



# Tigerlily Foundation

## METASTATIC BREAST CANCER DISPARITIES LISTENING SUMMIT

MARCH 20, 2019 | WASHINGTON, DC

# #ListenUpMBC

## @TigerlilyCares



# Summary Report



PRESENTED IN PARTNERSHIP WITH:





# METASTATIC BREAST CANCER DISPARITIES LISTENING SUMMIT REPORT

MARCH 20, 2019 | WASHINGTON, DC



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### THANK YOU

*Dear Summit Attendees,*

*Thank you for attending our Metastatic Breast Cancer Disparities Listening Summit. Your attendance, conversations, and partnership helped make this historic first step successful and insightful. We are excited to share this post report and remain grateful to our partners for the generous support.*

*As we move forward with the implementation of the ideas from the Summit, I invite you to continue our conversation using #ListenUpMBC and stay connected at [tigerlilyfoundation.org](http://tigerlilyfoundation.org).*

*In Service,*

Maimah S. Karmo  
President & Founder  
Tigerlily Foundation

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# METASTATIC BREAST CANCER DISPARITIES LISTENING SUMMIT

## By the Numbers

MARCH 20, 2019 | WASHINGTON, DC



**Tigerlily**  
Foundation  
*Beauty. Strength. Transformation.*

**1st** ■■■■■■■■■■  
Metastatic Breast  
Cancer (MBC) Disparities  
Listening Summit for young  
Women of Color (WOC)

# 1,030+

Social Posts Using  
#ListenUpMBC



### Voices At the Table

10 WOC Attendees Living with MBC

15 Attendees Living with MBC

33 Program Participants

67+ Attendees



### Summit Overview

2 Breakouts

6 Facilitators

1 Media Advisory

4 Panels

1 Press Release

7 Recorders

15+ Resources Shared

1 Workbook



### Attendees by Interest

86% BC Disparities

79% MBC Young WOC Ed

64% MBC Patient Advocacy

64% BC Leader Networking

64% Tigerlily Partnership

50% MBC



### Industries

16% Advocacy

12% Business

8% Campus

6% Caregivers

8% Community/Faith

10% Health Care

31% Patients

9% Pharma



# 99%\*



INTEREST IN  
DEVELOPING  
NEXT STEPS

*\*of survey respondents*

# 5



### Recommended Next Steps

MBC Disparities Mentorship Programs

MBC Disparities Advisory Committee

For Us by Us Activism & Conference

MBC Targeted Legislation & Advocacy

Partner with Existing Support Programs

*To learn more visit: [tigerlilyfoundation.org](http://tigerlilyfoundation.org)*



# Executive Summary

## Tigerlily Foundation

**METASTATIC BREAST CANCER DISPARITIES LISTENING SUMMIT**  
March 20, 2019 | 10 AM – 4 PM | Grand Hyatt Washington, DC



[Click here for Summit Photos](#)

@TigerlilyCares #ListenUpMBC

### PURPOSE

Approximately 150,000 people in the U.S. have **Metastatic Breast Cancer (MBC)**, also called stage 4 or advanced breast cancer, it is not a specific type of breast cancer, but rather the most advanced stage breast cancer that has spread to other organs (often the bones, lungs, liver or brain). MBC annually claims more than 40,000 lives a year. The African-American community is disproportionately impacted by MBC yet have lower enrollment in clinical trials and often go underrepresented in the conversation on the unique needs of women living with stage 4 breast cancer. Tigerlily Foundation partnered to mobilize young women of color to reduce breast cancer disparities through this MBC Disparities Listening Summit.

### DESCRIPTION

Young women, patients, caregivers, community leaders, creators, healthcare providers, advocates, researchers and policymakers gathered in our nation's capital to take a historic first step in engaging the African-American community at the first ever dialogue centered on understanding the gaps, misperceptions and barriers to educate young women of color on MBC. The Summit aimed to **listen** to insights shared and will now apply these recommendations to **create** culturally sensitive grassroots materials to **mobilize** ambassadors with tools to access clinical trials and engage others to lower African-American breast cancer mortality rates.

