



United States Senate Committee on Health, Education, Labor and Pensions

Written Testimony of

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Mr. Chairman, Ranking Member, and Members of the Committee, thank you for the opportunity to testify before you today about the need for comprehensive legislation to address our nation's cancer crisis. My name is Hala Modellmog, and I am President and CEO of Susan G. Komen for the Cure. While I am here in my role as President and CEO of Komen for the Cure, I speak on behalf of every cancer patient who has a stake in finding a cure for this disease and every patient advocate who has dedicated his or her life to ending cancer forever. I am a breast cancer survivor. I joined Komen in September 2006—five years to the week after my surgery—after a successful career in corporate America, most recently as president of a major food service company. Of all the jobs I've ever had, this—I firmly believe—is the most important of my life. I wake up every day with a purpose: to help put an end to a disease that has affected me and so many others, a disease that cost the lives of countless mothers. It is important for us to remember, on Mothers Day this weekend, how many mothers have been lost to breast cancer and all cancers, how many children have lost their mothers to this terrible disease.

Now is a turning point for the cancer community—we have come together to offer our suggestions and have advocated in unity for change. We are committed to moving beyond strategies that have focused on specific cancers and have limited attempts by Congress to comprehensively address all cancers. We are committed to speaking with a renewed and resounding single voice that calls for action now to end for all time the ugly reality of this disease, which kills 1,500 Americans every day. Because of this, any legislative effort will be that much more powerful, that much more comprehensive, and that much more effective.

Mission of Susan G. Komen for the Cure

Susan G. Komen for the Cure began with a promise from Nancy G. Brinker to her dying sister Suzy that she would do everything in her power to end breast cancer forever. In 1982, that promise became Susan G. Komen for the Cure and launched the global breast cancer movement. Today, Komen for the Cure is the world's largest grassroots network of breast cancer survivors and activists fighting to save lives, empower people, ensure quality care for all and energize science to find the cures. Thanks to events like the Komen Race for the Cure, in its first 25 years, Komen for the Cure invested \$1 billion to fulfill its promise, becoming the largest source of nonprofit funds dedicated to the fight against breast cancer in the world. To continue this progress, Komen for the Cure has pledged to invest another \$2 billion by 2017.

With \$100 million in scientific research grants awarded this year, we are well on our way to meeting our \$2 billion goal. This is the largest single-year investment in research in the organization's 26-year history and represents a landmark 30 percent increase over last year's award total of \$77 million. With this year's slate of 143 grants, Komen for the Cure has fully activated new funding mechanisms designed to speed the discovery and delivery of the cures for breast cancer. The 2008 slate funds projects designed to promote breast cancer research collaboration and cost efficiencies, arrive at reliable and replicable research results more quickly,

motivate bright young investigators to commit to breast cancer research careers and keep career researchers intensely focused on breast cancer. We've made it clear that our money will fund projects that focus on ways to significantly reduce breast cancer incidence and mortality within the next ten years.

While we invest in research to discover the cures of the future, we must ensure that everyone has access to the best cures we have today. We accomplish this through the community grant programs of our network of 122 Affiliates in the United States. Last year Komen for the Cure provided community grants to over 1,600 organizations, totaling over \$70 million. These funds provided over 180,000 women with free or low-cost mammograms, helped 18,000 with the physical, emotional, and financial effects of breast cancer treatment, and helped over 4,000 people enroll in breast cancer clinical trials. Many Affiliates fund treatment assistance programs that help breast cancer patients with day-to-day chores and provide monetary assistance with rent, utilities, and co-pays. Sadly, for women with advanced breast cancer, Komen grants help provide the legal assistance necessary to help these women put their affairs in order.

Through the newly formed sister organization, the Susan G. Komen for the Cure Advocacy Alliance, Komen for the Cure is taking the next logical next step in its evolution: expanding its reach in the health policy arena. The Komen Advocacy Alliance is directly engaging policymakers and opinion leaders to advocate for increased funding for cancer research and greater access to cancer screening and treatment. Our goal is to expand on the long history of Komen for the Cure's commitment to saving lives through public policy advocacy.

The Cancer "Crisis"

I am honored to be testifying today about the need for comprehensive legislation to address the cancer crisis our nation is facing. And we are facing a cancer crisis. A crisis in our

investment in prevention and early detection of cancers; a crisis in our dedication to innovative cancer research; and a crisis in patient access to the highest quality cancer care and treatment.

