

**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  
March 27-28, 2014  
Record of the Proceedings**

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**ADVISORY COMMITTEE ON BREAST CANCER IN YOUNG WOMEN  
March 27-28, 2014**

**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 March 27-28, 2014 in Building 107 of the CDC Chamblee Campus in Atlanta, Georgia.

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 ACBCYW meeting were open to the public (*Attachment 1: Participants' Directory*).

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.

**Opening Session: March 27, 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 March 27, 2014.

Dr. Fairley called the proceedings to order at 9:33 a.m. on March 27, 2014 and welcomed the participants to day 1 of the ACBCYW meeting. None of the voting members declared conflicts of interest for the record for any of the items on the published agenda.

**David Espey, MD**

Acting Director, Division of Cancer Prevention and Control  
Centers for Disease Control and Prevention

Dr. Espey extended his welcome to the participants and thanked the ACBCYW members for their tremendous accomplishments and progress in advancing the important issue of BCYW over the past few years. He emphasized that CDC is committed to fulfilling its leadership role at the national level in building the BCYW scientific base and widely disseminating evidence-based messages in this regard.

CDC has made every effort to ensure that its full BCYW portfolio is aligned with the Education and Awareness Requires Learning Young (EARLY) Act and its individual BCYW activities are conducted in a responsible manner to meet the needs of the target population. Most notably, CDC's BCYW projects are designed for and targeted to one of three categories: applied research, public health communications, and program support for young breast cancer survivors (YBCS).

CDC recognizes that significant gaps need to be filled in research, evidence-based interventions and policies in order to implement a large-scale BCYW public health campaign. ACBCYW's ongoing input on CDC's intramural and extramural BCYW activities will continue to play a critical role in evaluating whether data needs are being met in this regard. Dr. Espey concluded his opening remarks by confirming that he looked forward to reviewing ACBCYW's feedback and advice on CDC's most recent BCYW activities.

**Pamela Protzel Berman, PhD, MPH**

Deputy Director, Division of Cancer Prevention and Control  
Centers for Disease Control and Prevention

Dr. Berman thanked the ACBCYW members for continuing to contribute their valuable time, expertise and efforts in helping CDC to strengthen its BCYW portfolio. She also thanked CDC's grantees and partners for continuing to present updates during ACBCYW meetings to ensure that the members are well informed of ongoing BCYW activities in the field.

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

Clinical Director, Breast Oncology Center  
Dana-Farber Cancer Institute  
ACBCYW Chair

Dr. Partridge welcomed all of the participants to the meeting who were attending either remotely or in person. She announced that ACBCYW's most significant achievements to date have been

providing a unified voice and serving as a strong advocate to improve the diagnosis, care, treatment and research of young women who are at risk of or have developed breast cancer.

Dr. Partridge explained that the meeting would include updates by the ACBCYW Ad Hoc Workgroups and presentations of CDC's intramural and extramural BCYW activities, particularly its breast cancer survivorship projects. Open discussions would be held for ACBCYW to provide advice and guidance to CDC on its current BCYW activities. ACBCYW also would use the open discussions to explore its immediate next steps and future directions.

Dr. Partridge concluded her opening remarks by reminding the members to visit the ACBCYW webpage on the CDC.gov website. The webpage maintains ACBCYW's meeting minutes, recommendations to the HHS Secretary and CDC Director, presentations and other information that would be useful to the members and their stakeholder organizations.

## **PANEL PRESENTATION: UPDATES ON THE CDC DP11-1111 COOPERATIVE AGREEMENT**

The CDC Project Officer, a panel of three grantees, and the evaluation contractor presented a series of updates on the DP11-1111 Cooperative Agreement (CoAg). The updates are outlined below.

### **Update by the DP11-1111 Project Officer**

#### **Nikki Hayes, MPH**

Chief, Comprehensive Control Branch  
Division of Cancer Prevention and Control  
Centers for Disease Control and Prevention

Ms. Hayes presented an update on CDC's DP11-1111 CoAg, "Developing Support and Educational Awareness for Young (<45) Breast Cancer Survivors in the United States." The CDC Comprehensive Cancer Control Branch manages and oversees the CoAg with three teams: Program Evaluation and Partnership Team, Scientific Support and Clinical Translation Team, and Communication and Training Team. The three teams provide technical assistance (TA) and guidance to grantees to conduct their individual DP11-1111 programs.

CDC convened an objective review panel to evaluate and rank 53 applications that were submitted in response to the competitive Funding Opportunity Announcement (FOA). Eligible entities included for-profit and non-profit organizations (NPOs), small, minority and women-owned businesses, colleges and universities, research institutions, hospitals, and faith- and community-based organizations (CBOs). Specific roles and responsibilities are outlined to ensure that CDC and the grantees collaborate in achieving the overall goals of the CoAg. The three-year project period of the CoAg began on September 30, 2011 and will end on September 29, 2014.

Based on the findings of the objective review panel, CDC funded seven applicants for a total award amount of \$1.8 million annually.

- John C. Lincoln Health Foundation (Phoenix, AZ)
- Living Beyond Breast Cancer (Haverford, PA)
- Louisiana State University Health Sciences Center (New Orleans, LA)
- Sharsheret, Inc. (Teaneck, NJ)
- University of California at Los Angeles (Los Angeles, CA)
- University of North Carolina at Chapel Hill (Chapel Hill, NC)
- Washington University at St. Louis (St. Louis, MO)

The overarching purpose of the CoAg is two-fold. First, resources will be provided to select organizations to establish or enhance existing support services (e.g., patient navigation programs). Second, programs and resources will be provided related to psychosocial support for YBCS (e.g., resources to enhance support given to family members and caregivers as well as tools and resources to increase patient and healthcare provider (HCP) knowledge).

Activities by the grantees to implement their individual DP11-1111 programs are highlighted as follows: assure program readiness, oversight and management support; perform needs and resource assessments to identify gaps in capacity; identify 3-5 priorities based on findings from the needs assessment; establish new or enhance existing partnerships; develop and implement a program plan; evaluate and monitor progress in reaching targets; and create a sustainability plan.

Activities by CDC to assure the success of the grantees in implementing their DP11-1111 programs are highlighted as follows: provide guidance, programmatic and scientific support, TA and training; collaborate with grantees in the development of publications that relate to the purpose and goals of the CoAg; facilitate information sharing and partnership building; and conduct an overall evaluation of the CoAg across grantees.

## **Update by Living Beyond Breast Cancer**

**Arin Ahlum Hanson, MPH, CHES**  
Manager, Young Women's Initiative  
Living Beyond Breast Cancer

Ms. Hanson presented an update on Living Beyond Breast Cancer's (LBBC) DP11-1111 Program, "Young Women's Initiative" (YWI). LBBC is a national NPO that was established in 1991 with a mission to connect persons to trusted breast cancer information and a community of support.

LBBC was one of the first NPOs in the country to fill the need for breast cancer-related linkages, information and support after treatment. As the need for specialized services increased, however, LBBC expanded its programming to assist women at all stages of diagnosis, treatment

and survivorship. LBBC also offers tailored programs and resources for young women, women diagnosed with triple-negative breast cancer, women living with metastatic breast cancer and African American women.

LBBC's programming includes monthly webinars, an educational newsletter (*Insight*), the Breast Cancer Helpline to offer peer-to-peer telephone support, an interactive website (lbcc.org), and educational programs for HCPs. LBBC will host the "Women Living with Metastatic Breast Cancer Conference" on April 26-27, 2014 and its Annual Fall Conference on September 27, 2014 in Philadelphia. LBBC's travel grants assure that its conferences are well represented by diverse groups across the country.

LBBC developed and maintains a comprehensive library of printed and online publications that are free of charge. In addition to providing information to women with breast cancer and their families, LBBC's publications also are distributed in cancer centers and used to initiate dialogue between HCPs and their patients.

- *Topics for women diagnosed with early-stage breast cancer*
  - Guide for the Newly Diagnosed
  - Hormonal Therapy
  - Triple-Negative Breast Cancer
  - Fear of Recurrence
  - Treatment Decisions
  - Understanding Your Emotions
  
- *Topics for women diagnosed with metastatic breast cancer*
  - Guide for the Newly Diagnosed
  - Managing Stress and Anxiety
  - Treatment Options
  - Understanding Palliative Care
  
- *Topics for all women diagnosed with breast cancer*
  - Intimacy and Sexuality
  - Insomnia and Fatigue
  - Yoga and Breast Cancer
  - Lymphedema
  - Financial Concerns

LBBC launched YWI in November 2011 after receiving its DP11-1111 award from CDC. YWI is designed to expand and strengthen LBBC's existing programs for young women and develop new program resources for this population. LBBC initiated YWI by conducting a national needs assessment of young women to achieve three goals.

Information and support needs of young women affected by breast cancer would be assessed. Subgroup differences in terms of ethnicity, stage of breast cancer, time since diagnosis and age

at diagnosis would be evaluated. Existing gaps in program areas for young women would be identified. The national needs assessment of young women included four major components.

1. Key informant interviews with 12 HCPs and cancer advocates across the country
2. Four focus groups with 33 young women diagnosed with early-stage breast cancer at new, intermediate and longer points in time and young women living with metastatic breast cancer
3. An environmental scan and gap analysis of 29 organizations that provide services and programs to young women affected by breast cancer
4. A national survey of 85 questions with responses by 1,473 young women who were diagnosed with breast cancer before 45 years of age

LBBC used the findings from the needs assessment to select four program priorities for YWI. Tailored online resources would be developed for young women. Opportunities would be increased for young women to receive peer support through the LBBC Breast Cancer Helpline. HCPs would be educated about the unique needs of young women affected by breast cancer. Programming and resources would be expanded for key groups that were found to have unique needs or defined as “underserved” : women diagnosed with breast cancer before 30 years of age, women living with metastatic breast cancer, and African American women.

After selecting the four program priorities for YWI, LBBC focused on expanding three of its existing programs. In terms of web content, a section of the lbcc.org website was dedicated to providing resources to young women, including links to >100 website articles that specifically were developed for and targeted to young women. Data are continuously extrapolated from recent breast cancer research studies to develop easy-to-read summaries.

