



The Soar Issue

MAY 2024



Tigerlily
Foundation
Beauty. Strength. Transformation.

Imagine a young woman, newly diagnosed with cancer, her dreams and aspirations seemingly grounded. But within her, a spirit of resilience ignites, fueled by the collective voice of patient advocacy. Like a bird taking flight, she finds the strength to soar above her diagnosis, supported by a community that champions her well-being and fights for the best possible outcomes. This newsletter is dedicated to that very spirit – empowering young women cancer patients to rise above the challenges and soar towards a brighter future.



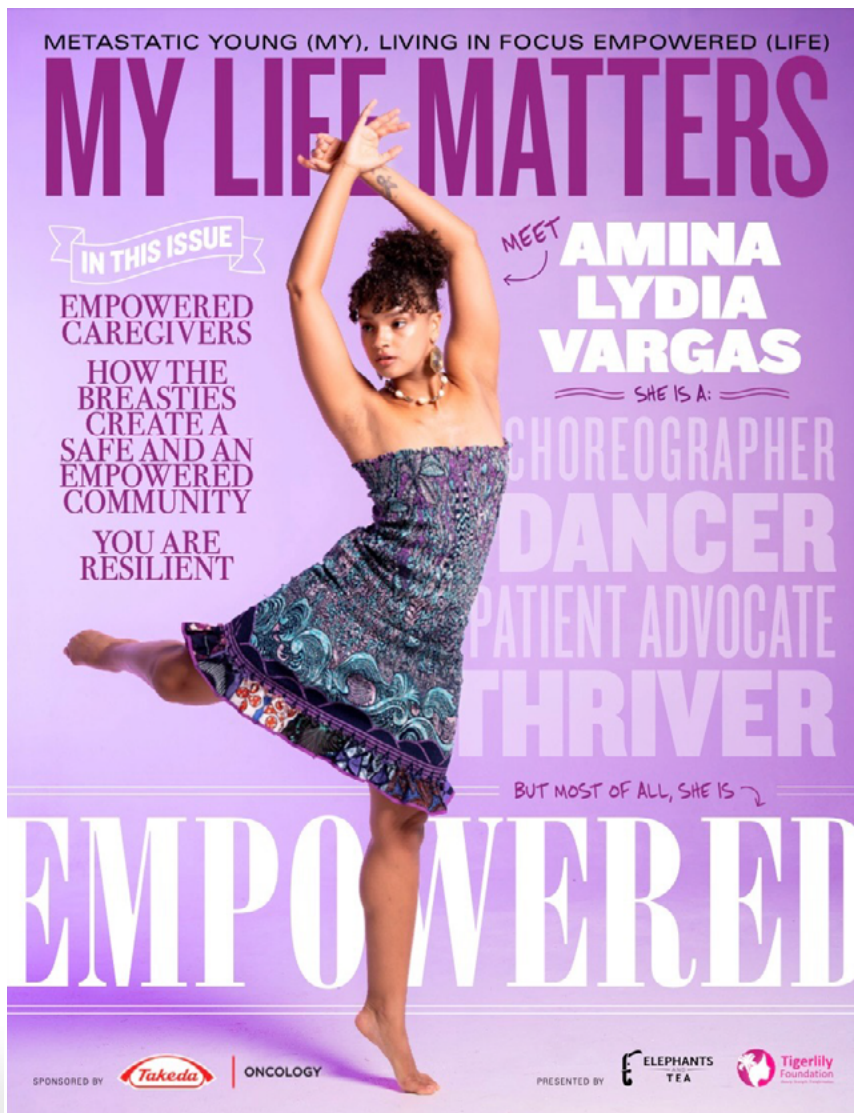
My LIFE Matters Magazine: Empowered Issue

This is an Elephants and Tea & Tigerlily Foundation collaboration focusing on stories of empowerment. Each amazing author shares how they have been empowered in life and through life's challenges that they have experienced as they navigate their cancer diagnosis, treatment, and survivorship. As you read these stories, be inspired and look inward to how you can become empowered as you navigate your own diagnosis and life.

