U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
CENTERS FOR DISEASE CONTROL AND PREVENTION
National Center for Chronic Disease Prevention and Health Promotion
Division of Cancer Prevention and Control

Teleconference Meeting of the Advisory Committee on Breast Cancer in Young Women
December 13, 2012

Record of the Proceedings

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U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
CENTERS FOR DISEASE CONTROL AND PREVENTION
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ADVISORY COMMITTEE ON BREAST CANCER IN YOUNG WOMEN
December 13, 2012
Atlanta, Georgia

Teleconference Meeting Minutes

The U.S. Department of Health and Human Services (HHS) and the Centers for Disease Control and Prevention (CDC), National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP), Division of Cancer Prevention and Control (DCPC), convened a teleconference meeting of the Advisory Committee on Breast Cancer in Young Women (ACBCYW). The proceedings were held on December 13, 2012.

ACBCYW is formally chartered to provide advice to the HHS Secretary and the CDC Director regarding the formative research, development, implementation, and evaluation of evidence-based activities designed to prevent breast cancer in young women, particularly those at heightened risk.

Information for the public to access the ACBCYW meeting via teleconference or Web conference was published in the *Federal Register* in accordance with Federal Advisory Committee Act regulations. All sessions of the ACBCYW meeting were open to the public (*Attachment 3: Participants' Directory*).

Opening Session

Temeika L. Fairley, PhD
Health Scientist, Division of Cancer Prevention and Control
Centers for Disease Control and Prevention
ACBCYW Designated Federal Officer

Dr. Fairley conducted a roll call of the ACBCYW voting members, *ex-officio* members, and liaison representatives. She verified that the voting members and *ex-officio* members participating on the teleconference constituted a quorum for ACBCYW to conduct its business (*Attachment 2: Roster of the ACBCYW membership*).

Dr. Fairley welcomed the participants to the ACBCYW teleconference meeting and called the proceedings to order at 9:44 a.m. EST on December 13, 2012. None of the voting members declared conflicts of interest for the record for any of the items on the published agenda (*Attachment 1: Published Meeting Agenda*).

Ann Hart Partridge, MD, MPH
Director, Adult Survivorship Program
Dana-Farber Cancer Institute
ACBCYW Chair

Dr. Partridge also welcomed the participants to the teleconference meeting. She thanked Dr. Fairley and Ms. Carolyn Headley, a Management and Program Analyst in DCPC, for their leadership, oversight, and outstanding efforts in convening the first ACBCYW meeting via teleconference. In the current environment of severe budget constraints, she was extremely pleased that DCPC staff was able to hold the second ACBCYW meeting in 2012 in a productive, effective and cost-efficient manner.

Dr. Partridge explained that the majority of the teleconference meeting would be devoted to the workgroup reports and ACBCYW's feedback on the proposed recommendations. Several documents were circulated to ACBCYW in advance to facilitate the discussions. The next steps after the teleconference meeting would be for the workgroups to revise the recommendations for ACBCYW's formal vote and approval for submission to the HHS Secretary in the first quarter of 2013.

Dr. Partridge concluded her opening remarks by conveying her strong interest in the success of the first teleconference meeting and the potential to replicate this model in the future to ensure CDC's continued support of two ACBCYW meetings per year.

Marcus Plescia, MD, MPH
Director, Division of Cancer Prevention and Control
Centers for Disease Control and Prevention

Dr. Plescia joined his colleagues in welcoming the participants to the ACBCYW teleconference meeting. He thanked the ACBCYW members for continuing to contribute their valuable time and expertise in helping CDC to address breast cancer in young women (BCYW) at the national level. He pointed out that ACBCYW's input on the findings of the workgroup would be extremely helpful in the development of recommendations and their potential integration into DCPC programs. Similar to Dr. Partridge, Dr. Plescia also hoped that the teleconference meeting would be more convenient for the ACBCYW members and more cost-effective for CDC.

Update by the ACBCYW Ad Hoc High Risk Workgroup

Rochelle L. Shoretz, JD
Executive Director and Founder, Sharsheret, Inc.
ACBCYW Member and Ad Hoc High-Risk Workgroup Chair

Ms. Shoretz devoted her update to a summary of the Ad Hoc High-Risk Workgroup's findings and suggested recommendations. The workgroup was formally charged with gathering initial background information and advising ACBCYW on (1) developing an understanding of the meaning of high risk for BCYW and (2) identifying potential evidence-based messages to disseminate to this population. The workgroup members include ACBCYW members, liaison representatives and clinical advisors.

The workgroup examined the following three key questions to fulfill its charge: (1) What are the definitions of average risk, higher risk, and high risk in the context of young women at risk of breast cancer? (2) What should ACBCYW consider when exploring components of effective health messages targeting young women? (3) What should ACBCYW consider when exploring components of evidence-based or evidence-informed messages targeting young women?

