



Not Just Once

The Bimonthly Newsletter of CMS' National Medicare Mammography Campaign

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WELCOME!

This issue features the announcement of a new resource – *Breast Health and Beyond for Women with Disabilities: A Provider's Guide to the Examination and Screening of Women with Disabilities*. (See page 2.) This guide was developed by Breast Health Access for Women with Disabilities (BHAWD), a California-based program which was first featured in the November-December 2002 issue of *Not Just Once*. BHAWD has kindly agreed to make copies of the guide available to the Centers for Medicare & Medicaid Services Quality Improvement Organizations. We salute and thank BHAWD Manager, Florita Maiki.

Other articles in this issue include updates from the National Breast Cancer Awareness Month Board of Sponsors and the National Cancer Institute, as well as local mammography promotion activities in Wisconsin and the greater Seattle area.

Not Just Once focuses on the work of the Medicare Mammography Campaign, contractors and other partners. As always, we encourage YOU to submit ideas or stories. Please send these to Editor Maribeth Fonner at mfonner@cms.hhs.gov or phone her at (816) 426-6349.

Sincerely,

Annette E. Kussmaul, MD, MPH

Medical Officer
Division of Quality Improvement
CMS, Region VII, Kansas City

Sandy Kappert

Director, Division of Partnership Development
CMS, Center for Beneficiary Choices



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New Resource Guide Addresses Breast Health for Women with Disabilities

-Florita Maiki, MA

Earlier this year, Breast Health Access for Women with Disabilities (BHAWD), a program of Alta Bates Summit Medical Center, Rehabilitation Services Department produced a new resource for medical and health care providers entitled, *Breast Health and Beyond for Women with Disabilities: A Provider's Guide to the Examination and Screening of Women with Disabilities*. The guide was made possible through grants from The California Endowment, The Heart Foundation, Inc., and The San Francisco Bay Area Affiliate of The Susan G. Komen Breast Cancer Foundation. It was reviewed and evaluated by a clinical team representing a variety of specialties.

Breast Health and Beyond for Women with Disabilities... has been designed to increase health care providers' knowledge and enhance clinical practice of providing breast health screening services to women with disabilities. It includes clinical protocols (algorithms) for clinical breast examination, breast self-examination teaching and mammography, specific adaptations and positioning, information on transfer techniques, and accessible equipment features and resources. In addition, the guide discusses ways to improve clinicians' personal interactions with women with disabilities.

Women with disabilities are just as susceptible to breast cancer as

women without disabilities. Ensuring their access to the various screening processes is of equal importance. Women with physical disabilities are at a higher risk for delayed diagnosis of breast and cervical cancer, primarily related to environmental, attitudinal and information barriers (Nosek et al., *Archives of Physical Medicine & Rehabilitation*, 1997).

Health care providers are encouraged to use the information in this guide to modify and adapt their breast health screening techniques in order to be inclusive of and responsive to women with disabilities. Unless issues of accessibility (both environmental and communication) have been anticipated and addressed, even highly motivated women with disabilities may be unable to utilize and fully benefit from clinical services. The techniques and strategies described in this guide not only promote the participation of women with disabilities but also benefit a wide segment of the population, including women who are aging and/or who have a chronic disease.

BHAWD is a grant-funded community partnership of women with disabilities, breast cancer survivors, medical professionals, and disability rights organizations. BHAWD's mission is to increase breast health information, screening and early breast cancer detection for women with disabilities. BHAWD's work is to remove

the obstacles that women with disabilities regularly encounter: clinical, attitudinal, emotional, informational, physical, and financial. To be most effective, BHAWD is continuing to develop and implement training, such as mammography training, and educational materials for medical and health care providers. By gaining a broader understanding of the diverse factors that affect the lives of women with disabilities, health care providers can better target clinical and service approaches to address the needs of this population. A model and leader for breast health accessibility, BHAWD has become the national and state award-winning advocate and catalyst for the development of accessible breast and women's health services.