Feeling empowered during your cancer journey can look and feel different for every single person. It can also be unique to each position within the care continuum from patient, caregiver, survivor, medical expert, to the community as a whole.

Be empowered to advocate, be empowered to educate yourself, be empowered to share your story to create awareness for others. Be empowered to help seek change in policy to improve health equity to end barriers of age, stage, color, and location. Be a caregiver who shares lived experiences and tips that can help others to feel empowered in caring for their loved ones as well as themselves. All of these unique types of empowerment showcase advocacy at its best.

We know the stories within these pages will resonate with you regardless of your cancer diagnosis or where you are at in your cancer experience.



Read the full magazine here!



BREATHE Tv Episode 8

Recovery and Discovery: Finding a Pathway to Heal From Your Scars.



Neosho's life was soaring – a successful PhD, a fulfilling academic career, and a bright future ahead. But then came the unexpected – a breast cancer diagnosis at the young age of 36. Navigating the healthcare system as a young woman with cancer proved challenging, highlighting the need for stronger awareness and support.

While the journey was arduous, leaving both physical and emotional scars, Neosho emerged with a renewed sense of purpose. Now, a published author, God's Got Jokes, and Tigerlily Foundation Advocate, Neosho shares her story to empower other young women facing similar battles, proving that even after a devastating diagnosis, hope and a vibrant future can still take flight.

Host: Maimah Karmo | 17 Year TNBC Breast Cancer Survivor
Guest: Neosho C. Ponder, Ph.D | Survivor | Tigerlily Lead
ANGEL Advocate | Author

Supported by Merck

[Watch the full episode](#)

Welcome to Our Newest ANGEL Advocates!



WE ARE
THE CHANGE

Tigerlily Foundation ANGEL Advocates



Tynisha Barron



Tiffany Grignon



Ranice Booth



Kate Wunsch



Jessenia Cisneros



Cynthia Johnson



Christina Mackey
Trainer



Myriam Perez

Cohort 26, trained by Christina Mackey, graduated last week!
Tynisha Barron - Modesta, CA, Tiffany Grignon - Morrisville, NC
Ranice Booth - New Orleans, LA, Kate Wunsch - Tiverton, RI
Jessenia Cisneros - Ocoee, FL, Cynthia Jefferson - Houston, TX
Myriam Perez - La Puente, CA

Help us celebrate their accomplishment at our monthly Pure Cat Virtual Dance Party on

Saturday May 4th 9:30PM EST

Join the Tigerlily Instagram live feed and get your groove on with **DJ Dimepiece!**

Interested in becoming an ANGEL Advocate?

Know somebody who would make a great addition to our ANGEL family?

[Click to apply to the
ANGEL Advocacy Program](#)

We have a new training cohort beginning **Saturday May 4th 10-11:30 AM EST** and running every Saturday through July 1. Email amanda.e@tigerlilyfoundation.org to register!

Advanced ANGEL Trainings for May

ANGEL Advocacy Training Program

Tigerlily's mission is to educate, advocate for, empower and support young women before, during and after breast cancer.



Register for our advanced ANGEL training sessions in May!
We're offering **Module 15: Holistic Living**.
If you'd like to register, email amanda.e@tigerlilyfoundation.org

Thursday, May 9th, 8-9:30PM EST
with Trainer Maricia Cole

Wednesday, May 22nd, 6:30-8PM EST
with Trainer Vicki Williams



Mark Your Calendars: 2nd Annual 2024 BEACON Symposium



Join Tigerlily Foundation in Washington D.C. for the BEACON advocates, healthcare leaders, and scientific minds to co-create real-world solutions for a symposium: Leading Transformative Healthcare with Patients! This second annual patient-centric care event brings together patient advocates, healthcare leaders and scientific minds to co-create real world solutions around care.

Don't miss this groundbreaking event where we'll redefine what "nirvana" looks like for patient care – together.

[Click here to learn more](#)

[Click here to see the 2023 BEACON Symposium Impact Report](#)

Mark Your Calendars: Tigerlily's Annual EmPOWER Ball!



