



# THE INCLUSION, CARE AND EQUITY ISSUE

JULY 2023



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



## The Inclusion, Care and Equity Issue

What began as a pledge for inclusion at scientific conferences four years ago has grown into a collective mission to end barriers to care for Black women in our lifetime. Together we joined hands with community-based organizations, national cancer centers, advocates and pharmaceutical partners to address health inequities across the nation. Our #inclusionpledge has strengthened collaboration and partnership through our RACE Alliance. May we continue to work together, hold one another accountable as we collectively push the needle forward on health equity.



## A Legacy of Love



### Tribute by Tigerlily's Founder & CEO, Maimah Karmo:

Anyone affected by breast cancer has been touched by the giant, who was Dr. Susan Love and the magnitude of her work through the [Dr. Susan Love Foundation for Breast Cancer Research](#).

We stand on the shoulders of women like her who have created and left an everlasting mark on this world.

Her entire career was focused on transforming breast cancer care and advocating for research, improved treatments, and the best patient care.

As passionate as she was in her work, she was humble. Hers was the first breast cancer book given to me after my diagnosis and she was one of my heroes. It was so humbling to meet her - I told her that I was in awe of her and she whispered that she was in awe of me.

She was kind, thoughtful, generous and one of the most giving humans I have been blessed to know as a hero and a friend. She was a trailblazer in every way and she's changed this space forever.

This is a sad day, and I am forever touched by having known her. Tigerlily Foundation honors and thanks you for your incredible work, Commitment and sacrifices. The entire breast cancer community is indebted to you and will carry your work forward!

Save the Date, Chicago! See you in August!



**Tigerlily Foundation**

**Patient Power**

# We Will Overcome

Navigating Obstacles to Breast Cancer Prevention and Care in Our Community

**August 13, 2023**  
2 pm - 6 pm CT

**Bridgeport Art Center**  
Sculpture Garden  
1200 W. 35th Street  
Chicago, IL 60609  
Enter on North Side off of Racine / 34th Place

**Partners:** Pfizer, Seagen, Daiichi-Sankyo, Eisai, Genentech, Gilead Oncology, Lilly, Merck

Calling all residents of Southside Chicago and its surrounding areas!

**Tigerlily Foundation and Patient Power are hosting a  
FREE in-person townhall entitled**

**“We Will Overcome: Navigating Obstacles to Breast Cancer and Care in  
Our Community”**

to be held on Sunday, August 13, 2023,  
from 2pm – 6 pm CT at the Bridgeport Art Center’s Sculpture Garden.

Highlights include interactive panel discussions with healthcare experts and breast cancer advocates, resources from area medical centers including Northwestern and University of Chicago Comprehensive cancer centers, and local non-profit organizations.

**Lunch provided!**

**CLICK HERE TO  
REGISTER!**

## Save the Date: Tigerlily Foundation at the Black Women's Expo - Chicago!



Stop by our booth for a meet and greet, raffle prizes, and to learn more about our ANGEL Advocacy Program empowering Black women to self-advocate for their health and wellbeing!

McCormick Place Convention Center - Chicago, IL  
Friday, August 4 – Sunday, August 6, 2023

**Meet us at booth 1313**

**LEARN MORE EVENT AND  
ENTERTAINMENT INFORMATION**



## Tigerlily Activation at Essence Fest!



On Saturday, July 2, 2023, Tigerlily Foundation, in partnership with HCA Healthcare, led an activation at the National Urban League's Women in Harmony: A Celebration of Sisterhood Luncheon at the Essence Festival in New Orleans. Thank you to all the women and men who took the time to visit our activation booth. Your presence and engagement made the event truly memorable. We are incredibly grateful for the opportunity to connect with each one of you, share our mission, and showcase the work we are doing to make a positive impact in communities around the nation. It is through these interactions that we are better equipped to address these health inequities and work towards meaningful change. We value your continued support and encourage you to stay connected with our organization





## Help us congratulate our newest flock of ANGEL graduates!



Andrea Hans  
Trainer



Brea Hickson



Christina Mackey  
Trainer in training



Clara Christenson



Danielle Hamilton



Juanita Miller



Monica McNeil

Cohort 18 has graduated from the ANGEL program, and we welcome them into our fabulous army of ANGEL advocates. This cohort was trained by trainer Andrea Hans and we look forward to the great work they will all do in the future!

