

Susan G. Komen: A Promise Renewed Advancing the Fight Against Breast Cancer

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> Who We Are: Executive Summary

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Susan G. Komen is widely viewed as the inspiration and leader of a breast cancer movement that has changed the world. In just 32 years, five-year relative survival rates for early stage breast cancers have climbed from 74 percent to nearly 99 percent in the U.S. Breast cancer death rates have declined by 34 percent in the U.S. in just the past two decades. Personalized and less-invasive treatments have replaced the radical and often debilitating treatments that were the norm not that long ago.

Perhaps most importantly, from a time of silence and shame around breast cancer, Susan G. Komen has built a global community, millions strong, that supports and cares for people with this disease. No woman or man—today—is alone with breast cancer.

These accomplishments are commonplace today but seemed impossible just one generation ago, when Nancy G. Brinker set out to deliver on her promise to her dying sister, Susan G. Komen, that Nancy would do all she could to end breast cancer. Nancy and a handful of volunteers launched what would become a transformational global movement.

Over the next 32 years, Susan G. Komen invested billions in a mission that funds more breast cancer research than any other nonprofit, along with community health and education programs that reach millions in the U.S. and across the globe. We educate, screen and care for breast cancer patients. We bridge gaps in the healthcare system to support the most vulnerable women and men. We advocate for them in world capitals, and we work to end breast cancer through partnership programs in more than 30 countries.

Millions of women and men are living with a breast cancer diagnosis today, with more options, and more hope, than at any time in our history. But there is much more to do when half a million women and men around the world will die of breast cancer this year, and more than 1.6 million will be newly diagnosed. Our work is essential, and our mission is far from done.

As we embark on the second generation of our journey, we are determined to continue to adapt to the needs of the breast cancer movement, while meeting and overcoming the "impossible" challenges that remain. We will be guided, always, by our true north: To end breast cancer forever.



KOMEN PRINCIPLES & PRIORITES

PRINCIPLES

Culture of Caring and Collaboration



PRIORITIES

Research Progress

+

Community Health and Advocacy

+

Global Partnerships

We will adhere to the fundamentals of our mission: Progress in Research, Community Health and Advocacy, and Global Partnerships. Collectively, these three pillars support and give shape to our work. We will achieve our goals through a continued culture of caring—a distinguishing hallmark of our organization—and a firm commitment to collaboration, always with the needs of those facing or living with breast cancer at our core.

In Research, we will accelerate progress by focusing on:

- Breast cancer prevention
- Finding and delivering treatments—and cures—for the most lethal forms of the disease
- Ensuring a continuity in breast cancer research by funding today's young scientists and clinicians
- Building new partnerships with other organizations to fund highreward research that can accelerate progress toward improved treatment for cancer patients

In Community Health & Advocacy, we will strengthen our already substantial Affiliate Network to build programs proven to reduce incidence and mortality, including:

- Programs that ensure access to quality cancer care for all women and men, regardless of socioeconomic or ethnic status
- Community health and public programs that will eliminate disparities in treatment and outcomes
- Evidence-based healthcare programs, such as patient navigation services, which have been shown to improve access to care and reduce mortality
- Advocating for public policies and programs, especially at the state and local levels, which affect women's health and the lives of those living with breast cancer

Across the globe, we will build on existing partnerships with corporations and non-governmental agencies to share what we have learned to reduce a growing global cancer crisis, especially in low-resource countries where breast cancer cases are expected to rise exponentially in the next decade

Most importantly, we will take affirmative steps to lead through partnership and collaboration for greater efficiency and impact—with our network of Komen Affiliates, and with the multitude of breast cancer, research and other organizations that share our common mission—to end breast cancer, forever.



Komen and the Breast Cancer Movement in Our Fourth Decade

Susan G. Komen has transformed the way the world treats breast cancer.

In our first 32 years, Susan G. Komen transformed the way the world treats breast cancer. The organization that started in a Dallas living room has grown to a presence in more than 30 countries, along the way funding more breast cancer research—more than \$804 million through 2013—than any other nonprofit, second only to the U.S. government.

Komen's \$1.7 billion investment in outreach to local communities, public policy advocacy and a global network has helped millions, providing education, screening, treatment support and a helping hand to women and men facing breast cancer wherever they live.

