

When society meets science

Nancy G Brinker

I still remember meeting her for the first time.

I had revered Mary Lasker for years, admiring from afar the gracious ferocity with which she raised the public consciousness as chair of the American Cancer Society, persuaded Congress to create the National Cancer Institute and boost funding for the National Institutes of Health, and convinced President Nixon to declare a national war on cancer in 1971.

In the final days of my sister Suzy's battle with breast cancer in 1980, she made me promise that I would do everything in my power to spare other women the pain and suffering she had endured. That promise became the Susan G. Komen Breast Cancer Foundation. And although I wasn't entirely sure at first how to tackle the enormity of eradicating this disease, I was fortunate that my personal role model was Mary Lasker.

Mary Lasker understood that no disease is cured in a laboratory alone. Society looks to science to help alleviate suffering. Science, in turn, looks to society for the funding and public support that make new discoveries, drugs and treatments possible. Advocates for medical research, therefore, must become what Dr. Jonas Salk once called Mary Lasker—"a matchmaker between science and society."

When I met her in her New York City apartment in 1990 courtesy of my friend Deeda Blair, Mary Lasker knew that the Komen Foundation was focused on raising funds from the private sector. She welcomed me warmly, said hello, and then locked her eyes onto mine. "The federal government will always be your largest funder of research," she said, "always."

"Yes, Mrs. Lasker," I replied. "That's why we hope to do both—to raise money and the consciousness of both government and the private sector."

I still don't know what Mary Lasker made of the determined woman from Texas she met that day, but I believe she'd be proud of the progress that has been made in mobilizing all spheres of society—government, business and the American people—in support of

medical research generally and breast cancer research specifically.

Mobilizing society

As Mary predicted, government remains the largest funder of breast cancer research, devoting nearly \$900 million to the cause every year.

At the same time, the private sector has enthusiastically joined our ranks. Two decades ago, corporate America listened politely to our ideas—and then showed us the door. Today, cause-related marketing is appreciated as a clear win-win for everyone. Companies win by contributing in a creative and targeted way to a worthy cause. Breast cancer research wins with millions of dollars in funding it never otherwise would have received.

At the grassroots level, the Komen Foundation's bold experiment in local entrepreneurship has succeeded beyond our wildest dreams. Our 115 local affiliates across 47 states have enabled us to raise three-quarters of a billion dollars for the cause, making the Komen Foundation the largest private provider of funds for breast cancer research and community outreach programs in the nation.

By mobilizing every part of society—the government, the private sector and the grassroots—we've changed the way our society deals with breast cancer.

We've changed the culture. When Suzy (Fig. 1) was diagnosed, breast cancer was still a silent epidemic. People called it 'the Big C,' as if you might catch cancer by just saying the word. Today, education and awareness campaigns have made cancer part of the culture. Instead of breast cancer being a mark of shame, patients, survivors and their families wear pink ribbons as a badge of courage.

Energizing science

In changing the cultural landscape, we've also changed the clinical landscape. At the time of Suzy's diagnosis, women were often bystanders in their own care, encouraged to keep quiet and not question a physician's



Figure 1 Sisters. Nancy G. Brinker and Susan G. Komen (left), 1978.

authority. Today, women have taken charge of their own health care, and more women understand the importance of early detection and optimal treatment.

Most importantly, by mobilizing society, we've helped energize the scientific community. When Suzy was in the hospital, there were only a handful of cancer drugs on the shelf. Today, hundreds of advanced-technology medicines are being tested to target specific cancers.

We're seeing amazing scientific advances that at one time we could only imagine. Vaccines, monoclonal antibodies and gene therapies give hope of taking aim at specific biological targets.

Today, a diagnosis of breast cancer is no longer a death sentence. Mortality rates are dropping. Patients are living longer and with a better quality of life. Patients—women, men, mothers, daughters, sisters, friends—who only a few years ago may have died are now survivors. We are getting closer to solving the breast cancer puzzle.



Figure 2 Race for the Cure. Nancy Brinker at the Komen National Race for the Cure in Washington, DC, 1999.

The people behind the promise

Any advocate, of course, is but a single voice in a chorus of many. Beyond Mary Lasker, I am forever indebted to so many family members and friends for their example.

As my older sister, Suzy never stopped teaching me, not even in her suffering. In her battle against breast cancer, she taught me about wisdom, bravery and faith—values that would sustain me several years later in my own struggle against the disease.

As Suzy's loss galvanized me, my parents' lessons sustained me. Growing up in Peoria, Illinois, my parents taught Suzy and me about service and stewardship. "You girls have to be stewards for your country," my mother, Ellie Goodman, would say. "If you don't like something, it's up to you to fix it." My father, Marvin Goodman, would add that "with perseverance and courage, you can succeed at anything."

When I was six, Suzy and I heeded our parents' words and held a variety show in our driveway to raise money for polio research. Suzy collected the money and I sang. I was certain that I had wowed the crowd. After the curtain came down, however, Suzy informed me that in the future, she would do the singing and I would collect the money. Thus, my career as a fundraiser had begun.

Our parents explained that our Jewish faith is about service and giving to others. They taught us about *tzedakah*—the importance of charity and righteous giving. They taught us about *tikkun olam*—that each of us could truly repair the world around us.

My faith has been constantly renewed by the compassion and generosity of all those who have joined the fight against breast cancer—the 75,000 passionate volunteers and staff who are the backbone of the Komen Foundation,

as well as the millions of people who take to the streets in the Komen Foundation's Race for the Cure (Fig. 2) to raise the money that funds the research that brings us closer to a world without breast cancer.