The “Learn About Breast Cancer and Young Women” section of the website includes 16 articles that are relevant to young women (e.g., advocacy, the use of social media to locate information and support, medical and psychosocial needs, bone health, sex and intimacy, fertility, menopause and effective communication with HCPs). Profiles of young women with breast cancer across the country are featured. A dedicated web writer and breast cancer experts assure that all messaging and other content posted on the lbcc.org/young women website are medically accurate and presented with a consistent voice.

In terms of the toll-free Breast Cancer Helpline (1-888-753-LBCC), LBCC expanded this resource to include additional volunteers from across the country and longer hours of operation from 9:00 a.m. to 9:00 p.m. EST Monday-Friday. In 2013, 22 young women with breast cancer completed the extensive Helpline volunteer training program. Of 100 active Helpline volunteers, 40% were diagnosed with breast cancer before 45 years of age.

The Helpline received 650 calls in 2011, but now receives 1,300 calls per year. Young women are estimated to account for 15%-20% of these calls, but demographic data cannot be reliably tracked. Helpline calls are confidential and participation in a post-call survey is optional.

National marketing campaigns were launched to increase the visibility of the Helpline, but these efforts resulted in only limited success.

In terms of publications, LBBC developed and distributed 7,000 copies of its print publications that are of great interest to young women: *Guide to Understanding Intimacy and Sexuality*, *Guide to Understanding Hormonal Therapy*, *Guide to Understanding Genetics and Family Risk*, and *Guide for the Newly Diagnosed* in an eReader version.

Additional materials are planned for publication later in 2014: *Guide to Complementary Therapies and Integrative Medicine*, the updated *Guide to Financial Concerns*, and *Guide for the LBGTQ Community*. All of LBBC's publications are developed in collaboration with a Medical and Consumer Review Committee.

In addition to expanding its existing programs, LBBC also developed new programs for YWI. The new "Let's Talk About It" Video Series for Young Women includes three videos with clear health education messages from young women and HCPs: "Let's Talk About Sex and Breast Cancer;" "Hear Me: Communicating with Your Healthcare Team;" and "What Young Women Should Know About Bone Health." The video series has received 2,600 combined views to date.

The development of three additional videos is underway and will focus on the financial impact of breast cancer, tools for young women living with metastatic breast cancer to communicate with their families and friends, and body image. Ms. Hanson presented a clip from one of the videos.

The new Young Advocate Program (YAP) is designed to help young women leverage their personal experiences to make a difference in their individual communities. YAP is targeted to women with incomes at or below 200% of the Federal Poverty Level and who are within three years of diagnosis or living with metastatic breast cancer.

The YAP training course includes eight hours of in-person training on multiple topics, such as the spectrum of advocacy, breast cancer health disparities, and effective sharing of personal breast cancer stories. YAP participants are required to complete at least two activities within their communities at a local or national level and share LBBC's publications with at least one HCP within six months of receiving training.

To date, 29 young women with breast cancer have completed the YAP training course. LBBC monitors and tracks activities of the YAP trainees and also uses social media, teleconferences, e-mail updates and national conferences to ensure the YAP trainees remain engaged over time. LBBC is extremely pleased that one of the initial successes of YAP has been to attract young women with breast cancer from rural parts of the country.

New HCP webinars were broadcast to strengthen relationships between HCPs and their young breast cancer patients. LBBC publicized the webinars through its existing HCP database and a purchased list of provider associations. The May 2013 and September 2013 HCP webinars

were “Understanding the Unique Needs of Young Women Affected by Breast Cancer” and “Bring It Up! How to Talk with Your Young Breast Cancer Patients About Sex.” Of >500 HCPs who participated in the webinars, an overwhelming majority reported a post-meeting increase in knowledge. Recordings of the webinars are available on the lbcc.org website.

An in-person HCP Symposium will be held on May 27, 2014 in Baltimore in conjunction with the Association of Oncology Social Work Annual Conference. Continuing medical education (CME) will be offered to oncology social workers and oncology nurses only, but the symposium will be open to all HCPs. The following courses will be featured at the symposium: “Talk Back: Defining the Needs of Young Women in Your Practice;” “Fertility: Educational Opportunities and Preservation Options;” “Let’s Talk about Sex!;” “Developing Survivorship Programming for Young Women;” and “Living with Uncertainty: Young Women and Metastatic Breast Cancer.”

Other new programming is planned for the future, including quarterly Twitter Chats, additional webinars for both young women and HCPs, and specific tracks and activities for young women with breast cancer at national conferences.

In addition to focusing on its new programming, LBBC’s next steps also will include the creation of strategies to address challenges related to the implementation of YWI.

- Measuring the impact and outcomes of YWI activities, particularly for web content, social media engagement and online videos
- Tracking the impact of marketing approaches to increase visibility of YWI
- Effectively reaching diverse populations and newly diagnosed young women
- Striking an appropriate balance between virtual and physical programming
- Striking an appropriate balance between the creation of inclusive general programming to meet the needs of young women and the creation of tailored programs specifically for young women

ACBCYW advised LBBC to consult with Internet marketing experts to increase traffic to and views of its video series and other online resources for YBCS. Meta tags, tailored questions with specific keywords, and sophisticated search engine optimization technology could be utilized to more prominently feature LBBC’s resources when individuals use Google or other search engines to perform YBCS-related searches.

## **Update by the Louisiana State University Health Sciences Center**

### **Donna Williams, DrPH**

Director, Louisiana Cancer Prevention and Control Program  
Assistant Professor, Louisiana State University Health Sciences Center  
School of Public Health

Dr. Williams presented an update on Louisiana State University Health Sciences Center’s (LSUHSC) DP11-1111 Program, “SurviveDAT.” LSUHSC responded to CDC’s FOA due to the

critical need to focus on YBCS. In the state population, Louisiana ranked fifth for breast cancer deaths among women <50 years of age in 2006-2010. In the national population, YBCS <45 years of age have higher rates of recurrence and death as well as lower rates of five-year survival. Breast cancer in young women typically is indicative of a genetic mutation. Young women with breast cancer face unique challenges in terms of their careers and relationships with families and friends.

LSUHSC implemented a stepwise approach after receiving its DP11-1111 award from CDC. One, a needs assessment survey was administered for YBCS, caregivers and HCPs to complete via telephone, mail, Internet or in person. The survey responses showed that fertility, psychosocial, genetics, nutrition, dating/relationship, body image, premature menopause and sexuality issues were the top priorities in the YBCS population.

Two, market research was conducted to identify the most effective outreach strategies for the small YBCS population in Southern Louisiana. The market research results are outlined below:

- Young persons are the largest group of social media users: 92% of persons 18-29 years of age and 73% of persons 30-49 years of age.
- Young women 25-44 years of age account for >50% of social media users. Data collected in August 2012 showed that 75% of women were users of social networking sites.
- Consumers spend 17% of their personal computer time on Facebook.
- By size, Facebook's population of 1 billion users would be ranked as the third largest "country" in the world behind China's 1.3 billion population and India's 1.2 billion population.
- By value, Facebook is worth more than nearly all multinational corporations: Hewlett Packard, Dell, Starbucks, Amazon, Disney, McDonald's, Humana, Aetna and Cigna.

Three, multiple state and local partners were engaged to ensure that resources, expertise and support would be provided to implement and sustain the DP11-1111 program over time.

Four, the needs assessment and market research findings were used to design and launch SurviveDAT in October 2012 with several key objectives: promote health, education and awareness; focus on the unique needs of YBCS; and serve as an online resource for YBCS, caregivers and HCPs. SurviveDAT includes both traditional approaches (e.g., in-person support groups, patient navigation and in-person workshops) and social media platforms (e.g., Facebook, Twitter, YouTube and other website content).

In terms of the SurviveDAT traditional approaches, LSUHSC has convened in-person support groups and held several workshops covering topics that are consistent with the top priorities for YBCS identified in the needs assessment: genetics, fertility, body image, psychosocial nutrition, premature menopause and relationships/sexuality. Audio recordings and videos of the workshops are available on the LSUHSC website, including personal stories from YBCS on the importance of genetics testing. Other features of the website include search engines for YBCS

to locate resources based on a particular topic or area of the state; a genetics quiz for YBCS to facilitate discussions with their HCPs; and a tab for HCP-specific information.

In terms of the SurviveDAT social media platforms, LSUHSC has leveraged technology to increase its reach to the YBCS population. A buffer application allows LSUHSC to more effectively use social media by automatically posting up-to-date information on Facebook and Twitter at specific times that young women are online (e.g., nights and weekends). Targeted advertising allows LSUHSC to specifically reach young women by their geographic location, gender or age. For example, 140,000 young women 18-45 years of age who live within 25 miles of New Orleans potentially could access LSUHSC's Facebook advertisement through their desktop computers or mobile devices.

Analytic tools (e.g., Facebook Ads Manager, Facebook Insights and Google Analytics) allow LSUHSC to track the reach and effectiveness of its targeted advertising and sponsored stories based on the number of clicks, impressions, page likes, event responses, cost per click, page consumptions, engagements, new user visits, and paid search traffic. Dr. Williams presented a series of slides to illustrate a typical SurviveDAT advertisement, increases in the number of Facebook fans and Facebook activity, a growth in website traffic, and specific content with the greatest interest (e.g., the online T-shirt shop).

Tracking data showed that the targeted advertising resulted in dramatic increases in website visits, page likes, page consumptions and engagements within six months of being launched. Women accounted for 99% of the population that was reached. Of these women, 97% were <45 years of age. Tracking data from July 2-December 31, 2013 showed that LSUHSC incurred a cost per click of \$0.91 for the targeted advertising to reach 2.1 million persons with 8.3 million impressions. Recent data showed that the SurviveDAT.org website had 1,006 likes as of March 26, 2014.

Overall, LSUHSC found that targeted advertising of SurviveDAT on social media was extremely effective in reaching the population of interest. Detailed analytics were tremendously valuable in refining messages and evaluating effectiveness. LSUHSC's future directions will focus on two key areas.

First, SurviveDAT service areas will be expanded to include Northern Louisiana, Mississippi and Alabama. Second, new technology will be leveraged to increase the reach of SurviveDAT and ensure that young women remain engaged over time. For example, young women increasingly are using Instagram. The Meetup platform will be used for YBCS to form support groups in their local communities throughout the state. Mobile applications will be particularly effective in reaching African American young women. Because each in-person support group has attracted only 3-4 participants, this resource will be offered online to be more appealing and responsive to the needs of YBCS.

