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

Meeting of the
Advisory Committee on Breast Cancer in Young Women
December 4-5, 2014
Atlanta, Georgia

Record of the Proceedings

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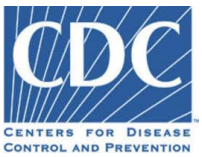

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ADVISORY COMMITTEE ON BREAST CANCER IN YOUNG WOMEN
December 4-5, 2014
Atlanta, Georgia

Minutes of the Meeting

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, Division of Cancer Prevention and Control (DCPC), convened a meeting of the Advisory Committee on Breast Cancer in Young Women (ACBCYW). The proceedings were held on December 4-5, 2014 at the CDC Chamblee Campus, Building 107, Room 1B/C in Atlanta, Georgia.

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 (BCYW), particularly those at heightened risk.

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

Opening Session: December 4, 2014

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 to determine the ACBCYW voting members, *ex-officio* members and liaison representatives who were attending the meeting. She announced that the voting members and *ex-officio* members constituted a quorum for ACBCYW to conduct its business on December 4, 2014 (*Attachment 2: Roster of the ACBCYW Membership*).

Dr. Fairley called the proceedings to order at 9:16 a.m. on December 4, 2014 and welcomed the participants to the ACBCYW meeting. None of the voting members publicly declared conflicts of interest for any of the items on the published agenda (*Attachment 1: Published Meeting Agenda*).

Ann H. Partridge, MD, MPH
Clinical Director, Breast Oncology Center
Dana-Farber Cancer Institute
ACBCYW Chair

Dr. Partridge also welcomed the participants to the ACBCYW meeting. She reviewed the agenda and noted a change in the regular meeting format. Day 1 would be more heavily weighted with presentations, including updates by CDC on the BCYW Campaign and its new Funding Opportunity Announcements (FOAs), overviews by grantees on their proposed BCYW activities that will be conducted during the current five-year Cooperative Agreement (CoAg) cycle, and workgroup reports. Day 2 would be entirely devoted to ACBCYW's discussion on the workgroups' draft recommendations and other guidance to submit to CDC for consideration and action.

Pamela Protzel Berman, PhD, MPH
Deputy Director, Division of Cancer Prevention and Control
Centers for Disease Control and Prevention

Dr. Berman joined her colleagues in welcoming the participants to the ACBCYW meeting. She was pleased to announce that Dr. Lisa Richardson was appointed as the new Director of DCPC and would attend the meeting on the following day. Dr. Berman thanked ACBCYW for continuing to provide CDC with valuable advice and guidance on its BCYW portfolio.

Update on CDC's Breast Cancer in Young Women 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 announced that she and three other speakers would provide an update on CDC's ongoing activities to establish a targeted national education campaign about breast cancer in young women. CDC has conducted numerous activities to address the central provisions of the Education and Awareness Requires Learning Young (EARLY) Act that was enacted in 2010: funded and performed critical formative research, implemented various projects in collaboration with partners, collected extensive data to expand the BCYW evidence base, and applied ACBCYW's input and guidance to actual practice in the field.

In April-May 2014, CDC launched the Know:BRCA social media initiative on Twitter and its web pages and began promoting the web-based Know:BRCA Clinical Decision Support (CDS) Tool across its digital and social media platforms. CDC's Twitter account hosts followers from the clinical and public health community that account for the majority of its ~65,000 Twitter followers.

To date, the #Know:BRCA hashtag has generated nearly 20 million impressions from 1,400 Twitter mentions by 952 users. In August-November 2014, four BCYW topics accounted for the most Twitter retweets and impressions: Breast Cancer Awareness Month, Hereditary Breast and Ovarian Cancer Week, the role of family health history in breast cancer risk, and resources for providers to learn more about breast and ovarian cancer genetics.

CDC launched a new Breast Cancer Facebook page that targets women who have an interest in this topic, HCPs and CDC/DCPC grantees, and relevant stakeholders. CDC established the Facebook page to achieve four key objectives:

- Create a forum for persons who are engaged in the fight against breast cancer to discuss issues, share their experiences, gain support and increase knowledge
- Drive traffic to the Breast Cancer section of the CDC.gov website
- Humanize CDC/DCPC
- Provide science-based information about breast cancer for users to both learn and interact by reading, linking, sharing and clicking

As of December 1, 2014, CDC's Breast Cancer Facebook page has generated 3,343 likes. CDC's BCYW target audience of women 18-44 years of age accounts for 56% of fans. BRCA posts have resulted in a total reach of 29,806 persons and 2,292 engaged users. Organizations such as the HHS Office on Women's Health, Sharsheret, Ovarian Cancer National Alliance, Tigerlily

Foundation and other key partners have widely shared the Know:BRCA materials and links across their social media platforms.

Data collected to date show that CDC's Facebook fans are increasing over time and during key events, such as Breast Cancer Awareness Month and Hereditary Breast and Ovarian Cancer Week. CDC also launched a new Pinterest board with relevant breast cancer content.

Karena Sapsis, MPH
Health Communications Specialist, DCPC
Centers for Disease Control and Prevention

Ms. Sapsis reported that CDC conducted a pilot digital campaign to provide education about BRCA, promote the Know:BRCA CDS Tool, and assess the utility of the pilot education resources. The pilot campaign included both web-based and social media components that were designed to disseminate tailored messages about BRCA and hereditary breast and ovarian cancer (HBOC). The scope of audiences and messages were focused to optimize formative research and maximize ad-buy dollars. For this effort, emphasis was placed on Ashkenazi Jewish women and women 18-44 years of age with a family history of breast cancer. HCPs were not a target audience in the pilot campaign.

CDC's formative research briefly explored women's knowledge, attitudes and beliefs regarding breast cancer, hereditary cancer and BRCA.[1] However, the major focus was targeted to testing messages to ensure the information was clear and caused no harm. CDC conducted a small number of in-depth interviews and focus groups to refine messages and images and test draft digital ads, video, and other materials with both the Ashkenazi Jewish and family history groups.

Findings from interviews with women in the family history group are summarized as follows. All of the women reported having discussed their family history of breast cancer with their providers, but reported significant variation in the level of engagement and types of screening/breast health management advice they received from their providers. Of note, many women had no knowledge of the term "BRCA gene."

With regard to the materials tested, women preferred advertisements with an upbeat and positive tone and images that reflected themselves in terms of demographics and psychographics. For example, women with small children identified more with advertisements that included children and families. Messages that encouraged women to engage in conversations with their family members tested well. The women had discussed breast cancer with their families and were interested in other women taking the same action.

[1]*Disclaimer:* The findings were acquired from a small sample of women for the purposes of formative research and should not be generalized to populations.

Findings from interviews with women in the Ashkenazi Jewish group are summarized as follows. Many women were aware of BRCA and its relationship to breast cancer, but only one participant had knowledge that Ashkenazi Jewish women were at increased risk for the gene mutation. All of the women had discussed their family medical history with their providers, but similar to the family history group, reported significant variation in the level of engagement and types of screening advice from their providers.

Only a few women reported that their providers were aware of their Ashkenazi Jewish ancestry. The respondents preferred advertisements with clear imagery and direct language that communicated messages specifically were for Ashkenazi Jewish women. The women did not view clear Jewish imagery to be stigmatizing or too overt. The women found messages targeted at the general population to be far less compelling.

Findings from women in the family history focus groups are summarized as follows. None of the women actively followed websites or organizations that focused on breast cancer prevention and awareness. Only one participant was familiar with the BRCA gene and its impact on cancer risk. More than 50% of the women reported that medical history was not openly shared in their families, but all of these women were first- or second-generation immigrants or part of a minority group. The women reported significant variation in screening advice from their providers. The women reported feeling confused and concerned by changes in screening recommendations and guidelines, such as the age and frequency to obtain mammography.

Findings from women in the Ashkenazi Jewish focus groups are summarized as follows. Many of the women self-identified as “cultural” or “non-practicing” Jews. The participants reported that orthodox or ultra-orthodox women likely would receive health information differently than other Jewish women. Most of the women did not follow media specifically for Jewish audiences. No women 18-35 years of age were familiar with the BRCA gene or were aware of the increased risk for breast cancer among Ashkenazi Jewish women. All of the women reported having open conversations with their families and providers about their medical histories. The women reported that their providers did not systematically collect data on their Ashkenazi Jewish ancestry.

Common findings across both the family history and Ashkenazi Jewish groups are summarized as follows. The women had no clear preference for a specific message or advertisement, but a positive, “non-scary” tone was desired. The women strongly emphasized that an issue as personal and important as cancer should not be trivialized in the campaign. The women appreciated distinguishable imagery that instantly was associated with the advertisement topic, such as the Breast Cancer Pink Ribbon or Know:BRCA logo.

CDC applied findings from the in-depth interviews and focus groups to pilot the Know:BRCA Digital Advertisement Campaign on September 27-October 17, 2014 (wave 1) and October 27-November 21, 2014 (wave 2). Traditional market research was used to locate the target audiences of Ashkenazi Jewish women and women with a family history of breast cancer 18-44 years of age. Advertisements were available on desktop computers, mobile devices and tablets.

The wave 1 campaign was targeted to Ashkenazi Jewish women through digital display, Facebook, newsfeed and Google search advertisements. The 6.3 million impressions of the wave 1 campaign were 100% more than forecasted. The number of clicks and click-through rates also exceeded expectations, while the cost per click was well below projected levels. Google searches resulted in 890 clicks to the Know:BRCA website in the wave 1 campaign. The top keywords were "genetic testing for breast cancer" (21%), "early breast cancer" (13.4%), and "breast cancer home test" (9.8%). Ms. Sapsis presented examples of the digital display, newsfeed, Facebook and Google search advertisements for Ashkenazi Jewish women.

The performance of the 1st wave of the pilot campaign was extremely effective overall, but CDC noted several areas that should be improved. Ad placement and messaging should be specifically tailored due to the complexities of the target audiences. Certain websites were not found to be effective in driving the target audience of Ashkenazi Jewish women to the Know:BRCA website. Comprehensive message testing is important and should be continued with larger sample sizes and broader demographic representation. In the next wave, more funds should be allocated to high-performance venues, such as Google searches and Facebook.

The 2nd wave of the pilot campaign was targeted to both audiences through digital displays, Facebook and Google searches. Display ads were available to Ashkenazi Jewish women on three websites that were different than those used in wave 1. Display ads were targeted to the family history group through health websites and other popular women's websites that frequently are visited by women 18-44 years of age. Additional resources were also allocated to expand outreach via SEO/Google searches. Ms. Sapsis presented examples of the digital display, Facebook and Google search advertisements for both target audiences.

Preliminary data through November 3, 2014 showed that in the 2nd wave of the pilot campaign, Facebook continued to deliver the highest click-through rate after Google paid searches (e.g., 0.64% for Ashkenazi Jewish women and 0.32% for the family history group). Facebook placements also had the lowest cost of all placements with an average cost per click of $0.43 for both audiences. The cost per click of $3.06 was driven by Google searches in the wave 2 campaign and was well below the projected cost of $6.33. Google searches resulted in 581 clicks to the Know:BRCA website in the wave 2 campaign. The top keywords were "genetic testing for breast cancer" (55%), "BRCA gene" (19%), and "self test for breast cancer" (8.6%).

Jennifer Wayman, MHS
Managing Director, Social Change
Ogilvy Public Relations

Junia Geisler
Vice President, Social Change
Ogilvy Public Relations

Ms. Wayman and Ms. Geisler presented an overview of plans for the upcoming BCYW Social and Digital Education Campaign. CDC awarded a contract to Ogilvy Public Relations in August 2014 to develop, launch and market the campaign. Ogilvy's network includes >85 offices in 35 markets worldwide. Ogilvy's expertise, knowledge, systems, data and research will be brought to bear to inform the development and implementation of the campaign and effectively reach the target audiences.

Ogilvy will apply its experiences, lessons learned and best practices in conducting social media, paid media, earned media and women's health campaigns to the BCYW Campaign. Ogilvy has extensive experience launching and managing public education campaigns. For example, Ogilvy launched CDC's "Inside Knowledge: Get the Facts About Gynecologic Cancer" Campaign to raise women's awareness about the signs and symptoms of gynecologic cancer. The paid media campaign resulted in >3 million clicks to CDC's gynecologic cancer web pages.

