

A close-up photograph of two young Black women with long, dark braids. The woman on the left is smiling broadly, showing her teeth. The woman on the right is wearing clear-rimmed glasses and has a gentle smile. They are both looking towards the camera. The background is a soft-focus outdoor setting with greenery and a blue sky.

Stand for H.E.R. A Health Equity Revolution

BREAST CANCER IMPACT REPORT
DECEMBER 2023

Impact Report

Stand for H.E.R. – A Health Equity Revolution

Susan G. Komen’s Approach to Achieving Breast Health Equity in the Black Community

Contents

Achieving Health Equity: A Strategic Priority	2
The Stand for H.E.R. – a Health Equity Revolution Strategy	3
Komen Health Equity Approach: Education.....	5
Educating Communities Through Worship in Pink	6
Educating About Genetic Counseling and Testing	7
Worship in Pink Genetic Counseling and Testing Program in Houston, Texas	8
Komen Health Equity Approach: Patient Support	9
Meeting Patients Where They Are Through the Patient Care Center	9
Komen Health Equity Approach: Workforce Development.....	13
Patient Navigation Training Program	13
Komen Health Equity Approach: Research.....	14
Advocates in Science	15
Disparities-Focused Research Grants	15
The Carolina Breast Cancer Study	18
Komen Health Equity Approach: Public Policy and Advocacy	19
Federal Policy & Advocacy	20
State Policy & Advocacy	21
Grassroots Advocacy	22
Connecting with the Black Community Through Stand for H.E.R.	24
Patient Messaging Campaigns.....	25
Invitation to Engage	26

Achieving Health Equity: A Strategic Priority

AT SUSAN G. KOMEN®, WE BELIEVE HEALTH EQUITY MEANS THAT EVERY PERSON SHOULD HAVE A JUST OPPORTUNITY TO BE AS HEALTHY AS POSSIBLE, regardless of their cultural or demographic background. It is at the core of our mission. It is a common thread that is woven throughout all our work.

Despite progress made against breast cancer, we know that people are still struggling, problems are not solved and our work is not yet done. To realize our vision of a world without breast cancer, we have made achieving health equity a strategic priority for our work.

Our health equity strategy has been designed to work with the communities we serve, using data-driven approaches to craft a plan, measure impact and foster partnerships to create systemic change.



Jeanelle had questions for her doctor when she felt that something was wrong with one of her breasts.

Although her doctor assured her that she was healthy and too young to have breast cancer, Jeanelle went around her doctor to get a referral for a mammogram from the receptionist. An ultrasound and biopsy later confirmed that Jeanelle had been right all along, and she was diagnosed with stage 3 triple negative breast cancer (TNBC).

Breast cancer is a concern for everyone, but it is a tragedy for the Black community. Black women in the United States are on average about 40% more likely to die of breast cancer than white women, and like Jeanelle, they are also more likely to be diagnosed at an early age, at a later stage and with more aggressive types of breast cancer.

These disparities in breast cancer outcomes are not only issues of health; they're also byproducts of a larger problem: discrimination and systemic racism. Racial, ethnic and social injustices create barriers to affordable, lifesaving health care, cultural responsiveness in the health care community and so much more.

Komen recognizes that a sweeping, significant change – a revolution – is needed to address the health care crisis of breast cancer disparities in the Black community. This impact report outlines our commitment to being part of that change.

“I’m not the only person going through this at my age. I’m not the only mom. I’m not the only person out here living life, you know? I’m never going to be done with breast cancer because it’s a part of me. This is my journey. But I’m not alone. And neither are you.”