## Update by Sharsheret

### **Rochelle L. Shoretz, JD**

Executive Director and Founder, Sharsheret  
ACBCYW Member & High Risk Workgroup Chair

Ms. Shoretz presented an update on Sharsheret's DP11-1111 Program, "Thriving Again: A Comprehensive Breast Cancer Survivorship Program for Young Jewish Breast Cancer Survivors" (YJBCS). Sharsheret is the Hebrew word for "chain" and was established in 2001 as a national NPO to support young Jewish women and their families facing breast cancer.

Sharsheret's mission is to offer a community of support to women who are diagnosed with or at increased genetic risk of breast cancer by fostering culturally-relevant, individualized linkages to networks of peers, health professionals and related resources. Sharsheret fulfills its mission by offering 12 national programs to help Jewish families from the time breast cancer risk is detected through diagnosis, treatment and survivorship.

After receiving its DP11-1111 award from CDC, Sharsheret conducted a needs assessment of YJBCS; created and implemented a detailed program plan based on the needs assessment findings; continually monitored the success of Thriving Again; and initiated an evaluation early in 2014. The Affordable Care Act (ACA) identifies YJBCS as being at increased risk of hereditary breast cancer.

Sharsheret conducted four major activities to develop Thriving Again. First, key informant interviews were conducted and a National Survivorship Advisory Board was formed. Experts in the field, medical professionals and breast cancer survivors participated in 24 telephone interviews. Of these participants, 14 were invited to join the National Survivorship Advisory Board to provide ongoing guidance on evolving research and the Thriving Again program components. The National Survivorship Advisory Board represents professionals in various fields, including oncologists, breast surgeons, genetic counselors, social workers, researchers, nurse navigators and NPO leaders.

Second, an extensive literature review was performed to collect available data on YBCS and JBCS. Examples of articles that were reviewed include the 2008 paper, "Implementing a Survivorship Care Plan for Patients With Breast Cancer," published in the *Journal of Clinical Oncology* and the 2010 paper, "Crisis, Social Support, and the Family Response: Exploring the Narratives of Young Breast Cancer Survivors," published in the *Journal of Psychosocial Oncology*. The findings of the literature review were used to develop a "living document" that will evolve as research is published.

Third, six national focus groups were held with women who self-identified themselves as YJBCS: two online focus groups and four in-person focus groups in Atlanta, Chicago, Los Angeles and New York to obtain a representative sample.

Fourth, a National Survivorship Survey was administered in partnership with 40 healthcare and Jewish organizations. The survey was available in both print and online formats and was publicized at conferences and through social media. Targeted advertising through Facebook was successfully utilized to reach the desired audience. The extensive outreach efforts resulted in the submission of 1,200 survey responses.

Key findings of the National Survivorship Survey are highlighted as follows. Women identified themselves as “survivors” at various stages of their breast cancer journey (e.g., as early as the “time of diagnosis” to as late as “never”). Needs and concerns were unique to each woman and could not easily be categorized by diagnosis or treatment stage. Women preferred to self-select the type, timing and delivery method of receiving specific information.

Women were interested in receiving both information and action-based tools to assist in implementing healthy living behaviors. Concerns that were unique to YJBCS included parenting and children, genetics, work and employment, exercise, fertility, family planning, finance, health insurance, and relationships and intimacy.

Sharsheret applied the outcomes from these activities to create the Thriving Again components. Program component 1 is professional and peer support. YJBCS have access to Sharsheret's 12 national support and education programs; a peer support network of >3,000 women across the United States; and four staff clinicians: two licensed social workers, a psychologist and a genetics counselor. This component provides YJBCS with an opportunity to access resources that are tailored to address their individual concerns at their specific time of need.

Program component 2 is free national educational teleconferences that cover topics identified during the Thriving Again program development process. Sharsheret posts transcripts and audio recordings of the teleconferences on its website. To date, 362 persons have participated in the three teleconferences.

- “It’s Complicated: Understanding and Managing Relationships as a Breast Cancer Survivor”
- “Am I A Survivor? What You Should Know Now About Breast Cancer Survivorship”
- “Breast Cancer Survivors: What You Need to Know About Recent Developments in Genetics”

Program component 3 is the Survivorship Care Plan for YJBCS to enter their basic information; contact information for their medical and support team members; and medical information (e.g., diagnosis, surgeries, treatment, reconstruction and follow-up care recommendations). A self-assessment form also is included for YJBSC to identify their level of anxiety or fatigue and document their concerns about family and other relationships.

The American College of Surgeons Commission on Cancer issued Cancer Program Standards in 2012 with the following recommendation: “By 2015, medical centers should develop and implement a process to provide a comprehensive treatment summary and follow-up plan for

patients who are completing treatment.” Recently published data show that only 20.2% of oncologists reported “always/almost always” providing survivorship care plans and only 43% of National Cancer Institute (NCI)-designated cancer centers deliver survivorship care plans to their breast or colorectal cancer survivors.

Sharsheret has presented its Survivorship Care Plan as a model to assist HCPs in building and implementing survivorship programs and plans by 2015 in accordance with the new accreditation standards for cancer programs. HCPs have been overwhelmingly receptive to adopting the Thriving Again Survivorship Care Plan for their individual cancer centers and practices.

Program component 4 is the free Personalized Survivorship Kit that is tailored to women based on their individual selections. The kit includes either a kosher or non-kosher *Healthy Living Cookbook*, a fitness DVD based on four levels of impact, and self-selected educational information and resources (e.g., smoking cessation and metastatic breast cancer). However, each kit contains a core set of resources that are priorities for YJBSC (e.g., information on genetics and bone health).

Program outcomes to date include mailing 1,200 Personalized Survivorship Kits to YJBSC; providing 115 Survivorship Kits for HCPs to display in their practices and offer to their patients; distributing >1,500 Thriving Again educational booklets; displaying exhibits at >20 conferences; and making eight survivorship presentations to HCPs.

#### *Presentations*

- Association of Oncology Social Workers
- National Consortium of Breast Centers
- C4YW (Conference for Young Women Affected by Breast Cancer)
- Association of Oncology Nurse Navigators
- Critical Mass: The Young Adult Cancer Alliance

#### *Exhibits*

- American Society of Clinical Oncology
- National Society of Genetic Counselors
- Oncology Nursing Society Congress
- San Antonio Breast Cancer Symposium

During its presentations and exhibits, Sharsheret was pleased to learn that YBCS activities conducted by CDC and all of the DP11-1111 grantees have caused radiologists, diagnosticians, nurse practitioners and other HCPs to change their traditional mindsets and begin to consider survivorship issues as early as the time of diagnosis. YJBSC who have participated in Thriving Again have been particularly pleased that the Personalized Survivorship Kit allows “important details to be kept in one place” and promotes feelings of being “more centered rather than off-balanced.”

Sharsheret initiated the Thriving Again evaluation process in early 2014 by conducting focus groups and administering an online evaluation survey. The next steps will be to complete the analysis of the initial evaluation survey and focus groups findings; disseminate the evaluation results to other organizations and HCPs; and create and implement a sustainability plan to build on the success and value of Thriving Again after the CDC project period ends in September 2014.

## **Update by the DP11-1111 Evaluator**

### **Mary Ann Kirkconnell Hall**

Senior Research Associate

ICF International

Ms. Hall presented an update on the evaluation of the DP11-1111 CoAg that ICF International is conducting. The overarching purpose of the evaluation is to determine strategies grantees are implementing to support YBCS and assess the extent to which these strategies are effective and sustainable. The evaluation includes a control group of non-funded programs.

The evaluation is designed to achieve several key objectives: provide an in-depth description of the DP11-1111 CoAg; assess the implementation of the CoAg activities and other interventions for YBCS; determine contextual factors that impact program implementation; explore differences between grantees and non-grantees as well as between clinical and non-clinical sites; and inform the development of recommendations for other YBCS projects in the future.

The *CDC Framework for Program Evaluation in Public Health* was used as the basis to design the evaluation plan and approach. The completed tasks include conducting evaluation planning activities and developing the evaluation questions, design and methodology. Ongoing and future tasks will include implementing the evaluation, analyzing data to answer the evaluation questions, and disseminating the evaluation findings.

The evaluation planning activities included reviewing interim and annual progress reports that the grantees submitted to CDC; conducting key informant interviews with grantee staff to obtain additional information on their YBCS interventions; developing grantee and DP11-1111 logic models; compiling and assessing existing evaluation efforts; and presenting a summary of the preliminary evaluation findings to CDC.

Relevant stakeholders were engaged to provide input on the development of seven questions that would be used to guide the evaluation.

1. What are the core components of the DP11-1111 CoAg?
2. What are the factors that affect implementation of DP11-1111 programmatic activities?
3. What support services and educational resources have grantees developed and/or implemented as a part of their interventions targeting YBCS?

4. What are the factors that affect the implementation of support services and educational resources?
5. How have CDC's TA and support activities contributed to the capacity and sustainability efforts of grantees?
6. How have interventions and strategies of the grantees affected awareness for, access to, and utilization of support services and educational resources among YBCS, HCPs and families/caregivers?
7. How have interventions and strategies of the grantees affected knowledge, attitudes and behaviors among YBCS, HCPs and families/caregivers related to BCYW risks?

A conceptual framework to support the DP11-1111 evaluation was developed in collaboration with CDC. The components of the framework include CDC and grantee inputs, process measures, implementation strategies and intended outcomes. The evaluation design and methodology include a multi-case study protocol and design, in-depth interviews with CDC program staff, data collection instruments, the evaluation plan and clearance packages for data collection.

Case studies will be conducted with the seven DP11-1111 grantees and five non-funded programs that currently are developing and/or implementing YBCS interventions and strategies. A systematic process was utilized to select the five non-funded programs as the control group due to their similarities to the DP11-1111 grantees in terms of target audiences, communication channels, intervention tools, strategies and settings, and implementation plans of key activities.

Inclusion of the control group in the evaluation will provide a broader understanding of YBCS interventions across various types of organizations; facilitate the creation of an inventory of existing efforts across the country aimed at providing education and support to YBCS; and allow CDC to explore similarities and differences between two case types with respect to specific organizational attributes. However, the control group is not intended to "match" the grantees or determine the effect of CDC funding. The following non-funded programs were selected as the control group for the DP11-1111 evaluation.

