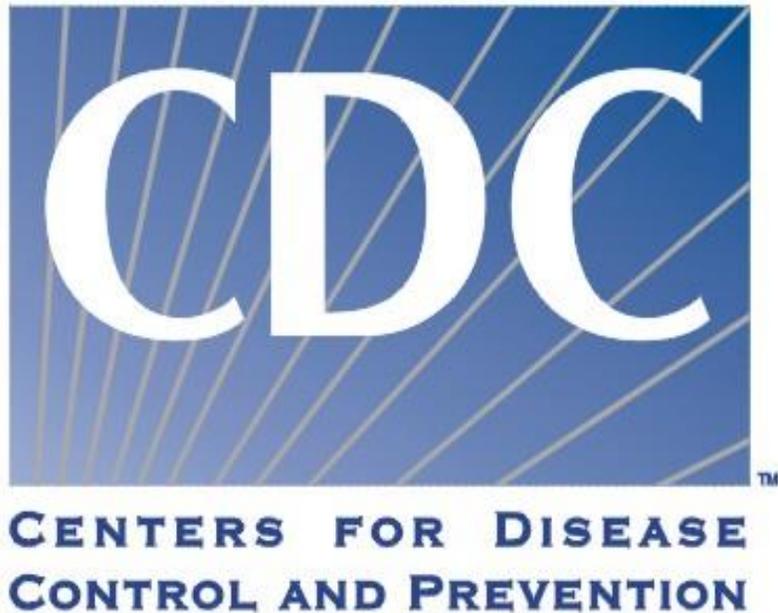


**CENTERS FOR DISEASE CONTROL & PREVENTION  
ADVISORY COMMITTEE ON BREAST CANCER IN YOUNG WOMEN**



**TELECONFERENCE MEETING  
APRIL 16, 2013  
ATLANTA, GEORGIA**

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**DRAFT Record of the Proceedings**

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**CENTERS FOR DISEASE CONTROL & PREVENTION (CDC)**  
**ADVISORY COMMITTEE ON BREAST CANCER IN YOUNG WOMEN (ACBCYW)**  
Teleconference Meeting  
April 16, 2013

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**MEETING OBJECTIVES:**

Committee members are charged with advising the secretary of the US Department of Health and Human Services (HHS) and the director of the CDC regarding the formative research, development, implementation, and evaluation of evidence-based activities designed to prevent breast cancer (particularly among those at heightened risk).

**OPENING: WELCOME, ROLL CALL, AND INTRODUCTIONS**

**Temeika L. Fairley, PhD**

Designated Federal Officer, DCPC, CDC

The day's meeting was called to order at 9:16 AM (EST). The operator welcomed the participants and gave instructions on how to answer questions during the discussion period. Participants were informed that the meeting was being recorded and anyone who objected could disconnect from the call.

Dr. Fairley conducted a roll call to ensure quorum. The following individuals were present on the call:

**Voting and Ex-Officio Members**

- Brandon Hayes-Lattin
- Maimah Kamo
- Karen Kelly Thomas
- Rochelle Shoretz
- Joy Simha
- Jeanne Steiner
- Wendy Susswein
- Beth Collins Sharp
- Gayle Vaday
- Nancy Lee
- Morrisa Rice
- Jo Anne Zujewski
- Ann Partridge
- Generosa Grana\*
- Lara Tillman\*

\*Note: It was determined that Dr. Generosa Grana and Dr. Laura Tillman were also on the call, but having technical difficulties. They expressed their comments in writing to Dr. Fairley.

**Liaison Representatives**

- Ngina Lythcott
- Elyse Spatz Caplan

- Kelly Hodges

- Susan Brown

Quorum was present.

Members were instructed to review the agenda and identify any conflicts of interest. No conflicts were identified.

**Ann H. Partridge, MD, MPH**  
ACBCYW Committee Chair, Dana-Farber Cancer Institute

Prior to providing a brief welcome to the members, Dr. Partridge called for a moment of silence in honor of those affected by the Boston Marathon Bombing, which occurred on April 15, 2013. She expressed her sentiments, for the family members and their loved ones.

Dr. Partridge expressed her pleasure, in having the Advisory Committee of Breast Cancer in Young Women convened today. She then reviewed the agenda and expressed her appreciation with Dr. Fairley and her team's administrative support to the Committee. The recommendations are a culmination of the Committee's work over the last 3 years.

For the day's meeting, members will be allowed to review the draft recommendations and suggest modifications.

