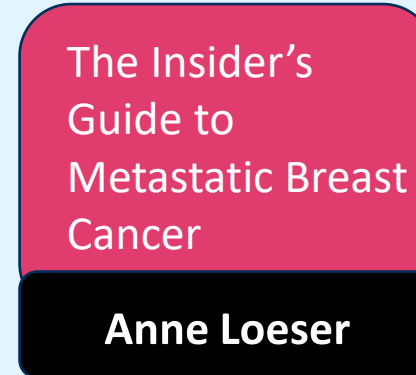
Shirley Mertz
President



Emily Garnett
Founder



April Stearns
Founder



Awareness & Education



Beth Fairchild



**Martha
Carlson**



**Janice
Cowden**



**Debbie
Denardi**



**Shonte
Drakeford**



**Roxana
Guerra**



**Deltra
James**



**Felicia
Johnson**



**Teri
Pollastro**



**Kelly
Shanahan**



**Lesley
Stephen**



**Jo
Taylor**

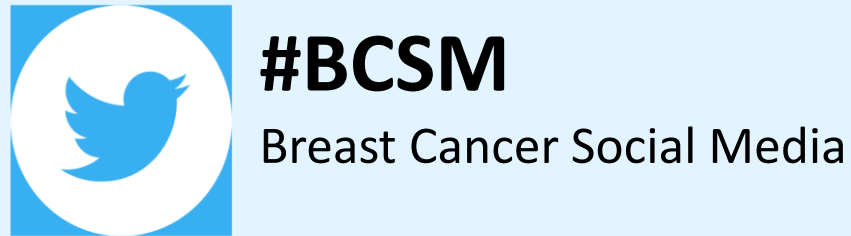


**Stacey
Tinianov**



Terlisa Sheppard

Connection & Support



Support for MBC Patients



LaKeshia Gordon
Founder



Shay Sharpe
Founder



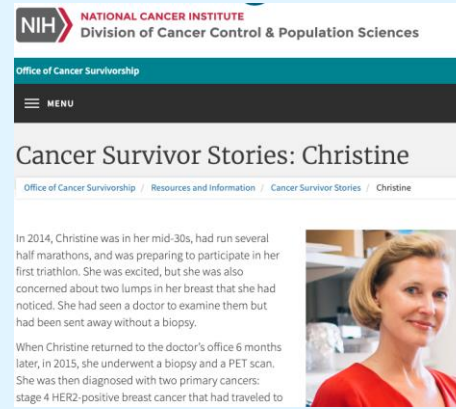
S T R E N G T H



Jersi Baker
Founder



From Patient to Patient Advocate



PATIENTS WHO INSPIRE RESEARCH

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

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 risk of breast and other cancers

Metastatic Breast Cancer

HealthMonitor.com/BreastCancer

36 WAYS TO FEEL YOUR BEST

- Partner with your healthcare team
- Be inspired by others who have stage IV breast cancer
- Get answers from a top breast cancer oncologist

Know your treatment options

"Four years later, I'm here, I'm hopeful, and I'm happy!"

Advocating for herself—and helping others do that, too—gives Christine

FREE take-home copy

Public Policy Advocacy



Beth Caldwell
Founder



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



NBOC
NATIONAL BREAST CANCER COALITION
Fran Visco
President



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

Funding MBC-Specific Research



Theresa Newby Harpole
Founder



**Dian "CJ"
Corneliussen-James**
Co-Founder



Lara MacGregor
Founder



METAVIVOR

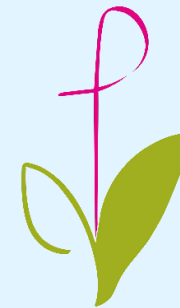
Metastatic Breast Cancer Research, Support and Awareness



**Rebecca
Timlin-Scalera**
Founder



Kelli Davis & Lisa Quinn Co-
Founders



TWISTED PINK®



Caroline Johnson
Founder

Funding or Conducting Breast Cancer Research



Dr. Susan Love
Founder



Metastatic
Breast Cancer
Project



SIDEOUT
FOUNDATION

Rick Dunetz
Founder, Executive Director



Accessing Clinical Trials



Research Advocacy



Bob Riter
Connects cancer survivors with
cancer researchers at Cornell
University