## Tigerlily's Annual EmPower Ball!

Join **Tigerlily Foundation**, as we celebrate patients, providers, supporters and raise funds for programs supporting young women – before, during and after breast cancer; and work to end disparities in our lifetime. Black Tie Optional

Grand Hyatt  
1000 H St NW  
Washington, DC 20001

**Program:**

6 – 7 pm: Cocktail Reception  
7 – 9 pm: Dinner & Awards  
9 – 11 pm: Dancing & Entertainment

**Tigerlily Annual  
EmPower Ball**  
November 11, 2023 | 6 - 11 PM EST

**BLACK TIE OPTIONAL**

**Early Bird Discount ends August 15th!**

Sponsorship Opportunities available!  
Contact us at [empower@tigerlilyfoundation.org](mailto:empower@tigerlilyfoundation.org)

@tigerlily\_foundation @tigerlilycares @tigerlilycares

**GET YOUR EARLY BIRD TICKETS  
BEFORE AUGUST 15!**

## MY LIFE Matters Health Literacy 2023 Issue is here!



This new issue of MY LIFE Matters highlights the importance of health literacy.

In a world where information is abundant yet often overwhelming, health literacy plays a pivotal role in enabling individuals to make informed decisions about their well-being. Our community of passionate Thrivers, Survivors, and health experts have delved deep into this critical subject, aiming to illuminate the path towards enhanced understanding and effective communication in healthcare.

This magazine issue offers a comprehensive exploration of health literacy, covering a wide range of topics designed to engage and inform. By equipping ourselves with the knowledge and skills we need to navigate the complexities of healthcare, we can bridge gaps, promote preventive care, and ensure better health outcomes for all.

KNOWLEDGE IS POWER, and together, we can unlock the doors to improved health literacy for a better tomorrow.

A special shout out to our Tigerlily ANGEL Advocated Kathryn Jackson, Keisha Stephney, Ms. Dallas and the cover advocate Michelle Anderson-Benjamin for their amazing editorials.

CLICK HERE TO READ THE MAGAZINE!

New Pure Cat class offering!

### Wellness Workshop

Every 1st & 3rd Wednesday | 6:00 PM EST

Stressing about nutrition?  
Let's start a conversation!

This is an interactive nutrition and wellness workshop, and for the pilot class, we will be discussing stress management, discovering strategies and leveraging resources to best serve you and your circumstances.

Rachael Geiger  
Health and wellness coach

The Pure Cat Health & Wellness program is growing yet again! In response to your requests we have added the Nutrition & Wellness Workshop every 1st and 3rd Wednesday 6-7PM EST. This bi-weekly workshop includes a different topic of focus and encourages questions and interaction between all participants. We all learn from each other every session. You can view our recent session focused on "sugars" in the Pure Cat video library found here:

Pure Cat Initiative - <https://www.tigerlilyfoundation.org>

Rachael Geiger is a health and wellness coach (certified by the American Council of Exercise) with a masters in human nutrition and food science. She is passionate about helping women learn to love and accept themselves, learn more about their bodies, and gain confidence they can make the changes to live the life they want.

SIGN UP HERE FOR OUR FREE  
PURE CAT CLASSES!

## Advanced ANGEL training modules

There are two more chances to further your education this month by registering for Module 8: Genes and Biomarkers.

Current ANGEL advocates and individuals who have completed the ANGEL application process are welcome to participate. Sessions will be offered Tuesday, July 11th from 8-9:30 PM EST and Wednesday, July 12th 6:30-8PM EST. Register for one of these sessions by emailing Amanda at [amanda.e@tigerlilyfoundation.org](mailto:amanda.e@tigerlilyfoundation.org) - include the date you want to register for.

## Calling all Advocates! You're Invited to join ANGEL Cohort 20

Our next ANGEL training cohort will kick off on Wednesday July 26th 6-7:30PM EST and will run 5 consecutive Wednesdays. This cohort will be facilitated by Karla Sandifer.



