

Not Just Once

The Bimonthly Newsletter of CMS's National Medicare Mammography Campaign

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WELCOME!

In this issue, we feature national-level updates from National Breast Cancer Awareness Month – which is celebrating 20 years of progress (page 2) – and federal efforts to improve coordination in breast screening promotion and outreach (page 4). Other stories address outreach to special populations, including Native American (page 3), African-American (page 7) and Asian-American women (page 5).

We encourage you to send us feedback and ideas for future *Not Just Once* articles. Please contact Editor Maribeth Fonner at mfonner@cms.hhs.gov or phone her at (816) 426-6349.

Sincerely,

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Leading Experts Discuss Past, Present, and Future of Breast Cancer at National Summit

Leading breast cancer experts, physicians and patient advocates from around the country gathered to discuss the progress of breast cancer treatment from the past 20 years at the National Breast Cancer Awareness Month (NBCAM) National Summit. The Summit, "20 Years of National Breast Cancer Awareness: The People, The Progress, The Future" was held on May 14, 2004 at the New York Hilton in New York City.

"Twenty years ago, people didn't talk about breast cancer and little was known about the disease. NBCAM brought together a number of breast cancer organizations with a single purpose of building awareness and promoting early detection," said Nancy Brinker, founder of the Susan G. Komen Breast Cancer Foundation and co-founder of NBCAM. "The Komen Foundation is proud to have been a part of this unified effort since the beginning. Together, we've made an enormous impact on women's healthcare practices and changed the cultural landscape of the disease."

"NBCAM was started at a time when few women received mammograms and public discussion of breast cancer was shunned," said Susan Nathanson, National Coordinator of the National Breast Cancer Awareness Month Board of Sponsors. "This summit provides leaders in the breast cancer community an excellent opportunity to look back at how far we have come and discuss what the future may hold. The efforts of NBCAM over the past 20 years have

significantly raised the awareness of the importance of early detection and have served as a model for other disease awareness initiatives."

The Summit featured several key thought leaders including:

- Larry Norton, MD, Deputy Physician-in-Chief for Breast Cancer Programs, Memorial Sloan-Kettering Cancer Center
- Daniel Kopans, MD, Professor of Radiology, Harvard Medical School and Director of Breast Imaging, Massachusetts General Hospital
- Robert Bazell, Chief Science Correspondent, NBC
- Diane Blum, MSW, Executive Director, CancerCare, Inc.
- Susan J. Blumenthal, MD, MPA, U. S. Assistant Surgeon General and Rear Admiral in the U. S. Department of Health & Human Services
- Susan Shinagawa, Co-founder/Co-coordinator, Asian Pacific Islander National Cancer Survivors Network

The speakers discussed a variety of important issues including the progress that has been made over the last two decades and the impact this will have on the future of breast cancer diagnosis and treatment. Topics included developments in mammography, breast cancer in the media, the evolving role of the patient, breast cancer detection and treatment disparities in minorities and

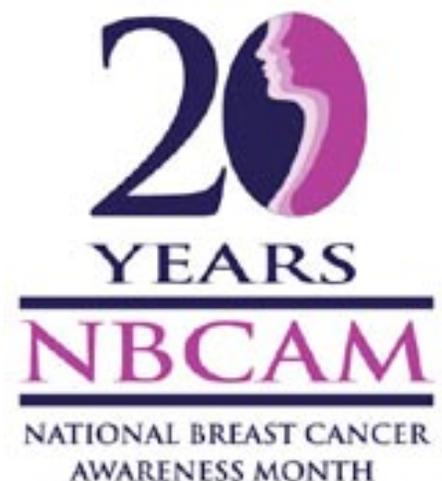
breast cancer as a critical women's health priority.

During the Summit, NBCAM honored remarkable individuals from the medical community, patient advocate organizations and government bodies for their outstanding contributions to the fight against breast cancer over the last 20 years. These individuals were among a select group that was honored for its accomplishments in raising awareness, encouraging women to understand their options and advocating for greater achievement in eradicating breast cancer.

About NBCAM

In 1985, NBCAM was born. An innovative model of collaboration and cooperation to educate and motivate people to take action against breast cancer, NBCAM was founded by the AstraZeneca Healthcare Foundation, CancerCare and the American Academy of Family Physicians.