JEANELLE ADAMS
Breast Cancer Survivor

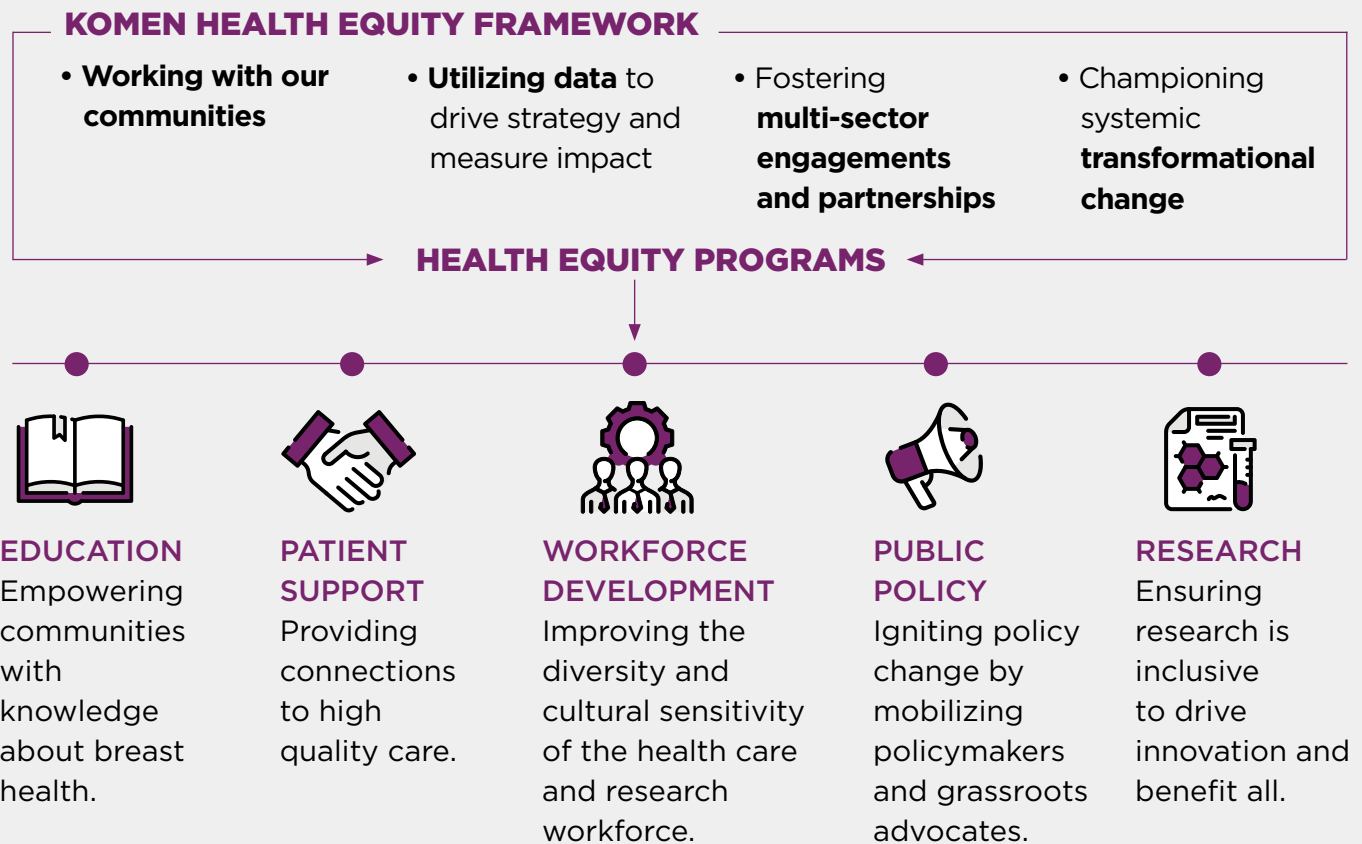


The Stand for H.E.R.- A Health Equity Revolution Strategy

AS MENTIONED EARLIER, CURRENT DATA SHOWS THAT BLACK WOMEN IN THE U.S. ARE ABOUT 40% MORE LIKELY THAN WHITE WOMEN TO DIE OF BREAST CANCER. That's simply unacceptable. To gain a better understanding of the existing barriers that drive these inequities, Komen worked directly with the Black community to launch a multiyear analysis of 10 metropolitan areas that experience the largest gaps in mortality between Black and white women.

In 2021, Komen published the results of this analysis in *Closing the Breast Cancer Gap: A Roadmap to Save the Lives of Black Women in America*, a series of reports that found Black women are often ignored by their health care providers and face significant barriers to receiving the care they need due to a legacy of systemic racism, implicit bias and below-standard care.

Stand for H.E.R. - A Strategic Approach



In response, Komen launched Stand for H.E.R. - a Health Equity Revolution, a program based on this analysis to remove the barriers to high-quality breast health care Black women across the U.S. need. Komen’s comprehensive approach through Stand for H.E.R. includes five key health equity drivers to create change:

- **Education** that equips specific groups and communities with knowledge about breast health
- **Patient support** that ensures connections to timely, high-quality care
- **Workforce development** that improves diversity and cultural sensitivity of health care workers
- **Public policy and advocacy** that promote health equity
- **Research** that is representative and benefits all

By leveraging this approach through Stand for H.E.R., Komen is committed to collaborating with Black communities, policymakers, researchers and other key allies to help **create a world without inequities, where Black people have the same chances of surviving breast cancer as anyone else.**



Education

Komen Health Equity Approach

STUDIES SUGGEST THAT A FAILURE TO SUCCESSFULLY EDUCATE PEOPLE ABOUT BREAST HEALTH may result in delayed screening and diagnosis of breast cancer, and this delayed diagnosis contributes to higher rates of advanced breast cancers and mortality in the Black community. These studies underscore the need for more breast cancer education programs tailored to the Black community.

Results of poor education lead to:

- Lack of awareness of breast cancer risks and screening methods
- Lack of knowledge about the need to get screened
- Lack of knowledge about the availability of services and location of providers
- Confusing and conflicting information about risk of developing breast cancer
- Misconceptions regarding breast cancer symptoms such as pain or itching and/or signs including lumps, dimpling, swelling or redness of the skin

Through Stand for H.E.R., Komen has developed culturally relevant and responsive educational resources and programs to equip Black people with accurate knowledge about breast health.

We provide educational resources tailored to the Black community on a variety of topics, including understanding your risk of breast cancer, screening basics, getting high-quality care and genetic counseling and testing (GCT).

Educating Communities Through Worship in Pink

For Deborah Branch, the support and love provided by her local church family was a source of hope after she received a surprise diagnosis of ductal carcinoma in situ (DCIS). Following her successful treatment, Deborah wanted to help others in a similar situation. She discovered Komen's Worship in Pink (WIP) program and decided to host an event at her church, where a speaker shared the importance of regular breast cancer screenings, as well as services and resources available through Komen.



Deborah Branch - Worship in Pink Ambassador (in center)

WIP is a grassroots effort developed by Komen to amplify the conversation about breast health within faith-based organizations, particularly those in under-resourced communities. The program, which began in 2005, trains volunteers like Deborah to become WIP Ambassadors for breast health within their local faith-based communities.

WIP Ambassadors provide members of their communities with vital information about breast health and Komen's programs and services, while also creating a compassionate support network and honoring those who have faced breast cancer. For members of the Black community, houses of worship are safe havens and a vital space for community and fellowship. Through WIP, Komen educates these communities in spaces that are rich in trust and social support.

- From 2022-2023, **WIP recruited 208 new Ambassadors** and **reached more than 38,000 participants** at congregations in **28 states and in Canada**.

“Breast cancer education is important. Awareness is not equivalent to education. It is urgent that we make sure that Black women understand the importance of knowing your family history, of getting screened, of knowing their normal, of making healthy lifestyle choices.”

THELMA BROWN

Komen Patient Advocate and
breast cancer survivor



Education

Genetic Counseling and Testing

Like many who have a history of breast cancer in their family, Kellie Goss was living each day with uncertainty about the future. When her doctor encouraged her to get genetic counseling and testing because of her mother’s diagnosis, the test results transformed her fear of the unknown into a solid game plan for her future health.

“Getting genetic counseling and testing changed my life because it armed me with enough information to be proactive instead of reactive. I could finally breathe. My life was no longer filled with fear and uncertainty. Seeing and knowing those numbers changed my life in all the best ways,” Kellie says.

