

Statement by Otis Brawley, MD Chief Medical Officer American Cancer Society

Before

The Committee on Energy and Commerce Health Subcommittee United States House of Representatives Wednesday, October 7th, 10:00 a.m. 2123 Rayburn House Office Building

Good morning, Mr. Chairman and distinguished members of the Committee. I am Dr. Otis Brawley, Chief Medical Officer of the American Cancer Society. On behalf of the eleven million cancer patients and survivors in America today, the Society thanks you for your continued leadership in the fight against cancer and commitment to enacting comprehensive health care reform this year. I greatly appreciate the opportunity to testify today on federal initiatives in the United States to help fight breast cancer.

Breast cancer is the most common cancer among women, accounting for nearly one in four cancers diagnosed. This year in the United States, over 192,370 women will be diagnosed with breast cancer and approximately 40,170 women will die from the disease. If every woman in the United States had access to accurate information about the disease, early detection and quality, timely treatment, more women would survive breast cancer. Unfortunately, many women lack access to public health programs and adequate health coverage that provide these life saving services. The consequences are detrimental to their health and can be devastating in terms of their prognosis.

My testimony today will focus on areas that are fundamental for improving breast cancer outcomes in the United States.

Access to Affordable and Adequate Health Insurance

As a practicing oncologist, I see firsthand what lack of adequate health insurance can actually mean. Some of the most disheartening stories are from people who cannot access appropriate health care because of the lack of finances and coverage. Forty-six million people in America are uninsured² and an additional twenty-five million Americans are underinsured³ such that their insurance will not provide affordable cancer screenings and/or adequate coverage if they're diagnosed with cancer.

² DeNavas-Walt, C.B. Proctor, and J. Smith. Income, Poverty, and Health Insurance Coverage in the United States: 2008. U.S. Census Bureau., September 2009.

¹ American Cancer Society. Breast Cancer Facts and Figures 2009-2010.

³ C. Schoen, S. R. Collins, J. L. Kriss, and M. M. Doty, How Many Are Underinsured? Trends Among U.S. Adults, 2003 and 2007, Health Affairs Web Exclusive, June 10, 2008;w298–w309.

Cancer remains one of the most costly medical conditions in the United States. In fact, forty-five percent of women accrued medical debt or reported problems paying medical bills in 2007.⁴ Women with cancer who have inadequate or no coverage have higher medical costs and on top of their diagnoses, must deal with the additional stress of financial instability. A 2006 national survey of cancer patients and their families conducted by the Kaiser Family Foundation found that one in five cancer patients with insurance used all or most of their savings when dealing with the financial cost of cancer.⁴ The situation is even worse among the uninsured. The same survey found that nearly half of uninsured cancer patients used all or most of their savings as a result of their cancer.⁴

We also know that lack of health insurance can be deadly. A recent study by the Society found that uninsured breast cancer patients are more likely to be diagnosed at a later stage of diagnosis and have a lower survival rate than women who are privately insured.⁵ The study revealed consistent associations between insurance status and stage at diagnosis across multiple cancer sites. Far too many cancer patients are being diagnosed too late, when treatment is more difficult, more expensive, and less likely to save lives.

No one should have to choose between saving their life and their life savings. But the current health care system puts many Americans in that terrible predicament. That is why the American Cancer Society (The Society) and its nonprofit, nonpartisan advocacy affiliate, the American Cancer Society Cancer Action Network (ACS CAN), have undertaken a broad, joint initiative to promote access to the full continuum of evidence-based, quality health care necessary to optimize health and well-being for all Americans. Looking through the cancer lens, the Society and ACS CAN are advocating for health system reforms that promote prevention and wellness and ensure quality of life throughout disease-directed treatment and continuing into survivorship and through the end of life. We believe that a health system that works well for cancer patients and survivors and those at risk for cancer will also work well for all Americans who may one day be faced with a serious medical condition.

Continued progress in the fight against cancer requires early diagnosis and timely access to medical care that gives all cancer patients an equal opportunity to battle this disease. To help accomplish this – to achieve a world with less cancer and more birthdays for everyone – health care reform must happen now. The cost of waiting to take action, both financially and in lives lost every year, is just too high.