Indeed, the Komen Foundation has always understood the power of society to energize science. We have a long tradition of using the funds we raise to support pioneering researchers who have made major discoveries. These discoveries include the two key genes known to be involved in breast cancer; the enzyme telomerase, that perhaps holds the clue to stopping the growth of cancer cells; and treatments, angiogenesis inhibitors, which cut off the blood supply that tumors need to grow.

Complacent at our peril

Yet for all our progress, we are complacent at our peril. The incidence rate of breast cancer is still rising. This year, nearly 270,000 women will be diagnosed with breast cancer (an estimated 211,000 with invasive breast cancer and 58,000 with early-stage carcinoma *in situ*). This year, some 40,000 Americans will die from the disease—more than 100 every day.

If terrorists unleashed a bioterror attack on the United States that killed 100 Americans every day, our government would declare a national emergency and mobilize every resource to find an antidote or cure. Yet more than 30 years into the war on cancer, that same sense of urgency needs to be reborn.

How can we re-energize this fight with the sense of urgency it deserves?

Being bold (again)

Throughout history, great breakthroughs in medical research have been achieved when innovators pushed boldly into the realm of the

unknown. Sadly, medical research today is too often the victim of larger forces—budgetary concerns in the public sector and competitive pressures in the private sector—that discourage the very risk and innovation that could lead to breakthrough drugs and treatments.

Both Mary Lasker, through her personal resources, and the Komen Foundation have taken calculated risks by funding groundbreaking projects, thereby jump-starting innovative research that has, in turn, stimulated government funding. Therein lies a message for the larger research community. Calculated risks must be embraced as an inherent part of discovery, and mistakes and false starts should be welcomed as the price of progress. Indeed, the greatest risk is taking no risk at all.

Communication and collaboration

A multifaceted disease like breast cancer demands a multifaceted approach. No one institution or individual will solve the breast cancer puzzle working alone. Yet cancer researchers often complain of insufficient communication and collaboration across disciplines.

Along with other leading cancer organizations, the Komen Foundation is working to develop an unprecedented online database to connect the world's researchers and to improve coordination and reduce duplication of research. At the same time, a greater investment in translational research would accelerate the progress of innovative drugs, treatments and therapies from the laboratory bench to the patient's bedside.

Even as we work to improve the communication among scientists, we must improve communication between scientists and society. I have been a breast cancer advocate for more than two decades, but I still find myself at scientific conferences where the



Figure 3 Hungary. Nancy Brinker leading a walk across Budapest's landmark Chain Bridge to promote breast cancer awareness, 2002.

presentations, although brilliant, are at times unintelligible to patient advocates.

We will never succeed in mobilizing the full energy of American society in support of cutting-edge research—including persuading more patients to participate in clinical trials—unless citizen advocates and patients better understand the science and research they are asked to support. We have the same goals. We must speak the same language.

Realizing the full potential of medical research also requires greater unity across disciplines and organizations. Too often, cancer researchers and advocacy groups treat one another as competitors for the same funding dollars. But cancer funding is not a zero-sum game. An advance in one area gives

hope to others. Instead of competing over limited resources, the cancer community should seek opportunities to reduce wasteful duplication and increase collaboration.

A question of causation

Looking ahead, researchers will continue to be challenged by one of the foremost questions in public health: what causes breast cancer? Compared to when I started the Komen Foundation, we're much closer to understanding the precise event—or series of steps—that turns a normal, healthy cell cancerous.

A renewed commitment to the question of causation must focus on several questions: what are the causes and risk factors of breast cancer? What part of breast cancer risk is genetic, biological, environmental or due to differences in lifestyle, and how do these multiple factors interplay with one another? What are the biomarkers—the molecules, proteins and genes—that might provide an early prediction of breast cancer long before the appearance of a tumor?

Confronting disparities, locally and globally

Just as we seek to mobilize every part of society in support of scientific research, we must ensure that science benefits all corners of society. But women of racial and ethnic minority groups and women in underserved communities continue to face barriers to healthcare, a higher risk of breast cancer, and higher mortality rates.

Key questions demand urgent attention: why do women of certain racial and ethnic minority groups have higher rates of incidence, morbidity and mortality? What is the role of genetics, biology, barriers to care and socioeconomic status in these disparities? What can be done to diminish these disparities and reduce barriers that prevent access to quality health care?

The challenge of disparities is by no means unique to the United States. In many cultures and corners of the world, simply discussing breast cancer—never mind treating it effectively—remains taboo or beyond the reach of local resources.

As US ambassador to Hungary, I had the opportunity to promote awareness and education in a society that still discussed breast cancer in whispers (**Fig. 3**). Since then, a national public health campaign has increased the percentage of Hungarian women screened for breast cancer from under 40 percent to 60 percent in just three years—a remarkable achievement that sends a powerful message of hope to women around the world.

Hope where none existed before

The power of awareness and hope was a message Mary Lasker understood deep in her heart. At the 1984 dedication of the US National Institutes of Health Center for Health Education and Research that bears her name, she said:

“The fruits of our labors throughout the years will alleviate pain where there is suffering, provide freedom to live in health so that we can fulfill our promise and quest in pursuit of happiness, and provide hope where none existed before.”

I can think of no better way to honor the life and legacy of Mary Lasker, or the spirit of the award named in her honor, than to rededicate ourselves to the mission and message of her life. Let us create the hope she engendered. Let us, like her, teach and inspire the next generation of advocates so that there will always be loving matchmakers between society and science.

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