



**Tigerlily**  
Foundation

YOUNG WOMEN'S  
METASTATIC BREAST CANCER DISPARITIES

# *Fireside Chat*

San Antonio Breast Cancer Symposium

December 10, 2019

7:00 – 11:15 AM

## *Impact Report*



# *#ListenUpMBC*



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

# YOUNG WOMEN'S METASTATIC BREAST CANCER DISPARITIES FIRESIDE CHAT

*By the Numbers*

December 10, 2019 | San Antonio Breast Cancer Symposium (SABCS)

## 8 MILL+ IMPRESSIONS

**+125 Attendees**  
engaged at SABCS &  
online [Twitter Chat](#)  
using #ListenUpMBC

**+4M Impressions**  
@Maimah Tigerlily's  
Founder & CEO trending  
online & at SABCS

**3.3M Impressions**  
online displays  
of #ListenUpMBC

**+400 Views of**  
streamed [Facebook Live](#)

## VOICES AT THE TABLE

15+ Women of color attendees living with MBC

25+ Attendees living with MBC

60+ Patient advocate attendees

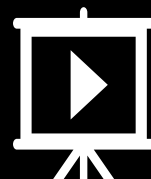
CLICK BELOW FOR MATERIALS



[Report  
Bios](#)



[Slides](#)



[Video](#)

## MEDIA

- [‘I belong here’: Advocate Works to Raise Profile of Black Women with Breast Cancer](#)
- [Tigerlily Foundation Hosts Historic Young Women's Metastatic Breast Cancer Disparities Fireside Chat](#)
- [What's New in Breast Cancer Research: #SABCS19 Edition](#)
- [Cancer Patient Advocates Find Strength in Numbers](#)
- [The Violence of Cancer](#)

CLICK ABOVE FOR ARTICLES



## #ListenUpMBC Pledge\*

I WILL

- Listen to diverse voices to hear their unique perspectives
- Create opportunities for diverse patients to lead
- Invite new diverse advocates and/or partners to convenings
- Participate only in MBC opportunities with diverse representation
- Invest in activities led by diverse leaders in their communities

\*Learn more, view event photos or take the pledge at [TigerlilyFoundation.org](https://www.tigerlilyfoundation.org)

## 99%<sup>\*\*</sup> OF

ATTENDEES BELIEVE  
A YOUNG WOMEN'S  
MBC DISPARITIES  
ALLIANCE IS NEEDED



\*\* of survey respondents



# Fireside Chat Agenda

**REGISTRATION & BREAKFAST**

**Opening Remarks**

**#ListenUpMBC  
Welcome Remarks**

**A Heart to Heart Conversation**

**MBC Disparities:  
Looking Back to Move Ahead**

**Collaborating to Accelerate  
Access to Innovations  
(Facebook Live)**

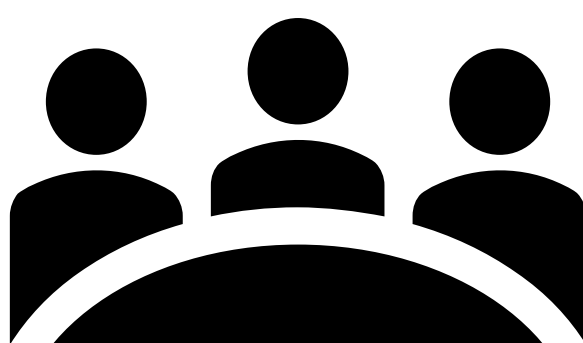
**Fireside Keynote  
Coming to the Table Together:  
From Provider to Patient  
to MBC Advocate**

**BREAK**

**#TweetUpMBC  
We Are Ending  
Clinical Trial Disparities  
(Twitter Chat)**

**#StandUpMBC  
Closing Conversation  
Mobilizing To End Young Women's  
MBC Disparities Together**

**If they don't give you a seat at the table  
bring a folding chair. - Shirley Chisholm**



## THANK YOU

*Dear Fireside Chat Attendees,*

*Thank you for attending our Young Women's MBC Disparities Fireside Chat at SABCS. Your attendance and insights helped make this historic next step impactful. We are excited to share this report, which features highlights from trending social media moments. We remain grateful that you amplified this important effort and to our partners for the continued support.*