Ogilvy launched the National Institutes of Health "Heart Truth®" Campaign to raise national awareness of heart disease as the leading cause of death in women. The social media campaign increased awareness from 34% in 2000 to 56% in 2012. Ogilvy launched the National Association of Broadcasters "OK2TALK" Campaign to educate Americans on mental health. Due to several high-profile school shootings, the public service announcement (PSA) and social media campaign primarily was targeted to teens and young adults to minimize stigma related to mental illness. The campaign has resulted in a 23% increase in the number of calls to suicide hotlines by young adults.

For the BCYW Campaign, Ogilvy will create a digital-media campaign which features young women sharing their personal experiences with breast cancer. CDC-owned media, social media, and paid ads will be utilized to prompt women and providers to visit the CDC website and obtain additional information on BCYW.

Interventions for the target audiences of women will include digital paid media, CDC-owned media, earned media, partnerships and consumer education materials. Additionally, interventions for the target audience of HCPs will include patient discussion aids, continuing medical education (CME), and conference exhibits and presentations. Ogilvy will launch the campaign in the spring of 2015 and will conduct ongoing outreach through September 2016.

Ogilvy described the process for identifying a campaign brand and presented a potential brand name for the new campaign, "Bring Your Brave: It's time to talk about breast cancer risk." However, this name has not been approved for use by CDC. Moreover, plans and scheduling for the campaign are contingent upon HHS approval and other procedural steps required to launch a health education campaign.
An environmental scan is being conducted to obtain insight on developing a credible and distinct social and digital media education campaign about breast cancer that will effectively reach women 18-44 years of age. The environmental scan includes four components:

- Review, analyze and audit the BCYW published literature, educational materials, communication materials and marketing articles.
- Conduct interviews with key informants who have experience in launching BCYW media campaigns.
- Review existing formative research and evaluation reports provided by CDC.
- Analyze BCYW discussions that are occurring through social media.

During the launch of the campaign, educational products will be disseminated to raise CDC's profile on the topic of BCYW. These materials will include behind-the-scene photography, a complementary infographic, and four 2- to 4-minute videos with personal stories on exploring and managing breast cancer risk.

Efforts are underway to recruit and feature the following individuals on the videos: (1) an HCP, possibly a genetic counselor; (2) a women with or without a family history who currently has or had breast cancer; (3) a woman with a BRCA 1/2 gene mutation, but no breast cancer; and (4) a woman who has not been tested, but has a mother or sister who had breast cancer and is BRCA 1- or 2-positive. The promotions will be featured on the CDC.gov site, paid media on Facebook, owned and earned media, and websites of partners.

ACBCYW expressed overall support of the proposed name and brand for the BCYW Campaign. The members also commended CDC and Ogilvy on their efforts to more effectively market messaging to Ashkenazi Jewish women and gain additional knowledge on genetic testing in this population. ACBCYW made several suggestions for CDC and Ogilvy to consider in further developing and launching the BCYW Campaign in the spring of 2015.

- Conduct rigorous and ongoing testing of the BCYW Campaign messaging and materials to avoid unintended consequences.
- Outreach to and target the BCYW Campaign to a broader group of HCPs beyond genetic counselors.
- Feature the BCYW Campaign on the LinkedIn and Up-to-Date websites to more effectively reach HCPs.
- Tailor and adapt existing family history tools as an additional resource in the BCYW Campaign.
- Closely partner with Baptist churches, synagogues and other faith-based organizations that are trusted by African American and Jewish women.

Update by Bright Pink

Lindsay Avner
Founder and CEO, Bright Pink
ACBCYW Liaison Representative

Ms. Avner presented Bright Pink's recent activities to address health care providers with information about hereditary breast and ovarian cancer (HBOC). Bright Pink is the only national non-profit organization focusing on the prevention and early detection of breast and ovarian cancer (BOC) in young women while providing support for high-risk individuals. The mission of Bright Pink is to save women's lives from BOC and empower women to live proactively at a young age.

Bright Pink's target audience includes young women 18-45 years of age at all levels of breast cancer risk. This population accounts for 52 million in the United States. Bright Pink directs 75% of its effort to education for the general public and medical professionals and 25% of its effort to support for high-risk women. Bright Pink's approach of educated and empowered women and providers results in lives saved.

Bright Pink's Brighten Up® Educational Workshops are targeted to women at all levels of breast cancer risk. To date, 150 volunteer Education Ambassadors have been trained across the country to conduct workshops with groups of $\geq$50 women in various settings, including workplaces, community organizations and academic institutions. The workshops feature a 20-minute presentation on the basics of breast and ovarian health, early detection, risk reduction and risk assessment.

All workshop participants are encouraged to complete a risk assessment quiz on the Bright Pink website. The workshop has provided lifesaving education to >15,000 women over the past year. Bright Pink currently is developing a web-based version of the face-to-face workshops. Bright Pink's support programs for women at high risk include activity-based support groups through experiential outreach and the PinkPal® peer-to-peer mentoring program.

Bright Pink's Emerging Medical Professional Program is targeted to HCPs and delivered through obstetrician/gynecologist (OB/GYN) residency programs. The program features a 50-minute lecture and a case study module, "Breast and Ovarian Cancer Prevention: A Practical Approach to Risk Assessment and Management in Young Women." Providers in the Bright Pink Medical Professional Corps conduct the program in Grand Rounds followed by a resident case discussion. The program provides education to prepare women to understand and manage their individual BOC risk.

Bright Pink piloted the program at Northwestern and New York University in 2012-2013 with 106 residents. The evaluation of the pilot showed promising results with 95% of residents reporting that the program increased their knowledge about risk reduction and early detection options available to young women.

Bright Pink obtained seed funding in 2014 to broaden the program, build an infrastructure for support, and reframe and expand the lecture content and cases. To date, 16 medical professionals from a broad range of specialties have been recruited and trained to deliver the lecture at 27 residency programs in academic institutions across the country. The lecture has been given to 1,000 residents, medical students, nurse practitioners, fellows and faculty.

Bright Pink will train ~15 additional speakers in January 2015 and a third group later in the year. The 21 residency programs that will participate in the lecture in 2015 are expected to cover ~700 audience members. The lecture will be featured during the plenary session of the Nurse Practitioners in Women's Health Conference with a strong focus on program evaluation and impact measurement.

Bright Pink is extremely pleased that the program has been well received, but its scope should not be limited to "emerging" medical professionals due to strong interest by fellows and faculty. Faculty or other internal champions who recognized and emphasized the importance of the program played a critical role in its success to date. The program has been presented at Harvard, Johns Hopkins and other distinguished institutions, but the need for the program is likely greatest at less prestigious institutions.

Bright Pink has established a five-year vision to institutionalize the program as a standard in all 240 OB/GYN residency programs by 2019. Moreover, efforts are underway to expand the program to include nurse practitioners, internal medicine providers, physician assistants and nurse midwives. If Bright Pink replicates its 2014 accomplishments, the program will reach ~3.4 million women each year (or 1,000 residents x 3,400 patients treated annually).

Bright Pink is now asking ACBCYW and other stakeholders to facilitate introductions to other physicians, institutions and residency program directors with a strong interest in early education and prevention for young women. Bright Pink also is interested in obtaining feedback on whether its program could be included as a CDC-funded initiative in the future.

Update by Breastcancer.org

Marisa Weiss, MD
President and Founder, Breastcancer.org
ACBCYW Liaison Representative

Dr. Weiss covered the following topics in her update to ACBCYW on Breastcancer.org's recent activities. Breastcancer.org is a non-profit organization that is dedicated to providing the most reliable, complete and up-to-date expertise on breast health and breast cancer. The mission of Breastcancer.org is to interpret complex medical and personal information about breast health and breast cancer to assist women in making the best decisions for their lives.

The need for trusted information is significant because breast cancer is the most common cancer in women and accounts for 29% of cases compared to all other sites. Moreover, awareness of breast cancer is high, but national surveys and focus groups have shown that knowledge of the disease is low. Demographics of Breastcancer.org visitors include women (98%), an average household income of ≥$75,000 (40%), U.S. residency (59%), college or post-graduate degree (64%), an expenditure of >15 minutes on the website (44%), and an average age of 40-59 years.

Breastcancer.org's reach includes >1.2 million visits each month and an online community of >145,000 registered members. Recent data showed that the impact of Breastcancer.org in 2013 was >15 million visits, >9 million unique visitors, and >56 million page views. Visitors represent 230 countries with North America accounting for 59%. A professional advisory board consults with Breastcancer.org to produce, reference and vet >7,000 pages of expert medical information.

The content of Breastcancer.org is tailored to address women's specific needs in several categories, including symptoms and diagnosis, treatment and side effects, day-to-day matters and strategies to lower risk. Other features of Breastcancer.org include content for the Spanish speaking audience, blogs and podcasts of major conferences in real-time, and the "Think Pink, Live Green" Prevention Program.

The prevention program includes two major resources: (1) a 30-page educational booklet with evidence-based action steps for women to lower their breast cancer risk from reproductive and environmental exposures and lifestyle factors and (2) a toolkit for organizations to tailor the program to address their specific needs. Breastcancer.org has distributed thousands of booklets to diverse audiences across the country.

Additional activities conducted by Breastcancer.org and its partners include the "Taking Care of Your Girls" presentation to school-age girls nationwide, breast health and wellness e-mail campaigns, and a meta-analysis of data to demonstrate the role of breastfeeding in reducing the risk of the most aggressive breast cancers. To date, the "Taking Care of Your Girls" presentation has reached ~15,000 girls and ~5,000 mothers through in-school assembly programs. Despite its accomplishments, Breastcancer.org recognizes the challenges in providing specialized information on breast health and breast cancer due to the increasing complexity of medical data, particularly in the area of genetic and protein testing on normal cells and cancer cells.

Breastcancer.org has taken steps to address this issue by offering visitors an opportunity to provide details on their individual diagnoses and treatment and receive articles that match their personalized information. Strong efforts are made to deliver personalized information with

appropriate messaging, dose, tone, style and level of literacy. Because knowledge is power, Breastcancer.org takes advantage of the Internet, mobile devices, social media and other technology to provide information to assist women in maintaining their health over time.

Breastcancer.org owns the name "Breasthealth.org" to promote primary and secondary prevention and implement risk reduction strategies for both healthy women and breast cancer survivors. Breastcancer.org also has released a new PSA to close the gap between awareness and knowledge and reach a younger audience. The PSA is intended to initiate a new dialogue to help young women make the connection between lifestyle choices and an increased risk of developing breast cancer. The PSA is available in both English and Spanish.

Update by Planned Parenthood Federation of America

Courtney Benedict, MSN, CNM
Manager, Medical Standards Implementation
Planned Parenthood Federation of America (PPFA)

Ms. Benedict covered the following topics in her update to ACBCYW on PPFA's recent activities. PPFA created the multifaceted and comprehensive Breast Health Initiative (BHI) in 2012 to standardize breast cancer screening across all of its affiliates. PPFA uses BHI to provide direct funding to support diagnostic breast services for uninsured women; standardize breast screening practices for PPFA's young, healthy patient population; and deliver public health education. The primary goals of BHI are to reach as many of PPFA's 1,770 clinicians across the country and strengthen the knowledge and skills related to breast cancer screening among these providers.

Component 1 of BHI is a breast cancer risk assessment tool for use in young women. Clients or clinicians can complete the Breast Risk Screening Questionnaire (BRSQ) for inclusion in electronic health records (EHRs). The BRSQ is completed during an initial well woman visit or a specific breast health visit and then repeated as often as necessary if the client's individual or family history changes. PPFA adapted an existing genetic high-risk assessment tool to develop the BRSQ with three simple questionnaires.

BRSQ-1 asks two questions to determine whether the client or a blood relative had BOC. The patient is recommended for average risk screening if the answer to both questions is no. BRSQ-2a is designed for clients who respond yes to BRSQ-1/question 1 (e.g., women with a personal history of BOC). Clients who respond yes to any of the 7 questions in BRSQ-2a are referred for genetic counseling. BRSQ-2b is designed for clients who respond yes to BRSQ-1/ question 2 (e.g., women with a family history of BOC). Clients who respond yes to any of the 6 questions in BRSQ-2b are referred for genetic counseling.