The workgroup is now requesting ACBCYW's input on topics in three categories: research gaps and additional data, considerations for content of breast cancer messages targeting young women, and considerations for delivery of breast cancer messages targeting young women. Ms. Shoretz summarized the workgroup's findings and suggested recommendations based on its research to date.

Suggested Recommendation A. ACBCYW's ad hoc high risk workgroup suggests that messages be crafted to target the following audiences of high-risk young women: (1) young women with hereditary susceptibility of breast cancer, (2) young women with biopsy-proven atypical hyperplasia or lobular carcinoma *in situ*; and (3) young women with a history of chest wall radiation during adolescence or early adult life.

If funds permit, messages also should be crafted to target the following audiences of young women at higher than average risk: (1) young women of Ashkenazi Jewish descent with unknown family history or family history that does not meet high-risk criteria, (2) young women with mammographically-dense breasts as documented by a breast radiologist, and (3) young women of non-Ashkenazi Jewish descent and family history that does not meet high-risk criteria. The workgroup agreed to eliminate the category of young women with high endogenous estrogen or testosterone levels.

Suggested Recommendation B. Messages should include evidence-based recommendations for activities with known breast cancer risk reduction. These activities include the following: (1) encourage young women to become familiar with their bodies and specifically their breasts to report abnormal conditions to their medical providers; (2) encourage young women to make healthy lifestyle choices (e.g., maintenance of a balanced diet and proper weight, smoking cessation, limited alcohol consumption, regular cardiovascular exercise), as healthy lifestyle choices may reduce breast cancer risk and risk of other diseases; and (3) encourage young women to breastfeed because breastfeeding may reduce breast cancer risk.

Suggested Recommendation C. Messages to young women should not cause undue harm or fear in the target audience. Messages correlating healthy lifestyle choices with overall health and wellness may have a greater impact than those correlating healthy lifestyle choices with a reduction of illness—specifically cancer—that may be perceived as frightening to young women.

Suggested Recommendation D. Messages should correlate with the interests of young women. Messages evoking images of exercise, fitness, and beauty may have a greater impact than those evoking images of illness and disease.

Suggested Recommendation E. Messages should communicate clear information about breast cancer risk and encourage specific actions on the part of the target audience (e.g., talk to your family, talk to your doctor).

Suggested Recommendation F. Message text should be mindful of health literacy and drafted at an appropriate reading level (e.g., not to exceed that of an eighth grade student).

Suggested Recommendation G. Message text and images should reflect the unique needs of diverse populations of young women.

Suggested Recommendation H. Messages should address the stigma associated with breast cancer in some communities, particularly the Orthodox and Hasidic Jewish community and the African American community.

Suggested Recommendation I. Consideration should be given to the replication of national messages that have already been developed to target the high-risk population.

Suggested Recommendation J. Messages should be delivered via social media (e.g., Facebook, Twitter). Communication strategies, such as text messaging, that are effective among young women should be utilized. However, consideration should be given to alternative methods of reaching young women who do not have access to these communication portals.

Following the workgroup's update during the previous meeting, ACBCYW suggested that focus groups be held or Web-based surveys be administered to gather additional data about effective messaging to young women at risk of breast cancer.

In discussions regarding the ACBCYW's suggestion, the workgroup agreed that the process of actually communicating messages to the target population might be delayed. The workgroup's position is that additional focus groups or Web-based surveys are not necessarily needed at this time because sufficient information on reaching young women has been gathered.

Ms. Shoretz concluded her update by turning ACBCYW's attention to the workgroup's draft report. Pages 5–6 provide definitions of average risk, higher risk and high risk in the context of young women at risk of breast cancer. For example, higher risk is defined as young women with a greater than average risk of breast cancer, but with no definitive evidence of high risk. High risk is defined as young women for whom existing data indicate the greatest risk of developing cancer compared with those at average risk (e.g., young women with hereditary susceptibility of 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).

Ms. Simha questioned the workgroup's rationale for proposing the delivery of evidence-informed messages in light of ACBCYW's charter to support the dissemination of evidence-based age-appropriate messages and materials.

Dr. Fairley responded that the workgroup's proposed delivery of evidence-informed messages was partly because of limited research on evidence-based messages for young women in the peer-reviewed literature. The workgroup also is exploring the possibility of recommending the replication of best practices in the field.

ACBYW commended the workgroup for devoting a considerable amount of thought and energy in drafting an outstanding report on a complex issue. Several members made comments and suggestions for the workgroup to consider in its next steps to finalize the draft report.

- The literature contains no evidence-based information regarding health messaging for BCYW. As a result, the workgroup should review the literature to identify effective health messaging for young women related to health conditions other than breast cancer that could be applied. However, the workgroup should take caution in applying evidence-informed messaging because the language could be misleading or unproductive. Some ACBCYW members were not in favor of revising the charter to accommodate the delivery of evidence-informed messaging. Instead, the workgroup should devote more time to gather evidence-based messaging and rank the level of evidence. ACBCYW agreed that a call for additional evidence-based research should be strongly emphasized in the report.