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

*In Service,*

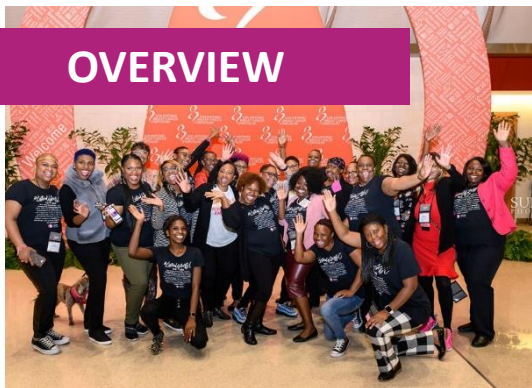
**Maimah S. Karmo**  
President & Founder  
Tigerlily Foundation





# Executive Summary

## OVERVIEW



centered on understanding the gaps, misperceptions and barriers faced by young women of color impacted by MBC disparities. Working with and learning from those at SABCS, “MBC ANGELS (Advocate Now to Grow, Empower & Lead)” raised their voices, received training and tools to make an impact in their communities. Our [#ListenUpMBC twitter chat](#), [Facebook Live](#) and campaign trended with over 8 Million impressions – demonstrating the need to mobilize to create a seat at the table to end MBC disparities for young women of color.

African Americans are 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. To mobilize against these facts, Tigerlily launched the Young Women’s MBC Disparities Initiative and partnered to host the [2019 MBC Disparities Listening Summit](#). Based on Summit recommendations the MBC Disparities Fireside Chat engaged young women of color who are usually not “at the table” in advocacy work and at scientific conferences. The Fireside Chat at the [San Antonio Breast Cancer Symposium](#)



## ATTENDEES



Convening of over **125 attendees in the room, including over 50 women of color and over 400 online** sharing their unique perspectives with scientists, health care providers, industry leaders, state and federal government leaders and policymakers. Digital media influencers including radio and tv, social media influencers and local celebrities.

**Tigerlily Foundation  
thanks our contributors  
for the generous support.**



## METHODS



Attainment of the Fireside Chat goals were assessed by reviewing qualitative and quantitative data sources and outcomes through this Report prepared by The IRIS Collaborative. Data Sources include on-site, post-hoc, exit survey, social media and informal observational data. Tigerlily will use this report to inform MBC education and advocacy for young of color.



# Speaker & Presentation Highlights



Welcoming our guests today is our MC, TV personality @ZoraAsberryTV to our Fireside Chat #listenupMBC #SABCS19



**Welcome Remarks** on how we are **Setting the Table for Change** were given by Tigerlily Foundation's CEO, Maimah Karmo, a 13-year breast cancer survivor who was diagnosed at 32-years old with stage 2 breast cancer with no family history of breast cancer. She recognized the MBC ANGEL Advocates, thanked partners, the Tigerlily team and shared why diverse patient perspectives at scientific conferences are vital to ending disparities.



**Dr. Kelly Shanahan** @stage4kelly · Dec 10, 2019  
Grateful to be @tigerlilycares event this AM at #SABCS19, especially to hear the late @CultPerfectMoms's husband @thejhcalldwell talk with @Maimah about being a #Caregiver. #bcsm



**MBC Disparities: Looking Back to Move Ahead** a presentation by Shawn Johnson medical student in the Pathways M.D. program at Harvard Medical School who explored how having open conversations with MBC patient advocates about equity and justice in medicine have impacted his work, the history of medical abuse and structural racism that led to current healthcare disparities, and solutions to address these issues by learning from social justice movements.

**Opening Remarks** were given by the emcee Zora Asberry, San Antonio TV personality, who shared the Fireside Chat's importance to her as her own mother was a breast cancer survivor. She highlighted the disparities in breast cancer outcomes for young women of color and the barriers to care. Zora encouraged attendees to use the ground rules to create a safe space which includes respect, honesty, speaking-up, agreeing to disagree, building trust and heart. Attendees were invited to share the conversation on social media @TigerlilyCares using #ListenUpMBC.