The BRSQ has been fully implemented as a required screening protocol in PPFA's Medical Standards and Guidelines. However, financial challenges have occurred in uninsured women who cannot afford genetic counseling. An evaluation is underway to determine the usability of BRSQ, but the assessment will be expanded over the next year to explore the validity and long-term impact of the risk screening tool in identifying high-risk women and detecting cancer at an earlier age.

Component 2 of BHI is a national training program that was designed with a train-the-trainer approach to maximize the reach of this initiative and enable individual PPFA affiliates to customize the curriculum based on the setting and needs of their local patient populations. To date, 100 trainers from 71 PPFA affiliates have been trained. The trainers were required to complete five breast cancer screening eLearning modules prior to attending the in-person training course.

The five eLearning modules cover a breast cancer overview; health history components and breast cancer risk screening, including use of the BRSQ; clinical breast examination (CBE) technique and documentation; breast cancer screening recommendations; and management of mammogram results. The in-person training course includes the following components.

- A didactic lecture and video demonstration of a CBE with a breast specialist
- Specific training exercises with CBE trainers, including case study discussions, an exercise to detect and document breast mass with a silicone breast model, and an exercise to practice CBE with standardized patients and obtain live feedback from the instructors
- A toolkit and resources to replicate and disseminate all of the training components at the local level

PPFA evaluated the training program to assess the overall quality of the curriculum components and obtain feedback; document specific curriculum components that were replicated by CBE trainers at the local level; and determine the ability of the training program to increase knowledge and standardize breast cancer screening practices among clinicians. The pre-training survey collected baseline knowledge of breast cancer screening recommendations, baseline CBE practices, and baseline confidence in providing these services. Post-training surveys at three and six months evaluated retention of information, the overall reach of the training program, and improvements in clinical practices compared to baseline.

The evaluation showed positive results overall. The participants found the five eLearning modules and CBE practice on standardized patients to be most helpful. The majority of participants also found the didactic lecture with the breast specialist to be useful. Practice with the silicone breast model was found to be helpful by 60% of trainers, but some participants did not view the model as lifelike. The participants found the resources and time devoted during the in-person training course to plan local trainings to be helpful.

Statistically significant changes in CBE practices were noted between pre- and post-training. The percentage of participants who spent ≥3 minutes on CBE increased from 56% pre-training to 95% post-training. The percentage of participants who used the circular breast search pattern during CBE decreased from 60% pre-training to 3% post-training. The percentage of participants who used the vertical strip breast search pattern during CBE increased from 46% pre-training to 89% post-training.

The mean knowledge scores of breast cancer screening guidelines increased from 15.9 pre-training to 18.5 post-training. The highest increases in knowledge were observed in screening recommendations for women 20-39 years of age, the appropriate time to initiate CBE screening, and guidelines for women with an increased genetic risk for breast cancer.

The 100 new trainers were able to train >1,000 PPFA clinicians in some curriculum component within the first six months of training. The five eLearning modules were easiest for trainers to implement without a large amount of resources. The case study exercises, didactic video lecture with the breast specialist and practice on the silicone breast model also were easy to conduct with minimal resources, but these curriculum components were more difficult to organize in PPFA affiliates with a large geographical spread of clinicians. Financial barriers allowed only ~50% of trainers to replicate CBE practice on standardized patients. However, other PPFA affiliates resolved this issue by performing observed CBE practice on staff or client volunteers.

Overall, the train-the-trainer curriculum components were successful in training a large volume of providers across a tremendous geographical area in a short period of time. The curriculum components were rated as "very helpful" by ≥50% of participants. Increases were observed in knowledge of breast cancer screening guidelines, confidence in counseling clients, and provision of standardized CBE practices.
The curriculum and train-the-trainer model were found to be effective in disseminating evidence-based breast cancer screening recommendations. Trainers were given 2.5 CME hours for completion of the five eLearning modules and 8 CME hours for completion of the in-person training course. Local clinicians were given 3.5 CME hours for completion of specific curriculum components.

ACBCYW commended the BCYW stakeholder organizations on developing exciting new tools and exploring new research areas. The members discussed the following topics with the panel of speakers.

- Strategies and tools for HCPs to set aside time during limited patient visits to discuss breast and ovarian health with young women.
- Plans for Bright Pink to sustain the Emerging Medical Professional Program over time, such as periodically updating the lecture and case study with more recent data and providing clinical tools.
- Ongoing research and education on environmental risk factors for breast and other cancers, such as PPFA's "Green Choices" Project.

Update on the CDC Young Breast Cancer Survivors Cooperative Agreement

Ena Wanliss, MS
Lead Public Health Advisor, Division of Cancer Prevention and Control
Centers for Disease Control and Prevention

Ms. Wanliss presented an update on the CDC DP14-1408 CoAg, "Multiple Approaches to Increase Awareness and Support Among Young Women Diagnosed with Breast Cancer." CDC received 25 applications in response to the FOA that was released in May 2014. The objective review was conducted in July 2014 and resulted in awards to 7 grantees.

The purpose of the five-year CoAg is to increase the availability of health information and support services for YBCS and their families. The grantees will conduct two major activities to achieve this goal: (1) support the development and implementation of strategic and integrated multimedia health education and awareness campaigns aimed at addressing the health information needs of YBCS and (2) support the enhancement of existing structured supporting services that address issues faced by YBCS at initial diagnosis.

CDC will allocate a total of $2.5 million per year for five years over the entire project period at an average award of $360,000 to each of the 7 grantees. CDC developed a logic model to guide grantees in conducting specific strategies and activities and achieving short-term, intermediate and long-term outcomes. The components of the logic model are highlighted below.

Component 1 Strategies and Activities

- Develop and maintain a diverse partnership network
- Develop a comprehensive communication plan
- Test appropriate health messages
- Test social media tools used by the target population
- Create and implement innovative social media strategies
- Disseminate health messages to YBCS

Component 2 Strategies and Activities

- Convene partners to discuss collaboration, enhancements and scale-up
- Conduct evaluation of preexisting support services
- Utilize evaluation findings to develop a five-year implementation and program plan
- Develop a sustainability plan
- Provide structure support services to YBCS
- Promote and facilitate utilization of support services

Short-Term Outcomes

- Increase the number of organizations that serve the YBCS community
- Increase organizational capacity to evaluate, enhance and sustain support services
- Increase the use of public health messages and strategies that are evidence-based and tailored to YBCS

Intermediate Outcomes

- Enhance partnerships that can facilitate and broaden the reach of the program
- Increase utilization of support services among YBCS and their caregivers
- Increase the availability of support services for YBCS and their caregivers

Long-Term Outcomes

- Increase awareness among YBCS regarding genetic counseling and testing
- Increase the availability of health information and other resources
- Enhance communication between YBCS and their providers
- Improve psychosocial functioning among YBCS and their caregivers
- Improve health seeking behaviors among YBCS
- Improve lifestyle behaviors among YBCS

Ms. Wanliss concluded her update by highlighting the activities proposed by the 7 DP14-1408 grantees.

DP14-1408 Grantee	**Proposed Activities**
Dana-Farber Cancer Institute	• Expand existing support services • Develop a national teleconference/webcast network
FORCE: Facing Our Risk of Cancer Empowered	• Create a program to translate complicated medical information and research news to the YBCS community
Johns Hopkins University	• Expand and scale-up existing support services
Living Beyond Breast Cancer	• Expand the existing program and incorporate new technologies to promote access
Louisiana State University Health Science Center	• Create strategic and integrated multimedia health education and awareness campaigns aimed at addressing the health information needs of YBCS
Sharsheret, Inc.	• Expand, enhance and scale-up the “Link Program” to provide patient navigation, peer support, genetics information and survivorship resources to YBCS

Young Survival Coalition, Inc.	• Expand the Navigator Series, Resource Link Guidebook, YSC SYNC, face-to-face and online support groups, national YBCS Summit and Regional Symposia

Overview of the FORCE DP14-1408 Cooperative Agreement

Sue Friedman, DVM
Executive Director, FORCE: Facing Our Risk of Cancer Empowered
ACBCYW Liaison Representative

Dr. Friedman presented an overview of activities that FORCE will conduct for the DP14-1408 CoAg. FORCE is a national non-profit organization with a mission to improve the lives of persons and families affected by hereditary BOC (HBOC). FORCE conducts several activities to fulfill its mission. Comprehensive, evidence-based information is provided on HBOC through multiple platforms to assist persons in making informed healthcare decisions. Patient-centered outcomes research is conducted. Recruitment is promoted for HBOC-specific research studies.

A toll-free help line, 50 outreach groups across the country and >150 trained volunteers are used to offer peer support and navigation. The HBOC community is united to advocate for more support, resources and research. FORCE's other activities and resources to empower its target audience include a mastectomy photo gallery, research advocate training, conferences, local support, webinars, newsletters and brochures.

FORCE is part of the American BRCA Outcomes and Utilization of Testing (ABOUT) Patient-Powered Research Network. ABOUT is a research registry that is organized by and for persons with HBOC and provides a platform to transform real-world experiences into patient-centered outcomes research. The network is used to study long-term outcomes for persons undergoing genetic counseling, testing and medical interventions related to the detection, prevention and treatment of HBOC.

ABOUT is one of 18 disease-focused groups participating in the National Patient-Centered Clinical Research Network (PCORnet). PCORnet is a national platform that is designed to conduct large-scale patient-centered outcomes research, collect and connect personal health data and outcomes from 70 million Americans, perform prospective follow-up, and implement representative large-scale research studies.

FORCE will conduct the "Examining Relevance of Articles for Young Survivors" (XRAYS) Program under its DP14-1408 CoAg. The XRAYS Program is an extension and expansion of FORCE's existing education and research programs. FORCE designed the XRAYS Program to achieve three key goals: (1) rate media articles and reports based on several criteria; (2) assign

a graphic representation and metric to score the relevance of information; and (3) correct inaccuracies and place statistics and information in perspective for young women to use to make informed healthcare decisions.

FORCE currently reviews articles and topics in a four-step process. Step 1 focuses on new and emerging research, surveys and needs assessments, and questions from community stakeholders. Step 2 focuses on literature and guideline reviews in consultation with an advisory board. Step 3 focuses on the development of articles to clarify information and guidelines and share knowledge gaps. Step 4 focuses on the dissemination of articles to consumers and HCPs to assist in informed and shared decision-making.

FORCE will use several enhancements in the XRAYS Program to build on its existing education efforts. Media outlets will be assessed and scanned to determine websites that are most heavily used by young women to seek breast cancer information. Young women will be surveyed across a wide spectrum (e.g., age, risk, disease severity, diagnosis and treatment) to determine their reliance on media for health and cancer information. A rating rubric and graphic representation will be created to generate an "at-a-glance" score for each article. The media articles will focus on young women and breast cancer and will be widely disseminated through strategic partnerships. The XRAYS Program will be evaluated to determine the number of persons reached, knowledge gained, usefulness in decision-making and media outlet response.

Dr. Friedman presented an example of rating an article, "BRCA Gene Mutations Linked to Salivary Gland Cancer," with the XRAYS Program. In a retrospective study of 5,754 persons from families of women who previously were diagnosed with breast cancer with a confirmed BRCA mutation, five cases of salivary gland cancers were detected. The five cases included one individual with a confirmed BRCA mutation; two persons in untested close relatives of mutation carriers who were likely carriers; and two persons in relatives who had either tested negative for a family mutation or likely were negative based on a pedigree analysis.

The overall risk for salivary gland cancers in BRCA mutation carriers was estimated at 0.052% compared to 0.003% in the general population. The ten-fold increase was found to be statistically significant, but the study design had several limitations. Although the findings were widely reported in the media, the study did not demonstrate a link between BRCA and salivary gland cancer for health and medical decision-making.

FORCE published a review of media articles on the study on its website to translate the science for a lay audience. Using the XRAYS Program, FORCE rated the media articles with an overall score of "low to medium," a score of "medium to high" for accuracy, and a score of "low" for impact. FORCE hopes to rate media articles with the XRAYS Program within one week of their release. FORCE's long-term goal is to develop versions of the XRAYS Program for ovarian cancer and women with BRCA gene mutations.

ACBCYW commended FORCE on its plans for a rapid one-week turnaround time between the release of media articles and application of the XRAYS Program to generate a score. However, the members advised FORCE to devise a contingency plan to rate prominently featured media articles that contain embargoed data at the time of their release.