My name is Karla ReNae Sandifer  
I live in Bakersfield California. I survived the storm and Manifested SheRa!

SheRa is first and foremost a Child of God. A lover of music, great food, and loves to make body butters infused with Cannabis for pain management! 41 years of fabulousness. The Best Auntie Ever to 4 Amazing nieces and nephews. Most importantly I am Savannah's Godmom!

On July 9, 2018 I was diagnosed at 38 years old with stage 2A Her 2 Negative Estrogen Positive Invasive Ductal Carcinoma. That day forever changed my life. I had to make a decision to press on and fight for my life. That was the best decision I've ever made along with the blessings from God, and my family by my side. 4 rounds of chemotherapy, Double Mastectomy with failed reconstruction, 25 rounds of Radiation, and another 6 months of chemotherapy pills called Xeloda!

On November 1, 2021 the last phase of my process I received the Lattisimus Dorsi Flap reconstruction surgery! I am currently under surveillance taking Tamoxifen daily and i recieve a monthly Lupron injection.

I had to go on a self love journey to heal myself within and now I'm ready for the next chapter!! I feel more beautiful than I've ever felt in my entire life!

Breasts will never define Karla ReNae Sandifer! I refuse to butcher myself for societies' standards! To each their own, but I love me enough to know my beauty shines from within. Today I am living Cancer free surviving and thriving! As a Bald and Beautiful Woman of Color. I had to go on a self love journey to heal myself within and now I'm ready for the next chapter!! I feel more beautiful than I've ever felt in my entire life!

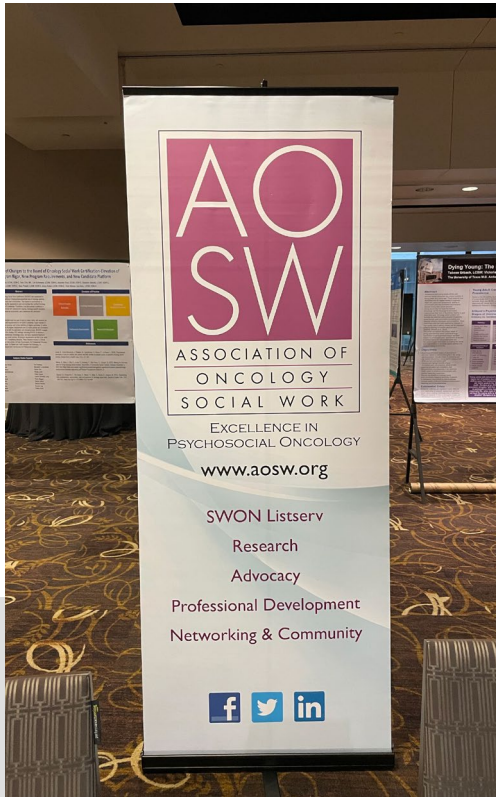
To my sisters in the struggle, always remember to choose life first. Keep your head held high in this fight and take control of your life. Value yourself and never allow breasts to define you. We are way more than that! Self love comes from within and it doesn't wear a bra! Also find a support group to help guide you on your journey. Do not suffer in silence!

Onward and Upward!!!

Karla Sandifer was diagnosed with Invasive ductal carcinoma stage 2A estrogen-positive (HER2-negative) and is currently taking Tamoxifen (endocrine therapy) Encourage dynamic, driven people you know to apply for the ANGEL program and register for this cohort! Register by emailing Amanda at [amanda.e@tigerlilyfoundation.org](mailto:amanda.e@tigerlilyfoundation.org)



## Tigerlily in the Community



The Tigerlily Foundation has been out in the community sharing current research projects with top leaders and public health professionals. Research Manager, Virginia Leach, attended several conferences this year. Her latest conference was the Association of Oncology Social Workers (AOSW) Conference in New Orleans, Louisiana.

Out of hundreds of submissions, Virginia was selected to represent the Tigerlily Foundation to share project insights detailing how Black women experience unique challenges as breast cancer survivors regarding their mental and emotional health. Only 25 abstract proposals were allotted to share academic research. Special thanks to Dr. Chiara Acquati, LMSW at the University of Houston for sharing this conference with TLF. Did you know that cancer patients and survivors can attend oncology conferences for free?