- ACBCYW was divided on the strength of the evidence to support the message in Recommendation B, breastfeeding may reduce breast cancer risk. On the one hand, studies in African tribes showed that breastfeeding generated benefits only when women breastfed many children over a period of nearly 10 years. On the other hand, the language should be retained because studies in African cultures do not represent ACBCYW's target population of young women. To resolve this dilemma, ACBCYW agreed that the recommendations should be crafted to be generalizable and robust with a high enough level of evidence. The recommendations also should recognize the limitations of all research, particularly studies that address diversity.
- The report should advise CDC to address the challenge of specifically targeting and focusing messages to high-risk and higher-risk populations to ensure that average-risk populations do not misinterpret these messages. This language should be included in Recommendation C: Messages to young women should not cause undue harm or fear in the target audience.

Update by the ACBCYW Ad Hoc Provider Workgroup

Generosa Grana, MD, FACP
Director, Cooper Cancer Institute
ACBCYW Member and Provider Workgroup Member

Dr. Grana covered the following topics in her workgroup report to ACBCYW. The workgroup was formally charged with gathering initial background information and advising ACBCYW regarding behavior change of providers as relates to (1) enhancing provider knowledge regarding BCYW by assessing gaps, guidelines, and issues related to messaging of BCYW and (2) improving the skills of providers regarding the delivery of care to young women at average and high risk of and/or facing breast cancer (e.g., survivors). As part of its charge, the workgroup would define providers. The workgroup has expanded its membership since the previous ACBCYW meeting.

The workgroup agreed to target the patient populations of women of reproductive age up to 45 years, pre-diagnosis women at average or high risk (including those at risk of relapse or second primary breast cancer), and post-diagnosis women. In the definition of "providers" for pre-diagnosis and early diagnosis women, the workgroup included general practice, family practice and internal medicine physicians, obstetricians/gynecologists, physician assistants, and primary care nurse practitioners. In its definition of "providers" for post-diagnosis women, the workgroup included medical, surgical and radiation oncologists, oncology nurses, and primary care physicians (PCPs) who are responsible for the care of cancer survivors.

The workgroup agreed to engage a number of professional societies and networks to effectively outreach and deliver messages to providers: American College Health Association, American Academy of Family Practice, American College of Physicians, American Congress of Obstetricians and Gynecologists, American Academy of Nurse Practitioners, American

Academy of Physician Assistants, American Society of Clinical Oncology, American College of Surgeons, American Society for Radiation Oncology, Oncology Nursing Society, and National Comprehensive Cancer Network.

The workgroup assessed several factors that play an important role in provider behavior change—including knowledge through training and continuing education; guidelines, materials, and other resources; communication and other skill sets to deliver messages; access to patients through utilization of care and opportunities for engagement; and accountability and measurement of provider performance through quality assurance/quality improvement.

The workgroup's discussions after the previous meeting have focused on addressing questions in four areas—

1. What steps can be taken to better assess the knowledge base of providers?
2. What steps can be taken to assure appropriate resources are developed and used? What steps can be taken to integrate with ongoing quality assessment and quality improvement efforts?
3. What steps can be taken to better assess provider skills in resource utilization and communication?
4. What steps can be taken to improve patient access and utilization?

In terms of the current status of health care providers, the workgroup found tremendous variation in the literature on utilization of and referrals to genetic counseling services, the appropriateness of referrals, and communication of risk information. CDC-funded research indicates that PCPs still have a need for education on genetic consultation and its appropriate use as well as the integration of genetic consultation into actual practice.

The workgroup reviewed two key studies to inform its decision-making. The 2011 Bellcross, *et al.* study was designed to determine the level of awareness and utilization of BRCA testing and the 2005 U.S. Preventive Services Task Force recommendations among PCPs in the United States. The 2007 Web-based DOCstyles National Survey was analyzed in the study with a random sample of 3,115 PCPs and a response rate of 48%.

DOCstyles asked whether PCPs actually ordered at least one test, but no questions were included in the survey on referrals for genetic counseling and testing, provision of counseling, or implementation of management recommendations. DOCstyles data showed that patients are increasing their use of genetic testing, but tremendous gaps persist. The workgroup agreed that opportunities exist to use DOCstyles as a tool to assess the use of chemoprevention, screening recommendations and genetic testing among PCPs and conduct additional research in this field.

The 2011 Trivers, *et al.* study analyzed a vignette-based survey instrument. The survey showed that 41% of PCPs would have appropriately referred high-risk women for ovarian screening, testing and counseling, while 22% of these PCPs would have inappropriately referred average-risk women for genetic counseling. The study findings indicate that PCPs would have under-utilized services for high-risk women and would have over-utilized services for average-risk women. The workgroup agreed that the survey instrument should be used to gather data needed to develop future recommendations about the utilization of these services by PCPs.

