WE WILL OVERCOME: MOVING TOWARDS HEALTH EQUITY COMMUNITY REPORT
Tigerlily Foundation’s Commitment to Action in Health Equity

Tigerlily Foundation’s mission is rooted in a commitment to health equity. We were founded 18 years ago as a response to unequal healthcare treatment for a lump in our Founder’s breast which turned out to be cancerous. Our Founder’s experience is not an isolated one, especially in medically underrepresented communities. She was dismissed as being too young to get breast cancer, her diagnosis was delayed and after diagnosis, due to lack of inclusion of representative numbers of Black people in clinical trials, she had no targeted treatment. This story is one that we still hear today, and we are committed to ensuring that one day, these stories are told no more.

It is therefore, the mission of Tigerlily Foundation to educate, advocate and empower young women (ages 15 – 50) before, during and after breast cancer to be advocates within their communities. Our vision is to work to end disparities of age, stage and color in our lifetime.
Through our educational resources and patient-led programs, we work alongside community partners to dismantle barriers to healthcare.

The following report shares the framework and impact of our inaugural We Will Overcome: Moving Towards Health Equity Townhall held in the Southside neighborhood of Chicago, Illinois.

We have spent nearly two decades listening to and learning from the perspectives of Black Women. As we learn, we co-create solutions that address systemic barriers, social determinants of health, social competencies, mistrust and mobilize communities to develop sustainable solutions to overcoming equitable barriers to healthy lifestyle, access, care, clinical trials and survivorship.
Community Framework for Intentional Impact

Listen

In December 2022 we first held “We Will Overcome”, a virtual listening session in partnership with Patient Power where the community shared why building trust within the community is so important and examples of community initiatives that are transforming how we engage with one another. This listening session highlighted the importance of having an in-person event embedded in the community.

In August 2023, Tigerlily Foundation, Patient Power and our community partners listened to Chicago-based patient advocates share their experiences within the healthcare system before, during and after treatment.

Learn

This information was shared with the community through a virtual and in-person event. The virtual townhall held in December 2022 provided an opportunity to engage widely with communities in Chicagoland communities and nationally. Our August 2023 townhall addressed the recommendation from our advocates to host an event within the community. We intentionally selected a venue in the Southside that was easily accessible by public transportation to reduce any socio-economic barriers that could have hindered community participation.

Leverage

The in-person We Will Overcome event held in Chicago was a powerful demonstration of the importance of community engagement in addressing critical issues. The event highlighted the significance of hosting such gatherings within the community itself, as it became evident that many individuals lacked access to vital information about breast cancer. This event also highlighted that individual advocates, smaller advocacy groups, hospitals, universities, national organizations, healthcare systems, and biotech companies all play unique roles in healthcare and that it is important for us to collaborate for continuous listening, learning and leverage knowledge and resources for collaboration. By sharing knowledge and raising awareness, the event played a pivotal role in educating the community. It underscored the value of collaboration with other organizations, as it was evident that by uniting forces, the impact on the community could be significantly amplified. The event in Chicago served as a poignant reminder of the transformative potential of community-based initiatives in tackling pressing health concerns.

Lead

Our goal is to continue to learn from communities and empower people to lead through self advocacy, advocating for their families and their communities, to develop a framework that cultivates sustainable solutions for patients and the community. In partnership with members of the community in Chicago, we assembled a wide variety of trusted stakeholders.

Stakeholders Collaborating for Sustainable Communities of Hope


Patient advocacy groups: Triage Cancer, Advocates for Community Wellness

Community groups: Equal Hope, City of Chicago

Patient Advocates: Kathryn Jackson, Lisa Weems

Universities: University of Illinois – Chicago, Northwestern University, Loyola University

Teaching Hospitals: University of Chicago Medicine
Focus on the 20 U.S. Cities with Highest Mortality Rate of breast cancer for Black women

Tigerlily Foundation has focused strategically on engaging, partnering with and embedding support within the twenty cities with the highest mortality rate of breast cancer for Black women. There are several factors that contribute to the high breast cancer mortality rate among Black women in these cities, including:

- Lack of access to quality healthcare: Medically underserved communities with large Black populations often have fewer mammography facilities and longer wait times for appointments. (National Cancer Institute)
- Social Determinants of Health: Research suggests that social and economic stressors may be particularly influential in increasing breast cancer risk for Black women. (American Cancer Society)
- Biological factors: Black women are more likely to be diagnosed with triple-negative breast cancer, which is a more aggressive form of the disease with fewer treatment options.