If you are interested in attending, representing TLF, and meeting inspiring peers, please reach out to Virginia Leach at [virginia@tigerlilyfoundation.org](mailto:virginia@tigerlilyfoundation.org) to learn how you can attend conferences. Your presence and voice are needed and wanted in these spaces!

## HEAL Policy Center of Excellence



**HEAL**  
POLICY CENTER  
OF EXCELLENCE

### Comprehensive Cancer Survivorship Act is reintroduced!

For the past several years, Tigerlily Foundation has been collaborating with Rep. Debbie Wasserman-Shultz and other organizations to better address equitable survivorship care plans for all. Tigerlily's HEAL Policy COE focused on this issue at our Young Women's Breast Health Day on the Hill in 2022, by hosting a listening summit on the topic and integrating the themes from that event into the feedback for the Bill draft and supported the introduction of the bill on December 14, 2022.

We are excited to announce the Comprehensive Cancer Survivorship Act (CCSA) was re-introduced in this Congress on June 23, 2023!

This landmark legislation will address gaps in survivorship care and develop desperately needed standards to improve the overall patient-centered quality of care and navigation needs of cancer survivors and their families! Tigerlily Foundation is proud to officially support this legislation.

The CCSA's key pillars:

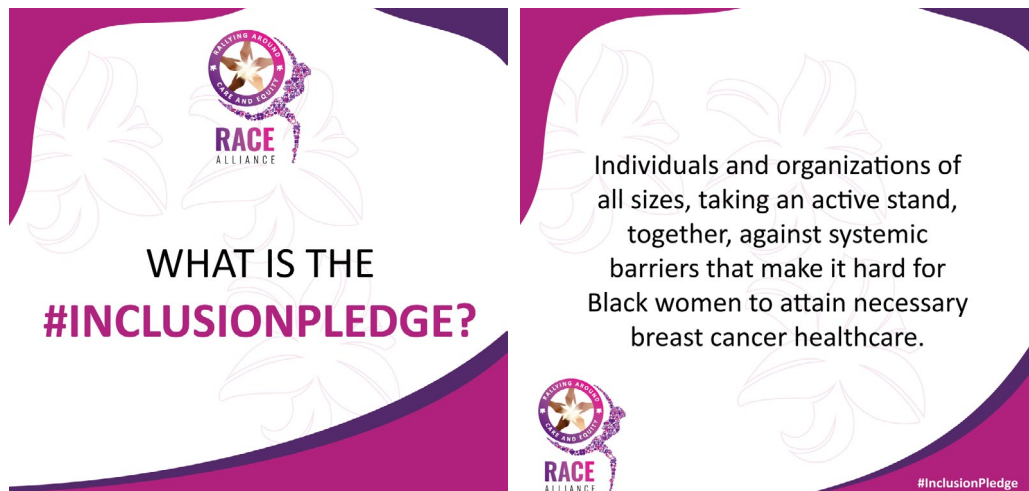
- **Care Planning and Transition:** Provides coverage to address the transition to primary care to help survivors and those living with metastatic cancer during treatment breaks develop personalized treatment care plans, standardizes processes, and consolidates treatments to guide survivorship and/or treatment break monitoring and follow-up care;
- **Alternative Payment Model:** Studies existing reimbursement landscape to develop an alternative payment model to ensure a coordinated approach to survivorship care across an episode of care;
- **Navigation:** Develops effective and comprehensive navigation services that emphasize the continuum of care, such as follow-up and health disparities and determinants, like food insecurity, housing, transportation, labor, broadband, telehealth access, and childcare;
- **Quality of Care:** Establishes grants to promote utilization of navigation, employment of risk-stratification, transition to primary care, utilization of care plans, potential use of at-home care, and better use of information technology for patient experience data;
- **Workforce:** Establishes workforce assistance grants to help survivors, their families, and caregivers when faced with a range of workforce challenges; and
- **Education, Awareness:** Creates resources for survivors and health professionals to promote early detection, preventive care and help providers provide high-quality services.

