Tigerlily Foundation

YOUNG WOMEN’S METASTATIC BREAST CANCER DISPARITIES

Fireside Chat

San Antonio Breast Cancer Symposium
December 10, 2019
7:00 – 11:15 AM

#ListenUpMBCC
Ground Rules
Respect.
Honesty.
Speak-up.
Agree to disagree.
Build Trust.
Heart.

Wi-Fi Information
Password: Cavalier

#ListenUpMBC

Getting Connected
If they don’t give you a seat at the table, bring a folding chair.

-Shirley Chisholm
Welcome Remarks
Maimah S. Karmo

#ListenUpMBC
Setting the table for change.
MBC ANGEL Advocates will combat disparities for black women in the U.S. who:

• Get breast cancer at about the same rate as white women, however **black women are nearly 40% more likely to die from breast cancer than white women**. In some areas this rate can be as high as 70% more.

• Often go underrepresented in the conversation on the unique needs of women living with stage 4 breast cancer.

• Are more likely to be screened at lower resourced and non-accredited facilities and experience longer intervals between mammograms, and between abnormal results and follow-up.

• **Due to a long history of injustices, mis-trust the scientific and health care system**, resulting in alarming outcomes, barriers to health care, lower participation in clinical trials and genetic testing.

• Are more likely than white women to be diagnosed younger and develop more aggressive forms of breast cancer such as triple-negative.
Young Women’s MBC Disparities Initiative’s Objectives:

- Build a global platform that will end breast cancer disparities among young women of color in our lifetime.
- Facilitate conversations with MBC patients, experts & partners to educate young women of color on MBC disparities.
- Demonstrate the importance of access to innovations in MBC treatments including clinical trials for women of color record the barriers & misperceptions faced by young women of color.
- Create partnerships, tools, content, messages, & methods to lower black breast cancer mortality rates.
- Mobilize a network of diverse MBC ambassadors and experts to partner with Tigerlily on how to best meet the needs of their community.
FOCUS

Tigerlily will listen to gather insights to create a metastatic breast cancer disparities advocacy, education and outreach campaign to mobilize young women of color to build a global platform that will end breast cancer disparities among young women of color in our lifetime.
METASTATIC BREAST CANCER DISPARITIES LISTENING SUMMIT

By the Numbers

MARCH 20, 2019 | WASHINGTON, DC

1,030+
Social Posts Using #ListenUpMBC

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

OF ATTENDEES INTERESTED IN DEVELOPING NEXT STEPS
*of survey respondents

99%

Voices At the Table
10 WOC Attendees Living with MBC
15 Attendees Living with MBC
33 Program Participants
67+ Attendees

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

Young Women’s Metastatic Breast Cancer Disparities Alliance

Young Women’s Metastatic Breast Cancer Disparities Alliance
Advocate, Now to Grow, Empower & Lead
ANGEL Advocates
1st Young Women of Color Metastatic Breast Cancer (MBC) Disparities Alliance

50 Patients, experts, caregivers, partners, policymakers & community leaders

1 Goal to establish priorities to form an alliance to end MBC disparities.

4 Cs of Coalition Building In Communities of Color

CREATE | Activities recommended to plan and initially organize
• Recruit a core planning committee
• Put relationships first
• Identify initial vision & common concerns

CONNECT | Help group to become grounded as an organization

COMMIT | How the group will function effectively over time

CELEBRATE | Importance of celebration to the coalition’s success

Action plan. Working group to draft a plan with proposed deadline for full Alliance review.

Next Meeting. January 28, 2019 | 12 – 1 PM ET
Virtual alliance meeting to develop the goals & objectives.

Follow Up Date. December 20, 2019
Hill Day follow up with meeting minutes, materials & next steps.

#ListenUpMBC we are MOBILIZED!
Together, MBC ANGEL Advocates Will:

**COMMIT**
Commit to advocacy program to learn, share, grow, host events & other outreach activities to educate your community.

**ATTEND**
Attend and actively participate in all Tigerlily Advocate trainings and at least 1 to 2 conferences with travel support.

