AUTHENTICATED
U.S. GOVERNMENT
INFORMATION
GPO

ADDRESSING THE SCREENING GAP: THE NATIONAL BREAST AND CERVICAL CANCER EARLY DETECTION PROGRAM

HEARING

BEFORE THE

COMMITTEE ON OVERSIGHT AND GOVERNMENT REFORM

HOUSE OF REPRESENTATIVES

ONE HUNDRED TENTH CONGRESS

SECOND SESSION

JANUARY 29, 2008

Serial No. 110–52

Printed for the use of the Committee on Oversight and Government Reform

Available via the World Wide Web: http://www.gpoaccess.gov/congress/index.html
http://www.house.gov/reform

U.S. GOVERNMENT PRINTING OFFICE

42–583 PDF WASHINGTON : 2008

For sale by the Superintendent of Documents, U.S. Government Printing Office
Internet: bookstore.gpo.gov Phone: toll free (866) 512–1800; DC area (202) 512–1800
Fax: (202) 512–2104 Mail: Stop IDCC, Washington, DC 20402–0001

COMMITTEE ON OVERSISGHT AND GOVERNMENT REFORM

HENRY A. WAXMAN, California, *Chairman*

TOM LANTOS, California
EDOLPHUS TOWNS, New York
PAUL E. KANJORSKI, Pennsylvania
CAROLYN B. MALONEY, New York
ELIJAH E. CUMMINGS, Maryland
DENNIS J. KUCINICH, Ohio
DANNY K. DAVIS, Illinois
JOHN F. TIERNEY, Massachusetts
WM. LACY CLAY, Missouri
DIANE E. WATSON, California
STEPHEN F. LYNCH, Massachusetts
BRIAN HIGGINS, New York
JOHN A. YARMUTH, Kentucky
BRUCE L. BRALEY, Iowa
ELEANOR HOLMES NORTON, District of Columbia
BETTY McCOLLUM, Minnesota
JIM COOPER, Tennessee
CHRIS VAN HOLLEN, Maryland
PAUL W. HODES, New Hampshire
CHRISTOPHER S. MURPHY, Connecticut
JOHN P. SARBANES, Maryland
PETER WELCH, Vermont

TOM DAVIS, Virginia
DAN BURTON, Indiana
CHRISTOPHER SHAYS, Connecticut
JOHN M. McHUGH, New York
JOHN L. MICA, Florida
MARK E. SOUDER, Indiana
TODD RUSSELL PLATTS, Pennsylvania
CHRIS CANNON, Utah
JOHN J. DUNCAN, Jr., Tennessee
MICHAEL R. TURNER, Ohio
DARRELL E. ISSA, California
KENNY MARCHANT, Texas
LYNN A. WESTMORELAND, Georgia
PATRICK T. McHENRY, North Carolina
VIRGINIA FOXX, North Carolina
BRIAN P. BILBRAY, California
BILL SALI, Idaho
JIM JORDAN, Ohio

PHIL SCHILIRO, *Chief of Staff*
PHIL BARNETT, *Staff Director*
EARLEY GREEN, *Chief Clerk*
DAVID MARIN, *Minority Staff Director*

CONTENTS

	Page
Hearing held on January 29, 2008	1
Statement of:	
Carey, Gail, recipient of breast and cervical cancer early detection program benefits and volunteer, American Cancer Society; Otis Brawley, medical director, American Cancer Society; Shelley Fuld Nasso, director, public policy, Susan G. Komen for the Cure Advocacy Alliance; Pama Joyner, Ph.D., director, Breast and Cervical Health Program, Washington State Department of Health; and Thomas Hoerger, director, RTI-UNC Center for Excellence in Health Promotion Economics and RTI Health Economics and Financing Program	56
Brawley, Otis	63
Carey, Gail	56
Fuld Nasso, Shelley	76
Hoerger, Thomas	105
Joyner, Pama	92
Henson, Rosemarie, Deputy Director, National Center for Chronic Disease Prevention and Health Promotion, U.S. Centers for Disease Control and Prevention, accompanied by Lisa Mariani, Assistant Branch Chief, Program Services Branch, Division of Cancer Prevention and Control, National Center for Chronic Disease Prevention and Health Promotion, U.S. Centers for Disease Control and Prevention	23
Letters, statements, etc., submitted for the record by:	
Brawley, Otis, medical director, American Cancer Society, prepared statement of	65
Carey, Gail, recipient of breast and cervical cancer early detection program benefits and volunteer, American Cancer Society, prepared statement of	60
Cummings, Hon. Elijah E., a Representative in Congress from the State of Maryland, prepared statement of	14
Davis, Hon. Tom, a Representative in Congress from the State of Virginia, prepared statement of	11
Fuld Nasso, Shelley, director, public policy, Susan G. Komen for the Cure Advocacy Alliance, prepared statement of	79
Henson, Rosemarie, Deputy Director, National Center for Chronic Disease Prevention and Health Promotion, U.S. Centers for Disease Control and Prevention, prepared statement of	26
Hoerger, Thomas, director, RTI-UNC Center for Excellence in Health Promotion Economics and RTI Health Economics and Financing Program, prepared statement of	107
Issa, Hon. Darrell E., a Representative in Congress from the State of California, prepared statement of	20
Joyner, Pama, Ph.D., director, Breast and Cervical Health Program, Washington State Department of Health, prepared statement of	94
Waxman, Chairman Henry A., a Representative in Congress from the State of California, prepared statement of	4

ADDRESSING THE SCREENING GAP: THE NATIONAL BREAST AND CERVICAL CANCER EARLY DETECTION PROGRAM

TUESDAY, JANUARY 29, 2008

HOUSE OF REPRESENTATIVES,
COMMITTEE ON OVERSIGHT AND GOVERNMENT REFORM,
Washington, DC.

The committee met, pursuant to notice, at 9:50 a.m., in room 2154, Rayburn House Office Building, Hon. Henry A. Waxman (chairman of the committee) presiding.

Present: Representatives Waxman, Davis of Virginia, Maloney, Cummings, Kucinich, Watson, Higgins, McCollum, Van Hollen, Welch, Shays, Platts, Issa, and Sali.

Staff present: Karen Nelson, health policy director; Sarah Despres, senior health counsel; Naomi Seiler, counsel; Teresa Coufal, deputy clerk; Caren Auchman, press assistant; Kerry Gutknecht, William Ragland, and Miriam Edelman, staff assistants; Tim Westmoreland, consultant; David Marin, minority staff director; Jennifer Safavian, minority chief counsel for oversight and investigations; Benjamin Chance, minority clerk; Jill Schmalz, minority professional staff member; and John Ohly, minority staff assistant.

Chairman WAXMAN. The meeting of the committee will come to order.

Almost everyone in this room has been touched by cancer either directly or by a friend or family member. Great medical advances have been made over the last few decades, but cancer continues to be a cruel and difficult opponent. We still can't prevent most cancers, and there are a number of cancers we can't cure.

But in the case of breast and cervical cancers, we have a very effective tool; early detection. For the many women and some men who will be diagnosed with breast cancer, the earlier the cancer is detected, the better the chance of survival. For cervical cancer, tests let doctors find abnormal cells before they even become cancerous. In other words, for cervical cancer, early detection is prevention.

The basic tools to give women a fighting chance against breast and cervical cancer, the mammogram and the pap smear, have been around for many years, but what we have seen over the last several decades is that many women were not getting screened at the recommended intervals or at all.

Women who were poor, women who were uninsured and often women of color were not getting tested at the same rates as other

women. These women were left to get cancer diagnoses at later stages, often once it was too late to be treated effectively. Many women in the United States who have died of cervical cancer never had a pap test.

In 1990, Congress stepped in to give women access to early cancer detection. With strong bipartisan support and after hearing testimony of the Vice President's wife, Marilyn Quayle, the Vice President at that time, Congress passed a law that created a program to cover breast and cervical cancer screenings to low income, uninsured and underinsured women. By passing this law, we sent the message that no woman should have to forego lifesaving tests because she couldn't afford them.

In 2000, we strengthened this program by passing another law allowing States to cover these women if a cancer is detected within their Medicaid programs. Since that time, all States have elected this Medicaid option.

We are here today to talk about what the National Breast and Cervical Cancer Early Detection Program has accomplished and what is left to be done. Over the past 16 years, the program has served over 3 million women. In 2006 alone, the program detected over 4,000 cases of breast cancer and over 5,000 cervical cancers and precancerous lesions.

Every single one of those cases represents a woman who might otherwise not have known she had cancer and might not have had the opportunity to fight it. For these women, the program has been successful.

But, overall, the women served only represent less than 15 percent of the eligible population. There are so many more women whose lives this program could save if only the Federal budget provided greater resources.

It is ironic that we spend money to create cancer awareness and urge women to get mammograms and then have clinics with long waiting lists for actually getting them. It is tragic that this underfunding and these waiting lists undoubtedly mean that women whose cancers could have been caught early and treated instead find out when their disease has progressed and spread.

This program has worked hard to address a particularly vexing problem, the issue of racial and ethnic disparities. This is critical because disparities in screening contribute to disparities in survival rates. For example: While screening rates for African American women have recently equaled those of White women, African American women face a higher mortality rate, possibly because their cancer is detected at later stages; a Hispanic woman diagnosed at the same age and at the same stage of cancer as a non-Hispanic White woman is 20 percent more likely to die within 5 years; and, for both cancers, women without insurance are screened at far lower rates than women who are insured.

These disparities mirror countless disparities in healthcare and health outcomes in the United States; disparities that we as Congress and as a Nation have to continue to investigate and address.

Today, we have the opportunity to focus on an area where an existing Government program is working hard to address these disparities, but which faces a serious challenge because of limited funding. We have some outstanding witnesses who are here to

share their expertise about breast and cervical cancer and about the national screening program.

I know that on both sides of the aisle we care deeply about this issue, and I look forward to an interesting and constructive discussion.

[The prepared statement of Chairman Henry A. Waxman follows:]

Statement of Rep. Henry A. Waxman
Chairman, Committee on Oversight and Government Reform
Hearing on Addressing the Screening Gap: The National Breast and Cervical Cancer Early Detection Program
January 29, 2008

Almost everyone in this room has been touched by cancer, either directly or via a friend or family member. Great medical advances have been made over the last few decades, but cancer continues to be a cruel and difficult opponent. We still can't prevent most cancers, and there are a number of cancers we can't cure.

But in the case of breast and cervical cancers, we have a very effective tool — early detection. For the many women, and some men, who will be diagnosed with breast cancer, the earlier the cancer is detected, the better the chance of survival. For cervical cancer, tests let doctors find abnormal cells before they even become cancerous. In other words, for cervical cancer, early detection *is* prevention.

The basic tools to give women a fighting chance against breast and cervical cancer — the mammogram and the pap smear — have been around for many years. But what we have seen over the last several decades is that many women were not getting screened at the recommended intervals — or at all.

Women who were poor, women who were uninsured, and, often, women of color, were not getting tested at the same rates as other women. These women were left to get cancer diagnoses at later stages — often once it was too late to be treated effectively. Many women in the United States who have died of cervical cancer never had a pap test.

In 1990, Congress stepped in to give women access to early cancer detection. With strong bipartisan support and after hearing testimony of the Vice President's wife, Marilyn Quayle, Congress passed a law that created a program to cover breast and cervical cancer screenings for low-income uninsured and underinsured women. By passing this law, we sent the message that no woman should have to forgo life-saving tests because she can't afford them. In 2000, we strengthened this program by

passing a law allowing states to cover these women, if a cancer is detected, within their Medicaid programs. Since that time, all states have elected this Medicaid option.

We're here today to talk about what the National Breast and Cervical Cancer Early Detection Program has accomplished and what is left to be done. Over the past sixteen years the program has served over three million women. In 2006 alone, the program detected over 4,000 cases of breast cancer, and over 5,000 cervical cancers and pre-cancerous lesions. Every single one of those cases represents a woman who might otherwise not have known she had cancer, and might not have had the opportunity to fight it. For these women, the program has been successful.

But overall, the women served only represent less than 15% of the eligible population. There are so many more women whose lives this program could save if only the federal budget provided greater resources. It is ironic that we spend money to create cancer awareness and urge women to get mammograms, but then have clinics with long waiting lists for actually getting

them. It is tragic that this underfunding and these waiting lists undoubtedly mean that women whose cancers could have been caught early and treated instead find out when their disease has progressed and spread.

This program has worked hard to address a particularly vexing problem — the issue of racial and ethnic disparities. This is critical because disparities in screening contribute to disparities in survival rates. For example:

- While screening rates for African-American women have recently equaled those of white women, African-American women face a higher mortality rate, possibly because their cancer is detected at later stages.
- A Hispanic woman diagnosed at the same age and at the same stage of cancer as a non-Hispanic white woman is 20% more likely to die within five years.
- And for both cancers, women without insurance are screened at far lower rates than women who are insured.

These disparities mirror countless disparities in health care and health outcomes in the United States, disparities that we as Congress and as a nation have to continue to investigate and address.

Today, we have the opportunity to focus on an area where an existing government program is working hard to address these disparities, but which faces a serious challenge because of limited funding. We have some outstanding witnesses who are here to share their expertise about breast and cervical cancer and about the national screening program.

I know that on both sides of the aisle, we care deeply about this issue. I look forward to an interesting and constructive discussion.

Chairman WAXMAN. Mr. Davis, I want to recognize you for an opening statement.

Mr. DAVIS OF VIRGINIA. Thank you, Mr. Chairman, for calling this hearing on the National Breast and Cervical Cancer Early Detection Program administered by the Centers for Disease Control and Prevention [CDC].

Today's discussion gives the committee an important opportunity to emphasize the priceless value of screening and early detection in the fight against breast and cervical cancers. We need to know what works, what we can do to make it work better to maximize the reach and effectiveness of Federal funding for screening low income, underinsured and uninsured women.

In the United States, one in eight women will be diagnosed at some point in their life with breast cancer. Yet, due to improvements in screening and treatments, breast cancer survival rates have risen steadily.

Likewise, over the last three decades, the cervical cancer incidents and mortality rate have declined by 50 percent. Cervical cancer is actually preventable and curable if it is detected early through proper screening.

These are important advances, but not all American women are sharing equally in these critical health gains. According to the CDC, essential screening tools—mammograms and pap tests—are underused 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.

Failure to get appropriate screening has, in part, resulted in these populations of women being diagnosed later and having higher mortality rates than the national average. Timely screening can prevent needless deaths.

Recognizing the value and importance of providing preventive services to low income women, in 1990, the Congress created the National Breast and Cervical Cancer Early Detection Program. Since 1991, the program has served almost 3 million women and diagnosed 26,000 breast cancers, 88,000 precursors to cervical lesions and 1,700 cervical cancers. The 1990's saw the program grow into maturity.

Every $3 in Federal funding must be matched from State or local sources and at least 60 percent of Federal funds must be spent on direct clinical services. Today, there are more than 65 State and tribal grantees who are given substantial flexibility to manage individual programs.

If a woman is diagnosed with cancer through these screening measures, a program case manager will assist her in getting the appropriate treatment. But because the program serves uninsured and underinsured women, finding affordable treatment can pose a significant challenge.

To address the gap between diagnosis and treatment, Congress, in 2000, allowed States to amend their Medicaid plans to cover treatment needs identified by this early detection program. All 50 States have amended their plans to allow these women to have access through Medicaid.

Despite clear success in reaching a vulnerable population, the percentage of eligible women reached through the program remains

low nationwide and varies significantly from State to State. The CDC and the U.S. Census Bureau found in 2002–2003 that only 13 percent of eligible women across the United States received a program-funded mammogram. Likewise, only 6 percent of eligible women received a pap test through the program.

Within that number, the study found a staggering variation in screening rates from just 2 percent to as high as 63 percent among eligible women between the ages of 40 to 64, the highest priority population.

This is an unmistakable indication some States have found ways to be far more effective than others at using Federal funds to reach eligible women. Is it just a question of money or are there important lessons all States can learn about increasing the efficiency and effectiveness of this vital public health effort?

Despite the fact that prevention pays for itself many times over in avoided costs and improved lives, resources for programs like this will always be more limited than anyone would like. Today, we need to talk about appropriate funding levels and about the innovations in best practices that will make sure those funds reach as many women as possible.

To help us with that important discussion, I want to thank our panelists today and I want to welcome Dr. Thomas Hoerger with RTI International. He is leading a study of the long term cost effectiveness of the CDC's early detection program. The first phase of the study will be published next month, and those findings should help us understand some of the factors causing the wide variability between State program costs for screening and diagnostic services.

He is here at the request of the minority members. We appreciate his willingness and that of all of our witnesses today to take time to testify today.

Thank you very much.

[The prepared statement of Hon. Tom Davis follows:]

HENRY A. WAXMAN, CALIFORNIA
CHAIRMAN

TOM DAVIS, VIRGINIA
RANKING MINORITY MEMBER

ONE HUNDRED TENTH CONGRESS

Congress of the United States
House of Representatives
COMMITTEE ON OVERSIGHT AND GOVERNMENT REFORM
2157 RAYBURN HOUSE OFFICE BUILDING
WASHINGTON, DC 20515–6143

Majority (202) 225–5051
Minority (202) 225–5074

Statement of Rep. Tom Davis
Ranking Republican Member
Committee on Oversight and Government Reform
Addressing the Screening Gap: The National Breast and Cervical Cancer Early Detection Program"
January 29, 2008

Thank you, Mr. Chairman, for calling this hearing on the National Breast and Cervical Cancer Early Detection Program, administered by the Centers for Disease Control and Prevention (CDC). Today's discussion gives the Committee an important opportunity to emphasize the priceless value of screening and early detection in the fight against breast and cervical cancer. We need to know what works, and what can work better, to maximize the reach and effectiveness of federal funding for screening low-income, underinsured and uninsured women.

In the United States, one in eight women will be diagnosed at some point in their life with breast cancer. Yet, due to improvements in screening and treatments, breast cancer survival rates have risen steadily. Likewise, over the last three decades the cervical cancer incidence and mortality rate have declined by 50 percent. Cervical cancer is actually preventable and curable if detected early through proper screening.

These are important advances. But not all American women are sharing equally in these critical health gains. According to the CDC essential screening tools - mammograms and PAP tests - are underused by women who have less than a high school education, are older, live below the poverty level, or are members of certain racial and ethnic minority groups. Failure to get appropriate screening has, in part, resulted in these populations of women being diagnosed later and having higher mortality rates than the national average. Timely screening can prevent needless deaths.

Recognizing the value and importance of providing preventive services to low-income women, in 1990 Congress created the National Breast and Cervical Cancer Early Detection Program. Since 1991, the program has served almost three million women and diagnosed 26,000 breast cancers, 88,000 precursor cervical lesions, and 1,700 cervical cancers.

The 1990's saw the program grow into maturity. Every $3 in federal funding must be matched from state or local sources and at least 60 percent of federal grants must be spent on direct clinical services. Today there are more than 65 state and tribal grantees who are given substantial flexibility to manage individual programs.

If a woman is diagnosed with cancer through these screening measures, a program case manager will assist her in getting appropriate treatment. But because the program serves uninsured and underinsured women, finding affordable treatment can pose a significant challenge. To address the gap between diagnosis and treatment, Congress in 2000 allowed states to amend their Medicaid plans to cover treatment needs identified by this early detection program. All 50 states have amended their plans to allow these women to access care through Medicaid.

