House Committee on Ways and Means

Statement of Nancy G. Brinker, Statement

Testimony Before the Full Committee
of the House Committee on Ways and Means

June 24, 2009

Statement of Nancy G. Brinker

Testimony Highlights

- The Susan G. Komen for the Cure Advocacy Alliance appreciates the Committee's focus on prevention, early detection and chronic disease management, as well as the goal of access to affordable, high-quality health coverage for all, including those with preexisting conditions.
- There are two key access issues we recommend adding to the draft legislation: extending access to **patient navigation** services to help guide patients through the complex health care system, and ensuring access to **clinical trials**.
- As the House of Representatives finalizes legislation to reform the nation's health care system, Members are asked to consider the unique needs of persons who are fighting or who have faced a disease like cancer, because they encounter the most challenging obstacles in the current U.S. health care system.

Introduction

Mr. Chairman, Ranking Member and Members of the Committee, the Susan G. Komen for the Cure® Advocacy Alliance appreciates your attention to prevention, early detection and chronic disease management in the health care reform draft proposal released earlier this month. We support your goal of ensuring access to affordable, high-quality health care for all Americans, including people who are currently deemed uninsurable because they have a preexisting condition like cancer.

Komen Advocacy Alliance's Principles for Health Reform

The Komen Advocacy Alliance is the nonpartisan voice for more than 2.5 million breast cancer survivors and the people who love them. Our mission is to translate the Komen promise to end breast cancer forever into action at all levels of government to discover and deliver the cures. Cancer patients and survivors have some of the most challenging experiences with the health care system at a time in their lives when they are most vulnerable. Thus, the Susan G. Komen for the Cure® Advocacy Alliance believes that health reform must:

- Increase investment in federal and state programs for underserved patients
- Protect cancer patients from excessive out-of-pocket costs
- Ensure access to affordable, high-quality insurance for all, including those with pre-existing conditions
- Enhance quality and value by focusing on prevention, wellness, and chronic disease management
- Address the shortage of cancer care specialists

Additional Issues to be Considered

The health care reform draft proposal addresses many of these priorities. However, there are two additional issues that should be included in the bill: extending access to patient navigation services to help guide patients through the complex health care system, and ensuring access to clinical trials.

Patient Navigation Services: We recommend that the Committee reauthorize and fully fund the Patient Navigator Outreach and Chronic Disease Prevention Act of 2005 (PL 109-18) for five years, FY2011 through FY2015. Current authorization expires at the end of FY2010. Komen recommends enhancement of the original Act by adding minimum core proficiency standards for patient navigators.

- Navigating the complex health care system can be an insurmountable task for patients facing a complicated or chronic disease, especially if they are underserved, have a lower level of medical literacy, or do not speak or read English well. Patient navigators are trained to serve as personal guides and help people overcome obstacles to receiving timely cancer treatment and care. This includes obtaining financial resources, tracking appointments and coordinating transportation.
- Patient navigation is a proven concept that is cost-effective, promotes prevention, saves lives, and addresses health disparities.
- Minimum core proficiency standards are vital because effective patient navigators should be culturally competent, good communicators, compassionate, and experts at navigating the health care system.
- The program should be fully funded; between FY2006 and the current FY2009, the Patient Navigator Act received only about $2.4 million (in FY2008) of the $25 million that was originally authorized.
- There is significant support for the Patient Navigator program in the cancer community, and it is widely applicable to other chronic diseases.

Access to Clinical Trials: Part of ensuring access to cancer care includes access to clinical trials. Barriers to clinical trials must be removed for all patients — including cancer patients — without regard to the type of health insurance plan or health status. This can be accomplished by 1) a codification in law of Medicare's current reimbursement policy for routine expenses for patients in approved clinical trials, and 2) making needed changes to ERISA, the Public Health Service Act and the Internal Revenue Code to accomplish the same policy for private insurance plans.

- Each year, thousands of people gain access to the highest-quality cancer care and receive new treatments before they are widely available by participating in a clinical trial. Millions more benefit from the findings. Yet, while more than 1.4 million Americans are diagnosed with cancer each year, fewer than 5 percent will participate in an approved clinical trial.
- Some health insurance companies do not cover routine medical care expenses for patients enrolled in approved clinical trials, or refuse to cover complications that sometimes occur during the course of an approved clinical trial. Failure to cover these items may mean otherwise eligible people are turned away, or are exposed to high out-of-pocket costs when they encounter complications.
- These issues could be addressed by including language from the "Access to Cancer Clinical Trials Act" (S.488) by Senator Sherrod Brown (D-OH).

