Committee on Oversight and Government Reform

U.S. House of Representatives

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 Center for Disease Control and Prevention's National Breast and Cervical Cancer Early Detection Program. My name is Shelley Fuld Nasso, and I am the Director of Public Policy for the Susan G. Komen for the Cure Advocacy Alliance.

Komen Background/History

Nancy G. Brinker promised her dying sister, Susan G. Komen, 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 in the next ten years. With awards of more than $77 million in research grants last year alone, Komen for the Cure is on track to award another $100 million this year.

Through the newly formed sister organization, the Susan G. Komen for the Cure Advocacy Alliance — a tax-exempt, 501(c)(4) nonpartisan organization — 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 breast cancer research and greater access to cancer screening and treatment, and expand on the long history of Komen for the Cure's commitment to saving lives through public policy advocacy. Komen has long been a champion of the National Breast and Cervical Cancer Early Detection Program (NBCCEDP), and we successfully advocated the program's reauthorization last year.

Overview of NBCCEDP Program and Its Operation

The Breast and Cervical Cancer Mortality Prevention Act of 1990[1] established the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) under the Centers for Disease Control and Prevention (CDC). The program is designed to reach underserved women to provide screening services for breast and cervical cancer as well as appropriate referrals for treatment and support services as necessary. In addition to clinical services, NBCCEDP programs develop and disseminate public information about the importance of screening, improve the education, training and skills of health professionals in the detection of breast and cervical cancer, engage in outreach efforts to serve as many eligible women as possible, monitor and evaluate the program, including the quality of screening services, and report certain data to CDC.

The heart of the program is to provide screening services to low-income, uninsured, and underinsured women aged 18 to 64 with incomes under 250 percent of the federal poverty level. The women served are often in at-risk populations and those least likely to be screened. According to the CDC, since 1991, the NBCCEDP has served more than 3 million women by providing more than 7.2 million screening examinations, and diagnosing 30,963 breast cancers, 1,934 invasive cervical cancers,

[1] Pub. Law No. 101-354 (1990).

and 101,624 precursor cervical lesions.[2] In Fiscal Year 2006 alone, state NBCCEDP programs screened 380,719 women for breast cancer and 367,200 women for cervical cancer. The programs diagnosed 4,013 breast cancers and 5,162 cervical cancers potentially saving these women's lives.[3] CDC receives an appropriation from Congress, which the agency then awards to states in the form of grants to establish state screening programs. Federal grants are matched $3 to $1 by state dollars, and many programs receive additional private funding or in-kind contributions as well. States can count private and in-kind contributions toward their matching requirement. Through its network of 125 local Affiliates, Komen for the Cure leverages federal and state funding to expand the reach of the program. Currently, all 50 states, the District of Columbia, 4 U.S. territories, and 13 American Indian/Alaska Native tribes or tribal organizations receive grants from CDC and have established screening programs. Finally, programs are required to spend at least 60 percent of their federal grant money on screening and referral services, no more than 40 percent of federal money on education and outreach efforts, and no more than 10 percent on administrative costs. In the 2007 NBCCEDP reauthorization, a provision allowed CDC to consider applications to waive the 60/40 screening/education split for up to five states for up to two years.[4]

Since 2000, states have also been given the option to extend Medicaid coverage for the duration of the breast or cervical cancer treatment to certain eligible women screened through the state NBCCEDP program.[5] Despite the success of this treatment option, unacceptable gaps in treatment for women remain, as explained below. Again, every state and the District of Columbia have implemented the Medicaid option, allowing women new avenues for treatment after being diagnosed with breast or cervical cancer.

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[2] CDC Overview of NBCCEDP Program, *available at* http://www.cdc.gov/cancer/NBCCEDP/about.htm.

[3] *Id.*

[4] National Breast and Cervical Cancer Early Detection Program Reauthorization Act of 2007, Pub. Law No. 110-18 (2007).

