



Centers for Disease Control and Prevention

ADVISORY COMMITTEE on
BREAST CANCER in YOUNG WOMEN



OVERVIEW OF THE ACBCYW: 2011-2015

JANUARY 28, 2016

CHARTER OF THE ADVISORY COMMITTEE ON BREAST CANCER IN YOUNG WOMEN

Authority

- The ACBCYW was established pursuant to Section 399NN of the Public Health Service Act, [42 U.S.C. §280m], as amended
- The committee is governed by the provisions of Public Law 92-463, as amended (5 U.S.C. App), which sets forth the standards for the formation and use of advisory committees.

OBJECTIVES AND SCOPE OF ACTIVITIES

The Secretary, Department of Health and Human Services (HHS), acting through the Director, Centers for Disease Control and Prevention (CDC), under Section 399NN of the Public Health Service Act, is authorized:

- to develop evidence-based initiatives to advance understanding and awareness of breast cancer among young women (particularly those at heightened high risk for developing breast cancer)
- to establish and conduct public and health care professional education activities
- to conduct prevention research
- to support the dissemination of evidence-based age appropriate messages and materials

DESCRIPTION OF DUTIES

The ACBCYW shall:

- provide 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 of young women who develop the disease
- The advice provided by the committee will assist in ensuring scientific quality, timeliness, utility, and dissemination of credible appropriate messages and resource materials

MORE SPECIFICALLY...

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
- E) the availability of health information and other resources for young women diagnosed with breast cancer

2011- REVIEW OF EVIDENCE

Highlight 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
- 4) increased risk of dying of breast cancer due to lack of access to care, and more aggressive disease (worse tumor biology and more advanced stage of disease at diagnosis) in young women

FORMATION OF 2 WORKING GROUPS

- High Risk Workgroup: high risk population of patients and the public
- Provider Workgroup: providers, researchers, and health care professionals

2013 RECOMMENDATIONS FROM THE ACBCYW TO THE SECRETARY OF HHS

- **Identify and Communicate Effectively with Young Women at Elevated Risk**
- **Support the Development and Utilization of Strategies to Engage Providers to Identify and Communicate with Young Women at Elevated Risk**
- **Engage Patients and Providers to Highlight and Address the Issues Unique to Young Women Facing Breast Cancer**

FORMATION OF ANOTHER WORKING GROUP

- General Population Workgroup: separate but aligned with high risk recs for women in the general population
- Continuation of work of the Provider and High Risk Workgroups

2015 RECOMMENDATIONS FROM THE ACBCYW TO THE SECRETARY OF HHS

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

2015 RECOMMENDATIONS FROM THE ACBCYW TO THE SECRETARY (CONT.)

- **Provide resources and promote research in areas that are poorly-understood and/or underfunded with regard to breast cancer risk in young women**
- **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**
- **Utilize advances in healthcare and electronic medical record (EMR) systems that can both reach women and providers need to be developed and evaluated**
- **Further research is critical and remains to be conducted in the field of effective outreach to healthcare providers**
- **Further support should be considered for groups that currently are conducting activities targeting healthcare providers**

2016-

- We shall see!

2016- FUTURE DIRECTIONS

- High Risk Workgroup
- Provider Workgroup
- General Population Workgroup
- Social Justice Workgroup