Overview of the Young Survival Coalition DP14-1408 Cooperative Agreement

Jean Rowe, LCSW, OSW-C, CIT
Associate Director, Survivorship Programs
Young Survival Coalition

Ms. Rowe presented an overview of activities that the Young Survival Coalition (YSC) will conduct for the DP14-1408 CoAg. YSC was founded in 1998 by three YBCS. YSC was the first national non-profit organization exclusively focusing on and dedicated to critical issues that are unique to BCYW. The mission of YSC is to collaborate with YBCS, caregivers, and the medical, research, advocacy and legislative communities to increase the quality and length of life for women diagnosed with breast cancer at ≤40 years of age.

Breast cancer is the most common cancer in U.S. women 15-39 years of age. Breast cancer is diagnosed each year in nearly 13,000 young women <40 years of age and in >26,000 women <45 years of age. No effective screening method has been developed to detect BCYW. Most notably, nearly 80% of young women diagnosed with breast cancer are responsible for detecting their own breast abnormalities.

Young women are more likely to have aggressive subtypes of breast cancer, including triple negative and human epidermal growth factor receptor 2-positive disease, larger tumor sizes, and a higher incidence of lymph node involvement. Of all breast cancer survivors currently living in the United States, 250,000 are estimated to have been diagnosed at ≤40 years of age.

Breast cancer issues that are unique to young women include a lack of research in this population, diagnosis during pregnancy, early onset menopause, fertility, child rearing, financial difficulties, education impacts, career challenges, body image, and relationship, intimacy and dating issues.

YSC provides a variety of programs, tools and resources to connect, educate and support BCYW, including a comprehensive website, access to national and local materials in various formats, summits and regional symposia, and virtual programming and online chats. The YSC Community Engagement Team includes ~60 state leaders across the country. The YSC SurvivorLink Program uses trained survivor volunteers to provide peer mentoring. Navigators are available to young women at various stages along the continuum of care, including a newly diagnosed treatment navigator, metastatic navigator, post-treatment navigator and long-term navigator.

YSC will use its DP14-1408 CoAg to evaluate, enhance, grow and sustain its existing activities and programs. YSC's diverse eight-member Steering Committee of oncologists, nurses and stakeholders will oversee all aspects of the CoAg in terms of review and feedback, assessment, analysis and sustainability planning. YSC will use supportive partnerships to build and expand collaborations, particularly to reach BCYW with a low socioeconomic status and limited access to services.

YSC will deploy its four regional field managers to make in-person presentations to HCPs and volunteers in local communities who serve YBCS. CME credits will be offered to HCPs who complete YSC programming, such as the YBSC fertility preservation course that will be offered during the YSC Summit in March 2015. YSC will use its summit, regional symposia and website to disseminate co-survivor materials. YSC published its research agenda in May 2014 that identified the top research priorities to improve the quality and quantity of young women's lives. YSC will link the research agenda to its DP14-1408 CoAg activities.

Overview of the Dana-Farber Cancer Institute DP14-1408 Cooperative Agreement

Ann H. Partridge, MD, MPH
Clinical Director, Breast Oncology Center
Dana-Farber Cancer Institute
ACBCYW Chair

Dr. Partridge presented an overview of activities that the Dana-Farber Cancer Institute (DFCI) will conduct for the DP14-1408 CoAg. DFCI has documented numerous gaps in its long history of providing clinical care to the vulnerable population of young women with breast cancer. Most notably, attention to supportive care and survivorship issues for young women has been deficient in several areas, including disease and treatment, fertility, psychosocial distress, genetic risk, menopausal concerns, body image and sexual functioning. DFCI acknowledges that even experts have been challenged in maintaining pace with emerging information and changing nuances in BCYW treatment and care.

DFCI established the "Young Women with Breast Cancer" Program in 2005 to address critical issues facing young women ≤42 years of age and improve their care and outcomes. DFCI re-branded the initiative with a new name, the "Young and Strong" Program, as well as a new logo and website. DFCI has provided direct clinical care to >2,500 young patients to date. In addition to a six-member leadership team, the Young and Strong Program also engages numerous clinical and research faculty and staff as well as patient advisors. The integrated and comprehensive program focuses on young women by providing patient and provider education, clinical care and research.

The Young and Strong Program includes clinical and patient education and support at three specific endpoints. At diagnosis, young women ≤42 years of age are identified and enrolled in the program. Initial introductions are made to a multidisciplinary clinical team, including medical, surgical and/or radiation oncology specialists. Early referrals are made to additional medical and supportive care services as needed, such as genetic and/or fertility consultation, social work or psycho-oncology services.

During short-term follow-up, education and outreach are provided to young patients through support groups, lectures, specialized workshops, the One-to-One Program and other events. Referrals are made to additional services as needed, including psychological counseling, plastic surgery consultation, sexual health consultation, and nutrition. Educational materials and information are disseminated through biannual newsletters, a resource center, blogs and e-mail communications. During long-term follow-up, additional survivorship services, programs and referrals are offered to assist young patients in addressing their long-term needs.

DFCI will modify the Young and Strong Program in several areas for its DP14-1408 CoAg. Findings from a virtual randomized clinical trial of the Young and Strong Program will be applied to expand clinical research and distribute more BCYW information to providers and patients. The virtual study is underway at 54 academic and community-based sites in North America and features a web-based and print-based education, information and supportive care intervention.

The logic model with inputs, activities, outputs, short- and long-term outcomes, and benchmarks to measure programmatic impact will be updated as needed. The BCYW target population will be expanded from ≤42 to ≤44 years of age. Materials will be translated into Spanish and another language that will be determined based on the needs assessment findings. Clinical services will be extended beyond DFCI's main campus in Boston to include 8 subsidiary affiliate sites, 4 satellite locations and 1 managed contract affiliate in Connecticut, Massachusetts and New Hampshire. Providers and staff at each satellite and affiliate location will be trained in delivering the Young and Strong Program.

Existing efforts will be expanded to increase and systematically target education to providers, formal tumor boards, and YBCS for survivorship navigation. Collaboration will be increased through national teleconferences with patients, other CDC grantees and other stakeholders. Advice will be solicited and the program will be rigorously evaluated. Existing structured support services and resources will be available to young patients and providers at each satellite and affiliate location, including educational materials and information, support groups, workshops, peer mentoring programs, referrals and consultation, the monthly lecture series, and treatment summaries and survivorship care plans tailored to young women.

Update on the CDC Cancer Genomics Cooperative Agreement

Katrina Trivers, PhD, MSPH
Epidemiologist, Division of Cancer Prevention and Control
Centers for Disease Control and Prevention

Dr. Trivers presented an update on the CDC CoAg, "Enhancing Cancer Genomic Best Practices Through Education, Surveillance and Policy." DCPC released a new five-year, non-research FOA in 2014 to continue and expand its programmatic activities in cancer genomics. CDC limited eligibility for funding to state governments and tribal organizations due to four key factors.

Current state-based activities are easiest to develop and expand. Existing expertise in education, surveillance and policy/system change at the state level can be brought to bear. State grantees have demonstrated capacity in effectively collaborating with state partners and informing state policies due to their existing linkages with cancer registries and health insurance providers. State-based models are easiest to scale-up for national approaches.

CDC awarded the CoAg to Connecticut, Michigan, Oregon and Utah in a competitive application process that was objectively reviewed. Each of the four grantees will receive awards ranging from $325,000-$350,000 in year 1. CDC will allocate a total of ~$7.5 million over the five-year CoAg. The grantees are required to use their CoAg funds to develop, enhance and evaluate education, surveillance and policy/system change activities related to the promotion of BOC genomics. The required activities must be targeted to HBOC, but the grantees also have the option of focusing on Lynch Syndrome. CDC provided examples of the education, surveillance and policy/system change activities in the FOA.

The grantees also are required to collaborate with both internal CDC programs and external partners, including the National Breast and Cervical Cancer Early Detection Program (NBCCEDP), Cancer Registry Program, Comprehensive Cancer Control Program, academic medical institutions, non-profit organizations, and clinical cancer genetics clinics. CDC provided the grantees with a logic model describing the short-term, intermediate and long-term outcomes that are expected to be achieved over the five-year Co-Ag.

	Short-Term Outcomes	Intermediate Outcomes	Long-Term Outcomes
Education	Increase knowledge of hereditary cancers and use of genetic counseling, genetic		Reduce the incidence and mortality of

	testing and associated clinical services		hereditary cancers, including HBOC
Surveillance	Improve ability to assess the burden of hereditary cancers and use of services	1) Increase appropriate use of services 2) Increase production and dissemination of surveillance reports	
Policy/ System Change	Increase knowledge among key clinical and policy stakeholders (e.g., health systems, lawmakers and health insurance decision-makers)	Improve access to and coverage of services	

The grantees have proposed several activities that are aligned with the short-term, intermediate and long-term outcomes outlined in CDC's logic model.

For education, **Connecticut** will update and disseminate educational booklets for providers, *Cancer Genomics Best Practices for Connecticut Healthcare Providers*. An innovative mentoring program will be developed and piloted with board-certified genetic counselors and primary care providers (PCPs) to assess current practices, provide education on best practices and offer ongoing mentoring. A *Family Health History Workbook* will be disseminated for public education. Partnerships will be established with college-based Jewish organizations.

For surveillance, Connecticut will maintain and enhance its Behavioral Risk Factor Surveillance Survey (BRFSS) to include questions pertaining to family health history and genetic testing. All-payer claims data (e.g., medical, dental and pharmacy claims in the state) by public and private payers will be analyzed to assess utilization of genetic services and other related clinical services. Cancer registry data will be analyzed to promote bi-directional reporting of these data.

For policy/system change, Connecticut will promote health plan coverage of recommended clinical practices for HBOC. Collaborations will be formed with health plans to improve coverage and impact policy. Breast health centers and cancer programs will be assessed to determine their compliance with clinical practice standards, such as the Commission on Cancer Standards.

For education, **Michigan** will use state-based and CDC materials to disseminate information on family history of cancer and hereditary cancer syndromes through a variety of channels. Blended learning opportunities will be developed and offered to PCPs through interactive in-person workshops and other formats. Materials will be directly provided to health plans, health systems and health professional organizations.

For surveillance, Michigan will add questions to its BRFSS to determine the prevalence of women in the state with a family history of breast and/or ovarian cancer who received genetic counseling. The comprehensive statewide Genomics Surveillance Network will be expanded to 18 clinical sites that have board-certified genetic providers to enable sharing of data on BRCA genetic counseling and testing. Cancer registry and vital records data will be analyzed to monitor cancer incidence rates, trends and mortality of cases that are most likely to have an underlying genetic predisposition for HBOC and Lynch Syndrome.

For policy/system change, Michigan will continue to recognize health insurance plans that are aligned with evidence-based guidelines. Health system models related to BOC risk assessment, referral and follow-up will be developed and promoted. Cascade screening best practices will be promoted utilizing health system policies, electronic reporting, social media, health insurance policies, laboratory reporting and position statements.

For education, **Oregon** will continue to engage providers within its state public health programs, such as NBCCEDP. The availability of telemedicine for genetic counseling services will be promoted to more effectively reach patients in rural areas of the state. Outreach will be targeted to high-risk individuals and underserved populations.

For surveillance, Oregon will analyze cancer registry data to facilitate bi-directional reporting. Data will be collected from BRFSS, a survey of providers in public health system, and a BRCA testing follow-up study. State-based hospital discharge data, Medicaid data and genetic testing data will be analyzed.

For policy/system change, Oregon will continue to engage with insurance companies, medical directors and policy staff to increase coverage. Ongoing activities with the Oregon Medicaid Health Evidence Review Commission will be continued to provide consultation on cancer genetics and associated clinical services and conduct annual analyses of Medicaid data. Policy guidance documents will be developed for the Oregon Medicare and Medicaid Coordinated Care Organization and the Oregon Commission on Care accredited programs.

For education, Utah will develop in-person and web-based educational sessions for physicians. A patient and provider educational website will be developed and launched, particularly to better reach patients in rural areas of the state with no access to genetic counseling or testing services. Education on genetic counseling and testing will be provided to family members of cancer survivors who test positive for BRCA 1/2 mutations or Lynch Syndrome.