Certain gene mutations that can pass from one generation to the next can have a large impact on breast cancer risk. This risk is compounded for Black women by the fact that they do not receive genetic testing as often as white women due to factors like systemic racism, fear of unethical practices in the health care system and personal discomfort about the possible results.

In response to this disparity, Komen developed educational GCT resources through Stand for H.E.R. that are tailored to the Black community and explain the benefits of genetic counseling and testing and how knowing your family history can affect your future health.



“There’s this feeling that you get in the pit of your stomach when your mom, sister or auntie gets breast cancer, and you wonder, am I next?”

KELLIE GOSS

Breast Cancer Previvor
and Advocate for
Genetic Testing



Attendees gather for Worship in Pink genetic testing pilot in Houston, Texas (Photo courtesy of Houston Chronicle)

Worship in Pink Genetic Counseling and Testing Program in Houston, Texas

To test an approach for increasing genetic counseling and testing in the Black community, Komen partnered with Wheeler Avenue Baptist Church, a predominantly Black church in Houston, Texas, and UT M.D. Anderson Cancer Center to give participants a chance to learn about breast cancer risk factors and the importance of understanding their family's health history. The program provided on-site genetic counseling and testing services to community and congregation members.

- In a room of 80+ church and community members, only three had ever been offered genetic testing previously. **After completing a screening assessment, 60% of the 80+ people were deemed high risk and qualified for genetic testing, which they were able to get that same day, on-site.**

In addition to providing access to GCT for members of the Black community, the program also showed how powerful it can be to learn about ways to take a more active role in one's health in a trusted, faith-based environment. Results from the pilot program were overwhelmingly positive, with 88% of those who completed a post-event survey reporting it had improved their feelings about the importance of genetic testing, while 82% felt more confident to seek genetic services, and 94% planned to discuss their family health history with family members.

Patient Support

Komen Health Equity Approach

Meeting Patients Where They Are Through the Patient Care Center

KOMEN'S PATIENT CARE CENTER (PCC) WORKS TO OVERCOME MANY OF THE BARRIERS EXPERIENCED BY THE BLACK COMMUNITY BY PROVIDING INDIVIDUALIZED, DIRECT PATIENT CARE AND SUPPORT ACROSS THE BREAST HEALTH CONTINUUM. The PCC is committed to addressing breast health disparities by meeting people where they are at any point in their breast health journey and helping them access high-quality breast care, no matter where they live across the U.S. and its territories.

Support from the PCC is easily accessible through a phone call or email to the Komen Breast Care Helpline, where people are immediately connected with a culturally responsive patient navigator who can provide emotional support, information and education, access to resources and more. The PCC's patient navigators help break down barriers to care by guiding people through the complex health care system and helping people for as long as they need us.



“When I’m working with people in treatment, I want them to know they can trust me to help find answers and resources. Cancer is the biggest blow, and I want to help cushion it.”

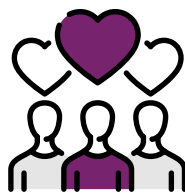
ROSELYN WHITE
Breast Cancer Survivor and
Komen Patient Navigator

After Tamarah Davis discovered a lump in her breast, and later, in a nearby lymph node, she was not prepared for the emotional and financial stress that followed a diagnosis of stage 4 estrogen receptor-positive (ER+) breast cancer. **When Tamarah was paired with Komen patient navigator Roselyn White, a Black woman who herself had previously been treated for ductal carcinoma in situ, her outlook improved dramatically.**

“We were able to talk about being Black women, and she was able to give me advice that I took, and I’m so glad I did,” says Tamarah. “I will deal with whatever comes my way. And I was able to ground my footing because Roselyn helped me get the resources I needed.”



From 2022-2023, Komen supported the Black community with numerous community health interventions through the Patient Care Center, all aimed at providing access to high-quality care to advance health equity:



MORE THAN
15,000
TOTAL SERVICES PROVIDED
TO BLACK COMMUNITIES



SCREENING &
DIAGNOSTICS
2,193
(BLACK PEOPLE SERVED)



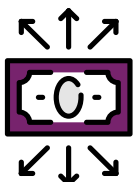
12,047
BARRIERS ADDRESSED
ACROSS ALL PATIENT CARE
CENTER PROGRAMS



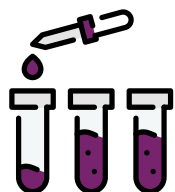
PATIENT NAVIGATION
6,437
(BLACK PEOPLE NAVIGATED)



GENETIC COUNSELING
288
(BLACK PEOPLE SERVED)



FINANCIAL ASSISTANCE
4,921
(BLACK PEOPLE ASSISTED)



GENETIC TESTING
227
(BLACK PEOPLE SERVED)

Patient Support

Financial Assistance Program

When Shareka Allen was diagnosed with HER2-positive breast cancer, the stress of her diagnosis was compounded by the financial burden of her treatments, which included six rounds of chemotherapy and a double mastectomy. Breast cancer treatment is extremely expensive, with an average treatment costing anywhere from \$20K-\$100K for an individual, depending on their insurance status and disease type/stage. These existing financial challenges are exacerbated for Black people who also have disproportionately low insurance coverage.

To address this critical need, the Komen Financial Assistance (KFA) program provides funding for essential out-of-pocket costs associated with breast cancer treatment and for everyday living expenses such as housing, transportation to and from medical appointments, utilities, childcare and groceries.

By reducing these financial burdens, the KFA program helps patients increase or maintain their quality of life as well as adhere to their treatments. **In the three years since this program was established, 8,836 Black people received more than \$4.7 million in financial assistance, 1,961 of whom are living with metastatic (also known as stage 4) breast cancer.** KFA recipients report their greatest financial struggles are paying rent, transportation costs and utility bills.

“You have a lot of stress when you’re going through breast cancer treatment. Even with working full time and support from loved ones and insurance, the copays and the doctors and the medicines and surgeries and the treatments, it’s a lot.”