The CCSA also addresses innovation and technology use, fertility preservation, long-term studies, survivorship resources, and provisions concerning childhood and adolescent cancer.



Tigerlily Foundation is proud to support this important legislation championed by Representative Wasserman Schultz. “Being diagnosed with breast cancer changed my life, and one of most challenging times was “after” treatment ends and the lack of survivorship care. I continue to hear this from patients even now 17 years later. With the number of cancer survivors growing – this means that patients will live longer – but with comorbidities and a variety of psychosocial, financial, quality of care and other needs. In addition, with the socioeconomic challenges and inequities that face BIPOC populations, we must ensure that patients have legislation that support and protect all, especially vulnerable populations. We are honored to have worked with Congresswoman Wasserman Schultz for so many years and look forward to seeing this survivorship legislation impact the lives of patients,” **Maimah Karmo, President and CEO, Tigerlily Foundation.**

## Diversity, Equity and Inclusion Corner



**WHAT IS THE #INCLUSIONPLEDGE?**

Individuals and organizations of all sizes, taking an active stand, together, against systemic barriers that make it hard for Black women to attain necessary breast cancer healthcare.

#InclusionPledge

### #InclusionPledge

Join Tigerlily Foundation, partner organizations and partner individuals in dismantling barriers that lead to health inequity.

Starting from Diversity, equity and inclusion corner July is #InclusionPledge month. Keep an eye on our social media for releases on the impact of the #InclusionPledge. July is a special month at Tigerlily Foundation for our #InclusionPledge. Although we focus on our #InclusionPledge year round in order to strengthen our partnerships and collaborations-July is when we are very intentional and focused on getting the word out about what we have been doing with our partners. This month on our social media you will see a mixture of individuals and organizations who have signed our #InclusionPledge and given that public statement that they are dedicated to dismantling barriers that lead to health inequity. Through the #InclusionPledge these members gather in a coalition called the RACE Alliance to action change throughout their communities and organizations.

**SIGN OUR #INCLUSIONPLEDGE**

## RACE Alliance

The RACE Alliance is a collaborative of patients, experts, caregivers, community leaders and partners, who have signed our #InclusionPledge, focused on establishing priorities and implementing measurable interventions to end disparities for underrepresented populations. Sign the #InclusionPledge to participate in our RACE Alliance Round Table Sessions.

These RACE alliance round table sessions are impactful and important because we bring together individuals and organizations to are actively working toward change. When we meet together not only do we collaborate on a resource and programmatic level but our coalition offers support to other members in areas that they have strengths. The impact of these sessions has the potential to be so powerful. Please join us!



**TAKE THE PLEDGE TODAY!**

## Brain Fog Study



Inova and Inova Life with Cancer, in collaboration with UT Dallas Center for Brain Health, are recruiting for a study which hopes to “test the test” for brain fog (aka chemobrain or cancer-related cognitive impairment). Currently there is no standard objective measure for brain fog and this study is testing one such measure developed by UT Dallas. The primary aim for this study includes the goal to recruit diverse study participants. The research team is working to build bidirectional relationships with community organizations and has developed an educational offering to help raise awareness and understanding about this common side effect. For more information about the Brain Fog study please contact the research team at [neuro-oncology@inova.org](mailto:neuro-oncology@inova.org), or go to the [study website](#). You can find a brain fog resource, sharing common experiences of brain fog and some ways to manage it, [here](#). This resource was created out of a collaboration between Inova Life with Cancer and the Tigerlily Foundation.

## Mind Over Matter Study

Managing hard feelings is a part of every life, and it is certainly a part of a life lived with cancer. Coping with difficult feeling is hard, but there are evidence-based strategies that can help. Life with Cancer built a 5-week program called Mind Over Matter to help teach some strategies and tools to cope with strong emotions. After early data on MOM came back promising, a multi-institution research team is preparing a study to see if Mind Over Matter is feasible and accessible for Black and African American women managing cancer. The research team is hoping to open enrollment in the fall of 2023. If you have questions about Mind Over Matter, the associated study, or can support recruitment for the study please contact Michelle Ferretti at [Michelle.Ferretti@inova.org](mailto:Michelle.Ferretti@inova.org)



