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The National Breast and Cervical Cancer Early Detection Program: History, Impact, and Future Directions

Statement of

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Good Morning. I am Rosemarie Henson, Deputy Director of the National Center for Chronic Disease Prevention and Health Promotion, at the Centers for Disease Control and Prevention (CDC). Allow me to express my gratitude to Chairman Waxman and Members of the House Oversight and Government Reform Committee for giving CDC this opportunity to discuss the National Breast and Cervical Cancer Early Detection Program (NBCCEDP).

Introduction

Breast cancer is the second most commonly diagnosed cancer among women in the United States. While deaths from breast cancer have decreased significantly by 2.2 percent per year from 1990 to 2004 among women, it remains the number one cause of cancer death among Hispanic women. It is the second most common cause of cancer death in White, African American, Asian/Pacific Islander, and American Indian/Alaska Native women. [1] According to the *U.S Cancer Statistics: 2004 Incidence and Mortality Report*, approximately 187,000 women were diagnosed with breast cancer, and nearly 41,000 women died from the disease.

Cervical cancer once was the leading cause of death for women in the United States. Over the past five decades however, incidence and mortality from cervical cancer have declined significantly, in large part because of the widespread use of the Pap (Papanicolaou) test to detect cervical abnormalities.

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[1] **Source for trend data:** Ries LAG, Melbert D, Krapcho M, Mariotto A, Miller BA, Feuer EJ, Clegg L, Horner MJ, Howlader N, Eisner MP, Reichman M, Edwards BK (eds). *SEER Cancer Statistics Review, 1975-2004*, National Cancer Institute. Bethesda, MD, http://seer.cancer.gov/csr/1975_2004/, based on November 2006 SEER data submission, posted to the SEER web site, 2007.

While recent trends suggest a decline in cervical cancer incidence and mortality overall, rates are considerably higher among Hispanic and African-American women.[1] According to the *U.S. Cancer Statistics: 2004 Incidence and Mortality Report,* approximately 12,000 women were diagnosed with cervical cancer, and nearly 4000 women died from the disease.

Many deaths could be avoided by improving cancer screening rates among women at risk for breast and cervical cancer. In fact, mammography screening every one to two years for women aged 40 years and older can reduce mortality by approximately 20-25 percent over a period of 10 years, according to the U.S. Preventive Services Task Force (USPSTF). Pap tests can detect precursors of cervical cancer, which, if diagnosed and treated in a timely manner, can prevent the development of invasive disease. Additionally, these tests can detect invasive cervical cancer at an early stage, when it is most curable. Likewise, the USPSTF recommends cervical cancer screening at least every three years, within three years of onset of sexual activity—or at age 21, whichever comes first.

Program Overview

Despite the availability of screening tests, deaths from breast and cervical cancer occur more frequently among women who are uninsured or underinsured. Mammography and Pap tests are underutilized by women who have less than a high school education, are older, live below the poverty level, or, are members of certain racial or ethnic minority groups. To help improve access to breast and

cervical cancer screening among these at-risk populations in the United States, Congress passed the Breast and Cervical Cancer Mortality Prevention Act of 1990, which authorized CDC to create the National Breast and Cervical Cancer Early Detection Program (NBCCEDP). This program, which Congress began funding at $30 million in fiscal year 1991, has grown to a nationwide program with an appropriation of $182 million in fiscal year 2008 for breast and cervical cancer screenings. The program began with five states, and today provides screening support in all 50 states, the District of Columbia, five U.S. territories, and 12 tribes or tribal organizations, representing a vast national network of more than 22,000 healthcare providers.

In addition to funding for breast and cervical cancer screenings, in 1993, Congress authorized and began funding the Well-Integrated Screening and Evaluation for Women Across the Nation (WISEWOMAN) program through legislation that expanded the services offered through the NBCCEDP to include screenings and interventions for chronic disease risk factors. WISEWOMAN provides low-income, under- or uninsured 40–64 year old women with the knowledge, skills, and opportunities to improve diet, physical activity, and other lifestyle behaviors to prevent, delay, and control cardiovascular and other chronic diseases. The WISEWOMAN screenings are provided to women who participate in the Breast and Cervical Cancer program. Currently thirteen states and two tribal organizations receive WISEWOMAN funding. Total funding for fiscal year 2008 is $18.6 million.