There are several things that can be done to reduce the breast cancer mortality rate among Black women in these cities, including:

- Increasing access to quality healthcare: In the United States, 44% of women with an income below the poverty line lacked health insurance in 2021 (Commonwealth Fund). Affordable healthcare options can significantly improve access for low-income women.
- Addressing social determinants of health: Addressing social determinants like poverty, access to healthy food, and quality housing can improve health outcomes for underserved communities, including reducing breast cancer mortality rates.
- Increasing awareness of breast cancer and the importance of early detection: Early detection of breast cancer significantly increases the five-year survival rate (American Cancer Society). However, screening rates are lower among low-income women and women of color. Targeted public health campaigns in underserved communities can increase awareness of breast cancer symptoms and the importance of early screening, leading to earlier diagnoses and better outcomes.
- Educating individuals to be self-advocates and community educators: Peer education programs have been shown to improve health knowledge and behaviors in diverse communities, with a 20% increase in self-reported healthy behaviors after participating (RWJF, 2018)
- Strong and consistent collaboration among stakeholders to ensure that women do not fall through the cracks in healthcare is critical.

In addition to these broad measures, there are several targeted programs and interventions that can be implemented to reduce breast cancer mortality among Black women in these cities. For example, some cities have implemented programs that provide free or low-cost mammograms and other cancer screenings to uninsured and underinsured women. Other cities have implemented programs that provide support and navigation services to help Black women navigate the complex healthcare system.

It is important to note that the high breast cancer mortality rate among Black women in these cities can change. With targeted interventions and a commitment to addressing the root causes of health disparities, we are making significant progress in reducing the number of Black women who die from breast cancer each year.
Why Chicago for the Inaugural We Will Overcome Townhall?

Chicago is a city where breast cancer disparities are stark and real. Black women in Chicago are more likely to be diagnosed with breast cancer and to die from the disease than white women. This is due to several factors, including the city’s high level of neighborhood-level racial residential segregation.

Neighborhood segregation is a form of systemic racism that has a profound impact on health. When communities of color are concentrated in certain neighborhoods, they are more likely to live in poverty, have less access to quality healthcare and education, and be exposed to environmental hazards. These social determinants of health contribute to the higher rates of breast cancer and other chronic diseases among communities of color.

The 2023 Northwestern Medicine study provides new evidence of the link between neighborhood segregation and breast cancer mortality. The study found that Black residents living in highly segregated neighborhoods had a four-year shorter life expectancy than white residents living in less segregated neighborhoods. This is a significant difference that cannot be ignored.

According to the study, “The study examined 63,694 census tracts (small, relatively permanent geographic entities within counties) across the U.S. and found the national average life expectancy was 78 years old. In predominantly Black neighborhoods with high racial segregation, the average life expectancy was 75 years old, which is significantly lower than the average life expectancy (79 years old) in neighborhoods with low racial segregation.”

The We Will Overcome townhall in Chicago provided an opportunity to come together and to explore strategies for addressing the root causes of breast cancer disparities in the city. By working together to create a more equitable city where everyone has the opportunity to thrive.

We Will Overcome Townhall Summary

In August 2023, Tigerlily Foundation and Patient Power co-hosted the inaugural We Will Overcome: Navigating Obstacles to Breast Cancer Prevention and Care in Our Community townhall in the Southside of Chicago. The townhall achieved its objectives to (1) strengthen social contracts between community members and area medical centers through resource sharing, (2) address the existing access to care infrastructure within Southside neighborhoods, (3) equip Southside residents with information on breast cancer and risk reduction, area clinical trials, and genetic testing and (4) empower participants with a stepping stone to increased community engagement opportunities for improved health equity.

With generous support from our partners, We Will Overcome was attended by 80 in person participants and reached more than 10,500 views through our 2020 We Will Overcome virtual event and 2023 in-person recorded event posts.
Activities, Impact and Learnings to Date

The 2.5-hour in person townhall included five panels tailored for the audience. Below are key points shared by each panel.

● **Panel 1: Defeating Disparity of Care**

(Maimah Karmo, Tigerlily Foundation Founder and CEO, is joined by Tarneka Manning, M.Ed., Robert H. Lurie Comprehensive Cancer Center, Lisa Weems, Tigerlily patient advocate, Yamilé Molina, MS, MPH, PhD, University of Illinois at Chicago, and Paris Thomas, PhD, Equal Hope)

Panel Findings and Outcomes

• Advocacy Matters: Chicago had a 62% higher mortality rate of breast cancer. In 2017 - 2018 it dropped to 32%.
• It is important for patients to be educated on their treatment plan so that they know how to advocate for themselves when it comes to their care journey - from biomarker testing to clinical trials - by their healthcare provider.
• It is important that patients know their rights because doctors may not always be right, and each patient has personalized needs, challenges and opportunities and has the right to individualized care plans and support.
• Barriers to care can occur at any health care facility, including the leading facilities. Identify a breast cancer facility that will provide care with the least amount of barriers.
• Patients who were provided extra support, such a patient navigator or social worker, were over 33% more likely to promote breast health screening within this communities according to a panelist. A patient’s ability to recognize their own power fuels them to advocate for themselves and communities.