### PARTICIPANTS

- More than 67 MBC patients, caregivers, advocates, navigators, healthcare providers, researchers, policy makers, civic, campus, community and business leaders.
- Bloggers, creators, radio and television personalities, social media influencers and local media.
- Partners: Tigerlily Foundation, Pfizer Inc., Lilly, Celgene, Metastatic Breast Cancer Project, Project H.U.M.B.L.E, Howard University, Harvard University and The IRIS Collaborative.

**Acknowledgements:** Tigerlily Foundation thanks our contributors listed below for the generous support of our first Metastatic Breast Cancer Disparities Listening Summit.



Kipp Burgoyne: Photography

Donation of Sabika Jewelry gifted by Char Kurihara in loving memory of her sister Lisa Monteleon.



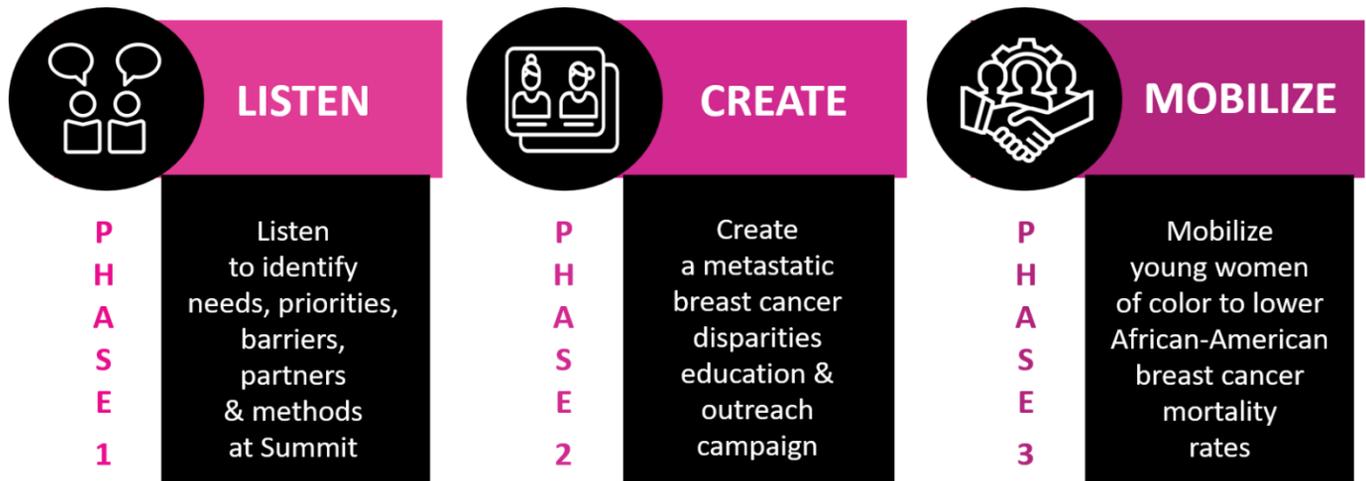
# Summit: Overview

## OBJECTIVES

- Facilitate conversations with African-American MBC patients, experts and partners to establish priorities to educate young women of color on MBC disparities;
- Demonstrate the importance of access to innovations in MBC treatments including clinical trials for African-American patients, record the barriers and misperceptions faced by young women of color;
- Create effective partnerships, tools, images, content, messages and identify methods to lower African-American breast cancer mortality rates; and
- Mobilize a network of African-American MBC ambassadors and experts to partner with Tigerlily on how to best meet the needs of their community.

## APPROACH

Tigerlily will partner to use a 3-phase approach to lower breast cancer disparities:



## EVALUATION GOALS

- Assess attainment of Summit objectives (Did we achieve what we intended?)
- To understand the impact of the Summit (What difference did the Summit make?)
- Determine effectiveness of gathering MBC education and engagement strategies (How well was the information gathered? How well were the listening exercises put into practice?)
- Determine what should be continued (What worked? What did not work?)