## Pull Up A Seat for Mental Health on August 11, 2023



#PULLUPASEAT  
**MENTAL HEALTH & BREAST CANCER**

**DR. CHALICE RHODES**  
LICENSED PROFESSIONAL COUNSELOR:  
GA, FL, DE, NJ

**CASSANDRA DUCKSWORTH**  
**MARICIA COLE**  
**DEEVA CRISP**  
**PARIS SMITH**  
**SHONI BROWN**

**AUGUST 11, 2023 | 11:00AM - 12:30PM EST**

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

Shining a light on the experiences of Black Women with Breast Cancer

Pull Up a Seat is Tigerlily Foundation's bi-directional conversations with allies including healthcare providers, researchers, scientists, and other stakeholders in industry and advocacy roles. Please join us on August 11, 11 am EST for this conversation focused on mental health. It is open to all. This session will explore the real experiences and journeys of those who have been touched by Breast Cancer. Often we don't consider the impact this journey can have on one's mental health, join this discussion to start the conversation and hear patient experiences.

If you would like to participate on this panel, please contact [dinisha@tigerlilyfoundation.org](mailto:dinisha@tigerlilyfoundation.org) by July 20.

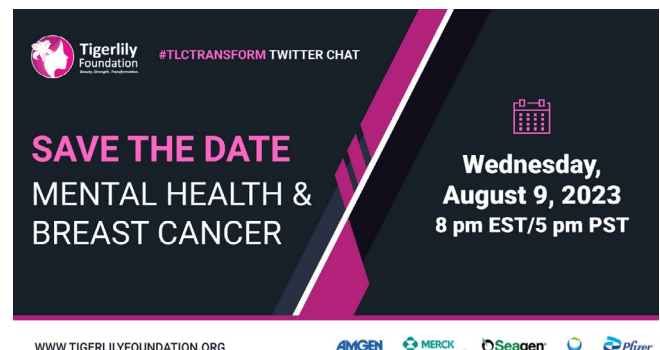
**REGISTER HERE!**

## Twitter Chat: Mental Health and Breast Cancer August 9, 2023

Tigerlily Foundation's August Twitter Chat on Mental Health and Breast Cancer discussion is a critical yet often overlooked topic. Join the conversation with our panel as we share mental health tips and resources.

Follow our twitter: @tigerlilycares or use the hashtag #TLCTransform to follow along the conversation!

If you are interested in being part of the Twitter Chat panel please reach out to [dinisha@tigerlilyfoundation.org](mailto:dinisha@tigerlilyfoundation.org)



**Tigerlily Foundation** #TLCTransform TWITTER CHAT

**SAVE THE DATE**  
**MENTAL HEALTH & BREAST CANCER**

**Wednesday,**  
**August 9, 2023**  
**8 pm EST/5 pm PST**

WWW.TIGERLILYFOUNDATION.ORG

AMGEN MERCK Seagen Pfizer

## Barrier Toolkit: Navigating Mental Health and Wellness During Times of Stress

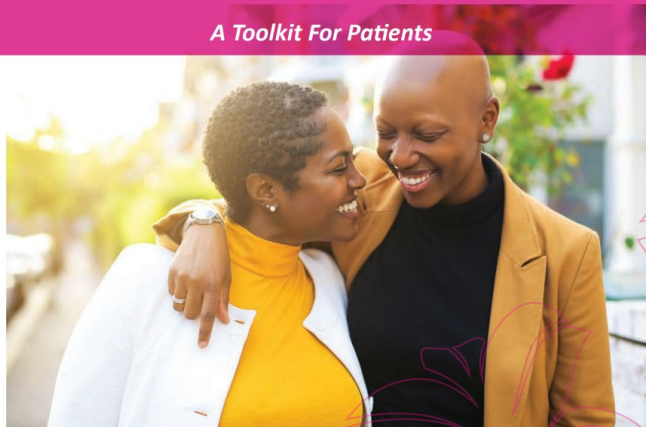
Our Barrier Toolkits tackle barriers from both the patient and practitioner lens.

This patient-centered toolkit focuses on navigating mental health and wellness during stressful times, particularly through one's breast cancer journey. Tips and recommendations are shared with the patient.

