



Centers for Disease Control and Prevention

ADVISORY COMMITTEE on BREAST CANCER in YOUNG WOMEN



CHAIR

Ann H. Partridge, MD, MPH

MEMBERS

Raquel D. Arias, MD
Ulrike Boehmer, PhD
Otis W. Brawley, MD
Sue Friedman, DVM
Generosa Grana, MD
Susan E. Kutner, MD
Brandon Hayes-Lattin, MD
Karen Kelly Thomas, PhD, RN
Karen Meneses, PhD, RN
Lisa A. Newman, MD, MPH
Jeanne L. Steiner, DO
Donald Warne, MD, MPH

DESIGNATED FEDERAL OFFICIAL

Temeika L. Fairley, PhD

EX-OFFICIOS

Jennifer Croswell MD, MPH
Susan Karol, MD
Jung-Min Lee, MD
Nancy L. Lee, MD
Morissa Rice, MHA
Gayle Vaday, PhD

LIASION REPRESENTATIVES

Lindsay Avner
Susan Brown, MS, RN
Shonta Chambers, MSW
Noreen Fraser
Arin Ahlum Hanson, MPH
Marc Hurlbert, PhD
Maimah Karmo
Ngina Lythcott, PhD
Devon McGoldrick, MPH
Jennifer Merschorf, MBA
Rochelle L. Shoretz, JD
Marisa Weiss, MD

May 20, 2015

The Honorable Sylvia M. Burwell
Secretary
U.S Department of Health and Human Services
200 Independence Avenue, SW
Washington, DC 20201

Dear Madam Secretary:

I am writing on behalf of the Centers for Disease Control and Prevention (CDC) Advisory Committee on Breast Cancer in Young Women (ACBCYW). As you know, the ACBCYW was established pursuant to Section 10413, Part V of the Patient Protection and Affordable Care Act (which established Section 399NN of the Public Health Service Act, as amended); Public Law 111-148. The ACBCYW recommends several initiatives in an effort to improve awareness, early detection, prevention, and care for the general population of young women in the United States.

Breast cancer in young women is a complex public health problem and several relevant features warrant attention. First, although the diagnosis of this disease in women under 45 years of age is not common, breast cancers are detected in more than 24,000 young women annually. Furthermore, the total number of women aged 20-45 years has grown by approximately ten million over the past three decades, and we are therefore seeing an increasing volume of women in this age range diagnosed with breast cancer. Historically, we have seen that younger breast cancer patients experienced worse survival rates compared to older patients but advances in treatment have reduced these differences. Unfortunately however, recent and alarming data suggest that the proportion of young women diagnosed with metastatic breast cancer is increasing. Lastly, the breast cancer burden of young women is also associated with race/ethnicity-specific susceptibility, with African American women more likely to be diagnosed with breast cancer at young ages compared to White American/Caucasian women, and African American women with breast cancer at any age have higher mortality risk compared to Caucasian women in the United States.

The Advisory Committee on Breast Cancer in Young Women provides advice and guidance to the Secretary, HHS, the Assistant Secretary for Health, and the Director, CDC regarding the formative research, development, implementation and evaluation of evidence-based activities designed to prevent breast cancer (particularly among those at heightened risk) and promote the early detection and support to young women who develop the disease.

Effective strategies are currently available to identify women that have a heightened likelihood of developing breast cancer at a young age, and appropriate use of breast imaging can detect cancers in these women at an early stage, when treatment is most likely to be successful. Given this background, the ACBCYW was charged with providing advice and guidance regarding the formative research, development, implementation, and evaluation of evidence-based activities designed to prevent or reduce the risk of breast cancer (particularly among those at heightened risk) and promote the early detection and support of young women who develop the disease. The advice provided by the ACBCYW is intended to assist in ensuring scientific quality, timeliness, utility, and dissemination of credible and age- and culturally-appropriate messages and resource materials. Out of recognition that there are areas for which there is only limited rigorous evidence yet there are observational data and high face validity for potential benefits of specific interventions, we have also considered “evidence-informed” activities in our evaluation and, ultimately, recommendations.

