

Not Just Once

The Bimonthly Newsletter of CMS's National Medicare Mammography Campaign

Volume 4, Issue 6 November-December 2002

SEASON'S GREETINGS!

In this issue, we feature a story about a California program that is providing – and promoting – breast cancer screening for women with disabilities, a neglected population (page 2). Also, we salute cartoonist Cathy Guisewite for including mammography messages in her “Cathy” comic strip during National Breast Cancer Awareness Month (NBCAM). Our thanks to Mary Suggett of Universal Press Syndicate and Ms. Guisewite for allowing us to reprint the comics on page 5.

Looking ahead to January-February 2003, we'll report on follow-up from the national collaboration with Wal-Mart Stores, Inc. for NBCAM. Other articles will highlight activities of Centers for Medicare & Medicaid Services (CMS) partners to promote screening. Won't you share your story? Please send articles, ideas & suggestions to Editor Maribeth Fonner at e-mail mfonner@cms.hhs.gov or phone (816) 426-5039.

Sincerely,

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Breast Health Access for Women with Disabilities – A California Program Addresses this Underserved Population

-Florita Maiki, MA

Breast Health Access for Women with Disabilities (BHAWD) is a community partnership of women with disabilities, breast cancer survivors, medical professionals, and disability-rights organizations. BHAWD is a program of the Rehabilitation Line of Alta Bates Summit Medical Center in Berkeley, California. The mission is to increase access to breast health information, screenings and early breast cancer detection for women with disabilities. The first program of its kind, BHAWD is a catalyst - nationally and internationally - for accessible breast health services.

BHAWD is developing specialized, potentially life-saving services for a population of women whose breast health needs, until recently, have been overlooked. Yet, barriers to access are so pervasive that 17% of U.S. women age 20+ face major obstacles to obtaining early breast cancer detection because of their disabilities.

BHAWD's work is to impact the obstacles that women with disabilities regularly encounter - clinical, attitudinal, emotional, informational, physical, architectural and financial. BHAWD is refining its existing clinical practices and developing adaptive protocols for clinical breast examinations, breast self-examinations, and mammography for women with physical and developmental disabilities.

To be most effective, BHAWD is continuing to devise, implement and disseminate training materials geared for medical and health provid-

ers and women with disabilities. The materials will give consumers greater knowledge and will add to the pool of health care providers that are sensitized to the special breast health needs of women with disabilities. Finally, through coalition building and advocacy, BHAWD strives to have these special health needs recognized throughout the State of California's women's health programs.

History

The impetus for BHAWD came from a question posed late in 1994 by a longtime disability rights activist. The activist, who has cerebral palsy and who survived breast cancer, asked a 30-year veteran oncology nurse whether there was a connection between her disability and the late detection of her cancer. Could the tremors caused by her cerebral palsy have prevented the mammography machine from capturing clear images that would reveal the cancer earlier, when it was smaller? The nurse was stumped and sought answers from colleagues and members of the disability community. Within a year, the nurse, the activist and other dedicated collaborators founded BHAWD - and paved the way for what has become a transformation in women's health care.

Activities

Since its founding in 1995, BHAWD has identified and successively reached out to various segments of the disability community, medical and health service providers, family members, media and the public in general.

BHAWD's current activities include:

- Operation of the nation's first dedicated breast health clinic for women with disabilities;
- Ongoing development of unique outreach techniques targeting women with different levels of independent function, with varying health conditions, and of diverse age, ethnicity and race;
- Development and ongoing expansion of its comprehensive, fully accessible, interactive website about access to breast health care for women with disabilities - the first in the nation;
- Development of health education materials specific to the targeted populations;
- Development of clinical protocols for each of the breast health practices: clinical breast examination, breast self examination, and mammography;
- Provision of technical assistance and training to organizations and medical providers seeking to understand and replicate or modify the BHAWD model;
- Identification of policy issues and approaches; and
- Presentations, testimony and poster sessions at major conferences on breast health, women's health, disability, oncology, rehabilitation etc.

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CMS, Physician Office QIOSC Release Patient Registry Toolkit

-Lee Anne Carroll, BS, RN

The Centers for Medicare & Medicaid Services (CMS), with support from the Virginia Health Quality Center's Physician Office Quality Improvement Organization Support Center (QIOSC) is compiling a Patient Registry Toolkit in support of Quality Improvement Organizations' (QIO) Seventh of Scope of Work outpatient efforts. Additional QIOs assisting in the toolkit's development include Idaho, Massachusetts, Montana, West Virginia and Wisconsin.

A patient registry is an electronic or manual tool for tracking clinical care of, and providing planned care to, a population. Registries can vary in sophistication from a 3x5 index card system to an electronic tool, tied to guidelines, that integrates clinical information and generates reports and reminders for care. For example, a provider can quickly generate from their registry reminders for women in need of a mammogram, lists of diabetic patients whose HbA1c levels need monitoring, lists of patients in need of a flu vaccination, etc. The

ultimate goal of a patient registry is to help providers be more proactive in managing their patients' conditions.

