Throughout 2022, we have focused on intentional impact. We remain committed to contributing to a future where a cancer diagnosis does not spark fear but ignites hope.

Thank you for being a gift to us through collaboration, advocacy and truth sharing.

Every December, Tigerlily collaborates with We Will Survive Cancer to provide presents to patient advocates and their families.

With gratitude we tie a bow on 2022.

Your Tigerlily Foundation Family
San Antonio Breast Cancer Symposium Recap!

Our internal Tigerlily team works remotely from all over the United States, Mexico, Canada and South Africa. On December 6-10, we joined together with other national leaders and supporters in the fight to end breast cancer at the San Antonio Breast Cancer Symposium (SABCS).

The momentum and love we felt for this work and the future, plus sharing on the national stage the tangible ways we’re transforming health inequities—was incredible for our team.

And to our Tigerlily ANGELS, who bravely shared your stories, thank you, thank you, thank you.
TNBC CAN’T WAIT: A SABCS Event Recap

On the first day of SABCS, Tigerlily Foundation along with Susan G. Komen, Cancer Support Community, and Gilead Sciences hosted an informative and interactive conversation about TNBC inequities. The vision for this event was to create a dynamic forum with audience participation to generate actionable solutions to remove barriers to care for Black, Hispanic and younger women who are most at risk for TNBC.

The experiences, knowledge, and recommendations that attendees—providers, researchers, patient advocates, patient advocacy groups, clinicians and more—contributed during this collaborative discussion were essential to the success of this event. Although this event was focused on TNBC, it is important to recognize that issues associated across the continuum of care for TNBC also exist for Black and Hispanic women affected by all types of breast cancer.

The opening audience poll showed that a lack of coordinated advocacy efforts is the leading barrier to advancing policy change. This indicates that there is an opportunity for increased collaboration and consensus across the breast cancer community. Our hope is that this session is the beginning of a unified effort across many diverse stakeholders to advocate for policy and practice reforms that result in measurable reductions in breast cancer disparities.

When we join forces, much can be accomplished as we are stronger together!

You spoke and we listened! Below are some of the key themes that emerged from attendees:

- There is an urgency to improve breast cancer risk awareness and education
- Reforms are needed to remove patient cost-sharing requirements for diagnostic services
- It’s critical to remove care and treatment barriers for metastatic patients
- Incentivizing care provision through health equity focused quality metrics can help to mitigate breast cancer disparities
- We must create reimbursement pathways for patient navigation services
- It’s imperative that we work with Congress and across Federal Agencies to increase diverse and equitable participation in clinical trials
- More data is needed on the impact of TNBC on Black, Hispanic, and younger women to drive reforms in guidelines and clinical recommendations
- Payers are often missing from the discussion about addressing inequities – we need to find a way of engaging them to help shape effective solutions

The three-part TNBC Inequities policy brief series that launched this discussion can be found here:

1. Inequities in Screening and Diagnosis of TNBC – Authored by Tigerlily Foundation
2. Inequities in Care and Treatment for TNBC – Authored by Susan G. Komen
3. Inequities in Patient Support, Wellbeing, and Treatment for TNBC – Authored by Cancer Support Community

Black, Hispanic and younger women who are disproportionately affected by TNBC Can’t Wait!
We Will Overcome: Navigating Obstacles to Breast Cancer Prevention and Care in Our Community (Virtual Recap)

On December 15, we co-hosted We Will Overcome, a powerful, virtual event focusing on breast cancer care, risk reduction, the importance of clinical trials, social determinants of health, and ways to improve quality of life. Be sure to click on the images and to watch the segments.

In this segment of We Will Overcome, Yamile Molina, MD, a scholar and activist focused on promoting the voices and agency of marginalized and resilient populations, and Danesha Lewis, the president and founder of the Minority White Coat Foundation and currently works as a medical education coordinator at Rush University where she is a PhD candidate, talk to the Tigerlily Foundation founder and CEO Maimah Karmo about zip codes and access to care. Together, they concentrate on the distinguishable obstacles within underserved communities and how to bridge those gaps so that everyone’s medical needs are met.

