

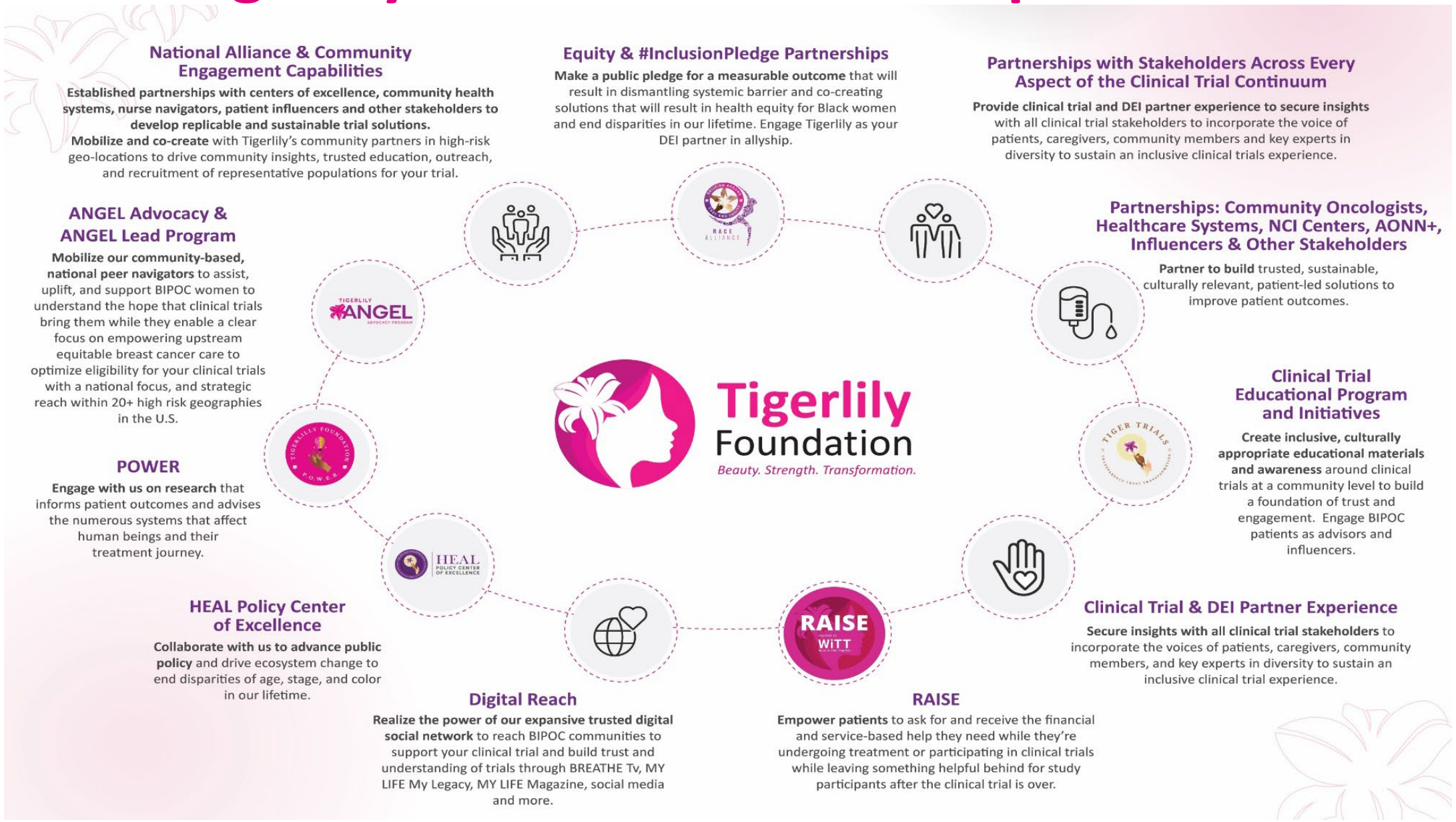
Strategic Priorities & Capabilities

SABCS 2024

Tigerlily Foundation

Beauty. Strength. Transformation.

Tigerlily Foundation Core Capabilities



National Alliance & Community Engagement Capabilities

Established partnerships with centers of excellence, community health systems, nurse navigators, patient influencers and other stakeholders to develop replicable and sustainable trial solutions.
Mobilize and co-create with Tigerlily's community partners in high-risk geo-locations to drive community insights, trusted education, outreach, and recruitment of representative populations for your trial.

Equity & #InclusionPledge Partnerships

Make a public pledge for a measurable outcome that will result in dismantling systemic barrier and co-creating solutions that will result in health equity for Black women and end disparities in our lifetime. Engage Tigerlily as your DEI partner in allyship.

Partnerships with Stakeholders Across Every Aspect of the Clinical Trial Continuum

Provide clinical trial and DEI partner experience to secure insights with all clinical trial stakeholders to incorporate the voice of patients, caregivers, community members and key experts in diversity to sustain an inclusive clinical trials experience.

ANGEL Advocacy & ANGEL Lead Program

Mobilize our community-based, national peer navigators to assist, uplift, and support BIPOC women to understand the hope that clinical trials bring them while they enable a clear focus on empowering upstream equitable breast cancer care to optimize eligibility for your clinical trials with a national focus, and strategic reach within 20+ high risk geographies in the U.S.

Partnerships: Community Oncologists, Healthcare Systems, NCI Centers, AONN+, Influencers & Other Stakeholders

Partner to build trusted, sustainable, culturally relevant, patient-led solutions to improve patient outcomes.

POWER

Engage with us on research that informs patient outcomes and advises the numerous systems that affect human beings and their treatment journey.

Clinical Trial Educational Program and Initiatives

Create inclusive, culturally appropriate educational materials and awareness around clinical trials at a community level to build a foundation of trust and engagement. Engage BIPOC patients as advisors and influencers.

HEAL Policy Center of Excellence

Collaborate with us to advance public policy and drive ecosystem change to end disparities of age, stage, and color in our lifetime.

Clinical Trial & DEI Partner Experience

Secure insights with all clinical trial stakeholders to incorporate the voices of patients, caregivers, community members, and key experts in diversity to sustain an inclusive clinical trial experience.

Digital Reach

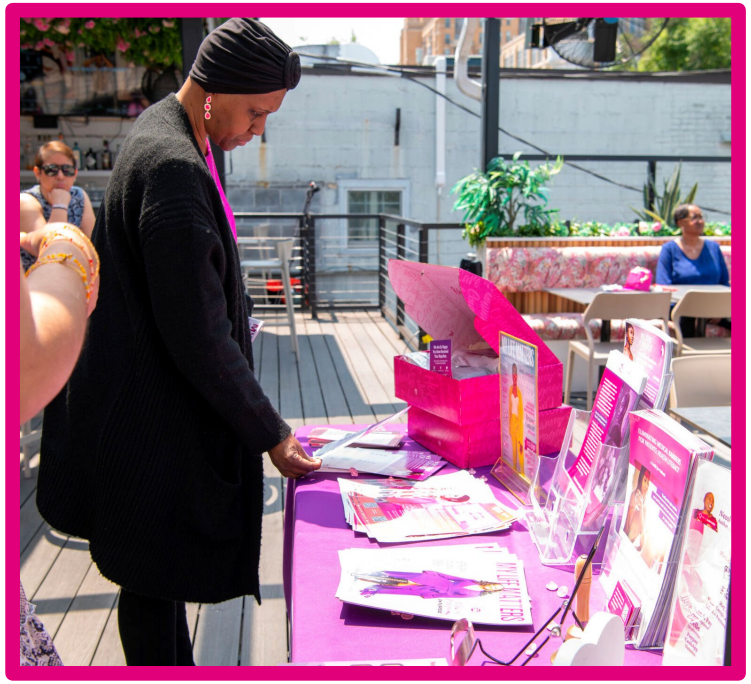
Realize the power of our expansive trusted digital social network to reach BIPOC communities to support your clinical trial and build trust and understanding of trials through BREATHE Tv, MY LIFE My Legacy, MY LIFE Magazine, social media and more.

RAISE

Empower patients to ask for and receive the financial and service-based help they need while they're undergoing treatment or participating in clinical trials while leaving something helpful behind for study participants after the clinical trial is over.

TIGERLILY ANGEL ADVOCACY PROGRAM

When you empower patients to collaborate with other patients and stakeholders who understand their lived experiences, and afford the opportunity to co-create solutions, it leads to better health outcomes and community engagement.





Force Multiply the Power of One



1

Educated, empowered thought leadership

Provide trained patient leaders who are prepared to mobilize BIPOC patients with expertise based on continuum of care domains and other interests of multiple health innovators.

2

DEI Engagement and Empowerment

Speak at and participate in corporate events based on DEI strategy and the needs of the workforce.

3

Gather Insights for Innovation

Integrate a heart-centered, safe space to support co-created initiatives by developing survey tools and trusted outreach approaches that will be used to gather patient insights from representative communities for impactful and meaningful innovation from the start.

4

Content Development & Feedback

Actively co-create and/or provide feedback on culturally sensitive, health literate and linguistically-appropriate discussion guides and educational materials, including multiple types of study materials for patients and providers before, during and after the clinical trial.

5

Multi-Stakeholder Advisory Board Development

Identify, assemble and develop advisory boards made of educated, empowered ANGELs and community patient leaders to gather insights into life science strategies along the cancer continuum of care.

6

Campaign Development and Launch

Curate BIPOC community members and patients to drive development of a national or local campaign with extensive trusted social network involvement and partners.

7

Patient Influencer Engagements

Launch storytelling and social media activations to support, educate and empower the patient community and other health care stakeholders and policy makers to be aware of the real-world implications of their work for action and change

8

Peer Navigation for Equitable Care throughout the Care Continuum

Expertly and compassionately find and recommend resources, provide connections and collaborate with community members and patients to build bridges between and amongst health care stakeholders throughout the continuum of care.

9

Community Trust Building

Support trusted community outreach events, relationship building and implementation of programs (such as Tigerlily's RAISE platform) in collaboration with Tigerlily's trusted Community Based Organizations, Faith Based Organization partners and health system leaders.

10

Clinical Trial Patient and Community Leadership & Advisement

Identify and address clinical trial site and community needs, trial participant eligibility, recruitment, retention, and participant SDOH needs before, during and after the trial. (Includes support for RAISE when used in a clinical trial)

11

Clinical Trial Site Engagement

Support trial site staff, provider and care ecosystem activities to ensure inclusivity and eliminate bias.

12

FDA Diversity plan goals

Support and ensure FDA guidance and legislative requirements for clinical trial diversity plans are met or exceeded and provide insights into other related research approaches (RWE, patient experience, outcomes research, SDOH research).

13

Research

Provide insights into research questions, methods, communications, posters, blogs and other publications.

14

Policy

Amplify diverse patient insights and increase representation in policy by empowering this community at a local, regional and national level. Capture and highlight the pulse of local policy issues which can turn into national policy issues.