[CLICK HERE TO DOWNLOAD THIS  
BARRIER TOOLKIT](#)

### NAVIGATING MENTAL HEALTH AND WELLNESS DURING TIMES OF STRESS

*A Toolkit For Patients*



#### CREATED WITH YOU IN MIND

Taking care of yourself is essential and to get through treatment, it becomes especially important. Self-care comes in the form of a healthy diet, exercise, and body products as explained in our Lifestyle toolkit. As woman of color, while we care for our bodies, and others, often times we neglect our mental health. As humans we all have physical, psychological and social needs. And improving the psychological status of women not only improves survival, but also the mental health of our families.<sup>1</sup> The physical pursuit of wellness combined with a positive mindset will allow you to press forward in a more conscious way. Taking care of yourself first, and prioritizing all aspects of your health will benefit you and the effects are amplified through friends and family. A great mental mindset will be beneficial and necessary as you undergo treatment for breast cancer.





## Inclusion by design: building equity in clinical trials through the lens of metastatic breast cancer



**'In the US, rates of metastatic breast cancer are higher among Black women than among White women, yet Black women are seriously underrepresented in clinical trials.'**

*Maimah Karmo, Tigerlily Foundation, US*

The  
Health Policy  
Partnership

sanofi

Many people with metastatic breast cancer do not get the opportunity to participate in a clinical trial. This can severely limit the effectiveness of new treatments for many people.

**READ MORE IN THIS NEW REPORT  
ON IMPROVING INCLUSION IN  
CLINICAL TRIALS**

## Tigerlily in the Media

Tigerlily's Founder & CEO Maimah Karmo recently featured in an article with Conquer Magazine! In this article Maimah talked about the importance of discussing your family health history and how this conversation can save lives!

“

One of the most important things we can do for our health is to share our family health history. Knowing our family's health history can help us understand our risk for certain diseases and take steps to prevent them or catch them early. This is especially important when it comes to breast cancer. A lot of people know me as the founder of the Tigerlily Foundation and a relentless champion for health, but this wasn't always the case. I stepped onto this path after facing a health scare that changed the course of my life.

”

Maimah Karmo

**CLICK HERE TO READ CONQUER MAGAZINE**

## Tigerlily Foundation featured in the FDA Oncology Center of Excellence Project Community Summer 2023 Newsletter!



### GETTING TO KNOW YOU!



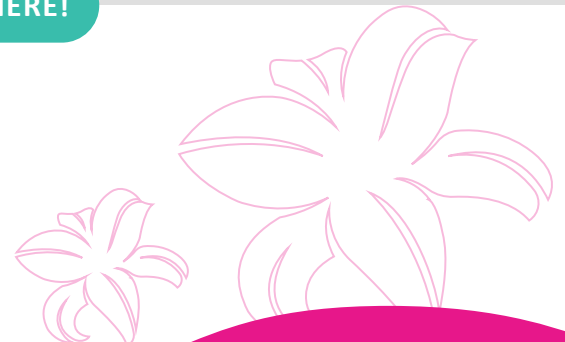
This month we are pleased to highlight [Tigerlily Foundation](#). Tigerlily is a national breast cancer foundation providing education, awareness, advocacy and hands-on support to young women ages 15 to 45 before, during and after breast cancer. Maimah Karmo, a breast cancer survivor and women's health advocate, is CEO of Tigerlily and a first-generation immigrant from Liberia. Project Community asked her for her thoughts on the following:

**Q: What are you currently working on that makes you feel excited or proud?**

**A:** Our [ANGEL Advocacy Program](#) is one of the programs I'm most proud of. The program works to educate Black Women about their breast health, with a focus on self advocacy and then taking that empowerment back to their families. Our ANGELS are also then given opportunities to lead in their communities and we provide them with opportunities to engage

In the Summer 2023 issue, our founder shared about current activities within Tigerlily, such as the [ANGEL Advocacy Program](#), Our current [Unstoppable ANGEL](#) Tour, and much more!

READ THE SUMMER NEWSLETTER HERE!







**Tigerlily  
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*Beauty. Strength. Transformation.*

**AMGEN**



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