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Barriers to Mammography Screening Among Native Women

-Lynn DeLorme, MPA: HA

There are many barriers to explain why Native women over the age of 40 do not receive specially focused early detection education, outreach, and assistance in accessing mammography. According to Dr. Linda Burhansstipanov, President and Executive Director of Native American Cancer Research, poverty-related barriers like lack of transportation and lack of child care are easiest to identify and least costly to address. Dr. Burhansstipanov, known as Dr. B. to her colleagues, has been a leading researcher in women's health issues for approximately 30 years and has written over 40 articles that address cultural and statistical issues relevant to cancer among Native women. The author is fortunate to have had the opportunity to obtain this invaluable information from Dr. B. via a phone interview.

According to Dr. B., socio-cultural barriers are harder to define and are usually more costly to address during the initial years of implementation. She reported that there are four major types of barriers that Native women may face: policy, poverty, psychosocial and socio-cultural. Psychosocial and socio-cultural barriers usually have a greater impact on participation in cancer prevention and control programs. However, many very well intentioned researchers focus their interventions on only the policy or poverty barriers; they believe that once these are addressed, the number of Native women who are screened for breast cancer will increase. Unfortunately,

this rarely occurs. Although policy and poverty barriers are real and should be addressed, Dr. B. indicates that an intervention that recruits Native women requires finding a strategy that addresses psychosocial and socio-cultural barriers as well.

But just what are psychosocial and socio-cultural barriers? Dr. B. reports that psychosocial barriers are usually related to misinformation, fear, and distrust and are mostly based on lack of appropriate communication, insufficient education or information. An example of insufficient education or information relates to common misconceptions about cancer in general, for instance, the belief that mammography screening actually causes cancer. Dr. B. stated that one solution to reduce this type of barrier is to provide culturally sensitive educational interventions.

Socio-cultural-related barriers are the hardest to address because these tend to be culturally and tribally-specific and are rarely evident in quantitative data collected by surveys. Examples of socio-cultural barriers for Native women include the following: (1) When one discusses cancer, one invites the cancer spirit into one's body or into the body of one's family. (2) Native languages do not have a word or phrase for cancer. (3) Beliefs that cancer is spread by white doctors who want to annihilate Native Nations. (4) To be diagnosed with cancer means that one is being punished by the Creator. (5) If a part of the body is amputated as part of the treatment for cancer, then one cannot walk the spirit

path of her ancestors and cannot be reunited with her people after she dies. According to Dr. B., one way to reduce this type of barrier is to provide Native women with effective cancer education print materials that provide relevant, culturally specific guidelines. Additionally, many of the socio-cultural barriers may be addressed through the development and implementation of culturally relevant educational programs.

Another example of a psychosocial barrier is the fear and discomfort Native women may face in western hospitals. A solution to this is to have some type of relaxed contact available to the Native woman who has just received an abnormal mammogram. This solution is called the navigator model and it involves a trained navigator who accompanies the Native woman to follow-up appointments to provide emotional support and patient advocacy. This support is usually initiated at the time the Native woman receives an abnormal mammogram result. The navigator model has been successful in increasing patient compliance as well as increasing access to cancer treatment involving advanced technology.

According to Dr. B., the many other barriers to mammography screening among Native women involve poverty-related ones, including: lack of transportation, lack of childcare, under-funded tribal breast and cervical cancer prevention programs, and uninsurance or underinsurance

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Federal Agencies Meet to Coordinate Breast Cancer Screening Educational Efforts

Representatives of 10 Federal Agencies met on Tuesday April 20, 2004 to discuss breast cancer screening educational activities and opportunities for future collaboration. Fostering this type of exchange will be valuable for both individual program planning efforts and in coordinating across Federal agencies.

The meeting in Bethesda, MD was organized by the National Cancer Institute (NCI) Office of Education & Special Initiatives (OESI). Dr. Annette E. Kusssmaul represented the Centers for Medicare & Medicaid Services (CMS) National Medicare Mammography Campaign. She was joined by Sandy Kappert and several others from CMS's Central Office. Other attendees included representatives of "sister" Dept. of Health & Human Services agencies, such as the Centers for Disease Control & Prevention (CDC), Agency for Healthcare Research & Quality, Food & Drug Administration, Health Resources & Services Administration (HRSA) and Office of Women's Health.