[5] National Breast and Cervical Cancer Prevention and Treatment Act, Pub. Law No. 106-354 (2000).

The NBCCEDP Program is Invaluable to the Women it Serves…

The NBCCEDP program is an invaluable service to women who are served by the program. There is no cure for breast cancer, a disease which takes an estimated 40,000 women's lives in the United States – women who are mothers, sisters, wives, daughters, and friends. Without a cure, early detection and treatment is key to survival. Timely mammography screening of women over age 40 could prevent 15 to 30 percent of all deaths from breast cancer. When breast cancer is detected early, while still confined to the breast, the five-year survival rate is more than 98 percent. Yet many low-income and minority women lack access to health coverage for breast cancer screening and treatment services, and are more likely to die from breast cancer. A woman's chance to survive the disease must not be dictated by the color of her skin, how much she earns or where she lives.

The Komen Community Challenge is a nationwide grassroots campaign to restore the sense of urgency to the breast cancer movement and Close the Gaps that make breast cancer deadlier for low-income women, women of color and those with little or no health insurance. Since last spring, we have visited 19 cities, where survivors whose breast cancer was detected through the NBCCEDP have spoken out and shared their stories of survival. All of these women acknowledge that without the life-saving services of the NBCCEDP, they may not have been able to survive the disease. Here are a few stories:

- **Deborah Catanese of Burbank, California.** Deborah Catanese returned to college in her 40s to get a journalism degree and begin a second career. When Deborah found a lump in her breast, she went to the campus clinic and was told she needed a biopsy. Deborah did not know how she could afford one because she was working part-time and was without health insurance. After some research, Deborah found California's Every Woman Counts screening program. She was quickly diagnosed, enrolled in Medi-Cal and started chemotherapy. A year after her mastectomy, Deborah is working as a writer and getting her life back together. She credits the Every Woman Counts program with saving her life.

- **Wanda Williams of Raleigh, North Carolina.** Wanda Williams worked full-time as a hair stylist but could not afford health insurance. In 2004, a medical ministry referred her to the North Carolina Breast and Cervical Cancer Control Program. Wanda's mammogram revealed tiny calcifications that she would not have been able to detect through self-exams. After her successful lumpectomy, Wanda said, "I was able to smile everyday during treatment, knowing I wasn't alone. I was grateful, knowing my life had been saved and I lived."

- **Theresa Racine of Harlem, New York.** Theresa Racine juggled three jobs, including teaching aerobics six times a week, but could not afford health insurance. Even so, the self-described "health nut," exercised, ate right and was proactive about getting annual mammograms through New York's Cancer Services Partnership. When a regular screening showed that Theresa had breast cancer, she was shocked -- she never even got colds. Luckily, Theresa got the treatment she needed free of charge through the Partnership at New York-Presbyterian/Columbia Hospital. The program continues to cover the costs of Theresa's care now that she is cancer free, including Tamoxifen (which helps to prevent recurrences).

- **Brenda Schnelle of Foreman, Arkansas.** Brenda Schnelle was a barber for 37 years. She had health insurance through her job -- until her boss's wife forgot to pay the premiums. Just after that, Brenda was diagnosed with breast cancer. She could not work and was not getting paid. Fortunately, Brenda found BreastCare, Arkansas' breast cancer screening and treatment program for low-income and under/uninsured women. With help from BreastCare, Brenda got the treatment that saved her life. She believes she received excellent care and hopes that other women will have the same chance to survive.

…Though Improvements Could Be Made.

However, despite the incredible successes of the program, improvements still could be made to the NBCCEDP that would greatly benefit the women it serves and expand the reach of the program.

(1) Lack of funding prevents NBCCEDP programs from reaching many eligible women.