For surveillance, Utah will assess the burden of hereditary cancer as well as knowledge, attitudes and use of genetic counseling, genetic testing and associated clinical services. A surveillance system will be established to monitor use of genetic counseling and testing services. The Utah Population Database and BRFSS data will be analyzed.

For policy/system change, Utah will establish a Cancer Genetics Consortium to provide continuing education and guidance on BRCA 1/2 counseling and testing to HCPs. Barriers and solutions to identifying underserved high-risk women in the Utah Breast and Cervical Cancer Early Detection Program will be determined. Increased use of recommended clinical practices will be promoted and system-level practices will be implemented to increase coverage.

CDC will have substantial involvement over the five-year CoAg by providing the four grantees with program consultation and technical assistance; subject-matter expertise on cancer genomics, epidemiology and evaluation; guidance on data collection, analysis and program evaluation; and help with the dissemination of results through presentations and other formats. CDC will utilize internal collaborations, leverage resources across and between programs, and disseminate national resources that will be relevant to the CoAg, such as the genomics application toolkit developed by the CDC Office of Public Health Genomics and the Know:BRCA Digital Media Campaign.

Update by the ACBCYW Ad Hoc Provider Workgroup

Generosa Grana, MD, FACP
Director, Cooper Cancer Institute
ACBCYW Member & Workgroup Chair

Dr. Grana covered the following topics in her workgroup report to ACBCYW. The workgroup expanded its membership to include grantees and other organizations that are conducting provider education activities (e.g., Oregon, Michigan, Bright Pink and the University of California (UC) Davis). The workgroup's charge of providing input, recommendations and guidance has resulted in the development of targeted and effective educational strategies to disseminate to the appropriate audience of HCPs.

The workgroup refined and expanded its target audiences of "patients" and "providers." Patients now include women 15-45 years of age, high-risk women with a strong family history of breast cancer or hereditary gene mutation, and YBCS. Providers now include PCPs with expertise in internal medicine, family medicine and obstetrics/gynecology, nurse practitioners, physician assistants, trainees, professional societies, insurers, licensing/accrediting bodies and naturopaths.

The workgroup reiterated the critical need to administer a national survey to improve provider education and identify gaps in practice. Topics for the national survey should include general breast health for young women, risk assessment and genetic testing, and the needs of YBCS. Mechanisms to consistently administer the national survey should include Doc Styles, insurers, licensing groups and professional societies. The workgroup also emphasized that activities by

CDC grantees in the areas of surveillance, policy and public/provider education on hereditary syndromes should be collected and compared across programs.

The workgroup discussed existing mechanisms that are effective in reaching HCPs, such as organizational meetings and conferences, licensing boards, training programs, insurance providers and health plan medical directors, national partners, and newsletters and e-mail blasts. The workgroup assessed ongoing provider education activities (e.g., CDC's genomics and communication CoAgs) and programs targeted to trainees to determine their potential use as resources.

CDC presented its "Inside Knowledge" Campaign that is designed to raise awareness about gynecologic cancer among internal medicine trainees. The campaign includes case-based modules on ovary/uterine cancer and genetics that are available on the CDC.gov website. The workgroup explored strategies to more widely disseminate and promote these resources to more effectively reach the target audience of HCPs.

Bright Pink presented its "Emerging Medical Professional Program" that is delivered through OB/GYN residency programs. The case study module, "Breast and Ovarian Cancer Prevention: A Practical Approach to Risk Assessment and Management in Young Women," has been delivered by 16 trained medical professionals at 27 residency programs to date. Bright Pink's goal is to institutionalize the program as a standard in all 240 OB/GYN residency programs by 2019. The workgroup explored strategies to adapt the program for nurse practitioners, internal medicine trainees, physician assistants and nurse midwives.

PPFA presented its Breast Risk Screening Questionnaire that is designed to identify women with a personal or family history of BOC and can be included in an EHR. PPFA also presented its national train-the-trainer program that is designed to standardize breast screening practices among 1,700 clinicians at 700 Planned Parenthood health centers and affiliates nationwide. PPFA's provider population includes nurse practitioners (75%) and physicians (25%).

PPFA offers CME credits to trainees after their completion of five eLearning modules and an in-person training course that includes case scenarios, an exercise to detect and document breast mass with a silicone breast model, and an exercise to practice CBE with standardized patients. The workgroup explored strategies to apply evaluation findings of the training program to more broadly improve changes in knowledge and practices regarding the use of guidelines, genetic testing and CBE beyond the PPFA provider population. The workgroup also discussed approaches to integrate the risk screening questionnaire into EHR systems outside of PPFA.

UC Davis presented its eLearning program that is targeted to trainees and practicing PCPs in rural areas. The program has now been expanded to residency programs in the UC system. The workgroup explored strategies to scale-up the program beyond the UC system.

The workgroup proposed several recommendations for CDC to consider based on the presentations and discussions during its previous teleconference.

Trainee Programs

- Identify best practices of trainee programs developed by CDC grantees and other organizations (e.g., PPFA, Bright Pink and UC Davis)
- Closely collaborate with grantees to make modules, best practices and materials widely available to other organizations
- Provide opportunities for grantees to regularly share experiences and lessons learned to foster collaboration and dissemination of findings

CDC CoAgs

- Utilize findings from the provider education component of genomics activities proposed by the Connecticut, Michigan, Oregon and Utah grantees to identify novel models to improve provider education
- Review shared elements and innovative components across grantee activities that focus on HCPs to avoid duplication of efforts and foster innovation
- Perform assessments to ensure that data collected from grantee activities will be complimentary

Update by the ACBCYW Ad Hoc General Population Risk Workgroup

Lisa A. Newman, MD, MPH, FACS
Professor of Surgery and Director
University of Michigan Health Systems
ACBCYW Member & Workgroup Chair

Dr. Newman covered the following topics in her workgroup report to ACBCYW. The workgroup is charged with drafting messages for CDC to target and promote among the general population of youngwomen in the United States. The workgroup began fulfilling its charge by performing an extensive literature review and answering five key questions.

Question 1: What is the target audience for general population risk messaging? The workgroup reviewed U.S. Census data that showed the population of women 20-45 years of age in the United States has substantially grown from ~42 million in 1980 to ~52 million in 2010 (or an increase of ~10 million women over the past 30 years).

Question 2: What is the breast cancer burden of the target audience? Has the burden been increasing over time? The workgroup reviewed the 2009 Anders, *et al.* study that used Surveillance, Epidemiology and End Results (SEER) data to document population-based breast cancer incidence rates by age and timeline. Population-based incidence rates of breast cancer

have not significantly changed in younger women <40 and <45 years of age since 1975, but changes have been observed in women >45 years of age. The overall incidence of breast cancer is lower in young women compared to older women and has been stable over the past 30 years.

Question 3: What are the race/ethnicity-associated variations in the breast cancer burden of young women? The workgroup reviewed SEER data that showed higher population-based breast cancer incidence rates in all age categories for white and African American women compared to women in other racial/ethnic groups. White women account for the highest breast cancer incidence rates overall, but population-based incidence rates are slightly higher in African American women <45 years of age. Of all breast cancer patients <50 years of age, white women account for ~20% and African American women account for ~33%. Breast cancer incidence increases with age for all women. The average age at breast cancer diagnosis is 61 years for white women and 57 years for African American women.

Question 4: Has the number of young women with breast cancer increased? The workgroup reviewed the 2008 Brinton, *et al.* study that was based on 1992-2004 SEER data for all breast cancers combined, *in situ* cancers only and invasive cancers only. Despite relatively stable incidence rates, the study reported a steady increase in breast cancer in young white and African American women over time due to the growth of the young female population in the United States.

Question 5: Are breast cancers in young women associated with worse survival? What are the race/ethnicity-associated variations in survival among young breast cancer patients? The workgroup reviewed five-year relative survival rates by year and age of diagnosis and death. The data showed steady improvements in breast cancer survival rates among all women in the 20-49, 60-64 and 65-74 age groups in 1975-2006.

By age, younger women had worse relative survival rates than older women in the past. However, differences in age-related survival rates have been decreasing due to advancements in systemic therapy for breast cancer subtypes that are more prevalent in young women. By race/ethnicity, relative survival rates have been persistently worse in African American women than in white women in both the <50 and ≥50 year age groups.

In addition to answering the five key questions, the workgroup also reviewed data to identify other relevant patterns related to breast cancer in the general population of young women in the United States. The 2013 Johnson, *et al.* study reported an increasing incidence of young breast cancer patients 25-39 years of age diagnosed with stage IV disease. The study documented a tremendous increase in the incidence of metastatic breast cancer in this population from 1.53/100,000 in 1976 to 2.90/100,000 in 2009.

The 2011 Amirikia, *et al.* study used population-based California Cancer Registry data to document incidence rates of triple-negative breast cancer by age and race/ethnicity. The study showed that the triple-negative breast cancer incidence rate was nearly two-fold higher in African American women compared to white women and those in other racial/ethnic groups in all age

categories. The workgroup revised its draft messages to the general population of young women based on feedback provided by ACBCYW during the August 2014 meeting and additional input by the workgroup members.

Message 1: Breast cancer is the most common malignancy diagnosed among women in the United States. Therefore, breast health awareness is important for women of ALL ages. Know:BRCA is a useful website for assessing individual breast cancer risk. Women should be aware of genetic counseling services.

Message 2: Breast cancer is relatively uncommon among the general population of women younger than 45 years of age in the United States. However, breast cancer is slightly less uncommon among young African American women compared to young white, Hispanic and Asian American women.

The workgroup agreed that CDC should disseminate message 2 with solid data and graphics to enhance its effectiveness and clearly distinguish between "relatively uncommon" versus "slightly less uncommon." In terms of data, the following points should be emphasized in message 2.

- For every 100,000 women in the United States 20-44 years of age, ~50 are diagnosed with breast cancer each year and ~5 will die from the disease.
- In most cases, age is a woman's greatest risk for developing breast cancer. For example, ~6 out of every 100,000 women 20-29 years of age develop breast cancer each year compared to 46 out of every 100,000 women 30-39 years of age who develop the disease.
- African American race is a risk factor for developing breast cancer at young ages. For every 100,000 women 20-44 years of age in the United States, ~4 additional African American women develop breast compared to white women. The risk of developing breast cancer increases with age for both African American and white women.

In terms of graphics, a chart created by Bright Pink can be used to compare breast cancer risk by age for women in the general population versus those with hereditary susceptibility based on a BRCA gene mutation. A chart created by the American Cancer Society can be used to demonstrate age-specific probabilities of developing invasive breast cancer. For example, the chart shows that the probability of a woman 20 years of age developing breast cancer in the next 10 years is 0.06% (or 1 in 1,760). The probability increases by age from 0.44% in women 30 years of age (or 1 in 229) to 3.73% in women 70 years of age (or 1 in 27).

Message 3: Young women should be aware of their individual risk profile and whether the profile suggests a breast cancer risk that is higher than in the general population of young women. An elevated risk will depend on three major factors:

- A family history of cancer and ancestral background, particularly in women with Ashkenazi Jewish and African heritage

- Prior biopsy results with the potential for increased risk (e.g., atypia or lobular carcinoma *in situ*)
- Prior chest wall radiation exposure with the potential for increased risk and the need for intensified breast cancer screening

Message 4: Young women should know that breast cancer is uncommon in the general population of American women younger than 45 years of age, but the disease CAN occur with subtle signs. Young women should be aware of clinically significant danger signs of breast cancer (e.g., bloody nipple discharge, new lumps, patches of nipple-areolar skin that appear scaly or eczematoid, a new or persistent rash, or inflamed breast skin). Young women undergoing mammography screening should be aware that mammograms have an increased false-negative rate for women younger than 50 years of age. Regardless of their most recent mammogram result, these women should seek medical attention if a clinically significant danger sign appears.

Message 5: Young women should be aware of specific actions to take to reduce their risk of developing breast cancer in the future. Any amount of breastfeeding is beneficial. Breastfeeding 12 months or more across one or more pregnancies offers the best level of protection. Alcohol intake should be reduced. Alcohol consumption increases the risk of breast cancer. The risk grows as the amount of alcohol consumed increases. Regular exercise for 4 or more hours per week may lower the risk of breast cancer, particularly for women of normal or low body weight. The workgroup agreed that CDC should enhance the effectiveness of message 5 by providing quantified information and references regarding specific body mass index goals and healthy body weights. The workgroup will submit these data and references to CDC for consideration.