- Knight Cancer Institute Adolescent and Young Adult Oncology Program at Oregon Health and Science University (Portland, OR)
- Program for Young Women with Breast Cancer at Dana Farber (Boston, MA)
- Tigerlily Foundation (Reston, VA)
- Young Survival Coalition (New York, NY)
- University of Colorado at Denver (Denver, CO)

Institutional Review Board approval of the evaluation has been obtained. The evaluation will be implemented after the Office of Management and Budget completes its review and clearance process within the next 60 days. Case studies will be conducted and the document review will be initiated.

The site visits will include in-depth interviews with program staff and partners; development and refinement of the program logic model; and onsite observations of key programmatic activities if possible, feasible or appropriate. The programs will receive a detailed case study report after the site visits are completed to be reviewed for accuracy before being finalized and submitted to CDC. TA calls will be offered to help the programs review their case study reports.

Atlas.ti software will be utilized to facilitate the qualitative data analysis and answer the seven evaluation questions. The evaluation findings will be presented to CDC in the form of a case study summary report for each individual program and a final report of the overall evaluation. A manuscript will be developed and presentations will be made at conferences to widely disseminate the evaluation results. The programs also will be able to present their individual case study summary reports to other funding entities and stakeholders.

Dr. Fairley provided details on CDC's rationale for contracting ICF International to conduct the DP11-1111 evaluation. CDC is aware of the limited scientific evidence base and the small number of peer-reviewed publications that focus on the evaluation of YBCS services. CDC hopes the DP11-1111 evaluation results will strengthen the YBCS body of evidence by documenting outcomes, specific products, added value and best practices of the grantees and non-funded programs.

Dr. Fairley further explained that high-level evaluations increasingly are becoming a requirement for federal grant recipients. CDC will use the findings of the DP11-1111 evaluation to increase its knowledge of ongoing YBCS projects in the field, assess the effectiveness of its TA services, determine the impact of federal funding on the programmatic growth of the grantees, and build evaluation capacity in both the funded and non-funded programs.

## **Overview of the Hollywood, Health & Society Cooperative Agreement**

### **Galen Cole, PhD, MPH, LPC, DAPA**

Associate Director for Communication Science  
Division of Cancer Prevention and Control  
Centers for Disease Control and Prevention

Dr. Cole presented an overview of CDC's CoAg, "Using Entertainment Education to Reach Women Regarding Breast Cancer Risk Factors." Hollywood, Health & Society is a program of the USC Annenberg Norman Lear Center and was the successful grant recipient of CDC's competitive FOA to integrate health messaging into popular TV storylines and ensure the accuracy of health messaging and narratives in TV programming.

CDC has sponsored the "Annual Sentinel for Health Award" since 2000 to recognize exemplary achievements of TV storylines that inform, educate and motivate viewers to make choices for healthier and safer lives. Hollywood, Health & Society screens each entry for eligibility, while experts from the public health, academic, advocacy and entertainment sectors select the final honorees.

CDC was pleased that the producers and writers of *90210* approved its idea of a BRCA storyline, particularly since young women are the major target audience of this TV program. The storyline was featured in eight consecutive episodes from March 6-May 15, 2012. Dr. Cole presented a clip from one of the *90210* episodes with the BRCA storyline.

The “*90210* Breast Cancer Gene Study” was designed as two sub-studies to systematically determine the impact of the eight-episode BRCA storyline on different audiences. Study 1 was a pre-/post-test for episode 1 only. The sample was recruited from a survey firm’s panel of regular TV viewers. The median age of the sample was 48 years with a range of 20-64 years of age. The median time of primetime TV viewing among the sample was 13.5 hours per week. Exclusion criteria were persons outside of the United States, persons who previously viewed  $\geq 1$  target episodes, and persons who were diagnosed with breast cancer. The total sample of 236 persons completed both the pre-/post-tests. Of the total sample, 93% had never viewed *90210*.

Increases in knowledge, attitudes and behavioral intentions were observed in the time period between the pre- and post-test.

#### *Knowledge*

- Increase in familiarity with the BRCA gene
- Increase in selection of “family history/genetics” as a risk factor
- Increase in the mean agreement (from 3.3 to 3.7) with the following statement: “Having a mastectomy is one possible option for preventing breast cancer.”

#### *Attitudes*

- Increase in fears about the consequences of the BRCA gene

#### *Behavioral Intentions*

- Increase in the number of participants who indicated plans to discuss BRCA gene testing with their physicians in the upcoming year
- Increase in the likelihood of participants discussing BRCA gene testing with their physicians in the next two years

The post-test results showed that of the entire sample of 236 persons, 12% scheduled a doctor’s appointment to discuss their breast cancer risk; 13% discussed BRCA gene testing with another woman; 17% searched for breast cancer information online; and 10% watched the next *90210* episode in the BRCA storyline.

Study 2 was a convenience sample of regular *90210* viewers who were recruited via links to an online survey instrument featured on the *90210* Facebook page. Wave 1 data were collected after episode 4 (April 5-17, 2012) and wave 2 data were collected after episode 8 (May 16-June 12, 2012).

Participants were not instructed to view any specific episode, but were asked to identify any of the eight episodes viewed in the BRCA storyline. Because e-mail problems did not allow wave 1 and 2 data to be matched for all participants, a decision was made to exclude wave 2 data from the study. Of the total sample of 494 persons, the median age was 22 years and the median time of primetime TV viewing was 6 hours per week.

A significant association was observed between the number of episodes viewed and familiarity with the BRCA gene. A significant negative association was observed between the number of episodes viewed and agreement with the following statement: "If someone tests positive for the BRCA gene, it means they already have breast cancer."

A significant increase in knowledge was observed in the percentage of participants who had ever heard of the BRCA gene: 30% among viewers of no *90210* episodes versus 63% among viewers of 4 episodes. A significant increase in behavior was observed in the percentage of participants who intended to learn more about their family history of breast cancer: 27% among viewers of no *90210* episodes versus 43% among viewers of 5-8 episodes.

Specific episodes were associated with changes in attitudes, intentions and behavior. Exposure to episode 4.23 was associated with a reduction in perceived barriers to testing. Independent of other episodes, exposure to episode 4.19 was associated with a likelihood of presenting for mammography screening and discussing BRCA gene testing with a physician. A significant association was observed between the number of episodes viewed and actual steps taken to learn more about family history.

ACBCYW was aware of CDC's inability to control the difference between health messages given to producers and writers upfront versus the actual content of TV programs that are broadcast. As a result, CDC was commended for utilizing its strong relationship with Hollywood, Health & Society to assure that the integrity and accuracy of health messages are maintained to the extent possible. CDC also was applauded for its efforts in using the powerful entertainment industry as a non-traditional approach to convey BCYW messages to the target audience of young women.

ACBCYW was pleased that the *90210* Breast Cancer Gene Study showed positive pre-/post-test changes in BRCA knowledge, attitudes, behaviors and intentions of the participants. However, several members expressed concern about the age appropriateness and overall factual content of the TV program storyline.

However, ACBCYW believed that CDC missed opportunities with the *90210* BRCA storyline and the *90210* Breast Cancer Gene Study to provide healthcare education and expertise on current standards of care. For example, the need to obtain genetic counseling before genetic testing is critical. The published oophorectomy literature contains a solid body of evidence on the low risk of women <30 years of age with a BRCA mutation to develop ovarian cancer. These evidence-based messages are extremely important, but were not emphasized in the *90210* BRCA storyline.

ACBCYW advised CDC to consider three suggestions to address these concerns. First, CDC should propose health messages only to producers and writers of TV programs who can be trusted to maintain the accuracy and integrity of the content in the final product.

Second, the *90210* Breast Cancer Gene Study should be continued as an ongoing assessment to gather continuous feedback on unmeasured negative consequences of the TV program and significant negative associations that were observed. Results of the extended study should be provided to Hollywood, Health & Society for producers and writers to consider and discuss while developing new scripts for other TV programs that will include BCYW-related storylines or themes.

Third, a “where to find more information” screen should be displayed at the end of each TV program with a BCYW storyline or theme. The *90210* BRCA storyline emphasized the need to “ask your doctor,” but this message is overly broad and ineffective, particularly for young women. CDC-funded studies have shown that the ability, knowledge, awareness, willingness or desire of HCPs to discuss breast cancer genomics with their patients or refer their patients to genetics specialists is extremely low. Anecdotal data also have shown that the dissemination of health messages without appropriate knowledge and expertise potentially could result in risk and harm to the public.

## **Update on the CDC DP11-1114 Cooperative Agreement**

### **Katrina Trivers, PhD, MSPH**

Epidemiologist, Division of Cancer Prevention and Control  
Project Officer, DP11-1114 Cooperative Agreement  
Centers for Disease Control and Prevention

Dr. Trivers presented an update on CDC’s DP11-1114 CoAg, “Enhancing Breast Cancer Genomics Practices Through Education, Surveillance and Policy.” The CoAg aims to fill gaps in the knowledge and practice of HCPs related to breast/ovarian cancer genomics. Data show that HCPs may lack of knowledge and confidence about family history and genetics. HCPs often are unable to identify high-risk women and inappropriately refer low- and/or average-risk women to genetic services.

HCPs have limited time during busy primary care appointments to discuss genetics and family history with their patients. Most of the existing risk assessment tools are too difficult and complex for HCPs to implement in primary care settings. The development of rapid tools is underway, but further study and validation are needed to determine the best tools. A shortage of genetic experts exists, particularly in non-urban areas.

At the national level, data show that 29% of HCPs would refer an average-risk women for genetic counseling and testing and 41% of HCPs would refer a high-risk women. At the state level, the Michigan Department of Community Health (MDCH) is one of the DP11-1114

grantees and administered a survey to determine the knowledge and practice of HCPs related to risk assessment, BRCA management, and existing federal laws related to BRCA. The MDCH survey showed the following results:

- Only 40% of HCPs correctly identified autosomal dominant gene mutations as the most common mode of inheritance for most hereditary cancer syndromes.
- Only 40% of HCPs collected ancestry or ethnicity data when obtaining a family history for cancer risk assessment of a patient.
- Only 32% of HCPs correctly identified prophylactic oophorectomy as the procedure with the greatest capacity to reduce the risk of cancer in women 40 years of age with a known BRCA mutation.
- Only 32% of HCPs were aware of the Genetic Information Nondiscrimination Act.

