

THE COMMUNITY ISSUE

AUGUST 2023



**Tigerlily
Foundation**

Beauty. Strength. Transformation.

The Community Issue

As summer winds down and fall is on the horizon, it is our hope that you take the month of August to rest and recharge. Lean on your community. In the words of Tricia Hersey, author of *Rest is Resistance: A Manifesto*, “Nothing we accomplish in life is totally free of the influence of spirit and community. We do nothing alone.”

Thank you to our community who continues to fuel our mission.

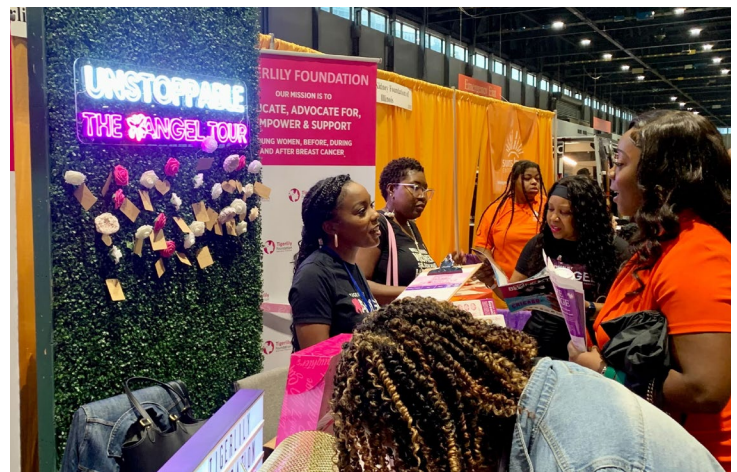
We Will Overcome: Navigating Obstacles to Breast Cancer Prevention and Care in our Community Recap!



On Sunday, August 13, Tigerlily Foundation and Patient Power hosted We Will Overcome: Navigating Obstacles to Breast Cancer Prevention and Care in our Community at the Bridgeport Art Center in Chicago. We were joined by a community of partners who came together to share resources, information and charges. A sincere thank you to Equal Hope, Robert H. Lurie Comprehensive Cancer Center of Northwestern University, University of Illinois at Chicago, University of Chicago Medicine, The WISDOM Study, Triage Cancer, Elevated Survivorship, Sisters Working It Out, Advocates for Community Wellness and Pfizer for coming together for this impactful townhall. Stay tuned for the recording from this in-person event.

ANGEL Tour Stop at the Black Women's Expo in Chicago

It was our joy to participate in the nation's longest running, intergenerational exposition tailored to Black women and their families in Chicago. With our Chicago ANGEL Advocates at the forefront, we engaged with thousands of women sharing our educational resources over a three-day period. We collaborated and uplifted our Chicago partners doing the work to ensure equal access to care in our communities.



You brought the energy and enthusiasm as we shared opportunities for empowerment, education, and community through the ANGEL Advocacy program!

SEE YOU AT OUR NEXT
#UNSTOPPABLEANGELTOUR STOP!

Congratulate our newest ANGEL graduates!

Help us congratulate our newest cohort of ANGEL graduates led by new trainer, Rheila Parker! Abena, Monique, Omodele, Tonya and Yvonne, we welcome you into the ANGEL community. Abena is in Maryland, Yvonne is in Florida, Monique and Tonya are in Georgia, and Omodele is in Nigeria. We look forward to supporting you as you become force multipliers in your communities.



WE ARE
THE CHANGE

Tigerlily Foundation ANGEL Advocates



Rheila Parker
Trainer



Abena Eldridge



Monique Wilson



Omodele Ibitoye Ejeh



Tonya Thomas



Yvonne Pink-Stewart

Are you interested in joining our next ANGEL cohort?

Do you want to make a difference in the lives of others by becoming an empowered patient advocate? You can begin your journey by joining our army of ANGEL advocates! Our next training cohort begins **Monday Sept 11th at 5:30PM EST** and will be facilitated by new trainer, Christina Mackey. If you want to register for this training and have completed the ANGEL advocate application process, please email amanda.e@tigerlilyfoundation.org. If you know of someone who would make a fantastic ANGEL advocate, encourage them to apply and join the training.