15

Equity for Life

Advance the understanding of all aspects of cancer health, comorbidities, and SDOH barriers within the BIPOC community.

Tigerlily Foundation

Beauty. Strength. Transformation.

Advocate Now to Grow, Empower & Lead

ANGEL Advocate Focus

Tigerlily ANGEL Advocates are young women (21-50) who could be or have been affected by breast cancer (patients, survivors, MBC thrivers, care givers, co-survivors, etc.) - with a focus, but not limited to women living in the 21 areas of the U.S. with the highest disparities, committed to ending breast cancer disparities and achieving health equity.

ANGEL Advocate Training

The Tigerlily ANGEL Program provides comprehensive training to equip individuals with education on every aspect of breast health, risk reduction, testing, the continuum of care, survivorship and more. They are also equipped to: 1) be their own best advocates; 2) work to change familial misperceptions/history; 3) become peer educators; 4) educate and empower their communities and more.



ANGEL Advocacy Opportunities

Tigerlily ANGEL Advocates are given opportunities to use their time & voices to influence change by speaking at events, on panels, with the media, with policymakers, educating their communities & engaging with health care providers, in science, researchers, clinical trials, building trust in communities, and more.

Lead ANGEL Advocates

Lead ANGEL advocates are experienced advocates who act as lay patient navigators in their local communities by connecting individuals with resources to overcome any barriers to quality breast care as well as local breast health & cancer providers in the community.

http://angel.tigerlilyfoundation.org

REQUIRED 6 MODULES TO BECOME AN ANGEL ADVOCATE

Module 1

Tigerlily Foundation: Who We Are

An introduction to Tigerlily Foundation and its programs, resources and support services available to all young women as well as breast cancer patients, survivors and thrivers.

Module 2

Creating a Living Legacy



An introduction to Living Legacies, MY Life is My Legacy stories, and how to frame your desires and work to create your own Living Legacy through your advocacy activities.

Module 3

Breast Cancer 101 Screening, & Diagnostics

This training emphasizes the importance of understanding the fundamentals of breast cancer to effectively advocate for yourself and others. It provides a comprehensive overview, covering what breast cancer is, how it is diagnosed and treated, and strategies for reducing risks. Whether you're navigating treatment and survivorship or dealing with metastatic breast cancer, this knowledge empowers you to make informed decisions and support others on their journey. Even if you are already familiar with some of this information from personal experience, the training ensures a solid foundation for advocacy.

Module 4

Clinical Trials & You

This training explains the need for clinical trials and the roles of those involved in the research process. It covers historical medical ethics failures and the safeguards now in place to protect participants. You'll learn about the differences between observational and interventional trials, the phases of clinical trials, and the use of placebos.The training also stresses the importance of diversity among trial participants.

Module 5

Psychosocial Support

This training program empowers cancer survivors and advocates by emphasizing the critical importance of emotional and mental well-being. Participants will gain valuable knowledge and skills to enhance their advocacy efforts and personal health. By the end of this training, participants will be well-equipped to advocate for and access essential psychosocial support services, ultimately enhancing their well-being and that of their community.

Module 6

Self-Advocacy and Introduction into ANGEL Community

This training introduces participants to the Tigerlily Foundation and the ANGEL Advocacy Program, guiding them through the foundations of advocacy. It includes group discussions to help define advocacy, share personal experiences, and set individual goals. The training also focuses on action planning through the "Ease On Down The Road" framework, helping participants map out their advocacy journey. Finally, it encourages becoming an active member of the ANGEL community and provides information on advanced trainings and next steps for continued growth in advocacy.

Tigerlily Foundation
Beauty. Strength. Transformation.

TIGERLILY ANGEL ADVOCACY PROGRAM

TIGERLILY ANGEL ADVOCACY PROGRAM

Advanced Track Modules

Peer Community Navigation & Support

- Peer Navigation
- Peer Support
- Genetic & Biomarker Testing
- Patient's Rights
- Self-Care & Holistic Living

Clinical Trials

- Advanced Clinical Trials & Research
- Genetic & Biomarker Testing

Outreach/Education

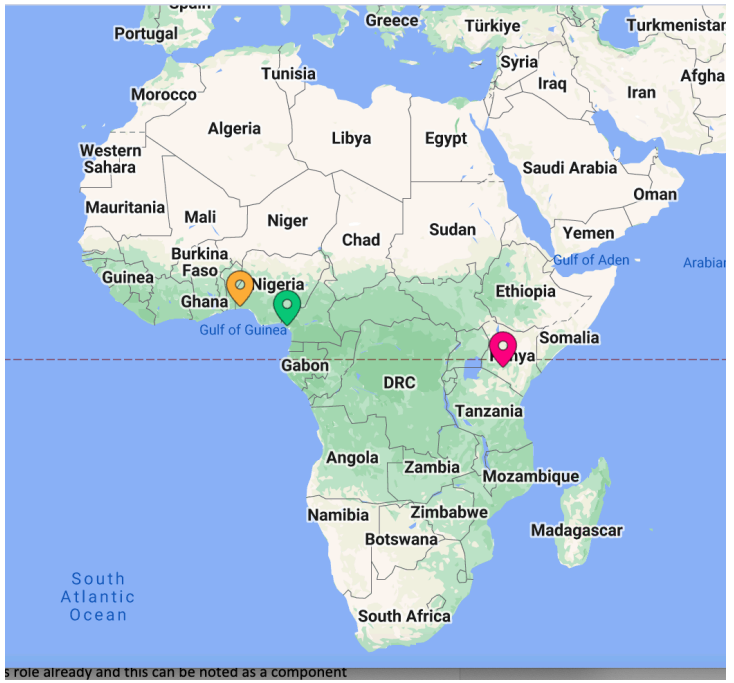
- Metastatic & Early Breast Cancer
- Survivorship
- Using Social Media in Your Advocacy
- Community Education & Advocacy

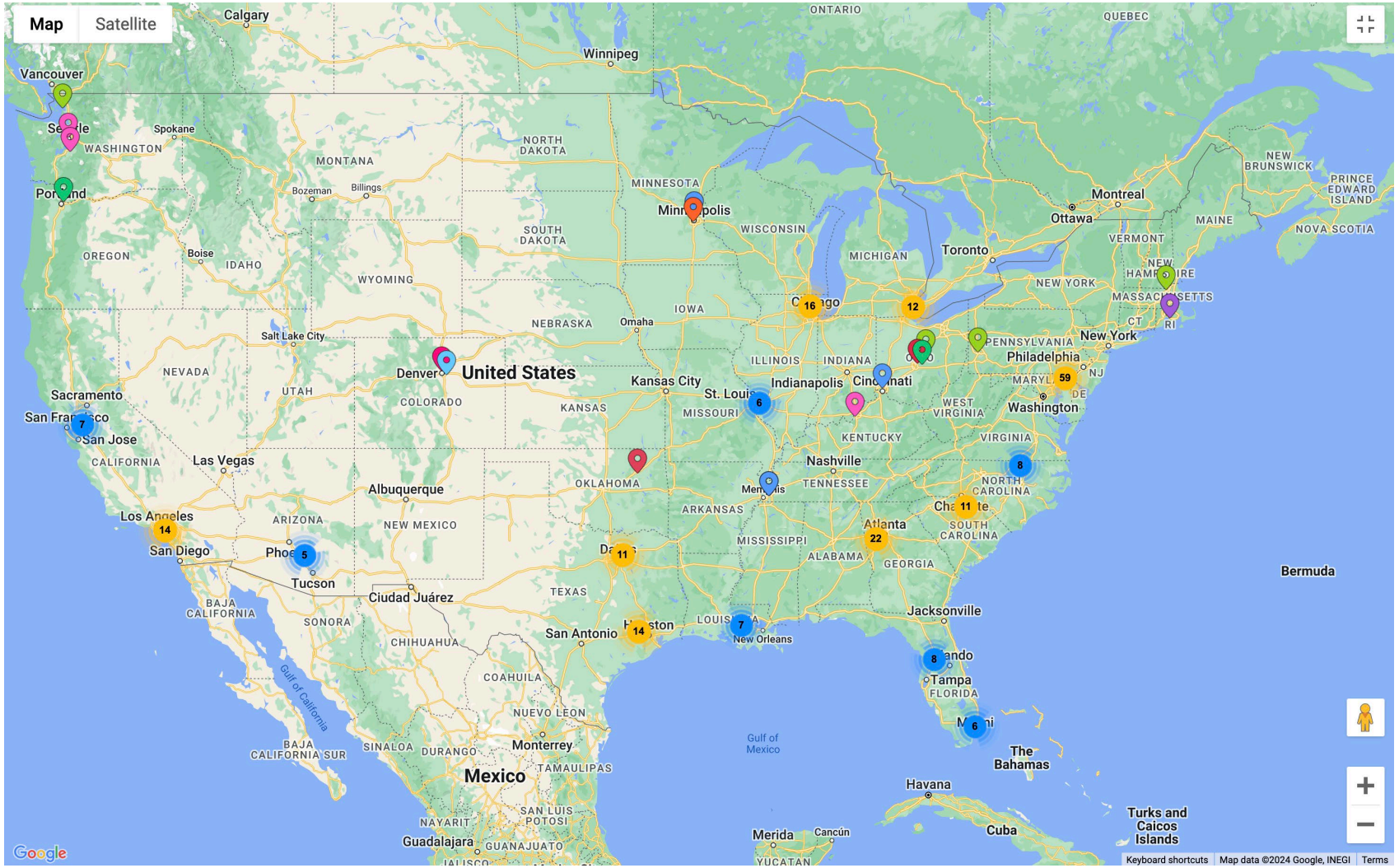
Policy

- Disparities in Breast Cancer
- Anti-Racism & Allyship
- Advance Policy Workshop

ANGEL Geographic Locations







We have also identified and mapped ANGEL LEADs that represent the 9 regions identified by the CDC.

TIGERLILY ANGEL ADVOCACY PROGRAM

The ANGEL Advocates program has an impressive 550+ candidates recruited from high disparity areas, and more than 350 advocates successfully trained (to date).

These passionate individuals have completed comprehensive training modules, gaining invaluable knowledge and skills.

Post-training assessments reveal a doubling of knowledge levels, a significant increase in self-advocacy, and enhanced empowerment to advocate for themselves and others.

Key Metrics

- 2x knowledge level of "excellent" post training vs. before training
- 97% report they are "very likely" to speak up for themself if a provider makes assumptions based on identity factors post training
- 82% reported feeling "very prepared" or "prepared" to address barriers to healthcare post training

Impact: 2,081,265 Black & Brown Patients Reached

2024 ANGEL Activities

200+ ACTIVITIES: in-person, digital and virtual

- Advocacy/Education
- In-person Community Events
- Virtual Learning Events
- Policy Support
- Digital Outreach and Publications
- Clinical Trial Projects
- Patient Listening Sessions
- Speaking Engagements
- Document and Protocol Reviews
- Social Media Outreach
- Health and Wellness Workshops
- Advanced Educational Trainings



Join Us in a City Near You!