SHAREKA ALLEN

Breast Cancer Survivor and Komen Financial Assistance Recipient



Genetic Counseling and Testing Services

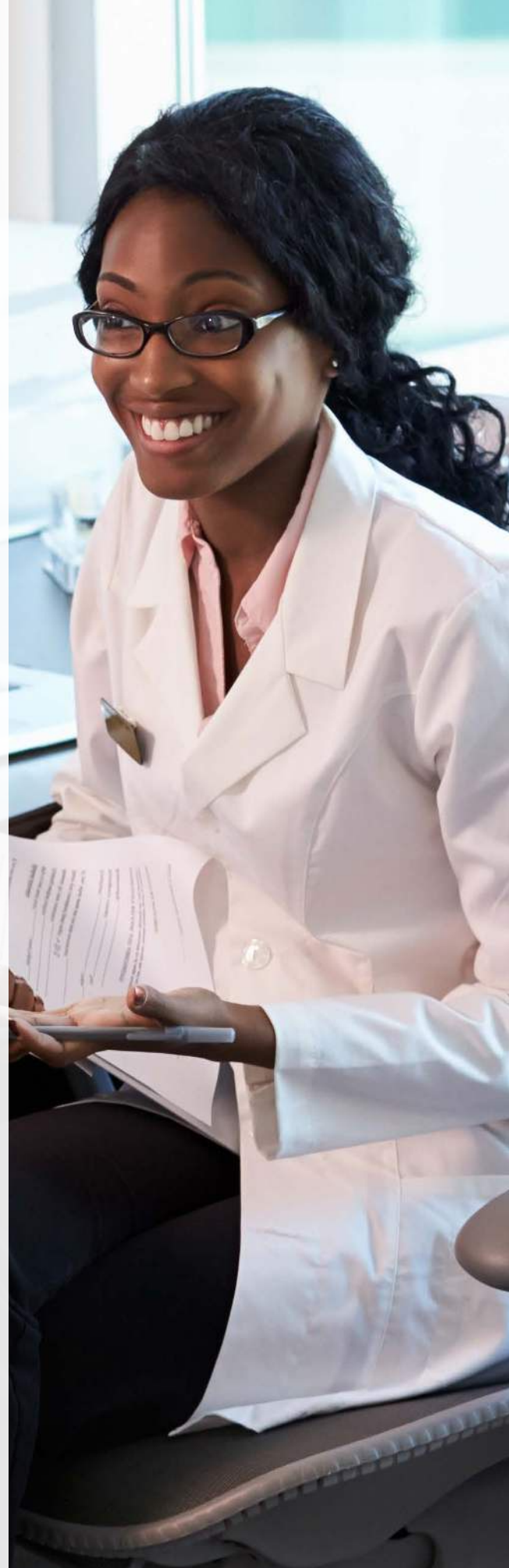
Even though genetic counseling and testing services have been available for more than 25 years, **Black women have historically shown a disproportionately lower rate of receiving genetic testing than white women.**

Komen provides access to genetic counseling and testing services for Black individuals who have been diagnosed with breast cancer or who have a family history of breast cancer. Komen provides these services through specific partnerships that serve individuals from under-resourced or marginalized communities who are more prone to aggressive breast cancers and experience barriers in access to genetic testing. **In the last year, Komen provided 204 Black people with genetic counseling and 187 Black people with genetic testing.**

Screening & Diagnostics Support

Komen has been providing educational, practical and emotional support to individuals seeking breast cancer screening and diagnostic services since the founding of our Breast Care Helpline, more than 30 years ago. Komen navigators provide one-on-one education to individuals seeking information about screening and diagnostic services, including information on how to talk with their doctor about when they should begin screening.

Our navigators also provide connections to safety net programs like the Breast and Cervical Cancer Early Detection Program where eligible people can access services. In select communities across the country where disparities are the highest for Black women, we also fund screening and diagnostic services for income-eligible people. These efforts combined have allowed us to support thousands of Black individuals to get access to high-quality screening and diagnostic services.





Workforce Development

Komen Health Equity Approach

DESPITE IMPROVEMENTS IN THE EDUCATIONAL PIPELINE, PEOPLE OF COLOR ARE STILL UNDERREPRESENTED IN THE HEALTH CARE WORKFORCE. A recent study showed that only 5.7% of physicians were Black individuals, though they constitute nearly 14% of the U.S. population. While the number of U.S. biomedical scientists increased from 27,500 (in 1990) to 69,000 (in 2014), an increase from 12% to 34%, the percentage of Black biomedical scientists only grew from 1% to 2% in this time.

A diverse health care workforce is proven to increase access to health care for communities of color. Komen leads the way with training programs led by experts in the field to prepare the next generation of health care leaders – from breast cancer researchers to patient navigators – who are representative of diverse populations. This ensures that we advance health equity and achieve better outcomes for all.

Patient Navigation Training Program

As part of its Stand for H.E.R. program, Komen developed a patient navigation training program that educates, equips and mobilizes Black patient navigators across the nation to deliver high-quality, culturally responsive navigation services.

The Komen Patient Navigation Training Program is comprehensive, including educational courses and interactive learning and community-building opportunities. Courses range from Patient Navigation 101 to in-depth responsive modules such as a one-of-a-kind module on overcoming racism and bias for Black patients in the health care system. Interactive events include panel discussions, coffee chats and more. Training topics and content are informed in real time by the experience of Komen's Patient Care Center patient navigators.

Over 1,000 navigators were trained from 2022-2023, multiplying the impact navigators across the country can have on addressing barriers to care that contribute to health inequities.

Research

Komen Health Equity Approach

RESEARCH IS THE FOUNDATION OF EVERY DISCOVERY THAT HAS IMPROVED OR SAVED PATIENTS' LIVES – IT PROVIDES HOPE AND A PROMISE OF BETTER CURES FOR TOMORROW. And while research has greatly improved treatments and overall outcomes for breast cancer patients, we know that these improvements have not been equitable among all populations.