The ACBCYW has met regularly since January 2010, and one of our earliest efforts involved the formation of two work groups to explore education initiatives targeting (a) the high risk population of patients and the public (“High Risk workgroup”), and (b) providers, researchers, and members of the health care system (“Provider workgroup”). The High Risk workgroup assessed issues of risk stratification and identification of young women who are at higher risk of developing breast cancer, and effective health messaging towards young women. The Provider workgroup assessed strategies to target front-line providers to improve their awareness and action on behalf of young women at risk for breast cancer. The recommendations of these two work groups (as approved by the entire ACBCYW) were previously submitted to prior HHS Secretary Kathleen Sebelius and the CDC has acted upon several of them.

In the course of reviewing the output of the High Risk workgroup it became apparent that a separate but aligned set of recommendations were needed regarding messages that should be promoted among the general population of young women in the United States. Another work group was therefore convened to address this need (the “General Population” workgroup). We also have a number of additional recommendations regarding strategies targeting providers who care for young women based on the ongoing work of the Provider workgroup and continuation of ongoing work focused on young women at high risk of developing breast cancer.

The ACBCYW respectfully offers the recommendations below aimed at improving the care and outcomes of women in the United States aged 20-45 years, with respect to breast cancer detection and diagnosis.

Recommendations from the ACBCYW:

1) Promote balanced messages to young women regarding their likelihood of being diagnosed with breast cancer

- a. Breast cancer is the most common malignancy diagnosed among women in the United States, and breast health awareness is therefore important for women of ALL ages
 - Know: BRCA is a useful website for assessing individual breast cancer risk, and this program should be promoted among women of all ages especially young women at potentially high risk of breast cancer
 - Women should be made aware of genetic counseling services available to them

- b. Breast cancer is relatively uncommon among the general population of women younger than 45 years in the United States.
 - However it is slightly less uncommon among African American women younger than 45 years (compared to White American and Hispanic-Latina American and Asian American)
- c. The ACBCYW recommends that CDC generate graphics appropriate for a lay audience to enhance the effectiveness of culturally-appropriate messages regarding age- and race-specific breast cancer risk. Young women at higher than average risk of breast cancer should be prioritized in this effort. Examples of graphics exist, such as those developed by Think Pink, for the general population.

2) Promote awareness of the fact that even though breast cancer is uncommon in the general population of American women younger than 45 years, it CAN happen, and the signs may be subtle.

- a. Young women should therefore be aware of clinically-significant danger signs of breast cancer (bloody nipple discharge; new lump; patches of nipple-areolar skin that appear scaly/eczematous; new, persistent rash or inflamed breast skin)
- b. Young women undergoing mammographic screening should know that mammograms have an increased false negative rate for women younger than 50 years, and they should seek medical attention if a danger sign appears, regardless of most recent mammogram result

3) Promote the importance of young women understanding their individual risk profile and whether that profile suggests a breast cancer risk that is higher than that of the general population of young women.

- a. Family history of cancer and ancestral background
- b. Ashkenazi Jewish Heritage (e.g., of eastern European descent); African heritage
- c. Prior biopsy results that may have indicated increased risk (atypia; lobular carcinoma in situ)
- d. Prior chest wall radiation exposure that increases risk
- e. Mammographically-defined extent of breast density
- f. Known or suspected genetic mutation that is not BRCA 1 or BRCA 2 but may be associated with increased risk of breast cancer

4) Promote awareness of the facts that young women can adopt several lifestyle practices and habits that are effective in reducing their future risk of breast cancer.

- a. **Breastfeeding.** Any amount of breastfeeding is beneficial. The best level of protection comes from breastfeeding 12 months or more (across one or more pregnancies).
- b. **Reduce alcohol intake.** Drinking alcohol increases the risk of breast cancer, and the risk increases as the amount of alcohol consumed increases.
- c. **Regular exercise.** Exercising four or more hours per week may lower the risk of breast cancer, especially for women of normal or low body weight.
- d. **Smoking avoidance or cessation.** Tobacco smoking has now been associated with increased risk of breast cancer.
- e. These lifestyle messages should be promoted along with specific information regarding target body weight and body mass index.
- f. Of note, these recommendations are based on the best available research available at this time.

5) Provide resources and promote research in the following areas that are poorly-understood and/or underfunded with regard to breast cancer risk in young women:

- a. Impact of poverty/socioeconomic factors on breast cancer risk and access to care as it affects disparate outcomes in young women (social justice issues)
- b. Environmental factors on risk of breast cancer in young women
- c. Breast cancer risk among sexual and gender minority (lesbian/bisexual/transgender) populations
- d. Access to risk counseling services
- e. Improved/more efficient methods of detecting breast cancer and reducing its mortality among young women
- f. Primary and secondary prevention strategies
- g. Research to understand more fully and develop interventions for higher than average risk women but not necessarily high risk women (e.g., young AA women without a family history)
- h. Prospective studies including randomized controlled trials to determine the impact of lifestyle practices (e.g., breastfeeding, regular exercise) on reducing risk in young women.