APPLY TO BE AN ANGEL HERE!

Save the Date: Tigerlily's Annual EmPOWER Ball!



Date: November 11, 2023 | 6-11 PM
Location: Grand Hyatt - Washington, DC 20001

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

PURCHASE YOUR TICKETS TODAY!

2023 Young Women's Breast Health Day on the Hill



Tigerlily's HEAL Policy COE will be holding this year's Young Women's Breast Health Day on the Hill (YWBHD) in Washington D.C. on October 17th. Save the date to join us in person or virtually as we focus on triple-negative breast cancer (TNBC) equity.

More details to come soon!

Diversity, Equity and Inclusion Corner

Cancer remains one of the most prevalent and impactful health issues worldwide, affecting millions of individuals and their families. Cancer advocacy encompasses a wide range of initiatives, including raising awareness, conducting research, providing support to patients, and influencing healthcare policy. As the field continues to evolve, an increasing body of research has highlighted the critical importance of incorporating diversity, equity, and inclusion (DEI) principles within the cancer advocacy space.

#InclusionPledge



Tigerlily Foundation
#InclusionPledge

In July, a powerful wave of change swept across social media platforms as the #InclusionPledge campaign rallied individuals from all walks of life to stand together for diversity, equality, and inclusion in the cancer space. The impact of this campaign exceeded expectations and left an indelible mark on the digital landscape.

The campaign's success was a testament to the growing desire for inclusivity and representation in the cancer space and beyond. By using the hashtag #InclusionPledge, participants showcased their commitment to breaking down barriers that lead to health inequity for our most vulnerable and underrepresented populations. The numbers alone speak volumes, but behind each number lies a story of change, empowerment, and unity.

Through Instagram, we shared personal stories, experiences, and insights, fostering connections that transcended borders and backgrounds. The platform's visual nature allowed the campaign's message to resonate deeply, inspiring countless individuals to join the movement and take the #InclusionPledge for themselves.



The campaign sparked conversations and discussions on Facebook that rippled through friend circles and online communities. People engaged in heartfelt conversations, shedding light on the importance of breaking down barriers and embracing action-based practices that will lead us to health equity in our lifetime. Tigerlily Foundation’s hope is that the campaign’s impact went beyond the screen, and for participants to bring the discussions to family gatherings, workplace conversations, and community events.

Twitter, with its succinct format, provided a platform to voice their support for the #InclusionPledge. The platform’s fast-paced nature amplified the campaign’s reach, with retweets and interactions creating a domino effect of awareness. Hashtags trended, sparking dialogues on Mental Health through our Twitter Chat and Pull Up a Seat topics being offered in August that centered around this. The campaign united activists, advocates, and everyday citizens in a virtual town square dedicated to dismantling obstacles that stand in the way of health equity.

However, the true essence of the campaign’s success was not just in the numbers, but in the stories of transformation it inspired. Participants shared how Tigerlily Foundation and the #InclusionPledge campaign encouraged them to take meaningful steps toward change. Friendships were formed, alliances were strengthened, and newfound empathy blossomed.

In July, we had 40 individuals commit to our #InclusionPledge. The #InclusionPledge campaign proved that social media is not just a space for scrolling, but a powerful tool for societal change. Through Instagram, Facebook, and Twitter, it fostered connections, amplified voices, and sparked conversations that reached far beyond the digital realm. The numbers merely hint at this campaign’s profound impact on individuals and communities, encouraging us all to strive for a world where inclusion isn’t just a pledge but a way of life.