Approximately 40 percent of Americans will be diagnosed with cancer at some point in their lives. More than 1.4 million new cancer cases will be diagnosed in the United States in 2008, and approximately 565,000 Americans will die from cancer this year. The National Institutes of Health (NIH) estimates the annual costs of cancer to be \$219 billion. And yet, despite a few highly successful cancer therapies, the fundamental goal of the “War on Cancer” launched in the 1970s—to diminish death and suffering—remains largely unrealized. In the 35 years since the declaration of the War on Cancer, scientific research has produced an abundance of extraordinary knowledge about the biochemical mechanisms that cause cancer. But this new scientific knowledge has led to only a modest reduction in overall age-adjusted cancer mortality rates, especially compared to the plummeting mortality rates for cardiovascular disease and stroke. Cancer now exceeds heart disease as the leading cause of death among people under 85 years old.

Through our Komen Community Challenge tour, a nationwide year-long campaign designed to bring communities and policymakers together to close the gaps in access to care, I have heard firsthand from patients, family members, and lawmakers just how severe this cancer crisis is. The impact of cancer on the lives of ordinary citizens is extraordinary, but often unimaginable to those who have not lived through it.

One of the more poignant moments of the Komen Community Challenge was in California. In Sacramento, actor Ricardo Chivara joined us at a rally to motivate the California legislature to expand access to early detection programs. Ricardo shared his reasons for being a breast cancer activist. He said, “I personally know that cancer does not only affect the victim, it

also affects his or her entire family. Mothers with breast cancer have an uncertain future for themselves and their children. Sick mothers cannot nurture and guide their children. Mothers suffering from breast cancer sometimes can't even make it to the grocery store to buy food to make dinner, or help you with that evening's homework. I remember on more than one occasion having to ride my bike several blocks with a 20 dollar bill to the grocery store to buy food, put it in my back pack, and ride back home. I was twelve. I remember my older sister balancing my mother's check book and paying all the medical bills, because my mother was vomiting from just having received chemo[therapy]. My sister was fifteen." Ricardo lost his mother, Elizabeth Ries Chivara to breast and cervical cancer when he was 16 years old, and he is an activist because he does not want to see other children suffer the way he and his sisters did.

In California, we also met Jamie Ledezma, a deputy district attorney from Fresno, who was 27 years old and 14 weeks pregnant when she was diagnosed with breast cancer on Valentines Day. Determined not to let her cancer diagnosis stop her dream of being a mother, Jamie underwent six months of chemotherapy during her pregnancy. Her son Blake was born healthy, with a full head of hair, and he accompanied his mother to Sacramento to help lobby California legislators. When Blake was a just a month and a half old, Jamie underwent a bilateral mastectomy. Jamie has a significant family history of breast cancer and tested positive for BRCA1. She is a breast cancer activist because she wants to ensure that legislation, such as the recently-passed Genetic Information Nondiscrimination Act, benefits her family.

In Massachusetts just last month, we met Cristina Moya, a lawyer who moved to the United States in 2000 from the Dominican Republic. In April 2005, she found a lump in her breast. She waited two months to see a specialist, who assured her that she had nothing to worry about. She did worry, because she had lost her sister to breast cancer and her mother to ovarian

cancer. Two months later, she saw yet another specialist, who again told her she had nothing to worry about. She continued advocating for herself, and finally in January 2006, nine months after she found the lump, she was diagnosed with breast cancer. She was fortunate to have health insurance and was treated at Dana-Farber Cancer Institute, where she had a patient navigator to help her through her treatment. Now she works as a case manager at Jamaica Plain Child Care Center. As a volunteer with the Boston Public Health Commission, Cristina trains women on breast health and the importance of early detection and screening. She said, “I want to help other women, especially women in the Latina community. In many parts of my community, cancer is considered a punishment from God. Women need to know this is a disease that you get treated. No shame should be associated with it.”

Cancer is a devastating diagnosis. I learn this every day in my own life, and every time I meet survivors and family members of survivors. From our work with activists, scientists, states and the federal government, Komen for the Cure believes that the fundamental gaps in the paradigm of cancer research and care are based on:

- ♦ Lack of investment in early detection of cancer;
- ♦ Inadequate funding for cancer research and barriers that is difficult to translate basic research into patient treatments; and
- ♦ Inconsistent access to high quality cancer care.

To discover and deliver the cures for cancer, we must address these gaps.

Early Detection of Cancer Saves Lives

Komen has long believed that early detection is critical to successfully treating cancer and has been a champion of early detection programs. Timely mammography screening of women over age 40 could reduce mortality by 20 to 35 percent. Moreover, the five-year survival

rate for women with early-stage breast cancer is 98 percent; for women with distant metastatic disease, the figure plummets to 27 percent. Early detection of prostate and colon cancers is similarly beneficial for patients: the 5-year survival for colon cancer is 90 percent when detected early, and the 5-year survival rate for prostate cancer approaches 100 percent due to early diagnosis and improvements in treatment.