Members of the Black community are still dying from breast cancer more than other populations due to the unique biology of their breast cancer, combined with inequities in health care that include access to quality care, insufficient insurance coverage, poverty and systemic racism. Through our Stand for H.E.R. program, Komen is investing in research that will help us better understand the root causes of these disparities and provide strategies to reduce them.

To date, Komen has invested nearly **\$140 million in over 320 research grants** and nearly **190 clinical trials** focused on this critical work. In 2023, **nearly 40% of our \$19.3 million research investment** focused on studies addressing inequities in breast cancer. As a result of our investment, **we currently have nearly 400 new strategies** to reduce breast cancer disparities in the research pipeline.

We understand that we not only need to invest in the science of tomorrow, but also in people who will carry this critical work forward and into the future. Research needs to reflect the diversity of our breast cancer community, and through Stand for H.E.R., Komen is training the next generation of diverse researchers in disparities-focused research as well as new patient advocates that can bring the diverse patient voice to research.

Over the last three years, Komen has awarded over 100 research grants that are supporting more than 320 professionals in research. Of this number:

- 37% reported their race and ethnicity, and of those that reported, 23% were Asian, 10% were Hispanic/Latino(a) and 8% were Black/African American.

In addition to research funding, Komen provides career development support to researchers from underrepresented racial and ethnic backgrounds to ensure the field is representative and as diverse as the breast cancer community, leading to better outcomes for all.

“In the Black community, there’s a stigma about treatment, clinical trials and research. We have to understand that there’s not enough data to help us if we get sick. There’s not enough data to create treatments that will help us. We need to participate in clinical trials.”

SHARON ELMORE-ANDERSON

Patient Advocate Living with
Metastatic IBC

Research

Advocates in Science

TO SUPPORT DIVERSE POPULATIONS MORE DIRECTLY, KOMEN IS TRAINING PATIENT ADVOCATES TO REPRESENT ALL PEOPLE DIAGNOSED WITH BREAST CANCER AND BRING THE PATIENT VOICE TO RESEARCH through its Advocates in Science (AIS) program. Aside from working with researchers and offering patient perspectives, AIS members also establish and maintain connections within their communities.

Thelma Brown is a two-time breast cancer survivor and AIS member who is passionate about increasing participation of more Black women in clinical trials as well as performing outreach and education for people affected by breast cancer.

“It is important to me to advocate for greater participation in clinical trials for all potential patients, but specifically for African American patients because of underrepresentation in these trials. I believe that the patient’s perspective in a trial is an essential key to the successful design and execution of a study.”

THELMA BROWN

Komen Patient Advocate and breast cancer survivor

Disparities-Focused Research Grants



Through our research grant program, Komen continues to support innovative research in breast cancer disparities and the development of a more diverse workforce. Komen is proud to support emerging disparities researchers like Briana Banks, a doctoral student from the University of Chicago who is passionate about addressing inequities for Black women with aggressive breast cancers.

“I’ve always wanted to do research that directly impacted women that look like me.”

BRIANA BANKS

Komen ASPIRE Grantee

Komen ASPIRE Grantee Briana Banks and her mentor, Dr. Matthew Brady

RESEARCH HIGHLIGHT:

Dr. Bryan Schneider

Black women tend to develop peripheral neuropathy, a painful and debilitating side effect from chemotherapy, more often than other patients. With support from a Komen research grant, Dr. Bryan Schneider found certain inherited genetic mutations put Black patients at higher risk for neuropathy, which compromises their ability to complete their treatments.

Building on these findings, Dr. Schneider received Komen funding to conduct the EAZ171 clinical trial, which is exploring alternative chemotherapy drugs that could deliver effective treatments without harmful side effects. This clinical trial is one of the first cooperative group studies to focus completely on Black breast cancer patients.

“We feel that this trial is really set up to potentially change the standard of care for Black patients in the adjuvant setting,” says Dr. Schneider.

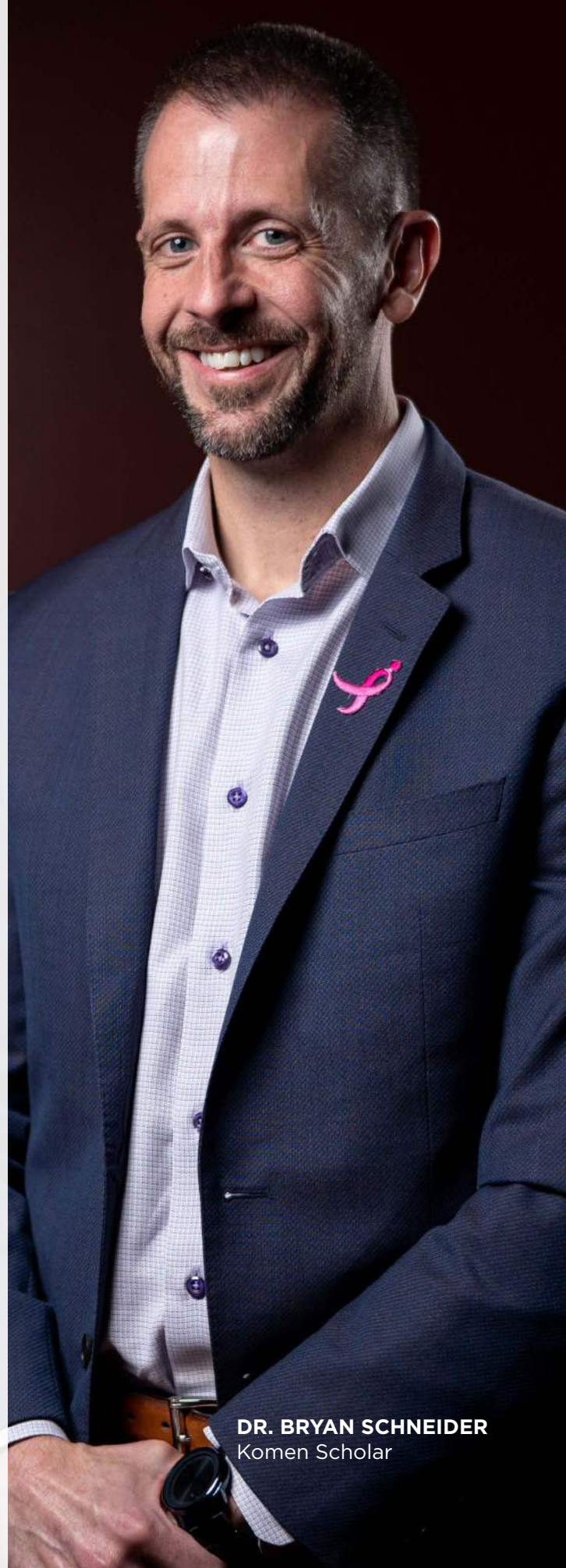
RESEARCH HIGHLIGHT:

Dr. Tuya Pal

While Black women tend to get breast cancer at an earlier age and are more likely to die from it than other groups, they are also more likely to experience barriers to genetic counseling and testing.

With support from a Komen research grant, Dr. Tuya Pal is developing a new interactive tool to automate the genetic counseling and testing process and make it more effective across diverse populations, including the Black community. Through this new tool, patients can obtain the right information to determine whether genetic testing is needed.

“Once they get back their results, they can have a more personalized discussion with a genetic counselor, with test results already in hand,” says Dr. Pal.



DR. BRYAN SCHNEIDER
Komen Scholar



Career Catalyst Research Grants

FOR MORE THAN A DECADE, KOMEN'S CAREER CATALYST RESEARCH (CCR) GRANTS PROGRAM HAS SUPPORTED PROMISING EARLY CAREER INVESTIGATORS BY EQUIPPING THEM WITH THE CRITICAL FUNDING, RESOURCES AND CONNECTIONS needed to help them establish or expand their innovative projects and emerge as key leaders in the fight against breast cancer. The goal of the 2022-2023 CCR grants is to support outstanding research focused on two aspects of precision medicine: the development of next-generation targeted therapies and interventions to eliminate breast cancer health disparities.

The CCR Grants program supports cutting-edge research projects that improve our understanding of and resolve factors that contribute to disparate outcomes, including the following:

- **Lauren McCullough, Ph.D., of Emory University** is working to understand the multilevel factors that influence metastatic breast cancer (MBC) outcomes for Black women and aims to identify innovative solutions to address racial disparities in MBC for the Black community.
- **Nathan Merrill, Ph.D., from the University of Michigan**, is evaluating a novel drug combination that prevents tumor growth and could offer a new treatment strategy for TNBC patients, especially Black women, who are twice as likely to be diagnosed with TNBC as white women.
- **Shearwood McClelland, M.D., from Case Western University** is exploring how patient navigation impacts access to short-course radiation therapy (RT) for Black breast cancer patients and how financial toxicities influence RT adherence. The goal of this research is to demonstrate how patient navigation and short-course RT can alleviate financial burdens and help Black breast cancer patients complete their RT treatments.

“We really have made great strides in improving longevity after a diagnosis of breast cancer.”

DR. LAUREN MCCULLOUGH

Komen Career Catalyst Research Grantee

ASPIRE Grants

Komen ASPIRE (A Supplement to Promote Inclusion for Research Excellence) grants provide funding to established breast cancer scientists to support and mentor research trainees from communities historically minoritized and underrepresented in biomedical research. By supporting these promising trainees early in their research careers, Komen seeks to ensure that a diverse group of highly trained scientists who reflect the communities we serve will emerge as the next generation of leaders in breast cancer research and end breast cancer forever.

Komen awarded **nearly \$1 million in ASPIRE grants to 11 Principal Investigators** who are mentoring 11 graduate students/postdocs from underrepresented communities. Of these 11 trainees, 9 reported their race and ethnicity, five are Black or African American and four are Hispanic/Latino.

TREND Grants

Komen developed the Graduate Training in Disparities Research (GTDR) and Training Researchers to Eliminate Disparities (TREND) grant programs to support graduate students, postdoctoral fellows and early career faculty members who are seeking careers dedicated to understanding and eliminating disparities in breast cancer outcomes. Support through the TREND program helped establish and sustain research training programs at multiple universities across the country.

Both GTDR and TREND grant programs attracted graduate students from underrepresented populations, ensuring that a diverse pool of highly trained scientists will emerge as the next generation of leaders in disparities-focused breast cancer research.

These programs **successfully trained 168 scientists through 36 research grants**, sustaining the field with a strong pipeline of researchers trained by leaders in the breast cancer disparities field. Of the 76% of GTDR/TREND trainees that reported their race and ethnicity, 31% were Black or African American and 14% were Hispanic/Latino. In addition, nearly 50% of GTDR and TREND trainee projects focused specifically on the Black and African American community.

The Carolina Breast Cancer Study

The Carolina Breast Cancer Study (CBCS) is a unique, regional population study investigating the causes, treatments and experiences of women in North Carolina living with breast cancer. Led by Komen Scholar Melissa Troester, Ph.D., from the University of North Carolina Lineberger Comprehensive Cancer Center, the study is also a leader in investigating the disparities faced by Black or African American women, as well as addressing the need for more clinical trials that represent the Black community.

The CBCS has assembled the largest population-based dataset of breast cancer patients to date, including subtype information. Included in the study's 3,000 participants are women from rural locations, and over half of its participants are Black women. To support this invaluable resource, Komen has funded the CBCS through just over \$3.4 million in grants since 2012.



RENEE WILLIAMS WHITE IS GRATEFUL THAT SHE WAS FINANCIALLY PREPARED FOR THE UNEXPECTED COST OF DIAGNOSTIC IMAGES REQUESTED BY HER DOCTOR, FOR WHICH SHE PAID NEARLY \$2,000. Following her treatment, she wondered, **what happens to a woman who doesn't have the money to pay \$1,800 or \$2,000 out-of-pocket before they even start their treatment?**

Renee decided that she wanted to help other women overcome this barrier and attended Komen's Maryland Advocacy Forum and Day of Action as an Advocacy Ambassador in Annapolis. By advocating with representatives from Komen's Center for Public Policy and testifying in support of legislation before state committees, Renee helped pass legislation in Maryland that eliminates out-of-pocket costs for individuals requiring diagnostic or supplemental breast imaging. This legislation brings promise to women in her community that face financial barriers for these services, removing a key financial barrier to earlier detection of breast cancer.