Despite clear success in reaching a vulnerable population, the percentage of eligible women reached through the program remains low nationwide and varies significantly from state to state. The CDC and U.S. Census Bureau found in 2002-2003 that only 13 percent of eligible women across the U.S. received a program-funded mammogram. Likewise, only 6 percent of eligible women received a Pap test through the program. Within that number, the study found a staggering variation in screening rates – from just 2 percent to as high as 63 percent - among eligible women between the ages of 40-64, the highest priority population. This is an unmistakable indication some states have found ways to be far more effective than others at using federal funds to reach eligible women.

Is it just a question of money, or are there important lessons all states can learn about increasing the efficiency and effectiveness of this vital public health effort? Despite the fact prevention pays for itself many times over in avoided costs and improved lives, resources for programs like this will always be more limited than anyone would like. Today, we need to talk about appropriate funding levels and about the innovations and best practices that will make sure those funds reach as many women as possible.

To help us with that important discussion, I want to welcome Dr. Thomas Hoerger with RTI International. He is leading a study of the long term cost effectiveness of the CDC's Early Detection Program. The first phase of the study will be published next month and those findings should help us understand some of the factors causing the wide variability between state program costs for screening and diagnostic services. He is here at the request of the Minority Members, and we appreciate his willingness, and that of all our witnesses, to testify today.

Chairman WAXMAN. Thank you very much, Mr. Davis.

I want to give any Member who wishes an opportunity to make an opening statement that chance.

Mr. Cummings.

Mr. CUMMINGS. Thank you very much, Mr. Chairman, and I thank you for holding this vitally important hearing to examine the National Breast and Cervical Cancer Program which is administered by the Centers for Disease Control and Prevention.

As you know, breast and cervical cancers pose a real danger to women's health. Nationwide, breast cancer is the leading cause of death for women between the ages of 20 and 59. In my home State of Maryland, the American Cancer Society estimated in 2004 that 4,090 new cases of breast cancer will be diagnosed and 760 women will die of breast cancer.

The statistics for cervical cancer are equally troubling. An estimated 11,150 women were diagnosed with cervical cancer in the United States last year. Notably, these diseases can be treated if caught early, but far too many women never get that chance.

Minority women are more likely to suffer from both diseases primarily because of poor access to healthcare. African American women develop cervical cancer at rates approximately 50 percent higher than White, non-Hispanic women. African Americans are also less likely than White women to be diagnosed at an early stage when the cancer is easier to treat.

Even more troubling, African American women are less likely than Caucasian women to have breast cancer but they are 36 percent more likely to die from the disease. This higher mortality rate has been attributed to late diagnosis, lower access to early treatment and biological differences.

I have had the pleasure of working with Dr. Vanessa Sheppard of the Lombardi Cancer Center at Georgetown University, an African American woman and cancer survivor herself who is conducting research into how to deliver lifesaving care to minority women. With grant support from the Susan G. Komen Foundation and the National Cancer Institute, Dr. Sheppard has developed two programs to help African American women and Latino breast cancer patients make informed decisions about their treatment. Both programs match patients with patient navigators who are often breast cancer survivors themselves.

Individuals like Dr. Sheppard are making a real difference for minority women and, as a result, we have begun to close the screening and treatment gap that is at the core of the unacceptable disparities that exist.

Further, programs like the CDC's National Breast and Cervical Cancer Initiative are vitally important to closing the screening gap. We know that we must lower barriers to care for lower income, uninsured and underinsured women, and this program aims to do just that. I am deeply concerned with recent cuts the program suffered and am interested to hear how it has affected the CDC's ability to achieve its mission.

I look forward to the testimony of today's witnesses, and I yield back the remainder of my time.

[The prepared statement of Hon. Elijah E. Cummings follows:]

CONGRESSMAN ELIJAH E. CUMMINGS OF MARYLAND
OPENING STATEMENT

"ADDRESSING THE SCREENING GAP: THE NATIONAL BREAST AND CERVICAL CANCER EARLY DETECTION PROGRAM"

COMMITTEE ON OVERSIGHT AND GOVERNMENT REFORM

TUESDAY, JANUARY 29, 2008

Mr. Chairman,

Thank you for holding this vitally important hearing to examine the National Breast and Cervical Cancer program which is administered by the Centers for Disease Control and Prevention.

As you know, breast and cervical cancer pose a real danger to women's health.

Nationwide, breast cancer is the leading cause of death for women between the ages of 20 and 59.

In my home state of Maryland, the American Cancer Society estimated in 2004 that 4,090 new cases of breast cancer will be diagnosed—and 760 women will die of breast cancer.

The statistics for cervical cancer are equally troubling. An estimated 11,150 women were diagnosed with cervical cancer in the United States last year.

Notably, these diseases can be treated if caught early—but far too many women never get that chance.

Minority women are more likely to suffer from both diseases—primarily because of poor access to care.

African-American women develop cervical cancer at a rate approximately 50 percent higher than white non-Hispanic women.

African-American women are also less likely than white women to be diagnosed at an early stage, when the cancer is easier to treat.

Even more troubling, African-American women are *less* likely than Caucasian women to have breast cancer, but they are 36 percent more likely to die from the disease.

This higher mortality rate has been attributed to late diagnosis, lower access to early treatment, and biological differences.

I have had the pleasure of working with Dr. Vanessa Sheppard of the Lombardi Cancer Center at Georgetown University—an African-American woman and cancer survivor herself—who is conducting research into how to deliver life-saving care to minority women.

With grant support from Susan G. Komen Foundation and the National Cancer Institute, Dr. Sheppard has developed two programs to help African American and Latina breast cancer patients make informed decisions about their treatment.

Both programs match patients with patient navigators who are often breast cancer survivors themselves.

Individuals like Dr. Sheppard are making a real difference for minority women—and as a result we have begun to close the screening and treatment gap that is at the core of the unacceptable disparities that exist.

Further, programs like the CDC's National Breast and Cervical Cancer initiative are vitally important to closing the screening gap.

We know that we must lower barriers to care for low-income uninsured and underinsured women—and this program aims to do just that.

I am deeply concerned with recent cuts the program, and am interested to hear how it is affecting the CDC's ability to achieve its mission.

I look forward to the testimonies of today's witnesses and I yield back the remainder of my time.

ELIJAH E. CUMMINGS
Member of Congress

Recognition of Dr. Shtern

I would like to take a moment to recognize Dr. Fay Shtern of the AdMeTech Foundation. Dr. Shtern was at involved with the development of mammogram diagnostics and has passionately thrown all of her energy and expertise behind the movement to develop similar technology to detect prostate cancer. I appreciate her presence and the ability to collaborate with her on the introduction of the PRIME Act, H.R. 3563.

Recognition of Dr. Sheppard

I would like to recognize Dr. Vanessa Sheppard of the Lombardi Cancer Center at Georgetown University

I have had the pleasure of working with Dr. Sheppard—an African-American woman and cancer survivor—who is conducting research into how to deliver life-saving care to minority women.

With grant support from Susan G. Komen Foundation and the National Cancer Institute, Dr. Sheppard has developed two programs to help African American and Latina breast cancer patients make informed decisions about their treatment.

Both programs match patients with patient navigators who are often breast cancer survivors themselves.

Individuals like Dr. Sheppard are making a real difference for minority women—and as a result we have begun to close the screening and treatment gap that is at the core of the unacceptable disparities that exist.

Chairman WAXMAN. Thank you very much, Mr. Cummings.

I am willing to recognize any Member who wishes to make an opening statement on this side of the aisle. We will give you another minute if you want.

OK, Mr. Issa, please.

Mr. ISSA. I will be brief and ask that my entire statement be put in the record.

Mr. Chairman, I just want to thank you for holding this bipartisan hearing.

I believe that it is very clear through the last Congress and into this Congress that we have a great opportunity to deal with particularly these two most detectable and preventable cancers, breast and cervical cancers, and it is that awareness and funding that is so critical.

I am proud that this previous Congress, in 2006, passed the Gynecological Cancer Education and Awareness Act known as Johanna's Law and has authorized funding for gynecological cancer education and awareness programs. It is clear we can do more.

It is clear that in America the difference between life and death is not necessarily access to healthcare but an awareness that you need care. So it is, in fact, those preventions, the early detection that would prevent the loss of at least 82,000 women who are diagnosed every year with gynecological cancer and the 27,000 who die, mostly needlessly, for lack of early detection.

As I said, I will put the rest of my statement in the record, and I thank the chairman for holding this hearing.

[The prepared statement of Hon. Darrell E. Issa follows:]

DARRELL E. ISSA
49TH DISTRICT, CALIFORNIA

WASHINGTON OFFICE:
211 CANNON HOUSE OFFICE BUILDING
WASHINGTON, DC 20515
(202) 225-3906
FAX: (202) 225-3303

DISTRICT OFFICE:
1800 THIBODO ROAD, SUITE 310
VISTA, CA 92081
(760) 599-5000
FAX: (760) 599-1178

SOUTHWEST RIVERSIDE COUNTY
(951) 893-2447

www.issa.house.gov

Congress of the United States
House of Representatives
Washington, DC 20515–0549

PERMANENT SELECT COMMITTEE ON INTELLIGENCE

COMMITTEE ON GOVERNMENT REFORM
SUBCOMMITTEES:
DOMESTIC POLICY—RANKING MEMBER
FEDERAL WORKFORCE, POSTAL SERVICE & THE DISTRICT OF COLUMBIA

COMMITTEE ON THE JUDICIARY
SUBCOMMITTEES:
COURTS, THE INTERNET & INTELLECTUAL PROPERTY
CONSTITUTION, CIVIL RIGHTS, & CIVIL LIBERTIES

REPUBLICAN POLICY COMMITTEE

January 29, 2008

Opening Statement of Rep. Darrell Issa

Chairman Waxman, Ranking Member Davis, thank you for holding this hearing. The National Breast and Cervical Cancer Early Detection Program is an important tool in the fight against two of the most common – and most treatable, if detected early enough – forms of cancer. Today we will have an opportunity to look more closely at this program and hopefully determine ways in which more eligible women may be served by this program.

In addition to diagnostic outreach programs like the NBCCEDP, awareness of the diseases, their symptoms and the treatment options available are important to the survival of our wives, our mothers, daughters and sisters.

In 2006, Congress passed the Gynecologic Cancer Education and Awareness Act, also known as Johanna's Law. Johanna's Law authorized funding for gynecologic cancer education and awareness programs.

Each year, more than 82,000 women will be diagnosed with a gynecologic cancer and more than 27,000 women will die, primarily because most were diagnosed too late to treat the disease effectively. Education and greater awareness of gynecological cancers are the key to saving women's lives.

By simply educating women about these cancers, we have an opportunity to save lives. The messages are simple: learn the symptoms, have an annual exam and talk to your doctor.

Gynecologic cancers, when detected early, can often be prevented from becoming fatal. Since all women are at risk—no matter their ethnic background or socioeconomic status—it is critical that we find a way to inform women about the steps they can take to maintain their health. The NBCCEDP is a step toward getting the message out to the women who are most at risk – those that are uninsured.

Now it is up to Congress to appropriate the right levels of funding so that programs like the NBCCEDP and Johanna's Law can make a difference and save women's lives.

PRINTED ON RECYCLED PAPER

Chairman WAXMAN. Thank you, Mr. Issa.

Ms. Watson.

Ms. WATSON. Thank you so much, Mr. Chairman. I join my colleagues in thanking you for having this hearing.

Breast cancer has a disproportionate impact on the different racial and ethnic groups. African American women are less likely than Caucasian women to have breast cancer. However, African American women are 36 percent more likely to die from breast cancer disparity.

That began in the 1980's and continues over time. The higher mortality rate is due to late diagnosis and lower access to early treatment.

Breast cancer is the most common cause of cancer death in Hispanic women. Hispanic women remain less likely than Caucasian women to have had a mammogram in the past 2 years. Screening access varies significantly by insurance status.

The diagnosis of 90 percent of women with breast cancer will survive their disease at least 5 years. Breast-conserving surgery or lumpectomy followed by local radiation therapy has replaced mastectomy as a preferred surgical approach for treating women with early breast cancer. Routine mammographic screening is an accepted standard for the early detection of breast cancer.

Cervical cancer is considered a preventable disease. It usually takes a very long time for precancerous lesions to progress to invasive cancers, and we have effective methods that can detect precancerous that can generally be cured without serious side effects.

Screening programs that are most effective in the United States have led to the drastic decline in the numbers of cervical cancer deaths in the last 50 years. Almost all cases of cervical cancer can be prevented through screening. For women who end up with cervical cancer in developed nations, 60 percent of them either have never been screened or haven't been screened in the last 5 years.

The importance of regular cervical cancer screening cannot be overstated. The importance of early screening and for low income women who would otherwise lack access to services are most needed.

So I thank you for bringing an experts panel and look forward to hearing from you. Thank you very much, Mr. Chairman.

Chairman WAXMAN. Thank you very much, Ms. Watson.

Ms. McCollum, do you wish to make an opening statement?

Ms. MCCOLLUM. Thank you, Mr. Chair.

I agree with all the comments that my colleagues have made before in generalities, if I may take a second and just talk about some specifics.

Minnesota has better health indicators and better rates of insurance than many States, and traditionally we are considered a homogeneous, high income, high insurance rate State.

However, the diversity of Minnesota is growing and is changing. We have populations of Hmong, Somali, Oromo, Tibetan, Latino, resulting in high translation and high outreach costs, and many of these people are the folks that are underinsured or sometimes not insured at all.

Many States are facing economic problems. Minnesota is one of them and, as our State moves forward with its budget process, it is my fear that once again the State will look to this program in cutting back.

There has been much focus on minority women, but I would like to speak for the Native American women just to say that they are often looked at as having access to wonderful healthcare through the Bureau of Indian Affairs. That is not the case. So I hope our testimony illuminates what Native American women could expect in outreach.

Mr. Chair, it is also understanding, because Minnesota has made some important investments in the health of our population and we have done fairly well, as I said earlier, in providing some access to insurance, this in fact may harm Minnesota in the long run. Minnesota has been very efficient in delivering its healthcare.

All too often then when the Federal Government looks at programs, we don't look at the ways Minnesota could continue to improve, to do better, to reach out to more women. Instead, they say, Minnesota, you have done a good job. We are not going to be involved in aggressively helping you do that next phase.

So, Mr. Chair, I thank you for this important hearing. There is much work to do, and I look forward for us all working together on this very important issue facing families.

Chairman WAXMAN. Thank you very much.

Mr. Welch, do you have an opening statement?

Mr. WELCH. I don't.

Chairman WAXMAN. Mrs. Maloney.

Mrs. MALONEY. Well, first of all, I truly and deeply want to thank the chairman for focusing on health, and this builds on his long commitment. His hearings and focus on the dangers of cigarettes really revolutionized and saved lives in our country.

Democrats are very committed to screening and prevention in healthcare. As he mentioned, we passed legislation to have Medicaid cover screenings. One of my first bills that passed Congress actually had Medicare cover the screening for breast cancer, and I have a bill in now that would have private insurance companies, require them to include screenings for cervical, breast and prostrate.

So this legislation and this hearing before us today will help save lives. We can screen. We need every tool we can get to get out there and screen better so that we are helping to save lives in our country.

I thank the chairman for his leadership on this issue.

Chairman WAXMAN. Thank you very much.

Mr. Shays.

Mr. SHAYS. Thank you, Mr. Chairman. I just want to thank our witnesses and thank you and the ranking member for holding this hearing. It is a very important hearing, and it is nice to have some hearings that we both can focus on together.

Thank you.

Chairman WAXMAN. Thank you.

For our first witnesses, we have Rosemary Henson who is the Deputy Director for the National Center for Chronic Disease Prevention and Health Promotion for the Centers for Disease Control.

Ms. Henson is responsible for providing leadership and guidance on activities addressing the leading cause of premature death and disability including cancer as well as heart disease, stroke, diabetes, arthritis and obesity.

She is accompanied by Lisa Mariani, the Assistant Branch Chief of the National Breast and Cervical Cancer Early Detection Program.

Ms. Henson will testify about the program's history, operations and challenges. Both she and Ms. Mariani are here to answer questions, and accordingly both witnesses are going to be sworn in which is the practice of our committee. So, if you would, please rise and raise your right hands.

[Witnesses sworn.]

Chairman WAXMAN. The record will indicate the witnesses answered in the affirmative.

We are pleased to have you here. Your prepared statements will be made part of the record in full.

We would like to ask you, if you would, to try to keep within a 5-minute timeframe for the oral presentation. We will have a clock. That little part there will be green when it is running, yellow when you have a minute to sum up, and then when it is red the time is expired.

Ms. Henson.

STATEMENT OF ROSEMARIE HENSON, DEPUTY DIRECTOR, NATIONAL CENTER FOR CHRONIC DISEASE PREVENTION AND HEALTH PROMOTION, U.S. CENTERS FOR DISEASE CONTROL AND PREVENTION, ACCOMPANIED BY LISA MARIANI, ASSISTANT BRANCH CHIEF, PROGRAM SERVICES BRANCH, DIVISION OF CANCER PREVENTION AND CONTROL, NATIONAL CENTER FOR CHRONIC DISEASE PREVENTION AND HEALTH PROMOTION, U.S. CENTERS FOR DISEASE CONTROL AND PREVENTION

Ms. HENSON. Thank you. Good morning. I am Rosemarie Henson. I am the Deputy Director of the National Center for Chronic Disease Prevention and Health Promotion at the Centers for Disease Control and Prevention and allow me to express my gratitude to Chairman Waxman and the distinguished members of the committee for giving CDC this unique opportunity to discuss the National Breast and Cervical Cancer Early Detection Program.

In my brief remarks today, I will refer to the program as the B&C Program.

I would like to begin with a survivor story. Nancy is a 60 plus Hispanic artist who lives in San Diego, CA. While listening to the radio in her studio on an October day, she heard a commercial promoting mammograms as part of Breast Cancer Awareness Month.

Guess what? She hadn't had a mammogram for over 10 years mainly because she didn't have health insurance. But she called the number that the radio displayed in its ad, and she was referred to the B&C Program at the Scripps Mercy Hospital.

The mammogram revealed a lump in her left breast which, after a sonogram and biopsy, was found to be an early stage breast cancer. Because the cancer had not spread, she received surgery

through the referral to the California Cancer Collaborative followed by chemotherapy and radiation, and today she is cancer-free.

Nancy's story can be retold by hundreds of women across the country who have been in touch with the B&C Program in their successful battles against breast cancer, the second most common cause of cancer death in women. Many other women have been spared of early deaths from cervical cancer due to the detection through pap tests provided by the B&C Program.

The history of all of these success stories goes back to 1990. That year, to help improve access to mammograms and pap tests among low income, uninsured and underinsured women, Congress passed the Breast and Cervical Cancer Mortality Prevention Act.

It authorized CDC to create the B&C Program which Congress began by funding five States at a total $30 million in fiscal year 1991. It has grown to be a nationwide program with a funding level of $182 million in fiscal year 2008.