Message 6: Additional research is needed in several areas to determine the impact of key factors on breast cancer risk.

- Poverty and socioeconomic factors
- Sexual and gender minorities (e.g., lesbian, bisexual and transgender women)
- Access to risk counseling services
- Primary and secondary prevention strategies to develop improved and more efficient methods of detecting breast cancer in young women and reducing mortality in this population

Message 7: Young women should be aware that routine mammography screening is associated with a wide range or spectrum of benefits. These benefits vary by age, but mammography becomes increasingly valuable with older age. ACBCYW recognizes that multiple factors might impact a woman's decision to initiate mammography screening at 40 rather than 50 years of age. Clinicians and other healthcare providers have issued different guidance regarding the age to initiate routine mammography screening. The workgroup explored two options in the context of message 7.

Option 1 would be for ACBCYW to continue to endorse CDC's current recommendation. "Women 50-74 years of age should undergo mammography screening every two years. Women are encouraged to discuss with their physicians whether to opt-in for screening prior to 50 years of age." The workgroup noted that several organizations have adopted the current CDC recommendation, including the American Academy of Family Physicians, American College of Physicians, and U.S. Preventive Services Task Force (USPSTF). This position of these organizations is based on data from several randomized clinical trials of mammography screening.

Option 2 would be for ACBCYW to endorse an alternative position. "Mammography screening should be initiated at 40 years of age. Patients are encouraged to discuss with their physicians whether to opt-in for screening prior to 50 years of age." The workgroup noted that a number of professional societies currently recommend mammography screening beginning at 40 years of age. Moreover, international programs in six countries recommend mammography screening beginning at 40, 45 or 47 years of age. However, the workgroup acknowledged that the relevance of international guidelines and practices to the U.S. female population is questionable due to substantial differences in demographics with respect to age, racial/ethnic diversity and disparities issues.

The workgroup reviewed the Presidential Proclamation that the White House issued for National Breast Cancer Awareness Month in October 2010. ACA ensures that persons diagnosed with breast cancer would not be excluded from coverage for a preexisting condition or charged higher premiums. Health insurance companies are now required to cover annual mammography screening for women >40 years of age with no additional cost. Following ACA implementation, USPSTF issued a Grade B recommendation for mammography screening every 1 to 2 years for women ≥40 years of age with or without CBE.

The workgroup reached consensus on the message for women to discuss mammography screening with their physicians. The workgroup also agreed on the need to fully engage the ACBCYW Ad Hoc Provider Workgroup in these discussions. However, the workgroup was divided on whether ACBCYW should endorse initiation of mammography screening at 40 versus 50 years of age.

Some workgroup members were in favor of ACBCYW remaining silent on this issue because CDC is unlikely to change its current recommendation. Other workgroup members agreed with ACBCYW's feedback during the August 2014 meeting for the Institute of Medicine (IOM) to conduct an evidence-based review on mammography screening data before providing guidance to CDC.

The workgroup's position is that a new IOM review would be warranted because the 2009 USPSTF review of mammography screening evidence did not address three key issues. First, disparities in breast cancer incidence and mortality are persistent in the United States. Breast cancer mortality disparities exist between African American and white women in all age

categories. Compared to young white women, young African American women face a higher likelihood of being diagnosed with breast cancer and biologically-aggressive tumors. Screening continues to be effective in the early detection of biologically-aggressive breast cancer patterns. The impact of mammography screening on breast cancer disparities in young women should be addressed.

Second, population-based breast cancer incidence continues to be lower in young women than in older women. Mammography screening of young women continues to have a lower proportional yield. However, the absolute volume or number of young women in the United States has substantially increased over the past several decades. The growth of this population has resulted in a larger absolute number of young breast cancer patients who would benefit from mammography screening. The impact of mammography screening in young women should address population changes and the magnitude of affected women.

Third, population-based data show increased rates of young breast cancer patients diagnosed with metastatic disease. Future studies should address the potential impact of mammography screening on efforts to reverse this trend.

Public Comment Session

Dr. Fairley opened the floor for public comments; no participants responded.

With no further discussion or business brought before ACBCYW, Dr. Fairley recessed the meeting at 4:46 p.m. on December 4, 2014.

Opening Session: December 5, 2014

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 to determine the ACBCYW voting members, *ex-officio* members and liaison representatives who were attending the meeting. She announced that the voting members and *ex-officio* members constituted a quorum for ACBCYW to conduct its business on December 5, 2014.

Dr. Fairley reconvened the proceedings at 8:14 a.m. on December 5, 2014 and welcomed the participants to day 2 of the ACBCYW meeting. None of the voting members publicly declared conflicts of interest for any of the items on the published agenda.

Lisa Richardson, MD, MPH
Director, Division of Cancer Prevention and Control
Centers for Disease Control and Prevention

Dr. Richardson thanked ACBCYW for continuing to provide outstanding guidance and expertise to improve CDC's BCYW portfolio. She particularly recognized and thanked the ACBCYW members whose terms expired on November 30, 2014 for their excellent service to CDC over the past four years.

ACBCYW Open Discussion

Ann H. Partridge, MD, MPH
Clinical Director, Breast Oncology Center
Dana-Farber Cancer Institute
ACBCYW Chair

Dr. Partridge announced that she would facilitate the open discussion for ACBCYW to formulate recommendations to CDC. To inform this effort, she asked ACBCYW to consider the updates by CDC and its grantees on their ongoing BCYW activities and the workgroup reports presented on day 1. She also advised ACBCYW to consider the diversity of the BCYW target audiences of women 18-44 years of age and HCPs in proposing guidance to CDC.

RECOMMENDATIONS FOR PROVIDER EDUCATION	
Recommendation	**Implementation Strategies**
Educate provider trainees	• Increase provider knowledge by including BCYW-related questions on certification examinations, particularly questions on family history and appropriate referrals to genetic counseling and testing services. • Promote inter-professional education through genetic training programs, schools of nursing, and school health programs in academic settings. • Conduct in-depth, in-person focus groups across the country to collect information that is more reliable than

	surveys on baseline knowledge of trainees and the most effective learning platforms for this provider population. • Revise medical school curricula to ensure students receive training on the practical management of patients with no disease and cancer genetics. • Compile best practices from provider training programs and tools developed by CDC grantees, including Bright Pink's Emerging Medical Professional Program and PPFA's Breast Risk Screening Questionnaire and national training program to standardize breast cancer screening. Rigorously evaluate and test best practices from these programs for national scale-up.
Educate practicing providers	• Change behaviors by emphasizing the potential legal implications for providers who fail to warn patients about their high-risk breast cancer status. • Provide professional societies with concrete action steps and messages to educate their memberships of providers. • Develop quality care indicators for providers of women 18-44 years of age due to the shift to pay-for-performance in the medical community. For example, "I asked my patient about her family history." For women found to be at increased risk, "my patient and I discussed her potential genetic predisposition for breast cancer." • Create an HBOC practice improvement module for providers to complete as part of the re-certification process. • Expand the reach of provider education nationally by partnering with federal programs. The HHS Office of Population Affairs has coverage of 4,400 clinics nationwide and provides breast health services to young women. The U.S. Department of Veterans Affairs develops policies and provides clinical services to a large proportion of women veterans <40 years of age.
Increase the focus on system-level changes	• Identify existing EHR systems (e.g., Epic and Kaiser) with the capacity to assist providers in targeting women with an increased HBOC risk, generate automated reminders, and distribute educational content to providers at point-of-care. ACBCYW should explore the possibility of forming a new "Electronic Heath Record Workgroup" due to the complexity of this issue. Dr. Marisa Weiss offered to lead the new workgroup if ACBCYW votes to undertake this effort.

	• Decrease the burden on PCPs because the 15- to 20-minute well woman visit covers breast and pelvic examinations in addition to overall health issues. Utilize medical homes with interdisciplinary teams of health educators and other disciplines outside of PCPs. • Expand the use of EHRs for women to more actively participate in their individual health care prior to a well woman visit. Women can use EHRs as an online tool to enter data, schedule mammogram appointments, and raise issues or concerns with their providers. EHRs are a critical tool to more efficiently serve broader populations with limited resources.
RECOMMENDATIONS FOR THE GENERAL POPULATION OF YOUNG WOMEN	
Recommendation	**Implementation Strategies**
Submit messages 1-6 drafted by the General Population Risk Workgroup as ACBCYW's formal guidance to CDC for consideration and action	N/A
Clarify message 7 on routine mammography screening before submitting formal guidance on this issue to CDC	• Collect and analyze more recent data to minimize confusion and reach consensus on recommending mammography screening initiation at 40 or 50 years of age. Commission an IOM review to focus on three key issues that were not addressed in the 2009 USPSTF review of mammography screening evidence: disparities in breast cancer incidence and mortality, particularly among young African American women; increased rates of young breast cancer patients diagnosed with metastatic disease; and the substantial increase in the absolute volume of young women in the United States over the past several decades. • Engage the HHS Office of Minority Health Advisory Committee and the Health Disparities Subcommittee of the Advisory Committee to the CDC Director because these groups also have a strong focus on health disparities. Joint recommendations on disparities in breast cancer and other health issues by three advisory bodies are likely to have a greater impact at the level of the HHS Secretary and CDC Director. • Make a clear distinction between the number of women needed to be screened at a population level to prevent a

	death versus the added value of mammography screening in specific populations.

Drs. Fairley and Partridge made announcements that potentially could have implications on the current membership submitting formal recommendations to CDC. The terms of several ACBCYW members, including the Chair, expired on November 30, 2014. CDC has submitted nomination packages to replace the outgoing members, but their terms can be extended for an additional 180 days if the nominees are not officially appointed before the next ACBCYW meeting.

The open discussion resulted in ACBCYW proposing an extensive set of recommendations to CDC on provider education and risk messaging for the general population of young women. Due to the large turnover of the ACBCYW membership, however, the workgroup chairs were asked to specify recommendations that should be submitted to CDC for consideration and action.

For provider education, Dr. Grana asked ACBCYW to focus on four key recommendations to CDC.

1. Conduct a systematic assessment to determine the current needs and practices of providers at the national level.
2. Scale-up ongoing BCYW activities conducted by CDC grantees (e.g., Bright Pink and PPFA) for implementation at the national level.
3. Promote system-level changes to more broadly reach the BCYW target audiences of providers and young women. These changes should include wider utilization of EHRs and data analyses to improve current provider practices.
4. Identify and leverage funding to support recommendations 1-3.

For risk messaging to the general population of young women, Dr. Richardson pointed out that none of the ACBCYW members opposed her recommendation to submit messages 1-6 as formal guidance to CDC. However, the open discussion did not result in ACBCYW formulating a definitive recommendation on the age at which to initiate mammography screening.

Drs. Fairley and Partridge described next steps based on the follow-up remarks by the workgroup chairs. ACBCYW was not in a position to vote on the recommendations at this time. The workgroups would review ACBCYW's feedback to refine the draft recommendations with more definitive and concrete language. CDC would convene a teleconference to engage in final discussions and take a formal vote on the draft recommendations.

Public Comment Session

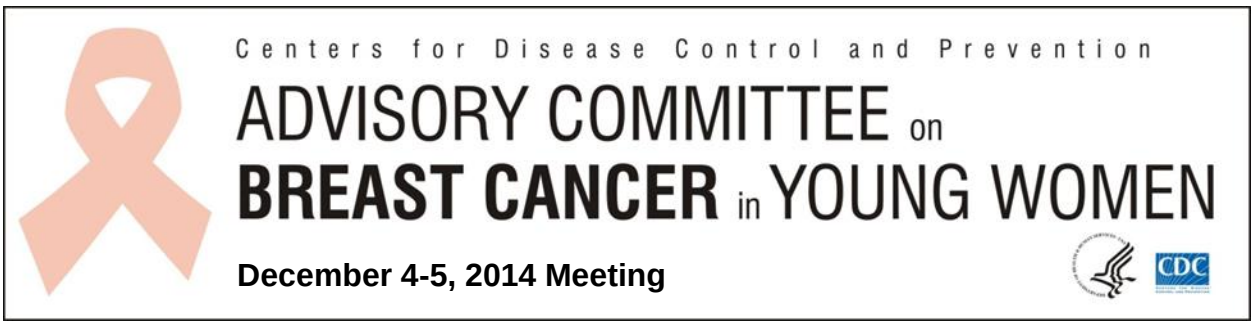
Dr. Fairley opened the floor for public comments; no participants responded.