Partner Highlight



THE LIGHT COLLECTIVE



The Light Collective was formed by a team of patient activists, coders, health experts, and data journalists to address the need of digital rights. They have signed Tigerlily Foundation's #InclusionPledge to break down barriers that lead to health inequity and are a part of the RACE Alliance. Currently, Tigerlily Foundation has joined the Light Collective Coalition to help build in building tech and digital rights for patient populations. The work The Light collective is doing is important as the voice in advancing patient rights when it comes to patient communities in healthcare technology. In 2023, Tigerlily Foundation will specifically be focused on understanding and researching cross site tracking tools. In October, The Light Collective will host an Informational Town Hall on the work that has been completed within the coalition so far. Tigerlily Foundation will be part of this Town Hall. Check our October Newsletter for updates on the date/time for this Digital Hygiene Town Hall. Tigerlily is proud to be part of the collective and work towards advocacy for digital rights on patient's behalf.

RACE ALLIANCE

“We must change. Each of us has a role to play in dismantling/rebuilding an unfair system. My eyes have been opened to the ways inequitable access and biases are deeply ingrained in healthcare.”

Andrea Downing
Founder of The Light Collective

The Power of One

Kawana Rucker, our Lead DMV ANGEL Advocate, visited Propel High School on behalf of TLF to share information about early detection and prevention of breast cancer.



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. RACE Alliance Round Table sessions are an opportunity for stakeholders to come together and share what they are doing to tackle and break down barriers in their communities. Sign the #InclusionPledge to participate in our RACE Alliance Round Table Sessions.

The Next RACE Alliance Round Table session will take place on September 14th around LACK OF ACCESS. Many patients lack the access to resources they need during and after diagnosis/treatment. In an attempt to break down this barrier we have brought partners together to share their programs and resources. Sign our #InclusionPledge to become part of the RACE Alliance and join this Round Table Session. During this session Rahul Mahadevan will speak on his initiative to tackle lack of access:



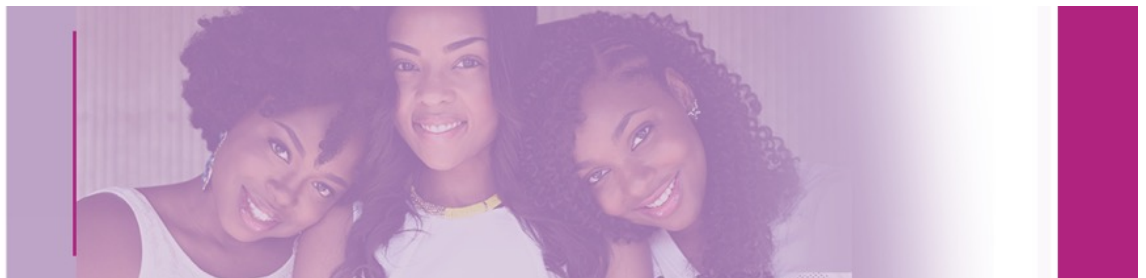
Rahul Mahadevan is an Inclusion Pledge signee and a RACE Alliance member who started The WiTT Group to address, and help overcome, two challenges that most Cancer patients face – Financial Toxicity and Health Equity.

Rahul is a Prostate Cancer survivor who, during his own treatment, met numerous patients who were choosing to delay or miss treatments because they did not have the non-clinical (both Financial and non-financial) support they needed as they went through treatment. Having worked in healthcare for over 20 years, he recognized that all the advances in treatment and technology only had an impact if a patient could get on the couch to be treated. The fact is, a majority of patients, especially the vulnerable population that is disproportionately comprised of people of color, never make it to the couch to be treated due to the lack of non-clinical support they have.

Rahul started WiTT to do two things: (a) make it easy for a patient to ask for and receive the non-clinical support they need as they go through treatment, so that they don't have to choose "home over health" and (b) create data that allows organizations (non-profits, providers, and life science & pharma companies) to identify gaps in care and implement programs that will increase access.

Rahul launched WiTT in the summer of 2022, and is collaborating closely with the Tigerlily Foundation to impact the needs of the patients they serve. In addition, he has been working with multiple non-profits and health systems to provide WiTT as a tool for patients, so that they can get the help they need, and focus on what is truly important, their health. To date WiTT has helped over 380 patients, generated over \$150K for them, and helped support over 1,000 of their needs.

Rahul believes he got cancer for a reason and is determined to use that experience to make a real impact to those in need. WiTT's goal is to exponentially increase the number of patients on the platform by working with organizations like yours and positively impact Financial Toxicity and Health Equity.