In terms of chemoprevention, the workgroup reviewed data from the 2000 National Health Interview Survey that showed >10 million women aged 35–79 years were risk-eligible for tamoxifen. Of this population, >2 million white women had a positive risk-benefit analysis. Despite these findings, the use of tamoxifen has been miniscule and is continuing to decrease (e.g., from 0.2% in 2000 to 0.08% in 2005).

In terms of the current status of patients, the workgroup reviewed the 2009 Olaya, *et al.* study that reported uptake rates for breast cancer genetic testing. The study showed that 50% of patients who are referred do not actually undergo genetic testing. This rate was unrelated to insurance coverage for testing, but was affected by the patient's previous diagnosis and educational level. The workgroup agreed on the need for counseling instruments to improve testing rates.

The workgroup explored the following three major opportunities to impact health care providers: First, training should be provided to students, physicians and other health care providers, including nurse practitioners and physician assistants. Specific modules should be created and disseminated to medical schools and schools of nursing to provide training on genetics, communication skills and clinical skills. Second, training should be provided to practicing clinicians at three key intervention points: the initial certification process, maintenance of certification and licensure, and ongoing continuing medical education. Training materials for practicing clinicians should cover BCYW. Third, electronic medical records (EMRs) should play a critical role in health care provider education for both knowledge and clinical practice.

In terms of ongoing activities targeted to health care providers, the workgroup discussed tools and resources that have been developed by federal agencies and potentially could be adapted, tested, and disseminated with appropriate funding. CDC piloted programs in Michigan, Oregon, and Georgia in 2003 and 2011 with a focus on patient and provider education, surveillance, and systems change with regard to genetics in high-risk populations. These initiatives could be expanded at the national level. CDC's BodyTalk Decision Support Tool is designed to enhance communication between providers and patients.

The National Institutes of Health developed the eDoctoring Program as an interactive online educational tool that covers ethics, genetics, clinical management, epidemiology, and communication skills. Potential users of the tool include medical and nursing students, residents and PCPs, but credentialing bodies also might use the program for certification and licensure. California and rural areas of Pennsylvania currently are testing the tool for its use in palliative care and end-of-life care.

The Agency for Healthcare Research and Quality (AHRQ) developed the Effective Healthcare Program as a forum to create educational materials for patients and health care providers. The AHRQ Accelerating Change and Transformation in Organizations and Networks (ACTION) is used to test and disseminate defined strategies. The workgroup emphasized the need to closely collaborate with AHRQ because of its role as the one of the potentially major innovators in the development of EMRs and health information technology.

The workgroup reached several major conclusions on the basis of the research to date. Guidelines have been developed to guide health care providers on issues related to genetic testing, risk assessment, and chemoprevention strategies for young women. However, significant gaps persist and research still is needed to assess the current level of knowledge of PCPs, determine their use of existing guidelines, and fill gaps in current research. Information learned from additional research should be used to develop focused strategies to target health care providers.

Dr. Grana summarized the workgroup's five suggested recommendations to guide ACBCYW's discussion.

1. A more detailed assessment should be conducted to determine the current level of knowledge and practice among PCPs regarding BCYW. To achieve this goal, collaborations should be established with medical and nursing primary care societies to develop and disseminate a survey instrument. The eDoctoring tool should be used to assess both provider knowledge and practice and evaluate the impact of these educational strategies. The use of tools that are available to CDC should be assessed as well (e.g., DocStyles, ongoing genomic initiatives).

2. The development of educational tools that are targeted to health care providers at various points in training should be fostered. To achieve this goal, the potential use of certification and recertification requirements should be assessed for their use in medical training, medical schools, nursing schools and residency programs. The eDoctoring module and other existing tools should be evaluated and expanded to examine the needs of providers and devise strategies to meet these needs.

3. The analysis of BodyTalk as a tool that focuses on both patients and health care providers should be continued. To achieve this goal, the potential effectiveness of the AHRQ ACTION Network in both the provider and patient groups should be evaluated. Effective dissemination strategies also should be explored (e.g., the AHRQ Effective Healthcare Program).

4. Ongoing EMR initiatives should be broadly expanded and evaluated through a CDC/AHRQ collaboration to focus on BCYW. (The workgroup noted its lack of knowledge in this area and emphasized the need for additional expertise to develop more detailed and specific guidance on EMRs in the context of BCYW.)

5. Collaborations should be established with ongoing national initiatives (e.g., the Tigerlily Foundation) that provide education to PCPs on BCYW and develop new risk assessment tools.

Ms. Maimah Karmo, founder of the Tigerlily Foundation (TF), provided additional details on recommendation 5. TF currently is creating a program with an overarching purpose to increase education and awareness of BCYW among health care providers and develop appropriate messages for young women to discuss their bodies and breast health risks with their providers.

Ms. Karmo was pleased to announce that Dr. Grana is a member of the new TF advisory committee established for this effort. She asked the ad hoc provider workgroup's permission to share the data, research findings, and conclusions from this presentation with the TF advisory committee. She also extended an invitation to other ACBCYW members to serve on TF's new advisory committee.