The B&C Program provides a full range of screening services from screening tests to diagnostic tests to referrals to treatment in all 50 States, the District of Columbia, five U.S. territories and 12 tribes or tribal organizations. Today, the B&C Program has in place a vast national network of more 17,000 screening sites.

Critical to the success of the B&C Program, its comprehensive and its coordinated approach is key. First, medically underserved women now have access to systematic screening services through the existing healthcare delivery system.

Second, the public awareness and outreach efforts inform women of the need for screening and help them get to services.

Third, public education addresses the risks for breast cancer and cervical cancer, recommended screening intervals and the fears that women may have about the screening process.

And, fourth, professional education and quality assurance ensure top quality screening and followup.

And, finally, tracking systems and case management ensure that women receive timely and complete followup for diagnostic care and referrals to treatment when needed.

Also critical to the B&C Program's continued success are active partnerships with national and private sector organizations like the American Cancer Society, Susan G. Komen for the Cure and the Avon Foundation. These partnerships are critical because they expand the reach, the capacity and resources of the B&C Program.

CDC places a very high priority on tightly managing the program. We continuously monitor the performance of funded programs to assess the completeness of followup for women screened for breast and cervical cancers, the timeliness of followup and the timeliness of the start of treatment.

In recent years, Congress has strengthened the B&C Program by amending Title XIX of the Social Security Act to give States and tribes the option to offer women screened through the B&C Program, treatment through Medicaid.

Of course, the most important measure of success of the B&C Program is its effectiveness in reaching medically underserved women. Let me now review those data with you and the key outcomes. Through 2006, the program served more than 3 million women and provided 7 million screening exams. These are women

who, without the B&C Program, would have not had the means to access screening services.

Another important issue that I would like to highlight is that, in fact, we are focused on reaching those women who are rarely or never screened and women from racial and ethnic minority communities. CDC data show that 60 percent of all women screened in the B&C Program are racial and ethnic minorities, higher than the estimated 56 percent of all women who are eligible for the program and members of minority groups.

I will stop there and be pleased to answer any questions that the chairman or other members of the committee would like to ask. Thank you very much.

[The prepared statement of Ms. Henson follows:]

Testimony
Before the Committee on Oversight and Government Reform
United States House of Representatives

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

Statement of
Rosemarie Henson, MSSW, MPH
Deputy Director, National Center for Chronic Disease Prevention and Health Promotion
Centers for Disease Control and Prevention
U.S. Department of Health and Human Services

For Release on Delivery
Expected at 10:00 a.m.
Tuesday, January 29, 2008

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.

[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.

Chairman WAXMAN. Thank you very much. I appreciate your testimony.

I want to ask you about the program's ability to reach its target population. What percentage of women eligible for breast and cervical cancer screenings does the program serve?

Ms. HENSON. Well, the States have done a wonderful job in terms of reaching women, but the reality is that we are able to reach about 15 percent of the need at this point in time.

Chairman WAXMAN. How many women in total did the programs serve in 2006?

Ms. HENSON. That is about 600,000 women.

Chairman WAXMAN. How many were served in 2007? Do you have an estimate of that?

Ms. HENSON. We have an estimate of that. We are actually forecasting about the same at this point, about 600,000 women.

Obviously, the current funding level certainly can impact the number of women screened, but there are other factors that we have to take into account in terms of emerging new technology such as digital mammography, outreach challenges particularly in rural areas, that type of thing. But we are confident that we are able to keep the numbers fairly high in terms of screening women because of the extensive network of providers and infrastructure that we have in place.

Chairman WAXMAN. Well, I don't think it is very high if you are only reaching 14 percent of the eligible women that would come in for these screenings.

You did get a little bit more money, but even I would guess it is predictable if you don't have increasing funds to do the job, while there may be other factors, you are just not going to be able to reach more women.

What are the other factors you say that are keeping you from increasing the number of women to be screened for breast and cervical cancers?

Ms. HENSON. Of course, we have spoken about the funding level, but I think the other factors are clearly we are seeing many changes in technology, for example, digital mammography which is going to cost more, the cost around diagnostic tests.

Chairman WAXMAN. So, if it is increased costs, that really goes back to the amount of money that you are getting. If you are not getting increased money and the costs are increasing, you are not going to be able to serve a greater number of people.

The program was authorized, I think, until 2012. Is the program receiving the full authorized amount for fiscal year 2008?

Ms. HENSON. No, the program isn't. The authorization amount for fiscal year 2008 was $225 million. We are receiving $182 million for the B&C Program at this point.

Chairman WAXMAN. How many women do you estimate you would have been able to screen in 2008 if you had the full funding that your authorization provides?

Ms. HENSON. I think we would be able to probably reach 740,000 women if we had the 225 available to us.

Chairman WAXMAN. So, for $40 million or thereabouts, we could have reached 740,000 more women, maybe saved their lives.

How many do you think you will screen, given the actual funding amount?

Ms. HENSON. I think at this point we are doing those estimates, but I think, given the funding amount, it is going to be in the area of about 600,000 women.

Chairman WAXMAN. Well, I am pleased that CDC has been able to serve as many women as it does, but I am concerned that you won't be able to keep making much progress without more resources and if the expenses keep increasing, you may well go downhill rather than uphill in reaching what, on a bipartisan basis, Congress wanted you to be able to do. That is to provide the screening and for those that have this early detection to be able to get the medical care they need, if nowhere else, through the Medicaid program.

Thank you for your testimony. We very much appreciate it.

Ms. HENSON. Thank you very much.

Chairman WAXMAN. Mr. Davis.

Mr. DAVIS OF VIRGINIA. Thank you.

Let me ask, what does it cost for a test?

Ms. HENSON. What does it cost for a test? That is a very good question.

For clinical services per women served, the number is about $248. Now, when we look at the entire program, that is to include the public health components of the program, the median cost per woman served is $550—$555, excuse me.

Mr. DAVIS OF VIRGINIA. Per patient.

Ms. HENSON. Yes, per woman.

Mr. DAVIS OF VIRGINIA. If you were to get a cervical cancer which has a very high incidence of mortality if it metastasizes or breast cancer, what are the costs of treatment for that once a cancer like that has metastasized?

Ms. HENSON. Let me make it very clear that this doesn't include data around treatment costs, and we are going to have to get back to you.

Mr. DAVIS OF VIRGINIA. I am just asking you, the treatment costs are very high, are they not?

Ms. HENSON. They certainly are.

Mr. DAVIS OF VIRGINIA. Can it run into the hundreds of thousands of dollars?

Ms. HENSON. It could, depending on the stage of the cancer and the kinds of needs that a woman would need.

Mr. DAVIS OF VIRGINIA. Correct. So, obviously, if you can catch it early, you save the whole system. You save hundreds of thousands, in some cases, tens of thousands, whatever.

Ms. HENSON. Absolutely.

Mr. DAVIS OF VIRGINIA. As well as the lives.

Ms. HENSON. Clearly, the program, and I didn't have an opportunity to say but we have been very good. The performance of the program is outstanding in terms of identifying early stage cancers both on the breast side and the cervical cancer side.

Mr. DAVIS OF VIRGINIA. Really, the old saying, a stitch in time saves nine, this is just living proof of that.

Ms. HENSON. Absolutely, yes.

Mr. DAVIS OF VIRGINIA. Now your written testimony notes that cervical cancer incidents and mortality rates are considerably higher among Hispanic and African American women than the general population. Is that correct?

Ms. HENSON. That is correct.

Mr. DAVIS OF VIRGINIA. Now, are these differences attributable to screening levels or could it be attributable to diet or some other cultural factors that maybe we haven't factored in?

Ms. HENSON. I think there are a number of factors there and certainly awareness in terms of the need to get screened for cervical cancer. Cervical cancer is really a disease of older women. Clearly, women that haven't been in this country very long are unaware that they need to get screened. It is really, again, access to the medical care system.

Mr. DAVIS OF VIRGINIA. So screening is really the major problem. If everybody got screened, then you could detect it much earlier and save them.

Ms. HENSON. That would certainly be our goal.

Mr. DAVIS OF VIRGINIA. With those two populations, your penetration in terms of getting the word out and getting them screened is much lower than with other populations.

Ms. HENSON. Clearly, what we do need to have in place and what we have in place is very strong and effective outreach strategies. And so, for those populations that normally don't come in for routine medical care, you know we have to do a fair amount of outreach to reach them and get them into service, and so that is critical.

Mr. DAVIS OF VIRGINIA. Now, if someone were in the country and were not here legally, for example.

Ms. HENSON. Excuse me?

Mr. DAVIS OF VIRGINIA. If someone were here illegally, if they were undocumented and were afraid to come forward and they developed a cancer, then the costs are still very high. Are there any prohibitions on them getting treatment in a case like that or does that go State by State in terms of eligibility?

Ms. HENSON. Certainly, the eligibility around people in the country that are not here legally, those decisions are made by the States. OK. In terms of offering screening services, Medicaid does not allow us.

Mr. DAVIS OF VIRGINIA. But let's just take this a step further. Let's say you worked here, that you weren't documented, that you entered illegally or maybe you came as a young kid and your parents entered illegally. You didn't have any say in it, but you came in.

You developed this. You developed cancer because you couldn't come forward and get treatment or you weren't aware of it or were afraid to come forward or whatever, but then you developed it. Our hospitals would still have to take you when you present yourself at the emergency room stage. Isn't that correct?

So the costs still get borne across it.

There are no prohibitions on language component or anything else in terms of getting the word out, are there, in terms of advertising?

Ms. HENSON. No.

Mr. DAVIS OF VIRGINIA. Are different States using different tactics to try to reach a minority?

Ms. HENSON. States use a whole variety of outreach strategies and tactics.

Mr. DAVIS OF VIRGINIA. What has been the best model as you look at States?

Ms. HENSON. Well, I think particularly with racial and ethnic minority women and women that are hard to reach, the actual community health workers, particularly in Virginia, that has been a very, very nice model in terms of lay health workers.

Clearly, getting into senior centers and getting into the community to have an opportunity to recruit women directly is very effective.

Mr. DAVIS OF VIRGINIA. But is there any State that can be a model for this that you can see, that you look for to say we think they have done this right versus States that maybe haven't done it right?

Ms. HENSON. I think that certainly we do have models out there, and we certainly would be willing to provide that for the committee.

Mr. DAVIS OF VIRGINIA. I think it would be helpful. I mean the whole idea of federalism is that these State and local governments are laboratories of democracy. They all try different things, and the ones that work can be replicated. The ones that don't, then you learn from their mistakes and you don't have to make them yourself.

Thank you.

Ms. HENSON. Thank you very much.

Mr. CUMMINGS [presiding]. Thank you very much.

Ms. Henson, does the CDC develop specific strategies at the national level in order to reach out to underserved groups?

Ms. HENSON. Certainly, the CDC is knowledgeable and works very closely with States in terms of developing education and outreach strategies to reach out to women that are hard to reach and racial and ethnic minorities. So that is a piece of work that we have done very closely in collaboration with States.

Mr. CUMMINGS. In my opening statement, I mentioned Dr. Sheppard at the Lombardi Center. Are you familiar with her work?

Ms. HENSON. No, sir, I am not.

Mr. CUMMINGS. All right. Well, apparently, they use a navigator type system where they get people, women who are survivors to work with other women.

It seems to me. I mean I have seen that work and that kind of system work in various areas such as Healthy Start. When you have mothers who have gone through the pregnancy process to be able to talk to first-time women who are pregnant. There s a relationship that is established, and a lot of those people are from the very neighborhoods.

I was just wondering had you all done any? Do you have any information on that?

Ms. HENSON. Sir, we certainly do have information on navigator programs, and we certainly can provide that to the committee. It is a very effective strategy in terms of helping women manage through our complicated healthcare delivery system.

Mr. CUMMINGS. A little earlier, the chairman, Mr. Waxman, asked you about if you had additional money, how many people we might be able to help.

I take it that here in the United States there are women who are suffering and possibly dying because we don't put the resources to the problem in a sufficient amount. Is that right?

Ms. HENSON. That is correct.

Mr. CUMMINGS. If you had to estimate how many women come under the category of could be diagnosed and get treatment but because they don't will likely perish in a year, what would you estimate that figure to be, if you can?

Ms. HENSON. That is a figure that we need to get back to you. I think that one point I want to make here is that we have estimated that there are 4 million women that would be eligible for this program.

Mr. CUMMINGS. Can you say that again?

Ms. HENSON. We have estimated that there are 4 million women in this country that are potentially eligible for this program.

Mr. CUMMINGS. And how many are reaching?

Ms. HENSON. We are actually, as was said earlier, we are actually reaching about 15 percent of that need.

Mr. CUMMINGS. That is sad.

Ms. HENSON. Yes, it is.

Mr. CUMMINGS. One of the things that is very interesting in my district in Baltimore, when I visit senior centers and I have an opportunity to bring medical people to the town hall meetings, one of the complaints that I get from my seniors is that mammograms hurt. I am just telling you what they say. I don't know.

But I mean is that something you all hear from women?

Ms. HENSON. Yes, certainly, we do hear that.

Mr. CUMMINGS. I can't hear you. I am sorry.

Ms. HENSON. I am sorry. Certainly, we have heard that from women. I mean they, women do have a variety of fears related to the screening process.

Mr. CUMMINGS. Have we looked at those fears and tried to address them?

It seems like let's say the services are available, the screening is available and if they are not taking advantage of it, it seems like we would want to try to get to the bottom line to try to alleviate their fears or concerns.

Ms. HENSON. Certainly, we do that through our public education and our direct outreach efforts to address those fears so that women certainly are more likely to take advantage of breast and cervical cancer screenings. We try to deal with that barrier in an effective way.

Mr. CUMMINGS. Now, last but not least, let me ask you this. Existing law has a requirement that out of the nonadministrative funds, 60 percent has to go to direct clinical services. Is that right?

Ms. HENSON. That is correct.

Mr. CUMMINGS. I understand that the new reauthorization creates a limited waiver that will give some States flexibility on this ratio. What is the purpose of that waiver?

Ms. HENSON. The purpose of that waiver, first of all, is to help strengthen the other public health components of the program: pro-

fessional education, public education, quality assurance, our tracking systems. But the other requirement is that, in fact, as we are doing that, that we maintain an expanded number of women to be screened.

So we can't forego screening women, but we also need to be able to leverage other non-Federal dollars to ensure that women are getting the services.

Mr. CUMMINGS. Has the CDC informed the States of the option?

Ms. HENSON. Yes. Yes, sir.

Mr. CUMMINGS. How many States have shown an interest in applying for it?

Ms. HENSON. We have about four States that have shown an interest at this point in time.

Mr. CUMMINGS. When will these waivers come into effect?

Ms. HENSON. June 30th of this year.

Mr. CUMMINGS. All right. Thank you very much.

Mr. Shays.

Mr. SHAYS. Thank you, Mr. Chairman, and thank you to our witnesses. To the second panel, I am the ranking member of a subcommittee that will be meeting, and I will probably miss a good part of that presentation.

We are dealing with an issue of flat funded over a number of years, and some States do a better job than other States is what I am hearing from the testimony.

Is there any documentation that shows that the States that don't do as good a job, that there are more cases of cancer that isn't detected soon enough and therefore dealt with and that you have the resulting higher deaths or are we doing it basically intuitive but not documented by statistics?

Ms. HENSON. Sir, we would definitely have to get back to you on that particular issue.

But I would like to add that CDC has a very, very nice performance-based funding system in place, and we do a lot of monitoring in terms of the ability of States to spend their dollars, the ability of the State to make realistic screening projections and to really monitor the quality of services.

Mr. SHAYS. Right. I am looking at this room and what I like about this hearing is there is nothing that comes between a Republican and Democrat on this issue, and it is a healthy thing to see. I mean I look at my colleagues on the other side, and they are champions on this issue, and I know that Republicans as well feel this is a very important effort.

But it is important, I think, for the things that we support most, to continue to continue to document. For instance, wouldn't it be stunning if you found out that in the States that didn't do as good a job, that the rates were even much higher and that you would have real life, not just anecdotal, but story after story of if only this person had known sooner and they would have been more likely to know sooner in another State that provided more?

I think that would be tremendously helpful.

Let me ask you about the cost, film versus digital.

Ms. HENSON. Cost.

Mr. SHAYS. First, what is the cost of the program per test? I have no sense of the cost per test.

Ms. HENSON. Let me give you the cost in terms of providing direct clinical services per woman.

Mr. SHAYS. No. Just a test, what does the test cost?

Ms. HENSON. OK, $79.

Mr. SHAYS. $79.

Ms. HENSON. $79 and $120 for digital.

Mr. SHAYS. OK, but the digital, I make an assumption, is far more accurate because it is a more clarified picture. Is that true?

I mean it has to be. Otherwise, why would we want to go to digital? What would be the advantage of digital over film?

Ms. HENSON. I think that clearly there are data to suggest that there are benefits to digital mammography, that it certainly would be more accurate in terms of women that have dense breasts.

Mr. SHAYS. Then let me ask you, is there any other type of test that is coming in that, rather than being more expensive, will be less expensive?

I mean if your testimony touched on it, I am sorry. I didn't catch it.

Ms. HENSON. No, sir, not another test that I am aware of.

Mr. SHAYS. OK, thank you.

Thank you very much, Madam Chairwoman.

Mrs. MALONEY [presiding]. Well, I want to thank my colleague for really supporting this initiative on women's health as you have so many others, and it is good to have something we both agree on, although we agree on a lot of things together, on 9/11 and so forth.

I would like to thank the witnesses and ask you, as you have noted, you are reaching fewer than 15 percent of the eligible women. When a clinic runs out of money, what happens to a woman seeking a mammogram?

Ms. HENSON. Well, certainly, that is a challenge for the program, and you are going to hear from the other witness around that. But I think that States really do try to get the women connected to a service, so they can receive mammography services or cervical cancer screening services, but it is a challenge that the program faces.

Mrs. MALONEY. I would agree with my colleague that getting and keeping good data will help build your case for the needed funds to go forward.

Since I have been in Congress, really, we have doubled, more than doubled the amount of money going into mammograms and cervical cancers and other cancers for women.

I recall when I came, one in seven women died of breast cancer. What is the number now? How many women die of breast cancer a year now?

That was the number that was always used, one in seven. It could be your sister, your mother.

Ms. HENSON. OK. It is one in seven women are diagnosed, and we have at this point, that we have about 40,000 women per year that die of breast cancer.

Mrs. MALONEY. Excuse me. He was talking to me. You say one in seven is diagnosed and how many?

Ms. HENSON. We have had about 40,000 women that actually die from breast cancer.

Mrs. MALONEY. 40,000 a year, that is still astronomical. One in seven is diagnosed and 40,000 die. Oh, my goodness.

What about the cervical cancer? What is the number on that?

Ms. HENSON. In this country, we have, unfortunately, about 4,000 women in this country that are dying of invasive cervical cancer.

Mrs. MALONEY. 4,000?

Ms. HENSON. Yes.

Mrs. MALONEY. But you said 40,000 died of breast cancer.

Ms. HENSON. Yes.

Mrs. MALONEY. So many, many more die of breast cancer than cervical cancer.

Ms. HENSON. Yes, and we have done a very nice job in this country in terms of getting cervical cancer services out to women. We have really made some very nice progress, but it is very hard.