From a high of $210 million in FY2004, funding for the NBCCEDP has either declined or remained essentially flat for the subsequent years. In FY2008, the program received only approximately $200 million, despite an authorization level of $225 million. CDC granted nearly $160 million to the states. Programs are severely strained by the lack of adequate resources— only 14.7 percent of eligible women were screened for breast cancer and only 6.7 percent of eligible women were screened for cervical cancer in 2006. Komen Affiliates have reported similar situations in their states: Programs run out of money mid-way through the year and are forced to suspend screening and referral services; states are forced to implement months-long waiting lists, which can cost women critical time in treatment; and programs do not have enough money to engage in outreach to hard-to-reach, vulnerable populations. While programs supplement federal grants with state and private money, it is not enough to reach all eligible women.

In addition to consistent level or reduced funding over the last four years, an increasing allocation for the Well–Integrated Screening and Evaluation for Women Across the Nation (WISEWOMAN) program, also run through CDC, means fewer dollars are available for breast and cervical cancer screening. WISEWOMAN is a CDC grant program to states primarily dedicated to providing low-income, uninsured, and underinsured women ages 40 to 64 with screening services and lifestyle interventions to prevent or control cardiovascular disease. WISEWOMAN and NBCCEDP serve similar populations of women and are under the same line-item appropriation for CDC. While cardiovascular disease is a devastating public health threat, Komen is concerned that further reducing NBCCEDP funding to shore up WISEWOMAN will only compound the problems states already face in screening eligible women for breast and cervical cancer. Increases for the WISEWOMAN program should not come at the expense of the NBCCEDP.

(2) Disparities in Care—the NBCCEDP must reach more African American, Hispanic, and rural women.

A second concern for Komen is the documented disparities in screening and care. According to the CDC, from July 2001 through June 2006, 40 percent of women screened through NBCCEDP programs were white, 14 percent were African American, and 34 percent were Hispanic.[6] Last spring, Komen for the Cure worked with Dr. Harold Freeman on the Breast Cancer Mortality Report, which examined eight communities with the highest breast cancer mortality rates in the country.[7] In Chicago, although breast cancer death rates have decreased in Caucasian women, many more African American women in the city are dying from breast cancer. In fact, the breast cancer mortality rate in Chicago is 68 percent higher for African American women than for Caucasian women — 24 in 100,000 white women

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[6] CDC, The National Breast and Cervical Cancer Early Detection Program: 1991–2002 National Report, *available at* http://www.cdc.gov/cancer/NBCCEDP/bccpdfs/national_report.pdf.

[7] Susan G. Komen for the Cure, Breast Cancer Mortality Report: Closing the Gaps in Eight Communities, *available at* http://www.komen.org.

die from breast cancer, versus 40 in 100,000 for African American women. Similarly unacceptable disparities in mortality exist in Washington, D.C., and Madison County, Mississippi.

As discussed in Komen for the Cure's State of Breast Cancer Report, many factors contribute to the disparities in care. Komen believes that the high mortality rates for African American women are due in part to lack of access to early detection programs, including the NBCCEDP. Barriers to screening, such as poverty, cultural issues and beliefs, lack of awareness about early detection programs and the benefit of screening, and geography (many women have to travel long distances to access screening services) contribute to disparities in care and mortality rates.

(3) Referrals to treatment work well for those screened through the NBCCEDP program, but gaps in treatment exist.

As of 2000, under the National Breast and Cervical Cancer Prevention and Treatment Act, states have the option to extend Medicaid coverage for breast/cervical cancer treatment to eligible women screened through the NBCCEDP program. The case management system implemented under the NBCCEDP appears to work well in most states in getting women who were screened through the NBCCEDP into Medicaid for their treatment. Case managers also follow women through treatment and monitor progress. However, the Treatment Act requires that women be "screened under the NBCCEDP" as a condition of eligibility for Medicaid treatment. States also have the option to expand eligibility for Medicaid treatment. Some states allow women screened through any provider to be eligible for Medicaid treatment, while others take a very restrictive view and allow only those screened through state NBCCEDP programs to be eligible. Komen surveyed program directors and found that 21 states have implemented the most restrictive approach, leaving women who are screened by non-NBCCEDP funded providers without the Medicaid treatment option (and often with no treatment option). Because, as noted above, only a very small percentage of eligible women are screened through NBCCEDP programs, the gap in treatment is particularly severe. One option to close this gap is additional funding for NBCCEDP programs to allow states to screen more eligible women. Komen supports a study by the Government Accountability Office (GAO) to explore additional options.