ACBCYW commended the workgroup on drafting a comprehensive report. The rich discussion by the members provided the workgroup with critical feedback and valuable insights to guide its next steps.

- The workgroup should place more emphasis on making recommendations to increase the dissemination of information and resources to young women at the point of care when their providers make a breast cancer diagnosis. This approach would increase access to information in a timelier fashion among young women and result in a more positive impact on their choices for genetic testing, fertility, and psychosocial support.

- The workgroup should explore the possibility of engaging adolescent medicine providers to strengthen the focus on pre-diagnosis women in younger age groups.
- The workgroup should include more language throughout the report to emphasize the role of nurse practitioners and physician assistants as pre-diagnosis providers in addition to PCPs. Because nurse practitioners and physician assistants also serve as resources or potential points of intervention for pre-diagnosis women, some modules and tools could be adapted and targeted to these providers.
- The workgroup should target recommendations to community resources that young women are more likely to access for care and information than PCPs (e.g., navigators, lay professionals, school nurses, college health centers). This guidance should be included in the Opportunities for Engagement section of the report to describe points in time (e.g., becoming sexually active or pregnant) when young women interact with an array of providers on health topics other than breast cancer. Komen's Mother-Daughter Program and other successful community-based models should be highlighted in this section as well. For example, TF's Peer Education Through Awareness and Leadership (PETALs) Program© focuses on educating young women about their breast health beginning at 15 years of age. The program is offered at middle schools, high schools, and college campuses with extensive involvement by teachers and nurses. The students then serve as peer educators to girls and young women at other schools. The PETALs Program also has been effective in reaching grassroots providers at schools and colleges across the country. The Opportunities for Engagement section also should place strong emphasis on educating providers who believe that lesions or lumps in young women could not possibly be breast cancer due to their age.
- The workgroup should review activities conducted by the 7 CDC-funded DP11-1111 grantees to learn from these initiatives. Some of the grantees might be focusing on provider education in the context of young women that could be useful to the workgroup in fulfilling its charge. Dr. Fairley confirmed that she would attempt to foster interaction and information sharing between the grantees and the workgroup. This collaboration also might avoid duplication of efforts.
- Strategies should be explored to empower young women who detect a lump or have a family history of breast cancer to self-advocate for them in the health care system. This guidance also should be targeted to family members who already have breast cancer to foster and strengthen self-advocacy in these young women. The High Risk Workgroup should discuss the possibility of crafting these types of messages (e.g., Speak up, Take action).
- The workgroup's recommendations on the need for additional research in provider knowledge and education are important, but will require a long-term investment. Due to CDC's budget constraints, the workgroup also should formulate concrete guidance that could have a significant impact in the short-term. Dr. Grana clarified that the workgroup's recommendations advise CDC to test, evaluate and disseminate existing research and tools (e.g., BodyTalk) rather than fund new studies. Dr. Beth Collins Sharp is the ACBCYW *ex-officio* member for AHRQ. She explained that AHRQ funds the ACTION Network, Effective Healthcare Program and other initiatives to provide training on the dissemination of outcomes research in the context of patient standards. She offered to serve as a conduit to identify opportunities in which AHRQ's tools and resources that are relevant to ACBCYW's activities could be tested and disseminated to the field.

- The workgroup advises CDC to collaborate with AHRQ to broadly expand and evaluate EMR initiatives in the context of BCYW. However, the recommendation should encourage a partnership between CDC and the Centers for Medicare and Medicaid Services (CMS) because CMS is the lead agency for Meaningful Use activities.

Dr. Plescia made several overarching comments in follow-up to the workgroup's update. CDC would address the complexity in formulating recommendations for EMRs in a future meeting. Background information, more specific guidance and staff support, including primary care academia with expertise in patient-centered medical homes, are possible topics for a presentation.

Dr. Plescia explained that much of the emphasis on quality improvement initiatives has been based on the need for cost savings. The greatest cost savings appears to be in cardiovascular disease. Less emphasis has been placed on cancer control despite well-demonstrated effectiveness in saving lives. EMR capacity may be extremely useful in adhering to evidence-based guidelines for the general population and delivering quality health care to ACBCYW's target population. AHRQ also may contribute its expertise and research on EMRs and decision support tools in this effort.

Dr. Plescia also suggested that the workgroup consider reviewing additional resources. First, the National Committee for Quality Assurance's (NCQA) Meaningful Use activities and quality indicators that drive patient-centered medical homes and the timeliness of follow-up care would be useful to review. There may be a need for more appropriate NCQA indicators to be developed to ensure that young women present to PCPs for diagnostic services in a more timely manner. Second, recommendations to increase innovation in cancer through Center for Medicare and Medicaid Innovation (CMMI) grants may be considered. Historically, cardiovascular quality issues in primary care medicine have been emphasized due to substantial cost-savings in this area. Although the existing body of evidence demonstrates that early detection of cancer saves lives, only a small amount of attention has been given to this issue.