Mrs. MALONEY. Is that because the pap smear as a screening device is more effective than the mammograms?

We have tremendous outreach on mammograms too now through the Medicaid program, Medicare and just advertisements. I know that in my home State there are literally billboards up, telling people to go get their mammograms. Why do you think that so many more die from breast cancer than cervical cancer? Do you think it is the screening?

What do you think is the reason?

Ms. HENSON. I don't think it is the screening tool. I think it is that women, clearly for many years, during their adolescent years, their younger years, certainly got accustomed to going for pap testing and screening, and I think that mammography is still a screening tool that women are aware of but at times fear.

I don't think there is a difference in terms of the screening tools, but I think that there is an issue in terms of attitude and——

Mrs. MALONEY. Use.

Ms. HENSON. Use, yes.

Mrs. MALONEY. Well, the chairman is very committed to helping this program. So could I ask you to supply for the record, if you don't have it with you today, your professional judgment of how much funding would be required to meet the needs of all eligible women?

Ms. HENSON. We certainly will provide that to you.

Mrs. MALONEY. I would like to talk a little bit about the tools and technology.

Both the mammogram and the pap test have been around for literally decades, and they are literally the primary screening tools used because they are both effective in detecting signs of cancer. But the law creating the program, which we are discussing today, stated that if newer technologies are developed and recommended, they can be covered as well.

Can you please explain how such coverage decisions are made and can you tell me about the two tests that we are reading about a lot, the digital mammograms and the HPV test, and does the screening program now cover these new technologies?

Ms. HENSON. Certainly. When the program is faced with this type of decision, what we do is we usually bring together experts to make those decisions, and basically they do look at the effectiveness of the screening tool as well as looking at the priorities of the program.

Currently, the program is providing a limited amount of resources for HPV as well as for digital mammography. We currently reimburse at the Medicare rate for these types of procedures, and that has become an issue for the States because the rates are low.

Mrs. MALONEY. Thank you.

Congresswoman McCollum.

Ms. MCCOLLUM. Thank you.

I would like to go back. When you were asked the cost of the screening, you came up with $500. Is that what you said for the cost of screening?

Ms. HENSON. $555 is the median cost per woman screened.

Ms. MCCOLLUM. I would like you to break that down because I served on the Health and Human Services Committee in Minnesota and screening per woman, when we talked about it on the House floor and recently, it has been screening at $88 per woman, then maybe $85 to recruit women.

Are you just putting that all together for you $500?

Ms. HENSON. Basically, what that number represents is clinical services as well as the public health components of the program. So that is why there is a difference in that particular number.

Ms. MCCOLLUM. Do you break that out by State?

Ms. HENSON. That is something that we are looking at right now. We have looked at nine States to get a handle of the cost, and we have a phase two initiative to look at more States.

Ms. MCCOLLUM. Well, I think best practices should really be moving forward because there are discussions in my State of the State actually cutting back on some of its costs.

Just listen to the State of the Union. If I advocated for a program now in Minnesota maybe to reach Somali women, it would be considered something terrible. It would be called an earmark to develop a best practice or something that States could use as a laboratory to move forward, to help other women around this country live healthy, productive lives.

Could you maybe speak a little bit about what you are doing with your efforts for Native American women?

I say this in particular because although States are laboratories, the funding goes toward States. Native American women are part of nations where the Federal Government has relationships with. So can you speak to what your plans are to increase this issue of Native American women not being screened because after all that then becomes a nation to nation issue?

Can you also address if the CDC monitors and starts becoming concerned or alarmed when States start cutting back on their participation in these programs? Because if the State cuts back, then the Federal match is less. So then that is good maybe for another State or maybe that is good for someone who is looking to cut the budget in these areas, which I don't think is a prudent thing to do.

Could you maybe speak to that, please?

Ms. HENSON. Sure. Well, let me begin with your question about the American Indian-Native American population. This program is one of the first programs at CDC that actually funded tribes directly along with a clear direction to States that they need to reach out to American Indian-Alaska Native populations. And so, we have been doing this work for many, many years.

Another part of this strategy is that——

Ms. MCCOLLUM. Excuse me. What is your success rate then if you have been doing it for so many years?

When you started out, you were at zero. Where are you now?

Ms. HENSON. Is there in terms of screening?

Ms. MCCOLLUM. Well, the first year, you had a baseline of how many women you screened. The second year, you had how many? I mean what is our success rate if you have been doing this for so many years?

Ms. HENSON. We certainly can get that data back to you. Actually, what I will do is get the actual numbers back to you, but we are reaching, at this point, about 3 percent of the women that are Alaska Native-American Indian.

Ms. MCCOLLUM. Three percent.

Ms. HENSON. I actually can give you actual screening numbers if you'd like to have them.

Chairman WAXMAN [presiding]. Could you speak into the mic?

Ms. MCCOLLUM. I had asked another question about States that cut back. I was waiting for the answer.

Ms. HENSON. OK. In terms of—can you please repeat your second question? That would be helpful.

Ms. MCCOLLUM. There are Federal dollars that go into the screening program. The States often match those Federal dollars, yielding more opportunities for women to be screened. Does the CDC become concerned?

Do they express through letters or questions why a State might be looking at cutting back in doing some of the outreach for women because when some of the dollars are pooled together, the dollars much more effective and much more powerful if someone is using best practices?

If a State pulls back, fewer women are going to be reached. That means those Federal dollars going into the program aren't going to be as effective as they could be.

Ms. HENSON. Certainly, the CDC expresses their concern. We clearly don't have control over the State dollars, but we work with the program to see what we can do to reach the women that, in fact, won't be screened because of the cutback in terms of State dollars or other sources of resources that are coming in for screening. So we do work with them.

We do provide a lot of technical assistance. We have a real clear sense in terms of how many women would not be screened if the State dollars or other sources went away from the screening program. We hold the States very accountable for the match requirement in the law.

Chairman WAXMAN. Thank you, Ms. McCollum.

Mr. Welch.

Mr. WELCH. Thank you and thank you for your good work.

In addition to funding, always a challenge, what are the other elements of making the screening test available to women?

Ms. HENSON. Well, I think that, clearly, the other parts of the program that are critical are certainly the public health components elements.

We would want to ensure that we have very good tracking systems, we have very good case management, that we have strong

public education and outreach programs on the ground, and clearly very strong professional education for the providers that are seeing these women. So those are all.

Mr. WELCH. I don't actually know what that means.

Let's say you are a low income woman living in the inner city, how do you find out about it? What are the impediments to access?

What are the impediments for the providers to making the service available when money is not the issue but some of these other practical obstacles are?

Ms. HENSON. Certainly. Well, clearly, there is the public education through a radio spot, through a television spot, recruitment in senior centers or other community-based organizations where we can talk to the women about the availability of services through this program.

If a woman says to us she doesn't have transportation, we assist with that. If she clearly needs some help in terms of getting to the screening site, she needs someone with her, we help her do that as well. And, clearly, if she is diagnosed with a cancer, we provide case management services.

Mr. WELCH. I think in response to Congresswoman McCollum's question or one of them, you said the cost of each screening was $555. Does that cost figure include these other support elements that go from advising the availability of the service to, in some cases, you mentioned providing transportation to the actual test itself?

Ms. HENSON. Yes, sir. It clearly does.

Mr. WELCH. Are many of the women who benefit from the screening test also women without Medicaid or Medicare or other form of health insurance?

Ms. HENSON. Certainly, we are talking about a population of women that are uninsured or underinsured. So they have no real form of health insurance.

Mr. WELCH. When you say uninsured, they are not even Medicaid or Medicare covered?

Ms. HENSON. Correct.

Mr. WELCH. So what then happens to those folks who have a need for further medical care because it is a positive test?

Ms. HENSON. Certainly. Well, through the screening program, if a woman has a positive test, then we will provide diagnostic services.

Mr. WELCH. Right.

Ms. HENSON. And then if she is diagnosed with cancer, we are able to refer her to Medicaid for treatment through the Medicaid option that was approved by Congress.

Mr. WELCH. Are there any impediments to that women then being made immediately eligible for Medicaid and getting the medical treatment for her cancer that is required?

Ms. HENSON. Excuse me. I didn't hear.

Mr. WELCH. Is there any impediments to that person being made eligible for Medicaid and then immediately getting the care or getting the care in a timely way for the cancer that has been diagnosed?

Ms. HENSON. Our finding is that, in fact, the whole process is pretty simple in that we have found that many of our women who

have been diagnosed with a cancer and that initiate treatment, that time period is actually very, very short. So that has been very, very helpful to have that Medicaid option for these women.

Mr. WELCH. Thus, the better survival rates from the treatment and the early diagnosis.

Ms. HENSON. Exactly. Exactly.

Mr. WELCH. Thank you very much.

I yield the balance of my time.

Ms. HENSON. Thank you.

Chairman WAXMAN. Thank you, Mr. Welch.

Mr. Higgins.

Mr. HIGGINS. Thank you, Mr. Chairman, and thank you for holding this important hearing.

Thank you, presenters here. Your message of prevention and early detection is urgent and timely.

My understanding is that less than 10 percent of cancer deaths are a result of the original tumor. It is when cancer spreads. It is when cancer metastasizes that cancer becomes deadly.

Over the years, the Nation has invested a lot of money in cancer research through the National Cancer Institute. You know 30 years ago, if you were diagnosed with cancer, less than 50 percent of those lived beyond 5 years of their diagnosis. Today, it is 65 percent for adults, 80 percent for kids. More people are living with cancer than are dying from cancer.

Despite this, it seems as though the Federal Government is pulling back on its investment into early detection, prevention programs and funding promising new research in therapies which become the basis for tomorrow's standard treatments.

I think the most important point here is that to a nation, to our Nation, it is much more expensive to treat advanced cancer than it is to treat early stage cancer. You, in your testimony, point that out.

My first year here, there were a bunch of cancer advocates from the entire Nation, who converged on Washington to promote what is referred to as the 2015 Campaign. I didn't know anything about it. I inquired about it. In the 2015 Campaign, the goal was to eliminate all human suffering and death due to cancer by the year 2015.

Upon further inquiry, I knew that there was also some controversy within the cancer community about whether or not that goal is attainable. Well, that is the wrong focus. So long as you are making progress toward the goal, that is what is most important.

But over the past 5 years, Congress cut cancer funding to the National Cancer Institute by about $250 million.

The goal or progress toward the goal of eliminating all human suffering and death due to cancer, eradication of cancer in our lifetime, should not just be the National Cancer Institute's goal or those that advocate along with them. It should be the Nation's goal.

But Congress has to insist on a massive investment behind cancer prevention, early detection and promoting new therapies that give great promise to effectiveness moving forward. As I mentioned, it is an investment. It is not only an economic issue. It is an important healthcare issue as well.

Any thoughts on that?

Ms. HENSON. Certainly, the concerns that you have raised and the priorities that you have raised are, from our perspective, very much on target.

I think that the National Breast and Cervical Cancer Early Detection Program has done a fine job with the types of resources that we have to reach underserved women. Clearly, to reach all women, we are going to have to make a stronger financial investment in this particular program.

But, clearly, what we have seen is we have strong accomplishments in terms of reaching these very hard to reach women, and we have really seen since the inception of the program that we have been very successful in terms of detecting early stage cancers.

Mr. HIGGINS. What happened to the 2015 Campaign?

You don't hear much about it anymore. Is it still the goal? Is it still established? What happened?

Ms. HENSON. Well, certainly, we can get back with you on that, but clearly 2015 continues to be a very important goal and very, very strong priorities. But we can get back to you in terms of what is actually happening.

Mr. HIGGINS. One word of advice, and I haven't been here all that long, but that first year all these cancer advocates asked Members of Congress to sign their petition, their resolution, a non-binding expression to promote increased funding to achieve the 2015 goal. In my response, I signed it respectfully, but the cancer community is letting Congress off too easily.

Yes. A non-binding recommendation means nothing.

I would encourage because as what is stated here, that everybody is touched by cancer, directly and indirectly and likely both. I think it is one of these issues that, as others have mentioned, doesn't have a partisan label to it, and I think that there is a consensus that if our Nation does not make that investment, we can't expect that anybody else will.

Ms. HENSON. Well, thank you very much for your support.

Mr. HIGGINS. Yes. I yield back.

Ms. HENSON. I much appreciate it.

Chairman WAXMAN. Thank you very much, Mr. Higgins.

Mr. Van Hollen.

Mr. VAN HOLLEN. Thank you, Mr. Chairman. Thank you for holding this hearing and thank you for your testimony.

As my colleagues have said, obviously, we need to commit, I think, a lot more national resources to this effort to make sure that we do get the screening programs and get as many people as we possibly can to take advantage of those programs and then be sure that we are providing the followup treatment for those who are detected with breast cancer, cervical cancer and other cancers.

I just want to followup on one of the questions by my colleague, Congresswoman Maloney on the new technologies because in both areas there are new technologies. I wanted to ask you with respect to the HPV DNA test that has been approved by the FDA, compared to the pap test, is the HPV DNA test better able to detect cervical cancer?

Ms. HENSON. In terms of cervical cancer, the recommendation is that we continue to do pap tests in conjunction with the HPV testing. Actually, what is happening now in the program is that we

don't offer it routinely, but we offer the HPV test for women that show up with certain abnormal findings at this point in time, but it is offered in conjunction with the pap test.

Mr. VAN HOLLEN. I guess my question is do the findings suggest that the HPV test in some instances is better able to detect cervical cancer?

In other words, could a woman come and take a pap smear and it show up as negative but the HPV DNA test show a positive finding?

Ms. HENSON. Sir, I would like to get back to you on that particular question. I don't have the information readily available to me.

Mr. VAN HOLLEN. OK. I mean there are two major issues here, obviously. One is we want to cover, obviously, more women in screening and the other is we want to be using the most up to date, the test that is best able to make that detection.

So I would be interested whether the findings suggest that someone who may test negative on a pap smear, that same person, if you use the DNA test, HPV DNA test would be found positive. Then the question is if that is the case, shouldn't we consider making that part of the original screening?

Could you talk a little bit about the state of the recommendations from CDC and other U.S. Government health agencies with respect to the vaccine for cervical cancer?

Ms. HENSON. The vaccine, well, certainly. Currently, the HPV vaccine is really targeted for girls and women, age 9 to 26 years old, and this is really not a population that is served by the National Breast and Cervical Cancer Early Detection Program.

We certainly would be pleased to provide you with the actual guidelines that particular program is managed. The science is managed in a different center at CDC, but clearly the focus is on girls and women that are much younger than the women that are actually through the B&C Program.

Mr. VAN HOLLEN. Right. I guess what I am trying to understand is what the current recommendations are from the CDC or others, from the U.S. Surgeon General if you know, with respect to recommending whether or not females between these ages should get the vaccine or not? Do you know what the current state is?

Ms. HENSON. Basically, the recommendation is at this point that women regularly receive cervical cancer screening through the pap test; that HPV vaccine for girls and women, age 9 to 26, is supported; that HPV vaccine for women, age 27 or older, is not supported. All women receiving the HPV vaccine should continue to receive a pap test according to the established screening recommendations.

We can get that to you in writing if that would be helpful.

Mr. VAN HOLLEN. That would be helpful. Thank you.

Thank you, Mr. Chairman.

Ms. HENSON. Thank you.

Chairman WAXMAN. Thank you very much, Mr. Van Hollen.

Ms. Henson and Ms. Mariani, thank you for being here and answering our questions and making your presentation. It has been very helpful to us. Thank you.

Ms. HENSON. Thank you very much for this opportunity.

Chairman WAXMAN. We are going to now hear from our second panel, but before I call on them I want to ask unanimous consent that the record be open for additional testimony that may be submitted to us for the record.

Our second panel will provide a broad range of information and perspectives on the National Breast and Cervical Cancer Early Detection Program.

Gail Carey is a breast cancer survivor from Long Island. She experienced firsthand the benefits of the screening program through the Healthy Women's Partnership in New York.

Dr. Otis Brawley is the medical director for the American Cancer Society where he is charged with promoting the goals of cancer prevention, early detection and quality treatment through cancer research and education. As an acknowledged global leader in the field of health disparities research, Dr. Brawley is a key leader in the Society's work to eliminate disparities in access to quality cancer care.

Shelley Fuld Nasso is the director of public policy for the Susan G. Komen for the Cure Advocacy Alliance and facilitates Komen for the Cure policy and legislative efforts. She also oversees the Komen Community Challenge, a series of events designed to make breast cancer a national priority and to help close the gap in access to care.

Pama Joyner is the program director for the Washington Breast and Cervical Health Program. She served as the 2006–2007 Chair of the National Association of Chronic Disease Directors Breast and Cervical Cancer Council.

Finally, Dr. Thomas Hoerger is the senior fellow in health economics for RTI International and the director of RTI's Health Economics and Financing Program. He is also the director of the RTI-UNC Center for Excellence in Health Promotion Economics and has led numerous research projects for the CDC and CMS.

We are pleased to welcome all of you to our hearing today.

It is the practice of this committee to ask that all witnesses that testify do so under oath. So, if you would please rise and raise your right hands.

[Witnesses sworn.]

Chairman WAXMAN. The record will indicate that each of the witnesses answered in the affirmative.

Your prepared statements will be made part of the record in full.

We would like to ask each of you to limit your oral presentation to 5 minutes, and we do have a timer. Right now, it is red, indicating there is time, but we will start off with green. It will turn to yellow when there is 1 minute left and then will turn red, indicating the time is expired.

Ms. Carey, why don't we start with you? There is a button on the base of the mic that will actually turn it on and be sure to pull it close enough so that it is picked up.

We are delighted you are here.

STATEMENTS OF GAIL CAREY, RECIPIENT OF BREAST AND CERVICAL CANCER EARLY DETECTION PROGRAM BENEFITS AND VOLUNTEER, AMERICAN CANCER SOCIETY; OTIS BRAWLEY, MEDICAL DIRECTOR, AMERICAN CANCER SOCIETY; SHELLEY FULD NASSO, DIRECTOR, PUBLIC POLICY, SUSAN G. KOMEN FOR THE CURE ADVOCACY ALLIANCE; PAMA JOYNER, PH.D., DIRECTOR, BREAST AND CERVICAL HEALTH PROGRAM, WASHINGTON STATE DEPARTMENT OF HEALTH; AND THOMAS HOERGER, DIRECTOR, RTI-UNC CENTER FOR EXCELLENCE IN HEALTH PROMOTION ECONOMICS AND RTI HEALTH ECONOMICS AND FINANCING PROGRAM

STATEMENT OF GAIL CAREY

Ms. CAREY. I am here to testify because I was fortunate to be a recipient of this network. When I was diagnosed with breast cancer, I also had no insurance. I know in this world, it is inconceivable.

From the time when I was a little kid, my mom had emphysema and she was forced go to on Medicaid, and we hated it. As little kids, we hated it because right after my mom got sick, my dad lost his job at Republic Aviation. Financially, they split up, and we were stuck on Medicaid for many years.

When I was 18, I went out on my own, got my own job. With my first job, I had insurance, and I never looked back. I always had insurance every single year, no matter what job I had.

When I got married, we had insurance. When I had my kids, we had insurance. When my husband and I also split up, still had a great job, still had insurance.