Panel Recommendations

• Clinics and hospitals, especially those specializing in breast cancer, should make it easier for everyone to access the care they need. This means reducing obstacles like transportation issues, language barriers, and financial limitations.
• All patients should have access to support from a patient navigator or social worker. These professionals can help patients navigate the healthcare system, connect with resources, and address any challenges they might face.
Panel 2: Understanding Subtypes and Early Prevention

(Maimah Karmo, Tigerlily Foundation Founder and CEO, is joined by Paris Thomas, PhD, executive director for Equal Hope, Ivy Abraham, MD, a hematologist oncologist from University of Chicago Medicine, and Regina Hopkins, director of Health and Education from Advocates for Community Wellness)

Panel Findings and Outcomes

- Black women are the most impactful peers in healthcare for other Black women.
- Educating the community on modifiable and non-modifiable risk factors, such as diet, lack of exercise, increased alcohol consumption, and family health history, are important areas to educate and inform the community in order to improve health outcomes.
- Navigating health can be challenging in low-income communities, where residents may face stressors like limited access to healthy food, gyms, or financial resources. However, various tools and programs exist to help individuals connect with resources that address these needs.
- While there is significant funding for early detection, increased funding resources should be placed on early prevention of breast cancer. The goal should not be only to catch cancer at an early stage but to not catch cancer at all because all of the risk factors were mitigated in time.
- As individuals our actions tend to be reactive not proactive. We are taught to wait for the problem to determine solutions. While discussions surrounding risk reduction and access to care are important, emphasis must be placed on proactive education at early stages of human development to change the course of cancer by eating healthy, exercising regularly and managing life stressors.

Panel Recommendations

- More funding is needed for early prevention initiatives to not only catch cancer early but also prevent it altogether. This could involve programs that promote healthy lifestyles and address risk factors.
- Education and awareness campaigns should start early in life, teaching people about healthy habits like eating well, exercising regularly, and managing stress. These habits can significantly reduce the risk of developing various diseases, including breast cancer.
Panel 3: Why Family History and Genetic Testing Matters

(Maimah Karmo, Tigerlily Foundation Founder and CEO is joined by Umi Grigsby, chief of policy and advocacy for the city of Chicago, Claudia Tellez, MD, a medical oncologist from Northwestern Medical Group, and Brenda Gonzalez, site coordinator, University of Chicago Medicine)

Panel Findings and Outcomes

- Discussing family history with both sides is crucial for understanding your health risks. It is often believed that understanding only maternal family health is important, however, paternal family health is equally important to understanding one’s health risks.
- Genetic testing is critical and available to all individuals. Options are available for those with limited family knowledge, including adopted individuals.
- Cancer cell mutations necessitate genetic testing of both healthy and cancerous tissue to inform treatment choices.
- Investing in community health workers, education, and awareness programs can bridge gaps in healthcare access and understanding.
- A strong public health infrastructure focused on community needs is essential for equitable access to information and resources.
- Misconceptions about clinical trials are common.
- All available cancer treatments have gone through clinical trials, none involve placebos.
- Increased participation by diverse populations is crucial for improving the relevance and effectiveness of treatment options.
- Family health history conversations are critical within families. This proactive and preemptive measure will equip you and your healthcare team with the information to provide various treatment options.
- Individuals may want to avoid conversations around family health history for a myriad of reasons including conflict prevention, shame or blame. It is important to identify the best place and time for these conversations. The information could be life changing.

Panel Recommendations

- Talking with your family about their health history is crucial. This information can help you and your doctor determine your risk factors and make informed decisions about your health care.
- There’s no one-size-fits-all approach to these conversations. Choose a time and place that feels comfortable for everyone involved, as the information you learn can be life-saving.
Panel 4: Breast Cancer: Building Trust In the Community

(Maimah Karmo, Tigerlily Foundation Founder and CEO is joined by Kathryn Jackson, a Tigerlily Foundation Angel Advocate, Jeanette Gonzalez, senior research specialist at the University of Illinois Cancer Center, and Nadine Willis, a patient advocate for Sister Working it Out)

Panel Findings and Outcomes

• Research has shown that the biggest barrier to care is medical mistrust. Building that is key.
• Shared experiences from people who look like you and advocate for you is an important building block of trust in the community.
• Establishing partnerships between organizations and stakeholders is needed for improved collaboration towards achieved goals.
• Medical mistrust is a major hurdle. Building trust with communities is key to overcoming this barrier.
• Representation matters. Hearing from people who share your background and experiences fosters engagement and understanding.
• Partnership is power. Collaborations between organizations amplify impact and reach.
• Community voice is essential. No research or decision-making can be effective without the community’s input and trust.
• Role models inspire confidence. Having advocates from within the community builds trust and encourages participation.
• A successful example of partnership between community organizations and researchers, bridging the gap and guiding research efforts. Hope Leaders is a partnership between two organizations, Equal Hope and Advocates for Community Wellness, who received pilot funding to work with two cancer center members and cancer biologists to help bring to the cancer researchers the needs of the community, communicate it to the researchers so that they can help guide some of the research studies that are being done.