Komen's mission is simply stated: To end breast cancer, forever. Investments in the first generation of the breast cancer movement have brought results:

- Death rates from breast cancer have declined by 34 percent since 1990 in the U.S.
- Five-year relative survival rates for early stage cancers are at 99 percent, versus 74 percent when Komen started its work
- Komen research funding has helped provide more treatment options for breast cancer patients than at any time in our history, with new breakthroughs in breast cancer science reported almost every day

We are moving closer to our goal, but breast cancer is not cured. More than 1.6 million women are expected to be diagnosed with breast cancer around the world in the coming year; more than 500,000 will die of the disease. In the U.S. alone, 232,000 people will be diagnosed with the disease and 40,000 will die. Access to quality care for low-resource women remains problematic. Disparities in treatment remain, leading to deaths that might have been prevented, especially in some minority and underserved groups. Cures for the most aggressive and lethal forms of the disease—along with prevention—remain elusive.

This adds even more urgency to our work, in an environment markedly different from our first generation.

From a time of very few breast cancer organizations, the movement has grown to number almost 1,400 organizations. While we have worked in partnership with many organizations throughout our history, we will strive to establish more meaningful collaborations with many more organizations so that we can more efficiently advance both research and care.

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We also must ensure that women understand that breast cancer is still a killer. Our successes may be leading some, especially younger women, to believe that breast cancer is either "cured" or easily managed, and that there is no need for the movement at all. This is dangerous thinking when 30 percent of those who will be diagnosed will suffer metastatic disease; for a disease that is still the leading cancer killer of women ages 40-59 in the U.S., and a disease that is growing worldwide.

Against this backdrop, it's clear that we must think more strategically, work more collaboratively, and focus on those programs that will be most effective for the women and men we serve.

Research Progress

We want to understand how to prevent breast cancer, how to detect it at its earliest stages (even before symptoms appear) and how to better treat it and cure it.

Komen's research investments have touched virtually every major advance in breast cancer science. In just one generation, the progress has been significant. Today, we know that breast cancer is more than a single disease. Today, treatments like tamoxifen and Herceptin, for example, are widely used and surgical interventions are often less invasive and less debilitating. Today, we have a better understanding of the genetics of the disease, and the critical need to tailor treatments to individuals through advances in precision medicine.

We couldn't have contemplated these results 32 years ago, and the next 10-15 years we will see more breakthroughs, thanks to progress in our understanding of the disease through medical science.

Like our overall mission, our mandate is straightforward. We want to understand how to prevent breast cancer, how to detect it at its earliest stages (even before symptoms appear) and how to better treat it and cure it.

To achieve this, we will continue building new partnerships with other organizations to fund studies, along the entire spectrum of research, which hold the most promise, and build upon our investments. We will continue to investigate environmental causes of breast cancer, vaccines to prevent recurrences, simple but very accurate blood or tissue tests to detect it, immune therapies to treat breast cancer, and precision medicine for optimal treatment especially for metastatic and aggressive disease.



At the same time, we consider it our responsibility to ensure the continuity of breast cancer research for the future. With federal research budgets tightening, this priority takes on added urgency: We cannot afford to lose promising young researchers for lack of funding. To that end, our research program will be heavily invested in the work of young researchers. We have set a 2015 goal of increasing by 30 percent the number of early career researchers funded by Komen, while continuing to fund the work of established basic and translational scientists and clinical researchers.

For today and the future, we will focus on opportunities to continue our leadership in advancing the most promising research opportunities.

Community Health and Advocacy

No other cancer organization has this extensive network of grassroots volunteers and staff dedicated to serving the unique needs of their communities.

Perhaps Komen's greatest strength lies in its network of 117 U.S. and three international Affiliates. No other cancer organization has this extensive network of grassroots volunteers and staff dedicated to serving the unique needs of their communities. Some Komen Affiliates serve heavily urban areas; others rural. Some work in areas with large minority populations; others address language, economic or cultural barriers to care that are prevalent in their regions.

Komen Affiliates know their communities; they understand their communities, and they grant to local health care organizations that meet the health, financial and psychosocial needs of local women and men facing breast cancer today. Seventy-five percent of funds raised in local areas fund health programs in the communities where they were donated.

For many years, Komen Affiliates focused on funding screening and education programs for low-income and uninsured women in their communities. With the advent of the Affordable Care Act (ACA), which covers well-woman doctor visits and screenings for many more, the opportunity may exist to shift our dollars to programs such as patient navigation programs, which have been proven to reduce mortality from breast cancer.

Patient navigators are trained to assist women and men working through a breast cancer diagnosis. They provide real-time help—for example, scheduling appointments, arranging transportation, navigating the health care system and ensuring compliance with treatment.



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While we believe that there will always be a need for Komen-funded education and screening programs for low-resource women, the Affordable Care Act's coverage may reduce the need for Komen to fund them at today's levels. As we assess the impact of the ACA, we have set a 2015 goal of developing a plan for patient navigation in each Affiliate's service area. If indicated within the Affiliate's Community Profile, patient navigation will be included as a priority focus for local Affiliates.