TIGERLILY ANGEL ADVOCACY PROGRAM

Bi-Directional Education & Training

Pull Up a Seat / Know More Disparities engaged **26** ANGEL Advocates and reached **60,000+** individuals through bi-directional conversations to co-create solutions for eliminating and overcoming barrier to accessing equitable care and outcomes for Black patients.

Clinical Trial & Research Listening Summits and Advisory Activities engaged **101** ANGELs and reached **10,000+** individuals.

Four *Listening Summits* engaged **12** ANGEL advocates and reached **3,000+** individuals.

ANGELS collaborating with **15+** partners on clinical trial initiatives.

TLF Clinical Trials Advisory Committee (CTAC) 20+ person advisory committee.

#TLC Transformation Twitter Chats engaged 5**0+** ANGELs and reached **5.2 million +** individuals.

Five clinical trial education and outreach projects ongoing, engaging **40+** ANGEL Advocates focusing on:

- Building trust in communities of color – 21 city tour
- Clinical trial education and building bridges
- Advisory boards
- Influencer engagement
- Campaign advisement
- Patient education materials review.

Impact: 5.2M+

ANGEL Advocacy Program
Barrier Identification & Resources

Tigerlily Barrier Toolkits are supplying women with the resources, knowledge, and tools necessary to better understand the most common barriers reported by our ANGEL Advocates and how to overcome them.

Toolkits were created to address the following topics:

- Psychological Barriers
- Emotional/ Trauma Barriers
- Literacy Barriers (Healthcare Providers and Patients)
- Financial/ Socio-economic Barriers
- Geographical Barriers
- Lifestyle Barriers
- Communication (External discrimination) Barriers
- Representation Barriers
- Environmental Barriers
- Clinical Trial Barriers
- Trust Barriers

ANGEL Advocacy Program
Global Expansion

- Tailoring successful programs for cultural applicability starting with patient education / health literacy and empowerment:
  - Strategic partnerships in Africa – Pilots in Liberia and Ghana
  - Strategic partnerships in South America – Pilot in Brazil
  - Strategic partnership exploration in Asia and Europe

- Future = Global Policy and Access



TIGERLILY ANGEL ADVOCACY PROGRAM

Launch of the Peer Support & Navigation Program

- The Peer Support & Navigation Program aims to enhance healthcare access and outcomes for BIPOC breast cancer patients.
- Peer navigators provide essential support by leveraging their experiences and fostering trusted relationships with patients.
- This program is designed to address patients' practical and social needs to provide well-rounded care.
- This model is specifically tailored to meet the needs of women 50 years old and younger with breast cancer or metastatic breast cancer.

TIGERLILY ANGEL ADVOCACY PROGRAM

Roles & Responsibilities of Peer Navigators

Assess & Understand Patient Needs to provide tailored and patient-centered care.	**Tailor Care to Each Patient**s' cultural background, ensuring appropriateness and relevance.	**Build Rapport with Patient**, fostering trust and open communication to create a supportive environment.	**Facilitate Communication between Patient & Health Care Team**, ensuring mutual understanding and cultural translation.	**Educate & Provide Resources to Patient** to empower informed decision-making, without giving medical advice.
Advocate for patients' preferences and needs, serving as liaisons between patients and healthcare providers.	**Engage in Continuous Self-Motivated Learning** to improve capacity to support and provide high quality care.	**Address Barriers to Care**, ensuring patients receive timely and appropriate care.	**Involve Family Members** in the care process, if the patient has expressed that they are an important part of their life and decision-making.	**Educate & Support Health Care Team** about diversity and culture, promoting culturally competent care provision among staff.

TIGERLILY ANGEL ADVOCACY PROGRAM

Peer Navigation Training Modules

1: Introduction to Peer Support and Navigation

2: Recognizing Health Disparities

3: Social Determinants of Health

4: Overcoming Barriers to Care

5: Enhancing Cultural Competency

6: Effective Communication Skills

7: Health Interpretation

8: Survivorship Care Plans

9: Referrals and Linkages

10: Interdisciplinary Collaboration

11: Navigating Health Insurance Coverage

12: ANGEL Empowerment Plan

13: Resources for Patients and Survivors

14: Boundaries and Professionalism

TIGERLILY ANGEL ADVOCACY PROGRAM

Outcomes Measurement & Impact

- We plan to measure:
  - The number of patients asking about patient navigators.
  - Quality of support patient navigators provide.
  - Number of referrals to patient navigators.
  - Overall patient experience.
  - Percent of ANGEL Empowerment Plan goals achieved.

- Expected Impact:
  - Improved access to direct psychosocial support focused on healthy coping strategies, mental health, reproductive health, financial assistance, and early palliative care.
  - Improved informed decision-making by patients, including treatment choices and adherence to treatment plans.
  - Enhanced empowerment and self-advocacy skills.
  - Over the immediate term, improved access to lifestyle programs and preventive services, enhanced navigation, and better communication and interactions with HCPs.
  - In the long run, improved health-related quality of life (HRQoL), better access to equitable support for more Black patients and carers.

TIGER TRIALS



TRANSPARENCY TRUST TRANSFORMATION

Comprehensive Clinical Trial Support

CO-DEVELOPMENT OF DIVERSITY PLAN

BUILD CLINICAL TRIAL AWARENESS IN BLACK AND BROWN COMMUNITIES

INFLUENCER IDENTIFICATION AND ENGAGEMENT

An end-to-end clinical trial support solution that encourages Black and Brown women with breast cancer to consider clinical trial participation.

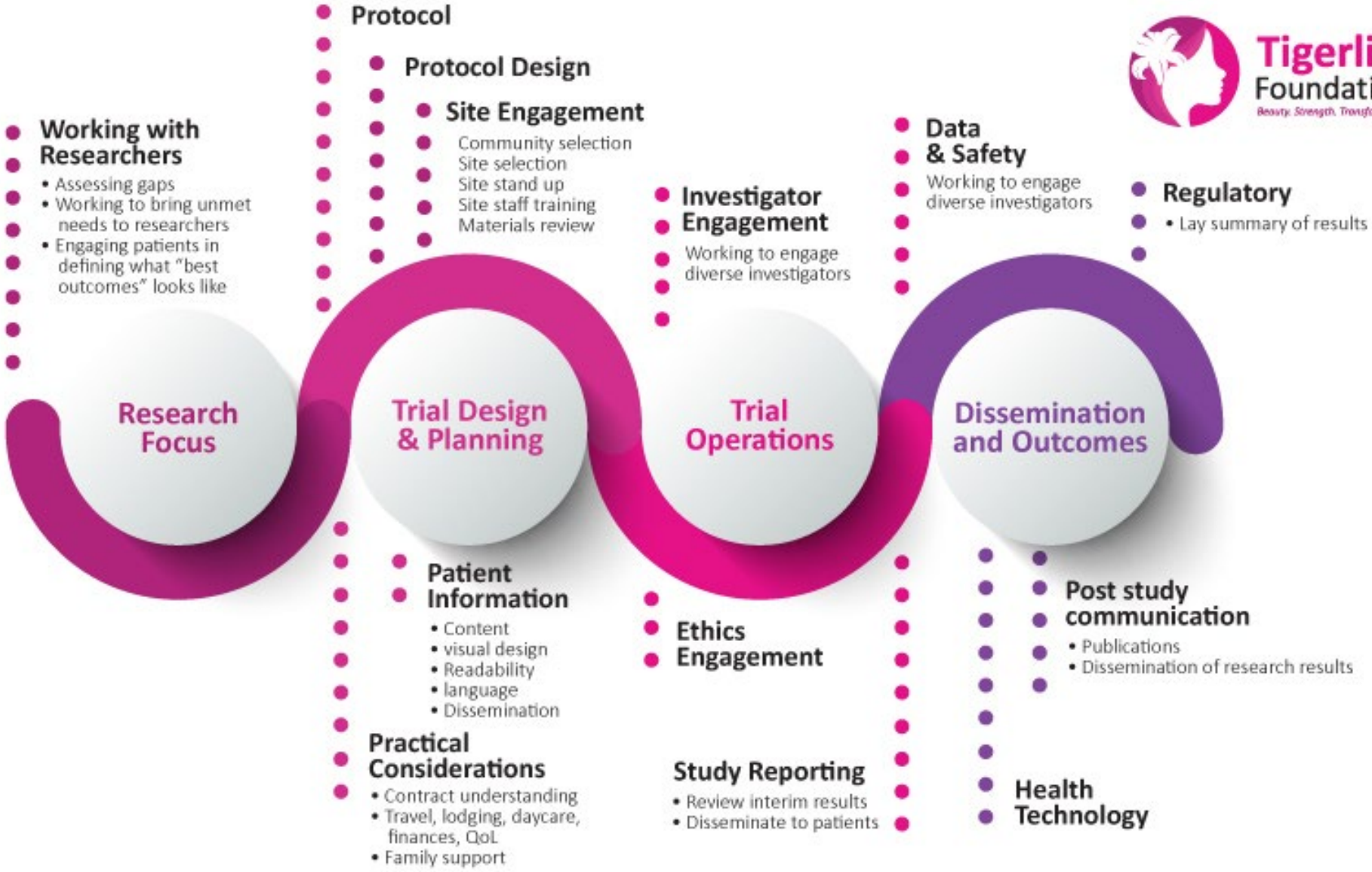
BUILD COMMUNITY RELATIONSHIPS, PARTNERSHIPS, AND TRUST

PROACTIVE, INTEGRATED, AND FULLY EMBEDDED CLINICALS PARTNER

CONTINUOUS PROACTIVE DIALOGUE TO ENSURE STRATEGY ALIGNMENT

MEMORABLE, OWNABLE MESSAGING UNDERPINS ALL PROGRAMMING

Tigerlily Foundation is working with stakeholders to engage patients at every intersection throughout the clinical trial journey



Clinical Trial Navigation
Bridging the Gaps in Research Participation

This collaboration aligns TLF's mission to end disparities in breast cancer with BreastCancerTrials.org's expertise in clinical trial access and navigation.

Together, we are designing a Clinical Trial Navigation Curriculum to equip our ANGEL Advocates with the tools and knowledge needed to empower communities and increase diverse representation in research.

Project Objectives:

1. **Develop a Customized Curriculum**: Leverage the expertise of both organizations to create a culturally relevant program tailored to Black and Brown women with breast cancer.
2. **Train ANGEL Advocates**: Equip Advocates with skills to guide individuals in navigating the clinical trials landscape.
3. **Increase Representation**: Empower communities to participate in research, addressing disparities and improving breast cancer outcomes.