Access to Prevention and Early Detection

Throughout the country, many women are forced to choose between preventive health care and more routine things, such as paying for food, housing, utilities or even the health

⁴ USA Today, the Kaiser Family Foundation, the Harvard School of Public Health. National survey of households affected by cancer, August 1 – September 14, 2006.

⁵ Halpern MT, Ward EM, Pavluck AL, Schrag NM, Bian J, Chen AY. Association of insurance status and ethnicity with cancer stage at diagnosis for 12 cancer sites: a retrospective analysis. Lancet Oncol. 2008;9(3):222-31

care of their kids and spouses, especially in hard economic times. ACS CAN conducted a national survey in April 2009 to understand how Americans are dealing with health care costs in the current economic environment, whether they are delaying preventive cancer care, and how prepared they may be to deal with an illness like cancer in the future. One in five women surveyed said that they or a family member in their home put off getting a cancer screening test in the past year. Furthermore, nearly one-third of Americans with household incomes less than \$35,000 said they put off potentially lifesaving screenings such as mammograms or colonoscopies.⁶

We are fortunate to have proven programs in place, such as the National Breast and Cervical Cancer Early Detection Program (NBCCEDP), that guarantees access to health care and helps reduce the unequal burden of cancer among low-income and medically underserved women. Through the NBCCEDP, women without health insurance, or with insurance that does not cover these tests, can get breast cancer testing for free or at very little cost. The NBCCEDP attempts to reach as many women in medically underserved communities as possible, including older women and women who are members of racial and ethnic minorities.

Since its establishment in 1991, the program has been implemented in all 50 states, the District of Columbia, four U.S. territories, and 13 American Indian/Alaska Native organizations. It has provided 8 million screening exams to more than 3.3 million medically underserved women. Women who are found to have cancer through the program have access to a Medicaid option that provides cancer treatment.

A new report by the United States Government Accountability Office (GAO) highlights the success of this program, which is the nation's only federal-state cancer screening and treatment program. But the GAO report also reveals that the program is grossly underfunded and thus unable to serve all eligible women. In fact, nationally, the program serves fewer than 15 percent of eligible women aged 40 to 64. The report clearly illustrates the need for comprehensive health care reform so that no woman has to go without critical breast and cervical cancer screenings or treatment because of her income or insurance status.⁷

Other initiatives, like Congressman Jerrold Nadler's Mammogram and MRI Availability Act (H.R. 995), also help increase access to early detection by requiring that insurance companies cover annual screening mammograms and magnetic resonance imaging (MRI) screenings for high-risk women. This bill would ensure that coverage is never a factor in deciding whether to get a screening test for breast cancer.

The Society's guidelines⁸ recommend that certain women with an especially high risk of developing breast cancer should get magnetic resonance imaging (MRI) scans along with

⁶ The American Cancer Society Cancer Action Network (ACS CAN). The Need for Health Care Reform Through the Eyes of Cancer Patients: A National Poll. http://acscan.org/pdf/healthcare/reports/healthcare-cancerpoll.pdf

⁷ United States Government Accountability Office. GAO-09-384: Source of Screening Affects Women's Eligibility for Coverage of Breast and Cervical Cancer Treatment in Some States. May 2009.

⁸ Saslow D, Boetes C, Burke W, Harms S, Leach MO, Lehman CD, Morris E, Pisano E, Schnall M, Sener S, Smith RA, Warner E, Yaffe M, Andrews KS, Russell CA; American Cancer Society Breast Cancer Advisory Group. CA Cancer J Clin. 2007 Mar-Apr;57(2):75-89.

their yearly mammogram. The two tests together give doctors a better chance of finding breast cancer early in these women, when it is easier to treat and the chance of survival is greatest.

The inability of millions of women to access proven preventive services such as breast MRI and mammograms that can help save lives is a failure of our health care system. Breast cancer is one of the few cancers that can be detected early. Without access to these tools, women are at risk of being diagnosed at later stages of the disease after the cancer has spread, when it becomes harder and more expensive to treat and the chance of survival decreases.

