

THE HERSTORY ISSUE

MARCH 2023



Tigerlily
Foundation
Beauty. Strength. Transformation.

In March, we celebrate Women's Herstory Month. Throughout the month we celebrate where we have come and where we are going as we push toward equal healthcare, pay, and ownership of our choices. We also shine a light on Triple Negative Breast Cancer Day. As we enter spring, may we be reminded of the seeds we are planting, sewing, and gathering. May we continue to pour into each other and ourselves.

“

“It's about Triple Negative Breast Cancer, which is the kind of breast cancer I had. When you hear the words, you have breast cancer, it's hard enough to think about what to do with that diagnosis, but TNBC has different repercussions. It's one that's more aggressive in Black Women, and it has higher death rates.”

Maimah Karmo
CEO & Founder
Tigerlily Foundation



March is Triple Negative Breast Cancer Awareness Month

Triple negative breast cancer (TNBC) is a rare cancer that affects about 13 in 100,000 women each year. It's one of the most challenging breast cancers to treat.

Our Founder and CEO, Maimah Karmo, is a TNBC Survivor who recently celebrated her 17-year canceriversary!

This month, we honor Maimah, and all the other TNBC patients and survivors who keep fighting!

In recognition of TNBC Awareness Month, check out these Tigerlily TNBC resources to learn more and share with your community to spread awareness!

TNBC Fact Sheet

TNBC Policy Brief

My Life Matters Magazine: TNBC Patient Voices

BREATHE Tv Season 3, Ep. 2: Navigating Emotional Aspects of TNBC

BREATHE Tv Season 3, EP. 3: TNBC Treatment, Diagnosis and Journey

TNBC Awareness Month Highlights

Advocacy in Action!



TNBC Resolution in Georgia! Earlier this March, Tigerlily ANGEL Advocates Paris Smith and Faridah Thomas went to the Georgia State Capitol in Atlanta to meet with Representative Sharon Cooper. There they shared their personal stories and testimonies of being diagnosed with Triple Negative Breast Cancer in support of the State TNBC Awareness Month Resolution (House Resolution 269) sponsored by Rep. Cooper and co-sponsored by Representatives Deborah Silcox, Kim Schofield, Michelle Au, and Penny Houston. Not only does the resolution officially declare the month of March as TNBC Awareness Month in Georgia for purposes of education and awareness of this subtype of breast cancer, but it also declares that the members support legislation to reduce triple negative breast cancer disparities in early detection and survival by improving education and awareness through health promotion initiatives targeting undeserved communities disproportionately impacted; ensuring equitable access to and the affordability of breast cancer screening, genetic counseling, and diagnostic testing; promoting cultural sensitivity and workforce diversity policies in health care provider training; and guaranteeing timely patient access to clinically appropriate treatment options identified in the National Comprehensive Cancer Network (NCCN) guidelines. Read [House Resolution 269 here](#).




Tigerlily would like to thank our partners at Gilead Sciences for their support with this work as well as Representative Cooper for her continued support of legislation that provides breast cancer patient protection and access to care.

Cancer Action Coalition of Virginia (CACV) TNBC Webinar

Tigerlily's HEAL Policy Center of Excellence was honored to be invited to host a webinar for the Cancer Action Coalition of Virginia (CACV) on triple negative breast cancer in late February. The program, *Understanding TNBC: A Clinical Perspective and the Patient Journey*, was moderated by our own Maimah Karmo who shared her personal story as a 17-year TNBC survivor, gave an overview of the state of breast cancer in Virginia including highlights of the disparities in TNBC and moderated a discussion on actions CACV members could take to continue the work for TNBC equity. Featured speakers included [*Kathleen Harnden*](#), MD, Director, Breast Medical Oncology, [*Inova Schar Cancer Institute*](#), Sharon Rivera Sanchez, TNBC Survivor, Founder/CEO, [*The Trials of Color*](#) and Kirsten Axelson, Senior Policy Advisor, [*Charles River Associates*](#).

You can learn more about the newly released 2023-2027 Virginia Cancer Plan [*HERE*](#).



Cancer Action Coalition of Virginia
invites you to a virtual event

***Understanding Triple Negative Breast Cancer:
A Clinical Perspective and the Patient Journey***

**Monday, February 27, 2023
1:00 – 2:00 pm**

Triple Negative Breast Cancer (TNBC) is an aggressive form of cancer that accounts for 10-15% of all breast cancers and most often affects women under 40.

Join us to learn more about TNBC through patient stories, a clinical perspective, and how education and advocacy can help patients and providers.

