



**EDUCATING,
ADVOCATING FOR,
EMPOWERING AND
SUPPORTING YOUNG
WOMEN - BEFORE,
DURING AND AFTER
BREAST CANCER**

**Tigerlily
Foundation**

Beauty. Strength. Transformation.



My Thriver, Warrior, Unicorn Journey



ONCE YOU CHOOSE
“ HOPE, ANYTHING’S
POSSIBLE. ”

- Talk with God
- Nature and nurture
- Immigrant journey
- Lazarus/Lead
- Oranges
- The promise

Maimah S. Karmo
President and CEO



Tigerlily Foundation



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“He who has a why to live can bear almost any how.”

- Frederick Nietzsche

FOCUSING ON ENDING DISPARITIES



AGE

Young women are often misdiagnosed because they are thought to be “too young” to get breast cancer.



STAGE

Young women’s breast cancers and generally more aggressive and more advanced at diagnosis resulting in lower survival rates.



COLOR

Black women have a 40% higher death rate from breast cancer and face even higher disparities when it comes to breast cancer.



Health Care Disparities in Breast Cancer

Disproportionate impact in the African American community and younger women.

40% more likely to die

2x more likely to be diagnosed with more aggressive and highly recurrent Triple Negative Breast Cancer (TNBC)

↑ incidence of early-age onset of breast cancer

↑ mistrust of the healthcare system, providers and industry

1/4 of black women delay or refuse treatment due to cost

↓ enrollment in clinical trials (< 5%) resulting in less understanding of physiology and therapeutic benefit of treatments.



WHY?

BECAUSE BARRIERS PERPETUATE DISPARITIES IN BREAST CANCER TREATMENT & CARE



Medical Racism

Racism persists today sometimes results in biased decision-making by medical providers, researchers, and people in positions of power.



Underrepresentation in Clinical Trials

People of color and other marginalized groups are underrepresented in clinical trials, and Black women are among the most underrepresented.¹



Underrepresentation in Healthcare Workforce

Black women are underrepresented among healthcare professionals in the United States.²



Lack of Access

Black women are disproportionately affected by systemic challenges that limits access to medical care, healthy lifestyle-promoting activities and environments, and support.³



Lack of Access, Cont'd.

Health literacy, Psychological/Trauma (Cultural), Financial, Geographical



Biased Media Portrayals

Breast cancer is typically depicted as a disease that affects white women.⁴

1. Flores Le, Frontera WR, Andrasik MP, et al. Assessment of the Inclusion of racial/ethnic minority, female, and older individuals in vaccine clinical trials. *JAMAOpen*.2021;4(2):e2037640.doi10.1001/jamanetworkopen.2020.37640

2. Perspectives - The Art of Medicine, Volume 397, Issue 10274, P573-574, FEBRUARY 13, 2021. [https://doi.org/10.1016/S0140-6736\(21\)00302-0](https://doi.org/10.1016/S0140-6736(21)00302-0)

3. Health Equity Among Black Women in the United States. Juanita J. Chinn, Iman K. Martin, and Nicole Redmond *Journal of Women's Health* 2021 30:2, 212-219

4. Allicock M, Graves N Gray K, Troester MA. African American women's perspectives on breast cancer: implications for communicating risk of basal-like breast cancer. *J Health Care Poor Underserved*. 2013;24(2):753-767.doi:10.1353/hpu.2013.0082



* Patient –> Leadership –> Transformation
-> Equal, Just, Right, Love*



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“ “Service is the rent we pay for living”

- Marian Wright Edelman

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**“I am only one but still I am one. – Edward Everett
(THE POWER OF ONE)**



TRANSFORMING LIVES THROUGHOUT PATIENT JOURNEY

Healthy people don't think about cancer and people with cancer can barely think at all – we have to walk in their shoes and hold them where they are in their journey

01.