Ironically, at one point, I was working for a medical facility. It was a panel of neurologists, and a young man came in. He was an immigrant, and he had been having seizures, and he had no insurance. The doctor was very reluctant to work with this child and sent him to the hospital across the way which was State-sponsored.

At that point, I said, you know what? I don't want to work for this doctor anymore.

I entered into a different world, and I worked for a trade show company. I worked for a trade show company doing air traffic control and whatnot. Again, always had insurance. It was always overlapping.

Unfortunately, I was working for the trade show company when the jets hit the World Trade Center and we all know what happened to the country, let alone trade shows. Everything just shut down. Everything immediately shut down. That was in September.

By March, our boss was paying us out of his own pocket. We knew he was just holding us on.

When I lost my job, of course, it was devastating because I also lost my insurance. Couldn't afford the Cobra because I didn't have a job. I had two kids. I had no husband. I was paying for my house. As a mom, most women know that your priority is your children and your house and keeping a house over their heads.

So I was going crazy for a couple of weeks, writing out my resumes. You know resumes that I hadn't had to prepare for many years, and at that time, in the interim, I found. I was taking a shower, and I felt what I perceived to be a lump.

Now I also have to preface this by saying that I also worked for a medical facility for some time in mammography. I knew exactly what cancer was. I had seen it a thousand times because I worked in the records.

I had seen dense breasts. I had seen young breasts. You know. I knew exactly about calcifications and carcinomas. I knew exactly what it was.

So when I saw it, of course, I panicked. But I thought, well, we have a history of cysts. Maybe it is just a cyst.

I scrambled to get a job. I worked little jobs, and then I finally found one job where he suggested after 3 months that I would get insurance.

Now I got laid off in April, discovered the cyst or what came to be my cancer a couple of weeks later. I started this job in July. So here I am waiting like 2 months to get this job that promised me medical benefits.

It is kind of like I took a pay cut just to get this job because it promised medical benefits. He said I would get them in 3 months.

Now I already knew I had a problem, but I thought to myself, OK, so I will gamble here. You know. I always had control over my life. This was the first time I didn't. So let me do this.

So I went from July to October and come October, I went to this boss and I said to him. I said, OK, I have put in my 3 months. You know I would like to get those medical benefits going because I have a problem I think that needs to be addressed.

I am sure he was aware of it because I had spoken to my manager about it. His answer to that was to call me into his office at about 10 minutes to 9, look at his watch and tell me I had 10 minutes to clean out my desk because I was fired.

So, here I was, 3 months later, still no insurance, no job, no prospects, still pushing my kids out of the hole that I dug them out of, and I realized that I was going to die. There, I had no choice.

I kind of walked out with dignity, and I just waved to him and said bye-bye. I got to my car and broke down and cried.

So I went home and I pooled all my resources, and I figured out everything I could do. There was no way I was going to go to a doctor. I knew from the neurologists that they frown on people that don't have money, let alone no insurance. So I was certainly not going to go to a doctor for a screening for what I already knew to be cancer. I already knew it.

So I pooled all my money, pooled it all together, my tax money and what-not, and I went out and I bought a little, tiny used car for my daughter. She was 18 at the time, and I said to myself, well, I am going to die. She is not going to be saddled with a car payment.

That was my mind set. I was just going to make sure. I was going to set up my life. A couple of weeks later, my girlfriend, Kim, who worked with me in the medical facility in mammography came over and says to me, I haven't seen you for a while. What is going on? What is happening?

That is when I broke down and cried and told her, Kim, I think I have a problem. And she goes, what is wrong? And I hadn't seen her in months, and she goes the very next day. It was October 31st,

Halloween, set me up for a mammography. She is a certified mammotech.

We both looked at the films. We both nearly threw up because we both knew it was. Not only was it a carcinoma, which is a lump, but it was already traveling to my lymph nodes at a very rapid rate. I was in big trouble. I was in big trouble. It was like stage three cancer.

She set me up immediately for a sonogram. Again, because I worked for this particular medical center, they were extending a courtesy. Normally, that particularly mammography would have cost me $200 which I did not have at the time. They told me that I could pay it off eventually.

They set me up with a sonogram which probably was going to cost about $1,000. Then I was like, Kim, I can't do this. It started with tech, biopsy, sonography. She said, we will do this. They did the biopsy. Of course, the lab tests came back positive, and I was just sick to death.

I went home and I told the girls. I said, OK, girls, listen. I think we are in trouble. Katie said, well, what is the matter? She was my 18 year old. She comes in from Halloween trick-or-treating, and I said, I think we are in trouble.

She goes, what is the matter? I said, I think I might be sick. I might have cancer. She goes, how much is it going to cost? Usually, we joke about if something is too expensive, we say it is going to cost $100. I said, well, it is going to cost more than $100.

The next day, Katie got on a bus after school and went to the mall to get a job because she was going to help me pay for this. Actually, it didn't have to happen that way because Kim went to the hospital where she worked, and she says there is this new program. She said, Gail, you are not going to believe this because New York State only just instituted it this month, this year. It is brand new.

It's the—we couldn't even. We didn't even get the name right. It was Woman's Healthy Partnership. We didn't even know what it was. They didn't even have forms. They have no cards. That had a brochure that described. It was a letter of introduction that described what this program was.

She goes, take this to the doctor. They set me up with a surgeon. She gave me the name of this wonderful women in the American Cancer Society in Hyde Park. Her name was Maureen Massellaro. She was my patient navigator. The women had wings, seriously. You look at her, and she was just an angel because she set me up with the surgeon and I called up the surgeon.

I went into the office. They asked me, do you have insurance? Do you have your insurance card? I wanted to run out of there. And I said, no, all I have is this letter, and I handed the letter. She goes, oh, OK, and she takes it. And I was like that's it? This letter of introduction? That was it.

Chairman WAXMAN. You were being covered by the program.

Ms. CAREY. It was covered by this program.

Chairman WAXMAN. By Medicaid.

Ms. CAREY. It was unbelievable. They took the letter, no problem. I spoke to the doctor. I spoke to the Secretary.

Chairman WAXMAN. But your Senator had a large part in adopting in the Congress.

Ms. CAREY. I was absolutely terrified with this disease. I think I was more terrified because I couldn't pay for it. I was absolutely humiliated that all I had was a letter. I thought they were going to laugh me right out of that office.

I was accepted immediately. They were so dignified. They were so encouraging. They were so sympathetic, and they absolutely said, no question, we will take care of this.

Chairman WAXMAN. Well, thank you very much, Ms. Carey. You have given us a good example of how this program has succeeded.

Ms. CAREY. Extraordinary.

Chairman WAXMAN. We want more people to be able to have the wings of angels come and fan them and help them as well.

Ms. CAREY. Amazing.

Chairman WAXMAN. Thank you.

Ms. CAREY. Thank you.

Chairman WAXMAN. Thank you very much for being here.

[The prepared statement of Ms. Carey follows:]

Gail Carey
Breast Cancer Survivor Screening and Treatment Recipient,
The Healthy Women's Partnership, New York's version of
the National Breast and Cervical Cancer Early Detection Program (NBCCEDP)

Before

The Committee on Oversight and Government Reform
United States House of Representatives
Tuesday, January 29, 2008, 10:00 a.m.
Room 2154, Rayburn House Office Building

Good morning, Mr. Chairman and distinguished members of the Committee. I am Gail Carey, a 5-year breast cancer survivor from Long Island, New York. I appreciate the opportunity to discuss a critical program that I credit with saving my life, the National Breast and Cervical Cancer Early Detection Program.

As one of nine children, I learned at a young age the importance of helping out around the house, especially since both of my parents worked. When my mother developed emphysema and had to stop working, my family struggled financially. My parents later separated, forcing my mother and my siblings to turn to Medicaid for health coverage.

My mother always reminded us that Medicaid was a temporary remedy, not a permanent solution. After my mom passed away, I was inspired to find a good job that would give me health benefits. I was fortunate to find a position with an advertising and trade show company in New York.

After the attacks of 9/11, the New York trade show market collapsed and I along with 90 percent of my co-workers lost our jobs. Losing a job also meant losing my insurance benefits. I had separated from my husband the year before the attacks, so I had

no one to rely on for assistance. A few weeks after losing my job, I found what felt like a lump in my breast.

Having had previous experience in the mammography division of a health care facility I knew how important it was to get the lump checked out quickly. But financially, I couldn't afford to pay for a screening. After a couple months of job hunting, I was hired by a company that promised health insurance after three months. I waited the required three months before asking my boss about health benefits. I indicated that I had a health concern that needed to be addressed immediately, so getting my insurance was critical. Instead of receiving the benefits I was promised, I was fired.

It had been five months since I first found a suspicious lump in my breast, and I was still uninsured. Five months could be the difference between life and death, so I was really playing with a loaded gun. Fortunately, a friend of mine told me about a program, "The Healthy Women's Partnership," New York's version of the National Breast and Cervical Cancer Early Detection Program (NBCCEDP) that provides low-income, uninsured women with free or low-cost breast and cervical cancer screenings. The program, administered by the Centers for Disease Control and Prevention (CDC), was created to assist medically underserved women like myself in getting screened for cancer.

I became involved with Maureen Massellaro, a patient navigator from the American Cancer Society who helped me get the screening process underway. Doctors confirmed the lump in my breast was in fact cancerous. My surgeon, Dr. Capizzi, performed a partial mastectomy, but he feared that the cancer had not been entirely removed, so he performed a follow-up full mastectomy. All of the follow-up treatment,

including medications, was covered by Medicaid, thanks to the Breast and Cervical Cancer Prevention and Treatment Act.

I feel blessed to have found this NBCCEDP program that covered my screening and ensured I would have access to treatment. Without them, I likely would not have survived. Throughout this whole ordeal, I was treated with such dignity. This program is a phenomenon. I thought I was going to die because I didn't have coverage, and nobody should have that as their only option.

The impact of this program is more extensive than you may think, since it impacted not just my well-being, but also the lives of my children, family and friends. Since my treatment, I have been around to see my oldest daughter marry and just recently became a first-time grandmother. I hope you will continue to support and strengthen this program because for women like me, it can be the difference between life and death.

Chairman WAXMAN. Dr. Brawley.

STATEMENT OF DR. OTIS BRAWLEY

Dr. BRAWLEY. Mr. Chairman and distinguished members of the committee, I am Otis Brawley. I am a medical doctor. I am a medical oncologist and epidemiologist, and I serve as chief medical officer of the American Cancer Society and, in that capacity, represent the 3 million volunteers of the American Cancer Society.

As a medical oncologist and epidemiologist, I treat and study outcomes. I should also tell you that I have served on the Advisory Committee to the CDC Breast and Cervical Cancer Program. I have also directed a cancer center which did participate and still does participate in the Breast and Cervical Cancer Screening Program from the CDC.

In that program, we have leveraged money from the Komen Foundation, the Avon Foundation, the American Cancer Society and the State of Georgia for education and outreach, and it is very important that we emphasize that education is a very big part of this program, a very necessary part of this program in addition to providing medical care.

I am very proud that over the 6-years that I was director of the cancer center, with CDC funding and funding from our partners, we were actually able to create a stage shift in a large county hospital in Georgia where we halved the number of advanced breast cancers diagnosed on an annual basis and doubled the number of early stage breast cancers.

Chairman Waxman, I wrote at this point I was going to say that I can't say it better than you said in your opening statement. I will amend that to say I can't say it better than you in your opening statement and Ms. Carey in her statement.

It is my belief that the CDC is to be congratulated but that the CDC has been tremendously handcuffed by the lack of funds. Fifteen percent of those who should be getting these services are getting these services. These are people of all races and, in many respects, race does not matter. Regardless of race, all people, all women over the age 40 ought to be getting these lifesaving interventions.

Indeed, for mammography and breast cancer screening with clinical breast exam, it has been document that it can decrease the death rate by 25 percent.

The fruits of research from the 1970's, 1980's and 1990's are not being enjoyed by a substantial number of individuals. These are women who are dying. They are White. They are Black. They are Asian. They are Native American. They are Hispanic. They are of all races and all ethnicities, and they actually have in common the fact that they are poor or people who do not have resources.

As an epidemiologist, I would conservatively estimate the number of deaths per year that could be avoided at being somewhere in the neighborhood of 2,000 to 3,000; 2,000 to 3,000 human lives that could be saved if we were to expand this program.

Now, since I am an epidemiologist, I will answer a couple of the questions, if you don't mind, that several of the Congressmen asked earlier.

It is about one in seven or one in eight women who will be diagnosed with breast cancer in their lifetime. Among women who get the screenings that they should be getting, it is about 3 percent of all women who will ultimately die of breast cancer.

Among women who do not get the screenings, it is going to be over 4 percent. That 25 percent decrease in death rate is a 4 percent lifetime rate going down to a 3 percent lifetime rate.

There were questions about digital mammography versus conventional mammography. Right now, we think of both of them as being equal in terms of their diagnostic abilities.

However, digital mammography allows for easier storage and increased computerization, ultimately in the next several years, will allow for computerized abilities to read a digital mammogram to assist the radiologist and perhaps create a mammogram of higher quality and more likely to pick up the mass. We are virtually on the verge of that right now.

Also, there were questions about HPV testing. Someone who has a positive HPV test does not necessarily have cervical dysplasia, a precancerous condition or cervical cancer. It means that they actually have an infection with the virus that causes the disease.

At this juncture, pap smears are the standard, and we should use HPV testing judiciously to augment pap smear testing, but all women should get a pap smear on a regular basis. A few women ought to get a pap smear along with HPV testing.

If I could just enter my written statement into the record, sir, I will conclude with that.

Chairman WAXMAN. Thank you very much. Your statement in its entirety is part of the record.

Dr. BRAWLEY. Thank you, sir.

[The prepared statement of Dr. Brawley follows:]

Statement by

Otis Brawley, MD
Chief Medical Officer
American Cancer Society

Before

The Committee on Oversight and Government Reform
United States House of Representatives
Tuesday, January 29, 2008, 10:00 a.m.
Room 2154, 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 three million volunteers of the Society, I appreciate the opportunity to discuss an issue of utmost importance to our organization and to me personally. Reducing the burden of cancer globally and especially among minorities and medically underserved populations is a key priority of the American Cancer Society. Today, I'd like to share with you the importance of cancer screening and specifically, what our organization is doing to fight the war on cancer and describe how communities of color and low-income Americans often face the greatest barriers to accessing quality health care.

Since 1972, the Society has funded more than $323 million in breast cancer research grants that examine ways we can improve upon the prevention, early detection and treatment of breast cancer including the Sister-to-Sister study, which will enroll 50,000 women who have a sister with breast cancer, in an effort to find the causes of breast cancer. We also work in communities nationwide implementing programs that directly impact women battling cancer and their families, including helping them navigate through the health care system during treatment; providing support through recovery by offering wigs and prostheses, and continuing what is often lifetime support through our survivors network. In addition, we hope that many of you have, or will join the almost 500,000 walkers who participate in our Making Strides Against Breast Cancer events held in 160 communities nationwide and which raised almost $50 million last year. Since 1993, 3.5 million walkers have raised more than $230 million to help fight breast cancer.

Tens of thousands of these walkers have joined with our other volunteers to advocate for additional funds at the state and federal level for the National Breast and Cervical Cancer Early Detection Program, a program that strives to reduce the unequal burden of cancer among low-income and medically underserved women. Today, unfortunately, the program is only serving 1 out 5 eligible women nationwide who are 50-64 years old. If you include women as young as 40 years old who should be screened according to ACS guidelines, coverage nationally drops to just 14 percent of eligible women. This is largely due to insufficient federal funding support for the program. Federal appropriations have remained essentially static for the past six years.

The Impact of NBCCEDP

The National Breast and Cervical Cancer Early Detection Program (NBCCEDP), run by the Centers for Disease Control and Prevention (CDC) is a positive partnership between the states and federal government to provide medically underserved women, who previously may not have received these services due to their insurance and economic status, access to critical cancer screenings. NBCCEDP brings breast and cervical cancer screenings and post-screening diagnostic services to low-income, uninsured, and underinsured women, and since 2000 when Congress passed the Breast and Cervical Cancer Prevention and Treatment Act of 2000, women who are found to have cancer are being saved through access to cancer treatment through a Medicaid option that has been adopted by all 50 states.

Since its establishment in 1991, the NBCCEDP has been implemented in all 50 states, the District of Columbia, 4 U.S. territories, and 13 American Indian/Alaska Native organizations. To date, the program has provided 7.2 million screening exams to more than 3 million underserved women. About 50 percent of the women who received screenings through the program were minority women. In addition to providing access to life-saving screening tests, the NBCCEDP invests in numerous outreach activities. Outreach is essential; especially to serve women who are harder to reach since they are often also the women who have never been screened. The NBCCEDP supports an array of strategies, including education, quality assurance and improvement, evaluation, partnerships and provider recruitment. These

accomplishments demonstrate a truly successful collaborative effort between the federal, state and local government. It builds on the existing public health infrastructure and involves all sectors of the community in the outreach and delivery of services.

The American Cancer Society, along with our sister organization the American Cancer Society Cancer Action Network[SM] (ACS CAN), recognizes the enormous impact this program has on saving the lives of low-income, uninsured, and underinsured women diagnosed with breast and cervical cancer. The proven success of this life-saving early detection program demands that we fully fund it and that we focus more attention on outreach into communities to find and serve the 4 in 5 eligible women who are not being screened. It is critical that we invest federal resources to figure out new ways of reaching women as well as to maintain a critical level of providers to serve the women in this program.

In this regard, ACS and ACS CAN work with the NBCCEDP at the local level to increase breast and cervical cancer awareness for women, provides resources and promotes the accessibility of breast and cervical cancer screening and treatment. In addition to advocating for NBCCEDP, the American Cancer Society also helped secure implementation of the Breast and Cervical Cancer Prevention and Treatment Act in all 50 states and the District of Columbia. This act ensures that low-income women diagnosed with cancer through the NBCCEDP are eligible for Medicaid coverage of their treatment. The Society continues to advocate at the state level to protect Medicaid dollars so that there is sufficient funding for treatment of these women.

Screening and Early Detection

Last year it was estimated 178,480 women in the U.S. would be diagnosed with breast cancer and another 40,460 would die from the disease in 2007 alone. Furthermore, an estimated 11,150 women would be diagnosed with cervical cancer and another 3,670 would die from it. Together, breast and cervical cancer account for 28 percent of the estimated new cancer cases in women.

Preventing or curing all cancers is our collective goal. We know today essentially how to prevent 100 percent of all deaths from cervical cancer. We are also able to prevent up to 30 percent of all deaths from breast cancer. This is not because of a new scientific breakthrough; it is because of cancer screening tests, some which have been around since the late 1940s. The American Cancer Society has strongly advocated routine screening for cervical cancer with the Pap test for the past 50 years and has recommended routine mammography screening since the 1980s.

Regular mammography use has been shown to reduce breast cancer mortality. In the United States, death rates from breast cancer in women have been declining since 1990, due in large part to early detection. Further reductions in breast cancer death rates are possible by increasing mammography screening rates and providing timely access to high-quality follow-up and treatment.