Program Presenters

Maimah Karmo, Founder/CEO, Tigerlily Foundation

Kathleen Harnden, MD, Director, Breast Medical Oncology Program,
Inova Schar Cancer Institute

Sharon Rivera Sanchez, TNBC Survivor

Kirsten Axelsen, Senior Policy Advisor, Charles River Associates

For more information & to register:
cancercoalitionofvirginia.org/upcoming-events/

This event is sponsored by Gilead.

PAJAMA GLAM RETURNS TO THE DMV!



Join us in supporting the Tigerlily Foundation at their annual Pajama Glam Party hosted by Kristen Berset Harris, Good Day Washington of WUSA9! This event, originated by Tigerlily Foundation Founder and CEO Maimah Karmo and her then 10-year-old daughter Noelle, is designed to attract young girls while educating them about their breast and body health. The event will feature music, a sneak preview movie screening, Zumba and yoga demonstrations, crafts, face painting, kid-friendly fare, sweet treats, and much more. Women and girls of all ages are invited along with their families! Let's come together to support the important work of the Tigerlily Foundation! Come walk the pink carpet experience for a day of health, wellness, bling, and sparkle while learning to be your own best health advocate! Get your discounted Early Bird tickets today starting at \$25 and you'll be gifted a pair of Tigerlily slippers (while supplies last)!

[Learn more and get your tickets here](#)

Interested in being a Pajama Glam volunteer or event sponsor?
Contact us at info@tigerlilyfoundation.org.

WE'RE HIRING!

FINANCE MANAGER

Tigerlily Foundation (TLF) is seeking an experienced, hands-on **non-profit Grants and Finance Manager** to provide broad customer service coordination, budget preparation, grants and funds management, and accounting services. The Manager serves as a primary contact for multiple project staff; provide financial analysis, management support and guidance.

[Learn more and apply here if you're interested!](#)

PROGRAM MANAGER, NATIONAL ANGEL ADVOCACY

Tigerlily Foundation's Program Manager, National ANGEL Advocacy is responsible for overseeing several Coordinators and multiple individuals in various metropolitan areas, and will work on building an "Army of ANGELS" through our ANGEL advocacy program. This individual will also help build Tigerlily Foundation's social media ambassador program.

[Learn more and apply here if you're interested!](#)

New ANGEL Graduates!

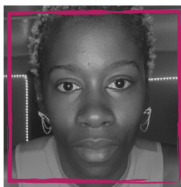
Please join us in congratulating our newest ANGEL Advocate Graduates of Cohort 14 & 15! These incredible and inspiring ladies have accepted the challenge to BE THE CHANGE and will be working in their communities to amplify the patient voice for health equity!

Want to be part of our ANGELs?

[APPLY HERE!](#)



Michelle Benjamin
Anderson



Rhea Alleyne



Brianna Osofisan



Maricia Cole
Trainer



Rheila Parker
Trainers in training



Karla Sandifer
Trainers in training



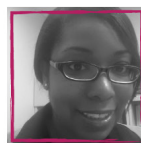
Andrea Hans
Trainers in training



Carlin Hafiz



Fonda McClain



Kimberly Wilson-Lewis
Trainer in training



Latia Maxwell



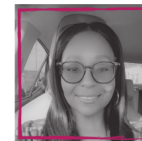
Lisa Barnes



Meisha Williams



Nicole Hicks



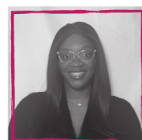
LaTonya Roberts



Vicki Williams
Trainer



Nicole Kirkendoff



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ANGEL Training

Beginning in March, we will be offering online training modules for current ANGEL advocates and those individuals interested in advocacy work. Each 1.5 hr live session will cover a specific topic in depth and be led by an experienced, dynamic ANGEL trainer. These classes are perfect for ANGEL advocates wanting more in-depth training on certain topics AND individuals interested in learning more about what it means to be an ANGEL advocate. Each class includes a live Zoom session and brief coursework within our Talent LMS platform. To sign up email Amanda Espenschied-Reilly, Tigerlily Foundation's Program Support Manager at amanda.e@tigerlilyfoundation.org with the date(s) of the session(s) you wish to attend. You DO NOT have to be a current ANGEL advocate to join these trainings.