In this segment of the recent We Will Overcome live program, the Tigerlily Foundation founder and CEO Maimah Karmo talks to Tigerlily ANGEL Advocate Kathryn Jackson, a survivor and fighter, about her compelling and resilient story. Breast cancer affects Black women disproportionately, so how can we empower Black women about early detection and self-advocacy? The panelists discuss understanding all the breast cancer subtypes, the power of research, self-awareness, and the unwavering pursuit of the answers to your medical questions.

In this segment of our recent We Will Overcome virtual event, Minister Dawn Watson, a three-time cancer survivor and passionate advocate, and Veita Bland, MD, a hypertension specialist practicing in North Carolina, talk to the Tigerlily Foundation founder and CEO Maimah Karmo about “having the chat” with family about cancer prevention and family history. Survivor and physician both share their vantage points and emphasize the importance of open conversations, patient/physician relationships, asking the right questions, and putting your best fight forward in the face of breast cancer confrontation and care.

In this segment from the virtual event We Will Overcome, Paris Thomas, PhD, Executive Director of Community Health Innovation and Health Equity Alliances, and Jazmine Lampkin, Tigerlily Angel Advocate and survivor, talk to Tigerlily Foundation founder and CEO Maimah Karmo about community engagement and health equity. They’ll discuss why building trust within the community so important and examples of community initiatives that are transforming how we engage with one another.

This program is presented by Tigerlily Foundation in collaboration with Patient Power. Support for this series has been provided by Merck & Co., Inc., Seagen Inc., Pfizer Inc., Genentech, Inc., Eisai Co., Ltd., Eli Lilly and Company, and Daiichi Sankyo Company, Ltd.
Please join us in congratulating our newest ANGEL Advocate Graduates! These incredible and inspiring ladies have accepted the challenge to BE THE CHANGE and will be working in their communities to amplify the patient voice for health equity.

Interested in becoming an ANGEL Advocate?

Apply Here!

New ANGEL trainings in January!

We have two upcoming trainings for potential ANGEL advocates in January. Both trainings will include a self-guided online course and five virtual weekly classes. We invite you to join one of two co-horts beginning Saturday January 7 at 11am – 12:30pm EST or Wednesday January 11th 6:30-8pm EST.

Please contact amanda.e@tigerlilyfoundation.org to register.
Screening for Communities to Receive Early and Equitable Needed Services (SCREENS) for Cancer Act (H.R. 8185/S. 4440)

The National Breast and Cervical Cancer Early Detection Program (NBCCEDP) is a critical safety-net program that provides breast and cervical cancer education, screening, and diagnostic services for underserved populations who are low-income, uninsured and underinsured who do not qualify for Medicaid. The program has a proven record of cancer detection and provides public education, outreach, patient navigation, and care coordination to increase breast cancer screening rates and reach these underserved populations. The Screening for Communities to Receive Early and Equitable Needed Services (SCREENS) for Cancer Act reauthorizes and modernizes the NBCCEDP by allowing:

- expansion of services for individuals at increased risk of breast cancer
- a greater emphasis on implementing innovative evidence-based interventions, and
- proactive outreach to underserved communities through media, peer educators, and patient navigators.

Access to screening is even more important as many people delayed or missed annual screenings due to the COVID-19 pandemic, likely resulting in more advanced cancers and increased cancer deaths; and new populations may need assistance to access basic cancer screenings due to the pandemic-related financial crisis. NBCCEDP is one of the only programs that serve these under-resourced, underserved communities throughout the country, as well as populations facing high disparities and morbidities from breast cancer. This piece of legislation is an important step toward ensuring that more women receive access to essential screening services before it is too late.

In addition, were urging Congress to include $10M in increased funding to allow for triple-negative breast cancer (TNBC) specific support, including education and diagnosis strategies in existing breast cancer screening, diagnosis, and linkage to health care programs. TNBC is an aggressive form of breast cancer that disproportionately impacts Black, Hispanic, and younger women and is often diagnosed at later stages of the disease with a poor prognosis. This funding, along with $3M allocated to expand awareness and prevention efforts for Breast Cancer Awareness for Young Women in connection with the goals of the Cancer Moonshot, will help address the significant TNBC inequities.