#MyLivingLegacy: Clinical Trial Media Campaign



My Living Legacy Campaign

September 2022 – January 2024

Tigerlily Foundation

Beauty. Strength. Transformation.

Tigerlily Foundation curated an educational campaign to drive clinical trial awareness and diverse patient engagement:

- Study: Tigerlily provided support through patient expert review of study recruitment materials. Twenty-eight Tigerlily ANGEL advocates reviewed the study recruitment poster, brochure, and tri-fold flyer.
- The *My Living Legacy* campaign provided educational content to individuals through in-person events and digital and traditional media platforms to encourage trust and awareness around clinical trials at a community level.
- The estimated audience or reach from the *My Living Legacy* campaign included the following:
  - **171 million+ listeners** through a radio PSA
  - **33 million+ readers** through interviews for online news outlets
  - **5 million+ viewers** through television news outlets
  - **1,600 unique visitors** to the campaign website
  - **286,000+ viewers** through patient advocate influencers on social media platforms
  - Direct, active engagement with **400+ individuals** at in-person community events


Tigerlily
Foundation
HEAL
POLICY CENTER
OF EXCELLENCE

Health Equity Advocacy & Leadership (HEAL) Policy Center of Excellence

Patient Advocacy Leadership

Tigerlily has a 17-year history in the policy landscape. Our goal has always been to advocate for impact by driving policy making to create equity for patients. Patient advocacy leadership has always been key—here within Tigerlily and in guiding public policy.

HEAL Policy Center of Excellence

Tigerlily is culminating our history of policy into our Health Equity Advocacy and Leadership (HEAL) Policy Center for Excellence (COE).



Policy Focus

The HEAL COE is committed to advancing public policy to further our mission. We are striving to make our vision of ending disparities of age, stage, and color in our lifetime a reality through:

- Health Equity
- Ending Barriers
- Access Improvement
- Leadership through Patient Innovation

Pillars of Policy Work

The HEAL COE educates, empowers, and lifts patient voices to ensure they are amplified, in order to achieve health equity and end disparities; and focuses on systemic changes through policy at the local, state and federal level to:

- End barriers to accessing and receiving quality, equitable care for all.
- Lead innovation through patient-leadership.
- Achieve health equity and eliminate disparities in breast cancer.

2024 – 2025 Policy Priorities

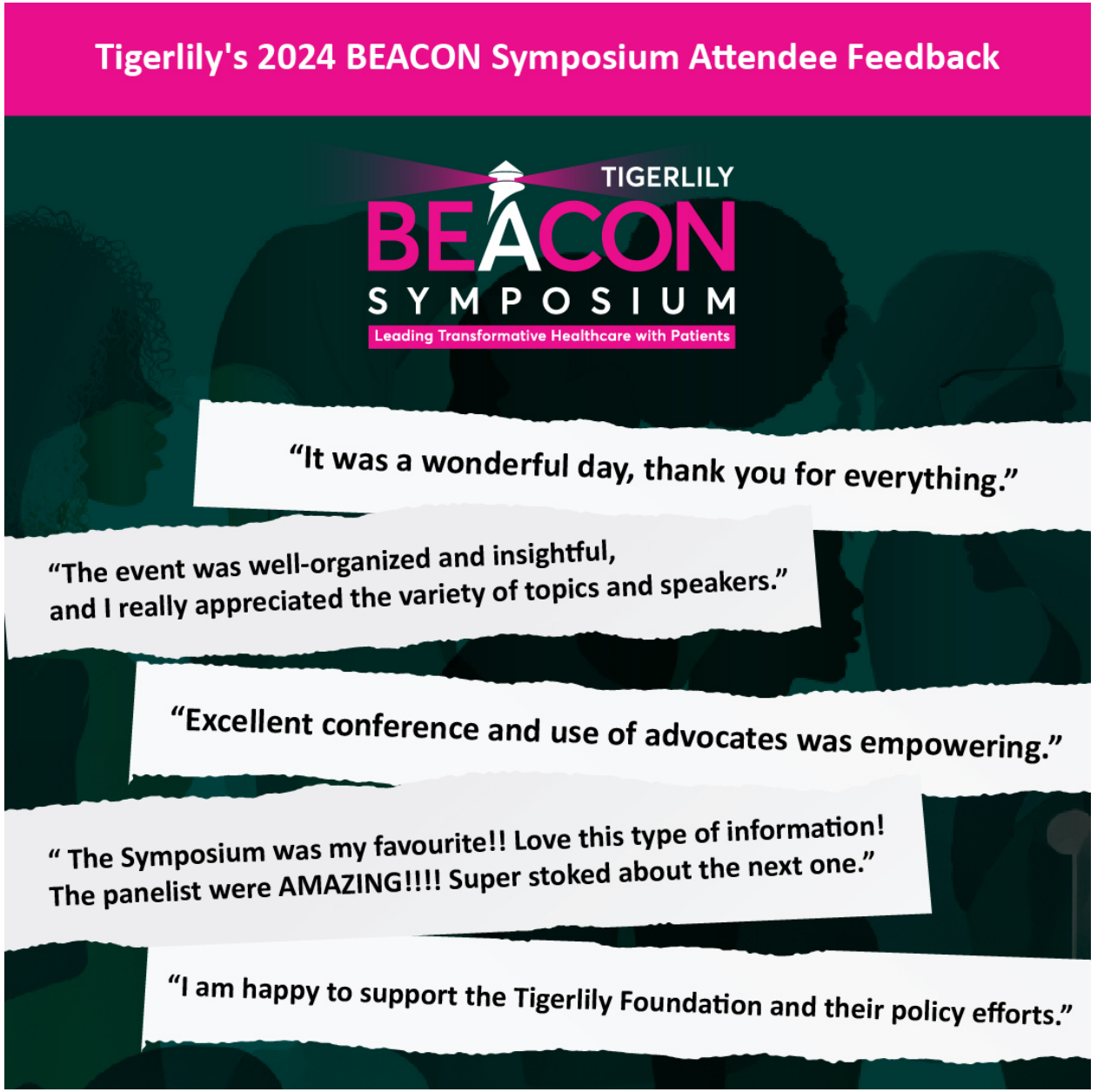
- **Inflation Reduction Act**
  - EPIC Act
  - ORPHAN Cures Act
- **State Prescription Drug Affordability Boards (PDABs)**
  - Upper Payment Limits
- **340B Reform**
- **Step Therapy / Utilization Management**
- **Co-Pay Accumulators**
- **PBM Reform**
- **Biomarker Testing**
- **Comprehensive Cancer Survivorship Act**
- **Clinical Trials Modernization Act**

Tigerlily Foundation | HEAL POLICY CENTER OF EXCELLENCE

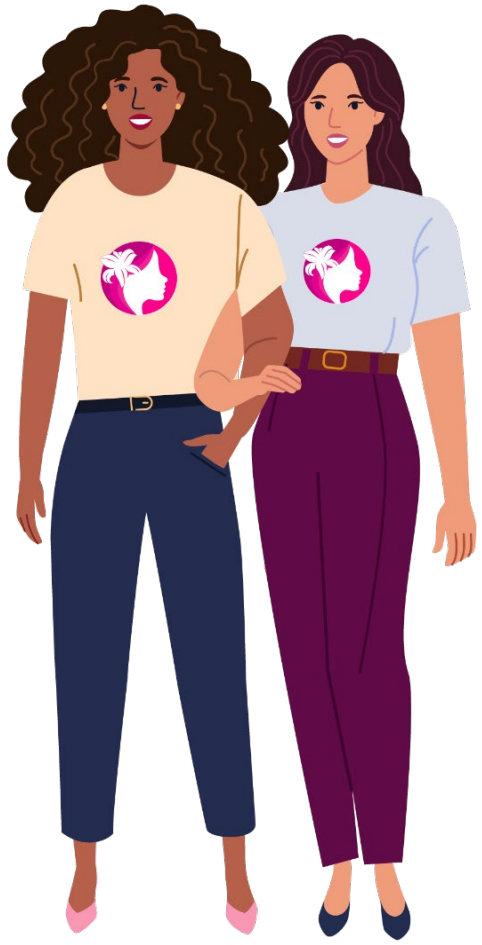
2nd Annual BEACON Symposium

October 19, 2024

- **Accelerating Access to Diverse Clinical Trials**
- **Policies for Affordable Drugs for Patients – Prescription Drug Cost Reduction Efforts & How Do We Ensure Meaningful Patient Benefits to Support Health Equity**
- **Making Science Accessible Through Health Literacy**



PDAB Initiative Roadmap & Opportunity



Opportunity: ANGEL Advocates can meaningfully contribute to the policy around the short and long-term impacts of PDABs and upper payment limits (UPLs) by sharing their lived experiences with state policymakers, regulators, and other key audiences.

Objective: Engage ANGELs in state advocacy efforts to ensure patient access to current treatments and the pipeline of future medicines are not negatively impacted.

Approach: Launch a three-phase plan to educate ANGELs, facilitate feedback and discussion, and provide resources to empower ANGELs to take action and build awareness of the potential impacts of PDABs and UPLs.

PDAB Initiative Approach

PHASE I: Education

EDUCATION MATERIALS:

Tigerlily Foundation will develop handouts and a slide presentation designed to educate and engage ANGELs in the PDAB conversation.

Tigerlily Foundation will provide resources for advocates to refer to in conversations on the issue.

PHASE II: Discussion

LISTENING SESSION:
Facilitate conversations to inform advocacy efforts around PDABs and discuss what tools and resources are needed to support ANGEL advocacy.

EXPERT WEBINAR:
Host a panel discussion and Q&A session to educate about the landscape of breast cancer treatments, policies that threaten access to these lifesaving medicines, and how YOU can raise your voice.

PHASE III: Action

ANGEL ADVOCACY TOOLKIT:
Provide social media content and digital resources to build awareness of key takeaways from the webinar and amplify your story with your networks.

ANGEL STORY COLLECTION:
Support ANGELs in sharing their story about your diagnosis and treatment experience to raise awareness about the importance of treatment access and affordability.

Advocacy in Action Example

Throughout 2024 state legislative sessions, TLF was actively engaged around PDABs and UPLs. Primarily, efforts have focused on **educating policymakers and other engaged stakeholders on the potential impact on patient access, innovation, and health equity**. Ahead of 2025 state sessions, Tigerlily will be developing resources and tools to help ANGEL Advocates engage on this critical issue.