More information about the resource guide, including the Table of Contents, is available at www.bhawd.org or phone Florita Maiki at (510) 204-4866.

Editor's Note: Through a special agreement with BHAWD, we have arranged for one complimentary copy of *Breast Health and Beyond for Women with Disabilities: A Provider's Guide to the Examination and Screening of Women with Disabilities* to be mailed to each Quality Improvement Organization. Additional copies will be available for purchase.

Ms. Maiki is the manager of Breast Health Access for Women with Disabilities.

20th Year of National Breast Cancer Awareness: The People, The Progress, The Future

-Susan N. Nathanson, PhD

2004 marks 20 years of progress in educating women about breast cancer detection, diagnosis and treatment. In recognition of this important milestone, the National Breast Cancer Awareness Month (NBCAM) Board of Sponsors (BOS) is bringing together thought leaders who have made significant contributions to the fight against this devastating disease to address the progress made over the last two decades and provide information on how this progress will impact the future of breast cancer diagnosis and treatment.

Over the last 20 years, NBCAM has reached out to millions of women urging them to obtain an annual mammogram starting at age 40. As a result, the number of women undergoing mammography screening has increased significantly. Increasingly important has been the message that early detection through mammography screening leads to the ability to treat breast cancer less invasively and extend survival time.

On May 14, 2004, at the New York Hilton in New York City, a national summit organized by the BOS will bring together patient advocates and key thought leaders from around the country who have been instrumental in the progress that has been made in the field of breast cancer. Topics

to be discussed include: early detection and future advances in diagnosis and treatment; breast cancer and the media; the role of patient participation; the politics of breast cancer; and breast cancer in minorities and disparities in care. The distinguished panel of speakers will include 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; and Diane Blum, Executive Director at Cancer Care, Inc., among others.

A special awards program during the luncheon will honor individuals and organizations who have made outstanding contributions in areas including: patient and family support, research on detection and treatment, and patient education and awareness.

The summit will be open to those patient advocates and their organizations, physicians, and researchers in the field of breast cancer. Additional information and registration will be available April 1 at www.nbcam.org

Dr. Nathanson is the national coordinator of National Breast Cancer Awareness Month.



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



NCI “Dialogue Meeting” Will Focus on Breast Health

The Office of Education & Special Initiatives at the National Cancer Institute (NCI) will host a “Dialogue Meeting” specifically for representatives from Federal agencies who are involved with breast cancer screening education efforts. The meeting will provide a forum for discussion and an exchange of information on current education efforts at the Federal level. A goal is to foster collaboration and coordination of programmatic activities in the future. The meeting is planned for April at the National Institutes of Health. Highlights of the meeting will appear in a future issue of *Not Just Once*.



CMS Seattle Regional Office Promotes Mammography. As part of the National Medicare Mammography Campaign, the Centers for Medicare & Medicaid Services (CMS) Seattle Regional Office placed mammography billboard ads (shown above) in the states of Oregon and Washington. These billboard ads were up for the

entire month of October 2003, which was National Breast Cancer Awareness Month. In Oregon, this billboard message was estimated as reaching at least 75,000 women with Medicare in the Portland metropolitan area alone. In Washington, the billboard placed in the city of Everett (northwest of Seattle-King County) was

estimated as reaching about 100,000 women age 40 and above. The CMS Seattle Regional Office plans to place similar messages this year, and will also use billboards to promote the 2nd Annual Latina Health Fair. CMS-Seattle is a key sponsor of the Health Fair, which will be held in Seattle on May 15, 2004.

A Public Radio Adventure

-Jay A. Gold, MD, JD, MPH

One of many great things about Wisconsin is Wisconsin Public Radio. Its Ideas Network offers many one-hour call-in programs in which experts present their ideas and respond to listener calls. I subscribe to a daily email that lists who will be on their programs the following day. So in January, I was very interested to see the following listing for January 12th:

"7:00 AM ... Connie Walker's guest says women are not fully informed about the risks involved with mammography, and that having a mammogram isn't always a safe choice. Guest: Maryann Napoli, associate director and writer of Healthfacts at the Center for Medical Consumers."