Cervical cancer incidence and mortality rates have decreased 67 percent over the past three decades with most of the reduction attributed to the Pap test, which detects cervical cancer and precancerous lesions. Between 60 and 80 percent of women who are found to have advanced cervical cancer have not had a Pap test in the past five years. For women whose precancerous lesions have been detected through Pap tests, the likelihood of survival is nearly 100 percent with appropriate evaluation, treatment and follow-up. Cervical cancer is now one of the most successfully treated cancers and with the recent approval of vaccine immunization against HPV among young girls, there is a great potential for further reducing the occurrence of cervical cancer in the US. The American Cancer Society has played a critical role in developing and promoting the use of both the Pap test and mammography screening.

The stage at which breast or cervical cancer is diagnosed has an enormous impact on mortality and 5-year survival rates. For example, the five-year survival rate drops from 98 percent when breast cancer is diagnosed at the local stage, to 26 percent when it is detected after having spread. Likewise, the five-year survival rate is 92 percent when cervical cancer is found in the local stage but drops to 14.6 percent when spread to other parts of the body. Low rates of screening or irregular screening increases the risk that the cancer will grow

larger, and eventually present at an advanced stage when prognosis is poorer than it would have been if the cancer had been detected while still localized. In so far as we presently are unable to predict with any certainty whether or not a woman will develop breast or cervical cancer in her life, and if so when, regular screening is a form of insurance against the risk of being diagnosed with an advanced cervical or breast cancer.

It is pretty clear, screening and early detection are critical for decreasing the mortality rates of breast and cervical cancer. Any reduction in cancer mortality depends on the increased use of mammography and pap tests for the early detection of the disease.

Despite increased awareness among women to utilize these screenings, many women continue to face barriers that prevent their screening participation. Approximately 40 percent of American women age 40 and older did not have a mammogram in the past year. The uninsured, low-income, and racial and ethnic minority women are especially at high risk. While there have been improvements in prevalence of mammography screening since the 1980s, racial disparities have grown and stagnated since the late 1990s. Many deaths from breast and cervical cancers could be avoided by increasing screening rates among minority and medically underserved women.

Cancer Disparities

Recent studies show that substantial disparities exist in breast and cervical cancer diagnosis, treatment, and survival among American women. Stage at diagnosis is consistently shown to be more advanced in racial and ethnic minority, lower income, and uninsured women. Much of the disparity in breast and cervical cancer screening and outcomes is due to underlying differences in income and health insurance, although quality of care, language barriers, unhealthy environments, region of residence, cultural and genetic differences, and racial discrimination also play a significant role. Minority women may be at a higher risk for dying of breast cancer because they are more likely to be diagnosed at later stages in which treatment is more difficult and prognoses are often worse. A recent study by American Cancer Society researchers found that breast cancer patients who are African American are

less likely to get a key diagnostic test to make appropriate treatment decisions and as a result are not receiving the quality treatment that they need [Halpern MT ,Chen AY, Schrag NM, Ward, EM. Disparities in receipt of lymph node assessment among early stage female breast cancer patients. Presented at the American Association for Cancer Research conference on The Science of Cancer Health Disparities in Racial/Ethnic Minorities and the Medically Underserved, Atlanta, GA. November 2007.].

Additionally, other socioeconomic factors, such as poverty and insurance coverage that lead to disparities in screening, may account for some of the differences seen between races in stage at diagnosis. Currently, less than one in three uninsured women were able to get a mammogram in the previous year. A new report from the American Cancer Society finds substantial evidence that lack of adequate health insurance coverage is associated with less access to care and poorer outcomes for breast cancer patients [Ward E, Halpern M, Schrag N, Cokkinides V, Desantis C, Bandi P, Siegel R, Stewart A, Jemal A. Association of insurance with cancer care utilization and outcomes. CA Cancer J Clin. 2008 Jan-Feb;58(1):9-31. Epub 2007 Dec 20]. The report finds the uninsured are less likely to receive recommended cancer screening tests, are more likely to be diagnosed with later stage disease, and have lower survival rates than those with private insurance for breast and several other cancers. For breast cancer, the article reports that:

- Women without health insurance are about half as likely as those with private health insurance to have received a mammogram in the past two years (38.1 percent of uninsured women versus 74.5 percent of insured women age 40-64), a pattern seen for all race/ethnicities studied (white, African American and Hispanic) at all levels of education.
- Twenty to 30 percent of uninsured women were diagnosed with late stage (stage III/IV) breast cancer, compared with ten to 15 percent of privately insured patients.
- Uninsured women were also less likely to be diagnosed with Stage I (early) breast cancer than privately insured women. In white women, where this disparity was greatest, almost 50 percent of those who were privately insured were diagnosed with early-stage cancer, compared to less than 35 percent of those who were uninsured.
- Among white women diagnosed with all stages of breast cancer, 76 percent of those who were uninsured survived five years, compared with 89 percent of those with private insurance; among African Americans, five-year survival rates were 65 percent for

uninsured and 81 percent for privately insured women; among Hispanics, five-year survival rates were 83 percent for uninsured and 86 percent for privately insured women.

- Differences in survival between privately insured and uninsured women were seen for all stages of breast cancer.

Conclusion

In conclusion, breast and cervical cancer have become two of the most preventable and increasingly curable life-threatening diseases – but only if we take the steps necessary to prevent it, detect it early and provide access to care. The only way we can continue to make progress in the fight against breast and cervical cancer is by working to ensure women continue getting their regular mammogram and pap test, which can detect cancer at its earliest, most treatable stage.

While we have made some strides, much work remains to be done to increase screening in medically underserved populations. We should make a commitment as a nation to remove any and all financial barriers to breast and cervical cancer screenings for the uninsured and underinsured women. The National Breast and Cervical Cancer Early Detection Program helps accomplish this but current funding is completely insufficient to continue the progress this program has made in reaching increasing numbers of women that might not otherwise receive these life-saving tests, and is not sufficient to maintaining a steady pool of providers.

Our goal at the American Cancer Society, working with our sister organization, the American Cancer Society Cancer Action Network, is to ensure that all women have access to existing and future detection methods and treatments so that breast and cervical cancer will eventually no longer kill so many of our mothers, sisters, wives and friends. We look forward to working with you on all of these efforts. Thank you again for inviting me here today, and I would be happy to answer any of your questions.

American Cancer Society Recommendations for the Early Detection of Cancer in Average Risk, Asymptomatic People

Cancer Site	Population	Test /Procedure	Frequency
Breast	Women, aged ≥20 years	Breast self-examination (BSE)	Beginning in their early 20s, women should be told about the benefits and limitations of BSE. The importance of prompt reporting of any new breast symptoms to a health professional should be emphasized. Women who choose to do BSE should receive instruction and have their technique reviewed on the occasion of a periodic health examination. It is acceptable for women to choose not to do BSE or to do BSE irregularly.
		Clinical breast examination (CBE)	For women in their 20s and 30s, it is recommended that CBE be part of a periodic health examination, preferably at least every 3 years. Asymptomatic women aged ≥40 years should continue to receive a clinical breast examination as part of a periodic health examination, preferably annually.
		Mammography	Begin annual mammography at age 40 years.*
Cervix	Women, aged ≥18 years	Pap test	Cervical cancer screening should begin approximately 3 years after a woman begins having vaginal intercourse, but no later than age 21 years. Screening should be done every year with conventional Pap tests or every 2 years using liquid-based Pap tests. At or after age 30 years, women who have had 3 normal test results in a row may get screened every 2 to 3 years with cervical cytology (either conventional or liquid-based Pap test) alone, or every 3 years with a human papillomavirus DNA test, plus cervical cytology. Women aged ≥70 years who have had 3 or more normal Pap tests and no abnormal Pap tests in the last 10 years and women who have had a total hysterectomy may choose to stop cervical cancer screening.

* Beginning at age 40 years, annual clinical breast examination should be performed prior to mammography.

How the American Cancer Society Helps Women with Breast and Cervical Cancer

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 Network℠ (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"™***
  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 and class discussions.

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 2005, more than 400,000 walkers across the country raised more than $34 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 4,700 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. As of January 1, 2006, through its extramural research grants program, the American Cancer Society funds 203 extramural research projects relating to breast cancer, totaling nearly $109 million. These projects include: research on antiangiogenesis drugs that block the supply of new blood vessels to breast tumors; 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

- American Cancer Society Cancer Action Network (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

- The Society's non-profit, non-partisan sister advocacy organization, the American Cancer Society Cancer Action Network℠ (ACS CAN) was founded in 2001. It uses issue campaigns and voter education aimed at lawmakers and candidates to support laws and policies that will help people fight cancer.

Chairman WAXMAN. Ms. Fuld Nasso.

STATEMENT OF SHELLEY FULD NASSO

Ms. FULD NASSO. Thank you very much, Mr. Chairman, and thank you to all the committee members for holding this very important hearing today and for allowing me to testify.

My name is Shelley Fuld Nasso, and I am director of public policy for Susan G. Komen for the Cure Advocacy Alliance.

Komen for the Cure was founded in 1982 and is the largest grassroots network of survivors, breast cancer survivors and activists and the world's largest non-profit source of funds for fighting breast cancer.

As you heard, one in eight women will be diagnosed with breast cancer in her lifetime, and every one of them deserves the same chance to succeed, to survive. Unfortunately, in the United States, whether you live or die from breast cancer depends in large part on how much money you earn, whether you have health insurance, the color of your skin and where you live.

This is unconscionable especially since breast cancer has become such a treatable disease. We know that when breast cancer is detected early and is still confined to the breast, the survival rate is 98 percent.

Over the past 10 months, we have been traveling around the country with the Komen Community Challenge, our grassroots campaign to restore the sense of urgency to breast cancer. Everywhere we go, we meet women like Ms. Carey who are alive today for one reason, because of the breast and cervical screening program. I was going to share a couple of their stories with you, but I think Ms. Carey said it all, and you understand how important this program is.

Some of the women were uninsured during transitions in their lives, like Ms. Carey, because they found themselves without insurance. Others were uninsured for longer periods of time. They maybe were poor and working, and some of them working multiple jobs but still couldn't afford health insurance. This screening program was a really important source for them to be able to have that care.

One of the women that spoke at one of our events was screened on a regular basis through the program which is very important. It wasn't just that she found a lump. She considered herself a health nut. She had no concerns, no lump that she felt, but she was screened regularly which is very important to helping treat, to detect the disease early.

The program saves lives every day, but as you know we are only reaching a fraction of the women who are eligible and serving less than one in five, and that means millions of women are going without the screenings that they need.

I am not an epidemiologist, so I wouldn't have estimated the number of women whose lives could be saved, but I appreciate your, Dr. Brawley's estimates because it is a very important question because we know that we don't have enough money for this program to save lives that need to be saved.

We have talked a little bit about digital mammography which we know is more expensive than standard mammography, but its use

is spreading rapidly. While it may be more effective for some groups of women, Dr. Brawley has said it is considered about equal.

But the concern is that as it spreads in its use, that women are not going to have access if a community in a rural area or an urban area has only digital access available, and providers are not necessarily willing to accept the lower reimbursement rates for standard mammography. And so, we are seeing anecdotally from our Komen affiliates around the country that some women are not able to have access because all of the facilities in their area have become digital.

We are asking Congress to support this program at a higher level, but we are not asking you to do it alone. We really believe that this is a true public-private partnership, and Komen and its 125 affiliates are doing their part.

Last year, we provided $70 million in grants to community health programs including $25 million around the country for the State programs and some of their providers to augment the screening services available. This funding provides State programs with more flexibility to maintain or increase the number of women screened per year, alleviating waiting lists and helping to detect cancer earlier.

One question was asked as to what happens when the money run out. Some programs really strategically use their money throughout the year so that the money doesn't run out, but in other States the funding does run out during the year.

Our mid-Kansas affiliate has helped to fill that gap when the program in Kansas has run out every year for the last 3 years. In addition, the Kansas program serves women 50 and older, and the Komen funds are used to serve the women in their 40's for the program.

In addition to funding, Komen affiliates have joined with other advocates like the American Cancer Society in urging State legislatures to do their part. Not all States do provide money for this program. We think that only about a third of the States are providing funding.

They do not have to provide their own dollars for that one to three match that we were discussing earlier, and some of our advocacy campaigns in conjunction with our colleagues have helped raise significant amounts of money at State legislatures. In North Carolina, the State assembly approved $2 million per year for the next 2 years which will allow an additional 8,000 women to be served. In Ohio, the State approved $5 million over 2 years which will triple the number of women who can be served.

In our first 25 years, Komen invested $1 billion in the fight against breast cancer, and we have pledged to invest another $2 billion in the next 10 years. So we are not asking the Federal Government to do it alone. But, at the same time, we can't do it without the Federal Government.

This program is an important, cost effective and lifesaving program. In order to close the gaps that make breast cancer deadlier for some women than others, we need the Federal Government to increase its commitment to funding the program because every

woman's life is valuable and every woman is someone's mother, wife, sister or friend.

Thank you very much for listening.

[The prepared statement of Ms. Fuld Nasso follows:]

Committee on Oversight and Government Reform

U.S. House of Representatives

Testimony of

Shelley Fuld Nasso
Director of Public Policy
Susan G. Komen for the Cure Advocacy Alliance

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.

---

[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

---

[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.

---

[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

---

[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 every 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.

Chairman WAXMAN. Thank you very much for you testimony.

Dr. Joyner.

STATEMENT OF PAMA JOYNER

Ms. JOYNER. And I am not a doctor but today I am, I guess.

Thank you, Mr. Chairman and distinguished members of the committee for the opportunity to testify before you today on the experience of Washington State with our Breast and Cervical Health Program and that of other members, States, tribes and territories of the National Association of Chronic Disease Directors Breast and Cervical Cancer Council.

My name is Pama Joyner, and I am the program director for Washington's program. My responsibilities include providing leadership for program implementation, overall program focus and direction, and establishing and maintaining key stakeholder relationships.

Early detection is the best way to reduce deaths from breast and cervical cancer and all States, the District of Columbia, 12 tribes and 5 territories support a variety of strategies to reach underserved women.

In Washington, our program not only saves lives but also enhances the overall health and well being of women who participate. Since the program's inception, we have offered vital services to thousands of Washington's most economically burdened women.

It is a core value that each woman enrolled received state-of-the-art screening, diagnostic and treatment services. The women's health examination, provided at initial enrollment and then repeated with each re-screening, is often the only primary care visit these women receive.

An increasing number of women across the Nation meet the eligibility requirements, yet system and resource capacity is pressed to even maintain existing service levels with each State only able to reach a fraction of the eligible population.

In Washington, we are reaching approximately 30 percent of the eligible uninsured population. In Virginia, they are screening 22 percent of their eligible uninsured population where Tennessee and New York are reaching 11 percent.

Illinois, where they recently received a substantial increase in State funding for their program, is still only able to screen 17 percent of the eligible population. In California, they are able to screen approximately 23 percent of the eligible uninsured and underinsured population for breast cancer and just 8 percent for cervical cancer.

States use a variety of strategies so that funding either meets their screening goals or ensures services are available throughout the year. Some States report they run out funding before the end of the program year due to meeting their screening goals early, and in other States the programs monitor enrollment and expenditures to ensure services are available all 12 months of the program year.

Waiting lists are a good indication of program need. However, many are uncomfortable in creating waiting lists as there is a sense that eligible women are being promised services the program may not be able to deliver.

In Washington State, when screening resources were limited to Federal and State funding only, waiting lists were instituted. At one point, more than 1,000 women across the State were waiting for screening services. We were able to stop having waiting lists upon receiving grant awards from the Susan G. Komen for the Cure to support breast health screening services.

In Virginia, providers have begun to maintain waiting lists. The program currently projects there are approximately 100 women waiting for services. Florida and Idaho also report similar numbers at some of their screening sites by the end of the program year. The reason, though, for Ohio's waiting list is not due to a lack of funding but to staffing and appointment limitations.

In Tennessee, there is no waiting list. The program projects it will need to stop screening mid-May and plans to ask women to call back after the start of the new program year, July 1st.

New technologies and increasing health costs impact a program's ability to increase their screening numbers. Level funding year after year is recognized as a cut, resulting in fewer women screened. Other operational costs continue to increase while funding remains relatively flat, impacting a program's ability to maintain or increase its screening numbers.

Tennessee experienced a significant cost increase when they decentralized their program. This created a greater demand for services as more eligible women became aware of the program, and it impacted their costs in other areas of the program. This includes advertising the service, providing the services and supporting access to treatment for those women diagnosed with cancer. All of these activities are required to meet the program performance measures.

Increasing financial resources to screen more women is necessary but having provider capacity to screen more women is critical. Many programs rely on the local public health agencies and network of community health clinics and others. While they use these systems, they also contract with individual providers and large private clinic systems.

In fiscal year 2007, Washington State screened 2,000 more women than they did in 2006 and, our goal this year is to screen 2,000 more women than we did last year. With just 10 percent more funding each year, we could continue to increase these numbers over the next 4 years and reach 41 percent.

Early detection is the best way to reduce deaths from breast and cervical cancer. Access to screening, diagnostic services and treatment is critical for all women, regardless of income, education, race or ethnicity.

However, women with low incomes are less likely to receive cancer screening and are more likely to be diagnosed with more advanced diseases than higher income women. This national program not only saves lives but also enhances the overall health and well being of the Nation's most economically burdened women.

Thank you.

[The prepared statement of Ms. Joyner follows:]

STATEMENT OF PAMA JOYNER
PROGRAM DIRECTOR OF THE
WASHINGTON BREAST AND CERVICAL HEALTH PROGRAM
WASHINGTON STATE DEPARTMENT OF HEALTH
BEFORE THE
COMMITTEE ON OVERSIGHT AND GOVERNMENT REFORM
UNITED STATES HOUSE OF REPRESENTATIVES

January 29, 2008

Dear Chairman Waxman and Ranking Member Tom Davis,

Thank you for the opportunity to provide testimony on the experience of Washington State with our Washington Breast and Cervical Health Program (WBCHP) and that of other member states of the National Association of Chronic Disease Directors (NACDD) Breast and Cervical Cancer Council. My name is Pama Joyner and I have worked for the Washington State Department of Health (DOH) for eight years. I am the Acting Unit Director for the Cancer Prevention and Control Unit and Program Director for WBCHP. My responsibilities include providing leadership for program implementation; overall program focus and direction; and establishing and maintaining key stakeholder relationships.

Today I will provide information on current state-level program operations and challenges to states' ability to reach eligible women. Specifically, given that **early detection is the best way to reduce deaths from breast and cervical cancer,** grantees support a variety of strategies to reach underserved women. These strategies include program management, screening and diagnostic services, data management, quality assurance and quality improvement, evaluation, partnerships, professional development, and recruitment.

Washington's Breast and Cervical Cancer Health Program (WBCHP) enhances the overall health and well-being of Washington women

In Washington, our WBCHP not only saves lives, but also enhances the overall health and well-being of women who participate. Since the program's inception, WBCHP has offered vital services to thousands of Washington's most economically burdened women. It is a core value of the program that each woman enrolled receives state-of-the art screening, diagnostic and treatment services. The women's health examination provided at initial enrollment, and then repeated with each rescreening, is often the only primary care visit an enrollee receives.

Challenges: System and resource capacity is pressed to maintain existing service levels

An increasing number of women across the nation meet the eligibility requirements, yet system and resource capacity is pressed to even maintain existing service levels.