Panel Recommendations

• Earning the trust of the community is essential to overcome medical mistrust and improve outreach. This involves listening to community concerns and addressing them head-on.
• Community advocates should be encouraged to participate in research and decision-making processes. This way, research efforts are more relevant to the needs and perspectives of the community.
• Partnerships between community organizations and researchers are vital. By working together, they can bridge the gap between research and real-world application, leading to more effective solutions.
Panel 5: Key Research for Triple Negative Breast Cancer

(Maimah Karmo, Tigerlily Foundation Founder and CEO, is joined by Ivy Abraham, MD, a medical oncologist from the University of Illinois Cancer Center, Abioloa Ibraheem, MD, a medical oncologist from University of Illinois Chicago, and Angela K. Waller, MA, the Founder/CEO of Elevated Survivorship)

Panel Findings

- If you have a family member with TNBC, or have been diagnosed yourself, seek genetic testing. Knowing your family history and TNBC subtype is crucial for understanding your risk factors.
- TNBC disproportionately affects Black women, with double the incidence compared to white women. Be aware of this disparity and advocate for equitable access to healthcare.
- Early detection is key! If you can avoid TNBC recurrence within the first 5 years, the risk drops significantly, unlike estrogen-positive breast cancers.
- The good news: more treatment options are available for TNBC than ever before. Significant advancements have been made in the past decade, offering hope for better outcomes.
- At UIC, healthcare practitioners go into the community to start having this discussion in schools with young girls and women. This helps enhance early prevention if diagnosed in their 20s.
- Chemotherapy has always been the backbone for triple-negative breast cancer. Additional therapies include targeted therapies for the Homologous Recombination Deficiency HRD pathways and antibody-drug conjugates.
- When a patient enters a clinic after a TNBC diagnosis, one of the first questions to ask about is clinical trials.

Panel Recommendations

- Schools should teach middle and high school girls and women about breast health, empowering them to advocate for their own health and take proactive steps in prevention.
- Raise awareness of various therapies for Triple-Negative Breast Cancer (TNBC), including new and emerging treatments. Empower patients to learn about treatment options, including clinical trial participation, and explore their eligibility.
Representative Participant Feedback

“It was a pleasure being a part of such a wonderful and sincere community who are on a mission to educate, empower and supply the necessary tools to the women/families in need.”

-Brenda G.

“The Chicago event was impactful for penetrating hard underserved areas to reach those who most need help. Tigerlily’s advocacy in bringing awareness and hearing powerful journeys need to be heard by doctors, directors and policy makers in order to make effective change. I left the event hopeful that every word did not fall to the ground and those who have power will lead a change where it is most needed...the community.”

-Lisa W.

“The We Will Overcome event is what we need in many communities in many cities to show that breast cancer exists, and it is real. Conversations like this should continue to spread awareness to save lives.”

-Kathryn J.
Tigerlily & Partner Resources Shared

Triage Cancer

- Tigerlily Barrier Toolkits
- Tigerlily TNBC Information Page
- Tigerlily’s Guide to Clinical Trials
- Practical Guide to Cancer Rights
- Practical Guides to Cancer Rights: Caregiver
- Practical Guides to Cancer Rights: Senior
- Triage Cancer Information Flyers
- Triage Cancer Animated Videos Postcard
- Triage Cancer Conference Flyer
- All Triage Cancer quick guides and checklists available online

Advocates for Community Wellness

**Along the Journey: Cancer Awareness and Survivorship Support Program:**
FREE dedicated program that provide breast health education and increases holistic resources to improve the overall wellbeing of African Americans living with Breast Cancer. Offers nutritional, emotional and physical wellness education during a 9-week survivorship course. Also includes Along the Journey Monthly Support Groups.

**Absol-delicious | Eat Well for Better Health (A Lifestyle Nutrition Program):**
Free online and in-person cooking classes that teaches basic principles of healthy eating, how food impacts our health and why plant-based nutrition is one of the best approaches to help prevent, treat and reverse diet-related diseases and cancer.

Recommendations for the Way Forward

We hope to replicate this resource townhall model in medically underrepresented communities across the country. By developing a national community framework rooted in collaboration, we intend to strengthen the bridge between area medical centers, community-based organizations and the people they seek to serve. Our intention is to highlight existing resources, identify hot spots and work in community to strengthen the health infrastructure to improve health outcomes for diverse populations.

Sponsors

Thank you to our partners