The name Maryann Napoli sounded halfway familiar. A quick search found that a front-page article in [The Washington Post](#) only a few days earlier, headlined "Some Fear Women Lack Facts About Mammograms," had quoted her as saying, "After 30 years of selling this to us, women are still not fully informed about the risks... It's been oversold. They're afraid they can't be fully honest because a lot of us would stop going for screening."

So at 7:00 AM on the 12th, I was ready with my tape cassette. Ms. Napoli was highly critical of mammograms, emphasizing false positives, with resulting anxiety, discomfort,

and risk of serious complications from biopsies.

I knew that Ms. Napoli was giving a very one-sided view of the issue, and was concerned that women who heard this program might be scared away from getting mammograms that might save their lives. So I set out to contact the producer of the program, to ask that a more scientifically-grounded viewpoint be presented as well.

I discovered that the producer, Kate Brown, would be in the studio for several hours. In the meantime, I contacted Dr. Annette Kussmaul, lead for the National Medicare Mammography Campaign. We both thought that Dr. Robert Smith of the American Cancer Society would be a good person to provide a strong counterpoint. Dr. Kussmaul emailed Dr. Smith, who was interested.

Early that afternoon, I got hold of Ms. Brown, and explained that as a physician who was familiar with this area, I was concerned that listeners would come away from that morning's program with a distorted idea about the value of mammograms. She agreed that it would be appropriate to broadcast an opposing viewpoint, and said that she was contacting the Wisconsin branch of the American Cancer Society for local expertise. She said she would get back to me if she ran into trouble finding a suitable expert.

This turned out not to be necessary. The next day, my emailed schedule listed for 7:00 AM on January 14th:

"Connie Walker's guests discuss the benefits of mammography and breast cancer screening.

Guest: Sue Toth, breast care coordinator at the Aurora Women's Health Pavilion in West Allis; Dr. Roger Kwong, oncologist at Gunderson Lutheran; American Cancer Society's Midwest Division Board of Directors."

Ms. Toth and Dr. Kwong did a superb job, emphasizing how the benefits of mammograms can far outweigh the risks. I suspect that lives may be saved as a result of their presentation.

If the story has a moral, it's this: It's useful to monitor the public media for stories on issues we work with, and producers may be open and even eager for timely rebuttals where we think they're called for.

Dr. Gold is the Principal Clinical Coordinator and HCQIP Director at MetaStar, Inc, the Quality Improvement Organization in Madison, Wisconsin.





Order Form - Mammograms NCI / CMS Materials



Name:		Fax:		
Organization & Shipping Address (no P.O. boxes):		Phone:		
Email:				
City:		State:		Zip Code:
Title & Contents Description	Language	Inventory Number	Size	Quantity
Mammograms... Not Just Once, But for a Lifetime Large-print, easy to read brochure that defines mammography, describes who needs to be screened, and Medicare information. (maximum order 5000)	English Spanish	H496 H497	8½ x 11	
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		
Breast & Cervical Cancer Programs in Your Community: A Guide for Outreach, Screening, and Follow-up Care This 205-page guide addresses program planning; establishing partnerships; outreach and education; coordination of screening, diagnostic, and treatment services; payment and health care delivery systems and more.	English	T408		
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 US. 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 US. 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		

Mail order form to:
National Cancer Institute
P.O. Box 24128
Baltimore, MD 21227

OR

Fax order form to:
410-646-3117

If receipt of your order is not confirmed the same day by fax or email, please re-send.

Orders take 7-10 days to process and deliver via UPS.

Call Paula Greenstreet in the Distribution Center at 410-644-6538 for questions.