The meeting began with two presentations selected to demonstrate successful federal-level partnerships. Dr. Stephen Taplin, Senior Scientist with the NCI's Applied Research Program, discussed the Cancer Collaborative, which is using the Institute for Healthcare Improvement model with teams from federally-qualified health centers (FQHCs), which are sponsored by HRSA. This project is on-going and NCI and CDC are also supporting it. Dr. Taplin indicated that the energy and hard work of the FQHC teams is the key in its success. Lenora Johnson, MPH, CHES, of NCI/OESI Cancer Education Branch, then presented a cooperative that involves NCI, CDC, the U. S. Dept. of Agriculture and the American Cancer Society. These agencies & organizations brought together state-level representatives (from 8 states) for training. Now, the representatives are working together to promote breast & cervical cancer in their states. **[Editor's Note: The implementation of this project in Missouri was discussed in a story in the January-February 2004 issue of *Not Just Once*.]**

In advance of the meeting, OESI asked participants to submit information about what breast cancer

screening education & outreach activities each federal agency is doing. These were summarized and this was discussed in small group breakout sessions. The plan was to identify programmatic gaps to inform individual program planning and to coordinate collaborative efforts.

After discussion, the group determined that they first needed to become better acquainted with each Agency's breast cancer screening and education materials and programs. OESI is organizing the group's information exchange and collaboration by compiling an inventory of breast cancer materials and programs. The group decided that cervical cancer materials and programs will also be included in the inventory. Future discussions will focus on redundancies, gaps and information needs.

For more information, please contact Rhonda Wilt DeJoyce of NCI/OESI Cancer Education Branch, dejoicer@mail.nih.gov

To read back issues of the *Not Just Once* Newsletter, please visit the website: www.cms.gov/preventiveservices/1a.asp



Mail Campaign Will Encourage Mammography in Missouri

-Deborah Finley, MPA

MissouriPRO, the Quality Improvement Organization in Missouri, has recruited 32 federally qualified mammography centers to participate in a reminder-recall campaign in 48 counties. This month, approximately 30,000 selected women with Medicare will begin receiving information in the mail about the importance of a yearly screening mammogram.

“Our materials include not only a positive message regarding mammography, but also a call to action,” said Richard A. Royer, Chief Executive Officer for MissouriPRO. “After researching possible messages, we decided to reinforce the benefits of a screening mammogram instead of using the traditional fear approach, and to list a place in their area that provides the test.”

Every woman will receive one flyer that explains the benefits of a mammogram, includes a call to action and lists contact information for a center in her local area. One-third of the women will receive two follow-up “call to action” postcards; another one-third will be sent two mammography newsletters.

Each flyer includes a perforated section for the woman to write down

her appointment date, time and location; women are asked to bring this card to their appointment. To help evaluate the campaign, participating mammography centers will collect these appointment cards and report the total number gathered when the project ends this summer.

Staff varied their approach to learn if one technique was more successful than another, and established a control group of 5,000 similar women with Medicare in the area who will not receive any mailed material. MissouriPRO will then evaluate the project by looking at claims data one year later to see how many of the targeted women received a mammogram.

“We want to learn which approach motivated more women to have a mammogram, and if women with disabilities or living in counties without a mammography center responded differently to the campaign’s messages,” Royer said.

How It All Started

To begin this campaign, Royer’s team sent a short questionnaire to all FDA-certified mammography centers in Missouri. Staff asked each facility their hours of operation, if they were equipped to serve persons with disabilities, if they require a physician referral, and if they were interested

in having MissouriPRO send a mammography reminder to Medicare patients in their area.

The team then developed messages that promoted three positive benefits of mammography: Peace of mind (“You deserve peace of mind”), affordability (“What a bargain”) and proactive care (“Take care of yourself today, and for years to come”). Working with a graphic designer, staff presented the messages in an attractive and compelling fashion.

A research analyst then examined Medicare claims data to identify particular women with Medicare who live close to one of the campaign’s participating mammography centers.

For copies of campaign materials, or to learn more about how the campaign was developed, contact Angela Green, MissouriPRO Communications Specialist, 800-735-6776 ext. 119 or e-mail her at agreen@moqio.sdps.org.

Ms. Finley is the Director of Communications at MissouriPRO in Jefferson City, MO.

Mammography Outreach to the Chinese Community

-Maria Monica Henderson

The 2003-2004 Asian-American Pacific Islander (AAPI) Mammography Project is on track. The Media One Network has developed a culturally sensitive script to encourage Chinese women to have a mammogram. The script was reviewed by six Chinese community centers and is currently being translated. The audio versions in Mandarin and Cantonese will be reviewed by Centers for Medicare & Medicaid Services staff in Regions I and II.

Once the script is finished, Media One will purchase airtime on Chi-

nese formatted radio stations in Boston, New York and San Francisco. The script directs the audience to call 1-800-MEDICARE for more information in English and to call the National Cancer Institute at 1-800-4 Cancer (1-800-422-6237). Future plans include a survey to determine the degree to which Chinese women have been persuaded to have a mammogram.

