Summary Report

PRESENTED IN PARTNERSHIP WITH:
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.

In Service,

Maimah S. Karmo
President & Founder
Tigerlily Foundation
METASTATIC BREAST CANCER DISPARITIES LISTENING SUMMIT

By the Numbers

MARCH 20, 2019 | WASHINGTON, DC

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

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
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.

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

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

LISTEN

P
Listen to identify needs, priorities, barriers, partners & methods at Summit

CREATE

P
Create a metastatic breast cancer disparities education & outreach campaign

MOBILIZE

P
Mobilize young women of color to lower African-American breast cancer mortality rates

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.
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.

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 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.
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

**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 & 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

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 Keeys, MA, Health Policy Advisor, U.S. Representative Robin Kelly

**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
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.

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.

Resources Shared

**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.
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.

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

**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
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.

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.
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”.

**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.
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.

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

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.

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.

"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
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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@TigerlilyFoundation

Tigerlily Foundation

Address: 42020 Village Center Plaza Suite 120-156 Stone Ridge, VA 20105
Email: info@tigerlilyfoundation.org
Phone: 888-580-6253
Fax: 703-663-9844

Save the Date!

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