Elda Railey & Mary Lou Smith
Co-Founders



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



Carole Baas



Thelma Brown



**Yvonne McLean
Florence**



**Jane
Perlmutter**



Patty Spears



Sandi Spivey

Research Advocacy Network

Research Advocacy



Christine Hodgdon
Co-Founder



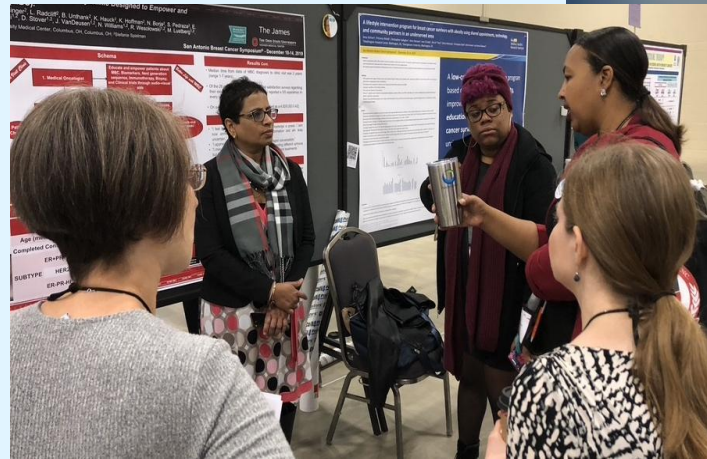
Julia Maués
Co-Founder



Marlena Murphy
Program Manager



Sandi Stanford



SAVE THE DATES

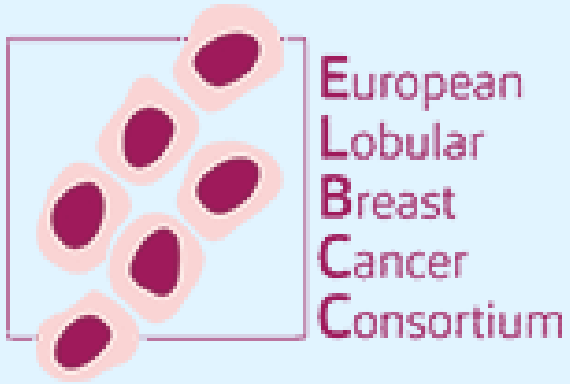
GRASP
GUIDING RESEARCHERS & ADVOCATES TO SCIENTIFIC PARTNERSHIPS.

2023 ASCO[®]
ANNUAL MEETING

WEDNESDAY-THURSDAY
JUNE 14-15, 2023

GRASP
GUIDING RESEARCHERS & ADVOCATES TO SCIENTIFIC PARTNERSHIPS

Rare & Special Breast Cancer Populations



Leigh Pate
Co-Founder



Ginny Mason
President



Claire Turner
Founder & Chair



Cheri Ambrose
Founder &
President



**Male Breast Cancer
Global Alliance**



FORCE
Facing Hereditary Cancer EMPOWERED

Sue Friedman
Executive Director, Founder

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



In memoriam

LaTasha Katris Judson
LaTarsha (Glam) Noland

Theresa Newby Harpole
Monique Headecker-Green
Philippa Hetherington
Grace Evelyn Johnson
Rebecca Timlin-Scalera

Ty Cmack
Lana Dunn
Erica Griffiths
Joy Jenrette
Kate Petrides
Anya Silver

Julia Wise



**Nunny Keyla
Reece**



**James
Weaver**



**Latonya
Wilson**



**Eileen
Youtie**



Michael Kovarik



**Brenda
Cho**



**Amanda
de Fiebre**



**Ryan
Keith**



**Chawnté
Randall**

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 Foust
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

Spirit Jones
Sarita Jordan
Champagne Joy
Marina Kaplan
Sharon Kidd
Marlene King
Diana Marie Lacaci
Lisa Laudico
Dr Bex Lewis
Wanda Lewis
Lorenita Lucas
Lara MacGregor
Nina Masoud
Caitlin Masterson
Linda Matzai
Sally Nyland
Katherine O'Brien
Vadalizza Padilla
Elizabeth Viaggianno



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

San Antonio Breast Cancer Symposium®, December 6-10, 2022

Thank you!



Christine Hodgdon, M.S.



christine@GRASPCancer.org



@christeeny513



Stephanie Walker, R.N.



stephaniewalker1303@gmail.com



@faceofstage4