One case control study on the effects of migration on the risks of breast and cervical cancer among Chinese, Japanese and Filipino living in California showed that Asian-Americans

born in the West have a breast cancer risk factor that is 60% higher than those born in the East. Furthermore, these risks double after a decade of residence in the West. (Ziegler)

Editor's Note: This project is part of the Asian-American Pacific Islander Initiative. For more information, please see the story in the May - June 2002 issue of *Not Just Once*.

Ms. Henderson is a Health Insurance Specialist in the Division of Beneficiary Services, Contractor Operations Branch, in CMS' Boston Regional Office. She is a Mammography Coordinator for Region I.

National Women's Health Week and National Women's Check-Up Day Celebrated in May

The 5th Annual National Women's Health Week (NWHW) was celebrated May 9-15, 2004. NWHW is a national effort by the Department of Health and Human Services and an alliance of organizations to raise awareness about manageable steps women can take to improve their health. The focus is on the importance of incorporating simple preventive and positive health behaviors into everyday life. The week started on Mother's Day and ended on the following Saturday, a time when there is much attention already being focused on women.

NWHW encourages awareness about key health issues among all women, including women with disabilities, and especially, African-American, Asian-Pacific Islander, Latinas and American Indian/Alaska Native women, since research has shown

there are significant health disparities among these groups compared to white women.

The 2nd Annual National Women's Check-Up Day was held Monday, May 10, 2004. This nationwide effort, coordinated by the U.S. Department of Health and Human Services, encouraged women to visit health care professionals to receive regular, preventive check-ups and screenings.

The purpose was to emphasize the importance of getting regular check-ups and asking a doctor about screenings for heart disease, diabetes, cancer, and sexually transmitted diseases. Maintaining regular check-ups is one of five health habits that can contribute to the betterment of women's health along with exercise, a healthy diet, not smoking, and following general safety rules.



May 10, 2004
National Women's Check-Up Day

Women can prepare themselves for their check-ups with "A Checklist for Your Next check-up," developed by HHS' Agency for Healthcare Research and Quality, which can be found at www.ahrq.gov/ppip/healthywom.htm

This story was adapted from NWHW & National Women's Check-up Day fact sheets and other information posted on the NWHW website, <http://4woman.gov/whw/2004/>

South Carolina's Media Campaign Reaches Out to African-American Women and Their Physicians

-Submitted by Andrea C. Fuller, BA and Donna S. Strong, MPH

Because a disparity in mammogram rates exists between African American and Caucasian women, Carolina Medical Review (CMR), the Quality Improvement Organization (QIO) in South Carolina, launched a media campaign in late April 2004 featuring 24-year breast cancer survivor and Florence County resident Mae Francis Brown. The campaign also features a Florence County physician, Bob Richey, MD. The overall theme of the campaign, which includes a television commercial as well as radio and newspaper ads, is: "It takes only two steps to detect breast cancer at an early stage: 1) the physician has to order the mammogram, and 2) the woman has to get the mammogram. Are you doing your part?" Campaign efforts will extend through the end of September and may begin again in January 2005.

Currently, the campaign is focused toward the South Carolina counties of Florence, Georgetown, Horry, Marion, and Williamsburg. According to Medicare Part B claims data, the total disparity rate is 11.2% in

those counties. For the period April 2001 - March 2003, the rate for caucasian women age 52-69 with fee-for-service Medicare was 66.5% while the corresponding rate among African-American women was only 55.3%.

According to research conducted by William Butler, MD, FACP, Director for Clinical Research at the SC Cancer Center, "The data suggest that, on the whole, more aggressive breast cancer develops in many African Americans." (For additional information on Dr. Butler's research, visit www.bco.org/article.asp?article=60&issue=26)

Studies show that women are more likely to get a mammogram if their physicians recommend one. However, according to focus group research, other barriers that prevent women from getting the needed screenings include fear, cost, and lack of transportation.

According to the AARP, recent studies show that physicians stress the



It takes only two steps to get a mammogram:

- 1) the doctor to prescribe one, and
- 2) the woman to get one.

Are You Doing Your Part?

If you are over age 40 and have not received a mammogram this year, **please** call your doctor to schedule an appointment. Medicare pays if you are eligible!

For more information, please call 1-800-922-3089.

importance of chronic care as a first priority, while preventive services are ranked lower in priority.

In addition, research shows that African American women are getting a more aggressive form of breast cancer at an earlier stage, resulting in a greater chance of death.