Closing Session

Dr. Partridge asked the participants to join her in applauding Dr. Fairley, Ms. Carolyn Headley, the ACBCYW Committee Management Specialist, and other DCPC staff for their continued efforts in planning, organizing and managing outstanding ACBCYW meetings.

Dr. Fairley thanked the outgoing ACBCYW members for contributing their valuable time and expertise over the past four years to assist CDC in developing, branding and improving its BCYW portfolio.

With no further discussion or business brought before ACBCYW, Dr. Fairley adjourned the meeting at 10:59 a.m. on December 5, 2014.



Attachment 1
Published Meeting Agenda

MEETING OBJECTIVES:
Committee members are charged with advising the Secretary of the U.S. 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 4, 2014

9:00 A.M. – 9:30 A.M. **Opening: Welcome, Roll Call, and Introductions**

Temeika L. Fairley, Ph.D.
Designated Federal Officer, DCPC, CDC

Ann H. Partridge, M.D., M.P.H.
Dana-Farber Cancer Institute
ACBCYW Committee Chair

Lisa Richardson, M.D., M.P.H.
Director, DCPC, CDC

9:30 A.M. – 10:45 A.M. **Updates from CDC and Open Discussion**

Temeika L. Fairley, Ph.D.
Designated Federal Officer, DCPC, CDC

Karena Sapsis, M.P.H.
Health Communications Specialist, DCPC, CDC

Junia Geisler
Vice President, Social Change, Ogilvy Washington

Jennifer Wayman, M.H.S.
Managing Director, Social Change, Ogilvy Washington

10:45 A.M. – 11:00 A.M. **BREAK**

11:00 A.M. – 12:30 P.M. **Updates from Stakeholders and Open Discussion**

Lindsay Avner
Founder & CEO, Bright Pink

Marisa Weiss, M.D.
President & Founder, Breastcancer.org

Courtney Benedict, M.S.N., C.N.M.
Director, Medical Education, Planned Parenthood Federation of America

12:30 P.M. – 1:45 P.M. **LUNCH**

1:45 P.M. – 3:00 P.M. **Updates from CDC and Open Discussion**

Temeika L. Fairley, Ph.D.
Designated Federal Officer, DCPC, CDC

Katrina Trivers, Ph.D.
Epidemiologist, CDC

Ena Wanliss, M.S./Angela R. Moore, M.P.H.
Lead Public Health Advisor, CDC

Sue Friedman, D.V.M.
Executive Director, FORCE

Jean Rowe, L.C.S.W., O.S.W.-C., C.J.T.
Associate Director, Survivorship Programs, Young Survival Coalition

Ann H. Partridge, M.D., M.P.H.
Dana-Farber Cancer Institute
ACBCYW Committee Chair

3:00 P.M. – 3:15 P.M. **BREAK**

3:15 P.M. – 4:15 P.M. **ACBCYW Workgroup Reports and Open Discussion**

Generosa Grana, M.D., F.A.C.P.
MD Anderson Cancer Center at Cooper
Ad Hoc Provider Workgroup

Lisa Newman, M.D., M.P.H., F.A.C.S.
University of Michigan Health Systems
Ad Hoc General Population Risk Workgroup

4:15 P.M. – 4:30 P.M. **PUBLIC COMMENT**

4:30 P.M. – 5:00 P.M. **Summary and Closing**

Ann H. Partridge, M.D., M.P.H.
Dana-Farber Cancer Institute
ACBCYW Committee Chair

Friday, December 5, 2014

8:00 A.M. – 8:30 A.M. **Opening: Welcome, Roll Call, and Recap**

Temeika L. Fairley, Ph.D.
Designated Federal Officer, DCPC, CDC

Ann H. Partridge, M.D., M.P.H.
Dana-Farber Cancer Institute
ACBCYW Committee Chair

8:30 A.M. – 10:15 A.M. **ACBCYW Working Group Open Discussion**

Lisa Newman, M.D., M.P.H., F.A.C.S.
University of Michigan Health Systems
Ad Hoc General Population Risk Workgroup

Generosa Grana, M.D., F.A.C.P.
MD Anderson Cancer Center at Cooper
Ad Hoc Provider Workgroup

10:15 A.M. – 10:30 A.M. **BREAK**

10:30 A.M. – 10:45 A.M. **PUBLIC COMMENT**

10:45 A.M. – 11:45 A.M. **ACBCYW Open Discussion**

11:45 A.M. – 12:05 P.M. **Closing**

Ann H. Partridge, M.D., M.P.H.
Dana-Farber Cancer Institute
ACBCYW Committee Chair

Centers for Disease Control and Prevention

ADVISORY COMMITTEE on BREAST CANCER in YOUNG WOMEN

December 4-5, 2014 Meeting

ATTACHMENT 2
Roster of the ACBCYW Membership

CHAIR

Ann H. Partridge, M.D., M.P.H.
Director, Adult Survivorship Program
Founder & Director, Program for Young Women with Breast Cancer
Dana-Farber Cancer Institute
Associate Professor, Harvard Medical School
450 Brookline Avenue, YC1250
Boston, MA 02115
Phone: 617-632-4587
Fax: 617-632-1930
E-mail: ahpartridge@partners.org
Term: 11/30/2010-11/30/2014

EXECUTIVE SECRETARY

Temeika L. Fairley, Ph.D.
Office of Program Development
Division of Cancer Prevention and Control
Centers for Disease Control and Prevention
4770 Buford Highway NE., Mailstop F-76
Atlanta, GA 30341
Phone: 770-488-4518
Fax: 770-488-4760
E-mail: tff9@cdc.gov

MEMBERS

Raquel D. Arias, M.D.
Associate Dean and Associate Professor
University of Southern California
1975 Zonal Avenue, KAM100cc
Los Angeles, CA 90089
Phone: 323-442-2552
Fax: 323-442-2663
E-mail: rarias@usc.edu
Term: 3/22/2013-11/30/2014

Ulrike Boehmer, Ph.D.
Associate Professor
Boston University School of Public Health
Community Health Sciences Department
801 Massachusetts Avenue Crosstown Center
Boston, MA 02118
Phone: 617-638-5835
Fax: 617-638-4483
E-mail: boehmer@bu.edu
Term: 1/24/2014-11/30/2016

Otis W. Brawley, M.D., FACP
Chief Medical Director
American Cancer Society
250 Williams Street NW.
Atlanta, GA 30303
Phone: 404-329-7740
Fax: 404-417-8056
E-mail: otis.brawley@cancer.org
Term: 3/22/2013-11/30/2014

Sue Friedman, D.V.M.
Executive Director
FORCE: Facing Our Risk of Cancer Empowered
16057 Tampa Palms Boulevard, W. PMB #373
Tampa, FL 33647
Phone: 954-255-8732
Fax: 954-827-2200
E-mail: suefriedman@facingourrisk.org
Term: 3/22/2013-11/30/2014

Generosa Grana, M.D., FACP
Director
Cooper Cancer Institute
900 Centennial Boulevard, Suite A
Voorhees, NJ 08043
Phone: 856-673-4252
Fax: 856-673-4226
E-mail: grana-generosa@cooperhealth.edu
Term: 11/30/2010-11/30/2014

Susan E. Kutner, M.D.
Chair
Kaiser Permanente Breast Care Leaders Group
280 Hospital Parkway, Department of Surgery
San Jose, CA 95119
Phone: 408-972-6017
Fax: 408-972-7759
E-mail: susan.e.kutner@kp.org
Term: 3/22/2013-11/30/2014

Brandon Hayes-Lattin, M.D.
Associate Professor of Medicine
Oregon Health and Science University
Medical Director
Adolescent and Young Adult Oncology Program
OHSU Knight Cancer Institute
3181 Southwest Sam Jackson Park Road
Portland, OR 97239
Phone: 503-494-8534
Fax: 503-494-3257
E-mail: hayeslat@ohsu.edu
Term: 11/30/2010-11/30/2013

Karen Kelly Thomas, Ph.D., R.N., FAAN
Chief Executive Officer
Kelly Thomas Associates
33 Seameadow Drive
Little Egg Harbor, NJ 08087-9726
Phone: (609) 812-5100
E-mail: karenkellythomas@comcast.net
Term: 11/30/2010-11/30/2014

Karen Meneses, Ph.D., R.N., FAAN
Professor and Associate Dean for Research
University of Alabama at Birmingham
School of Nursing, Center for Nursing Research
1701 University Boulevard
Birmingham, Alabama 35294
Phone: 205-910-3663
Fax: 205-996-4656
E-mail: menesesk@uab.edu
Term: 3/22/2013-11/30/2014

Lisa A. Newman, M.D., M.P.H., FACS
Professor of Surgery and Director
University of Michigan Breast Care Center
University of Michigan Health Systems
1500 East Medical Center Drive
Ann Arbor, MI 48109
Phone: 734-936-8771
Fax: 734-647-9647
E-mail: lanewman@umich.edu
Term: 11/30/2010-11/30/2013

Rochelle L. Shoretz, J.D.
Executive Director and Founder
Sharsheret
1086 Teaneck Road, Suite 3A
Teaneck, NJ 07666
Phone: 201-833-2341
Fax: 201-837-5025
E-mail: rshoretz@sharsheret.org
Term: 3/22/2013-11/30/2014

Jeanne L. Steiner, D.O.
Associate Professor of Psychiatry
Yale University School of Medicine
Medical Director
Connecticut Mental Health Center
34 Parks Street
New Haven, CT 06519
Phone: 203-974-7077
Fax: 203-974-7293
E-mail: jeanne.steiner@yale.edu
Term: 11/30/2010-11/31/2013

Donald Warne, M.D., M.P.H.
Associate Professor and Director
Master of Public Health Program
North Dakota State University
1401 Albrecht Boulevard
118H Sudro Hall
Fargo, ND 58102
Phone: 701-231-6323
E-mail: donald.warne@ndsu.edu
Term: 11/30/2010-11/30/2013

EX-OFFICIO MEMBERS

Agency for Healthcare Research and Quality

Jennifer Croswell M.D., M.P.H.
Medical Officer
540 Gaither Road
Room 6111
Rockville, MD 20850
Phone: 301-427-1583
Fax: 301-427-1595
Email: jennifer.croswell@ahrq.hhs.gov

Department of Defense

Gayle Vaday, Ph.D.
Program Manager
Congressional Directed Medical Research Programs
Department of Defense
1077 Patchel Street
Fort Detrick, MD 21702
Phone: 301-619-7071
Fax: 301-619-7796
E-mail: gayle.g.vaday.civ@mail.mil

Department of Health and Human Services Office on Women's Health

Nancy Lee M.D.
Deputy Assistant Secretary for Health,
Women's HealthDirector
Office on Women's Health
200 Independence Avenue SW.
Room 712E
Washington, DC 20201
Phone: 202-690-7650
Fax: 202-401-4005
E-mail: nancy.lee@hhs.gov

Health Resources and Services Administration

CDR Morrisa Rice, M.H.A., REHS, RS
Program Manager Officer
United States Public Health Services
Health Resources and Services Administration
Maternal and Child Health Bureau Division of State and Community Health
5600 Fishers Lane Room 18-41
Rockville, MD 20857
Phone: 301-443-6838
Fax: 301-443-8587
E-mail: mrice@hrsa.gov

Indian Health Service

Susan Karol, M.D.
Chief Medical Officer
Indian Health Service
Office of the Director
801 Thompson Avenue, Suite 440
Rockville, MD 20852
Phone: 301-443-1083
E-mail: susan.karol@ihs.hhs.gov

National Institutes of Health

Jung-Min Lee, M.D.
Assistant Clinical Investigator
National Cancer Institute
10 Center Drive
MSC 1906 Room 13N218
Bethesda, MD 20892
Phone: 301-443-7735
Fax: 301-402-0172
E-mail: lee6@mail.nih.gov

LIAISON REPRESENTATIVES

Avon Foundation Breast Cancer Crusade

Marc Hurlbert, Ph.D.
Executive Director
Avon Foundation for Women
777 Third Avenue
New York, NY 10017
Phone: 212-282-5560
E-mail: marc.hurlbert@avonfoundation.org

Black Women's Health Imperative

Ngina Lythcott, Ph.D.
Black Women's Health Imperative
8 Somerset Road
Provincetown, MA 02657
E-mail: nlythcott@me.com

Breastcancer.org

Marisa Weiss, M.D.
President and Founder
Breastcancer.org
3 East Lancaster Avenue, 3rd Floor
Ardmore, PA, 19003
Phone: 610-642-6550
Fax: 610-642-6559
E-mail: mweiss@breastcancer.org

Bright Pink

Lindsay Avner
Founder and CEO
Bright Pink
670 N. Clark Street
Chicago, IL 60654
Phone: 312-787-4412
E-mail: Lindsay@BeBrightPink.org

LIVESTRONG, The Lance Armstrong Foundation

Renee Nicholas
Director of Corporate Partnerships
LIVESTRONG
2201 East 6th Street
Austin, TX 78702
Phone: 512-279-8411
Fax: 512-699-0530
E-mail: renee.nicholas@livestrong.org

Living Beyond Breast Cancer

Arin Ahlum Hanson, M.P.H., CHES
Manager, Young Women's initiative
Living Beyond Breast Cancer
354 West Lancaster Avenue, Suite 224
Haverford, PA 19041
Phone: 610-645-4567
Fax: 610-645-4573
E-mail: arin@lbbc.org

Patient Advocate Foundation

Beth Patterson
President, Mission Delivery
Patient Advocate Foundation
421 Butler Farm Road
Hampton, VA 72366
Phone: 800-532-5274
Fax: 757-873-8999
E-mail: beth.patterson@patientadvocate.org

Sisters Network, Inc.