The schedule is as follows (all times are EST):

Tues. Mar 14th 8:00PM – Module 7 Disparities in Breast Cancer with Maricia Cole

Wed. Mar 22 6:30PM – Module 7 Disparities in Breast Cancer with Vicki Williams

Wed. Apr. 12th 6:30PM – Module 8 Genes and Biomarkers with Vicki Williams

Sat. Apr. 15th 11AM - Module 8 Genes and Biomarkers with Maricia Cole

Wed. May 10th 6:30PM – Module 9 Patient's Rights with Vicki Williams

Thur. May 11 8PM – Module 9 Patient's Rights with Maricia Cole

Meet the trainers:



Maricia (spoken as Mar-ee-ka) Cole was diagnosed with Stage 2 Invasive Ductal Carcinoma Breast Cancer in March of 2020 at age 36. Maricia was an otherwise healthy young mother surprised by this diagnosis, but she kept positive. Maricia had always tried to be aware of her body and get routine checkups. Once She discovered a lump and nipple discharge, she knew she should get a professional assessment. Following a mammogram and multiple biopsies it was confirmed that Maricia had breast cancer. She started chemotherapy right away followed by a double mastectomy and 28 rounds of radiation. Maricia is so grateful to now be in remission and on her survivorship journey. She's an advocate for other young women coming behind her hoping to give them resources and education she didn't have.

Vickie R. Williams-Cullins was diagnosed with Stage 1 Invasive infiltrating Ductal Carcinoma Breast Cancer in February 2008 at age 44. Vickie discovered a lump and had a mammogram. The radiologist told her that it did not have the characteristics of cancer and we can revisit it in 6 months. Vickie's boyfriend said no, let me see the old mammogram and the new one. He compared them and told the radiologist NO, we need to test this lump. The biopsy was done, I had cancer. This started my path. I had 5 surgeries(a lumpectomy, reexcision, mastectomy, port placement, and removal and saline implant. I had 6 rounds of Chemo-TAC (Taxotere, adriamycin and cyclophosphamide). Vickie is also a 14-year Breast Cancer Annihilator and is proof positive that being the Project Manager of your care is the key to claiming victory over this dreaded disease. In her spare time, Vickie enjoys spending time with her husband Terry (the boyfriend became the husband) and their miniature schnauzer, Sugafot.



Diversity, Equity and Inclusion: #InclusionPledge and RACE Alliance

#InclusionPledge and RACE Alliance members in 2023:

Our valued RACE Alliance members have started sharing their powerful vision of what they are working toward in 2023. Join Tigerlily Foundation and other individuals and organizations by [signing the #InclusionPledge to dismantle barriers that prevent access to health equity.](#)



Our RACE Alliance members below plan to attend the next RACE Alliance Round Table session on Networking. Individuals and organizations who sign the #InclusionPledge also become part of the RACE Alliance which provides opportunities to work as a collective in collaboration toward breaking down barriers that lead to health inequity. See some of their powerful initiatives for 2023:

- In 2023, Count Me In is working in collaboration with Tigerlily Foundation to create materials around Clinical Research that reflect patient voices. This powerful collaboration ensures that diverse representation and the voice of underrepresented women with metastatic breast cancer is present from the beginning of these Clinical Research Programs.
- Lobular Breast Cancer Alliance will work to break down literacy and representation barriers. They are already working tirelessly to translate patient resource documents into over 14 languages. The intent here is to make their materials and resources more accessible to diverse populations.
- Jessica Whorton signed the #InclusionPledge and is fighting toward providing 30 underinsured, unhoused patients with resources by August 1st, 2023.
- Eva May is working toward improving participation of underrepresented populations in Clinical Research.
- Tallulah Anderson, CEOP and Founder of 2 for 2 Boob, Inc. is 2023 working to engage 25-50 patients and survivors by providing access to information, resources and opportunities to advocate through sharing their experiences.
- Faridah Thomas plans to continue to build Survivorship throughout 2023 and beyond.
- Maricia Cole has committed to increasing representation in clinical trials and in marketing.
- Rosemary of 305 Pink Pack signed the #InclusionPledge. In 2023 they are working to provide women of color with direct services with access to cancer care by July 2023.



Pure Cat Monthly Schedule

Weekly Virtual Events (EST)

- Mondays 4:00pm Yoga with Valencia
- Wednesdays 9:00am Zumba with Joyce
- Thursday 5:30 PM 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

