



Centers for Disease Control and Prevention

# ADVISORY COMMITTEE on **BREAST CANCER** in YOUNG WOMEN



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May 1, 2013

The Honorable Kathleen Sebelius  
U.S. Department of Health and Human Services  
200 Independence Avenue, SW  
Washington, DC 20201

Dear Secretary Sebelius:

I am writing on behalf of the Centers for Disease Control and Prevention (CDC)/Advisory Committee on Breast Cancer in Young Women (ACBCYW) to share with you recommendations that the ACBCYW unanimously approved at our April 16, 2013 meeting. 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 (Affordable Care Act). The ACBCYW recommends several initiatives in an effort to improve awareness, early detection, prevention, and care for women at risk for or diagnosed with breast cancer at a young age.

Breast cancer in young women is a complex public health problem. While the diagnosis in women under 45 is not common, there are approximately 26,500 young women diagnosed annually in the United States (based on 2011 Surveillance Epidemiology and End Results, SEER, data submission). Most concerning, **breast cancer is the leading cause of cancer-related death and the second leading cause of overall death in women ages 20-39**. Given the availability of strategies to reduce risk of the disease in women at elevated risk and improve care and outcomes among women diagnosed, the ACBCYW is charged with providing advice and guidance to the CDC regarding the formative research, development, implementation, and evaluation of evidence-based and evidence-informed 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 the Secretary, acting through the CDC, in ensuring the scientific quality, timeliness, utility, and dissemination of credible age- and culturally-appropriate messages and resource materials.

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.

Specifically, the Affordable Care Act calls for the ACBCYW to assist the CDC in creating and conducting a national evidence-based education campaign to increase awareness and young women's knowledge regarding:

- A) breast health in young women of all racial, ethnic, and cultural backgrounds;
- B) breast awareness and good breast health habits;
- C) the occurrence of breast cancer and the general and specific risk factors in women who may be at high risk for breast cancer based on familial, racial, ethnic, and cultural backgrounds such as Ashkenazi Jewish populations;
- D) evidence-based information that would encourage young women and their health care professionals to increase early detection of breast cancer; and
- E) the availability of health information and other resources for young women diagnosed with breast cancer.

The ACBCYW began meeting in January 2011 and has considered much of the available evidence regarding the state of breast cancer in young women and young women at risk. With input from many stakeholders, members of the ACBCYW have reviewed data concerning the prevalence, prevention, risk reduction, treatment, and support of women with the disease and survivors, as well as health communication strategies for young adults, and communication with and behavioral change among providers. Our goal was to highlight several areas where young women's experiences as relates to breast cancer differ detrimentally from those of older women due to: 1) lack of awareness or responsiveness to a high risk personal or family history resulting in a failure to understand risks, test for known high-risk genetic changes, and potentially avail oneself of risk-reduction strategies; 2) diagnostic delays due in part to a lack of awareness in patients and providers that breast cancer can and does occur in young women despite its relative rarity; 3) lack of attention to and minimal or no available support for issues of great concern and potential impact on young women with breast cancer, including but not limited to fertility, genetic predisposition, and psychosocial health; and 4) increased risk of dying of breast cancer due to lack of access to care (as indicated above), and more aggressive disease (worse tumor biology and more advanced stage of disease at diagnosis) in young women.

The ACBCYW formed two working groups to explore education initiatives targeting: A) the high risk population of patients and the public (High Risk workgroup); and B) providers, researchers, and health care professionals (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 providers to improve their awareness and action on behalf of young women at risk for breast cancer.

The ACBCYW respectfully provides several recommendations below as a result of the work of the workgroups and the ACBCYW as a whole focused on improving the care and outcomes of young women at risk for and diagnosed with breast cancer, and assisting the CDC in developing and disseminating credible age- and culturally-appropriate messages and resource materials.

Recommendations from the ACBCYW:

### **1) Identify and Communicate Effectively with Young Women at Elevated Risk**

There are definitions of "high risk" and "higher than average risk" young women that should be considered for targeting health messages in the public arena and to their primary care physicians. Further, there are a number of considerations for effective health messaging aimed at diverse audiences of young adult women.