Comment Letters



Tigerlily Foundation

February 20, 2024

RE: The Negative Impact of Proposed Drug Affordability Board on Virginians Living with Cancer

To Honorable Members of the Virginia House Committee on Labor and Commerce:

The Tigerlily Foundation is a national women's health and oncology organization dedicated to education, advocacy, and hands

Tigerlily Foundation

April 1, 2024

RE: The Negative Impact of a Proposed Drug Affordability Board on Illinoisans Living with Cancer

Honorable Members of the Illinois Legislature:

The Tigerlily Foundation is a national women's health and oncology organization dedicated to education, advocacy, and hands-on support for young women before, during, and after cancer. I write to you today to express our organization's c

Tigerlily Foundation

May 30, 2024

RE: Proposed Drug Review Commission Will Negatively Impact Rhode Islanders Living with Cancer

To Honorable Speaker Joe Shekarchi and Members of the Rhode Island General Assembly:

Tigerlily Foundation is a national women's health and oncology organization dedicated to education, advocacy, and hands-on support for young women before, during, and after cancer focusing on eradicating the disparities of age, stage and color. I write to you today to express our organization's concerns over Senate Bill 2719 that would establish a Drug Cost Review Commission in Rhode Island, commonly known as a prescription drug affordability board (PDAB) in other states. **Establishing a drug cost review board in Rhode Island will block access to essential medicines that Rhode Islanders rely on to manage symptoms and lead healthier lives, particularly for patients living with cancer and other complex and chronic conditions. A Drug Cost Review Commission will only further exasperate already existing health inequities rather than helping move progress forward towards health equity in Rhode Island.**

Opinions & Articles



The Virginian-Pilot

Opinion: Governor's drug affordability board veto serves cancer patients
By Maimah Karmo

NBCSL

State Drug Boards Threaten to Compound Patient Access Challenges
By Maimah Karmo & Melissa Gong Mitchell, GCOA



Column: Governor's drug affordability board veto serves cancer patients



New Educational Resources

NOTE: Development of these resources will be informed by input from ANGEL Advocates.

- ✓ **Educational Listening Session Series**
- ✓ **Expert Webinar**
- ✓ **Social Media & Digital Toolkit**
- ✓ **Website Landing Page**
- ✓ **ANGEL Training Tools**
- ✓ **Advocacy Resource Toolkit**



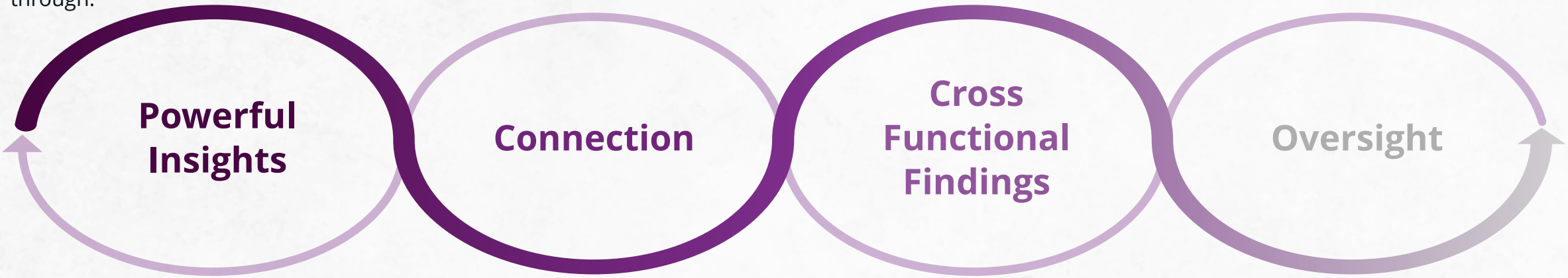
POWER (**P**eople-driven **O**utcomes through real-**W**orld **E**vidence and **R**esearch)

Tigerlily's POWER Center Patient Insights and Equity Research

Tigerlily Foundation POWER Center

Tigerlily's POWER Center is a driven by patients and leaders in the cancer community advocacy space, embedded in and working together with vulnerable communities. We are committed to bring out science-driven patient insights

Together we can co-create studies with patients and communities, working collaboratively to design, evaluate, implement and disseminate research through:



- Research findings provide science-driven actionable insights and understanding to the patient and caregiver needs
- Longitudinal mixed-methods data sets focusing on vulnerable populations
- New directions for patient-centered approaches to the next generation of healthcare delivery process

- Amplifies cancer community and stakeholders' voices through embedded structure in the communities
- Improving care and care delivery using health equity strategies
- Shaping the science of community engagement

- Increases community engagement; shapes policy through outcomes research using real-world data
- Deliver insights to improve survivorship and removing barriers to access to care

- Full project management and execution: identifying needs, mixed-methods multi-phased research design, implementation, recruitment, data collection, analysis, drafting programs based on research findings, execution, and evaluation

POWER (**P**eople-driven **O**utcomes through real-**W**orld **E**vidence and **R**esearch)



Top 5 Challenges

Tigerlily Foundation POWER Center

1. **Lack of Survivor and Caregiver Perspectives**
   Patient and caregiver perspectives are often excluded from clinical trial design and health care delivery processes, or are often an afterthought, leading to wider health disparity gaps
2. **Inclusivity**
   The voice of vulnerable communities are not often fully represented and integrated even less into the design and delivery of healthcare
3. **The Broken Link to Advocacy**
   Advocacy organizations are often limited to patient recruitment and post-research design feedback, but rarely co-create or lead insights, frameworks or patient-centered research
4. **Disconnection from Patient and Survivor Communities**
   Market research companies often take a prominent role in research and development with little contact with or knowledge of patient and survivor communities
5. **Shortcomings**
   Studies frequently lack foundational community embedded connections and can misrepresent target populations through biased data capture, further validating and contributing to patient and community linked mistrust in research organizations

Collaborative Opportunity

Tigerlily Foundation POWER Center



Patient-Led Co-Designed Studies

- Expert social and behavioral research
- Grounded by advocacy organization
- Responsible
- Trusted



Participant Engagement

- Authentic participant engagement
- Trusted patient organization by cancer communities
- Key Insights to Patient Perspective



Patient Investment

- Research co-led with patients ultimately resulting in increased trust, education and participation



National Impacts

- Tigerlily Foundation brings a nation-wide, community-driven footprint
- Trusted Diverse Advocacy and Research Partners
- Innovative Perspectives

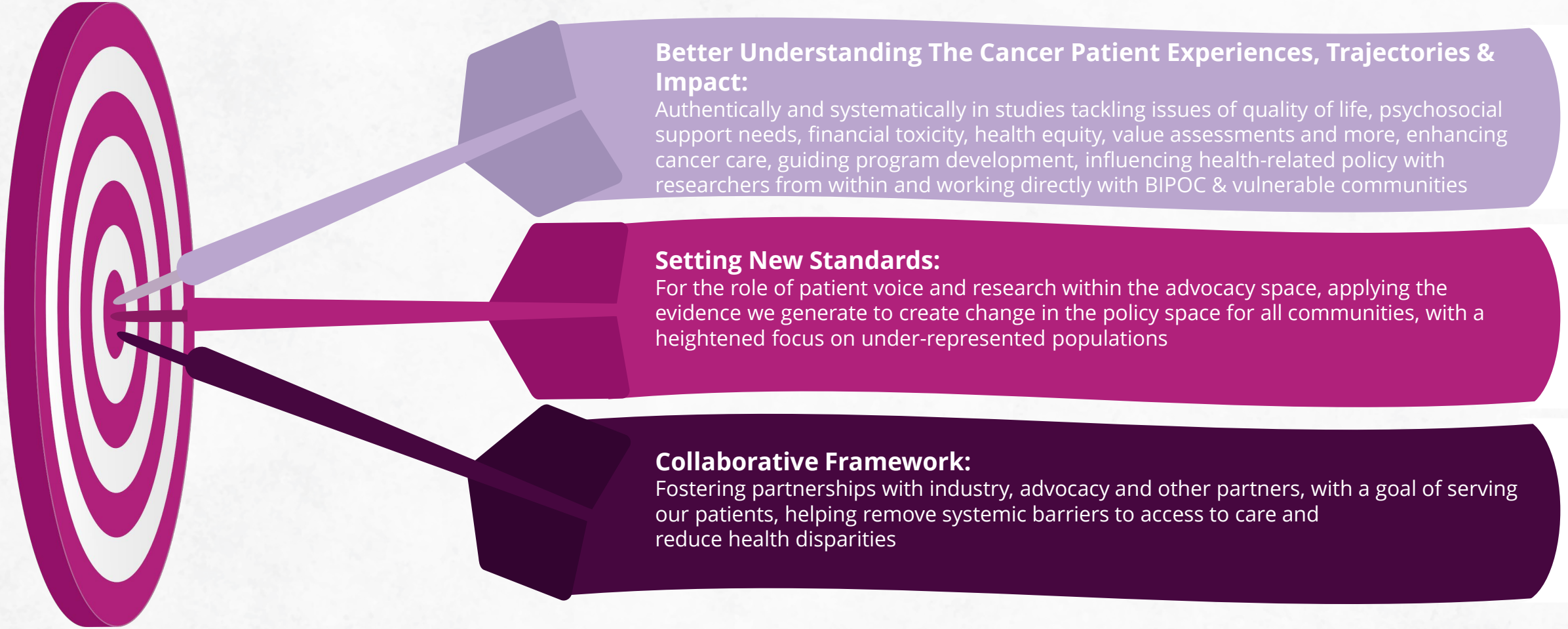


Healthcare Improvements

- Aligning Healthcare Needs
- Work Directly with Patients
- Shape the Next Generation of Healthcare Delivery

POWER Center Key Commitments

Tigerlily Foundation POWER Center



Better Understanding The Cancer Patient Experiences, Trajectories & Impact:
Authentically and systematically in studies tackling issues of quality of life, psychosocial support needs, financial toxicity, health equity, value assessments and more, enhancing cancer care, guiding program development, influencing health-related policy with researchers from within and working directly with BIPOC & vulnerable communities

Setting New Standards:
For the role of patient voice and research within the advocacy space, applying the evidence we generate to create change in the policy space for all communities, with a heightened focus on under-represented populations

Collaborative Framework:
Fostering partnerships with industry, advocacy and other partners, with a goal of serving our patients, helping remove systemic barriers to access to care and reduce health disparities



Research and Evaluation Goals

Tigerlily Foundation POWER Center

ASSESSING
Widely disseminated data on vulnerable populations to evaluate for accuracy and current applicability

DEVELOPING
New/improved measures, including patient reported outcomes (health-related quality of life, functional status, symptom burden, health behaviors, patient experience of care) for vulnerable and BIPOC women experiencing cancer, improving upon the most-commonly used white-centric measures

BUILDING
New measures of **empowerment** by conceptualizing and operationalizing a new set of tools specifically created to understand the unique experiences of vulnerable communities in navigating the healthcare system; building new composite measures to capture the effects of class, race, ethnicity, gender, rurality and subcultures for patients at entry points to the cancer care system

The Power Center team designs and leads all research and evaluation protocols, recruitment, data collection and analysis in house

SHARING/DISSEMINATING
Learnings and data gained from study designs and programs to drive transformation in research, evaluation, data collection and analysis

COLLABORATING
With partners in building clear metrics for understanding drivers of change and structuring most impactful programs, showing changes in attitudes, perceptions, decisions, experiences, and preferences; tracking and reporting improvements in areas of health literacy, health knowledge, rates of access to navigation of vulnerable cancer communities, and tracking changes in community trust rates