“Representatives need to see the real faces of women who are in the struggle, who are on the journey. I am glad that I was able to represent women in the state of Maryland. I'm excited to know that we're one of [20] states that has now passed this bill.”

RENEE WILLIAMS WHITE

Komen Advocacy Ambassador

As the cornerstone of Komen's Mission, the Center for Public Policy (CPP) believes that sound policy and advocacy, coupled with scientific progress and patient support services, will help us overcome barriers to care and end breast cancer deaths.

While Renee's story gives us hope, there are still many barriers to overcome before we have achieved health equity. Komen believes all people deserve equitable access to high-quality breast health care, and that sound government action is critical for making the broad, systemic and lasting changes we need to save lives and end breast cancer forever.

Public Policy and Advocacy

Komen Health Equity Approach

Federal Policy & Advocacy

Komen's Center for Public Policy is the leading voice on breast cancer policy in Washington, D.C. Our work includes supporting legislation, advocating for funding and engaging in the regulatory process. During the 117th Congress, which was in session from Jan. 3, 2021 – Jan. 3, 2023, we saw many important wins for the breast cancer community. Highlights include:

- **The National Breast and Cervical Cancer Early Detection Program (NBCCEDP)** received an increase in funding of \$3 million to bring program funding to \$200 million in FY23.
- **Passage of the Lymphedema Treatment Act**, which will increase access to custom-fitted lymphedema compression garments to those on Medicare and the Protecting Access to Lifesaving Screenings (PALS) Act, which continues no cost-sharing annual screening mammograms for women under 40 and continues annual screening mammograms at no cost to patients for women beginning at age 40 until 2025.
- **Language encouraging the Department of Health and Human Services (HHS) to examine opportunities to increase use of genetic counseling and testing for breast cancer** in Black women and requiring a report on how to improve access and utilization.
- **Legislation requiring manufacturers to create diversity action plans and reduce barriers** known to keep certain racial and ethnic groups, older adults, rural residents and those with limited incomes from being appropriately included in clinical trials.
- **Support of 56 bills** including the above and the DIVERSE Trials Act, NIH Clinical Trial Diversity Act, Improving Social Determinants of Health Act and more.

We have continued to build on this success in the 118th Congress, which began on Jan. 3, 2023. The Center for Public Policy has already supported nearly 30 bills that would expand access and remove barriers for the breast cancer community. Including our priority Komen-led bills:

- **Access to Breast Cancer Diagnosis Act (H.R.3851/S.2464)** - would eliminate financial barriers that prevent women from getting diagnostic imaging tests.
- **Screening for Communities to Receive Early and Equitable Needed Services (SCREENS) for Cancer Act (H.R.3916/S.1840)** - would reauthorize funding for a critical program – the National Breast and Cervical Cancer Early Detection Program – that provides access to breast cancer screening and diagnostic services for people with lower incomes, uninsured or underinsured people.
- **Metastatic Breast Cancer Access to Care Act (H.R.549/S.663)** - would remove the combined 29-month waiting periods for those living with MBC to receive Social Security and Medicare benefits.



State Policy & Advocacy

Over the past three years, the Center for Public Policy has strategically expanded and deepened our work with state legislatures across the country. Our state-level efforts are focused on the passage of legislation that removes barriers to care and government funding for key research and safety net programs. Key policy issues include:

- **Diagnostic and Supplemental Imaging**, which eliminates patient cost-sharing for medically necessary breast imaging.
- **Metastatic Step Therapy**, which prohibits step therapy protocols for metastatic cancer patients.
- **Breast and Cervical Cancer Screening Program funding**, which ensures maintained or increased funding for programs to provide for people with lower incomes, uninsured and underinsured women's breast screening services.
- **Genetic Testing and Evidenced-based Screening** to eliminate the patient cost-sharing for recommended genetic testing for inherited gene mutations and evidence-based screenings.

Since 2021, we have seen a 123% increase in the number of states where Komen is leading legislation. This year alone, the Center for Public Policy introduced legislation in 29 states, and 17 of those bills have been signed into law. Cumulatively since 2021, 27 Komen-led bills have become law impacting millions of people from coast to coast.

Komen supports many additional legislative issues in support of our health equity goals through coalition efforts. These issues typically impact the broader patient community and are not limited to only those with breast cancer and are focused on access to needed services and treatments without administrative or financial barriers. **Over the last three years, the Center for Public Policy supported more than 120 bills through coalition with 53 signed into law.**

Grassroots Advocacy

Speak Truth to Power

Speak Truth to Power was developed by the Center for Public Policy to provide an opportunity to engage Black community leaders and advocates to learn about the role of policy in addressing the alarming breast cancer disparities experienced by Black women across the country. Speak Truth to Power includes two programs: Advocating to Achieve Health Equity focused on opportunities at the federal level and Stand Up, Speak Up, which explores state policy solutions. Speak Truth to Power aims to:

- **CREATE** a diverse community of advocates to address breast cancer health disparities and inequities within the Black community.
- **STRENGTHEN AND EMPOWER** participants to impact public policy around breast cancer disparities.
- **INCREASE PARTICIPATION** in decision-making that affects access to health care and health care choices.

The Speak Truth to Power: Stand Up, Speak Up training provides a culturally responsive curriculum focused on the role of state-based public policy and advocacy in reducing breast cancer disparities, the importance of engaging in these efforts and collectively determining the most pressing policy initiatives needed to drive health equity.

The Center for Public Policy annually hosts Speak Truth to Power: Advocating to Achieve Health Equity as a pre-session to the Komen Advocacy Summit. **The program has brought together more than 300 advocates since its creation in 2019 to discuss federal policy interventions** that would have the most needed and immediate impact on existing Black breast cancer disparities and provide an opportunity for participants to directly engage with federal policymakers.