**Tambre Leighn** @tambreleighn · Dec 10, 2019  
#listenupMBC @Maimah getting us started at @tigerlilycares discussing disparities in metastatic breast cancer and "building your own table", if that's what it takes. #SABCS19 #bcsm #MBC



**A Heart to Heart Conversation**, J Caldwell sat down with Maimah to talk about how his wife, and her friend, Beth Caldwell, founding member of Metavivor and MET UP, pushed to bring the patient voice to scientific conferences. They shared how the "violence of cancer", ravages not only patients, but also families and loved ones. They closed with how patients, MBC patients and caregivers can come together to advocate and support each other.



**Stephanie Walker** @faceofstage4 · Dec 10, 2019  
Shawn Johnson said: the cases that need follow through are the ones who won't make money. That's me follow up and ask me. #SABCS19 #listenupmbc #LBBC #Metup #TeamStephanie







# Panel & Keynote Highlights



allison the metawarrior  
@1canonlybme

They look like me and have the same story....  
advocating for women of color [#listenupmbc](#)  
[#tigerilycares](#) we are fighting for disparities in our  
community. We fight to live, fight you treatment,  
fighting for our daughters and their daughters



**Collaborating to Accelerate Access to Innovations** panel was moderated by breast cancer survivor Nikia Blakey, Founder & Executive Director, The Champion Promise Foundation led a discussion on their experience with trials, community programs and initiatives to increase access for women of color with Angela (Jersi) Baker, Founder, Angel in Disguise, Inc., MBCp Ambassador, Count Me In and Sheila McGlown, MBC Advocate, Story Half Told. The conversation was streamed on [Facebook live](#) for those unable to attend SABCS to engage along with those in the room.

**Fireside Keynote - Coming to the Table Together: From Provider to Patient to MBC Advocate**, Dr. Lori Wilson, Division Chief of Surgical Oncology, Howard University reflected on her journey highlighted in [Ken Burns', Cancer: The Emperor of All Maladies](#) to her devastating recent diagnosis. Emphasizing patients should not be blamed, the need to be seen as people, not wanting to choose between quality of life and time and the importance of patient centered care.



Anastasia Renee' @TheEvolution\_Me · Dec 10, 2019

Thank you Dr Wilson for your transparency, vulnerability and your perspective! You are outstanding, amazing and beautiful!  
[#listenupMBC](#) [@tigerilycares](#)



Dr. Kelly Shanahan @stage4kelly · Dec 10, 2019

Dr Lori Wilson, head of surgical oncology at @HowardU, giving the keynote @tigerilycares #ListenUpMBC event. Dr Wilson herself has #MBC. She reminds us our MBC is not our fault. #SABCS19 #oncoalert



Stacey Tinianov @coffeemommy · Dec 10, 2019

Rockstar panel talking social media, disparities in research & advocacy. How Might We? Well... it's going to take a big arse village. Good thing this room is absolutely packed! [#SABCS19](#) [#bcsm](#) [#ListenUpMBC](#)



**We Are Ending Clinical Trial Disparities** panel and [twitter chat with the MBC Alliance](#) was informed by Zora, Ricki Fairley, Vice President, Strategic Partnerships & National Programs, Sister's Network; Dr. Virginia Kaklamani, Assistant Dir., Clinical Research Leader, University of Texas Health Science Ctr, San Antonio; Dr. Tatiana Prowell, Breast Cancer Scientific Liaison, Office of Oncologic Diseases, FDA; Associate Professor of Oncology, Breast Cancer Program, Johns Hopkins Kimmel Cancer Ctr; and Tiah Tomlin, Co-founder, My Style Matters.

**Closing Conversation, Mobilizing To End Young Women's MBC Disparities Together** with Maimah, Shonte Drakeford, MBC Advocate; Christine Hodgdon and Julia Maues, GRASP; and Jasmine Soeurs and Marissa Thomas, For the Breast shared how early stagers and later stagers can collaborate, [tools for cross-cultural partnerships](#) and ended with a pledge to only participate in opportunities that include MBC women of color as this community dies more and needs us all working together as allies.



swaggssheila @swaggssheila1 · Dec 10, 2019

Mobilizing to End Young Women's MBC Disparities Together [@tigerilycares](#)  
[@itsnot\\_pink](#) [@christeeny513](#) [@thebreastofus](#) [@Maimah](#)





# Tweetable Moments

**MBC is not my fault.**

- Dr. Lori Wilson

**We can talk about wanting a place at the table, or we can become our own table.**

- Maimah Karmo



**Spirit Jones** @SpiritJones6 · Dec 12, 2019

Replying to @leavesSailor @itsbunk and 13 others

This was my 1st time at SABCS and as a thrifter of mbc and 20 yr practicing mental health clinician, I can say that I walked away with patient advocacy skills and tools.