As a part of its DP11-1114 award from CDC, MDCH developed and has offered an in-person breast cancer genomics module, including interactive case-based presentations, to HCPs in Michigan since 2009. Based on the success of this initiative at the state level, MDCH, CDC, the National Coalition for Health Professional Education and Genetics, Moffitt Cancer Center, and the Georgia and Oregon DP11-1114 grantees initiated a collaborative effort in 2012 to develop, expand and scale-up a more sophisticated and comprehensive online version of the module at the national level.

The online Hereditary Breast and Ovarian Cancer (HBOC) Module ([www.nchpeg.org/hboc](http://www.nchpeg.org/hboc)) was launched nationally in January 2014 for HCPs to increase their competency in HBOC risk assessment, referral and management. Michigan State University will offer 2.0 CMEs at no cost until October 2016 to HCPs who achieve a post-test score of  $\geq 70\%$ , but the module does not permit retaking of the course. Nurses account for the vast majority of 30 HCPs who have completed the module to date.

Dr. Trivers presented an example of a case study in the module for HCPs to determine whether a patient would be at high risk of HBOC based on a specific scenario. HCPs can download tools to obtain assistance in completing the case study activity (e.g., a “red flag” checklist, family history collection, pedigree, screening guidelines and collaboration tools).

The case study activity guides HCPs to multiple choices of their next steps, such as referring the patient to a genetic counselor, ordering genetic testing, or gathering more information before making a decision on referral. Additional information on the patient, lessons learned and the “best choice” are displayed based on the answer selected by the HCP. The module describes and provides links to other clinical tools, educational materials and references.

The partners have widely publicized the availability of the HBOC CME Module through multiple networks and venues, including direct communications to HCPs on listservs maintained by states; notices to professional societies with memberships of HCPs and other provider specialty groups; announcements to grantees of the National Breast and Cervical Cancer Early Detection Program and other CDC-funded programs; and highlights on the CDC blog. However, outreach

to professional societies has not been effective in reaching primary care provider (PCP) specialty groups.

Other communication and dissemination platforms to increase awareness of the HBOC CME Module included commercial laboratories that perform BRCA testing, such as Myriad, GeneDX and Ambry. The MedEd Portal is an online hub for peer-reviewed health education teaching and assessment resources and also was used for broad outreach to HCPs.

Dr. Trivers concluded her update by requesting input from ACBCYW on additional mechanisms to increase the visibility and dissemination of the HBOC CME Module to HCPs. She committed to providing ACBCYW with a printed card set of the module for the members to use in their presentations at national conferences and to stakeholder organizations.

ACBCYW proposed several suggestions for CDC and its partners to consider in increasing the national reach, dissemination and implementation of the HBOC CME Module to HCPs.

- The ACBCYW Ad Hoc Provider Workgroup will explore approaches to increase the national reach and dissemination of the module to PCP specialty groups. The possibility of using electronic medical records (EMRs) and existing eLearning tools to support this effort will be explored. The cost-effectiveness, feasibility and potential added value of embedding new, standardized HBOC priorities, alerts and tools into EMR systems will be considered as well.
- Professional societies should be extensively engaged at the outset and throughout the creation of all educational tools, resources or materials to ensure endorsement and implementation by their members. Due to the overwhelming demand for their formal endorsement, professional societies typically are reluctant or unwilling to become involved at the end when guidance or materials already have been developed.
- Formal endorsement of any federal initiative by a professional society should be aligned with the priorities of the current president. Most notably, the American Congress of Obstetricians and Gynecologists (ACOG) has a long and successful history of advising its members to implement federal projects in the field, including those that are targeted to young women.
- CMEs should be offered to physician assistants and nurse practitioners who complete the module. These groups increasingly are becoming the primary care providers for patients.
- The possibility of expanding the module to include malpractice risk management and ethics CMEs should be explored. This incentive would be attractive because the medical profession requires HCPs to acquire and maintain CMEs in these areas.
- The module should be piloted with a small group of HCPs in their actual primary care practices to demonstrate and validate two major outcomes. First, only a minimal amount of time was required during the routine primary care visit for HCPs to discuss genetics and family history with their patients. Second, the discussion improved the performance of HCPs in less time and added value for patients during the routine primary care visit. If

the pilot project is successful, the findings should be widely publicized to facilitate implementation and dissemination of the module on a much larger scale.

- The Health Resources and Services Administration (HRSA) would be an excellent resource to increase the national reach, dissemination and implementation of the module to HCPs, particularly those in primary care settings. The module would be extremely beneficial to grantees of the HRSA Bureau of Health Professions that deliver primary health care in various health professions. The HRSA Bureau of Clinician Recruitment and Services could widely distribute the module to 9,000 PCPs who deliver comprehensive healthcare services at 5,100 HRSA-funded National Health Services Corps sites across the country. CDC and HRSA also should explore the possibility of piloting the module in HRSA-funded primary care sites.

## **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 covered the following topics in her update to ACBCYW on CDC's BCYW activities. BCYW is a public health issue due to the population of >250,000 young women who currently are living with a breast cancer diagnosis in the United States. Compared to older women with a breast cancer diagnosis, young women often are diagnosed at later stages with more aggressive disease and a severe prognosis. The impact of a breast cancer diagnosis on young women is substantial in terms of their quality of life, economics and survival.

The EARLY Act was enacted in 2010 as part of ACA and authorized CDC to conduct initiatives to increase the understanding and awareness of breast health and breast cancer among young women at high risk, including those <44 years of age. The EARLY Act further authorized CDC to provide support to young women with breast cancer, launch a national evidence-based education campaign, and establish ACBCYW as its formal advisory committee. The education campaign would be designed to target specific populations at risk and direct messages and educational resources to HCPs.

CDC addresses BCYW issues with a systematic public health approach that includes several key components: applied research, program support, health communications, surveillance and partner engagement. All of the components of CDC's BCYW portfolio are responsive to its Congressional mandate and the key provisions of the EARLY Act.

Component 1 is CDC's completed, ongoing and new BCYW applied research projects. The "Walking Together: Making a Path Toward Healing" Project was designed to examine issues related to breast cancer diagnosis, treatment and survivorship among young Native American

women and identify barriers to this population obtaining diagnoses and accessing post-diagnosis care and support.

The “Breast Cancer in Young Women: Reviewing the Evidence and Setting the Course” Literature Review and informal meeting of Subject-Matter Experts was commissioned to review the broad spectrum of evidence and provide CDC with advice on particular research areas that should be considered. The report was published in the *Journal of Women’s Health* in November 2013. The “Estimating Infertility Among Breast Cancer Survivors” Study was the first population-level study to provide estimates of infertility among YBCS.

The “Health Insurance Coverage for Genetic Services Across the United States” Study was designed as a review and analysis of health insurance policies that cover genetics and follow-up services. The “Economic Burden of Breast Cancer in Young Women Aged 15-44 Years in the United States, 2000-2010” Study was commissioned in response to ACBCYW’s request to better understand the economic impact of disease in this population. The study generated a paper that focused on breast cancer mortality in young women and the loss of income/wages due to their disease. The paper was published in January 2014.

CDC’s ongoing BCYW research projects include its contribution of fundamental public health questions for the national “Sister’s Study” and “Two-Sister’s Study” conducted by the National Institute of Environmental Health Sciences (NIEHS). The studies are designed as a longitudinal prospective cohort of YBCS who have a biological sister with a breast cancer diagnosis. Data gathered from the women included their experiences with breast cancer screening, genetic counseling and testing, health behaviors, and concerns or perceived risk of disease. CDC plans to include an update of the Sister Studies on the next ACBCYW meeting agenda.

The “Impact of Genomics and Personalized Medicine on the Cost-Effectiveness of Preventing and Screening for Breast Cancer in Younger Women” Study will be important for decision-makers so that resources could be allocated nationally at both policy and healthcare system levels.

CDC’s new BCYW research projects include the “Comparative Effectiveness and Clinical Utility of Risk Assessment Tools for Hereditary Breast and Ovarian Cancer” Study. The study is designed to identify the most appropriate, accurate and simple risk assessment tools for young women with HBOC. Once identified, they could be promoted and further advanced. The “Economic Impact of Late-Stage Breast Cancer Diagnoses and Benefits of Reducing Alcohol Consumption Among Women Aged 18-44 Years at High Risk for Breast Cancer” Study is designed to analyze the correlation between reducing alcohol consumption in young women and decreasing their breast cancer risks.

Component 2 is CDC’s BCYW program support activities. CDC is funding two CoAgs that will end in September 2014: three grantees of the DP11-1114 CoAg, “Enhancing Breast Cancer Genomics Practices Through Education, Surveillance and Policy” and seven grantees of the DP11-1111 CoAg, “Developing Support and Educational Awareness for Young (<45) Breast

Cancer Survivors in the United States.” Key findings from projects of both CoAgS will be compiled to provide organizations with best practices to better reach the target audiences.

The “Developing Psychosocial and Reproductive Health Support for Young Breast Cancer Survivors in the United States” CoAg ended in September 2013. The two grantees, Sisters Network, Inc. and Sharsheret, evaluated the effectiveness of existing survivorship support resources, assessed information needs, and tailored resources specifically for young African American and Ashkenazi Jewish women. The projects provided valuable lessons learned in the development, program support, cost and sustainability of these types of interventions in the field.

Component 3 is CDC’s BCYW communication activities. A CoAg was awarded to Hollywood, Health & Society to develop new projects. The “Using Entertainment Education to Reach Women Regarding Breast Cancer Risk Factors” Project included the eight-episode BRCA storyline on the *90210* TV program. The “Education, Awareness and Support for Minority and High Risk Women (<45) Who Are Living With or at Increased Risk for Breast Cancer” Project is ongoing.

The “Social Media Usage for Breast Cancer Awareness and Survivor Education” Study was designed to identify information gaps and develop a social media strategy to reach young women at risk of breast cancer and YBCS. Key findings of the study are highlighted as follows. Young women believe myths about breast cancer risk factors and need access to evidence-based messaging about breast cancer risk. Many young women have no knowledge of understanding of BRCA gene mutation and its connection to breast cancer.

Information sharing behaviors of young women are closely linked to imagery and the tone of messages. Messages need to be tailored and targeted because breast cancer continues to be associated with social stigma in some communities. Search behaviors in social media greatly differ between young women with an initial breast cancer diagnosis versus those with a longer-term diagnosis who have entered treatment.