Update on CDC's BCYW Research, Program, and Communication Activities

Temeika L. Fairley, PhD
Health Scientist, Division of Cancer Prevention and Control
Centers for Disease Control and Prevention
ACBCYW Designated Federal Officer

Dr. Fairley began her update by announcing changes to the ACBCYW membership. She asked the participants to join her in welcoming Dr. Beth Collins Sharp as the new *ex-officio* member for AHRQ. CDC submitted nomination packages to HHS to replace ACBCYW members whose terms expired on November 30, 2012. CDC anticipates that HHS will formally approve the nominees over the next 4–6 weeks, but ACBCYW will be notified if the new members are not officially appointed before the next meeting.

CDC currently is developing the 2013 meeting schedule and most likely will convene the next meeting on or around April 18–19, 2013. However, a save-the-date e-mail will be circulated to the ACBCYW members to confirm the next meeting date. The success of ACBCYW's first teleconference meeting and the possibility of replicating this format for the second meeting in 2013 will be considered in the development of the meeting schedule.

CDC is proud of its tremendous progress in conducting BCYW research at a rapid pace. CDC expects to publish several journal articles in 2013–2014 as a result of this research:

- “Breast Cancer in Young Women: Reviewing the Evidence and Setting the Course”
- “Estimating Infertility Among Breast Cancer Survivors”
- “Health Insurance Coverage of Genetics Services”
- “Sister’s Study and Two-Sister’s Study”
- “Economic Burden of Breast Cancer in Young Women Aged 15–44 Years in the United States, 2000–2010.”

CDC will forward PDF files of these papers to the ACBCYW members after their publication.

CDC launched a new project in 2012 focusing on the development and implementation of a comprehensive evaluation plan for programs that support young breast cancer survivors (YBCS). The overarching purpose of the project is to evaluate activities of the DP11-1111 cooperative agreement (CoAg), Developing Support and Educational Awareness for Young Breast Cancer Survivors (<45) in the United States.

The evaluation project was designed to achieve three key objectives: (1) Identify organizational elements that are essential for successful implementation of YBCS programs will be identified; (2) Identify promising practices or evidence-based interventions that can be broadly disseminated to the target population; and (3) Assess the overall effectiveness of the DP11-1111 CoAg in supporting organizations to conduct activities focusing on YBCS. CDC plans to provide grantees with technical assistance and expects to release the findings in the fall or winter of 2015.

CDC’s project with Sisters Network, Inc. (SNI) and Sharsheret, focusing on the development of psychosocial and reproductive health support for YBCS in the United States, has entered into its final project year. Under this mechanism, SNI has worked with CDC to develop the Young Sisters Initiative (YSI), a Web-based survivorship resource. YSI is in the final stages of development and will be launched for evaluation in the spring of 2013. Office of Management and Budget approval has been secured for this project.

Sharsheret worked with CDC to assess two of its existing programs—Genetics for Life Program and the Peer Support Network Program. Sharsheret began evaluating these programs in October 2012, after modifications were made based on focus group findings. Study findings from both the SNI and Sharsheret projects are expected to be released in the fall or winter of 2013.

CDC is continuing to conduct its health communications study focusing on social media usage for breast cancer awareness and survivors. The overarching purpose of the study is to provide background on, strategies for and recommendations for social media educational materials and interventions for young women aged 15–44 years who are at risk of breast cancer and survivors.

Social media conversations were scanned across multiple platforms to identify the most common, relevant, and important discussion occurring in the social media sphere during a set time period (February 2011–September 2012).

Researchers used defined search terms to collect and conduct both quantitative and qualitative analyses of the conversations. Social media strategies used by cancer organizations were analyzed as well. CDC's efforts to date show that a social media strategy must be developed with three major activities: (1) increase awareness among young women at high risk of breast cancer; (2) provide support to YBCS early in the diagnosis, during treatment and post-treatment; and (3) address prevention and treatment myths with scientific evidence.

CDC's next steps in the study will be to compile data to draft and test social media campaign strategies with three methods: (1) develop an Institutional Review Board protocol for formative research; (2) conduct interviews to gather feedback on the initial design, messaging, and placement of the campaign; and (3) revise the campaign strategies based on findings from the interviews.

CDC will engage the ACBCYW membership and partner organizations to guide the review and dissemination of the revised social media campaign strategies. External input from ACBCYW and other groups will be critical for CDC to craft messages for the social media campaign to ensure that no harm is caused to young women and the appropriate target populations are reached.

ACBCYW was extremely pleased with the direction of CDC's social media campaign for breast cancer awareness and survivors. The members made comments and suggestions in two areas for CDC to consider in its ongoing efforts to refine this initiative.

- Dr. Ngina Lythcott is the ACBCYW liaison representative for the Black Women's Health Imperative. She was extremely interested in serving as a reviewer of the social media campaign, particularly for strategy 3 to address prevention and treatment myths with scientific evidence. She noted that strategy 3 should have a direct link to strategy 1 for awareness and strategy 2 for support to continue to transmit information to these areas.
- The HHS Office on Women's Health (OWH) has the second highest number of Twitter followers of all HHS agencies/offices. OWH accounts for 500,000 followers on its Web site (www.womenshealth.gov) and an additional 10,000 followers each month. CDC should use OWH's Twitter account as an additional venue to launch the social media campaign.