#bcsn #SABCS19 #ListenUpMBC #Breakthrough2Better #SpiritLives #ClinicalTrialDiversity #IBC #Iobular #Infammat



**Carla Harvey** @Cmirah24 · Dec 16, 2019

We matter! #ListenUpMBC #bcsn

**Tigerlily Foundation** @tigerlilycares · Dec 10, 2019

BE AN ADVOCATE: "Taking part in a clinical trial involves trust. Unable to take comfort in substantiated data and results, the need to trust the medical team administering the trial is critical." Sheila McGlow, Tigerlily MBC Angel Advocate #ListenUpMBC



@docthecity

2 months ago

tigerlily's fireside chat #tabletalk: if they don't give you a seat at the table bring a chair-shirley chisholm #listenupmbc #sabcscancer #westumbc #standupmbc #tigerlily #tigerlilycares #sanantonio #sanantonio #sabcsc19 #tigerlily\_foundation @tigerlilycares @docthecity



**KD Richardson** @KDRichardson924 · Dec 10, 2019

What I'm experiencing in this room this morning is powerful. Young black women, before, during and after breast cancer. #ListenUpMBC #SABCS19



@tigerlily\_foundation

1 month ago

We are very proud of our President @maimahkarmo for hitting the highest impressions at @sabcscancersymposium2019! Thank you for all those who attended our Young Women's Metastatic Breast Cancer Disparities Fireside Chat! A special thank you to our ANGEL Advocates, Mentors, Speakers and our Sponsors for making the event as special as it was! 🌟🌟🌟 #ListenUpMBC



**Vatesha Boulter** @festivity · Dec 10, 2019

What an amazing symposium! So glad to be a part of this cohort of advocates! #SABCS19 #listenupmbc #breastcancer #support @tigerlilycares @Maimah @BraveBeauty26 @teaminpire @itsnot\_pink @kormenmagnolias @thebreastofus



If you missed the sign up or cannot attend the @tigerlily\_foundation Fireside Chat at San Antonio Breast Cancer Symposium on 12/10 do not worry! Registration is full, but you can follow #ListenUpMBC and join in with global experts in breast cancer and patient advocates. Follow us on Twitter @TigerlilyCares.



**Elpidia Argenziano** @mbc\_advocate · Dec 10, 2019

@timprowell suggests ways medical providers can increase trial participation among women of color: 1. Redesign trials to remove commodities that disproportionately impact them 2. Decentralize trials 3. Check self biases #ListenUpMBC #SABCS19 @tigerlilycares @LivingBeyondBC



DECEMBER 10, 2019

**MBC ANGEL Advocate**



@sancanet02

1 month ago

Last month, I was accepted as a MBC ANGEL with the Tigerlily Foundation. Last week, I was able to meet my angel sisters in San Antonio during the San Antonio Breast Cancer Symposium. The time I spent with these ladies learning, sharing and listening was amazing. Speaking with doctors, future doctors, scientists, founders, CEOs and so many more... with the common goal of better treatment, breaking disparity barriers and learning from each other. This experience was powerful! Although I have slayed this beast called cancer, I will continue to support not only my sister survivors but my MBC sisters that are living life every single day. Special shout out to all caretakers and loved ones surrounding them. Stepping into purpose, calling and life! #listenupmbc @tigerlilycares #sanantonio #sabcscancer #moonslightvision #evolutionofme #breastcancer #speaker #author #founder #evolutionofme #mbcangel #growthfacilitator #SABCS19



**METUP** @METUPorg · Dec 10, 2019

"My friend Beth said, Why don't we just chain ourselves to their doors until they hear us & make the changes we need them to make?" Shawn Johnson.