Pull Up a Seat

Pull Up a Seat is Tigerlily Foundations bi-directional conversations with allies including healthcare providers, researchers, scientists, and other stakeholders in industry and advocacy roles.

Our August Pull Up A Seat was a powerful discussion on mental health and breast cancer. Watch the recording below to see how patients and experts tackled the experience of mental health before, during and after their diagnosis and treatment journey into survivorship. We are forever grateful to those who brought their voices to this session.

WATCH THE AUGUST PULL UP A SEAT
RECORDING ON MENTAL HEALTH HERE

Mark Your Calendar: October Pull Up A Seat on Breast Cancer Awareness

#PullUpASeat

*Breast Cancer Awareness:
Learn and Take Action*



OCTOBER 13, 2023 | 11:00AM - 12:30PM EST

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



Topic: Breast Cancer Awareness

Date: October 13th

Time: 11-12:30pm ET

REGISTER NOW!

If you are a patient advocate, medical professional or individual who would like to speak at this event or future PUAS events- please reach out to adinisha@tigerlilyfoundation.org by September 20, 2023.

Twitter Chat

Tigerlily Foundation's Twitter Chats are created to provide education about breast cancer, MBC, clinical trials, health equity and disparities, and more. Our Twitter handle is: @tigerlilycares and we use the hashtag #TLCTransform during these sessions.

If you are interested in being on the Twitter Chat panel please reach out to dinisha@tigerlilyfoundation.org

YOU CAN VIEW THE TRANSCRIPT HERE!

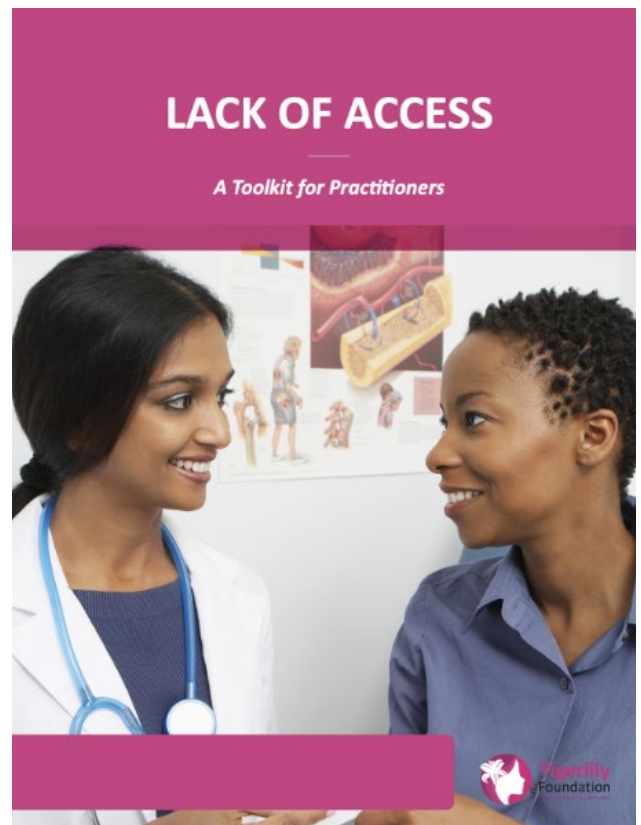
Be on the lookout for our next Twitter Chat:

- Topic: Breast Cancer Awareness-Join us on a 10-question journey to help highlight Breast Cancer Awareness. Patients, patient advocates and TLF ANGELS will be at this session to give real insight into their thoughts and experiences.
- Date: October 11th
- Time: 8pm-9pm EST

A Spotlight on Lack of Access Toolkit

Our Barrier Toolkits tackle barriers from both the patient and practitioner lens. [Fill out the form here](#), to download our Barrier Toolkits and learn more about breast health, lifestyle, wellness, prevention, and ways to lower your risk and experience #Nomorebarriers.