A magical evening of glamour and inspiration awaits in October! Join us as we celebrate the extraordinary stories of trailblazers and leaders in health advocacy. Be captivated by their courage, hope, and unwavering dedication to making a difference. Tickets will be available soon, so gather your friends and colleagues, and prepare to host a table for this unforgettable event!

[Learn more here!](#)

ANGELs In Action!

Check Out My Rack presented by Brem Foundation to Defeat Breast Cancer
May 8, 2024 @ 8 pm EST

BREM DETECT EARLY. SAVE LIVES.

CHECK OUT MY RACK
Putting Breast Health in Your Hands
May 8 @ 8 PM EST

Learn More and Register:
[Tinyurl.com/comr2024](https://tinyurl.com/comr2024)

 Athena Jones National Correspondent CNN Moderator	 Daria L. Ross Lead ANGEL Advocate Tigerlily Foundation Panelist	 Dr. Margaret Houser Breast Imaging Radiologist GW Breast Center Brem Fellow Panelist
 Perla Rodriguez Entrepreneur Survivor/Thriver Panelist	 Ali Rogin PBS NewsHour Correspondent Author, Beat Breast Cancer Like a Boss Panelist	 Cassie Baloue Miss District of Columbia USA 2023 Special Appearance

This online event will feature inspiring breast health advocates, young survivors, and advice from experts on how to take charge of your breast health even before it's time to start mammograms. We'll also focus on the importance of learning about your family history to determine screening age and when to explore genetic testing.

Check out our amazing line-up of panelists:

- Dr. Margaret Houser, [*Breast Imaging Radiologist and Brem Fellow at GW*](#)
- Daria L. Ross, triple-negative breast cancer survivor and [*Tigerlily Foundation*](#) Lead ANGEL Advocate
- Ali Rogin, PBS NewsHour Correspondent, Author of Beat Breast Cancer Like a Boss
- Perla Rodriguez, an entrepreneur and survivor/thriver
- Athena Jones, moderator, CNN National Correspondent
- Cassie Baloue, special appearance, Miss District of Columbia USA 2023

During the event, 5 lucky attendees will win gift certificates to Lyft and Aerie! Tag your squad and let's take a step towards better health together. You have to be present to win! Each tag = an extra chance to win!

[Learn more and register here!](#)

HEAL Policy Center of Excellence Updates

Thank you to Virginia Governor Youngkin for vetoing the Virginia Prescription Drug Affordability Board (PDAB)!

Tigerlily Foundation, along with other patient advocacy groups and patient advocates, urged Governor Youngkin to veto SB 274, a bill to establish a state-run prescription drug affordability board (PDAB).

The well-meaning goal was to lower drug prices, which is something we support. But the board would have gone about it in the wrong way while also exacerbating health inequities. Thankfully, Gov. Glenn Youngkin vetoed that bill with just hours to go before the deadline.

“Under the legislation, the PDAB would have been composed of five unelected officials charged with reviewing the prices of high-cost prescription medicines. Should those officials have determined that the price of a medication posed an “affordability challenge” for patients or the health care system, they could have capped reimbursement to any physician, hospital or pharmacist providing the drug to patients.

Put another way, five political appointees would have had the power to decide if a lifesaving medicine was worth paying for. Pharmacies would have had no choice but to stop stocking some drugs.

Additionally, some proposed PDAB “cost savings” would have gone to the state, not patients. They would have continued to be charged the same copays, while the state squeezed providers with lower reimbursements.

We are already working tirelessly towards a more equitable system. Black women die of breast cancer at higher rates than their white counterparts. Black Americans and other people of color remain underrepresented in clinical trials, and as a result do not have enough treatment options designed for our bodies, which may contribute to higher mortality rates. Slowing innovation would disproportionately affect people of color.”