CDC released the BodyTalk Clinical Decision Support Tool (BodyTalk) in 2012 to help young women and HCPs assess individual risk of BRCA gene mutation and determine whether genetic counseling and testing would be warranted. CDC redesigned and re-branded BodyTalk based on broad and diverse input from multiple partners, ACBCYW, BCYW grantees in the field, and genetic counselors and researchers. Input from stakeholders showed that the “BodyTalk” name, appearance and functionality would not be appealing to young women.

CDC partnered with the Oak Ridge Institute for Science and Education, Bright Pink and Multiple, Inc. to apply the stakeholder input in re-branding and redesigning BodyTalk as “Know:BRCA, *Knowing Your BRCA Gene Mutation Risk Can Save Your Life.*” Know:BRCA has been tested with young women, including those who are and are not at increased risk of having a BRCA gene mutation. Dr. Fairley presented several screen shots of the beta version of Know:BRCA and pointed out major improvements that have been made in the transition from BodyTalk.

- Know:BRCA will be more effective than BodyTalk in reaching the target audience of young women 18-44 years of age due to its responsive design as a web-based clinical decision support (CDS) Tool that can be accessed on any computer, tablet or mobile device.
- Know:BRCA will allow patients and HCPs to increase their knowledge of BRCA gene mutation and assess individual risk. Definitions and easily understandable terminology will help to facilitate patient/provider discussions on BRCA.
- Know:BRCA will provide specific information to women who are found to be at increased risk of having a BRCA gene mutation, such as ACA-mandated insurance coverage for BRCA gene testing and privacy/confidentiality issues.
- Know:BRCA will provide links to the HBOC CME Module and other resources for HCPs to obtain additional information on breast cancer genomics.

The social media component of Know:BRCA will target young women at high risk of developing breast or ovarian cancer and also will focus on education and awareness of BRCA gene mutation. This initiative is based on the current body of evidence on breast cancer genomics and gaps identified in the national “Sister’s Study” and “Two-Sister’s Study.” For example, study participants expressed concern that discussions with their providers on family history and genetics lacked detail. Their knowledge and understanding of BRCA gene mutation and its connection to HBOC were not increased. Their providers made no referrals to a genetics counselor for counseling and testing.

CDC is taking steps to prepare for the national launch of its new BCYW communication activities. Know:BRCA will be launched in May 2014, but CDC will make the beta version available on April 2, 2014 for ACBCYW members and other key stakeholders to test the tool and provide feedback on any problems or areas of improvement. CDC will use social media to introduce and continually discuss the topic of BRCA with young women from an evidence-based perspective. CDC’s social media conversations on BRCA will highlight the published literature, subject-matter expertise, ACBCYW guidance, and relevant research findings.

CDC’s Know:BRCA efforts will inform the development of a broader and more comprehensive “National Breast Cancer in Young Women Social Media Education and Awareness Campaign.” A public relations firm will conduct the national social media campaign in the spring of 2015 to reach the target audiences of young women 15-44 years of age who are at elevated risk of and/or living with breast cancer and HCPs. The purpose of the national social media campaign will be to educate young women and HCPs about breast health, BRCA gene mutation and other breast cancer risk factors, and survivorship among young women.

ACBCYW thanked CDC for the upcoming opportunity to test, assess and submit feedback on the beta version of the web-based Know:BRCA CDS Tool. Several members made comments for CDC to consider in the interim.

- Evidence-based messaging that is simple and easy to understand should be prominently featured in Know:BRCA: “The inherited BRCA gene is rare and accounts for only 5%-10% of breast cancer in women.” The messaging should be used to correct the myth that young women with a family history of breast cancer will “automatically” or “inevitably” develop breast cancer.
- The inclusion of young women 15-18 years of age in the national BCYW social media campaign is extremely problematic. The published breast cancer literature contains virtually no scientific data, evaluated messaging or evidence-based interventions for this age group. Note: This comment reflects the opinions of members of the ACBCYW. CDC acknowledges its congressional mandate (e.g., EARLY Act) to reach young women in the aforementioned age group with breast health messages.
- The initial page of the web-based Know:BRCA CDS Tool includes a tab, “Is This Assessment For Me?” Women with self-identified breast cancer symptoms should be prohibited from completing the remainder of the assessment and advised to seek medical attention. This feature would serve as an alert to women who might be at risk for breast cancer, but do not have the BRCA gene.
- Know:BRCA will provide information on ACA-mandated insurance coverage for BRCA gene testing to women who are found to be at increased risk of having a BRCA gene mutation. However, the language should be revised to clarify that ACA requires insurance coverage of BRCA gene testing only for women who have never been diagnosed with cancer.
- The medical profession requires internists, obstetricians/gynecologists (OB/GYNs), surgeons and other PCPs to demonstrate and document improvements in their practices to maintain board certification. For example, internists must complete a practice improvement module that is either self-developed or chosen from the American Board of Internal Medicine (ABIM). CDC should explore whether Know:BRCA could be designated as an ABIM-approved practice improvement module with a pre-/post-test design. With this module, PCPs would conduct a chart review to compare the number of their patients 18-44 years of age who received a hereditary assessment before and after implementation of the Know:BRCA CDS Tool.
- Know:BRCA and CDC’s other BCYW communication activities should be offered in alternate formats beyond a web-based CDS tool or an online social media campaign. For example, these platforms would not reach women with severe mental illness or women living in poverty who receive care from Federally Qualified Health Centers and cannot afford computers or Smartphones. A key feature of BodyTalk was that the tool would be available to underserved women through kiosks in healthcare facilities and iPads in the field. This feature should be maintained in Know:BRCA.
- Know:BRCA should clearly distinguish between the “chance” and “risk” of young women developing breast cancer. “Risk” should be used to describe a negative, evidence-based percentage, while “chance” should be used to describe a positive outcome to promote action.

## Public Comment Session

### **Soletchi Seya, MPH**

Wellness Program Manager  
Center for Black Women's Wellness

Ms. Seya made the following comments to ACBCYW. The Center for Black Women's Wellness (CBWW) is an NPO in Atlanta, Georgia that receives funding from multiple sources to provide breast cancer prevention services and referrals to mammography and other diagnostic services. CBWW and its organizational partner will begin providing BRCA education in April 2014, including referrals to genetic counseling and testing for women who are found to be at high risk.

The patient population of CBWW is low-income and uninsured women. Sufficient resources should be available to CBOs to serve the larger population of low-income and uninsured young women who will have more knowledge and/or concerns about breast cancer after the national launch of Know:BRCA and CDC's other BCYW communication activities.

ACBCYW raised the possibility of submitting a formal resolution to the HHS Secretary with a request to address this concern in the next iteration of the ACA National Prevention Strategy. ACBCYW's resolution would emphasize that ACA requires coverage of certain interventions, including BRCA gene testing, but no additional funding is provided to CBOs to support this effort.

### **ACBCYW Open Discussion**

Dr. Partridge facilitated ACBCYW's open discussion on CDC's intramural and extramural BCYW projects as well as ACBCYW's next steps and future directions. However, Dr. Fairley began the open discussion by responding to ACBCYW's question regarding the guidance that has been most helpful and valuable to CDC.

- The workgroup recommendations (e.g., strategies to effectively reach and target messaging to women at high risk of breast cancer and approaches to increase outreach to and educate providers on BCYW issues)
- Available resources of the ACBCYW members and their stakeholder organizations
- Methods to disseminate BCYW activities and messages at the local community level

ACBCYW's key comments and suggestions from the open discussion are highlighted below.

- CDC should explore the possibility of using ACBCYW as an ongoing "objective review panel" for its BCYW projects. This approach might be more effective than forming separate ACBCYW workgroups that recommend activities CDC and its grantees already

are conducting, such as needs assessments and the development and dissemination of educational materials and tools.

- ACBCYW should engage in a thoughtful discussion on the need to form a new “Communication and Dissemination Workgroup” or expand the charges of the two existing workgroups. This effort should focus on communication and dissemination at two different levels: (1) HCPs and provider systems and (2) NPOs and local/national networks.
- CDC’s BCYW portfolio focuses on high-risk women, but the large segment of young women who are not at high risk of breast cancer or do not have a known genetic risk factor are being overlooked. Know:BRCA should be used as an opportunity to target messaging to this population to decrease their risk through weight management, exercise and other healthy lifestyle behaviors. However, other ACBCYW members noted that caution must be taken in this area because the EARLY Act requires CDC’s BCYW activities to be evidence-based. No studies have substantiated or documented weight management and exercise as interventions to prevent breast cancer in young women. All of the members agreed that more research is needed to better determine young women who are at risk for breast cancer beyond those in the high- and intermediate-risk groups.
- CDC’s BCYW activities that are designed to increase awareness should include a follow-up and monitoring component. In addition to increasing awareness, the ultimate goal of BCYW activities should be to ensure that young women are linked to and access screening, genetic counseling or other necessary services to promote optimal behavior changes.
- CDC’s BCYW messaging should place far more emphasis on the scientifically proven role of breastfeeding in reducing breast cancer risk in young women. CDC could strengthen the evidence base in this regard because the published breastfeeding literature primarily is devoted to benefits to the infant rather than the mother. OB/GYNs should be a key target audience of breastfeeding messaging. Moreover, breastfeeding language is included in ACA, such as options for breastfeeding at the workplace and the provision of breast pumps to low-income women at no charge.
- CDC’s BCYW activities specifically have targeted the risk groups of young African American and Ashkenazi Jewish women, but young Latina women also should be included as a key target audience. Data have shown that young Latina women have an increased genetic risk of breast cancer.

With no further discussion or business brought before ACBCYW, Dr. Fairley recessed the meeting at 4:40 p.m. on March 27, 2014.

## Opening Session: March 28, 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 March 28, 2014.

Dr. Fairley reconvened the proceedings at 9:05 a.m. on March 28, 2014 and welcomed the participants to day 2 of the ACBCYW meeting. None of the voting members declared conflicts of interest for the record for any of the items on the published agenda.

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

Clinical Director, Breast Oncology Center  
Dana-Farber Cancer Institute  
ACBCYW Chair

Dr. Partridge also welcomed the participants to day 2 of the ACBCYW meeting. She reported that the first day was devoted to updates on CDC's intramural and extramural BCYW projects. The updates showed that CDC is fulfilling its Congressional mandate because its entire BCYW portfolio is aligned with the key provisions of the EARLY Act: applied research, program support to BCYW and communications. Dr. Partridge thanked ACBCYW for providing guidance that would be helpful to CDC in improving its BCYW initiatives.