Click here to send a letter to your representatives to let them know this is important to you and the breast cancer community!

Click here for the SCREENS Act and TNBC factsheet.
Please also consider sharing on your social media to encourage others to support this important work. #HEALCOE #TLCTransform

Click on the images to download & share!

Comprehensive Cancer Survivorship Care Plan Update

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 earlier this year, by hosting a listening summit on the topic and integrating the themes from that event into the feedback for the Bill draft.

We are excited to announce that on December 14, U.S. Rep. Debbie Wasserman Schultz (FL-23), Sen. Amy Klobuchar (D-MN), Sen. Ben Cardin (D-MD) Rep. Brian Fitzpatrick (PA-1), and Rep. Mark DeSaulnier (CA-11) introduced The Comprehensive Cancer Survivorship Act (CCSA), landmark legislation that 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. 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.

Read the one-pager on the Comprehensive Cancer Survivorship Act here

Read the full Press Release here

To learn more about this issue and Tigerlily’s work, visit the HEAL Policy COE website here

Research Study Opportunity
Are you interested in sharing part of your breast cancer experience?

Grace Sikapokoo is a future ANGEL Advocate and completing her graduate studies at Ohio University. As a Black breast cancer survivor, her aim as a scholar is to help understand how best to help Black women recovering from breast cancer live their best quality of life. You will receive a $25 Amazon voucher for participating. Check out Grace’s Instagram (@oforiwa0312), Facebook (Grace Sika-Pokoo), and LinkedIn (Grace Sikapokoo) to stay connected!

If you’re interested in speaking with Grace, click this link to fill out the survey and get started.
New Pure Cat class alert!

We’re excited to add a new class to our fantastic Pure Cat line-up! Ketty Urbay will be leading a unique dance experience! Every week is a new theme and a whole new set of moves to a variety of music.

Who: Everyone who loves to dance and thinks they can’t do it! Everyone who loves to dance and wants to keep dancing in a fun and safe space!

What: Dance and music can heal your mind, body and soul. This is a 1-hour dance class set to a carefully curated musical playlist that will inspire and elevate. Have fun following easy to learn dance steps and creative movement exercises that will spark your joy and creativity.

When: Every Tuesday at 11am EST beginning Dec. 6th

Class Instructor: Born in Cuba and raised in Miami, Florida, Ketty has a double bachelors in Dance and Psychology from Florida International University. She has facilitated movement and creative writing workshops for 15 years with at risk teenage girls. Her desire to bring the healing and transformative power of music and dance into women’s lives has birthed her new community, Simply M The Movement, and brought her here to the Pure Cat community.

Interested in becoming a Pure Cat instructor?
Please contact amanda.e@tigerlilyfoundation.org.
We’re always interested in discussing new course offerings!
RACE Alliance Inclusion Pledge: Count Me In

Tigerlily Foundation highlights Count Me In for their continued work to increase representation and break down barriers in cancer care. We recently had the pleasure of reconnecting with Colleen Nguyen, who was able to answer some important questions on the work they’ve done and continue to do.

What was the original Inclusion Pledge commitment? Has it changed? If so, what has it changed it to?

Our original Tigerlily Foundation #InclusionPledge commitment focused on cancer research equity by addressing the underrepresentation and participation of historically marginalized and intentionally excluded communities in cancer research - in this case, specifically for Black/African American individuals diagnosed with breast cancer. After all, to truly address the inequities gap that exists across breast cancer - all of cancer - we understand that we must directly partner and collaborate with patients, advocates, caregivers and loved ones, and members across the larger community, to build and shape a cancer research process that is equitable, representative, and truly works for all. We are still committed to this pledge and this particular work.

What are expected outcomes/deliverables from this commitment?

Our hope is that if we’re truly building an equitable cancer research process that works for all, then we will see the following outcomes and deliverables - proportional (if not over) representation of Black/African American patients within our clinical research studies, the integration of patients and related community members as partners with us in every part of the research process, and relationships cultivated with trust, transparency, and accountability.

What collaborators/stakeholders have you involved to meet your goals?