These facts illustrate why all Americans should have access to preventive services as part of health care reform. We must transform our current 'sick care' system into one that focuses on prevention and ensures access to the full continuum of quality, affordable care necessary for cancer and other chronic diseases by fully investing in effective programs like the NBCCEDP, and advancing policies that require coverage and remove cost-sharing of evidence-based screening tests that will help reduce barriers to accessing lifesaving screening and treatment.

Bridging the Gap in Program and Services for Young Breast Cancer Patients

An essential part of health care reform is shifting focus to promote health and disease prevention. To achieve this, we need to encourage young adults to take a more active role in their own health and wellness. For example, we should encourage young women to talk to their health care providers about the importance of healthy behaviors that promote wellness, knowing their family cancer history and good breast health habits.

We also need to provide a range of programs to meet the unique needs of young women with breast cancer and their families. Young women with breast cancer identify a variety of health concerns, including: discrimination, a sense of disempowerment, and emotional and psychosocial health issues. At the same time, very little research is currently focused on issues unique to this population of young adults, including their concerns about preserving fertility during and after treatment, genetic predisposition to disease, the impact of hormonal status on the effectiveness of treatment, and late effects of treatment and other long-term survivorship issues.

How young women with breast cancer fare is determined, in part, by their ability to achieve a balance in their life while minimizing health problems. We must provide health care that integrates health promotion strategies that not only promote longevity but enhance quality of life. On behalf of the Society and ACS CAN, we applaud Congresswomen Debbie Wasserman Schultz in facing her breast cancer diagnosis with courage and tenacity, including her introduction of the Early Act (H.R. 1740) a bill that will ensure evidenced-based programs and services are available to help address the unique needs of young women who have breast cancer or who are at risk for breast cancer.

Decreasing Disparities and Improving Quality of Care for Breast Cancer Patients

Excessive breast cancer mortality in minority populations, especially Black women, has long been recognized. The statistics are alarming: Black women are less likely than white women to survive 5 years: 78% vs. 90%, respectively. This difference can be attributed to both later stage at detection and poorer stage-specific survival. Recent studies have shown concerning differences in quality of care provided and treatment practices among certain populations. For example, in a study published last year, we found that Black women experienced longer treatment delays, regardless of stage at diagnosis and were 5 times more likely to experience delays in starting treatment greater than 2 months compared to white women. We also found that for local-regional breast cancer, Black women were significantly less likely to receive surgery (7.5% vs. 1.5% of white women). On the statistic of th

Another study found that use of a less invasive surgical procedure for breast cancer was largely influenced by the patient's age, ethnicity, and insurance status. ¹¹ Sentinal lymph node biopsy is a newer, less extensive procedure in which only a single "sentinel" node in the armpit is removed to determine if the cancer has spread. Not removing the lymph nodes under the arm usually minimizes risks and complications after breast cancer surgery, including the risk of painful arm swelling (lymphedema). Therefore, better outcomes are associated with sentinal lymph node biopsy compared with the alternative, axillary lymph node dissection. In this study, colleagues at the American Cancer Society reviewed information about 491,000 patients with breast cancer who underwent surgical treatment including lymph node sampling between 1998 and 2005. They found that fewer Black women and women who were uninsured were likely to receive the less invasive test compared to white women. ¹⁰

It is important for physicians to actively involve patients in decisions about their care and educate them about their choices. Decisions about length of stay in the hospital to recover from breast surgery or choosing what type of biopsy to perform should be made by patients and their doctors and should not be dictated by patient income, race, or health insurance status. The Society supports the ability of a physician and patient to discuss and decide together what treatments and care is medically necessary and appropriate for the patient. To that end, the Society opposes any effort on the part of a health plan or health insurance organization that seeks to arbitrarily limit patient access to available treatments deemed medically necessary by a physician.

The goal of expanding coverage, which is the purpose of Congresswomen Rosa L. DeLauro's bill, the Breast Cancer Patient Protection Act (H.R. 1691), is a significant step forward to help remedy some of the existing barriers to accessing quality breast cancer care for all women.

¹⁰ Lund MJ, Brawley OP, Ward KC, Young JL, Gabram SS, Eley JW. Parity and disparity in first course treatment of invasive breast cancer. Breast Cancer Res Treat. 2008 Jun;109(3):545-57.