**Marcus Plescia, MD, MPH**  
Director, DCPC, CDC

Dr. Plescia also articulated his appreciation to Committee for their participation on today's call. He was enthusiastic about the draft recommendations developed by the Committee and looked forward to hearing the members' comments. He closed by thanking everyone for their diligence to this effort.

**UPDATES FROM CDC**

**Temeika L. Fairley, PhD**  
Designated Federal Officer, DCPC, CDC

Dr. Fairley provided a few updates from CDC. She acknowledged that Carolyn Headley, the committee management specialist, was on maternity leave and that Ms. Alicia Ortner would be assisting the Committee in her absence.

She provided a status report on new member appointments to the Committee. The ACBCYW will fill 8 vacancies on the Committee this spring. These vacancies are due to the following reasons: 1) resignations of two members; or 2) completion of tenures of service for six members. HHS has approved the appointments of these eight new members. CDC will announce the names of these individuals in the coming weeks. She thanked the members of the Committee whose tenures were ending for their work and dedication to this effort. Retiring members of the Committee include the following:

- Dr. Otis Brawley
- Maimah Kamo
- Joy Simha
- Rochelle Shoretz

- Mavis Nitta

- Wendy Susswein

Dr. Fairley notified the ACBCYW of pending research publications, with emphasis on a specific paper, [Opportunities for Public Health Communication, Intervention, and Future Research on Breast Cancer in Younger Women](#), to be published in the *Journal of Women's Health* this month. CDC will share this paper with the Committee and make it available on the ACBCYW Web site. The paper addressed potential areas of public health research and identified gaps in the early onset breast cancer communications and survivorship literature that needed to be addressed.

In conclusion, Dr. Fairley solicited the members for questions or comments. None were voiced.

## **REVIEW AND DISCUSSION OF ACBCYW'S PROPOSED RECOMMENDATIONS**

**Ann H. Partridge, MD, MPH**

ACBCYW Committee Chair, Dana-Farber Cancer Institute

Dr. Partridge provided the Committee with a final review/overview of the proposed recommendations to the HHS Secretary. The review focused on content with minor edits to improved clarity of the items listed. Dr. Partridge requested that additional editorial comments be submitted to her via email within a week or so. Members were asked to provide their critiques after each slide.

The Committee developed three major recommendations based on its charge, from the Affordable Care Act. Within each major recommendation, sub-recommendations have been identified. The three recommendations are as follows:

1. *Identify and communicate effectively with young women at elevated risk.*
2. *Support the development and use of strategies to engage providers to identify and communicate with young women at elevated risk.*
3. *Engage patients and providers to highlight and address the issues unique to young women facing breast cancer*

Members were asked for their thoughts on the three recommendations. No further comments were provided.

Dr. Partridge then presented sub-recommendations to each of the three major recommendations.

Major Recommendation 1:

- *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.*

The Committee recommended that messages be crafted to target the women that are clearly at high risk. No further comments were expressed.

- *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 mammographically-dense breasts (as documented by a breast radiologist).*

The sub-recommendation targets women with higher than average risk, such as young Jewish women of Ashkenazi Jewish descent, those with known or unknown family history, and women whose family history does not move them into the high-risk group.

The sub-recommendations generated several comments. Dr. Lee felt there were many specific details around mammographically dense breasts that are more clinical than the messages suggest. She inquired about the delivery of the messages. Would they be by the clinicians or by nonclinical means? If it were to be by nonclinical means, the statement “documented by a breast radiologist” would be difficult to include in the message. Dr. Lythcott said the Committee needed to make sure that it included women with dense breasts, with the understanding that not all women who think they have dense breasts actually do; that breast density is also related to stage of development or growth. She suggested that emphasis be placed on women who had a clinical diagnosis of dense breast and that the Committee follows the research on this. Ms. Simha noted that messages stating that young women with mammographically dense breasts as documented by a breast radiologist are higher than average risk, may prompt young women of average risk to pursue screening mammograms to determine whether they have mammographically dense breasts.

Ms. Shoretz suggested that the wording be tweaked to say “young women with clinically-demonstrated, mammographically, dense breasts,” which Dr. Lee felt was more suitable, but she still was concerned about the message delivery. If the message is provided in a clinical setting, then it would much easier for her to agree with the recommendation. Ms. Shoretz felt Dr. Lee’s concern went beyond the scope of recommendations’ purpose and was more related to the

Committee's "phase 2" activities, which will determine where messages will be rolled out.