- *Each state is only able to reach a fraction of the eligible population*

Nationally, the program is only able to reach 14.7% of the eligible uninsured and underinsured population for breast cancer and 6.7% for cervical cancer. In Washington we are reaching approximately 37% the eligible uninsured populations.

For example, the state of Virginia is able to screen 22% of its eligible uninsured population; Tennessee is screening approximately 11% of the eligible uninsured; in New York State they too are screening approximately 11% of their eligible population. Illinois, where there has recently been a substantial increase in state funding for their program, is still only able to screen 17% of its eligible population. In California, they are able to screen approximately 23%

of the eligible uninsured and underinsured population for breast cancer and just 8% for cervical cancer.

■ *States use a variety of strategies so that funding either meets screening goals or ensures services are available throughout the year*

Some states report they run out of funding before the end of the program year due to meeting their screening goals early. In other states, the program monitors enrollment and expenditures to ensure services are available all 12 months of the program year. Minnesota projects that they will run out of funds before the end of the current program year due to two principal causes: 1) They are screening significantly more women for cancer than anticipated; and, 2) a higher proportion of the women they are screening are uninsured which means that all of the diagnostic tests are paid for by the program. Such tests, over the past eight years, have become more costly.

California has experienced an increase in clinical demand resulting in the state allocation of tobacco tax revenues near the end of the fiscal year in order that all women seeking screening are served. Similar to Minnesota, the program reports the increased number of more costly diagnostic procedures leads to funds running out before the end of the program year.

In Virginia, a capped rate is paid for each woman screened, covering all screening and diagnostic procedures, plus any follow up. Providers contract to serve a specific number of women at the established capped rate. Virginia reports that many of their providers are cutting back clinic days/appointments since they have reached the number of women they were contracted to serve or are very near to reaching their contract goal. Just half-way through the current program year, several providers in Virginia are accepting only symptomatic women in order to prioritize their caseload.

In the state of New York, screening goals are established but funds may run out before the end of the program year due to screening in excess of the goal or from higher than anticipated costs for the women screened.

Texas fully expends their federal award each year. And, each year about half of their providers spend out their contracts before the end of the contract period. Most of their providers limit enrolling new clients before the end of the contract funding period and carefully schedule rescreening so that funds are available to pay for priority diagnostic services until the end of the contract period.

The state of Idaho reports that they carefully manage enrollment and screening to prevent over enrollment. However, their current screening numbers indicate that they will have to stop enrollment/screening before the end of the fiscal year and employ waiting lists statewide.

Maryland operates a decentralized program with funds allocated to local health jurisdictions. The state monitors expenditures of each jurisdiction and has the ability to shift funds between them when one might be running out of funds and another might not be spending funds fully. The primary cause for those local jurisdictions that run out of funds is due to over-enrollment.

In past program years, Ohio ran out of funds before the end of the program year. Learning from past funding cycles, it developed strategies to better estimate screening projections, closely monitored expenditures and had to stop screening around March or April. Further impacting the Ohio program and other states are increased costs for diagnostic services and more clients requiring those procedures. For the coming program year (2008 – 2009) Ohio will for the first time have state funds to assist the program in not running out of resources before the end of the program year.

■ *Waiting lists can be useful, but they also have drawbacks.*

Waiting lists are a good indication of program need. However, many programs are uncomfortable in creating waiting lists as there is a sense that eligible women are being promised services the program may not be able to deliver. In Washington State, when screening resources were limited to federal and state funding only, wait lists were instituted. At one point, more than 1,000 women across the state were waiting for screening services. We were able to stop having waiting lists upon receiving grant awards from the Susan G. Komen for the Cure to support breast screening services.

In Virginia, providers have begun to maintain waiting lists. The program currently projects there are approximately 100 women waiting for services. Florida reports similar numbers at some of its screening sites by the end of the program year.

In Tennessee, there is no waiting list. The program projects it will need to stop screening mid-May and plans to ask women to call back after the start of the new program year, July 1, 2008.

New York's program assures that women are not turned away for services by securing additional state funds to assure payment to service providers.

Before receiving a significant increase in state funds, Illinois maintained waiting lists and implemented a policy that prioritized services for women reporting symptoms, thus asymptomatic women only were placed on the waiting list. These waiting lists (per Lead Agency) were generally fewer than 100 women.

Ohio, too, developed and continues to maintain a waiting list. Currently there are less than 100 women on the list in two out of eleven regions in the state. The reason for the waiting list is not due to lack of funding, but to staffing/appointment limitations.

■ *New technologies and increased health costs impact the ability to maintain or increase screening numbers*

New technologies and increasing health costs impact a program's ability to increase screening numbers. Level funding year after year is recognized as a cut, resulting in fewer women screened.

Each state manages increasing costs with different strategies. In California the reimbursement rates are tied to Med-Cal, the state Medicaid system, realizing some cost savings over the standard practice of reimbursing at Medicare rates. This strategy is becoming less effective, as California reports that without a significant increase to Med-Cal rates in several years – rates are the lowest in the nation – makes it very difficult for the program to recruit and retain providers. Furthermore, the state has seen a 55% increase in the number of women screened since 1999, whereas the costs for screening have increased by 142%.

In Virginia, because it uses a capped system, the impact is not as great as in other states as the excess financial burden has fallen onto the provider. However, many of those providers have begun to push back and ask for a higher capped rate.

Texas, too, has experienced significant cost increases related to new technologies. The program reports that from 1999 to 2005 new patient office visits increased by 27%, whereas established patient office visits increased by 40%. Screening mammograms went up 29% and conventional Pap tests 106%.

In Maryland, some radiology facilities have stopped participating in the program as they have switched to digitized mammography and will not accept conventional mammography reimbursement rates for the service.

Washington State experienced a 72% increase in screening and diagnostic costs between 1999 and 2005. Costs are higher for first-time enrollees to this program. Over 70% of the pre-cancerous conditions and cancers diagnosed in the program have been in newly enrolled women. Previously screened women most often have normal screening results that end up being less costly. These are typical screening outcomes for most programs.

Other operational costs continue to increase while funding remains relatively flat impacting a program's ability to maintain or increase its screening numbers. Tennessee experienced a significant cost increase when decentralizing its program. A greater demand for services was created (more eligible women became aware of the program) which impacted costs in other areas of the program. This included advertising the service, providing timely and adequate services, and supporting access to treatment services for those women diagnosed with cancer. All of these are activities required to meet the performance measures of the program.

Ohio reports that multiple factors impact their ability to maintain and/or increase their screening numbers. While clinical services alone has increased almost 20% in the last 3 years another substantial increase in costs are in the area of program infrastructure necessary to support the enrollment and screening of clients. This includes staff costs and the associated costs of "doing business." Unlike the larger health care arena, where staffing and infrastructure costs are shared across many funding sources or payers, state programs are finding it more and more difficult to maintain, let alone increase their screening numbers, when funding levels remain flat.

■ *Additional funds and provider capacity would allow states to screen more women*

Increasing financial resources to screen more women is necessary but having provider capacity to screen more women is critical. Many programs rely on local public health agencies and/or the network of community health clinics in their state. Other programs use these systems but also contract with individual providers or private large clinic systems.

In FY 2007, Washington State screened 2,000 more than FY 2006. Our goal is to screen an additional 2,000 more women in FY 2008. With just 10% more funding each year we could continue to increase these numbers over the next four years and reach 41% of the eligible uninsured population by FY 2012. At this point we would need to assess the current provider network capacity and begin to identify and secure contracts with other providers.

The Missouri program states that with additional financial resources they believe they could increase the number of women they screen by 5 to 10% more if they can get more providers.

New Hampshire just started receiving state funds to support their screening program. They believe with more financial resources they could screen 25 to 35% of their eligible population.

In Virginia, if more funding resources were available they could immediately screen 35 to 50% more women and work toward increasing the overall percentage of the eligible population screened over time. The program notes however this also will require strengthening their provider network and capacity.

Tennessee projects they could handle at least 25 to 35% more women than they currently screen, whereas New York, Maryland and Florida all state they could screen between 25 and

35% of the eligible population if financial resources were available. California believes that to sustain good quality care for all eligible women, the program could expand its service delivery system by 5% annually, about 145,000 more women each year.

An assessment would need to be done to determine what the existing service delivery system in each state could handle. Planning would also be needed to incrementally expand services based on the number of new providers in which each state could secure agreements or contracts.

■ *Low reimbursement rates serve as a disincentive to program participation*

In 2006, Washington's Medical Advisory Committee (MAC) successfully intervened when a contracted local radiology practice refused to perform stereotactic breast biopsies due to low reimbursement rates, resulting in women from five counties traveling up to 100 miles to access services. The MAC wrote a letter to this practice explaining the reasoning behind the reimbursement policy and the impact of their decision on the community. After receiving two letters, the practice agreed to continue contracting with WBCHP to provide these services. DOH plans to use this strategy in the future as reimbursement policies continue to impact access to clinical services.

California reports that some providers have voluntarily left the program due to Medi-Cal (Medicaid) rates. Virginia reports its providers are having difficulty negotiating contracts with their subcontractors, impacting their client's ability to access mammograms and diagnostic tests. This situation is tied to drops in Medicare reimbursement rates. Florida reports it is having difficulty keeping providers in some areas of the state due to reimbursement rates.

In New York, oncologists and surgeons in certain geographic areas of the state will not participate in the Medicaid program or no longer accept Medicaid clients for cancer treatment due to low reimbursement rates. In the northern part of the state, the reimbursement issue is especially troublesome, as the only Oncology practice refuses to accept Medicaid clients. As a necessity, clients travel outside the county to receive their vital cancer treatment. Furthermore, oncologists are unable to purchase many of the cancer drugs they administer to clients for prices less than the Medicare amounts. Clients transitioned to the state Medicaid program who are terminally ill are transferred to Social Security due to disability and their cancer drugs are paid for by Medicare.

There is a perception by providers that if they accept one Medicaid client they will need to open their door to all Medicaid clients.

Texas routinely hears from its contractors that they have trouble finding providers who will accept the screening program's Medicare reimbursement rates. A new provider signed on for the current program year, and after two months, terminated the contract as the medical community in that service area would not accept clients for diagnostic procedures or cancer treatment services. Idaho, too, reports problems are encountered when trying to access diagnostic tests, surgical consults, and cancer treatment services.

In Ohio, the program is starting to hear from providers that are limiting the number of Medicaid and/or Medicare clients they will take on during the program year. In addition, Ohio reports providers are frustrated services cannot be reimbursed due to NBCCEDP program policies for procedures covered by Medicaid and/or Medicare.

Transition to Treatment Program: In Washington we find that regardless of the total number of women screened (increasing number each year), the percentage of women diagnosed

with cancer each year is 1.5% of the total number screened. Many of the other states report this same type of trend.

Private/Local Partnerships: For grantees fortunate to have state and private resources there is greater flexibility to maintain or increase the number of women screened each year. A few states receive direct funding from affiliates of the Susan G. Komen for the Cure® and from their local American Cancer Society in their state. Many other states have providers who receive grants from affiliates of the Susan G. Komen for the Cure® and, in many instances, these services are coordinated with the state program. However, there remain a number of grantees who operate their programs with federal funds only, or with limited additional resources. These programs continue to struggle with maintaining or increasing screening rates when funding remains flat.

Summary

Early detection is the best way to reduce deaths from breast and cervical cancer.

Access to screening, diagnostic services and treatment is critical for all women regardless of income, education, race or ethnicity. However, women with low incomes are less likely to receive cancer screening and are more likely to be diagnosed with more advanced disease than higher-income women.

To reach these underserved women, all grantees support a variety of strategies, including program management, screening and diagnostic services, data management, quality assurance and quality improvement, evaluation, partnerships, professional development, and recruitment.

Chairman WAXMAN. Thank you very much, Ms. Joyner.

Dr. Hoerger.

STATEMENT OF THOMAS HOERGER

Mr. HOERGER. Thank you. Mr. Chairman and members of the committee, I am pleased to appear before you today to provide you with information regarding a cost analysis conducted by researchers at RTI International of the National Breast and Cervical Cancer Early Detection Program.

I am Tom Hoerger, a senior fellow at RTI International and also director of the RTI-University of North Carolina Center of Excellence in Health Promotion Economics. RTI International is an independent, non-profit research organization based in North Carolina that conducts a wide range of research and technical services for the U.S. Government and private sector clients.

The study in question was conducted by RTI researchers in collaboration with researchers from the U.S. Centers for Disease Control and Prevention. Although I am not an author of this particular study, I am very familiar with its findings and have significant experience in conducting similar studies. The study will appear in the February 2008 issue of the journal, Cancer.

The study analyzed the costs associated with the Breast and Cervical Cancer Program established by Congress in 1990 to deliver breast cancer and cervical cancer screening to medically underserved, low income women.

The study looked at nine participating programs in nine different States to answer three economic questions. No. 1, what is the cost per women served in the program? No. 2, what is the cost per woman served by program component? And, No. 3, what is the cost per cancer detected through the program?

There was wide variation in the nine programs from State to State in terms of organization, reliance on in-kind contributions and the number of women served. These and other factors contributed to a fairly wide variation in costs.

We found that the median cost in the nine State programs was $555 per woman served. This figure includes the value of in-kind contributions such as donated goods and services. Without in-kind contributions, the cost was $519 per woman served.

The term, women served, includes the number of women screened in the program plus the number of women who were screened outside the program and were referred to the program at the diagnostic stage for followup of abnormal results.

When looking at the screening alone, screening for breast cancer costs $94 per patient while the cost for cervical cancer screening was $56 per patient. These estimates are within the range of estimates for the costs of breast and cervical cancer screening in other settings and programs.

The median number of breast and cervical cancers detected per program was 75 and 26, respectively. Based on these figures, the study found that the cost per breast cancer detected was $10,566. The cost per detection of cervical cancer was $13,340.

Based on the research, there is also some evidence of possible economies of scale in that average costs may go down with the number of women screened. However, the evidence is not conclu-

sive because only a small number of programs were surveyed. In addition, the sites were not randomly selected.

The study also assessed the program's allocation of funds. Almost 60 percent of the program funds were used for direct clinical services which include screening and diagnostic followup, referral for treatment and case management.

The remaining 40 percent of program resources were dedicated to activities including public education and outreach, professional education, quality assurance and improvement, surveillance and evaluation. These activities help address issues other than financial barriers that prevent low income women from receiving cancer screening services.

Studying only nine of the programs for just 1 year leaves some limitations in the findings because the sample size is small and we know that funding and other sources of resources vary from year to year depending on activities planned.

However, we are currently conducting a second phase of this study that will provide a more comprehensive examination of the costs associated with screening in the program. Phase two of the study is examining all 68 breast and cervical cancer programs operating in the United States.

Collecting cost data from all of the programs will provide a much richer understanding of program variation and will support econometric analysis of cost determinants. We will test for economies of scale and be able to control for differences in cost of living between programs. The data may allow us to identify best practices and learn more about the optimal mix of spending across program activities.

This study is expected to be completed in 2009.

Thank you for your time.

[The prepared statement of Mr. Hoerger follows:]

Prepared remarks
of

Thomas Hoerger, Ph.D.
Senior Fellow, RTI International, and
Director of the RTI-University of North Carolina
Center of Excellence in Health Promotion Economics

before the
House Oversight and Government Reform Committee

regarding

"Breast/Cervical Cancer Screening Gap"

January 29, 2008

RTI
INTERNATIONAL

Mr. Chairman and Members of the Committee, on behalf of RTI International, I am pleased to appear before you today to provide you with information regarding a cost analysis conducted by researchers at RTI of the *National Breast and Cervical Cancer Early Detection Program.*

I am Dr. Tom Hoerger, a Senior Fellow at RTI International and also director of the RTI-University of North Carolina Center of Excellence in Health Promotion Economics. RTI International is an independent, nonprofit research organization based in North Carolina that conducts a wide range of research and technical services for the U.S. Government and private sector clients.

The study in question was conducted by RTI researchers in collaboration with researchers from the U.S. Centers for Disease Control & Prevention. Although I am not an author of this particular study, I am very familiar with its findings and have significant experience in conducting similar studies. The study will appear in the February 2008 issue of the journal *Cancer.* [1]

The study analyzed the costs associated with the Breast and Cervical Cancer Early Detection Program, established by Congress in 1990 to deliver breast cancer and cervical cancer screening to medically underserved, low-income women.

The study looked at nine participating programs in nine different states to answer three economic questions:

1. What is the cost per woman served in the program?
2. What is the cost per woman served by program component?
3. What is the cost per cancer detected through the program?

There was wide variation in the nine programs from state to state in terms of organization, reliance on in-kind contributions, and the number of women served. These and other factors contributed to a fairly wide variation in costs.

---

[1] Donatus U. Ekwueme, James G. Gardner, Sujha Subramanian, Florence K. Tangka, Bela Bapat, Lisa C. Richardson. "Cost Analysis of the National Breast and Cervical Cancer Early Detection Program: Selected States, 2003 to 2004." *Cancer*, 2008.]

We found that the median cost in the nine state programs was $555 per woman served. This figure includes the value of in-kind contributions such as donated goods and services. Without in-kind contributions, the cost was $519 per woman served. The term "women served," includes the number of women screened in the program, plus the number of women who were screened outside the program and were referred to the program at the diagnostic stage for follow-up of abnormal results.

When looking at the screening alone, screening for breast cancer cost $94 per patient, while the cost for cervical cancer screening was $56 per patient. Those costs refer to the cost of screening a woman who received either a mammography and a clinical breast examination or the Pap test for cervical cancer. These estimates are within the range of estimates for the costs of breast and cervical cancer screening in other settings and programs.

The median number of breast and cervical cancers detected per program was 75 and 26, respectively. Based on those figures, the study found that the cost per breast cancer detected was $10,566. The cost per detection of cervical cancer was $13,340.

Based on the research, there is also some evidence of possible economies of scale, in that average costs may go down with the number of women screened, but the evidence is not conclusive. Only a small number of programs were surveyed; in addition, the sites were not randomly selected.

The study also assessed the program's allocation of funds. Almost 60 percent of the NBCCEDP program funds were used for direct clinical services, which include screening and diagnostic follow-up, referral for treatment, and case management.

The remaining 40 percent of program resources were dedicated to activities including public education and outreach, professional education, quality assurance and improvement, surveillance and evaluation. These activities help address issues other than financial barriers that prevent low-income women from receiving cancer screening services.

Studying only nine of the NBCCEDP programs for just one year leaves some limitations in the findings, because the sample size is small and we know that funding and other sources of resources vary from year to year depending on activities planned.

However, as you probably are aware, we are currently conducting a second phase to this study that will provide a more comprehensive examination of the costs associated with screening in the NBCCEDP.

The study is examining all 68 NBCCEDP programs operating in the United States. Collecting cost data from all of the programs will provide a much richer understanding of program variation and will support econometric analysis of cost determinants. We will test for economies of scale and be able to control for differences in cost-of-living between programs. The data may allow us to identify best practices and learn more about the optimal mix of spending across program activities.

This study is expected to be completed in 2009.

As always, there is still much more to learn, but I hope our research will help to answer your questions and provide you with information to assist you in your decisions.

I will be happy to answer any questions. Thank you for your time.