(4) Digital Mammography

X-ray images of the breast are either captured on film (standard mammography) or stored directly onto a computer (digital mammography). It appears film and digital mammography are similar in their ability to detect cancer for the population as a whole. However, studies suggest digital mammography is a more accurate screening tool for some women, including women younger than 50, women who have dense breasts, and women who are pre- or peri-menopausal (meaning that they have had at least one menstrual period within the last year).[8] Digital mammography also offers the advantage that images can be stored and retrieved easily, as well as transmitted electronically to facilitate review by multiple radiologists. However, digital mammography is more costly than film mammography and may not be any more accurate for women who do not fall into one of the above categories.

Despite the higher cost of providing digital mammograms, the NBCCEDP reimburses for digital mammography at the rate for standard mammography. Many providers are unwilling to perform digital mammography at the lower reimbursement rates, and are opting out of the NBCCEDP program. This presents barriers to access for women in some areas of the country. The use of digital mammography is spreading rapidly. As the marketplace evolves and the technology become commonplace, the NBCCEDP will fall behind the times. While we do not have data on the percentage of U.S. markets that only have digital mammography providers, anecdotally we have heard from Komen Affiliates across the country that increasingly, film mammography is not available in their communities. Komen for the Cure believes that digital mammography should be covered in order to ensure access to screening for uninsured and underinsured women. An important caveat: because digital mammography is more expensive than film mammography, if the NBCCEDP begins covering digital mammography without additional funding, then fewer women will be screened.

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[8] Pisano ED,Gatsonis C, Hendrick E, et al., for the Digital Mammographic Imaging Screening Trial (DMIST) Investigators Group. Diagnostic performance of digital versus film mammography for breast-cancer screening. *N Engl J Med.* 2005;353:1773-1783.

(5) Decline in Mammography Rates, Importance of Outreach

Last year, a report by the CDC and NCI showed that almost a million fewer women in the U.S. had mammograms in 2005 than in 2000.[9] What's more, women who have traditionally used mammography at high rates, including women with higher incomes, more education, and access to private insurance, are getting screened less often. There are many possible explanations for this downward trend, as well as the fact that more than one in four women in the U.S. age 40 and older still do not receive regular mammograms. In the State of Breast Cancer report, Komen outlined some of the possible reasons. In addition to poverty and insufficient funding for the NBCCEDP, other factors include: cultural issues and beliefs and practical barriers such as being able to get time off from work, lack of child care, and lack of transportation. Geography is a factor for women living in both rural and urban areas. In rural areas, women may have to drive an hour or more to get to a screening facility. Even in large cities, long distances from affordable facilities or from public transportation may discourage low-income women from getting screened. Misperceptions and lack of awareness also play a role, as some women believe they are not at risk or are unaware of the importance of early detection. Finally, recent declines in cancer-related deaths may lead to a false sense of security that breast cancer is not a major concern.

We want to understand these perceptions and misperceptions more clearly, which is why we recently made a grant to the CDC to fund a study that will examine women's knowledge, attitudes, and beliefs about breast cancer screening, especially mammography. The series of focus groups will include women who adhere to screening guidelines, those who do not adhere, and those who have never been screened. This study will inform interventions to improve regular screening and will help us develop media campaigns and messages to increase regular mammography screening.

It is these cultural beliefs, misperceptions, lack of awareness, and false sense of security that make outreach and education such an important component of the NBCCEDP. To complement the 2007

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[9] U.S. Centers for Disease Control and Prevention. Use of mammograms among women aged $\geq$ 40 years – United States, 200-2005. *MMWR*. 2007;56:49-51.