There is no doubt that early detection saves lives. The single most important factor in the relative success of a cancer treatment regimen is often the stage at which the cancer is diagnosed. However, despite the expansion of screening programs in recent years as the result of greater awareness of the importance of early detection, 45 percent of all women over 40—the age after which the National Cancer Institute (NCI) recommends an annual mammogram—still do not receive an annual mammogram. Screening for colorectal cancer is similarly disturbing. Despite the high survival rate of patients when colorectal cancer is discovered early, only 39 percent of cases are diagnosed at the early, localized stage. According to the American Cancer Society, of the 49,960 people expected to die of colorectal cancers in 2008, appropriate testing could save more than half.

In the breast cancer community, we have advanced screening and imaging techniques which can accurately identify the early stages of cancer. For many other cancers there are no such early detection modalities. Ovarian cancer is a particularly devastating example: there is no screening diagnostic, thus a diagnosis is most often made after the cancer has spread when a symptomatic patient presents to her physician. According to the American Cancer Society, when ovarian cancer is detected locally, the survival rate is 92 percent; however, only 19 percent of cases are detected at this stage, and the overall five-year survival rate is only 45 percent. Survival rates are even more disturbing for lung and pancreatic cancers. In addition to improved

education and outreach for current diagnostic screening, the wave of the future lies in the discovery of biomarkers and the development of effective early detection diagnostics for all cancers. Armed with these biomarkers and early detection tools, we must also apply our knowledge of genomic and molecular data to the development of targeted, low-toxicity medications and dosing regimens that are tailored to an individual patient's genetic makeup.

Personalized medicine holds enormous potential to advance oncology care and treatment. With the discovery and clinical uptake of targeted diagnostics and therapeutics, we could save countless lives and reduce untold suffering. We must dedicate substantial resources to the development of biomarkers and to the delivery of personalized medicine.

Continued Commitment to NIH Funded-Research

Previous investments in research have allowed us to make significant progress toward discovering and delivering the cures for cancer. The “doubling” of the National Institutes of Health (NIH) budget from 1998-2003 fostered incredible advances in our understanding of the molecular etiology of the disease. And yet, since 2003, the NIH has been consistently flat funded. When adjusted for inflation, flat funding translates to an actual decline in NIH purchasing power. According to the NCI, when funding is adjusted to reflect the Biomedical Research and Development Price Index, the NCI has experienced a significant loss in purchasing power each year since 2004, resulting in a 19 percent—or \$1 billion—loss for FY 2008. We cannot engage in cutting edge science and maintain our status as the global leader in biomedical research without adequate NIH funding.

Susan G. Komen for the Cure is particularly concerned with funding for young researchers. According to recent statistics from “A Broken Pipeline: Flat Funding of the NIH Puts a Generation of Science at Risk”, only one in four NIH grants is awarded to a first-time

grantee. Young investigators are often the source of the most innovative, creative ideas in science, but we are losing a generation of young researchers due to chronic under-funding of the NIH. The NIH must reevaluate its commitment to young researchers by creating dedicated funding streams for young scientists, establishing mentoring programs and restructuring the grant review process to encourage funding for high risk proposals sponsored by young, but highly qualified, investigators.

Komen for the Cure is also concerned that the proliferation of basic scientific knowledge about cancer has not been matched by the capacity of the American cancer research enterprise to translate that knowledge into improved diagnosis and treatment. For example, the NCI-supported translational research enterprise is not keeping pace with the enormous opportunities presented by advances in knowledge and technology in the last four decades of cancer research. Advances in basic science are critical, but just as important is the translation of those discoveries into treatments and therapies to benefit patients. To improve the translational research framework at NIH and NCI, we should expand methods for identification of the most promising early translational research opportunities, streamline intellectual property agreements to facilitate collaborative research, and develop standards for storage and access to biospecimens to assist translational researchers. The Institute should also provide opportunities for young researchers to engage in translational research.

Komen for the Cure also encourages the establishment of public-private partnerships to advance translational research. Komen believes strongly that collaboration is the best way to advance scientific discoveries. Collaboration eliminates duplication of effort and allows individuals to benefit from the pioneering ideas of others. Komen for the Cure's own recent focus on partnerships and sponsored programs has resulted in highly visible and productive

relationships with the American Association for Cancer Research, with whom we are partnering to create public efforts that address disparities in general cancer research, cancer prevention and breast cancer research; and with the American Society of Clinical Oncology, with whom we are creating programs to look at the quality of cancer care across all regions of this country. Komen also led an effort to bring all key opinion leaders in breast cancer together for the first Collaborative Breast Cancer Summit, held in November 2007. The meeting facilitated discussion around eliminating duplication of effort, sharing information and resources and creating collaborative programs to fund broad initiatives. Partnerships between the NIH and private industry, non-profit organizations, universities, and others could be equally beneficially as we work toward finding a cure for cancer. Komen encourages the development of incentives to foster collaborative efforts as well as the removal of barriers that hinder such relationships.