We also will direct more of our public policy work to advocating for local and state programs to treat uninsured, underinsured and low-income women, while maintaining vigilance at the federal level (and with other cancer organizations) to ensure that breast cancer research funding and cancer care access programs remain significant priorities.

Global Partnerships

Today, Komen works in partnership to educate, screen and develop treatment programs in more than 30 countries.

Komen first expanded internationally through research granting in the mid-1990s. By the early 2000s, Komen understood the need to also move community outreach and education programs beyond U.S. borders to areas of the world where medical resources are scarce, and shame and stigma exists around breast cancer. Today, Komen works in partnership to educate, screen and develop treatment programs in 30 countries, with a focus on low-resource countries in Africa, Asia, the Middle East, Latin America, the Caribbean and Europe.

Komen's outreach and leadership has led to innovative partnerships such as the Breast Health Global Initiative, and the Pink Ribbon Red Ribbon program to screen for both cervical and breast cancer in Africa. In recent years, we've developed specific programs with corporate partners in China and the Middle East to educate and screen women for the disease. We work in partnership in each of the countries we serve, sharing what we have learned in 32 years of breast cancer work.

Going forward, we will continue to support these existing initiatives—and develop new ones—and actively seek partnerships to support our efforts to help tackle a coming cancer tsunami in the developing world, where breast cancer cases will grow at a disturbing rate by 2025.



How We Will Work Together and With Others—A Move to Greater Collaboration

We will seek more opportunities for collaboration among major breast cancer, cancer and health organizations, with the needs of breast cancer patients and survivors as our primary focus.

Susan G. Komen is the largest breast cancer organization, but we are not the only organization. A significant priority going forward will be to serve as a convener for collaborative initiatives among breast cancer organizations, health care organizations and other nonprofits, including foundations. This is key to achieving more meaningful results, expeditiously and efficiently, in critical areas.

Komen demonstrated how this approach can be successful in our fall 2013 collaboration with the Dr. Susan Love Research Foundation and the Young Survival Coalition to jointly enlist participants for Dr. Love's Health of Women study on breast health and side effects from breast cancer treatment. There was a time when neither Dr. Love nor Komen would have considered such a partnership—our philosophies are very different—but we have found that positive results can accrue when we put those differences aside to achieve important common goals for the benefit of patients.

We're finding the same positive benefits as founding members of the 16-member Metastatic Breast Cancer Alliance (MBCA), also established last fall. This group brings together the leading experts and advocates for people with aggressive and metastatic disease—the forms of breast cancer responsible for the majority of breast cancer deaths in the U.S. Together, we are building strategies for research, awareness, and programs that will better meet the specific psychosocial needs of people living with aggressive and metastatic breast cancer.

Although we have worked in partnership with hundreds of organizations throughout our history, we will seek more opportunities for collaboration among major breast cancer, cancer and health organizations, with the needs of breast cancer patients and survivors as our primary focus.

And With Each Other...

Susan G. Komen is stronger and more effective when we work as one toward clearly identifiable and definable goals. Our Affiliate Network is a key differentiator for Susan G. Komen and a source of real strength—serving as both the heart and face of our mission work in local communities across the country. To fulfill our mission going forward, we must work together to evolve our relationships and how we do business.



We have made significant strides over the past year in terms of redefining and rebuilding the alliance between our Affiliate Network and our headquarters organization. We are experiencing increased communication and collaboration with our Affiliates through our national Affiliate Leadership Council. Thanks in large part to their efforts, we now benefit from the stability and clarity of a new Affiliation agreement and associated Komen Operating Guidelines for the entire organization.

During the coming year, we will work closely with these Affiliate representatives to set the future direction of our network and address sustainable opportunities for enhanced revenue and mission programs in our communities.

Conclusion

Susan G. Komen will be defined by our mission, our relevance, our leadership in 2014 and beyond, and the difference we make by saving lives.

Our first 32 years are prologue to the next—a renewal of a promise between sisters that has become our promise to all women and men: To end breast cancer, forever.

Susan G. Komen will be defined by our mission, our relevance, our leadership, our partnerships and the difference we make by saving lives in 2014 and beyond. We will lead the way to more research breakthroughs, through community outreach to reduce both incidence and mortality from breast cancer, through a culture of caring and collaboration and always with the needs of current and future breast cancer patients as our highest priority.

We will not be satisfied—and our work will not be done—until we have put breast cancer in the history books.





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