- The ACBCYW recommends that messages be crafted to target the following audiences of "high risk" young women (see Appendix A):

- Young women with hereditary susceptibility (see Appendix A) to breast cancer
- Young women with biopsy-proven atypical hyperplasia or lobular carcinoma in-situ
- Young women with a history of chest wall radiation during adolescence or early adult life
- Messages should also be crafted to target the following audiences of young women at “higher than average” risk:
  - Young Jewish women (with a specific target of women of Ashkenazi descent) with known or unknown family history or family history that does not indicate a hereditary susceptibility of breast cancer
  - Young women with clinically-determined mammographically-dense breasts
- Messages should be targeted specifically to those at “high risk” or “higher than average risk”, where applicable, and should be clear in that they are not meant to address young women at average risk.
- Messages should include robust evidence-based recommendations for activities with known breast cancer risk reduction, making clear that they will not prevent breast cancer for all young women. These activities include:
  - Encouraging young women to become familiar with their bodies, and specifically their breasts, so that they can report changes or abnormal conditions to their medical providers;
  - Encouraging young women to make healthy lifestyle choices such as maintaining a balanced diet, maintaining proper weight, smoking cessation, limiting alcohol consumption, and exercising, as healthy lifestyle choices may reduce breast cancer risk and risk of other diseases; and
  - Encouraging young women to breastfeed because breastfeeding may reduce breast cancer risk.
- Messages to young women should not cause undue harm or fear in the target audience. Messages that correlate healthy lifestyle choices with overall health and wellness may have greater impact than messages that correlate healthy lifestyle choices with a reduction of illness, and specifically cancer, which may be perceived as frightening to young women.
- Messages should correlate with the interests of young women. Messages that evoke images of exercise, fitness, and beauty may have greater impact than messages that evoke images of illness and disease.
- Messages should communicate clear information about breast cancer risk, and encourage a specific action on the part of the target audience (e.g., “Talk to your family”, “Talk to your doctor”, “You can speak up”, “Exercise regularly”, “Breastfeed your baby”).
- Message text should be mindful of health literacy and drafted at an appropriate reading level not to exceed that of an eighth grade student.
- Message text and images should reflect the diverse populations of young women.
- Messages should address the stigma associated with breast cancer in some communities.
- Consideration should be given to those national messages that have already been developed to target the population at elevated risk.
- Messages should be delivered via social media (e.g., Facebook, Twitter), and should utilize communication strategies that work effectively among young women (e.g., text messages). Consideration should be given to alternative methods of reaching young women who do not have access to these communication portals.
- Any effort to communicate with younger women about their risks and risk reduction should be conducted in an iterative fashion with robust evaluation to gather additional data about effective messaging to young women at risk of breast cancer, further developing effective messaging in collaboration with, and with feedback from, the target population of young women.

## **2) Support the Development and Utilization of Strategies to Engage Providers to Identify and Communicate with Young Women at Elevated Risk**

Guidelines have been developed to guide healthcare providers on issues related to genetic testing, risk assessment, and chemoprevention strategies for young women at risk for breast cancer. Significant gaps exist

and additional research is needed to assess current level of knowledge of primary care providers and to fill in the gaps identified by the above referenced studies. Information thus learned could then be used to develop focused strategies to target healthcare providers.

- The ACBCYW recommends:
  - The assessment of the current level of knowledge and practice of primary care providers around the topic of breast cancer in young women
    - Work with primary care societies (e.g., Medical and Nursing) to develop and disseminate a survey instrument.
    - Use available tools such as the eDoctoring tool, developed at the University of California Davis ([http://edoc.ucdavis.edu/Public\\_site/](http://edoc.ucdavis.edu/Public_site/)), to assess both knowledge and practice and impact of education on health care providers.
    - Assess use of tools available to CDC such as DocStyles ([http://www.cdc.gov/cfs/programs/cdc\\_research/2009\\_5yr\\_research\\_plan.html](http://www.cdc.gov/cfs/programs/cdc_research/2009_5yr_research_plan.html)) and ongoing genomics initiatives to determine utility in reaching health care providers.
  - Foster development of educational tools targeted to education of healthcare providers at various points of training:
    - Assess potential use of certification and recertification requirements as opportunities to enhance education in this area.
    - Assess and expand tools such as eDoctoring to both study the needs of providers and to meet those needs.
    - Incorporate information about breast cancer in young women as part of the E-learning series (<https://cancersurvivorshipcentereducation.org/>) about cancer survivorship for PCPs recently launched as a collaboration between CDC and American Cancer Society ([www.cdc.gov/cancer/survivorship/basic\\_info/](http://www.cdc.gov/cancer/survivorship/basic_info/)).
  - Continue support and study of programs like the BodyTalk ([http://www.cdc.gov/cancer/breast/pdf/BodyTalk\\_FACA\\_presentationWcole.pdf](http://www.cdc.gov/cancer/breast/pdf/BodyTalk_FACA_presentationWcole.pdf)) decision support tool developed by CDC as it relates to patients and healthcare providers:
    - Potentially use the Agency for Healthcare Research and Quality's (AHRQ) Action Network or some other mechanism to evaluate the effectiveness of BodyTalk in both target groups.
    - Search for effective dissemination strategies for this tool such as the AHRQ Effective Healthcare Program.
  - Focus on the electronic medical record (EMR) as a tool to both educate healthcare providers and monitor their performance as it relates to the area in question and foster potential collaboration between CDC and AHRQ on EMR build outs and evaluation.
  - Collaborate with other initiatives addressing healthcare providers and the topic of breast cancer in young women.