## Update by the ACBCYW Ad Hoc High Risk Workgroup

### **Rochelle L. Shoretz, JD**

Executive Director and Founder, Sharsheret  
ACBCYW Member & High Risk Workgroup Chair

Ms. Shoretz covered the following topics in her workgroup report to ACBCYW. The workgroup was charged with gathering initial background information and advising ACBCYW on (1) developing an understanding of the meaning of "high risk" in the context of BCYW and (2) identifying potential evidence-based messages to disseminate to this population.

The workgroup has completed several major tasks over the past three years. In 2010-2012, the workgroup initiated research on breast cancer risk in young women in accordance with ACBCYW's charge. In 2012, the workgroup presented its report to ACBCYW that outlined relevant research findings, key topics for ACBCYW to consider, and draft recommendations for

ACBCYW's formal action. In 2013, the workgroup's draft recommendations were finalized for incorporation into ACBCYW's letter to the HHS Secretary.

The workgroup reconvened on February 12, 2014 to discuss future directions for research with a sole focus on high-risk young women, but the discussion was expanded to include messaging for average-risk young women. The workgroup proposed a number of future directions in its discussion.

1. Conduct further review of and develop a response to the December 2013 U.S. Preventive Services Task Force (USPSTF) Guidelines, "Risk Assessment, Genetic Counseling and Genetic Testing for BRCA-Related Cancer in Women."
2. Conduct national research on existing prevention messages in the public health arena.
3. Conduct research on risk assessment for young women who might develop triple-negative breast cancer.
4. Develop messaging to young women at average or increased risk of breast cancer (compared to those in the high-risk group).
5. Develop a *Layperson Guide* to increase understanding of individual risk.
6. Educate media partners about messaging and research studies.
7. Correlate knowledge with awareness because "awareness" of risk is high, but actual "knowledge" of risk is low.
8. Review national advertising campaigns targeted to the high/higher-risk population, including Myriad Genetics advertisements, the CDC Cascade Screening Campaign, the Genetic Alliance infographic, and materials addressing risk prepared by NPOs that are represented on ACBCYW.
9. Review and respond to updated follow-up data from the Canadian mammography trial for women 40-49 years of age.

The workgroup members submitted risk and risk messaging materials from their organizations to further consider and discuss the proposed future directions.

- "Evaluating the Opportunity and Need for Communicating Breast Cancer Risk Reduction Messages to U.S. Women" Poster Presentation (Dr. Marisa Weiss, Breastcancer.org, presented at the 2013 Breast Cancer Symposium in San Antonio)
- "What Every Young Woman With Breast Cancer Should Know" Brochure (Dr. Sue Friedman, Facing Our Risk of Cancer Empowered (FORCE))
- "Breast Cancer Screening for High Risk Women" Brochure (Dr. Sue Friedman, FORCE)
- "Your Jewish Genes: Hereditary Breast Cancer and Ovarian Cancer" Educational Booklet (Ms. Rochelle Shoretz, Sharsheret)
- "Have the Talk" Social Media Campaign (Ms. Rochelle Shoretz, Sharsheret)

During the current meeting, the workgroup plans to obtain advice and guidance from ACBCYW on prioritizing further risk-related research for both average- and high-risk young women. The workgroup also will adjust its charge as needed based on ACBCYW's decision. The workgroup will reconvene to conduct further research and make additional recommendations to ACBCYW.

Ms. Shoretz acknowledged and thanked the workgroup members for continuing to contribute their time and effort to the BCYW high-risk activities.

## **Update by the ACBCYW Ad Hoc Provider Workgroup**

### **Generosa Grana, MD, FACP**

Director, Cooper Cancer Institute

ACBCYW Member & Provider Workgroup Chair

Dr. Grana covered the following topics in her workgroup report to ACBCYW. The workgroup was charged with gathering initial background information and advising ACBCYW on the behavior change of providers in terms of (1) enhancing provider knowledge of BCYW by assessing gaps, guidelines and issues related to messaging of BCYW and (2) improving provider skills regarding the delivery of care to young women at average and high risk of and/or facing breast cancer (e.g., survivors).

The workgroup defined specific terms to guide its activities. “Providers” for breast cancer pre-diagnosis, early diagnosis and post-diagnosis women would include all professionals who provide services to or act as an information source for young women: general practice, family practice and internal medicine physicians; OB/GYNs; physician assistants; primary care nurse practitioners, nurse oncologists, and college/high school nurses; medical, surgical and radiation oncologists; and PCPs who provide care to cancer survivors.

“Patient populations” would include women of reproductive age up to 45 years, pre-diagnosis women at average or high risk (including those at risk of relapse or second primary breast cancer), and post-diagnosis women.

Findings from the workgroup’s literature reviews and research were summarized and included in ACBCYW’s letter to the HHS Secretary. Guidelines have been developed to guide HCPs on issues related to genetic testing, risk assessment and chemoprevention strategies for young women at risk of breast cancer. Significant gaps persist and more research is needed to assess the current level of knowledge of PCPs, determine their utilization of existing guidelines, and fill gaps in current research. Information learned from additional research should be used to develop focused strategies to target HCPs.

The workgroup completed phase 1 of its charge by drafting five recommendations for ACBCYW to consider. However, Dr. Grana informed the new members that previous meeting minutes could be reviewed to obtain details on specific objectives to achieve each recommendation.

1. A more detailed assessment should be conducted to determine the current level of knowledge and practice among PCPs regarding BCYW.

2. The development of educational tools that are targeted to HCPs at various points in training should be fostered.
3. The analysis of BodyTalk (now Know:BRCA) as a tool that focuses on both patients and HCPs should be continued.
4. Ongoing EMR initiatives should be broadly expanded and evaluated through a CDC/ Agency for Healthcare Research and Quality (AHRQ) collaboration to focus on BCYW.
5. Collaborations should be established with ongoing national BCYW initiatives that are targeted to HCPs.

The workgroup currently is conducting phase 2 of its charge by exploring implementation strategies for the five recommendations. The workgroup is addressing several key questions in this effort.

1. *Who are the providers in the target group?*
  - HCPs in multiple disciplines
  - Providers at various points in training
  - Third-party payers that increasingly are defining coverage provided to high-risk women or young women in general
2. *What tools or resources should be used to fill gaps in provider education and practice?*
  - State surveys by the Georgia, Michigan and Oregon DP11-1114 grantees
  - A new national survey to more broadly determine the needs of all “providers” as defined by the workgroup
  - CDC’s BCYW activities
3. *What existing provider education and decision support tools can be adapted for national dissemination?*
  - The HBOC CME Module (CDC, the three DP11-1114 grantees and other partners)
  - A live conference (the Georgia DP11-1114 grantee)
  - The Know:BRCA CDS Tool and social media campaign and the “Inside Knowledge Campaign” focusing on gynecologic cancers (CDC)
  - The interactive, online educational “eDoctoring” tool covering ethics, genetics, clinical management, epidemiology and communication skills (Wilkes, *et al.*)
  - Resident education materials (Bright Pink)
4. *What are the best methods to tailor and disseminate existing educational materials, decision support tools and other resources to reach the broader population of PCPs?*

The workgroup has focused on addressing two of the four questions over the past month. For question 2, the workgroup reviewed findings from surveys that have been conducted to identify gaps in the current knowledge and practice of HCPs. Efforts are underway to determine

whether HCPs should be surveyed at regional or national levels. Specific survey methods are being explored as well, such as state professional societies, national professional associations, or ABIM, ACOG and other licensing or certification entities. The workgroup acknowledged that funding sources would need to be identified upfront to support a large-scale regional or national provider survey.

For question 4, the workgroup discussed various options to disseminate educational materials, decision support tools and other resources to reach the overall provider community. The potential strategies include training courses for medical residents, nurse practitioners and physician assistants; board certification modules; licensing requirements; enhancements to existing EMR systems; and AHRQ's major innovations in the development of EMRs and health information technology.

Dr. Grana thanked the workgroup members for continuing to contribute their time and effort to the BCYW provider activities. She also acknowledged the new members that have added tremendous value to the workgroup: Dr. Katrina Trivers of CDC; the Georgia, Michigan and Oregon DP11-1114 grantees; and other partners.

### **Public Comment Session**

Dr. Partridge opened the floor for public comments; none of the participants responded.

### **ACBCYW Open Discussion**

Dr. Partridge facilitated the open discussion and asked ACBCYW to particularly focus on providing in-depth and concrete advice to CDC in the following areas.

- Strategies to more effectively reach and change behaviors of HCPs related to young women at risk of breast cancer and YBCS. (The Provider Workgroup specifically should address this issue.)
- National dissemination and evaluation of the Know:BRCA CDS Tool and social media campaign. (The High Risk Workgroup specifically should address this issue.)
- Evaluation of the DP11-1111 CoAg. (The four remaining grantees will need to present updates to ACBCYW.)

ACBCYW's key comments and suggestions from the open discussion are highlighted below.

#### ***Risk Groups***

- ACBCYW should advise CDC to target additional risk groups and underserved minority populations in its BCYW activities: young women in sexual minority groups, young Latina women, young low-income women, and young women with low literacy levels.
- ACBCYW should consider two areas to formulate new recommendations to CDC. First, the published literature contains decision support tools to help U.S. women decide when

to initiate mammography screening at specific time points in their lives. ACBCYW should conduct a review to determine whether any of the existing decision support tools could be adapted for the BCYW population. Second, ACBCYW should develop messaging to minimize alarm and increase awareness about breast health in young women. Clinicians historically have informed their young patients that young women <45 years of age do not develop breast cancer. CDC created a booklet that provided a context for breast cancer risk compared to other risks for young women (e.g., heart disease, motor vehicle accidents, skin cancer, and adverse health outcomes related to smoking or substance abuse). ACBCYW should review, update and use the booklet as a source for the development of breast health messaging to young women.

- ACBCYW should focus its future activities on risk groups in the following areas.
  - Agreement was reached during the January 2014 virtual meeting to restructure the High Risk Workgroup as a broader “Risk Workgroup” with an additional charge of developing and targeting evidence-based messages to young women <45 years of age at “average risk” of breast cancer. ACBCYW should take formal action at this time on forming a new workgroup that specifically would focus on decision-making, information dissemination and screening of average-risk young women.
  - A new workgroup should be formed to specifically focus on support for YBCS.
  - Appropriate public health messaging should be framed regarding the relationship between breast cancer and environmental risks and exposures.
  - As CDC’s formal advisory committee on BCYW issues, ACBCYW should release an evidence-based statement on the appropriate time young women should initiate mammography screening.