Open ACBCYW Discussion

Dr. Partridge opened the floor for the ACBCYW members to revisit any issues raised during the teleconference meeting or describe ongoing or new initiatives that are relevant to ACBCYW's mission to improve the care, health outcomes, and lives of young women with breast cancer and those who are at risk. Comments by the ACBCYW members are highlighted below.

- CDC's presentation to the High Risk Workgroup on preliminary findings from the social media study should be repeated for the Provider Workgroup. The presentation could be helpful to the workgroup in formulating recommendations to providers on mechanisms young women use to obtain information on early diagnosis of breast cancer. Dr. Fairley confirmed that she would distribute the slide set for the social media study to the members of the Provider Workgroup over the next week.

- A study recently was published that separated breast density and hormone levels as two separate risk factors instead of one interchangeable risk factor for breast cancer. The new study might have implications for the High Risk Workgroup in terms of its charge of defining "risk." Dr. Otis Brawley is a member of both ACBCYW and the High Risk Workgroup. He explained that the new study cannot be used to make public policy at this time, but its implications should be revisited in 1–2 years.

Public Comment Session

Mollie Williams
Planned Parenthood Foundation of America (PPFA)

Ms. Williams was pleased that the Provider Workgroup proposed PPFA as a potential partner in educating PCPs on BCYW. Most notably, the diverse components of the PPFA Breast Health Initiative could play a significant role in this effort—provider education, including skill building in clinical breast examination (CBE); public education delivered by *promotoras* and affiliates across the country; risk assessment; and digital education delivered through social media.

PPFA has a natural synergy with ACBCYW's activities because 90% of its patient population is <40 years of age. Moreover, PPFA provides direct financial support to numerous affiliates to cover the cost of diagnostic services for women who receive abnormal CBE results or other findings and are ineligible for Breast and Cervical Cancer Programs (that provide breast and cervical cancer screenings and diagnostic services to low-income, uninsured, and underinsured women) in their states.

Ms. Williams invited ACBCYW to contact her at mollie.williams@PPFA.org to obtain additional information on the PPFA Breast Health Initiative.

Jody Schoger
Alamo Breast Cancer Foundation/Women with Cancer

Ms. Schoger is a breast cancer advocate and survivor who devotes a considerable amount of time to addressing this issue through social media. Most notably, she hosts a Twitter chat on breast cancer each Monday evening. She thanked ACBCYW and CDC for their informative presentations and excellent discussions. She also asked for information on becoming more involved with ACBCYW's activities.

Dr. Fairley explained that ACBCYW is a federal advisory committee and the members are officially appointed by HHS to serve multiyear terms. She encouraged Ms. Schoger to send her request for information to abcyw@cdc.gov. Dr. Fairley would provide Ms. Schoger with Web links and other materials to describe ACBCYW's mission, purpose, and activities to date.

Cara Tenenbaum
Ovarian Cancer National Alliance (OCNA)

Ms. Tenenbaum was extremely appreciative of the outstanding presentations by ACBCYW and CDC. In its focus on young women with a hereditary risk of breast cancer, she hoped ACBCYW also would give attention to ovarian cancer in situations that are appropriate, evidence-based, and scientifically accurate.

Ms. Tenenbaum noted that even among breast cancer survivors, knowledge and awareness of the risk of ovarian cancer are minimal. Similar to her request to ACBCYW, she confirmed that OCNA also would increase its focus on breast cancer.

Lisa Schlager
FORCE (Facing Our Risk of Cancer Empowered)

Ms. Schlager requested additional information in follow-up to the Provider Workgroup report—(1) What components are included in genetic services? (2) Will health care professionals be educated on specific patients who should be referred to genetic counseling and testing or given skills to identify the warning signs of hereditary breast cancer? She confirmed that FORCE would support ACBCYW's ongoing efforts in educating physicians on genetic testing and counseling.

Dr. Grana made several comments to respond to Ms. Schlager's questions. Some of the existing literature is limited to whether physicians ordered genetic testing and made referrals. Guidance is not given for physicians to provide genetic counseling to their patients or take appropriate actions with test results.

The eDoctoring module, BodyTalk tool, and other resources are designed to educate physicians on the overall process of genetic testing and enhance skills to identify high-risk families. These tools provide guidance on identifying patients who are appropriate for genetic counseling and testing and making recommendations, but gaps continue to exist. As a result, education for physicians on the complexities of genetic testing, the need to offer counseling and appropriate recommendations for young women at risk for breast cancer continues to be critical areas to address.

Dr. Fairley added that CDC awarded CoAg funds to Georgia, Michigan, and Oregon to improve education to physicians on genetic counseling and testing. Outcomes from this CoAg and CDC's other ongoing projects are expected to strengthen the knowledge base in this area.