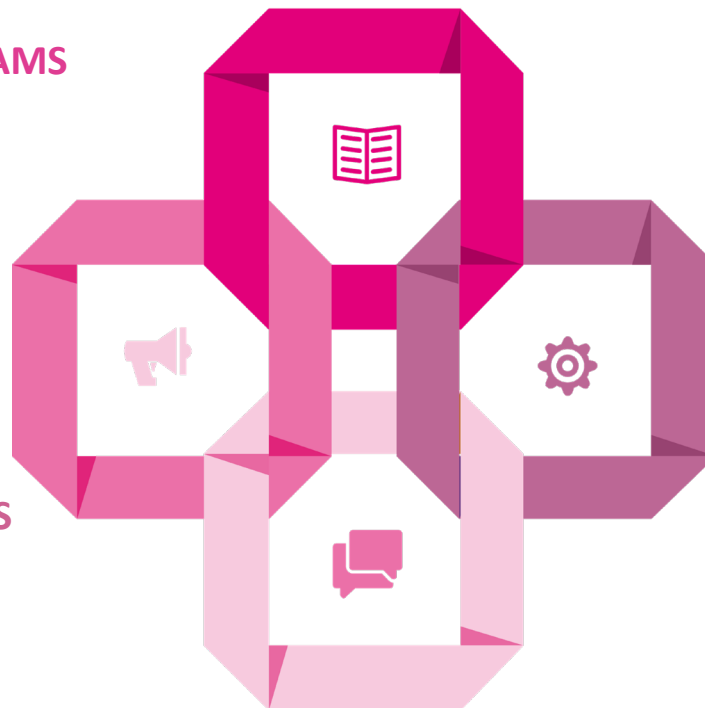
EDUCATIONAL PROGRAMS

- Pink Power Alerts
- PETALS
- Masterclass
- **Tiger Trials**

03.

ADVOCACY PROGRAMS

- HEAL Center of Excellence
- ANGEL Advocacy Training
- **#InclusionPledge**
- **#KnowMoreDisparities** and **#PullUpASeat**



02.

EMPOWERMENT PROGRAMS

- Hope Box
- New Normal Journal
- BREATHE Tv
- CARE Coaching

04.

SUPPORT PROGRAMS

- MY LIFE Program
- SPIRIT Program
- Pure Cat
- Tigerlily & Unity 24/7 Prayer Line
- Funds for Families



ADVOCATE NOW TO GROW, EMPOWER & LEAD (ANGEL) PROGRAM

ANGEL ADVOCATES – COMMUNITY- BASED/CAPACITY BUILD

Tigerlily ANGEL Advocates are young women (21-50) living in the 20 areas of the U.S. with the mortality disparities who have been affected by breast cancer (patients, survivors, MBC thrivers, care givers, co-survivors, etc.) that are committed to ending breast cancer disparities and achieving health equity. Let's force multiply. Your patients and loved ones can be a part of this change!

ANGEL ADVOCATE TRAINING

The Tigerlily ANGEL Program provides comprehensive training to arm individuals with the education & support they need to be comfortable & empowered to leverage their voice to effect change in breast cancer, care, research, access and more.

ANGEL ADVOCACY OPPORTUNITIES – FORCE MULTIPLY

Tigerlily ANGEL Advocates use their time & voices to influence change by speaking at events, on panels, with researchers, scientists, the media, with policymakers, educating their communities & engaging with health care providers & researchers/pharma.

ANGEL ADVOCATES - LEAD

Lead ANGEL advocates 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.





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Tigerlily Foundation's [#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.