### **3) Engage Patients and Providers to Highlight and Address the Issues Unique to Young Women Facing Breast Cancer**

Young women diagnosed with breast cancer face issues of fertility, genetics, and psychosocial concerns arising from or accentuated by their age and life circumstances. There are a number of initiatives underway to support these patient and their providers to facilitate and provide resources to address these concerns.

- The ACBCYW recommends the continued support, evaluation, and expansion of ongoing funding initiatives including DP11-1111, “*Developing Support and Educational Awareness for Young (<45) Breast Cancer Survivors in the United States*” to:
  - Identify organizational elements that are essential for the successful implementation of young breast cancer survivor programs;

- Identify promising practices or evidence-based interventions that can be broadly disseminated to the target population;
- Assess the overall effectiveness of young breast cancer survivor programs.

In developing and disseminating messages aimed to educate young women at average risk about breast cancer, the ACBCYW encourages consideration of the overall content and style recommendations outlined above in Section 1 (“Identify and Communicate Effectively with Young Women at Elevated Risk”).

Although not our direct charge, the ACBCYW also strongly recommends continued support of basic, translational, clinical, and epidemiologic research aimed at improving the understanding, risk reduction, and treatment of women with breast cancer in general. We respectfully submit that studies focused on young women, in particular, should be given special priority, given the disparate outcomes of young women diagnosed with breast cancer. This is particularly true for young African American women and women of other under-represented minority groups in the United States. As more data becomes available, we anticipate additional understanding of specific groups. It is imperative to encourage and facilitate further research to understand the genetic and psychosocial underpinnings of the significantly poorer prognoses of young women after a diagnosis of breast cancer, and the development of interventions to mitigate them.

The ACBCYW understands that there are many competing demands on public health dollars and that young women with breast cancer and those at risk for the disease are only two needy populations 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 these recommendations and would be happy to work with you in the future toward their implementation. We thank you for your leadership and hard work aimed at improving the health of all of those in the United States.

Respectfully,

Ann H. Partridge, MD, MPH  
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. Marcus Plescia  
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

## Appendix A

The ACBCYW reviewed numerous definitions of breast cancer risk as presented by government agencies, health care professional organizations, and cancer organizations.

The following is the definition of “high risk” used by the ACBCYW in making its recommendations:

**High Risk:** Young women for whom existing data indicate the greatest risk of developing cancer compared to those at average risk, including:

- Young women with hereditary susceptibility of breast cancer (see below)
- Young women with biopsy-proven atypical hyperplasia or lobular carcinoma in-situ
- Young women with a history of chest wall radiation during adolescence or early adult life

### Factors Indicating a Hereditary Susceptibility of Breast Cancer

- At least two first-degree relatives with breast cancer
  - At least one diagnosed <50 years old
- At least three first- or second-degree relatives with breast cancer
- Both breast and ovarian cancer among first- or second-degree relatives
- First-degree relative with bilateral breast cancer
- Male relative with breast cancer
- Ashkenazi Jewish heritage and any first-degree relative with breast or ovarian cancer
- Ashkenazi Jewish heritage and two second-degree relatives with breast or ovarian cancer
- Member of known or suspected Cowden’s or Li Fraumeni syndrome family
- BRCAPRO or other model indicating hereditary susceptibility