Kelly P. Hodges, M.S.
National Program Director
Sisters Network,Inc.
2922 Rosedale Street
Houston,TX 77004
Phone: 713-781-0255
Fax: 713-780-8998
E-mail: kphodges@sistersnetworkinc.org

Susan G. Komen for the Cure

Susan Brown, M.S., R.N.
Managing Director, Community Health
Susan G. Komen for the Cure
5005 LBJ Freeway, Suite 250
Dallas, TX 75244
Phone: 972-855-1635
E-mail: sbrown@komen.org.org

Tigerlily Foundation

Maimah S. Karmo
Chief Executive Officer
Tigerlily Foundation
11654 Plaza America Drive, #725
Reston, VA 20190
Phone: 888-580-6253
Fax: 703-663-9844
E-mail: maimah@tigerlilyfoundation.org

Young Survival Coalition

Jennifer Merschdorf, M.B.A.
Chief Executive Officer
Young Survival Coalition
61 Broadway, Suite 2235
New York, NY 10006
Phone: 646-257-3001
Fax: 646-257-3030
E-mail: jmerschdorf@youngsurvival.org

ATTACHMENT 3
Participants' Directory

Agency for Healthcare Research and Quality
Jennifer Croswell, M.D., M.P.H. ★•
Agency for Healthcare Research and Quality
Rockville, MD

American College of Obstetrics and Gynecologists
Raquel Arias, M.D. ★
American College of Obstetrics and Gynecologists
Los Angeles, CA

Black Women's Health Imperative
Valerie Rochester ★•
Black Women's Health Imperative
Washington, DC

Breastcancer.org
Marisa Weiss, M.D. ★
Breastcancer.org
Ardmore, PA

Boston University
Ulrike Boehmer Ph.D. ★
Boston University School of Public Health
Boston, MA

Bright Pink
Lindsay Avner ★
Bright Pink
Chicago, IL

Sarah Storey •
Bright Pink
Chicago, IL

Centers for Disease Control and Prevention
Pamela Protzel Berman, Ph.D., M.P.H.
Centers for Disease Control and Prevention
Atlanta, GA

Jameka Blackmon, M.B.A., CMP
Centers for Disease Control and Prevention
Atltanta, GA

Annie Brayboy
Centers for Disease Control and Prevention
Albuquerque, NM

Natasha Buchanan, Ph.D.
Centers for Disease Control and Prevention
Atlanta, GA

Janine Cory, M.P.H.
Centers for Disease Control and Prevention
Atlanta, GA

Cheryl Cunningham
Centers for Disease Control and Prevention
Atlanta, GA

Temeika L. Fairley, Ph.D.
Centers for Disease Control and Prevention
Atlanta, GA

Alyse Finkel, M.P.H.
Centers for Disease Control and Prevention
Atlanta, GA

Yvonne Green, M.S.
Centers for Disease Control and Prevention
Atlanta, GA

Carolyn P.R. Headley, M.S.P.H.
Centers for Disease Control and Prevention
Atlanta, GA

Teri Larkins, Ph.D.
Centers for Disease Control and Prevention
Atlanta, GA

Greta Massetti Ph.D.
Centers for Disease Control and Prevention
Atlanta, GA

Jacqueline Miller, M.D.
Centers for Disease Control and Prevention
Atlanta, GA

Mike Mizelle
Centers for Disease Control and Prevention
Atlanta, GA

Hang Nguyen
Centers for Disease Control and Prevention
Atlanta, GA

Lisa Richardson, M.D., M.P.H.
Centers for Disease Control and Prevention
Atlanta, GA

Kari Sapsis, M.P.H.
Centers for Disease Control and Prevention
Atlanta, GA

Dan Stowell, M.P.H.
Centers for Disease Control and Prevention
Atlanta, GA

Cheryll Thomas, M.S.P.H.
Centers for Disease Control and Prevention
Atlanta, GA

Melonie Thomas, M.B.A.
Centers for Disease Control and Prevention
Atlanta, GA

Mary White, Sc.D.
Centers for Disease Control and Prevention
Atlanta, GA

Arica White, Ph.D., M.P.H.
Centers for Disease Control and Prevention
Atlanta, GA

Faye Wong, M.P.H.
Centers for Disease Control and Prevention
Atlanta, GA

Connecticut Department of Public Health
Beverly Burke, M.S.W. ◆◆
Connecticut Department of Public Health
Hartford, CT

Cooper Cancer Institute
Generosa Grana, M.D. ★
Cooper Cancer Institute
Voorhees, NJ

Dana Farber Cancer Institute
Ann Partridge, M.D., M.P.H. ★
Dana Farber Cancer Institute
Boston, MA

Department of Defense
Dan Monson M.D. •
Department of Defense Breast Cancer Research Program
Frederick, MD

Nicole Williams M.D. •
Department of Defense Breast Cancer Research Program
Frederick, MD

Gayle Vaday, Ph.D. ★ •
Department of Defense Breast Cancer Research Program
Frederick, MD

Department of Health and Human Services
Nancy Lee, M.D. ★
Department of Health and Human Services
Office on Women's Health
Washington, DC

FORCE: Facing Our Risk of Cancer Empowered
Sue Friedman M.D. ★
FORCE: Facing Our Risk of Cancer Empowered
Tampa, FL

Health Resources and Services Administration
Morrisa Rice, M.H.A., REHS, RS ★ •
Health Resources and Services Administration
Office of Women's Health
Rockville, MD

Indian Health Service
Carolyn Aoyoma CNM, M.P.H. •
Indian Health Service
Rockville, MD

Celissa G. Stephens RN, BSN, M.S.N. •
Indian Health Service
Rockville, MD

Kaiser Permanente Breast Care Leaders Group
Susan Kutner M.D. ★
Kaiser Permanente Breast Care Leaders Group
San Jose, CA

KellyThomas Associates
Karen Kelly Thomas M.D. ★
Kaiser Permanente Breast Care Leaders Group
San Jose, CA

Living Beyond Breast Cancer
Arin Ahlum Hanson, M.P.H., CHES ★
Living Beyond Breast Cancer
Haverford, PA

Michigan Department of Community Health
Debra Duquette, M.S., CGC ◆•
Michigan Department of Community Health
Lansing, MI

Sarah Mange ◆•
Michigan Department of Community Health
Lansing, MI

National Cancer Institute
Jung-Min Lee, M.D. ★•
National Cancer Institute
Bethesda, MD

Jennifer Hayes Ph.D. ◆•
National Cancer Institute
Bethesda, MD

Oak Ridge Institute for Science and Education (ORISE)
Jennifer Reynolds M.P.H. •
Oak Ridge Institute for Science and Education (ORISE)
Quincy, MA

Ogilvy
Jennifer Wayman, M.H.S. ◆
Ogilvy
Washington, DC

Junia Geisler ◆
Ogilvy
Washington, DC

Oregon Health Authority
Summer Cox •
Oregon Health Authority
Portland, OR

Rani George •
Oregon Health Authority
Portland, OR

Darren Yesser •
Oregon Health Authority
Portland, OR

Oregon Health and Sciences University
Brandon Hayes-Lattin, M.D. ★
Oregon Health and Science University
Portland, OR

Karen Kovak ◆•
Oregon Health and Science University
Portland, OR

Patient Advocate Foundation
Shonta Chambers, M.S.W. ◆
Patient Advocate Foundation
Hampton, VA

Planned Parenthood Federation of America
Courtney Benedict •
Planned Parenthood Federation of America
New York, NY

Sharsheret
Adina Fleischmann ◆
Sharsheret
Teaneck, NJ

Susan G. Komen for the Cure
Susan Brown, M.S., R.N. ★
Susan G. Komen for the Cure
Dallas, TX

Tigerlilly
Maimah Karmo ★•
Tigerlilly
Reston, VA

Britt Weinstock •
Tigerlilly
Reston, VA

University of Alabama at Birmingham
Silva Camata
University of Alabama at Birmingham
Birmingham, AL

Karen Meneses, Ph.D., R.N., FAAN. ★
University of Alabama at Birmingham
Birmingham, AL

University of Maryland
Amy Wu ◆•
University of Maryland
College Park, Maryland

University of Michigan Breast Care Center
Lisa Newman, M.D., M.P.H. ★
University of Michigan Breast Care Center
Ann Arbor, MI

Utah Department of Health
Lynne Nilson M.P.H., MCHES ◆•
Utah Cancer Control
Salt Lake City, UT

Camille Roundy ◆•
Utah Department of Health
Salt Lake City, UT
Kristi Smith ◆•
Utah Department of Health
Salt Lake City, UT

Young Survival Coalition
Jean Rowe LCSW, OSW-C, CJT ◆
Young Survival Coalition
New York, NY

Deborah Jo Gibson ◆
Young Survival Coalition
New York, NY

★ Advisory Committee Member, *Ex-Officio* Member, or Liaison Representative
◆ Pre-Registrant
• Virtual Attendee

Attachment 4
Glossary of Acronyms

ABOUT	American BRCA Outcomes and Utilization of Testing
ACA	Affordable Care Act
ACBCYW	Advisory Committee on Breast Cancer in Young Women
BCYW	Breast Cancer in Young Women
BHI	Breast Health Initiative
BOC	Breast and Ovarian Cancer
BRFSS	Behavioral Risk Factor Surveillance Survey
BRSQ	Breast Risk Screening Questionnaire
CBE	Clinical Breast Examination
CDC	Centers for Disease Control and Prevention
CDS	Clinical Decision Support
CME	Continuing Medical Education
CoAgs	Cooperative Agreements
DCPC	Division of Cancer Prevention and Control
DFCI	Dana-Farber Cancer Institute
EARLY Act	Education and Awareness Requires Learning Young Act
EHRs	Electronic Health Records
FOAs	Funding Opportunity Announcements
HBOC	Hereditary Breast and Ovarian Cancer
HCPs	Healthcare Providers
HHS	U.S. Department of Health and Human Services
IOM	Institute of Medicine
NBCCEDP	National Breast and Cervical Cancer Early Detection Program
OB/GYN	Obstetrician/Gynecologist
PCORnet	Patient-Centered Clinical Research Network
PCPs	Primary Care Providers
PPFA	Planned Parenthood Federation of America

PSA	Public Service Announcement
SEER	Surveillance, Epidemiology and End Results
UC	University of California
USPSTF	U.S. Preventive Services Task Force
XRAYS	Examining Relevance of Articles for Young Survivors
YBCS	Young Breast Cancer Survivors
YSC	Young Survival Coalition