⁹ American Cancer Society. Breast Cancer Facts and Figures 2009-2010.

¹¹ Chen AY, Halpern MT, Schrag NM, Stewart A, Leitch M, Ward E. Disparities and trends in sentinel lymph node biopsy among early-stage breast cancer patients (1998-2005). J Natl Cancer Inst. 2008 Apr 2;100(7):462-74.

Investing in Cancer Research

Researchers are making remarkable progress in every area of breast cancer prevention, early detection, treatment and care – moving discoveries from laboratories to the bedside. Excellent breast cancer research is being done, including thorough programs like the Breast and Ovarian Cancer Family Registries Project at National Cancer Institute (NCI), research from the Office of Research on Women's Health, and the technological advances brought about in part through the Human Genome Project that underlie the Genes, Environment and Health Initiative at the National Institutes of Health (NIH).

Despite all the breast cancer research advances we have seen in early detection and treatment, scientists have not yet discovered a way to prevent breast cancer altogether. Moreover, despite what we know about the importance of early detection for breast cancer, only about 60% of women aged 40 and older have had a mammogram in the last year. Research is also required to better apply what we know about breast cancer early detection in all populations so we can save more lives. Increased funding for NIH and NCI targeted toward these problems would enhance and complement current efforts, and would allow the scientific community across the country to identify gaps in our knowledge, design ways to address those gaps and collaborate on the best research needed to respond.

The stimulus law (American Recovery and Reinvestment Act) provided a good down payment on our nation's public health priorities. However, our continued success in reducing gaps in knowledge in breast cancer is directly tied to our sustained commitment to adequate funding. The Society and ACS CAN strongly support President Obama's goal of doubling cancer research funding at the National Institutes of Health and look forward to working with you in support of high-quality and high-impact cancer research that will advance our mutual goal of ending suffering and death from cancer.

Conclusion

Breast cancer deaths have declined about 2 percent each year in the United States since 1990. If we want to eliminate breast cancer suffering, we need to do more. All women must have access to accurate information, existing and future detection methods and quality treatments so that we can reach a day when breast cancer will no longer steal years of life from our mothers, sisters, daughters, wives and friends. We appreciate the leadership and commitment of the Energy and Commerce Committee in helping achieve this through the work that will be described today and through health care reform.

Thank you once again for inviting me to testify today. The Society and ACS CAN look forward to continuing to work with you as we proceed ahead.

¹² American Cancer Society. Cancer Prevention and Early Detection Facts and Figures 2009.

Appendix: How the American Cancer Society Helps Women with Breast Cancer

The American Cancer Society offers several resource programs for breast cancer patients and their families to guide them through every step of the cancer experience so they can focus on getting well. Some of the resources are described below:

American Cancer Society Nationwide Services

• National Cancer Information Center (1-800-ACS-2345)

Trained cancer information specialists are available 24 hours a day, seven days a week, to offer the comfort of live support and to answer questions about cancer, link callers with resources in their communities, and provide information on local events. Spanish-speaking information specialists are available, and callers who speak languages other than English and Spanish can also be assisted.

• American Cancer Society Web site (www.cancer.org)

This user-friendly Web site includes an interactive cancer resource center containing in-depth information on every major cancer type. The site answers questions about breast and cervical cancer, risk factors, strategies for early detection, new diagnostic techniques, and the latest treatment options. Additionally, select content is available in Spanish.

• Cancer Survivors NetworkSM (www.cancer.org)

This virtual community provides connectivity, anonymity, and accessibility for survivors and their caregivers. The Cancer Survivors Network's online services contain survivor and caregiver content, including radio talk show conversations/interviews, personal stories, personal Web pages, discussion forums, an expressions gallery, and survivor-recommended resources.

American Cancer Society Programs

• Reach to Recovery®

A one-on-one peer support program, Reach to Recovery trains breast cancer survivors to respond to concerns of people who are going through breast cancer diagnosis or treatment. The success of this program is rooted in the idea that women facing breast cancer benefit from receiving health information and support from someone who has been through what they are experiencing.