[Read the full article published by The Virginian-Pilot here](#)



Prescription Drug Affordability Boards (PDABs) & The Impact on Black Communities

What PDABs Mean for Patient Access & Efforts to Eliminate Health Disparities

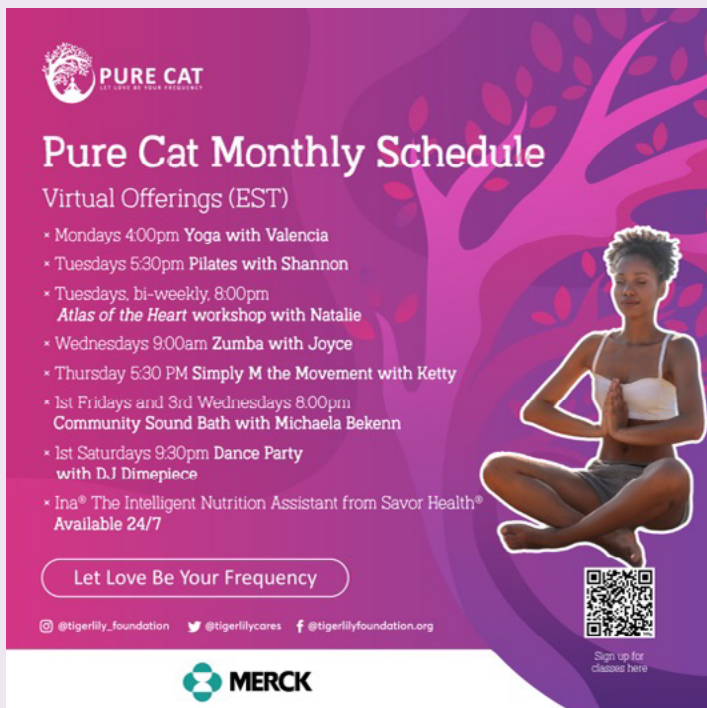
Tigerlily's CEO, Maimah Karmo was a featured panelist at the National Black Caucus of State Legislators' (NBCSL) quarterly meeting for the panel presentation on Prescription Drug Advisory Boards (PDAB) on Saturday, April 6 in Houston, TX. Here, Maimah shared about Tigerlily's concerns about PDABS, notably the adverse affect on access to drugs for patients and the lack of cost savings trickle down to patients. She also shared our priorities, including:

1. Seek out, include and ACT ON patient input
2. Do not use arbitrary Upper Payment Limits (UPLs)
3. Exclude Orphan Drugs
4. And do not use QALY methods in drug evaluations

Following this panel presentation, our friends published a one-pager around PDABs based on the engagement and leadership on this topic.

[See the one-pager and learn more here](#)

Spring into Health and Wellness with Pure Cat!



PURE CAT
LET LOVE BE YOUR FREQUENCY

Pure Cat Monthly Schedule


Virtual Offerings (EST)

- Mondays 4:00pm Yoga with Valencia
- Tuesdays 5:30pm Pilates with Shannon
- Tuesdays, bi-weekly, 8:00pm
Atlas of the Heart workshop with Natalie
- Wednesdays 9:00am Zumba with Joyce
- Thursday 5:30 PM Simply M the Movement with Ketty
- 1st Fridays and 3rd Wednesdays 8:00pm
Community Sound Bath with Michaela Bekenn
- 1st Saturdays 9:30pm Dance Party
with DJ Dimepiece
- Ina® The Intelligent Nutrition Assistant from Savor Health®
Available 24/7

Let Love Be Your Frequency

@tigerlily_foundation | @tigerlilycares | @tigerlilyfoundation.org

Sign up for classes here



Tigerlily's FREE Pure Cat Classes has something for everyone! Whether you want to relax to a sound bath or get upbeat with a Zumba or movement class, we've got it all!

[Sign up for our free classes here!](#)

Clinical Trials Corner

Have you checked out Tigerlily Foundation's Clinical Trials newsletter? Our TRIALS newsletter is a great place to learn more about new developments in the pharmaceutical industry, read stories from clinical trial participants and clinical researchers, learn more about how trials are run, and to find out more information on some of Tigerlily's trusted partners. You can find past issues on [this page](#) of Tigerlily's Clinical Trials website. Keep your eyes out for a new issue coming soon!



Read our latest Trials newsletter here!