Breast Cancer Mortality Report, Komen produced a video that profiles women in two of the communities studied. At age 46, Nancy Lewis of Madison County, Mississippi, refused to have a mammogram, despite losing her mother and three sisters to breast cancer. She said, "If I had breast cancer, I really wouldn't want to know." Dorothy Julius, who conducts outreach for the G.A. Carmichael Clinic in Canton, Mississippi, through a Komen-funded program, worked on Ms. Lewis for six months, mainly at church, to convince her to get a mammogram. Finally, Ms. Lewis did get a mammogram and was relieved to have a normal result. The common refrain of "I don't want to know" underscores the critical need for outreach. Despite all of the educational efforts of many government and advocacy organizations, many women either do not know that they can get a low-cost mammogram or are afraid to find out the results. Program staff report unique methods of reaching women: at hair salons, Parent Teacher Organizations (PTO) meetings at schools, and street fairs – anywhere their message can be heard. They are even known to go door-to-door, visit patients' homes, and make multiple follow-up and reminder calls to spread the message and ensure patients' adherence to scheduled appointments and follow-up care.

These critical outreach and education activities are part of the 40 percent cap on outreach, education, and administration costs. While Komen supports screening as many women as possible, which is the intent of the 60 percent requirement for screening dollars, the reality is that in order to reach women who are underserved or not frequently screened, outreach is critical. While in many states, women are being turned away due to lack of funding, there are many, many other women who need the program but do not even know about it. In some states, the 60/40 requirement does not allow for the needed outreach and advertising. In some cases, Komen Affiliates help to provide these critical dollars.

Public/Private Partnership – Komen Grants and Advocacy

With the belief that the NBCCEDP and state programs should be a true public/private partnership, Komen for the Cure leverages federal and state funds by contributing additional resources in local communities. Last year alone, local Komen Affiliates provided more than $70 million for screening, education, outreach, case management and treatment services in communities around the

country. Since the NBCCEDP covers fewer than one in five eligible women, Komen is doing its part to fill the gaps. Komen and its Affiliates have committed to partnering with state programs. In some areas, Komen provides funds directly to the state or county health departments; in other states Komen provides grants directly to providers affiliated with the state program. Last year alone, Komen provided nearly 490 grants directly to NBCCEDP providers, totaling $25 million. Komen's resources provide state programs with more flexibility to maintain or increase the number of women screened each year — alleviating waiting lists and helping to close the gap to women denied screening services due to states' rationing of scarce resources.

In addition to funding, Komen Affiliates have joined with other advocates like the American Cancer Society (ACS) in persuading state legislatures to appropriate funds for the programs. States are required to provide a $1 match for every $3 in federal funding. Some states use Komen grants to satisfy the match, while others use state general funds or revenues from tobacco taxes. New York and California provide state funding well in excess of the grant from CDC, while many states do not provide any of their own dollars. Komen for the Cure believes that a true public-private partnership requires commitment on the part of the both the federal and state governments, in addition to the private backing of Komen, ACS, and other private funders. Unfortunately, only about a third of states receive funding beyond the grant from CDC. In recent years, Komen's advocacy campaigns have resulted in more than $10 million in additional state funding across a number of states.

Following are a few examples of the strong partnerships, in both funding and advocacy, between Komen Affiliates and state programs:

- **Illinois**. The Komen Evansville Affiliate provides funding directly to providers. In 2007, the Affiliate made grants to providers in Indiana, Kentucky and Illinois, to supplement the state and federal funding. Komen's four Illinois Affiliates joined together to advocate for an expansion of the Illinois Breast and Cervical Cancer Program (IBCCP). Last year, Governor Rod Blagojevich took executive action to ensure <u>every</u> uninsured woman in Illinois can receive free breast and cervical cancer screening. He has assured there will be no income limit and no uninsured woman will be turned away.