Attached to this testimony are more detailed comments on the health reform draft proposal, including the importance of patient navigation and clinical trials, as well as the need for a continued

focus on prevention, wellness, chronic disease management and access to care for underserved populations.

Susan G. Komen for the Cure Advocacy Alliance

Comments on the Health Reform Draft Proposal

Committee on Ways & Means

United States House of Representatives

As your Committee continues deliberations on reforms to the nation's health care system, we urge you to consider the unique needs and challenges of people with pre-existing conditions like cancer. Cancer patients and survivors have some of the most challenging experiences with the health care system at a time in their lives when they are most vulnerable. Thus, the Susan G. Komen for the Cure® Advocacy Alliance calls on your Committee to:

- Increase the investment in federal and state programs that provide cancer screening, treatment and patient navigation services for underserved populations.
- Protect cancer patients who have health insurance from excessive out-of-pocket costs that may lead to severe financial hardship and even bankruptcy.
- Ensure access to affordable, high-quality health insurance for all, including people with "pre-existing" conditions like cancer — so everyone can continue to have health insurance, even if they lose or change jobs.
- Enhance the quality and value of health care by focusing on prevention, wellness and chronic disease management.
- Address the chronic shortage of cancer care specialists, particularly in underserved areas.

1. Increase the investment in federal and state programs that provide cancer screening, treatment and patient navigation services for underserved populations.

PROBLEM: Almost 46 million Americans lack health insurance.[1] Without reforms, the number is projected to climb another 7 million or more by 2010, due in part to rising health costs and high unemployment.[2] Lack of adequate health insurance has a decidedly negative effect on cancer screening rates, as well as the stage at diagnosis and a person's chances of survival:[3]

- Patients with private insurance are more likely to be diagnosed at earlier stages, and are more likely to survive at all stages of diagnosis than the uninsured.
- Cancer patients who are uninsured — and those who were Medicaid-insured at time of diagnosis — are 60 percent more likely to die in 5 years than those with private insurance.
- In addition, disparities in cancer incidence and mortality rates must be addressed. For example, those with lower socio-economic status and people in underserved areas are more likely to be diagnosed and are more likely to die from cancer.[4]

As the ranks of the uninsured swell, demand grows for public health programs, including programs that provide cancer screening and cancer care services. Unfortunately, federal and state safety net programs are dramatically underfunded, leaving huge gaps for the neediest Americans. For example:

- The National Breast and Cervical Cancer Early Detection Program (NBCCEDP) provides potentially life-saving cancer outreach, case management, and screening to low-income,

uninsured and underinsured women. Yet, the program is so underfunded it is only able to reach less than one in five eligible women.[5] The program is increasingly forced to turn women away or establish waiting lists for these vital services.

- All states allow underserved women to access Medicaid for breast or cervical cancer treatment if they are uninsured, need treatment for breast and cervical cancer, and meet other eligibility criteria. However, 20 states only allow this access to Medicaid if the woman's screening is funded by the state or tribal screening program — a large concern given the dramatic underfunding of those programs.[6]
- Navigating the complex health care system can be an insurmountable task for many patients facing a complicated or chronic disease, especially when they are underserved, have a lower level of medical literacy, or do not speak or read English well. To address this, Congress passed the Patient Navigation Act, a pilot grant program to provide patient navigation services to those in need. Unfortunately, the Patient Navigation Act has received only a small portion of the $25 million that was originally authorized.

SOLUTIONS: As Congress overhauls the health care system, it must close the gaps plaguing federal and state safety net programs that provide vital cancer screening, treatment and patient navigation services for our nation's underserved populations.

2. Protect cancer patients who have health insurance from excessive out-of-pocket costs that may lead to severe financial hardship and even bankruptcy.

PROBLEM: Having health insurance does not necessarily protect a person from financial harm in the event of a health event like a cancer diagnosis:

- A recent survey of employer-sponsored health insurance plans shows employees' out-of-pocket spending grew more than a third between 2004 and 2007, while wages remained stagnant.[7]
- The exposure to high costs can be disastrous. A recent study by Harvard University found that half of all bankruptcy filings were partly the result of medical expenses, and 68 percent of those who filed for bankruptcy had health insurance.[8]
- A national survey commissioned by the American Cancer Society Cancer Action Network shows one in five cancer patients has significantly or completely depleted their savings because of medical costs — one in seven has incurred thousands of dollars in medical debt.[9]

Many health insurance policies have annual and lifetime caps on benefits or other limitations and exclusions. Patients may be exposed to large out-of-pocket expenditures because cancer treatments can be very expensive — some therapies run hundreds of thousands of dollars a year and may require extensive and long-term monitoring and follow up.