## EVALUATION METHODS

Assess the attainment of Summit goals by reviewing qualitative and quantitative data sources and outcomes through a post Summit Report prepared by The IRIS Collaborative, LLC. Tigerlily will use this report to inform next steps for MBC education and advocacy for young women of color.

### Data Sources

- On-Site, Post-Hoc, Exit Survey, Online Survey
- Summit Mood Boards, Sessions and Breakout Assessment and Social Media and Digital Engagement
- Informal Observational Data
- Follow-Up Informal Interviews of Key Informants

## DESCRIPTION OF ACTIVITIES & SESSIONS

The following pages provide information on the Summit activities and sessions.



# Summit: Collaborating & Innovating



## LISTENING SUMMIT GOALS

Listen to patients, experts, partners and the community to establish priorities to educate young women of color on MBC.

Demonstrate the importance of access to innovations such as clinical trials and the barriers for young women of color.

Mobilize a network of diverse MBC ambassadors and experts to lower African-American breast cancer mortality rates.

## Opening Remarks

Madeline Long Poole

The MBC Disparities Listening Summit **Opening Remarks** were given by the emcee Madeline Long Poole, who shared the Summit's importance and goals, asked attendees to use their workbooks to organize their thoughts, which will shape our afternoon breakouts and to share on social media: @TigerlilyCares #ListenUpMBC.

**Welcome Remarks** were given by the Tigerlily Foundation's CEO, Maimah Karmo, who is a ten-year breast cancer survivor diagnosed at 32-years old with stage 2 breast cancer with no family history of breast cancer. She recognized those living with MBC, thanked the Summit sponsors, partners, Hyatt staff and the Tigerlily team and shared why this day is important as we manifest a better world together.

## Welcome Remarks

Maimah S. Karmo



## Collaborating to Accelerate Impact: Metastatic Breast Cancer Project (MBCp)

Angela Baker  
Imani Boykin  
Carla Harvey  
Sheila McGlown  
Colleen Nguyen  
Latonya Wilson

A conversation style panel on **Collaborating to Accelerate Impact: MBC Project** and HUMBLe which bring patients and researchers together as partners to access scientific discoveries and educate communities. Panelists shared the most effective ways to educate young women of color on MBC and their experiences living with MBC.

**Moderator:** Colleen Nguyen, MPH, Community Engagement Lead, Count Me In

### Panelists:

Angela Baker, MBCp Ambassador, Count Me In

Carla Harvey, MBCp Ambassador, Count Me In  
Sheila McGlown, MBCp Ambassador, Count Me In  
Latonya Wilson, MBCp Ambassador, Count Me In  
Imani Boykin, Howard University Metastatic Breast Cancer Learning Experience (HUMBLe)

Dr. Janeen Azare, Oncology Field Medical Director, Breast Cancer at Pfizer, Inc. prepared a presentation on **Diversifying Clinical Trials & Advancing Access to Innovation**. Our partners at Pfizer, Inc. graciously opted to reallocate their presentation time for the important patient and caregiver conversations that organically developed at the Summit.

## Diversifying Clinical Trials & Advancing Access to Innovation

Dr. Janeen R. Azare





# Summit: MBC & Panels

Kimberly Alcantara  
Shonte Drakeford  
Brandon Garrett  
Dr. Lori Wilson



## Metastatic Breast Cancer & Me

### Panelists:

Shonte Drakeford, RN, MBC Advocate

Kimberly Alcantara, MBC Advocate

Lori Wilson, MD, FACS, Division Chief of Surgical Oncology, Howard University, MBC Advocate

The **MBC & Me** panel provided insight into MBC patient, caregiver, provider and navigator experience. The following panelists addressed questions and shared thoughts on what MBC resources young women of color and caregivers need, what they have learned as a physician and what they need as patients. The following speakers shared their perspectives:

**Moderator:** Brandon Garrett, Chief Operating Officer, National Minority Quality Forum

The **MBC & The Community** panel was a conversation with community leaders on best practices to educate, engage and reduce barriers faced by young women of color impacted by MBC. Discussion topics included the role social media, faith, business and health care plays in educating and engaging patients and young women on MBC. The following speakers shared their perspectives:

**Moderator:** Ricki Fairley, CEO, Dove Marketing

### Panelists:

Ruth Travis, Breast Cancer Advocate,

Keith Gregory, MBA, Senior Director Radiation Oncology Operations, Inova Schar Cancer Institute

Jasmine Jones, Founder & COO, Cherry Blossom Intimates.