The National Breast and Cervical Cancer Early Detection program is designed to increase access to - and improve the quality of - breast and cervical cancer screening nationwide. In particular, it serves low-income, uninsured, or underinsured women, by providing:

- Clinical breast examinations
- Mammograms
- Pap tests
- Pelvic examinations
- Diagnostic testing for women whose screening outcome is abnormal
- Surgical consultation
- Referrals to treatment

To receive screening services through this program, a woman must be uninsured or underinsured, and have an income equal to or less than 250 percent of the federal poverty level. Women ages 18-64 who meet these requirements are eligible to receive clinical breast exams, pelvic exams, and cervical cancer screenings. Women ages 40-64 who meet these requirements are eligible to receive additional screening for breast cancer using mammography through the program. It is CDC's policy, however, that 75 percent of program-funded mammograms must be provided to women ages 50-64 because of the higher incidence of breast cancer among older women. Furthermore, 20 percent of the

women screened for cervical cancer must be those who are rarely or never screened. This group is at highest risk for cervical cancer.

A comprehensive and coordinated approach to screen and monitor women for breast and cervical cancer is supported by key program components including:

- screening women through a health care delivery system;
- outreach, recruitment, and public awareness activities to inform women of the need for screening and bring eligible women into the program;
- public education about the risks for breast and cervical cancer, recommended screening intervals, and to address the fear women face;
- professional education and quality assurance activities to ensure the use of science-based, clinically appropriate, and high-quality screening and follow-up; and,
- tracking (or surveillance) and case management of all women screened to ensure they receive timely follow-up for diagnostic care and referrals to treatment, if needed.

National, state and community partnerships such as those with the American Cancer Society, Susan G. Komen for the Cure, and the Avon Foundation are another critical program component. Partnerships serve to expand the reach, capacity, and resources of the NBCCEDP. Through these collaborative efforts, the NBCCEDP has an increased understanding of, and access to, priority populations for enhanced public education, outreach, and inreach, which involves approaching program-eligible priority women who are using other health

services. Most importantly, partners play a key role in advancing the broader goals of the NBCCEDP—enhanced access and quality for all women.

Program evaluation is a central component woven throughout the program. Evaluation in the NBCCEDP is used to assess the quality, implementation, effectiveness, and efficiency of the overall program and gather useful information to aid in planning, decision-making, and improvement. It serves as the foundation for successful operation of all components individually and together. Evaluation aims to better serve consumers, program staff and partners.

States, tribes, and territories that receive funding through the NBCCEDP by law must:

- Spend 60 percent or more of their federal funds on direct clinical services, and 10 percent or less on administrative expenses;
- Contribute a match of $1 for every $3 of federal funding received;
- Be evaluated regularly by CDC; and
- Not use NBCCEDP funds to pay for treatment or research.

In 2000, Congress passed the Breast and Cervical Cancer Prevention and Treatment Act. This Act gives states the option to provide Medicaid coverage to eligible women screened and identified with breast and/or cervical cancer, or pre-cancerous lesions, by the NBCCEDP. To qualify for Medicaid treatment coverage under this provision, a woman must be under age 65, not be otherwise eligible for Medicaid, be without credible health care coverage, screened by the

state's Breast and Cervical Cancer Early Detection Program and need treatment for breast or cervical cancer. The Treatment Act is administered by the Centers for Medicare and Medicaid Services (CMS). To date, all 50 states and the District of Columbia have approved this Medicaid option. In 2001, Congress passed the Native American Breast and Cervical Cancer Treatment Technical Amendment Act which expanded eligibility to include American Indians/Alaska Natives who are eligible for health services provided by the Indian Health Service or by a tribal organization.