For more information about CMR's media campaign efforts, visit www.mrnc.org or contact Donna Strong, MPH, Interventions Specialist, at 803-731-8225.

Ms. Fuller is an Outreach Specialist and Ms. Strong is an Interventions Specialist with Carolina Medical Review in Columbia, SC.

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The NBCAM Board of Sponsors is comprised of 16 national public service organizations, professional medical associations and government agencies working in partnership to raise awareness and provide access to breast cancer screening services. The NBCAM developed Program Leaders around the country to reach women where they live, work, play and worship. 2004 marks 20 years of NBCAM, educating women about breast cancer detection, diagnosis and treatment. NBCAM has been funded for 20 years by an unrestricted educational grant from the AstraZeneca Healthcare Foundation and through the enormous dedication of time and talent of the national Board of Sponsor member organizations.

NBCAM Board of Sponsors, Past and Present:

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 American College of Radiology
 American Medical Women's Association
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 CancerCare
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 Men Against Breast Cancer
 The Susan G. Komen Breast Cancer Foundation*
 National Alliance of Breast Cancer Organizations*
 National Cancer Institute
 National Medical Association
 Oncology Nursing Society
 Y-ME National Breast Cancer Organization

* Former Sponsors

This story was adapted from an NBCAM press release, which is available on the NBCAM website at www.nbcam.org/newsroom_news.cfm

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among Native women. These more common barriers have been known for approximately 30 years, but new health care workers who have never practiced in Indian Country do not know of them and do not take the time to read the reports discussing solutions to these easier-to-address barriers.

Compounding this is the problem of racial misclassification where a health care worker incorrectly reports a Native woman who has just received an abnormal mammogram as belonging to some other race and ethnic group, which results in a underreporting of the number of Native women who have breast cancer.

One solution to increase mammography access for Native women is to provide funding for a mobile mammography unit and technicians to travel to rural Indian communities where screening services are not available. Unfortunately, mobile mammography units face financial challenges: Dr. B. explains that it costs about \$20 to x-ray a broken arm; to do comparable work for a mammogram costs \$70, plus technicians have an enormous amount of paperwork to complete. She reports that the level of accuracy of a mammogram provided via a mobile unit may be decreased due to human errors such as fatigue experienced by the technicians who often have to travel great distances as well as complete extensive paperwork for each mammogram.

Dr. B. suggests that a viable option to fund these expensive mobile mam-

mogram units is to have tribal casinos subsidize the units.

The solutions proposed by Dr. Burhansstipanov may be very challenging to fulfill, but the bottom line is that Native women need to have the same level of healthcare as other ethnic and racial groups and that our health delivery system needs to be culturally respectful of the local Indian community in order to accomplish this. Community-based interventions may require more time than other types of interventions, but in the long term, these interventions will remain in the Indian community long after funding ceases to be available.

Ms. DeLorme is the Women's Health Promotion Program Coordinator with the Northwest Portland Area Indian Health Board in Portland, Oregon.

CMS's Regional Mammography Coordinators

CMS's Regional Mammography Coordinators are a wonderful resource for partners working on breast cancer projects focusing on older women. We encourage you to make contact with our coordinators listed below and learn more about how we can be of assistance to you.

Monica Henderson or
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Mammograms for Older Women Poster Includes slogan with Medicare information. A poster featuring an older woman, available for display in health care settings. (minimum order: 20, maximum 5000)	English Spanish	G500 G501	11 x 17	
Mammograms for Older Women Bookmark Includes slogan with medicare information. Bookmark features an older woman with facts in breast cancer, mammography, and Medicare coverage. (maximum order 5000)	English Spanish	Z498 Z499	2 x 8	
Ad Slicks Camera-ready ads in a variety of sizes featuring older women. Includes slogan with Medicare information	English	C135		
Mammogram Reminder Pad A pad for clinicians with fifty tear-off fact sheets on mammograms to give to patients. Includes NCI's screening recommendations, Medicare mammography coverage, and sticker for patients' calendars reminding them of their appointment.	English	Z448		
"Do it for yourself, Do it for your family" Asian American and Pacific Islander (AAPI) women have the lowest mammography screening rates of major ethnic groups in the U.S. Breast cancer is the most common type of cancer for Chinese women, the second most common for Vietnamese women, and the leading cause of death for Filipina women living in the U.S. These brochures are written in three Asian languages and in English to inform AAPI women about the benefits of mammography, NCI screening recommendations and Medicare coverage.	English Chinese Vietnamese Tagalog	P048 P082 P089 P141		

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