In August we highlight our LACK OF ACCESS barrier toolkit. We will be having a LACK OF ACCESS RACE Alliance Round Table session in September and encourage those who will attend, and those who will not attend to use this toolkit to inform themselves on this disparity. Black women are affected by socio-economic and systemic challenges and psycho-social trauma that limits access to medical care, healthy lifestyle-promoting activities and environments, and support systems. This barrier toolkit can be used by practitioners to address lack of access concerns. Please visit our [Barrier Toolkit page](#) to download and use this toolkit.



Pure Cat Classes

Join us for our diverse offering of free, online health and wellness classes by joining our Pure Cat program. You can take classes in real time or anytime by watching the recordings in the media library.

If you have a suggestion for a new Pure Cat class, know a certified instructor, or are a certified instructor please contact amanda.e@tigerlilyfoundation.org. We're always interested in adding new offerings.

Do you participate in Pure Cat classes? We'd love to hear from you! Please email amanda.e@tigerlilyfoundation.org and tell us why you love Pure Cat classes and why you'd recommend them to others!

“

Tigerlily Pure Cat classes are so helpful to my mental and physical health. The instructors are motivational and make everything fun and engaging. They set the pace for all levels and abilities and help me to prioritize self-care and wellness into my day-to-day life.

”

Jacqueline Selymes

“

I have to admit I was not interested in online classes when I first heard about Pure Cat but I gave them a try and am hooked now! I look forward to them each week and month! They've been a great and fun way to move my body and get some exercise, practice some self-care and take care of my mental health as well. I highly encourage everyone to take advantage of these free and fun classes!

”

Lizzie Wittig

A purple and pink graphic for the Pure Cat Monthly Schedule. It features a woman in a yoga pose on the right. The text includes the Pure Cat logo, the title 'Pure Cat Monthly Schedule', and a list of weekly virtual events. A QR code is provided for sign-ups, and social media handles are listed at the bottom. Sponsors like Seagen, Genmab, AMGEN, HOLOGIC, and sanofi are also mentioned.

PURE CAT
LET LOVE BE YOUR FREQUENCY

Pure Cat Monthly Schedule

Weekly Virtual Events (EST)

- * Mondays 4:00pm Yoga with Valencia
- * Wednesdays 9:00am Zumba with Joyce
- * 1st and 3rd Wednesdays 6:00pm Nutrition & Wellness with Rachael Geiger
- * Thursday 5:30pm Simply M the Movement with Ketty
- * 1st Fridays 8:00pm Community Sound Bath with Michaela Bekenn
- * 1st Saturdays 9:30pm Dance Party with DJ Dimepiece

Let Love Be Your Frequency

@tigerlily_foundation @tigerlilycares @tigerlilyfoundation.org

Sign up for classes here

Seagen Genmab AMGEN HOLOGIC sanofi

SIGN UP FOR OUR FREE CLASSES TODAY!

Book Club facilitator needed

The Pure Cat program is interested in adding a bi-monthly book club. If you have interest and experience in facilitating/hosting a book club please contact amanda.e@tigerlilyfoundation.org.

BREATHE Tv Season 4 Loading...



Tigerlily Foundation's BREATHE Tv is a sacred space, an educational and inspirational breast cancer lifestyle web series that brings together patients, providers and loved ones in a space of purpose, while engaging in authentic and meaningful conversations about cancer.

CATCH UP ON OUR PREVIOUS SEASONS HERE!

HEAL Policy COE Policy Win!



Access to DIEP Flap Reconstruction

Your voices were heard! Thank you to all who wrote comment letters to CMS and joined supporting this issue with Tigerlily and others to protect access to breast reconstruction options! On August 21, CMS announced that it will maintain HCPCS codes S2068, S2067, and S2068, and it will not sunset their availability on December 31, 2024. The decision was published in the HCPCS codes summary document [HERE](#), on pages 83-87.

“Based on the public comment, we are persuaded that the transition period through 2024 is not sufficient. Consistent with the comments CMS received, we have observed press reports of various private payers pausing or reversing their transition or payment policies for CPT® code 19364 after engagement with providers. We also heard reports of difficulties for providers in reaching private payers to discuss a transition. We received only one comment from private payers, providing limited insight for CMS in regard to the transition plans of private payers. As such, we will be maintaining HCPCS Level II codes S2066, S2067, and S2068 and will not sunset their availability on December 31, 2024.”