Ricki Fairley  
Keith Gregory  
Jasmine Jones  
Rev. Dr. Ruth Travis



## Metastatic Breast Cancer & The Community

The **MBC & Public Policy** panel gathered leaders with diverse perspectives in how participant's voices impact policies that improve access to MBC treatment and research for young women of color. The panelists shared how physician's, patient advocate organizations, local and federal government leaders can impact public policy. The following speakers shared their perspectives:

**Moderator:** Mia Keeyes, MA, Health Policy Advisor, U.S. Representative Robin Kelly

Tammy Boyd  
Dr. Regina Hampton  
Dr. Sara Horton  
Mia Keeyes  
Dr. Shalewa Noel-Thomas



## Metastatic Breast Cancer & Public Policy

### Panelists:

Tammy Boyd, MPH, JD, Chief Policy Officer, Black Women's Health Imperative

Regina Hampton, MD, FACS, Medical Director, Doctors Community Hospital

Sara Horton, MD, Oncologist, Howard University

Shalewa Noel-Thomas, MPH, PhD, Chief, Cancer and Chronic Disease Prevention Bureau,

DC Department of Health



# Summit: Remarks & Keynote



Jackii Wang  
U.S. Representative  
Debbie Wasserman  
Schultz



## Advocating for Young Women

**Advocating for Young Women** remarks on behalf of Rep. Debbie Wasserman Shultz were given by Jackii Wang who serves as the Congresswoman's Legislative Assistant. She shared the importance and progress of the EARLY Act, the impact of the legislation, collaborations and campaigns to the expanded focus on younger women since its passing, which the Tigerlily Foundation was instrumental in developing.

Henrietta Lacks' immortal HeLa cells continue to lead to some of the greatest scientific advancements of our time. This humble African-American woman from Virginia who came to live in Baltimore left behind 5 young children and a community that adored her when she passed at 31 years old after cancer metastasized throughout her body. Markette Sheppard, Host of Great Day Washington, WUSA 9 and David Lacks, Jr., Henrietta Lacks' Grandson explored the Lacks family experience with patient rights, medical advances made by their grandmother and how they partner with the health, research, scientific and entertainment industries to ensure patient access and empowerment through education and advocacy. **The Keynote Conversation** closed with questions and presented a gift.



David Lacks, Jr.  
Markette Sheppard

## Keynote Conversation

## Resources Shared

Below are highlights of the resources shared during panels and discussions at the Summit.

**FDA Oncology Center of Excellence Summer Scholars Program:** Exposes high school students and recent graduates to career opportunities in government, regulatory medicine and cancer advocacy.

**Have the Chat:** Resources, videos and tips to broach the topic of breast cancer and its impact with loved ones. This video highlights Shonte Drakeford who is a young woman living with MBC.

**Cherry Blossom Intimates:** Beyond the Pink Wall is a web series creating open conversations about breast health, self-care, self-love, bra fittings, and sisterhood.

**No More Martyrs:** Mental health resources committed to building a community of support for black women with mental health concerns.

**Story Half Told:** Pfizer's MBC education initiative to elevate understanding and conversation.

**Angle in Disguise:** Founded by Angela Baker, who is living with MBC and helping those impacted by breast cancer with tasks that they are unable or incapable of completing alone.