#InclusionPledge PARTNERS

12,000 + signatories
80+ organizations

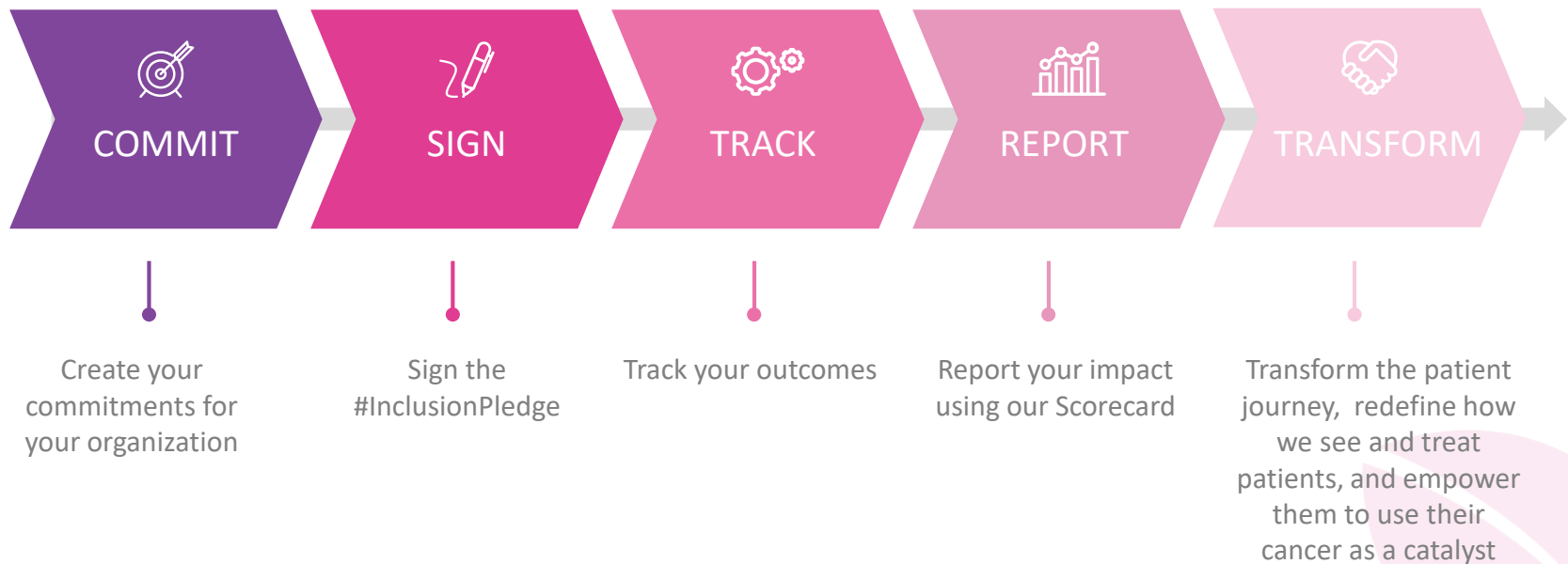
AMGEN



Lilly



WHAT DOES THE #InclusionPledge MEAN FOR MY ORGANIZATION?



TIGERLILY FOUNDATION CLINICAL TRIALS PROGRAM TIGER TRIALS

Tigerlily Foundation's Clinical Trials Program is a transformational initiative to accelerate delivery of innovative treatments to our patients, with a strategic focus on populations that are facing the highest disparities. The facts are that most patients are not offered trials until their cancers are at a more advanced stage. People of color are represented as only 3% of clinical trials participants, yet have the highest mortality rates across multiple disease states. Ensuring diversity in clinical trials is not a one-size-fits all approach and we endeavor to reach people where they are. Our program provides educational and tangible resources designed to eliminate barriers, while collaborating with all stakeholders at the table.

TRUST, TRANSPARENCY, TRANSFORMATION

We are focused on building trust and transparency between patients and science and stakeholders, eliminating barriers to inclusion, achieving equity, and transforming the future of clinical trials. This work is essential to our mission to create a more equitable future for all people with cancer because we cannot develop truly precise treatments without diverse data gathered from BIPOC trial participants.

COLLABORATION IS KEY

Our Clinical Trial Team works closely with our DEI and ANGEL Advocacy programs to create patient driven, culturally competent materials for Tigerlily Foundation and Partner organizations.



MEETING PATIENTS WHERE THEY ARE

Understanding the details about each clinical trial is critical to understanding how it will work for a patient's treatment journey and lifestyle. This is why we create clinical trial education and outreach materials in plain language patients use and understand.

A MORE EQUITABLE FUTURE

Reaching a state of true health equity is not possible without transforming clinical trial participation. We are committed to building bridges between patients and our industry partners to increase trust and engagement in lifesaving clinical trials.



TIGERLILY FOUNDATION CLINICAL TRIALS PROGRAM TIGER TRIALS

PATIENT-DRIVEN TRIALS (BEGINNING to END – PARTNERING WITH SPONSORS, CROs and SYSTEMS

CLINICAL TRIAL PATIENT EXPERTS

PATIENT-DRIVEN CLINICAL TRIALS IN COMMUNITIES

PATIENT CURATED CONTENT (GUIDEBOOK, GUIDANCE, TRIALS, PERSPECTIVE

CONVERSATION SERIES – TRUST IN SCIENCE

BIPOC APPROVED TRIALS

COLLABORATIONS



BARRIER TOOLKIT



BARRIER 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.



Literacy, financial barriers, access, social, systemic, and other issues should not be determinants of life and health equity.

**13 PATIENT CURATED TOOLKITS
to OVERCOME BARRIERS in
HEALTHCARE**

BARRIER TOOLKIT



- Policy Advocacy Training - > Tools ->
Activate - Accountability to Equity for All



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HEAL

POLICY CENTER
OF EXCELLENCE

Health Equity Advocacy and Leadership

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Patients must not only survive but thrive. Our job is to inspire empowered leaders to walk beside as we accelerate equity and access for all, so at the end of our lives, we can say that we lived and loved boldly, fully, with purpose and passion. –

Maimah Karmo