A first draft of the registry toolkit was released in August 2002. The framework includes: 1) supporting literature and resources; 2) recruitment strategies; 3) implementation strategies; 4) sustained-use strategies, and 5) QIO experiences. The supporting literature/resources section references published literature, QIO literature, and related websites. Recruitment strategies include tools and marketing methods for individual and group practices. The emphasis of the implementation section is to provide registry installation/system requirements and training needs for physician office staff. QIO follow-up is reflected in post-implementation efforts, as well as sustained use techniques. QIO experiences include lessons learned, barriers, and keys to success information.

The final version of the toolkit is scheduled for release in December.

It will include outcomes and lessons learned information from the "What Works" survey findings. The purpose of the "What Works" survey was to identify strategies from QIOs with patient registry recruitment and implementation experience that were successful, as well as those that were unsuccessful but produced knowledge, in order to ultimately improve QIOs' ability to facilitate patient registry use by clinical partners. WebEx training demonstrations of QIO registry software, as well as additional tools and resources to expand the initial framework, will be included in the final version.

For more information on the Patient Registry Toolkit, please contact the QIO in your state. A directory of QIOs is available on the internet via www.cms.hhs.gov/qio/ - click on "Directory" on the menu at right. QIOs may access the toolkit posted on their intranet.

Ms. Carroll is a project coordinator with the Physician Office QIOSC, the Virginia Health Quality Center, in Glen Allen, VA.

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



Screening Mammography: Your Recommendation is More Important than Ever

-Annette E. Kussmaul, MD, MPH

“Doctor, do I really need a mammogram?”

These days, your patients may have more questions than ever – about a screening test you have already discussed several times. Recently, mammography has been in the popular press on a weekly basis, and a few stories have questioned its efficacy. Other articles have supported its use. These conflicting messages can contribute to confusion – and questions in the examination room.

Eight major randomized controlled trials have shown that screening mammography every 1-2 years decreases mortality from breast cancer.¹ These studies were conducted in Europe and North America in the 1960s-1980s. The current controversy started last fall when two Danish researchers, Ole Olsen and Peter Gotzsche, questioned the validity of six of these studies, saying randomization in the studies was flawed. Based on the results of the two remaining trials, they concluded that screening mammography shows no benefit. Olsen and Gotzsche published a summary of their findings in *The Lancet* in October 2001.²

A flurry of response letters strongly disagreed. So did major medical organizations, the National Cancer Institute, and most patient advocacy groups. But public debate, stimulated by continued media coverage, questioned the value of mammography.

As a result, ten health organizations – including ACOG, the American Medical Association and the American Cancer Society – co-signed a full-page ad in the January 31, 2002 *New York Times* “strongly urging” women to follow the advice of their physicians and obtain mammograms.

Three weeks later, Health and Human Services Secretary Tommy G. Thompson announced an updated recommendation regarding breast cancer screening from the U. S. Preventive Services Task Force (USPSTF). This independent group of experts systematically reviews evidence of effectiveness and makes recommendations for clinical preventive services. The USPSTF recommended screening mammography, with or without clinical breast exam, every 1-2 years for women age 40 and over.³ The “B” recommendation of the USPSTF means that the review found at least fair evidence that mammography improves important health outcomes and concluded that benefits outweigh harms.

More recently, a March 16 paper in *The Lancet* reported on the long-term follow-up of four original randomized controlled trials conducted in Sweden. The authors found that screening mammography reduced the risk of breast cancer death by 21%.⁴ The effect was greater for women in their 60s.

Nonetheless, the recent press coverage may have raised doubts for some patients. They will be looking to you for information and guidance. Remind patients that their risk of

breast cancer continues to increase as they age, that they do not “out-grow” their risk of breast cancer. Mammography, although not perfect, is the only screening tool available at present.

Having a system of care in the office will ensure that you and your staff regularly remind patients about and refer them for screening mammography and other important preventive services. Quality Improvement Organizations, under contract with Medicare, can assist you in setting up in-office systems. For more information about the Quality Improvement Organizations, including contact information for the organization in your state, see www.natbreastcancer.com

Some patients may ask about mammography; some may not. But your recommendation is more important than ever. Talk to your patients about the benefits and limitations of screening mammography.

Editor’s Note: Reprinted with permission from The American College of Obstetricians and Gynecologists, *ACOG Clinical Review*, 2002, Volume 7, Issue 6, pages 1-2.

For more information about ACOG Clinical Review, see www.elsevier.com/locate/clinrev or www.sciencedirect.com.

Disclaimer: The opinions herein are the author’s and not necessarily those of the Centers for Medicare & Medicaid Services.

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Screening Mammography...
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Dr. Kussmaul is a Medical Officer in the Division of Clinical Standards & Quality in CMS's Kansas City Regional Office. She is the lead for the National Medicare Mammography Campaign.

¹ Smith RA, D'Orsi CJ. Screening for breast cancer. In: Harris JR, ed. Diseases of the breast. 2nd ed. Philadelphia: Lippincott Williams & Wilkins, 2000: 104-9.