Tigerlily in the Community

41st Miami Breast Cancer Conference / CURE®'s Educated Patient® Breast Cancer Summit

The Tigerlily Foundation has been on a mission to amplify the voices of Black women who have been impacted by breast cancer. ANGEL Advocate, Aliya Whipple, was a speaker at the 41st Miami Breast Cancer Conference / CURE®'s Educated Patient® Breast Cancer Summit in March. Out of hundreds of speakers, Aliya was selected to share her experience with breast cancer and how we can better support patients, survivors, and thrivers in the aftermath of cancer. We cannot forget the psychological and social (psycho-social) factors throughout the cancer care continuum. It is important that Tigerlily Foundation continues to advance health equity in and beyond oncology. We are grateful to Aliya for getting on stage and speaking her truth. We look forward to future opportunities to partner with her and other ANGEL Advocates across the United States and globally!



Midwest Sociological Society (MSS) Annual Meeting

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 her first conference of 2024 last month. This conference was the Midwest Sociological Society (MSS) Annual Meeting. Out of hundreds of submissions, Virginia was selected to represent the Tigerlily Foundation to share project insights detailing the need to increase research surrounding Black women diagnosed with breast cancer. Current frameworks such as Social Determinants of Health (SDOH) only explain part of the reality of breast cancer patients, survivors, and thrivers.

Tigerlily Foundation was one of 10 non-profit organizations presenting primary research at the conference this year. Special thanks to the faculty members and students who supported TLF at the event.

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 to learn how you can attend conferences. Your presence and voice are needed and wanted in these spaces!



In Case You Missed It – March Pull Up A Seat Recording on HER2+

**#PullUpASeat
HER2+**

📅 April 26, 2024 | 🕒 11:00AM - 12:30PM EST

Cassandra Duckworth
TLF ANGEL
Breast Cancer Thriver & Advocate

Andrea Hans
TLF ANGEL Trainer
Health Advocate

Cotilya Brown
TLF ANGEL
Breast Cancer Survivor & Advocate

**Tigerlily
Foundation**
Brings Strength, Transforms Lives

Tigerlily Foundation co-hosted a virtual #PullUpASeat discussion on Her2+ Breast Cancer with our ANGEL Advocates: Andrea Hans, Cassandra Duckworth and Cotilya Brown on April 26. Watch the recording of this session and be inspired by the stories of our Advocates!

[Watch the full recording here!](#)

Partner Corner

Survive and Thrive Day

The Johns Hopkins Breast Cancer Program

SURVIVE AND THRIVE SYMPOSIUM 2024



Keynote speaker: Dr. Bhuvanewari Ramaswamy,
Medical Oncologist & Professor of Internal Medicine
The Ohio State University Comprehensive Cancer Center

EVENT IS FREE!
Breakfast and Lunch
included!

Topics

- New Therapies
- Living your best life
- Caregivers
- Nutrition and physical activity

Lunch with an Expert

- Surgical Oncology
- Radiation Oncology
- Palliative care
- And more!



Survivors, Thrivers, and Care partners are all invited!
Event is free but registration is required, space is limited
Register with QR code or email
breastevents@jhmi.edu

The Johns Hopkins Breast Cancer Program invites you to attend their free Survive and Thrive Day which is an in-person event **at the BWI Marriott on Saturday, May 18th from 9 AM-1 PM**. Topics to be covered include New Therapies and Approaches, Living your Best Life after a Breast Cancer diagnosis and more. Lunch will be with an expert at each table including surgical oncology, radiation oncology, palliative care, nutrition, Integrative Medicine and more. Lunch and breakfast will be provided. Breast Cancer Survivors, Thrivers and their Care Partners are included. Event is free but registration is required, and space is limited.

Survivors, Thrivers, and Care partners are all invited! Event is free but registration is required, space is limited Register with QR code or email breastevents@jhmi.edu



Date: Saturday, May 18, 2024



Time: 9:00am - 1:00pm
Registration and breakfast start at 8am



Location: BWI Airport Marriott Hotel
1743 West Nursery Road
Linthicum, MD 21090



JOHNS HOPKINS
MEDICINE





**Tigerlily
Foundation**

Beauty. Strength. Transformation.

AMGEN



Daiichi-Sankyo

sanofi

Lilly



MERCK



Seagen