With the collapse of these codes, many patients’ access to DIEP flap reconstructive breast surgery and other less invasive reconstruction options was being threatened, causing patients to face having to pay out of pocket for this surgery, having a different surgery that may not have been their best option or forgoing their reconstruction all together. All these barriers to accessing equitable care are unacceptable and are now being re-evaluated thanks to advocates mobilizing and speaking up.

A special thank you the National Coalition for Cancer Survivorship and the Community Breast Reconstruction Alliance and the many other groups that joined us on signing on to our group letter to CMS in April as well as to you all for banding together to advocate on behalf of individuals in need of breast reconstruction! This is an important win and success!

Living Beyond Breast Cancer Presents - Knowledge is Power: The Black Breast Cancer Experience



This three-part series features discussions about disparities in breast cancer care, how to get the care you deserve, and strategies for living well beyond your diagnosis.

Speakers include leaders from our partner organizations, researchers, medical and wellness experts, as well as Black women diagnosed with breast cancer.



**Knowledge
is power**

THE BLACK BREAST
CANCER EXPERIENCE

LEARN MORE AND FIND DATES HERE!



Dana-Farber BRCA-P Study

A flyer for the Breast Cancer Prevention Study (BRCA-P). The top left has a purple header with the text "Breast Cancer Prevention Study". Below this is a photo of a woman and a young girl. To the right is a photo of four women of diverse backgrounds. Text on the flyer includes: "Women with a BRCA1 mutation have a 50-70% lifetime risk of developing breast cancer." "The BRCA-P Study is an international research study for women (ages 25 to 55) who are born with a mutation (change) in one of their BRCA1 genes." "The study will be conducted at more than 30 research sites across the United States. About 2,918 women from around the world will participate in this study. We encourage women of diverse backgrounds to participate in this study, so that it fully represents all populations affected by BRCA1 mutations." "If successful, our study can give future generations a new option to reduce breast cancer risk without surgery. Join us to help make a difference." The flyer also includes the BRCA-P logo, the website BRCaPStudy.org, and a version date of 02/10/2023.

Our partner at Dana-Farber are introducing their BRCA-P Study!

The BRCA-P Study is an international research study for women ages 25-55 who are born with a mutation in one of their BRCA1 genes.

About 2,918 women from around the world will participate in the study. The main purpose is to find out if the study drug, denosumab, can decrease the risk of developing breast cancer compared to a placebo (inactive substance) in women with a BRCA1 gene mutation.

You can contact the national BRCA-P Study team at BRCaPStudy@dfci.harvard.edu or learn more at <https://brcapstudy.org/>

Please join Wisdom Study August 28th, from 4-5pm PST, from 4-5pm PST, for the monthly community forum!

A flyer for the WISDOM Study Community Forum. It features two circular portraits of speakers: Peggy Reynolds, PhD, MPH, Epidemiologist at UCSF, and Kim Badal, PhD, Postdoctoral Scholar at UCSF. The text on the flyer reads: "WISDOM Study Community Forum", "Environmental Exposures & Risk for Breast Cancer", "Monday, August 28th", "4-5pm PST". The background is purple with stylized hands in various colors.

This month we will discuss the relationship between environmental exposures (exposure to contaminants and other factors in the physical environment) and risk for breast cancer. The conversation will be led by Peggy Reynolds, PhD, MPH. Dr. Reynolds is an epidemiologist with research interests focused on environmental risk factors for cancer. She will be joined by Kim Badal, PhD. Dr. Badal is a postdoctoral scholar and non-profit leader whose research and interests focus on machine learning/AI and breast cancer, as well as environmental exposures and breast cancer risk. Date: August 28th, 2023 Time: 4-5pm PST

CLICK HERE TO REGISTER!



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

AMGEN



Daiichi-Sankyo

sanofi

Lilly



MERCK

Seagen®