- *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. These activities include the following:*
  - *Encouraging young women to become familiar with their bodies, and specifically their breasts, so that they can report 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.*
  - *Encouraging young women to breastfeed because breastfeeding may reduce breast cancer risk.*

Ms. Simha recalled a conversation she had with Malcolm Pike, a leading epidemiologist studying factors related to breastfeeding and breast cancer. Mr. Pike felt most of the evidence, for the last 7 to 10 years, showed that breastfeeding helped to prevent breast cancer in cultures where women typically breastfeed for long periods of time (e.g., developing or rural countries and cultures). The evidence for this recommendation was based mostly on research done outside of the United States. If that were the case, she wondered if breastfeeding was a potential risk reducer for the American women who do not traditionally breast feed as frequently or as long. Dr. Partridge acknowledged the many debates and studies related to breastfeeding and its impact on breast cancer. Closer examination of the impact of breastfeeding will be included in the Committee's future work along with other risk factors, such as obesity.

Dr. Caplan commented on the first bullet. Most women do not know how to identify abnormal conditions. The Committee's intent is to encourage women to become more aware of their bodies, but she felt women might not be able to identify an abnormal condition. A member (unidentified) suggested the wording to be changed to "reporting abnormal conditions or other changes to their medical providers."

No additional comments were provided for the following sub-recommendations.

- *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 use 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.*

The following sub-recommendations were crafted to Major Recommendation 2:

- *Conduct assessment of current level of knowledge and practice of primary care providers around topic of breast cancer in young women.*
  - *Work with primary care societies (e.g., medical, nursing) to develop and disseminate survey instrument.*
  - *Use eDoctoring tool, developed at UC Davis, or other similar tools to assess both knowledge and practice and impact of education on health care providers.*
  - *Assess use of tools available to CDC such as DocStyles and ongoing genomics initiatives to determine use in reaching health care providers.*
- *Foster development of educational tools targeted to education of health care 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 about cancer survivorship for PCPs recently launched as a collaboration between CDC and American Cancer Society.*
- *Continued support and study of programs like the BodyTalk decision support tool developed by CDC as relates to patients and health care providers:*
  - *Potential use of AHRQ Action Network to study the effectiveness of the Body Talk decision tool in both target groups.*
  - *Search for effective dissemination strategies for this tool—potential use of AHRQ Effective Health Care Program.*

Dr. Fairley suggested that a Web link be provided, in the letter to the HHS Secretary, for each of the noted programs. She will assist Dr. Partridge with gathering the Web links.

- *Focus on EMR as a tool to both educate health care providers and monitor their performance as it relates to the area in question and foster potential collaboration between CDC and AHRQ on EMR build out and evaluation.*
- *Collaborate with other initiatives addressing health care providers and the topic of breast cancer in young women.*

No further changes were suggested to the above sub-recommendations.

Major Recommendation 3 contained the following sub-recommendations.

- *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.*

*DP11-1111, “Developing Support and Educational Awareness for Young (<45) Breast Cancer Survivors in the United States,” a CDC-funded program, provides funding to seven organizations to develop and enhance programmatic efforts to support and care for young women who have already been diagnosed with*

breast cancer ([http://www.cdc.gov/cancer/breast/what\\_cdc\\_is\\_doing/grant.htm](http://www.cdc.gov/cancer/breast/what_cdc_is_doing/grant.htm)). Dr. Partridge will add a Web link to further information on the initiative.

There were additional recommendations, which were not crafted by the workgroup, but the Committee felt should be included in the letter.

- *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 in Section 1 (“Identify and Communicate Effectively with Young Women at Elevated Risk”).*
- *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, in particular for women in underrepresented minority groups.*

An unidentified member queried whether underrepresented minority groups should also include Japanese women, whose breast cancer numbers are raising primarily due to years of generations in the United States. Dr. Partridge noted that there are some small reports of minority groups, such as Hispanic and Native-Americans that are also experiencing some elevations in breast cancer incidence. The decision was made to add women of other minority groups with a qualifying sentence, such as “as more definitive data becomes available, other groups will be specifically identified.” African-Americans, however, will be specified in the current recommendations.

Dr. Partridge thanked the Committee for its input and expressed gratitude to Ms. Shoretz and Dr. Grana, for their assistance in preparing the recommendations for the meeting.