CREATING
Longitudinal mixed-methods data sets establishing baselines and tracking changes in patient behavior, attitudes, preferences, perception and knowledge through their trajectories

MAPPING
Barriers, needs and pathways to changes in awareness, knowledge, and attitudes toward clinical trials, and working to increase clinical trial participation rates for vulnerable populations; patient trajectories on treatment options, building visual maps helping patients in decision-making

POWER Center Capabilities



Tigerlily Foundation POWER Center

Highest Standards:
We design and implement a wide range of studies employing the most rigorous social and behavioral scientific methods, working with both proprietary and non-proprietary data, delivering internal reports, white papers, conference posters and published manuscripts

All Inclusive Mixed-methods Research:
We design and implement studies from start to finish, from protocol development, IRB approval, recruitment, data collection and analysis with multi-phased comprehensive mixed-methods research projects

Patient Focused Research:
Recruit from within patient communities, working with a wide network of advocacy, research and clinical partners

Advanced Qualitative Analysis:
Conduct focus groups and interviews, and use the most advanced qualitative analysis techniques, including software assisted content, discourse and thematic analysis, build interactive patient and provider feedback platforms, match patient socio demographic and validated medical history with qualitative data

Advanced Survey Research:
Build and field **custom surveys** with stratified samples; conduct descriptive and inferential analysis of survey data, compare qualitative interview data with survey data

Patient Preference Studies and Journey Maps:
Conduct studies to understand patient and caregiver decision-making processes at every step of their trajectories

Cost and Value Assessments:
We work with commercial and federal claims data to understand the financial impact of policies

POWER Center in the Research Community

Tigerlily Foundation POWER Center

Tigerlily engages in research projects with top leaders in the industry, academia, and with public health professionals, to build a rigorous dissemination and publication record

Sample Peer Reviewed Publications, Abstracts and Posters by POWER Center team members (2023-24)

- Andac-Jones E, Gonzalo MB, Wilson GT, Saks R, Power NJ. Understanding barriers to LGBTQ+ cancer clinical trial participation: A qualitative inquiry. Journal of Clinical Oncology. 2023;41(16_suppl):e18675-e18675. doi:10.1200/JCO.2023.41.16_suppl.e18675.
- Andac-Jones E, Newell A, Szamreta EA, Gonzalo MB, Hoffman J, Monberg M. Relative and functioning sleep disturbance and fatigue: Impact on patients with ovarian cancer. Journal of Clinical Oncology. 2023;41(16_suppl):e24102-e24102. doi:10.1200/JCO.2023.41.16_suppl.e24102.
- L. Vidal, Z. Dlamini, S. Qian, P. Rishi, M. Karmo, N. Joglekar, S. Abedin, R.A. Previs, C. Orbegoso, C. Joshi, H.A. Azim, H. Karkaria, M. Harris, R. Mehrotra, M. Berraondo, G. Werutsky, S. Gupta, N. Niikura, I. Chico, K.S. Saini. Equitable inclusion of diverse populations in oncology clinical trials: deterrents and drivers, ESMO Open, Volume 9, Issue 5, 2024, 103373, ISSN 2059-7029, https://doi.org/10.1016/j.esmoop.2024.103373.
- Karmo, M., Cornish, K., Leach, V. et al. Patients Drive Authentic Trusted Solutions for Inclusive Clinical Trials. Curr Breast Cancer Rep 16, 76–83 (2024). https://doi.org/10.1007/s12609-024-00526-5
- Virginia Leach, Jeanne Regnante, Maimah Karmo, Lizzie Wittig. How we learn from Black TNBC patients to act for equitable and unbiased care [abstract]. In: Proceedings of the 16th AACR Conference on the Science of Cancer Health Disparities in Racial/Ethnic Minorities and the Medically Underserved; 2023 Sep 29-Oct 2;Orlando, FL. Philadelphia (PA): AACR; Cancer Epidemiol Biomarkers Prev 2023;32(12 Suppl):Abstract nr A034.
- Jeanne Regnante et al., The case for acceleration of prospective multi- stakeholder led community-based research in young Black women with triple negative breast cancer (TNBC). JCO 41, 1089-1089(2023). https://doi.org/10.1200/JCO.2023.41.16_suppl.1089
- Karmo M, Pierre A. Pull Up a Seat: Engaging Patients as Empowered Partners in Health Equity Transformation. J Adv Pract Oncol. 2022 Apr;13(3):202-204. https://doi.org/10.6004/jadpro.2022.13.3.3. Epub 2022 May 23. PMID: 35663168; PMCID: PMC9126325.
- Anampa-Guzmán A, Freeman-Daily J, Fisch M, Lou E, Pennell NA, Painter CA, Sparacio D, Lewis MA, Karmo M, Anderson PF, Graff SL; Collaboration for Outcomes using Social Media in Oncology. The Rise of the Expert Patient in Cancer: From Backseat Passenger to Co-navigator. JCO Oncol Pract. 2022 Aug;18(8):578-583. https://doi.org/10.1200/OP.21.00763 . Epub 2022 Mar 28. PMID: 35344398; PMCID: PMC9377686


RALLYING AROUND
CARE AND EQUITY
RACE
ALLIANCE

Tigerlily Foundation #Inclusion Pledge

THE #INCLUSIONPLEDGE

We pledge to take specific actions to dismantle and eradicate systemic barriers, working to end disparities for Black women in our lifetime.

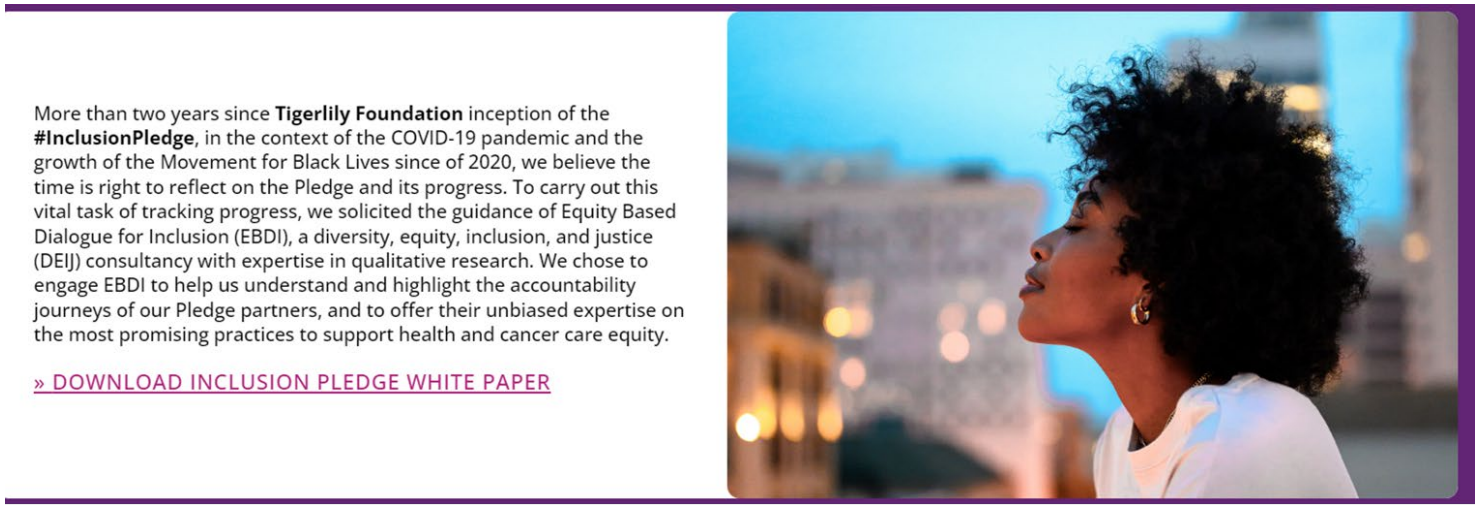


HOW CAN I GET INVOLVED?

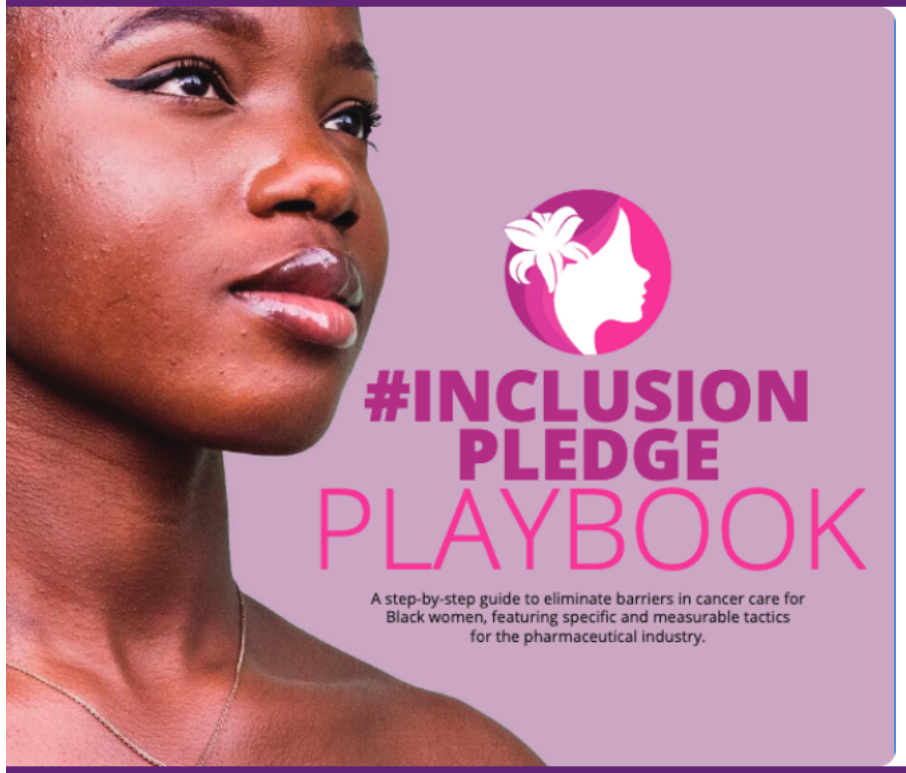
Tigerlily Foundation #InclusionPledge

- Tigerlily Foundation is committed to ending healthcare disparities in our lifetime by advocating for and initiating measurable systemic change across all sectors that impact lifespan of women of color (as a partner to patients, caregivers, treatment teams, other advocacy organizations and industry).

- The #InclusionPledge provides a transparent and tangible framework across stakeholders to identify and track equity actions, holding organizations accountable to making specific, measurable outcomes that will result in dismantling systemic barriers, and co-creating solutions that will result in health equity for Black women and end disparities in our lifetime.