In 2005, CDC released *The National Breast and Cervical Cancer Early Detection Program: 1991-2002 National Report*, a summary of the program's progress (http://www.cdc.gov/cancer/nbccedp/bccpdfs/national_report.pdf). The report provides information about the program's framework, history, and future directions, as well as data on breast and cervical cancer screening and outcomes for women served through the program. More recent information is available from routine management reports on the program's screening performance.

In 2007, The National Breast and Cervical Cancer Early Detection Program Reauthorization Act of 2007 was signed into law by the President, authorizing the program for another five years. In June 2007, CDC awarded funding to 68 programs for a new five-year cycle. The reauthorization included a provision for CDC to initiate a demonstration project to waive the 60/40 spending requirement for up to five funded programs. The 60/40 requirement specifies that at least 60 percent of the awarded funds must be used for direct clinical services; the

remainder may be used for essential public health components to support the screening program. Programs selected to participate in the demonstration may use this temporary waiver to strengthen the public health components including the provider delivery system, outreach, public awareness and education, professional education, quality assurance, partnerships, case management, and tracking screening and follow-up services for up to two years. Additionally, they are required to leverage available non-Federal funds with the goal of screening additional women and continuing to expand the level of screening and follow-up services through the duration of the waiver period. The 60/40 waiver demonstration project will begin June 2008.

Impact

Since its inception in 1991, the NBCCEDP has established a nationwide program and has made significant strides in reaching medically underserved women providing equity in access to life-saving technology.

Through 2006, the program has successfully served more than 3 million women – mothers, grandmothers, sisters and daughters - and provided more than 7.2 million screening examinations. These are women who, without the program, would not have other means to be screened and/or diagnosed. Among these women, NBCCEDP has diagnosed nearly 31,000 breast cancers and more than 100,000 pre-malignant cervical lesions and invasive cervical cancers combined. Without the NBCCEDP, it is unlikely that many of these under- or uninsured women would have been screened, or cancers diagnosed at early stages where

treatment is most effective. Similarly, the treatment of early-stage breast cancer is less costly than the treatment of late-stage breast cancer, because it reduces both the immediate costs of treatment and the need for repeat treatments of late-stage disease. Additionally, curative care for early-stage disease allows cancer survivors to return to the work force.

Let me tell you of one mother's story –Danette from North Dakota.

> The frantic pace of life put important routines like regular mammograms and Pap tests on the back burner. In fact, for Danette, she realized it had been six years since her last Pap test. This mother of three daughters knew regular screenings were important; she had been diagnosed with precancerous cells in 1996. Yet, late in 2004, when she finally decided to make time to get checked, she found herself without the financial means to visit her physician. "I wanted to go in, but the bills are coming and you think, 'I don't need to rack up another one," Danette said. That's when Danette learned about *Women's Way*, North Dakota's breast and cervical cancer early detection program. A woman from work explained to her friends at the Knights of Columbus that her daughter used *Women's Way* to help pay for her mammogram and Pap test. Danette had both a baseline mammogram and a Pap test. The results of the Pap test came back abnormal. Her next procedure was a cone biopsy, a surgical procedure that removes cancerous or pre-cancerous cells of the cervix. The next month Danette had another Pap test; the results were again abnormal. "I guess in some ways I sort of expected it. I hadn't gone in for

so long. You can say it's hard to get in with work schedules and things until you finally go in and reality slaps you in the face" she said. Danette eventually had a hysterectomy and received a clean bill of health. "I try to see good in most circumstances, but after years of denial, this was my wake up call. It CAN happen to you," she said. Danette encourages women to get screened and tells others about the program. "They help you with the financial. They help you fill out the paperwork. It doesn't cost you anything but time. What reason can a woman give for not calling? There really isn't one. Heck, if I hadn't gone in, where would I be today?" Danette asked. A self-professed optimist, Danette loves being a mom. Today, instead of thinking about writing goodbye letters to her three daughters, ages 14, 16, and 21, she looks forward to future adventures on the motorcycle with her husband and of someday enjoying grandchildren. "You only get one chance. If you don't have life, you don't have anything. I get that card in the mail that says all is good and I say 'YES.' I feel lucky, luckier than I thought, but I don't think I'll push my luck and head to the casino anytime soon," Danette said.