Sign up for classes here

Logos: Seagen, Genmab, AMGEN, Hologic, sanofi

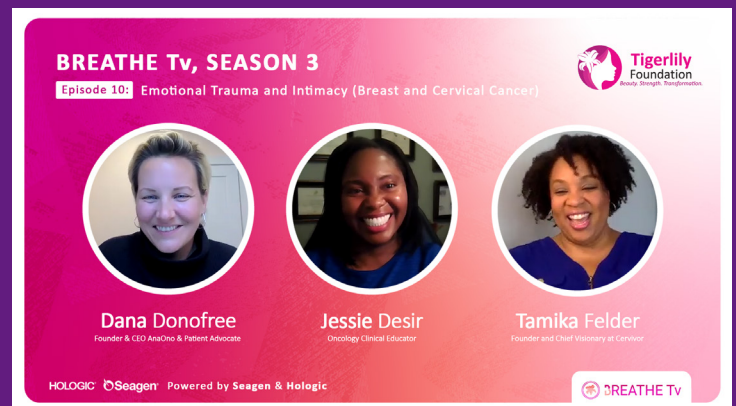
Pure Cat Updated Monthly Schedule!

We're bringing something exciting for your Thursday evening! Simply M the Movement with Ketty is moving to Thursdays at 5:30pm EST beginning March 16th. Finish your workday and rejuvenate with this fun, reflective dance class offered via our Pure Cat program. Pure Cat classes are free and offered to anyone who wants to join in real time or watch the video recordings posted to our Hey Marvelous platform. We hope to see you in a class soon!

[Sign up for our Pure Cat Classes!](#)

BREATHE Tv Season 3, Episode 10 Emotional Trauma and Intimacy Impact of Breast and Cervical Cancer

Join Maimah as she sits down with two courageous women - Dana Donofree, Patient Advocate and CEO of AnaOno, and Tamika Felder Founder and Chief Visionary at Cervivor, who have been impacted by breast and cervical cancer, respectively at a young age. Both women open up about the emotional and physical trauma of breast and cervical cancer. Listen as they share their experience and are joined by Oncology Clinical Educator Jesse Desir who has focused her career on this topic and is supporting patients and educating providers.



BREATHE Tv, SEASON 3

Episode 10: Emotional Trauma and Intimacy (Breast and Cervical Cancer)

Dana Donofree
Founder & CEO AnaOno & Patient Advocate

Jessie Desir
Oncology Clinical Educator

Tamika Felder
Founder and Chief Visionary at Cervivor

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BREATHE TV

[Watch Episode 10 here!](#)



BREATHE Tv, SEASON 3

Episode 11: Empowerment Through Advocacy

Na'Diah Smith
Tigerlily ANGEL Advocate

Maimah Karmo
Host - BREATHE Tv Founder, Tigerlily Foundation

Rinad Bsharat
Tigerlily ANGEL Advocate

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BREATHE TV

[Watch Episode 11 Here!](#)

BREATHE Tv Season 3, Episode 11 Empowerment Through Advocacy

Join Maimah as she sits down with two empowering advocates - Patient Advocate, Rinad Bsharat, author of Take Me or Heal Me, and Na'Diah Smith, Tigerlily ANGEL Trainer/Advocate, and mentor. Both women were impacted by cancer at a young age Rinad at 23 and N'Diah at 33.

Be inspired as they share how cancer revealed their passion and true purpose. Listen as they each share their cancer journey and empowerment through advocacy that has changed their lives.

BREATHE Tv Season 3, Episode 12 HER2+ Empower listening series

We are excited to launch a special edition series on the HER2+ Empower Listening Summits hosted in partnership with Puma Biotechnology! In this third episode, we explore “HER Pathway Forward” with ANGEL Lead Advocate and author Neosho C. Ponder, as well as Patient Ambassador Sherry Hughes and Clinical Nurse Educator, Marnae Colston-Jackson.

Listen, Learn, and be Informed.



[Watch the recording here!](#)



[Click here to read the blogs](#)

SABCS ANGEL Advocate Patient Expert Blogs

Be sure to check out Tigerlily’s Blog section on the website to see new SABCS Patient Expert Blogs! Tigerlily ANGEL Advocate experts and thought leaders attended the 2022 San Antonio Breast Cancer Symposium in December in-person and virtually to learn about the latest and greatest related to breast cancer. We’ve added more blogs where you can read about what they learned, what ignited hope, what questions they still have, and what they want other advocates, patients, survivors and thrivers to know.

South By Southwest

South by Southwest® (SXSW®) is a widely acclaimed global gathering that brings together leading innovators, thought leaders, and creatives from a diverse range of industries, including technology, film, music, education, and culture. This year’s event, held in Austin, Texas, featured Maimah Karmo, President and Founder of the Tigerlily Foundation, and her daughter, Noelle. They were both excited to participate in the event and engage in insightful conversations with other healthcare leaders.

Listen, Learn, and be Informed.



[Listen to the panel on Innovative Data Approaches to CTR](#)



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