Inclusion Pledge White Paper



The **Tigerlily Foundation #InclusionPledge** Playbook is a roadmap for the pharmaceutical industry and highlights specific, measurable, and timebound tactics which can be taken by stakeholders to eradicate barriers in cancer care for Black women while focusing on achieving health equity. Simply stated, this #InclusionPledge Playbook highlights what is possible when pharmaceutical companies commit to transparency, truth, and transformation.

Within the playbook:

- Information, statistics, actions, and strategies to help educate companies about the healthcare disparities faced by Black women.
- Knowledge to help make a commitment to anti-racism and invest in and develop specific, measurable actions to dismantle systemic barriers, while simultaneously co-create solutions that will result in health equity for Black women and end disparities in our lifetime.

» DOWNLOAD PLAYBOOK

Tigerlily #InclusionPledge Playbook

INDUSTRY GUIDES

Tigerlily Foundation has created a standard of best practices to dismantle systemic barriers that Black women face by sector.

The Industry Guides to the #InclusionPledge serve to help a variety of stakeholders end racial disparities in our lifetime.

» Pharma Industry Guide to Inclusion Pledge

» Healthcare Providers Guide to Inclusion Pledge

» Clinical Trial Entities Guide to Inclusion Pledge

» Researchers Guide to Inclusion Pledge

» Advocacy Guide to the Inclusion Pledge

» Clinician Guide to the Inclusion Pledge

» College Guide to the Inclusion Pledge

» Diagnostics Guide to the Inclusion Pledge

» Faith Based Guide to the Inclusion Pledge

» Fraternity and Sorority Guide to Inclusion Pledge

» Government Advocacy Groups Guide to the Inclusion Pledge

» Insurance Providers Guide to Inclusion Pledge

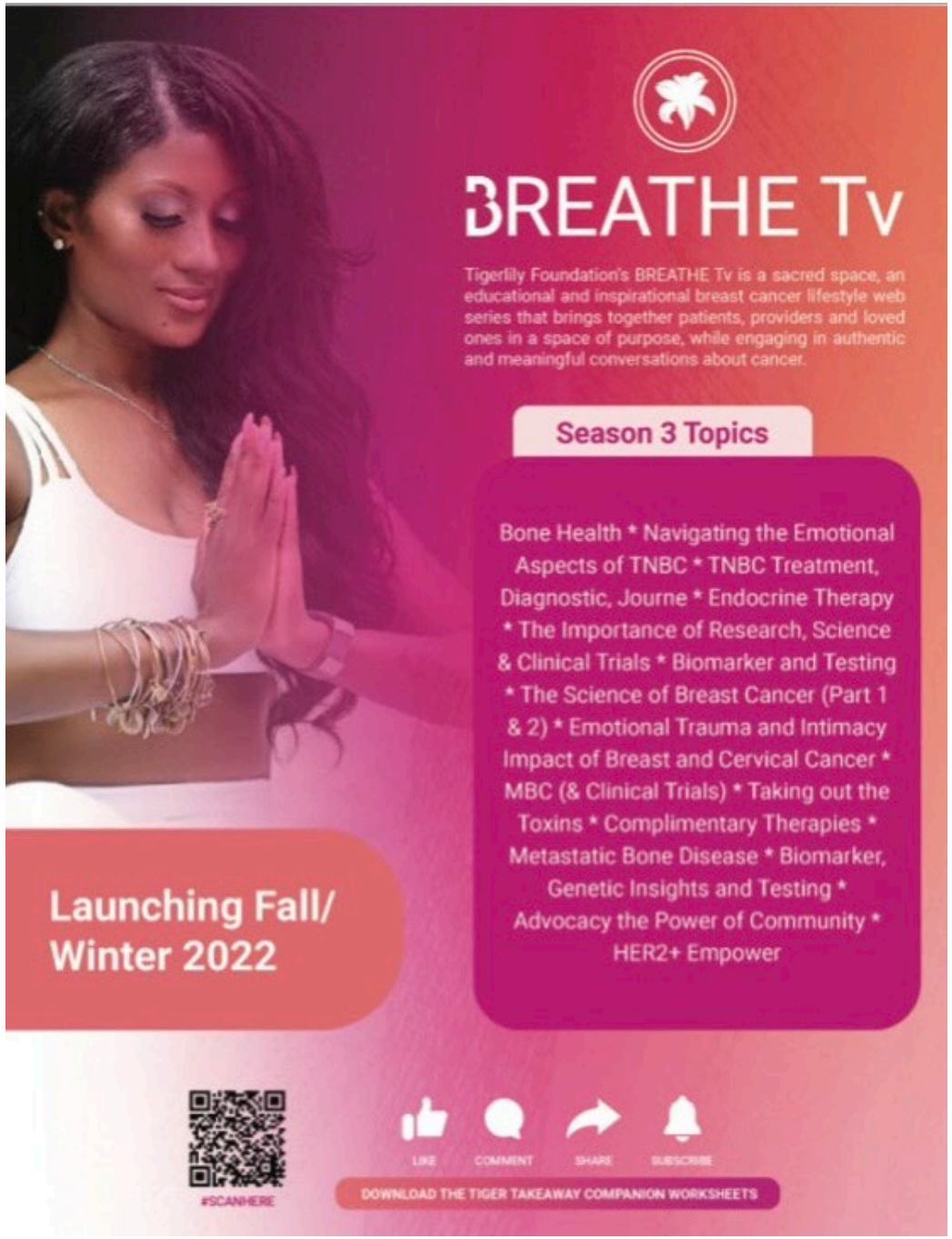
» Patient Navigators Guide to the Inclusion Pledge

» Physician Associates Guide to Inclusion Pledge

» Physicians Guide to the Inclusion Pledge

» Policy Makers Guide to Inclusion Pledge

» Public Health Guide to Inclusion Pledge



BREATHE Tv

Season 3

- 16 episodes filmed.
- Hosted 3 listening summits.
- Released in 2023 and continues to be featured throughout 2024.
- Featured and shared the stories of **42** advocates, patients and industry experts.
- Average Facebook views per episode: 105,000.





BREATHE Tv

BREATHE Tv Season 4

Launched January 2024 – August 2024

- 11 episodes covering various topics such as *Understanding TNBC, Living with Cervical Cancer, Survivorship: Life with Cancer*, and more.
- Partnered with BlackDoctor.org for a second year. BDO is the world's largest online health resource specifically targeted to African Americans.

Season 5 launched on December 5th:

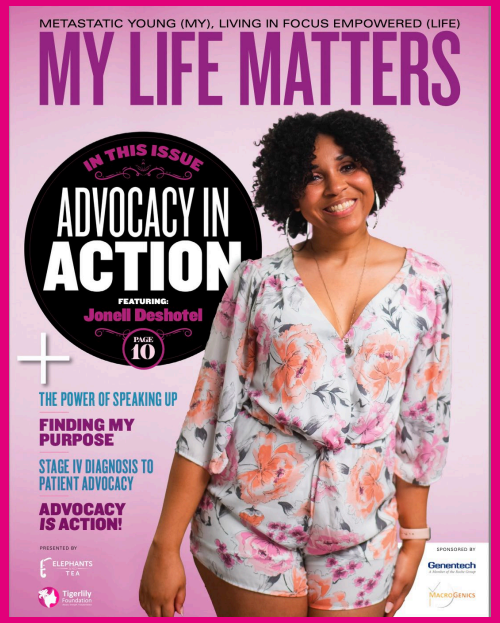
https://www.youtube.com/watch?v=ebbeBykJEA8&t=1s

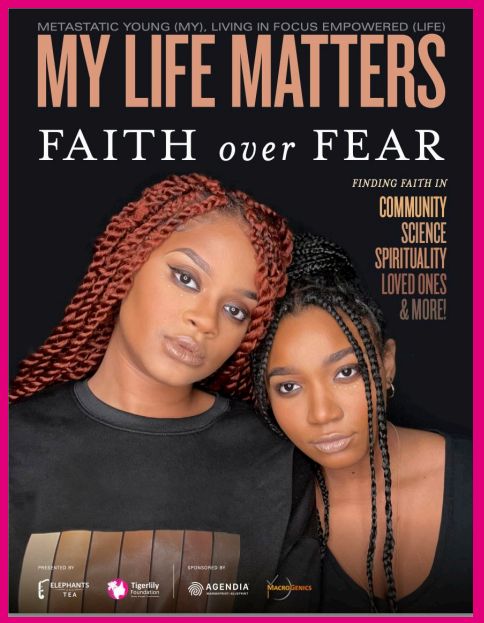


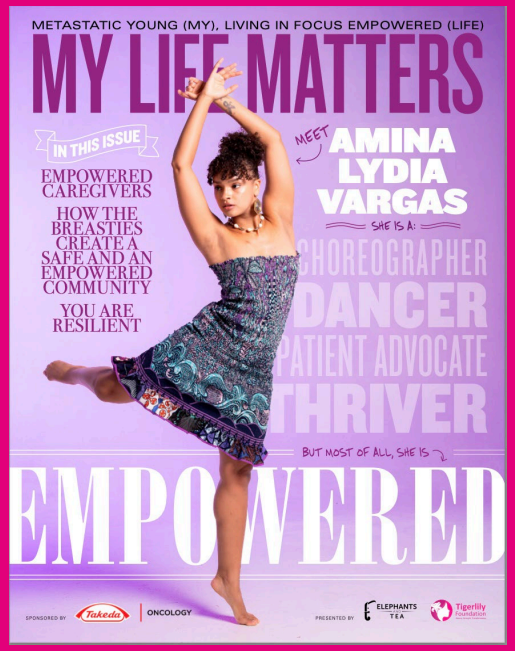
#MyLifeIsMyLegacy series by Tigerlily Foundation is a collection of intimate vignettes showing the lives and living legacy of remarkable individuals. Personal stories of people living with metastatic disease , early stage cancer in addition to medical experts, industry trailblazers, caregivers who have not been diagnosed with cancer. These stories build a bridge of knowledge, love, faith, hope and transformation that help us understand the impacts of cancer and provide guidance that will help generations to come.

#MYLIFEISMYLEGACY


MY LIFE MATTERS
Black Health
MY LIFE MATTERS
POWER
MY LIFE MATTERS
20th Anniversary
MY LIFE MATTERS
ANGEL ADVOCATE
Sharon Kidd
MY LIFE MATTERS
Life of Purpose, ON PURPOSE!
MY LIFE MATTERS
HEALTH AND WELLNESS
MY LIFE MATTERS
FEARLESS & DETERMINED
STORIES ABOUT HEALTH LITERACY


METASTATIC YOUNG (MY), LIVING IN FOCUS EMPOWERED (LIFE)
MY LIFE MATTERS
IN THIS ISSUE
ADVOCACY IN ACTION
FEATURING:
Jonell Deshotel
PAGE 10
THE POWER OF SPEAKING UP
FINDING MY PURPOSE
STAGE IV DIAGNOSIS TO PATIENT ADVOCACY
ADVOCACY IS ACTION!