**Black Women's Health Imperative:** 2019 National Health Policy Agenda.

**Breast Cancer High Risk Assessment:** Myriad Genetics high risk education and quiz.



# Summit: Breakout & Report Out

**Mobilizing Against Metastatic Breast Cancer Disparities** Facilitators (listed to right) guided group discussion using the **Purpose to Practice (P2P) Model** to generate our shared purpose, principles, participants, and practices. By shaping these elements together, participants clarified how they can organize themselves to adapt creatively and scale up for success. Each Recorder (listed to right) captured the group discussion of the **4 P2P Questions** listed below.

## Mobilizing Against Metastatic Breast Cancer Disparities



**Lead Facilitator:** Shyrea Thompson | IRIS

**Lead Recorder:** Irene Rainville, MS, PhD, LCGC | Myriad

### Group Facilitators & Recorders Listed Below

Janeen Azure, PhD, MSPH | Pfizer

Imani Boykin | HUMBLE

Beth Burnett | Pfizer

Dionne Jones-Dendy | Pfizer

Ricki Fairley | Dove Marketing

Keith Gregory | Inova

Coral Jean-Mary | HUMBLE

Patti Fine Jewell | Pfizer

Colleen Nguyen, MPH | Count Me In

Dannielle Patterson | Lilly

Gloria Ward-Ravenell | SOSI

Lauren Wood | Humanly

<h3>Purpose</h3> <p>Why is the work important to you /the community?</p>	<h3>Principles</h3> <p>What rules must we follow in our pursuit of our purpose?</p>	<h3>Participants</h3> <p>Who must be included to achieve our purpose?</p>	<h3>Practices</h3> <p>What are we going to do and how will we do it?</p>
<p><b>"I Am A Survivor"</b></p> <p><b>Education</b> (MBC awareness, breast health, patient &amp; provider education, medical distrust)</p> <p><b>Disparities in WOC Treatment &amp; Outcomes</b> (save lives, younger late stage, AA mortality rate, diagnosis, timely follow-up, quality of life vs. time)</p> <p><b>Genetics</b> (family history &amp; impact on detection)</p> <p><b>Advocacy</b> (communication, sharing narratives, empower women, cultural, generational, community representativeness)</p>	<p><b>"My Voice Matters"</b></p> <p><b>Compassion</b> (individualized treatment &amp; engagement, empower informed decisions)</p> <p><b>Cultural Competency</b> (speak to your experience)</p> <p><b>Respect to Build Trust</b> (shared decision making, allow questions, transparency, be part of &amp; go to community in their safe places)</p> <p><b>Relevant Messaging</b> (use social media, real patients, target young, minority, multilingual, simplify the message)</p> <p><b>Dismantle Myths</b> (clinical trial myths, discussion dispel fears)</p> <p><b>Trusted In/Outreach</b> (share opportunities with those who can help)</p>	<p><b>"It Takes A Village"</b></p> <p><b>Policymakers</b> (local, state, federal)</p> <p><b>Patients</b> (diverse by race, age, geographic)</p> <p><b>Small Business</b></p> <p><b>Pharma/Corporate</b></p> <p><b>Nonprofit</b> (foundations, community, activists)</p> <p><b>Sororities &amp; Fraternities</b></p> <p><b>Media/Entertainment</b></p> <p><b>Students</b> (youth, colleges)</p> <p><b>Military/Veterans</b></p> <p><b>Incarcerated</b></p> <p><b>Health Care</b> (navigators, doctors, nurses, hospitals, primary care physicians, insurers, social workers, administrators)</p>	<p><b>"Give People HOPE"</b></p> <p><b>Communication</b> (AA clinical trials outcome success stories, public interest stories, network of voices, video series, engage influencers of all ages, ethnicities &amp; demographics, use apps)</p> <p><b>Education Partnerships</b> (community, faith, salons, family, sororities, national orgs, HBCUs, concerts, foster care, laundromats, sports events, high school advocacy curriculum)</p> <p><b>Health Care</b> (patient navigation, breast health educators, social workers, physicians, hospital administrators &amp; insurers, role play patient-provider communication to build empathy &amp; relationships)</p> <p><b>Patient Support</b> (caregivers, peer support pilot Tigerlily to partner w/health care institutions to offer all MBC patients local support)</p> <p><b>Policy</b> (patient advocacy training, match constituent needs, testify for bills, legislative diversity: local, state, federal)</p>



# Summit: Next Steps & Closing

Planning for Impact

What?