SOLUTIONS: Congress should protect patients from high out-of-pocket costs by reducing or eliminating annual or lifetime limits on the benefits, and possibly by establishing an annual maximum limit on out-of-pocket medical expenditures.

3. Ensure access to affordable, high-quality health insurance for all, including people with "pre-existing" conditions like cancer — so everyone can continue to have health insurance, even if they lose or change jobs.

PROBLEMS: For the 161 million Americans with employer-provided health insurance, a change in employment also likely means a new health insurance company with different benefits and

network providers. But persons with pre-existing conditions like cancer may run into challenges: [10]

- Cancer patients and survivors with employer-provided health insurance may lose jobs, change jobs, or have to cut back hours or leave a job during treatment — and lose their group health insurance.
- As a result, cancer patients or survivors may experience "job lock," in which they cannot leave their current job for fear of losing their health insurance. This runs counter to the trend of today's mobile workforce, in which people frequently move from job to job in pursuit of new opportunities.
- Even cancer survivors who have been in remission for years with a good long-term prognosis have trouble finding coverage in the individual market because of medical underwriting and the existence of their pre-existing condition.

Clinical Trials: Part of ensuring access to cancer care includes access to clinical trials.

- Each year, thousands of people gain access to the highest-quality cancer care and receive new treatments before they are widely available by participating in a clinical trial. Millions more benefit from the findings. Yet, while more than 1.4 million Americans are diagnosed with cancer each year, fewer than 5 percent will participate in an approved clinical trial.[11]
- Some health insurance companies do not cover routine medical care expenses for patients enrolled in approved clinical trials — or refuse to cover extra scans, doctor visits and drugs to address complications that occur during the course of an approved clinical trial.

SOLUTIONS: Congress should require health insurance companies to provide coverage to all, with no pre-existing condition limitations. In addition, barriers to clinical trials must be removed for all patients — including cancer patients — without regard to the type of health insurance plan. This can be accomplished by 1) a codification in law of Medicare's current reimbursement policy for routine expenses for patients in approved clinical trials, and 2) making needed changes to ERISA, the Public Health Service Act and the Internal Revenue Code to accomplish the same policy for private insurance plans. The issues related to clinical trials could be addressed by including language from the "Access to Cancer Clinical Trials Act" (S.488) by Senator Sherrod Brown (D-OH).

4. Enhance the quality and value of health care by focusing on prevention, wellness and chronic disease management.

PROBLEM: The U.S. health care system often focuses too much attention on treating people once they become sick, and not enough attention on keeping people healthy or detecting chronic diseases like cancer early, when there are more treatment options and the chances of survival are often greater.

Prevention, Early Detection & Wellness: Prevention saves lives. Applying proven tobacco control strategies could eliminate a third of all cancer deaths.[12] Cancers related to obesity, physical inactivity and poor nutrition could also be prevented. And many of the more than 1 million skin cancers that are expected to be diagnosed in 2009 could be prevented by protection from the sun's rays and avoiding indoor tanning.

For other cancers, early detection is the key to survival. Regular screenings can detect cancers of the cervix, colon and rectum by detecting precancerous growths that can be removed, and can detect

breast, colon, rectum, cervix, prostate, oral and skin cancers at early stages when they are most treatable.

- For breast cancer, the 5-year relative survival rate is 98 percent when breast cancer is detected at an early stage, 84 percent for regional disease and 27 percent for distant-stage disease.[13]
- Yet, for women who are uninsured and underinsured, cost is a significant barrier to getting preventative care — only 67 percent of underinsured women over the age of 50 received a mammogram in the past two years, compared with 85 percent of adequately insured women.[14]
- For women with health insurance or Medicare, even a relatively small co-payment can significantly reduce mammography rates, particularly for underserved populations.[15]

Clinical Effectiveness: Komen supports the use of clinical effectiveness research (CER), which will arm patients and their doctors with the best available information on effectiveness and safety of drugs, devices and diagnostic tests. To that end, a comprehensive national comparative effectiveness research program should better identify the most effective health care options, and ensure information gained through CER is incorporated into clinical practice to better inform decisions made among patients, their health care providers and payers. A CER program should also link data from public and private entities to build upon existing data collection and research capabilities and support the development of "personalized" or stratified medicine.

Coordination of Care and Survivorship Care Planning: A key aspect of chronic disease management is the coordination of care. To that end, cancer patients should have a coordinated plan for treatment and follow-up from the time they are diagnosed through the years of their survivorship. With a written cancer plan and the opportunity to review it in person with their doctor, cancer patients will better understand the process ahead, monitor their health, and participate in decisions about their care. And a written plan will help coordinate care among a patient's many doctors and providers, reduce medical errors, and ultimately improve patient care.