Closing Session

Dr. Partridge thanked the ACBCYW members for their outstanding feedback on the workgroup reports, their time and engagement during the teleconference meeting, and their overall enthusiasm. She found the teleconference meeting to be extremely productive, effective and efficient.

Dr. Partridge thanked Dr. Fairley, Dr. Plescia, Ms. Headley and other DCPC staff for their continued stewardship of ACBCYW. She also thanked the members of the public for their participation on the teleconference.

Dr. Plescia thanked the ACBCYW members for participating on the excellent teleconference and continuing to devote their valuable time and expertise to developing the workgroup reports. He also thanked Dr. Partridge for continuing to provide outstanding leadership as the ACBCYW Chair.

Dr. Fairley thanked the workgroup members for their tremendous contributions over the past year that has resulted in the development of the draft reports. She was excited about ACBCYW's future directions and was pleased that the successful teleconference meeting potentially could be replicated in the future. She emphasized that teleconferences with the workgroups have been extremely beneficial for the entire ACBCYW membership.

With no further discussion or business brought before ACBCYW, Dr. Partridge closed the teleconference meeting at 12:36 p.m. EST.

I hereby certify that to the best of my knowledge, the foregoing Minutes of the proceedings are accurate and complete.

____
Date

____
Ann Hart Partridge, MD, MPH, Chair
Advisory Committee on Breast Cancer in
Young Women

Centers for Disease Control and Prevention

ADVISORY COMMITTEE on BREAST CANCER in YOUNG WOMEN

December 13, 2012 Teleconference Meeting

Attachment 1

Published Meeting Agenda

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

Thursday, December 13, 2012

9:30 AM – 9:45 AM	**Opening: Welcome, Roll Call, and Introductions** *Temeika L. Fairley, PhD* Designated Federal Officer, DCPC, CDC *Ann H. Partridge, MD, MPH* Dana-Farber Cancer Institute ACBCYW Committee Chair *Marcus Plescia, MD, MPH* Director, DCPC, CDC
9:45 AM – 11:30 AM	***Administrative Session (if necessary)*** *(Session is closed to the public)*
9:45 AM – 11:30 AM	**ACBCYW Workgroup Report and Open Discussion** *Rochelle Shoretz, JD* Sharsheret Ad Hoc High Risk Workgroup *Ann H. Partridge, MD, MPH* Dana-Farber Cancer Institute ACBCYW Committee Chair *Temeika L. Fairley, PhD* Designated Federal Officer, DCPC, CDC
11:30 A.M. – 11:45 A.M.	**BREAK**

11:45 AM – 12:30 PM **WORKING LUNCH**	**Updates from CDC** *Temeika L. Fairley, PhD* Designated Federal Officer, DCPC, CDC
12:30 PM – 2:15 PM	***ACBCYW Workgroup Report and Open Discussion*** *Generosa Grana, MD, FACP* Cooper Cancer Institute Ad Hoc Provider Workgroup *Ann H. Partridge, MD, MPH, MPH* Dana-Farber Cancer Institute ACBCYW Committee Chair *Temeika L. Fairley, PhD* Designated Federal Officer, DCPC, CDC
2:15 PM – 2:30 PM	**PUBLIC COMMENT**
2:30 PM – 3:15 PM	**Wrap-Up/Announcements** *Ann H. Partridge, MD, MPH* Dana-Farber Cancer Institute ACBCYW Committee Chair

Centers for Disease Control and Prevention

ADVISORY COMMITTEE on BREAST CANCER in YOUNG WOMEN

December 13, 2012 Teleconference Meeting

ATTACHMENT 2

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Centers for Disease Control and Prevention

ADVISORY COMMITTEE on
BREAST CANCER in YOUNG WOMEN

December 13, 2012 Teleconference Meeting

Attachment 4
Glossary of Acronyms

ACBCYW	Advisory Committee on Breast Cancer in Young Women
ACTION	Accelerating Change and Transformation in Organizations and Networks
AHRQ	Agency for Healthcare Research and Quality
BCYW	Breast Cancer in Young Women
CBE	Clinical Breast Examination
CDC	Centers for Disease Control and Prevention
CMMI	Center for Medicare and Medicaid Innovation
CMS	Centers for Medicare and Medicaid Services
CoAg	Cooperative Agreement
DCPC	Division of Cancer Prevention and Control
EMRs	Electronic Medical Records
FORCE	Facing Our Risk of Cancer Empowered
HHS	U.S. Department of Health and Human Services
NCQA	National Committee for Quality Assurance
OCNA	Ovarian Cancer National Alliance
OWH	Office on Women's Health
PCPs	Primary Care Physicians
PETALs	Peer Education Through Awareness and Leadership
PPFA	Planned Parenthood Foundation of America
SNI	Sisters Network, Inc.
TF	Tigerlily Foundation
YBCS	Young Breast Cancer Survivors
YSI	Young Sisters Initiative