Shawn, we can help make that happen! DM us - let's talk! 🙌

#ListenUpMBC #SABCS19 #BCSM

**Ricki Fairley** @RickiDOVE · Dec 10, 2019



**Tatiana Prowell, MD** @timprowell · Dec 11, 2019

I was that doctor. I got schooled. @tigerlilycares #ListenUpMBC

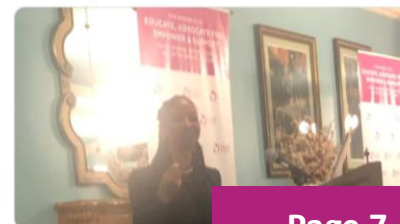
**Tambre Leighn** @tambreleighn · Dec 10, 2019

This is why healthcare needs to sit at the table & listen... #advocate just educated a doctor that a \$3 copay can be a barrier to access. What other barriers are HCPs unaware of that lead to adherence challenges? You won't find those answers in a Petri dish. #listenupmbc #SABCS19



**Ricki Fairley** @RickiDOVE · Dec 10, 2019

Dr. Lori Wilson @HowardHospital black women are not represented in the research. @tigerlilycares #listenupmbc #mbc #mtnbc is not a placeholder for the next step. I want to live my life.







# Trends & Findings

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

## KEY POINTS LEARNED AT THE FIRESIDE CHAT



### Listen to Patients

Actively Involve  
Women of Color  
Ask MBC Patients



### Education

Community Education  
Resources  
Questions to Ask Doctors  
Social Determinants of Health



### Respect

Patient Centered  
Patient Experience  
Patient Needs



### Treatment

Access to Best Therapies  
Patient Centered  
Quality of Care  
Barriers to Care



### Advocacy

Speak Up  
MBC Never Ends  
Health Equity  
Historical Injustices

## INTERESTS IN ATTENDING



1. Breast cancer disparities
2. Networking with other breast cancer leaders
3. Educating young women of color on MBC
4. MBC patient advocacy
5. Metastatic Breast Cancer (MBC)
6. Young Women's MBC Disparities Alliance
7. Ally/Accomplice
8. Health Resources & Tools

## OPPORTUNITIES



Participants noted the following:

- **Format:** Expand to full day with breakout sessions, social media training, a larger room, and live stream entire day
- **Frequency:** Host more often
- **Collaborate:** Include grassroot and rural orgs
- **Materials:** Provide more resources

## YOUNG WOMEN'S MBC DISPARITIES ALLIANCE SUGGESTED ROLE



- Education & Young Women's Education
- MBC Research & Diversifying Research
- Engage Moms & Nurses
- Power In A Group with Our Voices
- Direct Funding
- Advising & Sharing Resources
- Older & Young Diverse Women's Disparities

## INFORMAL OBSERVATIONS



The Fireside Chat featured frank discussion on historical injustices, social determinants of health, experiences of women of color, MBC patients and caregivers. **Attendees expressed real perspectives in a safe space for honest discussion. The closing pledge was a call to action that presented a tangible way for attendees to contribute to a solution using their platform to end disparities.**

## CONCLUSIONS



The Fireside Chat aimed to provide young MBC women of color, advocates and caregivers access to clinicians, scientific leaders at SABCS to share their unique perspectives while learning which was achieved, as 100% of attendees felt the Fireside Chat met their expectations and 99% are interested in developing next steps. Tigerlily will apply these learnings to **mobilize at scientific meetings, through advocacy, social media and partnership to lower African-American breast cancer mortality rates.** Join the #ListenUpMBC conversation and follow our progress at: [tigerlilyfoundation.org](https://tigerlilyfoundation.org).