**AMPLIFY**
Amplify the conversation on social media via Facebook, Instagram, Twitter, LinkedIn, and blogging.

**HOST**
Host at least 3 Tigerlily supported educational or outreach events to engage and educate community members.

**PARTICIPATE**
Participate in monthly Advocate calls for training, updates, partnerships, and opportunities.

+60 Local MBC Education & Outreach Activities
+12 MBC Advocate Social Media Resources
8 MBC Advocate Modules & Training Sessions
+20 MBC Advocates Participate in Conferences
20 CITIES.
20 MBC ANGEL ADVOCATES.
OUR AREAS OF IMPACT

Memphis       Detroit
St. Louis     Cleveland
Dallas Fort-Worth     Miami
Los Angeles      Charlotte
Virginia Beach   Oakland
Atlanta         New York
Chicago         New Orleans
Houston         Jackson, MI
Washington, DC    Camden, NJ
Philadelphia
Baltimore
A Heart to Heart Conversation

J Caldwell
Maimah S. Karmo
MBC Disparities: Looking Back to Move Ahead

Shawn Johnson
How Patient Advocates Changed Me

“Of all the forms of inequality, injustice in health is the most shocking and the most inhumane.” – Martin Luther King Jr.

Shawn Johnson
Harvard Medical School
M.D. Candidate, Class of 2021
“This isn’t a good patient to follow...you won’t learn anything from it.”
My First Lesson – Whose voices do we prioritize?
My First Lesson – Whose voices do we prioritize?

Trump Administration Ends Protected Status for Thousands of Hondurans

The New York Times

Trump Administration Says That Nearly 200,000 Salvadorans Must Leave

Politics

Trump administration announces end of immigration protection program for ‘dreamers’
My First Lesson – Whose voices do we prioritize?
My First Lesson – Whose voices do we prioritize?
My First Lesson – Whose voices do we prioritize?
My First Lesson – Whose voices do we prioritize?
“We can’t do that...it’s too complicated.”
My Second Lesson – No longer accepting “This is the way it’s always been”, “It’s too complicated”, etc
My Second Lesson – No longer accepting “This is the way it’s always been”, “It’s too complicated”, etc

Trastuzumab after Adjuvant Chemotherapy in HER2-Positive Breast Cancer
My Second Lesson – No longer accepting “This is the way it’s always been”, “It’s too complicated”, etc.

<table>
<thead>
<tr>
<th>Variable</th>
<th>1 Yr of Trastuzumab (N=1694)</th>
<th>Observation (N=1693)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Region — no. (%)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Western and Northern Europe, Canada, South Africa, Australia, New Zealand</td>
<td>1208 (71.3)</td>
<td>1222 (72.2)</td>
</tr>
<tr>
<td>Asia Pacific, Japan</td>
<td>203 (12.0)</td>
<td>202 (11.9)</td>
</tr>
<tr>
<td>Eastern Europe</td>
<td>189 (11.2)</td>
<td>175 (10.3)</td>
</tr>
<tr>
<td>Central and South America</td>
<td>94 (5.5)</td>
<td>94 (5.6)</td>
</tr>
<tr>
<td><strong>Race — no. (%)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>1411 (83.3)</td>
<td>1406 (83.0)</td>
</tr>
<tr>
<td>Asian</td>
<td>210 (12.4)</td>
<td>207 (12.2)</td>
</tr>
<tr>
<td>Black</td>
<td>12 (0.7)</td>
<td>8 (0.5)</td>
</tr>
<tr>
<td>Other</td>
<td>57 (3.4)</td>
<td>67 (4.0)</td>
</tr>
<tr>
<td>Missing</td>
<td>4 (0.2)</td>
<td>5 (0.3)</td>
</tr>
</tbody>
</table>
My Second Lesson – No longer accepting “This is the way it’s always been”, “It’s too complicated”, etc

<table>
<thead>
<tr>
<th>Age</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Median (range) — yr</td>
<td>62 (30–89)</td>
<td>61 (28–88)</td>
</tr>
<tr>
<td>&lt;65 yr — no. (%)</td>
<td>263 (59.2)</td>
<td>141 (63.5)</td>
</tr>
<tr>
<td>≥65 yr — no. (%)</td>
<td>181 (40.8)</td>
<td>81 (36.5)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Race — no. (%)†</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>344 (77.5)</td>
<td>172 (77.5)</td>
</tr>
<tr>
<td>Asian</td>
<td>65 (14.6)</td>
<td>30 (13.5)</td>
</tr>
<tr>
<td>Black</td>
<td>8 (1.8)</td>
<td>3 (1.4)</td>
</tr>
<tr>
<td>Other</td>
<td>27 (6.1)</td>
<td>17 (7.7)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>ECOG performance status — no. (%)‡</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>257 (57.9)</td>
<td>102 (45.9)</td>
</tr>
<tr>
<td>1</td>
<td>178 (40.1)</td>
<td>117 (52.7)</td>
</tr>
<tr>
<td>2</td>
<td>9 (2.0)</td>
<td>3 (1.4)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Disease stage at initial diagnosis — no. (%)</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>51 (11.5)</td>
<td>30 (13.5)</td>
</tr>
<tr>
<td>II</td>
<td>137 (30.9)</td>
<td>68 (30.6)</td>
</tr>
<tr>
<td>III</td>
<td>72 (16.2)</td>
<td>39 (17.6)</td>
</tr>
<tr>
<td>IV</td>
<td>138 (31.1)</td>
<td>72 (32.4)</td>
</tr>
<tr>
<td>Unknown</td>
<td>36 (8.1)</td>
<td>12 (5.4)</td>
</tr>
<tr>
<td>Other or data missing§</td>
<td>10 (2.3)</td>
<td>1 (0.5)</td>
</tr>
</tbody>
</table>