Our collaborators and stakeholders are and always have been cancer patients themselves, as well as caregivers/loved ones, and advocates. We’ve also been fortunate enough to partner with a number like minded and committed advocacy organizations focused on addressing the inequities gap, particularly for Black/African American patients.

What is the timeline/status of you achieving your goals?

We understand that this work is never one upon which we will ‘arrive’. It is an ongoing process to continually improve and strive towards cancer research equity alongside patients, their caregivers/loved ones, advocates, and our partner organizations. However, it is our hope that we will begin to see increased participation and more representation within our cancer research studies over the next year - with improvements to follow in the subsequent years.
New BREATHE Tv Episodes

Episode 5: The Importance of Research, Science & Clinical Trials

Guest: Dr. Angelique Richardson | board-certified medical oncologist who specializes in the diagnosis and treatment of breast cancer.
Guest: Kimberly Skinner | ANGEL Advocate
Host: Maimah Karmo | 16 Year Breast Cancer Thriver

The importance of Research, Science & Clinical Trials from the perspective of patient and provider. Both women see the “hope” that science, medicine, and clinical trials can bring to the lives of patients living with cancer.

Kimi works in the healthcare industry but nothing prepared her to hear the words “you have cancer”. Kimi has faced a number of challenges being diagnosed at the beginning of a global pandemic but she has also learned how to advocate and look at Research, Science & Clinical Trials in a new light.

Dr. Angelique Richardson is working to bridge that gap between patient and provider. Listen as she provides heart-centered insights into medical mistrust and the health and survival disparities for Black women and how changes are being made at the institutional level and how Dr. Angelique Richardson is linking research, science, and clinical trials.

Watch Episode 5 here

Episode 6 - The Science of Breast Cancer and Integrating Soul

Guest: LaToya Bolds-Johnson | ANGEL Advocate
Guest: Kimberly Wyatt | ANGEL Advocate

Join us for the newest episode of BREATHE Tv on the topic of The Science of Breast Cancer and integrating soul. Maimah sits down with ANGEL Advocates Kimberly Wyatt and LaToya Bolds-Johnson in an intimate conversation about the science of breast cancer and the way it impacts the mind, body, and soul. You will be inspired by how these women have transformed their lives through their breast cancer experience and with faith and hope, and how they are helping those around them.

Watch Episode 6 here
Episode 7 of BREATHE Tv welcomes ANGEL Advocate Ashley Dedmon as we discuss the generational impact that hereditary breast cancer has had on three generations of women in Ashley’s family. Learn how Ashley changed the trajectory of cancer in addition to the empowering decisions Ashley has made for herself, her daughters and generations to come.

Listen as guest speakers Dr. Regina Whitfield and Gwen Turner help us to understand how the cycle can be broken through genetic testing and by learning about your family health history. Learn how you can be empowered and evaluate your family health history, when and how to get genetic testing, and ways you can work with high-risk specialists to be proactive and make informed health decisions.

**Watch Episode 7 here**

**HER2 + Empower Listening Summit Part 1: Understanding HER2+**

We are excited to launch a special edition series on the HER 2+ Empower Listening Summits hosted in partnership with Puma Biotechnology!

In this first episode, we explore “Understanding HER 2+” with ANGEL Advocate Kimberly Wyatt, Psychologist & Patient Ambassador Irmaly Sosa and Clinical Nurse Practitioner Tijuana Bradley.

Listen, Learn, and be Informed.

**Watch Part 1 here**
While breastfeeding, Aisha, a mother of four detected the lump that forever changed her life. Most of us judge our bodies, but these very insecurities can take on a whole new perspective when facing cancer. Aisha’s treatment journey included a double mastectomy - her pain went more than skin deep - it was physical, emotional and traumatic.

From what started as a prayer to God, “You can use me, I will inspire and advocate for other young women” has turned into a living legacy to advocate, empower, and inspire others to be their own unique selves and to fully embrace themselves as they are. To live and love one’s life fully is our greatest gift.

This is Aisha’s legacy.

