The Love Issue
FEBRUARY 2024

Tigerlily Foundation
Beauty, Strength, Transformation.
Love. It’s the invisible thread woven through our communities, the fierce spirit that fuels us. In this month’s newsletter, we celebrate the multifaceted meaning of love: the self-love that empowers us to prioritize our health, the love that binds us together as a community, and the love that compels us to raise our voices and demand change. Join us as we share inspiring stories of strength and resilience and discover how you can turn your love into action.

BREATHE Tv: Episode 3 - Understanding Triple Negative Breast Cancer (TNBC)

In Episode 3, we talk with two survivors diagnosed with triple negative breast cancer (TNBC). Maimah Karmo and Jonell Deshotel. Watch, listen and learn as they get personal about their experience in addition to sharing facts, empowerment and education.

Jonell, a warrior with a story etched in her soul, knew the moment she felt the lump. Growing up alongside her mom’s own battle with breast cancer, she became a caregiver, then a fighter, and now a beacon of hope as a Tigerlily ANGEL Advocate Lead.

“This fight isn’t just mine,” she declares. “More and more young women, especially Black women, are facing TNBC, an aggressive form that hits harder and faster. But we’re not going down without a fight. We’re joining forces, raising our voices, and demanding better outcomes.”

TNBC tends to grow and spread more quickly than most other types of breast cancer, studies also reporting African-American women are 3 times more likely to develop TNBC than white women. We are doing something to empower Black women and working together to make sure we have a better outcome.

Host: Maimah Karmo | 17 Year TNBC Breast Cancer Survivor
Guest: Jonell Deshotel | TNBC Survivor | Tigerlily ANGEL Advocate Lead

Watch the full episode here!
Welcome our newest ANGELs!

Welcome our newest “host” of ANGEL Advocates! Cohort 24 was trained by the fabulous Karla Sandifer - onward and upward! Betsy Torres joins us from Camden, SC and Rosalind Ross is in Fort Mill, SC. Rosilyn Gborogen resides in Ypsilanti, MI. Nicole Rogers and Wanda Gardner live in Fort Washington and Upper Marlboro, MD respectively. Christina Lawhorn is from McKinney in the great state of Texas. Leah Castelbury is in the windy city of Chicago, IL. Jennifer Dean is in the nation’s capital city. Also, we welcome Ravan Patrick (Cohort 23) who completed recently as well.

Advanced ANGEL Trainings for February

Register for our advanced ANGEL training sessions this month. We’re offering two sessions of Allyship and Anti-Racism. If you’d like to register, email amanda.e@tigerlilyfoundation.org with your choice of date.

• Thursday Feb 15th 8-9:30PM EST with Trainer Maricia Cole
• Wed Feb 28th 6:30-8PM EST with Trainer Vicki Williams

Recruiting for ANGEL Advocate Training Cohort 26

If you have a passion for healthcare equity and patient advocacy, you should consider applying to our ANGEL advocate program. Our next ANGEL training course will begin Wed. March 6th 5:30-7PM EST and will run weekly until Wed. April 3rd. This cohort will be trained by the energetic and dynamic ANGEL trainer, Christina Mackey from Texas. If you’d like to participate in this training and become a member of our ever-growing ANGEL family, please email amanda.e@tigerlilyfoundation.org to reserve your spot!
Check out our diverse offerings of free, online health and wellness classes at www.purecat.tigerlilyfoundation.org. Take the classes real time via Zoom and access our library of recordings at your leisure. Instructions to register for classes and to access the library are at that link. Special offerings this month are made possible through our partnership with The Smith Center for Healing and the Arts! Tues Feb 27th 12-1PM EST is Pop Up Book Club - The Myth of Normal: Trauma, Illness and Healing in a Toxic Culture and Wed Feb 28th 6-7PM EST is Exploring Balance Meditation & Mandala Workshop.
Tigerlily Foundation has partnered with WiTT Forever to establish the RAISE platform. RAISE, which stands for Resources and Assistance for Support and Empowerment, is a platform that makes it easy for patients to get support without feeling as though they are burdening others. Tigerlily understands that patients with chronic disease often face challenges that lead to the need to make difficult decisions about paying for groceries, childcare or life-saving medical care. Individuals on the RAISE platform can list out the things they need help with – both financial and non-financial – and other people can view this list and claim items for which they’re able to provide help. This platform is created by and for patients and will continue to be patient-focused as additional enhancements are added.

RAISE formally launched on May 11, 2023 after a brief ANGEL advocate-led beta test in April 2023. Currently, there are over 180 patients signed up on the RAISE platform! Feedback has been positive, with patient users sharing how easy they felt the platform was to use and how helpful it is to them to create a list of their needs to share broadly. As Tigerlily moves forward, we hope to establish long-term partnerships within the healthcare industry that will bolster support for RAISE patient users.

Learn more about RAISE here!

RAISE Testimonial

“Thank you so much. Just recently, I was told that I would no longer get assistance with groceries for my kids and me. I was praying for extra funds to come in to buy groceries until I figured things out and then this. Thank you, thank you, thank you, beyond words!!”