SOLUTIONS: Congress should reduce or eliminate copayments or deductibles for preventative services like diagnostic imaging and screening, and should provide incentives for providers to focus on prevention, wellness and chronic disease management.

5. Address the chronic shortage of cancer care specialists, particularly in underserved areas.

PROBLEM: There is a shortage of cancer care specialists, particularly in underserved areas. This shortage will only intensify as the population ages, which will bring along with it a significant increase in the number of cancer cases each year. Congress clearly recognizes this is an issue. The economic stimulus package passed earlier this year included billions for community health centers, training for the health care workforce and an investment in health information technology.

The promotion of a robust health information technology network could also help alleviate the shortage of cancer care experts, particularly in rural areas. Electronic medical records will ultimately improve health care quality for cancer patients by improving coordination of care. And it also allows for second opinions and reviews of patient records from anywhere in the world.

SOLUTIONS: Congress should include provisions to strengthen the health care workforce by forgiving student loans, providing grants to increase faculty in nursing programs, providing financial incentives to encourage health care professionals to practice in underserved areas, and

investing in health information technology. Congress should also encourage partnerships between community hospitals and large cancer centers.[16]

---

[1] U.S. Census Bureau, "Income, Poverty, and Health Insurance Coverage in the United States: 2007," August 2008. Available online: http://www.census.gov/prod/2008pubs/p60-235.pdf.

[2] Todd Gilmer and Richard Kronick, "Hard Times And Health Insurance: How Many Americans Will Be Uninsured by 2010?," Health Affairs, Web Exclusive, w573-577, May 28, 2009.

[3] Elizabeth Ward, et al., "Association of Insurance with Cancer Care Utilization and Outcomes," CA: A Cancer Journal for Clinicians, Vol. 58, No. 1, January/February 2008, p.9-31.

[4] American Cancer Society, "Cancer Facts & Figures 2009."

[5] See the Center for Disease Control's website for the National Breast and Cervical Cancer Early Detection Program. Available online at: http://www.cdc.gov/cancer/NBCCEDP/.

[6] Tally of states based on M&R Strategic Services, "Treatment Act Survey: Final Report," February 16, 2007, updated based on the experience of Susan G. Komen for the Cure Advocacy Alliance. The Treatment Act is the subject of a forthcoming report by the Government Accountability Office, which Komen helped initiate.

[7] John Gabel, et al., "Trends In Underinsurance And The Affordability of Employer Coverage, 2004-2007, *Health Affairs Web Exclusive*, w595, June 2, 2009.

[8] Himmelstein, et al., "Illness and Injury as Contributors to Bankruptcy," *Health Affairs Web Exclusive,* w563, Febrary 2, 2005.

[9] Lake Research Partners and American Viewport conducted the survey, which was sponsored by the American Cancer Society Cancer Action Network, May 1 through 11, 2009, among a national sample of 1,057 adults age 18 and older, in households with cancer or a history of cancer. Available online: http://www.acscan.org/pdf/healthcare/reports/poll-05202009.pdf.

[10] Karen Schwartz, et al., "Spending to Survive: Cancer Patients Confront Holes in the Health Insurance System," Kaiser Family Foundation and the American Cancer Society, February 2009. Also see the Lake Research Partners and American Viewport survey.

[11] American Cancer Society.

[12] American Cancer Society.

[13] American Cancer Society, *Breast Cancer Facts & Figures 2007-2008*, Atlanta: American Cancer Society, Inc. (Available online at http://www.cancer.org/downloads/STT/BCFF-Final.pdf).

[14] Sheila Rustgi, et al., "Women at Risk: Why Many Women are Forgoing Needed Health Care," The Commonwealth Fund, Issue Brief, May 2009. (Available online: http://www.commonwealthfund.org/content/publications/issue-briefs/2009/may/women-at-risk.aspx.)

[15] Amal N. Trivedi, et al., "Effect of Cost Sharing on Screening Mammography in Medicare Health Plans," *The New England Journal of Medicine*, Vol. 358, January 24, 2008, pp. 375-383. (Available online: http://content.nejm.org/cgi/content/full/358/4/375). The study examined 174 Medicare managed-care plans from 2001 through 2004, which included 550,082 individual-level observations for 366,475 women between the ages of 65 and 69 years.

[16] Congress could consider building on the NCI's Community Cancer Centers Program, which is a pilot program to provide private medical surgical and radiation oncologists with close links to NCI research and the network of 63 NCI-designated Cancer Centers principally based at large universities. http://ncccp.cancer.gov/