# Young Women's MBC Disparities Initiative

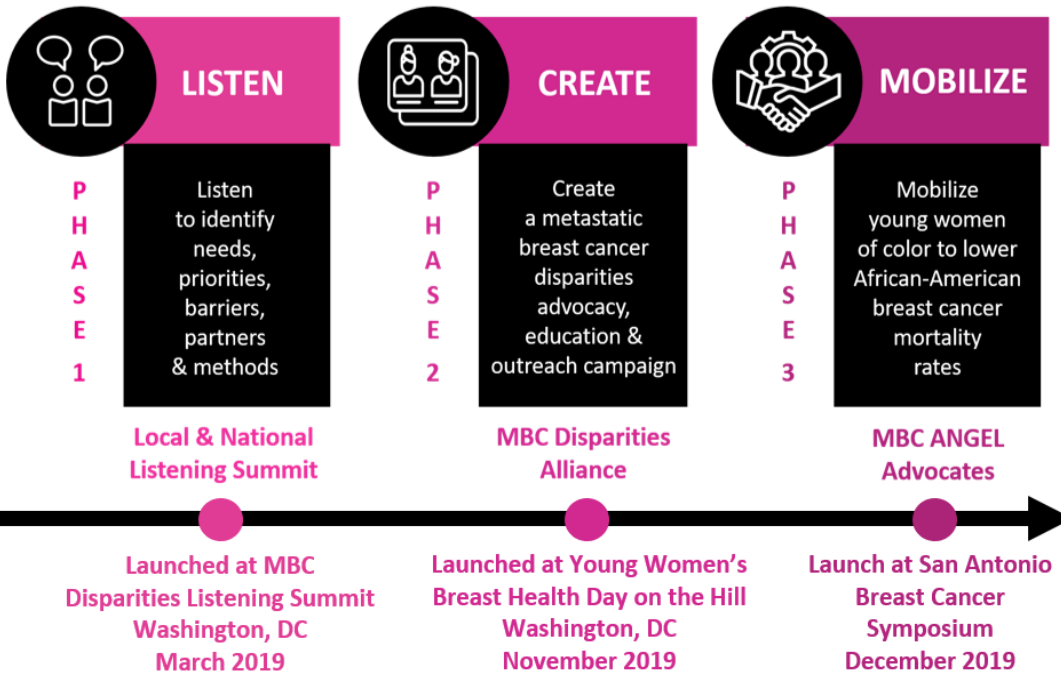
**Tigerlily**  
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**Defining Impact: 3 Phases. 1 Focus.**



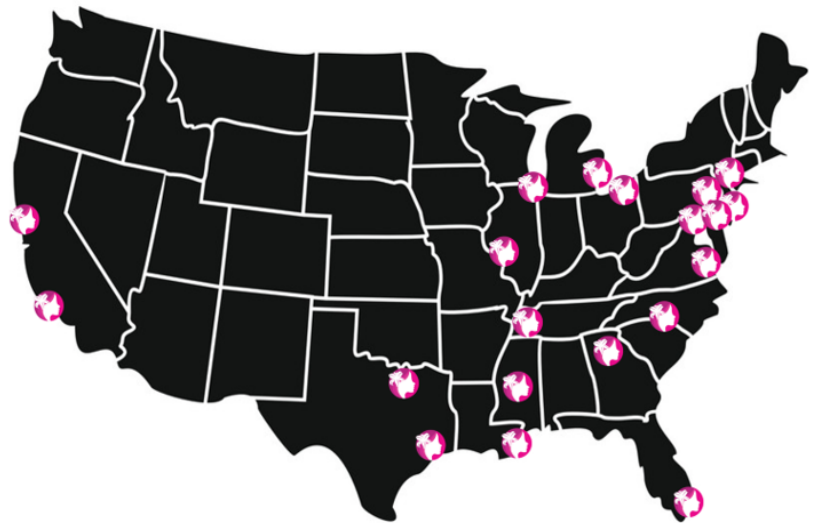
## FOCUS

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.



## 20 CITIES. 20 ADVOCATES. OUR AREAS OF IMPACT

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



*#ListenUpMBC* 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.

## ACTIVATIONS

- +60 Local MBC Education & Outreach Activities
- +20 MBC Advocates Attend Scientific Conferences
- 8 MBC Advocate Modules & Training Sessions
- +12 MBC Advocate Social Media Resources



# Stay Connected

## PROGRAMS & RESOURCES



### 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.

For a full list of programs, visit [tigerlilyfoundation.org](http://tigerlilyfoundation.org)



**Tigerlily**  
Foundation

# #ListenUpMBC

We will end metastatic breast cancer disparities among young women of color in our lifetime.

## Join the Conversation



[@tigerlilycares](https://twitter.com/tigerlilycares)



[@tigerlilyfoundation](https://www.facebook.com/tigerlilyfoundation)



[@tigerlily\\_foundation](https://www.instagram.com/tigerlily_foundation)



[@tlfcare](https://www.pinterest.com/tlfcare)



[@TigerlilyFoundation](https://www.youtube.com/TigerlilyFoundation)

## Contact Us:

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## Learn More At

[www.TigerlilyFoundation.org](http://www.TigerlilyFoundation.org)

# Save the Date!



We're Setting the Table for Change at the 2020 ASCO Annual Meeting  
June 2020 | Chicago, IL