- **Kansas**. In 1994, the Komen Mid-Kansas Affiliate helped the state bring the NBCCEDP to Kansas, and the Affiliate has had a strong partnership with the Early Detection Works (EDW)

ever since, serving on the advisory council and assisting in the enrollment of providers. Kansas, like numerous other states, targets its funding to screen women ages 50 and over, and the Mid-Kansas Affiliate fills the gap by funding all women under age 50 who are screened through program. For three straight years, the state program has run out of funds during the year, and the Affiliate provided stopgap funding. In 2007, the Mid-Kansas Affiliate granted $400,000 directly to EDW or its regional nurses. Additionally, the Affiliate and its grassroots champions were instrumental in securing the first-time state appropriation of $230,000 for the program in 2005.

- **Minnesota**. The Komen Minnesota Affiliate granted $580,000 directly to the state's Sage Screening Program, as well as grants of $350,000 to breast cancer screening providers, to expand screening, education and case management. Additionally, the Affiliate works closely with the state program on promotion, funding outreach positions, training of contracted outreach workers, providing health education materials to sub-contractors, and providing funds for mobile mammography.

- **Missouri**. The Greater Kansas City, Mid-Missouri, and St. Louis Komen Affiliates joined forces last year to secure a first-time $500,000 appropriation for the Show Me Healthy Women program, allowing an additional 2,000 women to be screened.

- **North Carolina**. The Komen NC Triangle Affiliate granted $154,000 to five North Carolina Breast and Cervical Cancer Control Program (BCCCP) providers in 2007 to supplement the program's funding. All four Komen Affiliates in North Carolina advocated for state funding for the program, and last year the North Carolina Assembly approved a first-time appropriation of $2 million per year over the next two years for the BCCCP, which will allow more than 8,000 additional North Carolina women to be screened.

- **Ohio**. The Komen Northeast Ohio Affiliate has granted almost $1.3 million to the Cuyahoga County Board of Health and the Columbiana County Board of Health to compliment their Breast and Cervical Cancer Project (BCCP) programs since 2001. Komen dollars cover the costs for women and men ineligible for BCCP in Ohio. Additionally, the Affiliate has partnered with the National Cancer Institute, the American Cancer Society and the state program to develop a training day to educate people about the BCCP process from referral to treatment. Komen's four Ohio Affiliates joined together to successfully advocate for a state appropriation for the BCCP of $5 million over two years, tripling the number of women screened over the next two years.

- **Texas**. The Komen Houston Affiliate provided almost $2.9 million in funding to allow more women to be served and to allow providers to screen younger women and women who do not meet the residency requirements. Last spring, Komen's 12 Texas Affiliates successfully advocated for state funding of $5 million dollars over two years for the Breast and Cervical Cancer Control Program. Additionally, the Texas legislature expanded eligibility for coverage under the BCCPTA.

These represent but a few examples of Komen's support and collaboration with state NBCCEDP programs to supplement limited government funds. These investments expand access to life-saving screening services for women who might otherwise fall through the gaps.

Conclusion

Last week, as part of its *I Vote for the Cure*™ campaign, the Komen Advocacy Alliance released the results of a new survey of registered voters, in which six in 10 voters support raising taxes to ensure all women have access to high quality breast cancer screening and treatment. A majority of voters, 62 percent, believe breast cancer is the most critical health problem facing women today. And more than 90 percent of voters want the federal government to pay more attention to breast cancer research, screening and early detection, and access to quality care for all. Voters recognize there are disparities in access to quality breast care. Seven in 10 think income level impacts quality of care and five in 10 say ethnicity is also a factor. While Komen is not advocating a tax increase, we believe that the survey results show the strength of voters' support for funding critical breast cancer research, early detection and treatment. The NBCCEDP is an important, cost-effective, life-saving program. In order to truly close the gaps that make breast cancer deadlier for some women than others, we need the federal government, as well as state governments, to step up their commitment to funding the program.