THRIVING with MBC for 25 Years

Her oncologist said “you’re the longest living person I know of” and the doctors don’t know why? Diagnosed with Stage IV from the start, Lori just completed her PhD and was ready to begin a new career when cancer entered her life. Lori’s ambitions streamlined into one goal and that was to live as long as possible.

Congratulations Lori, 25 years and THRIVING with metastatic breast cancer. Lori says she is the luckiest person she knows, showing the world how to thrive with MBC.

This is Lori’s legacy.
Boob Inclusive

Dana was a 28-year-old fashion designer in New York when cancer forever changed her life. Diagnosed with a very aggressive HER2+ breast cancer, her medical team had one goal – to at least extend her life for 5 years. This all changed when she was able to receive new drug treatments that specifically targeted HER2+ proteins. This revolutionary medical advancement has her living her best life 12 years and counting.

Beyond the physical and emotional pain, Dana was not able to find a bra to fit her body, so she decided to do something about it and her mission to create the most comfortable and beautiful bras for all boob types. Dana is the Founder and CEO of AnaOno, boob inclusive lingerie. Her creativity has completely revolutionized the bra industry, “whether you have two boobs, one boob, no boobs or F(oo) Bs” Dana has thought of you. Since launching AnaOno in 2014, she has received countless accolades, but most importantly, she is able to reach thousands of individuals impacted by breast cancer, as her most satisfied customers are her breasties!

This is Dana’s legacy.

You Are Not Alone

Noelle wants kids out there who have a parent who has or has had cancer that YOU ARE NOT ALONE. Growing up with a parent with cancer is scary, overwhelming and can be all consuming, causing stress and anxiety that can have a lasting impact on your life.

Noelle has also had other life altering experiences. “The last few years I have dealt with mental health illness, and I know how hard that can be for people.” While she’s still navigating what can be a lifelong journey, Noelle had life changing support through therapy, her healthcare team, family and by implementing lifestyle changes, that have altered the trajectory of her life. Noelle is now studying psychology with the intention to dedicate her career to helping others with mental health. She wants to use her experiences as a gift.

This is Noelle’s legacy.
We Should All Be Thinking About Clinical Trials

Dr. Hamilton is committed and passionate to break down barriers and make clinical trials more accessible to all people. It is her love for oncology and passion around cancer care, specifically clinical trials is where Dr. Hamilton and her team are finding new ways to improve treatments and the quality of life for patients. At any point during the cancer journey we should all be thinking about clinical trials.

Dr. Hamilton wants clinical trials become a household name and is working with her research team at the breast cancer research program at Sarah Cannon Research Institute at Tennessee Oncology to provide access, education and support to decrease disparities in clinical trials and improve quality of life for all.

This is Dr. Hamilton’s legacy.

Living Life Now

Lisa wants Women of Color living with breast cancer to be passionate about living life now.

Lisa did not have an easy life growing up, but her fierce determination to be successful and make something meaningful of her life brought her to the U.S. Navy at a young age. Military life provided many life lessons, it helped Lisa evolve physically and mentally while providing her with the skills to take on any challenge. Faith is a guiding force in Lisa’s journey. One of her mantras is, “I shall live and not die, but declare the works of the lord.” These words are a constant reminder to make every moment count.

Lisa was told she could expect 5 years to live, to know Lisa is to know she would beat those odds. As a 2x breast cancer survivor and metastatic breast cancer THRIVER, Lisa refused to live life on a timer - she makes every moment count. “If you do not fight for you, who will?” Lisa is mentor, leader, and role model not only in the breast cancer community, but for us all.

This is Lisa’s legacy.
Calling all TNBC advocates

Black women diagnosed with Triple Negative Breast Cancer between (25-50yrs)

BE THE CHANGE by using your voice
Participate in this short survey

Click to learn more and start the survey

Offering $100 gift card to the first 100 participants

Are you between the ages of 20-50 years old and have been diagnosed with Triple Negative Breast Cancer? We want to hear from you!

Tigerlily Foundation wants to hear about your healthcare experience to help us shape the future of health services, engagement and education for Black women who are affected by Triple Negative Breast Cancer in America.

The first 100 participants will receive a $100 gift card!

Take the survey here