Eboney Thompson
Tigerlily ANGEL Advocate
I Am Included Framework

Calling all Site Leaders!!

When the faces around me reflect my own, I find strength in knowing that my journey matters. The site staff becomes a mirror reflecting the beautiful diversity of the patient population. In their faces, we find the promise of equitable healthcare for all.

Danielle Mitchell
Black Women in Clinical Research

Tigerlily and Labcorp are honored to share the I AM INCLUDED framework to support site leaders and research centers advance inclusivity in #ClinicalResearch that will benefit all populations. Our hope is this framework will inspire, reimagine, and accelerate site-specific strategic plans and partnerships resulting in practices that include representative communities where you work, live, and pray.

We thank patient experts like Danielle Mitchell, for paving the way forward with us! #IAmIncluded

Register and Download #IAmIncluded Here!
Diagnosed at 32 with triple negative breast cancer, Maimah Karmo fought for her life and saw progress. Now, she fears price controls will harm patients and stifle innovation, especially for communities hit hardest.

Read the full article here!

**Key Takeaways:**
Price controls threaten access to critical treatments and future innovations. Cancer, especially in underserved communities, will be disproportionately affected.

Lawmakers need solutions that balance affordability with continued research and development. This is about life and death, not just cost.

Join Tigerlily Foundation in urging lawmakers to prioritize policies that support both patient affordability and continued innovation in cancer research and treatment.

Visit our HEAL Page here!
The Hope Box helps patients face the future, armed with knowledge, and resources inspired with a new focus on them. Donate a Hope box and spread hope to a newly diagnosed patient today.

Click here to donate!
Partner Corner

Are you a patient who has considered breast reconstruction after a mastectomy? Learn more about the survey below!

What is the Purpose of this Study?
Are you a patient who has been diagnosed with breast cancer, or a genetic predisposition (i.e. BRCA gene), and have considered breast reconstruction after mastectomy? We want to learn more about what women value when considering a decision to have breast reconstruction and study how treatment preferences may be different across various patient populations. Your responses to this study will help us develop a tool that can help educate and improve shared decision-making for women considering breast reconstruction surgery.

Who Can Participate?
- Black women who have been diagnosed with breast cancer, or who have a genetic predisposition to breast cancer (BRCA1, BRCA2, etc.).
- Individuals who are 18 years old and over

Would You Like to Participate?
- You will be asked to complete a 30-minute online survey.
- If you would like to receive a $50 gift card as a thank you, please enter your email at the end of the survey.
- For more information, call Ronnie Shammas at 252-341-8948 or email Dr. Ronnie Shammas at Ronnie.shammas@duke.edu.

Click here to take the survey!
Join Living Beyond Breast Cancer for the Conference on Metastatic Breast Cancer

*Thriving Together: Conference on Metastatic Breast Cancer*

is back April 19-21, 2024, at the Hilton Philadelphia at Penn’s Landing in Philadelphia, Pennsylvania. This year’s conference offers new topics, speakers, and special wellness events.

Nothing fills our cup like community, and we are excited to hold space for attendees to come together in person again this year. If you are unable to attend in person, our keynote sessions will be available via livestream. Registration for the livestream option will be available in March.

Visit Living Beyond Breast Cancer’s website to view the full schedule, learn about our speakers, apply for travel assistance, and register!
Germline Testing in Patients With Breast Cancer: ASCO–Society of Surgical Oncology Guideline

Abstract
Purpose
To develop recommendations for germline mutation testing for patients with breast cancer.

Methods
An ASCO–Society of Surgical Oncology (SSO) panel convened to develop recommendations based on a systematic review and formal consensus process.

Results
Forty-seven articles met eligibility criteria for the germline mutation testing recommendations; 18 for the genetic counseling recommendations.

The American Society of Clinical Oncology (ASCO) and the Society of Surgical Oncology (SSO) published joint guidelines for germline testing which expand upon the population of breast cancer patients recommended to test.

The testing recommendations published include:

- BRCA1/2 mutation testing should be offered to all newly diagnosed patients with breast cancer ≤65 years (expands indicated population beyond NCCN which currently has 50 and younger as the age cut-off) and to select patients >65 years based on personal history, family history, ancestry, or eligibility for poly(ADP-ribose) polymerase (PARP) inhibitor therapy.

- All patients with recurrent breast cancer who are candidates for PARP inhibitor therapy should be offered BRCA1/2 testing, regardless of family history.

- For patients with prior history of breast cancer and without active disease, testing should be offered to patients diagnosed ≤65 years and selectively in patients diagnosed after 65 years, if it will inform personal and family risk. (expands indicated population for testing beyond NCCN’s)

- Testing for high-penetrance cancer susceptibility genes beyond BRCA1/2 should be offered to those with supportive family histories; testing for moderate-penetrance genes may be offered if necessary to inform personal and family cancer risk.

- Patients should be provided enough pretest information for informed consent; those with pathogenic variants should receive individualized post-test counseling. (strengthens deferring genetic counseling to post-test if results are positive)