METASTATIC YOUNG (MY), LIVING IN FOCUS EMPOWERED (LIFE)
MY LIFE MATTERS
FAITH over FEAR
FINDING FAITH IN
COMMUNITY
SCIENCE
SPIRITUALITY
LOVED ONES
& MORE!


METASTATIC YOUNG (MY), LIVING IN FOCUS EMPOWERED (LIFE)
MY LIFE MATTERS
IN THIS ISSUE
EMPOWERED CAREGIVERS
HOW THE BREASTIES CREATE A SAFE AND AN EMPOWERED COMMUNITY
YOU ARE RESILIENT
MEET AMINA LYDIA VARGAS
SHE IS A:
CHOREOGRAPHER
DANCER
PATIENT ADVOCATE
THRIVER
BUT MOST OF ALL, SHE IS
EMPOWERED


METASTATIC YOUNG (MY), LIVING IN FOCUS EMPOWERED (LIFE)
MY LIFE MATTERS
The Fertility Gap
Advocacy for Equal Access and Informed Choices
Survivor and Thriver Stories Inside
Annie Swanson:
Our Journey to Parenthood

MY LIFE Matters Magazine 2023 – 2024 Issues

Each publication has an initial digital release with an average reach of 7,000 – 10,000 individuals that continues to grow.

Followed by a targeted print release of 9,500 magazines shipped across the country.

Clinical Trials Issue 2023

Health and Wellness Issue 2023

Health Literacy Issue 2023

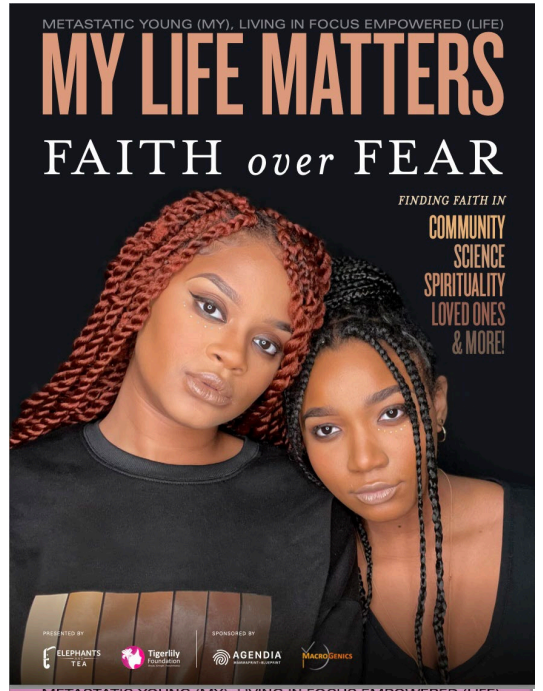
Advocacy in Action Issue 2023

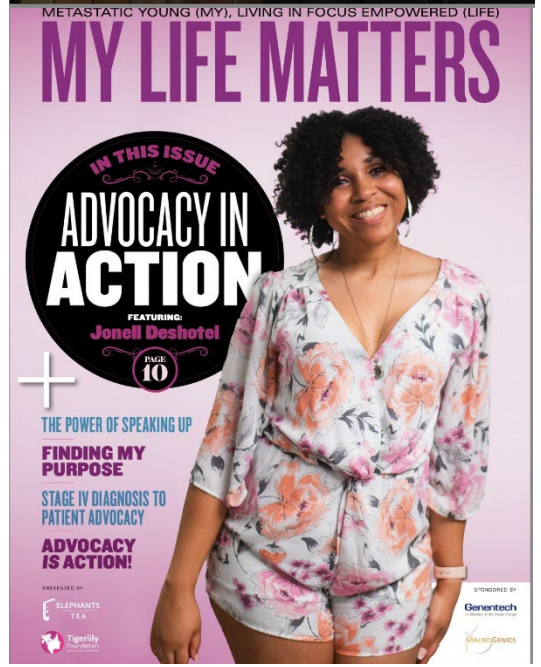
Faith Over Fear Issue 2024

Empowered Issue 2024

The Fertility Gap Issue 2024

Pathways to Hope Issue: 2025 Q1





PERKATORY - BREWING TOUGH CONVERSATIONS TO HELP EACH OTHER FACE CANCER

- Perkatory is a unique, open-mic style event in which members of our community read their stories aloud to a virtual audience.
- Each event has a specific theme of interest pertaining to adolescent and young adult cancer.
- For our MY LIFE Perkatory series, we feature amazing authors from our MY LIFE publications, opening the conversation about disparities in healthcare and creating a community surrounding feeling less alone in what you are going through.

Your story MATTERS ♥ Join the conversation

Scan to register for the virtual Perkatory event series



Tigerlily Foundation
Beauty. Strength. Transformation.

ELEPHANTS AND TEA

MY LIFE Matters Magazine Perkatory

The Fertility Gap:
Advocacy for Equal Access and Informed Choices
Wednesday, October 23rd
@ 7:00pm ET


Annie Bond


Tamika Felder


Annie Swanson

Scan to Register!

Brewing Tough Conversations to Help Each Other Face Cancer

ELEPHANTS AND TEA

Tigerlily Foundation
Beauty. Strength. Transformation.

MY LIFE Matters Magazine Perkatory

EMPOWERED
Wednesday, March 27th
@ 7:00pm ET


TrevisMichelle


Katrina Johnson


Amina Vargas

Scan to Register!

ELEPHANTS AND TEA

Tigerlily Foundation

Educational Toolkits

BREAKING THE BARRIERS TO CLINICAL TRIALS

A Toolkit For Patients



Shifting the perspective from "Experimental" to "Revolutionary"
– Shonte Drakeford

CREATED WITH YOU IN MIND

We see you. We hear you. We've got you covered.

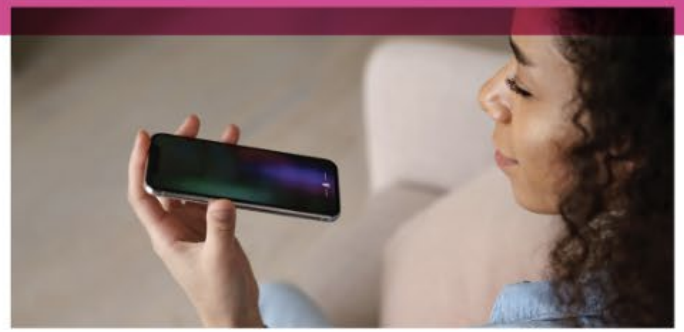
We have witnessed, heard and personally experienced racial challenges, specifically for Black women, due to both systematic and systemic racism within healthcare. For these reasons, we've carefully crafted this toolkit with you in mind. Our goal is to help you make more informed decisions by providing you with the right tools and information to help you navigate clinical trials.

People of color and other marginalized groups are more likely to be underrepresented in clinical trials, and Black women are among the most underrepresented groups. The goal of this toolkit is to provide you with the information that you need ahead of time to empower you and allow you to make the best decisions for your health. Understanding clinical trials and getting access to trials is vital when seeking all avenues for treatment.

Tigerlily Foundation

BREAKING THE GEOGRAPHICAL BARRIERS FOR GETTING YOU THE CARE YOU NEED

A Toolkit For Patients



We see you. We hear you. We've got you covered.

Where you live can impact your access to care, quality of care and even, the ease to live a healthier lifestyle. Your zip code can even determine your likelihood of getting breast cancer in your lifetime.

Whether you are newly diagnosed or going through treatment, the distance that you live from medical facilities can pose a real challenge. We have developed this toolkit to provide you with the information and resources that you need to break through geographical challenges.

WHY IS THIS IMPORTANT?

Awareness around the impact of your location is important as it can help you to anticipate some challenges that you may face. Awareness provides you with the foundation you need to navigate the challenge and create solutions. You may be located far from a care center, having a plan before hand to account for appointments and emergencies will help to provide peace of mind, better care and safety for you.

Tigerlily Foundation

BUILDING TRUST WITH YOUR HEALTHCARE TEAM THROUGH SELF - ADVOCACY

A Toolkit for Patients



CREATED WITH YOU IN MIND

We see you. We hear you. We've got you covered.

We have witnessed, heard and personally experienced racial challenges specifically for Black women due to systematic racism within healthcare. For these reasons we've carefully crafted this toolkit with you in mind. The goal of this toolkit is to:

1. Equip you with the right tools to build trusting relationships with your health care providers, based on mutual respect, understanding and empathy

2. Give you information on what you can do if you feel like you're not being heard or adequately cared for.

Racism in medicine is an unfortunate reality that no one should suffer the consequences of, and we hope that this toolkit can help you navigate interactions with your providers, advocate for yourself and seek the best care that you are entitled to. You are your own best advocate, so let's make sure that you have the tools you need to do what is best for *you*.

Tigerlily Foundation

Hope Box Program

Tigerlily Foundation's **Hope Box** program delivers just-in-time resources to patients after a breast cancer diagnosis.

Leveraging relationships with nurse navigators, patients request Hope Boxes.

Items included in the boxes:

- patient education materials;
- a navigation journal;
- and Barrier Eradication toolkits that empower patients to overcome barriers throughout their care journey, while addressing social determinants of health.



Successes

- ✓ Over **550+** ANGEL Advocates trained.
- ✓ Collaborating with **45+** biotech companies to increase diversity in clinical trails.
- ✓ Working with **15+** global pharma organizations on clinical trial engagement / outreach activities.
- ✓ Relationships with **45+** NCI centers & partnerships to support health equity / clinical trial initiatives.
- ✓ **15+** Engagements with ANGEL Advocates in health equity and diversity initiatives.
- ✓ Successful National ANGEL Advocate Program focusing on educating and empowering Black women in **21** cities with the highest disparities.
- ✓ National Community Alliance Pilot launched.
- ✓ Community-Based Organization **H**ealth equity **U**plift & **G**rowth (HUG) launched and focused on capacity building (Supporting and increasing collaboration amongst 5 Black non-profit organizations).
- ✓ Launch of RAISE (platform that provides direct patient support to eliminate barriers in clinical trials) – currently in BETA.
- ✓ Collaboration with healthcare systems to study the science of breast cancer in Black women.
- ✓ Support for HEAL Policy Center of Excellence to drive and influence policy and legislation.
- ✓ Resource Bank for communities of color (in development).



Tigerlily Foundation
Beauty. Strength. Transformation.

Tigerlily Foundation is a leading organization offering young women unique tools to navigate their lives and cancer journey.

Our mission is to educate, advocate for, empower and support young women – before, during and after cancer.

Our vision is to work to end disparities in our lifetime.

GET IN TOUCH WITH US

Email: info@tigerlilyfoundation.org

Phone: 888-580-6253

www.tigerlilyfoundation.org

twitter.com/tigerlilycares

/tigerlilyfoundation

/tigerlily_foundation/