• "tlc" TM

A "magalog" (magazine and catalogue in one) that provides medical information and special products for women newly diagnosed with breast cancer, breast cancer survivors, and any woman experiencing treatment-related hair loss. This convenient, nationwide catalog is sent directly to homes upon request. Products in "tlc" include a variety of hats, turbans, kerchiefs, hairpieces, mastectomy bras, and breast forms. Silicone prostheses are also offered.

• I Can Cope®

This series of educational classes is for people with cancer and their families and friends. Doctors, nurses, social workers, and other health care professionals provide information about cancer, encouragement, and practical hints through presentations.

American Cancer Society Special Events

• Making Strides Against Breast Cancer®

A nationwide series of noncompetitive walking events, Making Strides Against Breast Cancer is designed to raise funds and awareness to fight breast cancer. In 2008, nearly 600,000 walkers across the country raised more than \$60 million to help the American Cancer Society help fight this disease.

• Relay For Life®

This unique community event celebrates survivorship and raises money for cancer-fighting programs. Teams of eight to 15 people camp out overnight at a local stadium, park, or fairground and take turns walking around a track or path for 12 to 24 hours. The event usually begins with a survivor lap in which cancer survivors take a victory lap around the track. Later, a candlelight ceremony is held to honor cancer survivors and remember those lost to the disease. Relay for Life events are held in more than 5,000 communities across the country.

Collaborative Programs

• Look Good...Feel Better®

This free, national public service program is sponsored by the American Cancer Society, the Cosmetic Toiletry and Fragrance Association Foundation, and the National Cosmetology Association. Look Good...Feel Better is dedicated to teaching female cancer patients beauty techniques to help restore their appearance and self-image during cancer treatments. Services include two-hour group makeover workshops and one-on-one salon consultations. The program also provides educational materials.

Research

• The American Cancer Society's comprehensive research program has four components, all involved with breast cancer research: extramural grants, intramural epidemiology and surveillance, the intramural behavioral research center, and the intramural statistics and evaluation center. Currently, through its extramural research grants program, the American Cancer Society funds 220 extramural research projects relating to breast cancer, totaling nearly \$120 million. These projects include: effectively communicating mammography results

- to underserved women; how differences in the ability to metabolize alcohol influence breast cancer risk; and how a woman's genetic makeup determines her response to treatment.
- The Society's Department of Epidemiology and Surveillance conducts studies of breast cancer, such as the relationship between obesity and breast cancer, and performs surveillance research to monitor long-term trends and statistics. The Behavioral Research Center, through its long-term study of cancer survivors, is studying the unmet needs of breast cancer survivors. The Statistics and Evaluation Center will analyze data provided from all components and from local American Cancer Society programs to ensure that results are evidenced based.

Advocacy

The American Cancer Society and its nonprofit, nonpartisan advocacy affiliate, the American Cancer Society Cancer Action NetworkSM (ACS CAN), are involved in advocacy efforts at both the federal and state levels that seek to increase access to quality breast cancer screenings, diagnostic services and treatment, and care for all women; increase government funding for breast cancer research; and be a voice for the concerns of breast cancer patients and survivors.

- ACS CAN works with state advocacy and media advocacy staff to ensure they have the most updated information, research, and news on federal cancer issues. ACS CAN organizes an annual National Lobby Day for Society volunteer advocates and staff in Washington, D.C. and schedules meetings for advocates with their Members of Congress or their staff. Additionally, the One Voice Against Cancer Coalition (OVAC) was established in 2000. OVAC is a coalition of nearly 40 cancer-related advocacy groups supporting cancer program funding at the National Cancer Institute, National Center on Minority Health and Health Disparities, National Institute of Health, Centers for Disease Control and Prevention, and Health Resources and Services Administration.
- State government relations and advocacy departments educate and mobilize state advocates to take action on policy issues at the local, state, and federal levels. Volunteers participate in organized one-on-one visits with lawmakers, special advocacy and media events, call-to-action issue alerts, and other modes of communicating to and with lawmakers, like letters to the editor to apply pressure on cancer issues such as state funding for the Breast and Cervical Cancer programs and Medicaid which provides treatment for women served through these programs.