2016
My Second Lesson – No longer accepting “This is the way it’s always been”, “It’s too complicated”, etc
“Cancer Centers occupy a unique role in their communities. They are expected to perform research of particular relevance to their catchment area and engage the populations within their catchment area in the research they conduct. In order to facilitate this, Centers thoroughly analyze the demographics and cancer burden of their catchment area. In addition, Centers are expected to engage communities within their catchment area to decrease their cancer burden, particularly among minority and underrepresented populations.” – National Institutes of Health
My Second Lesson – No longer accepting “This is the way it’s always been”, “It’s too complicated”, etc

Washington, D.C.

Houston

New York City

Race

47.7%

58.5%

42.8%

White

Black or African American

American Indian and Alaska Native

Asian

Native Hawaiian and Other Pacific Islander

Some Other Race

Two or More Races

40.7%

22.9%

24.3%

9.5%

6.7%

14.0%

15.1%
My Second Lesson – No longer accepting “This is the way it’s always been”, “It’s too complicated”, etc
My Second Lesson – No longer accepting “This is the way it’s always been”, “It’s too complicated”, etc
My Third Lesson – The “Impossible” Can Be Changed When Patients Have A Voice
My Third Lesson – The “Impossible” Can Be Changed When Patients Have A Voice

Tigerlily Foundation

Featured Speakers

Sheila McGlown
MBC Advocate

Dr. Lori Wilson
Oncologist & MBC Advocate

Ricki Fairley
Patient Advocate

YOUNG WOMEN’S METASTATIC BREAST CANCER DISPARITIES

Fireside Chat

Together, we will end breast cancer disparities among young women of color in our lifetime. Join the conversation. Follow @TigerlilyCares and share using:

#ListenUpMBC

DECEMBER 10, 2019 | 7:30 – 11 AM CST
LIVE FROM SAN ANTONIO BREAST CANCER SYMPOSIUM

PRESENTED IN PARTNERSHIP BY:
Still, it is a mistake to attribute African Americans’ medical reluctance to simple fear generated by the Tuskegee Syphilis Study, because this study is not an aberration that single-handedly transformed African American perceptions of the health-care system. The study is part of a pattern of experimental abuse, and many African Americans understand it as such, because a rich oral tradition has sustained remembrances of pain, abuse, and humiliation at the hands of physicians.

“Know from whence you came. If you know whence you came, there are absolutely no limitations to where you can go.” – James Baldwin
In August of 1619, a ship appeared on this horizon, near Point Comfort, a coastal port in the British colony of Virginia. It carried more than 20 enslaved Africans, who were sold to the colonists. No aspect of the country that would be formed here has been untouched by the years of slavery that followed. On the 400th anniversary of this fateful moment, it is finally time to tell our story truthfully.
“At the expiration of that time, [Dr. Thomas Hamilton] set to work to ascertain how deep my black skin went. This he did by applying blisters to my hands, legs and feet, which bear the scars to this day. He continued until he drew up the dark skin from between the upper and the under one.

He used to blister me at intervals of about two weeks. He also tried other experiments upon me, which I cannot dwell upon. Altogether, and from first to last, I was in his hands, under treatment, for about nine months, at the end of which period I had become so weak, that I was no longer able to work in the fields.”
My Fourth Lesson – We Cannot Forget How We Got Here
My Fourth Lesson – We Cannot Forget How We Got Here

Burning Our Birthmarks, Blemishes of the Skin and Even Turning a Negro White with the Magic Rays of Radium, the New Mystery of Science!

This operation is a new development in the treatment of cancer. The Philadelphia Hospital, in cooperation with the University of Pennsylvania, has perfected a new method of treating cancer with radium. This operation is said to be successful in a large number of cases.

The procedure involves the insertion of radium in the affected area. The radium is then slowly removed, allowing the body to heal itself. After a few weeks, the radium is removed, and the patient is cured.

The results have been very promising, and many patients have been cured of cancer using this method. The procedure is painless, and the patient is left with no permanent damage.