² Olsen O, Gotzsche PC. Cochrane review on screening for breast cancer with mammography. *Lancet* 2001; 358: 1340-2.

³ Agency for Healthcare Research and Quality. Screening for breast cancer. Recommendations and rationale. February 2002. Available at: www.ahrq.gov/clinic/3rduspstf/breastcancer/brcanrr.htm. Last accessed June 21, 2002.

⁴ Nystrom L, Andersson I, Bjurstam N, Frisell J, Nordenskjold B, Rutqvist LE. Long-term effects of mammography screening: Updated overview of the Swedish randomized trials. *Lancet* 2002; 359: 909-19.

The Mammography Campaign Salutes "Cathy"

"Cathy" continues to be a partner in this educational effort. In October 2002, Cathy told her mother about the importance of regular screening mammography, "...This article says all women over 40 need

mammograms, especially women your age who are least likely to do things to take care of themselves ... if problems are caught early, almost all women can live long healthy lives..."

CATHY



CATHY



CATHY



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*Breast Health Access...
continued from page 2*

BHAWD continues to place foremost emphasis on partnership and collaboration with members of the disability community. BHAWD seeks to promote full inclusion for women with disabilities to breast health services and information. Women with disabilities are partners in all aspects of BHAWD's work, i.e., development, leadership, policy, implementation, dissemination and evaluation. Over the next five years, BHAWD plans to strengthen itself as a national model women's health program for women with disabilities with an emphasis in three areas: clinical services, education (provider, practitioner, and consumer) and public policy.

More information about BHAWD is available on the internet at www.bhawd.org. Or contact Florita Maiki, MA at (510) 204-4866.

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

CMS Region X Participates in "Block Walk" for Breast Cancer Awareness

-Margaret Medley

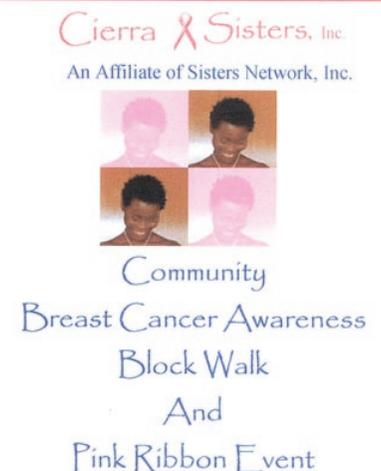
On October 26, 2002, staff from the Centers for Medicare & Medicaid Services (CMS) Seattle Regional Office provided technical support and participated in the first Community Breast Cancer Awareness Block Walk & Pink Ribbon Event. This event was hosted by Cierra Sisters, Inc., a recently-formed African-American breast cancer support and survivors' organization.

Local community partners such as the American Cancer Society, the Regional Cancer Information Service, City of Hope, and the Susan G. Komen Breast Cancer Foundation, as well as CMS provided mammography & other health education materials. These were placed in plastic bags for dissemination in the Rainier Beach (Seattle, WA) residential area. Twenty-five breast cancer survivors, along with family and friends, walked around the Rainier Beach neighborhood in teams of five. They handed out (or left at the doors) health information packets. These contained materials addressing the importance of early detection of breast cancer, Medicare coverage of preventive services, Healthy Kids 2001 (a children's nutrition program), and assistance in accessing quality health care.

After a one hour block walk, the teams returned to the meeting facility, at which time the "Pink Ribbon/Welcome Back" program commenced. Guest speakers included Dr. Nancy

Anderson of the Washington State Medicare/Medicaid Program and Carol Crowder, PA, a Women's Health Specialist from Group Health Hospital. Dr. Anderson discussed the State Medicaid Program for underserved and uninsured women with breast cancer. Ms. Crowder gave helpful information about coping skills after breast cancer treatments. Local community partners hosted information booths, and were available to answer questions and provide additional information to the walking teams and audience members.

Ms. Medley is a Health Insurance Specialist with the Customer Relations Branch, Division of Beneficiary Services in CMS's Seattle Regional Office. She is the Mammography Coordinator for Region X.



Saturday
October 26, 2002
8:30 a.m. – 1:00 p.m.
Rainer Community Center

P.O. Box 1634 Renton, WA 98057 (206) 505-9194 Cierra_Sisters@hotmail.com

CMS's Regional Mammography Coordinators

CMS's Regional Mammography Coordinators are a wonderful resource for partners working on breast cancer projects geared to 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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Seattle, WA 98121-2500
(206) 615-2355
mmedley@cms.hhs.gov or
lmatos@cms.hhs.gov



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		
Knowledge & Behavior of Women Ages 65 and Older on Mammography Screening & Medicare (Limited quantities available) 25-page bound report with findings from a telephone survey conducted in Spring of 1999. Also available at: http://newscenter.cancer.gov/pressreleases/hcfarpt.pdf	English	T162		
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 **UPDATED** 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" ** NEW ** 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 Dawn Brown in the Distribution Center at 410-644-6538 for questions.