Members suggested the following areas to be revised:

- Second page of the letter, first paragraph with “ACBCYW began meeting in January,”—instead of stating young women and women at risk, it should read “breast cancer in young women and young women at risk.”
- Last page of the letter, next to the last paragraph, last sentence with “further research to understand the genetic and psychosocial underpinnings of their significantly poor.”—significantly is misspelled.
- Letter—change the start date of work from January 2010 to January 2011.

Ms. Simha wanted to ensure the recommendation to breastfeed, in order to decrease breast cancer risk, is not misinterpreted as blaming women for their

breast cancer because they choose not to breastfeed. An unidentified member replied that any time lifestyle changes are discussed, there is a risk of being seen as blaming the victim and there is no way to counter that misconception. Dr. Fairley provided some clarity. There is a difference between prevention and risk reduction. It should be stated explicitly that risk reduction does not mean that a woman will not develop breast cancer but rather that her risk of developing the disease may be reduced.

Dr. Partridge said diverse audiences have to be considered when any message is developed. There is a risk of unintended consequences to audiences that were not the target of the message. The evaluation and beta testing of messages will be critical. The intent is not to blame the victim, but prevention and risk reduction measures must be conveyed. Ms. Shoretz suggested an addition to the third page of the letter, where it says, “messages should include robust, evidence-based recommendations, for activities with known breast cancer risk reduction;” a comma should be placed after it and the statement “making clear that these activities may not prevent breast cancer” be added.

Dr. Partridge polled the group on their reactions. Dr. Steiner felt to add another set of messages that may seem slightly in conflict was not the priority of the letter. She felt the letter presented a nice tone, in saying there is information that can be helpful to people and the intent is not to alarm them.

With no further discussion, Dr. Partridge suggested the Committee prepare to vote on the recommendations.

Dr. Fairley familiarized the Committee on the voting process and next steps. Since the formal recommendations were put forward by the Committee, they require a vote from each member to either approve or not approve. Minor tweaks and adjustments to the recommendation and letter will be made as the Committee suggested. Once the final letter is received from Dr. Partridge, a copy will be forwarded to the Committee, and it will then be sent through the appropriate channels. The letter will be final when the HHS Secretary receives it.

Once received by the HHS Secretary, the decision will be made to publish the letter and recommendations in the HHS Secretary’s prescribed format. After that, it will be ready for release to the public. The Committee will be kept up-to-date on the progress. Dr. Vaday asked if a disclaimer would be included to say that other agencies involved in the designing of the letter and recommendations were voting as members of the committee and not representing their agency. Dr. Fairley advised her that ex-officio members do not hold a vote, but are on the Committee in an advisory capacity. The ex-officio members would; however, receive a copy of the letter.

Dr. Fairley called out each member’s name, for his or her vote. The vote was to **unanimously approve** the recommendations and letter to the HHS Secretary.

## **PUBLIC COMMENT**

The operator opened the phone line for public comments. Below is a summary of comments and suggestions raised by members of the public.

Ms. Cara Tenenbaum, from the Ovarian Cancer National Alliance, said she continues to be disappointed when ovarian cancer is not mentioned along with high-risk breast cancer issues. Due to genetic mutations, many women will be at risk for ovarian cancer. She felt this was a missed opportunity for CDC and asked if her organization should write to CDC or the HHS Secretary.

Dr. Fairley, after thanking Ms. Tenenbaum for her comment, replied the Committee is only at the start of its work. There may be opportunity to address ovarian cancer as related to breast cancer; however, the decision to do so will be at the discretion of the Committee. Dr. Partridge and Dr. Plescia agreed with Dr. Fairley's response. The Committee is charged with focusing on breast cancer, but there will be opportunities to speak to related issues. Ms. Tenenbaum was provided the ACBCYW's e-mail information, [ACBCYW@cdc.gov](mailto:ACBCYW@cdc.gov), where she could share her concerns with the Committee.

With no further comments expressed, the public comment period was concluded.

## **WRAP-UP/ANNOUNCEMENTS**

**Ann H. Partridge, MD, MPH**

ACBCYW Committee Chair, Dana-Farber Cancer Institute

Dr. Partridge provided closing thoughts. She thanked the Committee and the Public for their support and insightful comments. The work to date is just a start, and the Committee has done tremendous work to try to highlight the issues in a careful and thoughtful way. There are more issues to be cover. Members were instructed to submit additional minor modifications, which do not relate to content, since the content has already been unanimously approved.

She also looks forward to the new members coming aboard and expressed gratitude to the committee members rotating off, for their hard work.

Dr. Fairley solicited additional comments or questions from the Committee. With none voiced, the meeting was adjourned.

## **ADJOURN**