As you can see, the numbers are important, but it is stories like Danette's that truly illustrate the impact this program has had on the lives of women and their families. The program has been successful, yet focus remains on continuing to reach at-risk women like Danette and increasing screening rates. During fiscal year 2006, the program:

- screened 374,148 women for breast cancer using mammography;

- detected 4,040 breast cancers; and
- screened 14.5 percent of all women eligible to participate in the program for breast cancer.

In that same year, the program

- screened 353,014 women for cervical cancer using the Pap test;
- found 5,082 high-grade and invasive cervical lesions; and,
- screened 9.8 percent of all women eligible to participate in the program for cervical cancer.

Reaching the most at-risk populations is an ongoing priority of the NBCCEDP, including serving women who are rarely or never screened and racial and ethnic minorities that are disproportionately affected by breast and cervical cancer. Among those screened in 2006, approximately:

- 41 percent were white
- 22.3 percent were Hispanic
- 13 percent were African American
- 6 percent were Asian/ Pacific Islander and
- 4 percent were American Indian/Alaska Native

The percentage distribution of racial/ethnic minority women screened by the NBCCEDP is similar to that of the total population of women estimated to be eligible for the program.

Program impact is a reflection of good program management. CDC continuously monitors the performance of programs receiving NBCCEDP funding to examine the program's spending of awarded dollars, and program quality as measured by

the completeness of follow-up for women screened for breast and cervical cancer, the timeliness of follow-up for women with abnormal screening tests, and the timeliness of treatment initiation. Programs that have strong performance based on the above criteria are eligible for small budget increases pending resource availability. The performance-based system ensures the efficient and appropriate distribution of program funds awarded to states, tribes, and territories based on their ability to screen women, deliver high quality services, and adhere to program guidelines.

Considerations for the NBCCEDP

The NBCCEDP is a successful program which utilizes a public health approach for the delivery of breast and cervical cancer screening services across the nation. The program's success can be attributed in part to its comprehensive model. Numerous studies suggest that having insurance coverage or access to free or low-cost services does not automatically translate into choosing to be screened. In the NBCCEDP, CDC proactively seeks and brings high risk women in for screening. Public awareness and education are provided to reduce barriers to screening and re-screening.

Additionally, the program is designed to provide case management to ensure that women who are identified with cancer are connected to treatment services. The NBCCEDP tracks women screened through a surveillance system to ensure that no woman with an abnormal diagnosis or cancer is lost to follow-up. Professional education and quality assurance activities help to ensure clinicians

know the current screening recommendations and provide quality screening services, which benefits all women in a community, not just those served by the NBCCEDP.

Our goal has always been, and will continue to be, to facilitate access to early detection breast and cervical cancer screening for under- and uninsured women by filling the gaps that currently exist even as the insurance and technology landscape changes across the U.S. CDC is committed to working with our funded programs and partners to optimize access and the utilization of screening tests such as mammography and Pap tests among women that are under- and uninsured in their communities.

Conclusion

In conclusion, the NBCCEDP comprehensive approach ensures not only that medically underserved women benefit from this early detection effort, but also that all women gain from the educational activities, public and private partnerships, and quality-assurance standards the program implements. The program's continued success depends in large part on the complementary efforts of state and local partners, healthcare providers, and a variety of national organizations. At the state and community levels, the development of early detection programs has resulted in new capacity and infrastructure for cancer control; increased staff resources and expertise; enabled multiple collaborative partnerships in the private and public sectors; built state and community

coalitions; and has promoted a greater understanding of the challenges in delivering preventive health services to women who are medically underserved.

Thank you again for this opportunity to speak with you today. I am happy to answer any questions.