6) **Support, provide resources and promote formative research needed to assess the needs of various constituents of providers and also to identify effective strategies that allow targeting of high-risk groups by provider/provider systems.** To the extent that best practices can be identified, these should be widely disseminated and their impact evaluated:

- a. Several national programs, ranging from academically- to advocacy-based and many with CDC funding, are in various stages of dissemination and evaluation across the country. Each of these programs is focusing on innovative approaches to reach healthcare providers.
- b. Evaluation and expansion of these programs should be fostered along with strategies to bring providers together with at-risk women to help drive toward evidence-based, values-informed decisions.

7) **Utilize advances in healthcare and electronic medical record (EMR) systems that can both reach women and providers need to be developed and evaluated.**

- a. The target audience of healthcare providers should include the following groups:
 - i. Primary care physicians (e.g., specialties in internal medicine, family medicine and obstetrics/ gynecology)
 - ii. Students in schools of health professions in nursing, physician assistant and medical schools, as well as trainees
 - iii. Other practicing providers including nurse practitioners/physician assistants, naturopaths
 - iv. Insurance providers
 - v. Professional societies
 - vi. Healthcare plans
- b. The following strategies should be considered to reach healthcare providers:
 - i. Organizational meetings
 - ii. Licensing boards and accrediting bodies
 - iii. Integration into curricula of students in health professional schools
 - iv. Training programs (e.g., Bright Pink Training Program; University of Southern California Radiation Oncology Residency Training Program; Sharsheret Supports Cultural Competency Training Programs)
 - v. Insurance providers
 - vi. Health Plan Medical Directors (e.g., the Michigan model)

- vii. National partners (e.g., Aetna, United Health and Cigna)
- viii. Newsletters
- ix. E-mail blasts
- x. Conferences for providers
- xi. Social networks that connect patients with providers
- xii. Online education
- xiii. EMR innovations at point-of-care (e.g., through organizations such as the Patient-Centered Clinical Research Network, PCORnet, a nationally distributed research network that will link 70 million Americans to their EMRs, with whom CDC is a partner)

8) **Further research is critical and remains to be conducted in the field of effective outreach to healthcare providers.** Research focused on identifying the needs of various audiences and developing successful strategies to reach these audiences must be conducted. The effectiveness of existing programs in changing practice and outcomes must be studied. Additional research is also needed to develop and define indicators to consistently measure effectiveness and success across programs.

9) **Further support should be considered for groups that currently are conducting activities targeting healthcare providers.** It is imperative to identify these groups and explore platforms to foster their collaboration. Funding opportunities should be identified to support, evaluate and expand the activities of these groups. Examples include: Academic/community partnerships (e.g., Dr. Michael Wilkes at the University of California-Davis, Moffitt Cancer Center, and University of Michigan); Patient advocacy and online support groups (e.g., Bright Pink, FORCE, and Sharsheret Supports National Cultural Competency Trainings); CDC and its grantees; and existing clinical initiatives (e.g., Planned Parenthood).

The ACBCYW understands that there are many competing demands on public health dollars and that young women with breast cancer as well as those at risk for the disease are only two populations in need of attention among many. However, as your federally appointed advisors for these concerns, we are compelled by the urgency of this issue and the fact that there are available remedies which, if successfully implemented, would have great potential to improve outcomes and potentially prevent the tragedy of more young women suffering from and dying of breast cancer. We greatly appreciate your review and consideration of this issue, and thank you for your leadership and hard work aimed at improving the health of all Americans

Respectfully,

Dr. Ann H. Partridge
Chair
Advisory Committee on Breast Cancer in Young Women (ACBCYW)

cc:
Dr. Thomas R. Frieden
Director CDC

Dr. Ursula Bauer
Director, National Center for Chronic Disease Prevention and Health Promotion, CDC

Dr. Lisa Richardson
Director, Division of Cancer Prevention and Control, CDC

Dr. Temeika L. Fairley
Designated Federal Official, ACBCYW, Division of Cancer Prevention and Control, CDC

ACBCYW Members