Ensuring Access to High Quality Cancer Care

Komen for the Cure has dedicated itself to ensuring that all women have access to high quality cancer care. We believe that all women deserve access to the highest quality treatment and care, regardless of race, ethnicity, socio-economic status or geographic location. Unfortunately, many of these factors do play a role in the quality of care a patient receives—for breast cancer, and for all cancers. For every person with cancer who has benefited from early detection and the best available care, there are many others who have not, and will not, benefit from the advances we have made over the past 25 years. For example, African American women have a 35 percent higher rate of mortality from breast cancer than Caucasian women, despite overall lower rates of incidence of breast cancer. Only 38 percent of Hispanic women over the age of 40 receive regular mammograms. Those who live in rural communities may have to

travel long distances for screening or treatment. And, for all cancers combined, uninsured patients are 60 percent more likely to die than their insured counterparts.

Last fall, the *Wall Street Journal* profiled Shirley Loewe, who was working as a hairdresser when she was diagnosed with breast cancer in 2003. Unfortunately, Shirley did not have health insurance and went to the wrong clinic for her screening and diagnosis. As a result, she was unable to access Medicaid to help with her treatment. After three years of delays in treatment and care patched together through multiple sources, Shirley succumbed to the disease last summer, leaving her daughter Niko Ferguson and her children without their mother and grandmother. Niko runs in the Komen Denver Race for the Cure in honor of her mother. Sadly, Shirley is only one of many to deserving patients who do not have access to cancer care.

Komen's first annual "State of Breast Cancer Report," which was released in 2007, found that disparities in care were pervasive throughout the continuum of cancer: from unequal representation in clinical trials to disparities in access to early detection services and high quality treatment. A recent study showed that ethnic and racial minorities make up only 10 percent of participants in clinical trials testing cancer drugs. Low-income women and women living in rural areas have difficulty getting to mammography facilities and often do not receive regular screening mammograms. Language barriers and lack of insurance prevent many other women from receiving appropriate treatment for their cancer.

These disparities are not unique to breast cancer and must be addressed if we are to find and deliver the cure to every deserving American. We must provide access to high quality care to every cancer patient. To ensure that research is applicable to both genders and to all ages and racial minorities, the NIH should promote participation in clinical trials by addressing the financial and regulatory barriers that make it challenging for oncologists to offer clinical trials in

their practices, including encouraging inclusion of minorities and other under-represented groups as a condition of reimbursement for clinical trials. To ensure equal access to early detection and screening services, we must continue to educate about the importance of early detection and consistently fund early detection programs and early detection research. To ensure access to high quality treatment of cancer, we should strive toward culturally sensitive and coordinated oncology care. Patient navigation services are one critical component to addressing barriers to quality cancer care, particularly for minority and underserved patients who often do not speak English, have low literacy skills, are uninsured and/or live long distances from treatment centers. These patients have difficulty accessing quality care and have trouble coordinating their cancer care, leading to disjointed treatment, inadequate patient-doctor communication, difficulty with follow-up appointments and poor adherence to treatment regimens. Patient navigators help patients “navigate” the maze of doctors, insurers and patient support groups.

Thank you for this opportunity to testify. I have offered only a few of the many suggestions, changes and improvements we must make to address the nation’s cancer crisis. But on behalf of Komen for the Cure and the many cancer patient advocacy groups who are working tirelessly to find a cure for cancer, let us together meet the challenge of directing our research efforts toward the detection of cancer at its earliest stages when our chances of stopping it are the highest. Komen’s mission is to reduce mortality from breast cancer, but we cannot improve the survival rate from breast cancer, or all cancers for that matter, without investment in early detection of cancer biomarkers. We must devote time, energy and resources to discovering breakthrough, next generation measures for the early detection of cancer and for predicting its behavior before the cancer has spread. We must also continue the promising research on

developing tailored therapies to treat individual advanced cancers that have already spread. Personalized medicine is the cornerstone to successful treatment of cancer. And accurate diagnosis at the earliest possible moment is critical to successful treatment.

A second challenge is to ensure that every cancer patient in America has access to high quality, affordable care that meets the highest standards set by experts and physician societies. It is unconscionable that we cannot guarantee every American access to lifesaving medical care and unacceptable that we have not addressed this issue.

We come here today to respectfully challenge you to join us, along with the rest of the cancer community, to act boldly, comprehensively, across all fronts – research, prevention, early detection, access and treatment – to win the fight against cancer, and with it, save the lives of millions of Americans.