Chairman WAXMAN. Thank you very much for your testimony. I want to thank all of you for your presentations.

I want to start the questioning. For Ms. Joyner, I want to thank you for your work in Washington State and for the National Council of State Programs. I would like to ask some questions about the shortfalls you have described in various States' breast and cervical cancer screening programs.

First of all, all States have to make some contribution to their screening program. Isn't that correct?

Ms. JOYNER. Yes, that is correct.

Chairman WAXMAN. Have all States been able to contribute additional State funds?

Ms. JOYNER. No, not all States contribute State funding. So, in terms of their in-kind or match that they are needing to come up with, they can either find providers are kicking or another way would be looking at what the usual and customary cost is of a particular test and when you subtract the Medicare reimbursement rate, whatever that balance is can also be counted as an in-kind cost.

Chairman WAXMAN. So they have a number of streams of funding. Is there always a steady stream that State directors can rely on for their annual planning?

Ms. JOYNER. No.

For Washington State, we do have an annual or biennial budget in State funds. We have our Federal grant which through the 5-year cooperative agreement, and then we receive funding from three Komen affiliates, a private local foundation and, most recently, American Cancer Society. And those, of course, are all annual grant awards that we apply for and are contingent on the priorities of the affiliates' boards.

Chairman WAXMAN. I would imagine the States with high numbers of eligible women might be among the States least equipped to allocate State dollars to screening. Is that an accurate statement?

Ms. JOYNER. I think there is a variety of States that have a high eligible population, and some of those States do have State funding and some don't have any State funding.

Chairman WAXMAN. When a State program runs out of money for the year, what happens to women who are seeking mammograms?

Ms. JOYNER. Well, a number of things can happen. In some States, they have the ability to make resources available, especially if they have women who are calling, who are reporting systems of some sort. So they would not turn them away. So they have that assurance that women needing services will continue to be screened.

In other States, they have to just stop and either start taking names or asking women to call back after the start of the new program cycle.

Chairman WAXMAN. So they either put them on a waiting list or they refer them then to public clinics?

Ms. JOYNER. They could refer them to the public clinic, again, where they might be facing looking at a sliding fee scale or taking on bills that they can't pay.

Chairman WAXMAN. Dr. Brawley, a vaccine to prevent infection with several of the cancer-causing strains of HPV have been licensed by the FDA and is recommended for young women and adolescents from age 9 to 26. A second vaccine, HPV vaccine, is in the pipeline.

This is a potentially lifesaving advancement, but the vaccine is more expensive than many of the older vaccines. Isn't that correct?

Dr. BRAWLEY. Yes, sir. The vaccine is somewhere in the neighborhood of $200 a dose, and it requires three doses.

Chairman WAXMAN. So $200 for each dose or $200 for the three?

Dr. BRAWLEY. Yes, sir, per dose, $600 total.

Chairman WAXMAN. $600.

The Vaccines for Children Program will provide vaccines for eligible girls 18 and under, but there is no comprehensive program to make the vaccine available to uninsured or underinsured women from age 18 to 26.

Are you concerned that uninsured and underinsured women will not be able to afford this vaccine and will therefore miss out on its benefits?

Dr. BRAWLEY. Yes, sir. I am tremendously concerned about that, sir.

Chairman WAXMAN. Representative Roybal-Allard and I on the House side and Senator Kennedy on the Senate side have introduced legislation to create a Federal Vaccine for Uninsured Adults Program. This program is modeled on the Vaccines for Children and would give women who may not be able to afford the HPV vaccine, access to this vaccine as well as other important adult immunizations.

I hope that the American Cancer Society will take a look at this legislation. We would love to have your support.

Dr. BRAWLEY. Sir, I can promise you, we definitely take a look at it, and I would be shocked if we don't support it.

Chairman WAXMAN. OK. Thank you.

One of the unfortunate disappointments to me in this so-called stimulus package that we are going to be voting on, on the House floor today is that we didn't provide more money for the Medicaid program for the States. We did last time there was a recession and we passed a stimulus program, a one-time stimulus.

I think that is something that many of you might want to speak up about because if the States, looking at more people losing their jobs, more people losing their insurance, more people going on Medicaid because they have no other alternative, whether it is for this program or any other, they are going to be hard put because the States are going to be cutting back on Medicaid. They will be generating less revenues as unemployment goes up. That is what we call counter-cyclical.

I am disappointed it is not in this package, but I think we ought to be pushing to get some more help for Medicaid because we are going to need those funds as more people find themselves, even in surprising ways, unexpectedly uninsured, like the situation Ms. Carey had to confront.

Thank you very much.

I want to recognize my colleague for questions for 5 minutes.

Mr. HIGGINS. Thank you, Mr. Chairman.

Dr. Brawley, I would just like to ask you about, again, the status of the 2015 Campaign. Where are things at and is it still a stated goal?

Dr. BRAWLEY. Well, sir, there were two 2015 goals out there. The first was the American Cancer Society's goal which was to halve the incidents of cancer and significantly decreased mortality from cancer from 2015, and it is still there.

We are slightly off target. Part of the reason that we have been pointing out the access to care is a huge problem in the United States is because we need to fix the access to care problem to get back on track for the ACS 2015 goals, which are still reachable.

But this is a breast and cervical cancer hearing, but I will tell you one is better off in this country with stage two colon cancer and insurance than to have stage one colon cancer and no insurance. Better to have the more advanced disease with insurance than to have the less advanced disease without insurance because the 5-year survival rate of a stage two insured patient in the United States, regardless of race, is superior to the 5-year survival of a stage one patient without insurance.

But that is a long-winded way of saying we need to look at access to care. We need to look at all kinds of programs like this to get treatments that are proven.

You gave a wonderful talk about research. I was at the National Cancer Institute for years, and I am a tremendous believer in doing more research, but we are talking about today is research that has already been completed that people do not get to enjoy.

Mr. HIGGINS. The 14 or 15 percent of those who are getting treated, who are eligible for the Breast and Cervical Cancer Early Detection Program, what is the approximate breakdown? Anybody from the panel, what is the approximate breakdown of the sources of funding for those programs?

I am trying to get, I suppose, at the level to which the Federal Government is responsible for that 14 percent of those who are eligible.

Ms. JOYNER. So all 68 programs receive Federal funding from CDC, and then out of those 68 programs a variety have some State funding, have Komen funding, have American Cancer Society funding, but there still are a handful of States that have only Federal funding and no other sources.

Mr. HIGGINS. How are those moneys distributed?

My understanding is a lot of the cancer research funding, there are comprehensive cancer centers that do research, and then they apply to the National Cancer Institute for funding relative to promising research. How is the Federal piece accessed, I suppose?

Ms. JOYNER. For the screening program?

Mr. HIGGINS. Yes.

Ms. JOYNER. OK. Well, the screening program doesn't have, first of all, anything to do with research.

Mr. HIGGINS. Right.

Ms. JOYNER. So, and each grantee has their way of going about allocating funds.

So, in Washington State, we have a service delivery system which we call our prime contractors. Those are seven organizations. Four are local public health jurisdictions. Two are hospitals, and

one is a community-based organization. They, in turn, subcontract with providers that are made up of community health networks, private practices and some larger clinical systems.

Mr. HIGGINS. Given limited funding, is that an efficient way to distribute those moneys?

Ms. JOYNER. It has been an extremely efficient way of expending the funds. Prior to moving the decentralized model, we operated as a centralized State where the State Health Department put all the dollars out, collected all the data, ensured that all the women were being screened, and there were many challenges and the funding was not expended in the most efficient manner.

Mr. HIGGINS. You would identify Washington State as a model for efficient delivery of those?

Ms. JOYNER. For what works for the geographic regions of our States, how we are laid out, the system that we built, yes.

Mr. HIGGINS. I have no more questions, Mr. Chairman. Thank you.

Chairman WAXMAN. Thank you very much, Mr. Higgins.

I want to ask a few more questions if I might.

Ms. Carey, one of the concerns that many of us have is whether women know about this program for screening and then for care if they need it. You found out about it through the American Cancer Society. Is that right? Somebody from the American Cancer Society told you about it?

Ms. CAREY. Actually, I found out about it from this woman who worked at the hospital because she worked at the mammography division of the hospital as a certified mammotech, and I mean she is my best friend. She was frantic to save my life, and she found out because they had the literature at the center itself.

And I think that would be part of the problem is that they are not reaching enough people, but then also the problem is that the people they are reaching, like they say, they are over-booked.

I mean I was extremely fortunate. I say that I am extremely lucky. I shouldn't be sitting here today. If not for Kim letting me know, I wouldn't have known because I had gone to. I went to the HIPP center for Medicaid. I was looking for a Healthy New York type of program, like a policy for insurance just to get me through until I could have my own insurance.

And the woman took all my identification, my pay slips and my identification and my birth certificate, and then she very flippantly says. Well, she goes.

I said, well how long do you think it will take to process this?

She goes, well, this could sit on somebody's desk for 2 months.

And I was panicking. I said, well, I don't have 2 months, and I just gathered up all my stuff. I said, you know what? Just forget about it.

That is when Kim came to me. She said, Gail, you are not going to believe this, and I didn't believe it.

Chairman WAXMAN. Well, the program just started in New York.

Ms. CAREY. It had only just started that month, that year.

Chairman WAXMAN. We hope that more women hear about it even if they don't have a very close friend, personally, to tell them about it.

Ms. CAREY. Absolutely.

Chairman WAXMAN. So you think the outreach to women to let them know, the education about such a program is essential, I would assume.

Ms. CAREY. Absolutely, and they have made huge strides in the past 5 years alone, huge strides. It is unbelievable how many people they have been able to reach and caught this so much earlier.

And, again, you know what they have stressed here, because I was so advanced in my cancer, the cost of my treatment was absolutely cost-prohibitive. I am embarrassed to say. Again, the reason that I am here is because I am absolutely paying back for the rest of my life because I am that grateful because if I hadn't been so frightened and so proud about, I would have sought treatment a great deal earlier.

If this program, for women who seek treatment, the cost is unbelievable. I would have gotten screening. I would have been treated. I would have had no problem.

Chairman WAXMAN. You were trying to get into Medicaid, and that was taking time.

Ms. CAREY. I absolutely was trying. I was frantic.

Chairman WAXMAN. Getting right through the screening program got you into the Medicaid program right away for the care you needed.

Ms. CAREY. Right through, immediately.

You know what? The other misconception, and I really want to address this, is a lot of people say, oh, my gosh, you know every year we are going to have to pay for these people in Medicaid.

It is not that way. We are not looking for a handout. We are people who have worked all of our lives. We have paid our taxes. We have paid our insurance. We have always had insurance. We are not deadbeats.

I was frantic to save my house. When I finally did get my feet, when I was able to establish that I actually had.

I mean even my boss. I started working at this, for a doctor actually. Two weeks later, I was diagnosed with this cancer, and she held my job for me here, 5½ years later, and I am still with the same doctor. He is extremely sympathetic for the program, for anybody else who is on Medicaid.

Chairman WAXMAN. Let me ask you one other question, and then I want to ask some of the other members in the short time I have left.

Ms. CAREY. Yes.

Chairman WAXMAN. The program is not just to screen, as important as that is. Originally, that is all we got was a screening program for breast and cervical cancer.

Ms. CAREY. Right, right.

Chairman WAXMAN. I remember when Mrs. Quayle came in, and I was chairman of the subcommittee and authored the bill to provide for the breast and cervical cancer program.

Ms. CAREY. Wow. Thank you.

Chairman WAXMAN. But I said what if we find out that they have cancer? What are we going to do then?

She said, well, at least we want to give them that information. Of course, it is pretty harmful.

Ms. CAREY. But they don't leave you hanging.

Chairman WAXMAN. Yes, it leaves you hanging.

Ms. CAREY. They don't.

Chairman WAXMAN. Once you're covered for treatment, what I have heard and from your own experience, is that it is really essential to have a case manager to help you through the whole process.

Ms. CAREY. Yes, unbelievable. Yes.

Chairman WAXMAN. Did you think that was essential for you?

Ms. CAREY. That was the most astounding thing. It was a brand new program, and they had such a network. It was like I was passed from person to person to person from oncologists, surgeons, hospitals, and you never ever felt like you were being dropped.

The support system through the American Cancer Society was like nothing I have ever seen. You don't realize how important the Society is until you have the opportunity to use them, and I have been so blessed by this Society.

Chairman WAXMAN. You are a very strong and excellent spokesperson for this effort from your own experience.

Ms. CAREY. Thank you, and I have since gotten off the program. I am on my own insurance now. So I am saying it is not a handout. It is just hand up.

Chairman WAXMAN. Absolutely not.

Ms. CAREY. We just need to get from one place to the other.

Chairman WAXMAN. Absolutely not. I agree with you completely.

Ms. CAREY. Now I am good to go. So, thank you. Thank you so much.

Chairman WAXMAN. Even though my time is expired, since I am the chairman, I am going to take advantage of the opportunity to ask Ms. Fuld Nasso a question. [Laughter.]

Your organization helps a number of States to address the gap in breast screening programs. How do you make the decisions of where the Komen funds are going to go?

Ms. FULD NASSO. We have a network of 125 affiliates around the country.

Chairman WAXMAN. Is your mic on?

Ms. FULD NASSO. Let me pull it closer.

We have a network of 125 affiliates around the country, and they raise money through events like the Komen Race for the Cure and other events in their community. They keep 75 percent of that, of the money in their community and give 25 percent to our research programs.

Each one of those affiliates has a grants committee that reviews requests for grants, and so in some cases they give the money directly to the State program in order to supplement. Like the example that Ms. Joyner said, in Washington where she receives money, her program receives money from three of the affiliates in Washington.

In other cases, the affiliates work with the State program to identify the right providers that need additional funding and give that money directly to those providers. Sometimes it is also to help with the outreach and the advertising.

Chairman WAXMAN. It first goes to the people. It first goes to the area where the people who are raising the money direct it.

Ms. FULD NASSO. Right, it goes in the community where the affiliate is. Right.

Chairman WAXMAN. Then 25 percent can go elsewhere to other places where there is a huge gap in funding?

Ms. FULD NASSO. The 25 percent actually to our national research program, and we are planning to grant $100 million for research this year, and that comes from money that we raise in headquarters and also money that our affiliates around the country raise.

Chairman WAXMAN. Well, I would assume that you probably have a pretty good sense of where the holes in screening are around the country.

I want to ask you for the record if you would send us this information, recommendations you would make about how the Federal and State governments can systematically narrow that screening gap in the areas where we have seen it. If you would send that information, we would welcome it.

Ms. FULD NASSO. Yes, we can definitely get you that information.

Chairman WAXMAN. I thank all of you very much for your presentation. I hope this hearing will be able to give us the ability to make the case, as you have eloquently done, why this program is essential, why we need to fund it adequately, and the absolute benefit of putting money into find cancer at an early time when it can be dealt with.

I thank each and every one of you.

Ms. FULD NASSO. Thank you very much.

Chairman WAXMAN. That concludes our hearing today, and the committee stands adjourned. Thank you so much.

[Whereupon, at 11:55 a.m., the committee was adjourned.]

[Additional information submitted for the hearing record follows:]

NBCC

NATIONAL BREAST CANCER COALITION

grassroots advocacy in action

February 7, 2008

The Honorable Henry Waxman
Chairman
Committee on Oversight and Government Reform
United States House of Representatives
2204 Rayburn House Office Building
Washington, DC 20515

Dear Chairman Waxman:

On behalf of the National Breast Cancer Coalition (NBCC), I am writing to thank you for holding a hearing on "Addressing the Screening Gap: The National Breast and Cervical Cancer Early Detection Program" (January 29, 2008). We appreciate your continued commitment to ensuring that low-income women diagnosed with breast cancer have access to the care they deserve.

When Congress created the CDC Breast and Cervical Cancer Early Detection Program through passage of the bipartisan Mortality Prevention Act of 1990, it did so with the best intentions: to reduce mortality from breast cancer and save lives. NBCC appreciated Congress' efforts in this area, but we were concerned that the federal screening program did not have a federal treatment component. Detection alone does not save lives. The program's lack of support for a reliable system of care left many low-income women with nowhere to turn after they were diagnosed.

An NBCC member and advocate from California, Jan Eik-Swigart, first envisioned the solution that NBCC fought to enact. You were an important leader from the beginning in recognizing the need for the treatment component, and in working with us to push for passage of the **Breast and Cervical Cancer Treatment Act** (P.L. 106-354). As you know, enactment of this critical law allowed states to receive federal funding to help cover the cost of treatment through Medicaid for low-income, uninsured women who had been diagnosed with breast or cervical cancer through CDC's Early Detection Program thus repairing the flaw in the existing screening program.

Following passage of the Treatment Act, the Centers for Medicare and Medicaid (CMS) commended NBCC for encouraging a record number of states in less than a year to take advantage of the Medicaid waiver option. We are very proud that all fifty states and the District of Columbia opted to participate in the program. This success demonstrates the perseverance and dedication of women around the country who believe that a federal screening program should guarantee treatment.

NBCC remains committed to preserving the Breast and Cervical Cancer Treatment Program, as well as working to protect the Medicaid program overall and ultimately ensuring that all individuals have access to high quality health care. While we appreciated CDC's hearing testimony about the 4,000

1101 17th Street, NW, Suite 1300, Washington, DC 20036 phone: (202) 296-7477 fax: (202) 265-6854 www.stopbreastcancer.org

women being diagnosed with breast cancer through the Early Detection Program, we should be asking questions that get to the core of our beliefs and yours: How well is the treatment program working? What is happening to these women? Are their survival rates improving? Is the limited investment of federal resources improving their quality of life? In short, are the screening and treatment programs achieving the goal of saving lives?

During the hearing, CDC also testified about funding issues around the screening portion of the program. While funding is essential, it is but one aspect of a needed strategy to evaluate and improve both programs and ensure that they are adequately serving all eligible women.

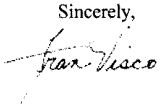
The National Breast Cancer Coalition has heard anecdotally that there are problems within the treatment program. There is great variation between and even within states in how the program is implemented and how eligibility for treatment is determined. Some women who meet the eligibility requirements have been screened for breast cancer outside of the program and thus are technically ineligible for treatment. In these circumstances women and providers must resort to "gaming" the system, by for example having women get a pap smear from the program so that they meet the definition of being "screened by the program." Other women have been turned away because they have found a lump or suspect a problem and are told that they are ineligible for the screening program because they need a diagnostic mammogram rather than a screening mammogram. Clearly, the vagaries of the process impede rather than advance the goal of helping this group of women.

We know that anecdotes are powerful but not sufficient evidence on which to base public policy. We would like to work with you to get more information and pinpoint the real problems, so we can work together to develop the right solutions and improve the program and the lives of the women who benefit from it.

Chairman Waxman, by convening this hearing you have demonstrated your continued commitment to strengthening this program and saving lives. We all need to know what is happening to women who are diagnosed through the screening program and if there is more we can do to help them. NBCC looks forward to working with you to examine the effectiveness and impact of the treatment program, and ultimately to ensure that all individuals have access to high quality health care.

We respectfully request that this letter be made a part of the hearing record. If you have any questions, please do not hesitate to contact me at (202) 296-7477.

Sincerely,



Fran Visco
President

○