Janice Parker, a 10-year breast cancer survivor learned about Komen’s Speak Truth to Power: Stand Up, Speak Up program through an invitation from her local Komen office and signed up hoping the program would give her “more tools in the toolbox to help with local outreach” as she shared her personal story. Through the program, Janice learned how she could provide vital information to her community as a breast health advocate.



“When I attended Speak Truth to Power, I was blown away. I learned that advocacy is power. I learned that there is more racism and bias in health care than I knew about, but I also learned ways I can help advocate for people I work with on how to address those inequalities.”

JANICE PARKER

Breast Cancer Survivor, Komen Advocacy Ambassador and Komen Breast Health Advocate



TINA BROWN

Komen Advocacy Ambassador at the
2023 Speak Truth to Power Session

Advocacy Ambassador Program

The Center for Public Policy launched the Advocacy Ambassador Program in 2020 to provide grassroots advocates with an opportunity to become more engaged with Komen's public policy and advocacy efforts and a goal to diversify our advocates to better represent those impacted by breast cancer. The program seeks to address health disparities by educating, empowering and engaging these individuals to use their voice and advocate for health equity and access to care for all, regardless of race.

This exclusive program allows committed advocates to amplify their voices with federal and state lawmakers across the country while also allowing them to join a community of like-minded volunteers who are passionate about advocating for policy change. Ambassadors are invited to attend virtual and in-person events with CPP staff, take an active role in calls to action and be ambassadors for policy change in their local communities.

The Advocacy Ambassador Program consists of more than 300 Ambassadors representing 42 states and 188 Congressional districts, 33% of whom identify as Black. We look forward to growing this program as we continue to work toward creating an equitable health care system for all.



Connecting With the Black Community Through **Stand for H.E.R.**

AS PART OF OUR MISSION TO ELIMINATE BARRIERS FOR INDIVIDUALS AND COMMUNITIES EXPERIENCING HEALTH INEQUITIES, we believe that everyone should have access to vital information about their breast health. To do this, we need to connect with the community where they are. Through our focused digital campaigns, **we extended our reach of Stand for H.E.R. marketing into the Black community, bringing 60,000 visitors to our landing page in just over nine months.** This number included 50,000 new users.



Stand for H.E.R. patient messaging was so powerful that the patient-facing video about the program earned the 2022 eHealthcare Leader Silver Award in the category of Best Rich Media for a Consumer Disease-Focused Site, as well as eHealthcare Leader distinction for the video in the category of Best Short Video Content – 2 Minutes or Less for a Consumer Disease-Focused Site.



Black women are about 40% more likely to die of breast cancer than white women.

Patient Messaging Campaigns

OUR STAND FOR H.E.R. DIGITAL MESSAGING CAMPAIGN WAS ALSO SUCCESSFUL IN DIRECTLY REACHING PATIENTS VISITING THEIR DOCTOR'S OFFICE. For those receiving primary care or more specialized services, these digital messages were a timely source of information that raised awareness about Stand for H.E.R. and how Komen is addressing the breast cancer inequities faced by Black women.

This **six-month digital messaging campaign** was deployed in an **average of 475 patient exam rooms** and in an **average of 330 health care provider back offices** in the 10 U.S. cities identified as having the greatest Black breast health disparities. In that time, the patient-facing messaging **received nearly 8 million impressions**, or exposures to the information, based on the number of patient visits during that period, and **an average of 2,054 providers viewed a video** in their back office.

In addition to the marketing campaign, the Stand for H.E.R. program also garnered earned media attention, helping to raise awareness about the breast cancer inequities Black women face and the resources Komen offers to support this community. The program was spotlighted by CBS Chicago and also received editorial coverage in print/digital publications with Black audiences including:

- ***Ebony Magazine* - Aug. 7, 2022:** Susan G. Komen's 'Stand For H.E.R.' Initiative Aims to End Breast Cancer Disparities Among Black Women
- ***The Atlanta Journal-Constitution* - Sept. 16, 2022:** More Than Pink Walk to benefit breast cancer health equity
- ***The Root* - Oct. 6, 2022:** There's a New Fight to Improve Breast Cancer Outcomes for Black Women



Invitation to Engage

FOR MORE INFORMATION ABOUT HOW KOMEN IS WORKING TO ADVANCE HEALTH EQUITY,
or for more opportunities to engage with us, check out the following resources:

Get Involved

Visit our Health Equity home page:

komen.org/about-komen/our-impact/breast-cancer/health-equities-initiative

Learn more about Stand for H.E.R.

komen.org/standforher

Join ShareForCures:

komen.org/shareforcures

Become a Policy Advocate:

komen.org/how-to-help/advocacy

Become an Advocate in Science:

komen.org/how-to-help/advocacy/komen-advocates-in-science/become-an-advocate-in-science

Learn more about Worship in Pink:

komen.org/how-to-help/programs/worship-in-pink

Get Help

Learn more about the support available through the Patient Care Center:

[Komen.org/patientcarecenter](https://komen.org/patientcarecenter)

Learn more about our Financial Assistance Program:

komen.org/financial-assistance-program

Contact our Breast Care Helpline:

komen.org/support-resources/breast-cancer-helpline

Learn more about your risk and family health history:

komen.org/about-komen/our-impact/breast-cancer/health-equities-initiative/know-your-history

Access our Breast Cancer 101 Interactive Tool:

komen.org/breast-cancer-101/en/kbc_01_01a.htm

“Susan G. Komen is more than just a breast cancer organization working to save lives – it’s a tightknit community that fosters hope and inspiration ensuring that no one faces a diagnosis alone.”

CANDACE BRAVO

Development Director, New Jersey
at Susan G. Komen

*Candace and her daughter are featured
on the cover of this report.*

Ending breast cancer needs **All Of Us.**



Komen's Breast Care Helpline
1-877 GO KOMEN | (1-877-465-6636)
helpline@komen.org