So What?

Now What?

## Next Steps

Report Outs

Shyrea Thompson, The IRIS Collaborative, Founder & Principal served as Lead Facilitator and Dr. Irene Rainvinelle, Genetic Counselor and Medical Information Liaison with Myriad Genetic Laboratories served as Lead Recorder. The discussion addressed: "What are the key observations and trends? So, what do these observations and trends mean? Now what actions will you take, and should we take?" Using the "What, So What, Now What" Next Steps model the following themes were recorded, clarified and confirmed by attendees at session close.

### What?

Key Observations & Trends

- Advocacy
- Education
- Patient Navigation
- Vulnerable populations
- Cultural competency
- Social Media
- Respect / Compassion
- Come to US

### So What?

Meaning & Thoughts

- Mammogram age restriction
- Medical education / sensitivity training
- Loosen restrictions on consultancy
- Campaigns to reach our community

### Now What?

Actions & Next Steps

- Mentorship programs
- MBC advisory committee
- MBC targeted legislation and advocacy
- Partner with existing support programs
- For us by us activism and conference

The Tigerlily Foundation's CEO, Maimah Karmo, **Reflection** on why we came together, recognized those living with MBC, honored those who passed from MBC and addressed some of the observations from the day and how she envisions moving ahead – through love and collaboration. She thanked the attendees for coming to this first historic step. Madeline closed out the Summit by asking attendees to submit their evaluations and to take the spirit of the day with them into their work.

## Reflection

Maimah S. Karmo

I manifest  
love.



# Evaluation Findings

When asked, Summit survey respondents gave the answers grouped into the following themes:

## Key Points Learned at the MBC Disparities Listening Summit



### MBC Disparities

Young women  
Women of Color



### Education

Representativeness  
Resources  
MBC Awareness  
Media/Communications



### Respect

Compassion  
Patient Experience  
Patient Needs



### Treatment

Access to Best Therapies  
Patient Centered  
Patient Adherence



### Advocacy

Speak Up  
Advocate  
Community Engagement  
Influencers

## Suggested MBC Young WOC Education Campaign Offerings

- **Genetic Testing** | Create awareness of health history to guide decisions on certain therapies, e.g. PARP inhibitors.
- **Clinical Trials** | Resources and support; listen to patients; therapies and clinical trials by breast cancer type.
- **Materials** | Educate our own communities, such as video or brochures; reading materials, monthly chats.
- **MBC Education** | Information on the different types of metastatic breast cancers: “not all MBC is the same”.
- **Patient Navigation** | Lead a policy making effort; provide culturally competent navigation; and support to help patients “stay the course and not deviate from the process”.

## Suggestions for Tigerlily’s Top Priority in Educating Young WOC on MBC



### Education

Clinical Trials Access  
MBC Can Affect Anyone  
MBC Curriculum & Guide  
MBC’s Cultural Impact  
Healthy Lifestyles



### Actions

Public Policy & Advocacy  
More Summits/Sessions  
In/Outreach  
Black Church Partnerships  
Early Detection & Intervention

## Summit Key Informant Interviews

*Follow up interview highlights grouped below:*

- **Caregiver Support:** More resources for multilingual families.
- **Policy:** Create MBC WOC network/alliance.
- **Campus:** Train students to educate others.
- **Business:** Partner with diverse businesses.
- **Patient Care:** Patients should not have to choose between quality of life and long life. We need MBC experts, not just oncology generalists.