In conclusion, the use of radium in the treatment of cancer is a revolutionary development that has changed the way we treat this disease. With continued research, we may be able to find even more effective ways to treat cancer using radium.
The Tuskegee Syphilis Study (1932-1972)
[Peter Buxtun] learned of the study and immediately risked his job by writing his superiors to ask that it be stopped. A handful of PHS physicians responded by holding meetings, at which they lectured Buxtun on the scientific merits of their work and decided to continue the study.

In 1972, Buxtun, exasperated by seven years of PHS inaction, told a journalist friend about the study. On July 25 of that year, Jean Heller broke the story for the Associated Press.

The news media, physicians, politicians, and ordinary citizenry, black and white, expressed horrified anger and demanded an explanation from the government and some sort of assurance that such cruelty would never again be sanctioned by the PHS.

“Still, it is a mistake to attribute African Americans’ medical reluctance to simple fear generated by the Tuskegee Syphilis Study, because this study is not an aberration that single-handedly transformed African American perceptions of the health-care system. The study is part of a pattern of experimental abuse, and many African Americans understand it as such, because a rich oral tradition has sustained remembrances of pain, abuse, and humiliation at the hands of physicians.”

Collaborating to Accelerate Access to Innovations

Nikia Blakey
Angela (Jersi) Baker
Sheila McGlown
Breast Cancer: A Story Half Told

Breast Cancer: A Story Half Told is an initiative by Pfizer in partnership with advocates, patients and healthcare professionals that aims to elevate public understanding of metastatic breast cancer, dispel misperceptions, combat stigma and expand the breast cancer conversation to be more inclusive of metastatic breast cancer.

- Empowers people with MBC to be storytellers, capturing their lives through photography,

- The initiative included diverse patients including Khadijah Carter, an African American female from New York, and Esther Garza, a Hispanic woman from Texas

- Resources also include statistics on ethnic disparities and public perceptions

- Since the initiative launch in 2014, the social media reach and website metrics (i.e. page views, visits) represent almost 29.7 million impressions

  - In 2017, the program will launch it's first male MBC patient to include men in the conversation

"Additionally, most people believed breast cancer death rates are the same across various ethnic groups. In reality is that while death rates are decreasing across ethnicities, five-year survival is much lower in certain ethnic groups than in the Caucasian population. African-American women with breast cancer are on average 40 percent more likely to die of the disease than white women with breast cancer. For Hispanic women, breast cancer is the leading cause of cancer death."
YOU
• 1 min: YOUR 1 word that describes the culture of engaging metastatic young women of color in scientific conferences
• 4 mins at table to each discuss YOUR 1 word.

TABLE
• 3 mins - word that represents the entire TABLE.

EVERYONE
• What can we do to shift this culture?
• Is the solution at this table?
• Do we need to invite someone else to this table?
YOU
• 1 min: YOUR 1 word that describes the culture of engaging metastatic young women of color in scientific conferences
• 4 mins at your table to each discuss YOUR 1 word.

TABLE
• 3 mins to pick the word that represents the entire TABLE.

EVERYONE
• What can we do to shift this culture?
• Is the solution at this table?
• Do we need to invite someone else to this table?
Dr. Lori Wilson
Howard University

Fireside Keynote

Coming to the Table Together: From Provider to Patient to MBC Advocate
Don’t Forget:
Grab your mobile device of choice and return ready for the tweet-up!
We Are Ending Clinical Trial Disparities

Zora Asberry
Ms. Ricki Fairley
Dr. Virginia Kaklamani
Dr. Tatiana Prowell
Ms. Tiah Tomlin

#TweetUpMBC

Together we will end breast cancer disparities among young women of color in our lifetime. Help amplify our message. Follow @TigerlilyCares and share using: #ListenUpMBC
3 ways to share your voice using #ListenUpMBC

▪ Take A Pic!: Share a photo of your group using #ListenUpMBC and your message

▪ Video/Boomerang / GIF: Share a quick video or loop of your group using #ListenUpMBC and your message

▪ Ah Ha Moment: Post, Share or Tweet your group’s favorite thought, quote or moment from today using #ListenUpMBC
Mobilizing to End Young Women’s MBC Disparities Together

Maimah S. Karmo
Shonte Drakeford
Christine Hodgdon
Julia Maues
Jasmine Soeurs
Marissa Thomas

OUR GUIDE TO BEING AN ACCOMPlice

At For the Breast of Us, we exist to build community among and elevate the narratives of women of color who thrive without accomplices. While an ally is someone who stands by your side, an accomplice actively participates. We invite those who do not identify as women of color to be a #BreastCancerBadass accomplice in our fight for WOC and the health disparities they create.

#ListenUpMBC
@tigerlilycares
ANGELS@TigerlilyFoundation.org

Thank You!