## Summit Concepts to Implement in Your Work

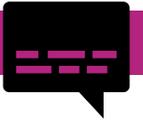
- **Representativeness** | Images of women with MBC need to represent WOC, and not be predominantly white middle-age or older women; and listening to the unique voice of MBC patients.
- **Education** | MBC and breast health education needs - what is it, whom does it effect, treatment options, resources, etc.; meet people where they are and to inform the next generation.
- **Collaboration** | Working with community organizations to address the disparities gap; supporting one another; provide help; and get resources from prominent people that already have a seat at the table.
- **Advocacy** | Talking to lawmakers about breast cancer survivors who do not have insurance; informing youth audiences on their impact on advocacy.
- **Respect** | Respect and compassion; “for us, by us”; and hearing and listening.



# Discussion & Recommendations

After reviewing the Summit activities and evaluation data, detailed recommendations are below.

## Discussion



Survey feedback, informant interviews, post Summit discussions indicated the following:

- The Summit's **patient focused approach** created a safe place to meaningfully engage, share and have honest conversations which **addressed historical injustices and disparities patients and WOC face.**
- **Diversity of attendee's race, gender, age, occupation and knowledge fostered insightful discussion** on access to timely and **culturally concordant treatment; advocacy** and patient centered care.
- Purpose to Practice P2P and **What, So What, Now What Breakout Sessions** provided a clear **framework for trends, thoughts and next steps.**
- The attendee **workbooks** and program participant **Know Before You Go Briefing** were noted to be helpful tools to follow and prep for the Summit.

## Informal Observations



The Summit featured extensive frank discussion on experiences of WOC and MBC patients. **Attendees expressed their real perspectives on how WOC should be treated, empowered and engaged; and created a safe space for honest and candid discussion.**

## Opportunities



Participants noted the following:

- **Network/Alliance:** Advocacy Training & Support
- **Genetic** Testing Information
- **Access:** Travel stipend & Online Opportunity
- **Summit Format:** More breaks to engage with speakers/attendees and break out sessions.

## Recommendations



Based on Summit participant, partner, expert, patient and caregiver feedback the following **recommendations** were prioritized by attendees:

- **MBC Disparities Mentorship Programs**
- **MBC Disparities Advisory Committee**
- **For Us by Us Activism & Conference**
- **MBC Targeted Legislation & Advocacy**
- **Partner with Existing Support Programs**

**Additional recommendations** include:

- **Hosting a Virtual Summit/Series**
- **Creating an MBC Disparities Alliance/Network**
- **Providing Travel Stipends for Future Summits**
- **Providing Sessions on Genetic Testing**

*"This Summit has the most women of color living with MBC that I've ever met." - Shonte*

*"MBC doesn't have a color; it can affect anyone." - Anonymous*

*"Women have faced disparities for years, women of color have faced inequities for many years, MBC patients have faced disparities for many years. It's time to end that triple threat to women." - Maimah*

## Conclusions

**The Summit aimed to listen** to insights which was achieved, as 100% of attendees felt the Summit met their expectations and 99% are interested in developing next steps. Tigerlily will apply these recommendations to **create** culturally sensitive materials to **mobilize** ambassadors **through advocacy and partnership to lower African-American breast cancer mortality rates.** Join the #ListenUpMBC conversation and follow our progress at: [tigerlilyfoundation.org](http://tigerlilyfoundation.org).



# Stay Connected #ListenUpMBC

## Programs



### Have the Chat

Resources, videos and tips to broach the topic of breast cancer and its impact with loved ones.



### My Life

My Life offers resources and views of young women living with metastatic breast cancer.



### New Normal Journal

The New Normal Journal provides young survivors with tools to navigate life during and after breast cancer.



### SPIRIT Retreat

4-days at Unity Village to enjoy the beauty of nature, rejuvenation, and spiritual support tools for you and your caregiver.



### 24/7 Prayer Line

Young women with breast cancer call 888-803-4680 for confidential support.



### YWBHD on the Hill

Young Women's Breast Health Day on the Hill (YWBHD) brings together researchers, policy makers, patients, caregivers, physicians and healthcare professionals to advocate for quality care for young women – before, during and after breast cancer.

## Social



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## Tigerlily Foundation

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## Save the Date!

Young Women's Breast Health Day on the Hill  
**October 2019 | Washington, DC**