#### ***Data Gaps/Research Needs***

- ACBCYW is chartered to provide advice and guidance on evidence-based BCYW prevention activities, particularly among women at heightened risk. ACBCYW has been extremely conservative in recommending BCYW messages for average-risk young women due to the multitude of unknown areas, uncertainties and controversies. The BCYW evidence base is severely limited at this time. Due to current data gaps, ACBCYW uses subject-matter expertise, “evidence-informed” findings and USPSTF guidelines as the bases of its guidance on BCYW clinical and public health support. Although research is underway, the BCYW evidence base is likely to remain limited for quite some time.
- Analyses and assessments of self-reported screening and prevention outcomes are conducted to determine whether the USPSTF guidelines did or did not increase patient knowledge and understanding. ACBCYW should advise CDC to use the USPSTF guidelines to conduct a similar evaluation in the BCYW population to strengthen the evidence base in this area.
- ACBCYW should advise CDC to conduct a risk assessment to identify young underserved women who do not have a genetic risk of breast cancer. CDC’s BCYW guidance has emphasized the need to “talk to your doctor to assess your risk,” but this simple message excludes young underserved women who do not have access to physicians and other resources. An assessment of this population could be helpful in

generating more accurate and comprehensive breast cancer screening data in young women.

The ACBCYW open discussion resulted in the following outcomes.

**CONSENSUS AGREEMENT: A new ACBCYW workgroup will be established.**

*Name*

- “Messaging to the General Population of Women <45 Workgroup” (working title: General Population Messaging Workgroup)

*Charge*

- Discuss and identify the current state of affairs regarding breast cancer messaging to young women.
- Identify areas of concord and discord related to these messages.

*Potential Tasks/Issues for Consideration*

- Identify existing evidence-based recommendations for the general population of women; determine areas of uncertainty and controversy in current messaging that would be guided by informed decision-making; use these findings to inform the development and dissemination of new breast cancer messaging for the general population of young women.
- Conduct an environmental scan of breast cancer messages for young women that have been developed by NPOs and are well disseminated in the general population.
- Take extreme caution in recommending a specific age that young women should initiate mammography screening because evidence-based, peer-reviewed and rigorously evaluated guidelines already have addressed this issue.
- Review and identify gaps in existing guidelines and meta-analyses to inform the creation of a research agenda on breast cancer messaging to the general population of young women.
- Identify well-established and emerging environmental risks of breast cancer. Prioritize the top modifiable risk factors and relative risk reduction strategies to inform the creation of messages for the general population of young women. CDC will invite NIEHS to the next ACBCYW meeting to make a presentation on environmental risks of breast cancer.
- Develop 3-5 key messages regarding breast health awareness that CDC should promote to the general population of young women.
- Present the first update at the next ACBCYW meeting.

*Membership*

- Chair: Dr. Lisa Newman
- Members
  - Ms. Lindsay Avner (and/or Ms. Carly Feinstein of Bright Pink)
  - Dr. Ulrike Boehmer
  - Dr. Otis Brawley

- Dr. Jennifer Croswell
- Dr. Sue Friedman
- Dr. Susan Kutner
- Ms. Jennifer Merschdorf
- Dr. Ann Partridge
- Dr. Jeanne Steiner
- Dr. Marisa Weiss
- Dr. JoAnne Zujewski (and/or Dr. Jung-Min Lee of NCI)
- Ms. Rochelle Shoretz as the liaison to the High Risk Workgroup
- CDC staff for subject-matter expertise

**CONSENSUS AGREEMENT: The two existing ACBCYW Workgroups will be maintained.**

Dr. Grana described the Provider Workgroup's next steps. The workgroup will further review provider surveys conducted by the Georgia, Michigan and Oregon DP11-1114 grantees to identify and recommend areas for scale-up. The workgroup believes that its role in the area of decision support tools would be more appropriate as a "consultant" rather than an "advisor." For example, the workgroup could serve as a consultant to CDC during the development of Know:BRCA dissemination strategies.

The workgroup will focus more on the use of EMRs as a method to disseminate provider strategies. To assist the workgroup in this area, CDC agreed to identify internal staff or outside experts with knowledge of incorporating new resources into existing EMR systems. Dr. Susan Kutner, an ACBCYW member, also agreed to answer EMR-specific questions posed by the workgroup and attempt to identify an EMR expert within the Kaiser Permanente Breast Care Leaders Group.

The workgroup will engage additional expertise in its new activities: Dr. Tuya Pal, of the Moffitt Cancer Center; a representative of the nursing community if Dr. Karen Kelly Thomas is no longer able to serve in this capacity; an expert in CME and other components of professional education identified by Dr. Katrina Trivers; and a genetics counselor.

Ms. Shoretz described the High Risk Workgroup's next steps. Additional materials with messages related to high-risk young women will be collected from the workgroup members and thoroughly vetted. Distribution channels and networks will be identified for broad dissemination of the materials. The workgroup will review emerging research on the correlation between awareness and knowledge and propose strategies to fill gaps between these two areas. The workgroup will serve as a consultant to CDC during the national launch of Know:BRCA.

The ACBCYW members asked the High Risk Workgroup to consider an additional area in its future activities. With the exception of chemoprevention, ACA does not require insurance coverage of any interventions for women at high risk of breast cancer. As a result, high-risk women will incur tremendous costs for breast magnetic resonance imaging, mammography and other screening services.

The workgroup should propose a recommendation for ACBCYW's adoption and CDC's formal action. CDC should consult with AHRQ to explore the possibility of obtaining a USPSTF Grade A or B recommendation for basic screening services for high-risk women. Insurance companies would then be required to cover these services. The workgroup also should compile a list of resources and financial assistance options for screening and genetic counseling and testing, particularly since Know:BRCA is likely to identify a new population of high-risk young women.

**CONSENSUS AGREEMENT: Suggestions for other new ACBCYW activities will be tabled.**

ACBCYW will limit its focus at this time to the new General Population Messaging Workgroup, the two existing workgroups, and the provision of feedback to CDC on Know:BRCA. The formation of a new YBCS Workgroup was suggested during the open discussion, but ACBCYW will determine whether the new workgroup would be warranted after updates by the remaining four DP11-1111 grantees and the final evaluation results of the DP11-1111 CoAg are presented.

## **Closing Session**

Dr. Partridge thanked the members for their thoughtful input and helpful guidance over the course of the meeting to strengthen CDC's BCYW portfolio and clarify ACBCYW's future directions through the workgroup activities.

The participants joined Dr. Partridge in applauding Dr. Fairley, Ms. Carolyn Headley, the ACBCYW Committee Management Specialist, and other DCPC staff for their outstanding management of ACBCYW in terms of organizing and planning meetings, maintaining up-to-date communications, preparing background materials, and facilitating logistical arrangements.

Dr. Fairley announced that the terms of several members would end on November 30, 2014. CDC released a call for nominations to fill these vacancies and would solicit feedback from the current members during the vetting process of the nominees. She thanked the CDC staff, both within and outside of DCPC, for providing subject-matter expertise, making informative presentations and contributing relevant research to support ACBCYW's activities.

The next in-person ACBCYW meeting would be held in November or early December 2014. Ms. Headley would poll the members to determine an exact date.

With no further discussion or business brought before ACBCYW, Dr. Fairley adjourned the meeting at 11:46 a.m. on March 28, 2014.

## Attachment 1: Participants' Directory

### Agency for Healthcare Research and Quality

Jennifer Crowell, M.D., M.P.H. ★•

### American College of Obstetrics and Gynecologists

Raquel Arias, M.D. ★

### Breastcancer.org

Marisa Weiss, M.D. ★

### Bright Pink

Lindsay Avner ★•

Carly Feinstein •

### Center for Black Women's Wellness

Soletchi Seya M.P.H. ♦

### Centers for Disease Control and Prevention

Pamela Protzel Berman, Ph.D., M.P.H.

Jameka Blackmon, M.B.A., CMP •

Karen Boone, R.N., M.N., M.P.H. •

Annie Brayboy

Phaeydra Brown

Natasha Buchanan, Ph.D.

Galen Cole, Ph.D, M.P.H.

Donatus Ekwueme, Ph.D.

David Espey, M.D. •

Temeika L. Fairley, Ph.D.

Alyse Finkel, M.P.H.

Carolyn P.R. Headley, M.S.P.H.

Ann Larkin, M.P.H.

Jun Li, M.D. •

Greta Massetti, Ph.D. •

Jacqueline Miller, M.D.

Mike Mizelle

Genise Nixon, B.S.N. •

Demetrius Parker

Cheryll Thomas, M.S.P.H. •

Katrina Trivers, Ph.D., M.S.P.H.

Mary White Sc.D.

Debra Younginer •

### Cooper Cancer Institute

Generosa Grana, M.D. ★

### Dana Farber Cancer Institute

Ann Partridge, M.D., M.P.H. ★

### Department of Defense

Kristy Lidie, Ph.D. •

Gayle Vaday, Ph.D. ★•

### Department of Health and Human Services

Nancy Lee, M.D. ★

### FORCE: Facing Our Risk of Cancer Empowered

Sue Friedman, M.D. ★

### Fulton County Women's Health Program

Monica Hendrickson, NP ♦

Karen Russell ♦

### Georgia Department of Public Health

Barbara Crane APRN ♦

### Health Resources and Services

#### Administration

Morrisa Rice, M.H.A., REHS, RS ★•

### ICF International

Shelby Cash, M.P.H, CHES ♦

Mary Ann Hall ♦

Marnie House, Ed.D, M.P.H. ♦•

Ashani Johnson-Turbes ♦

Jennifer Mezzo ♦

### Kaiser Permanente Breast Care Leaders Group

Susan Kutner, M.D. ★

### Living Beyond Breast Cancer

Arin Ahlum Hanson, M.P.H., CHES ★

### National Cancer Institute

Jung-Min Lee, M.D. •

Jo Anne Zujewski, M.D. ★•

### North Dakota State University

Donald Warne, M.D., M.P.H. ★•

**Oak Ridge Institute for Science and Education (ORISE)**

Jennifer Reynolds ♦

**Oregon Health and Sciences University**

Brandon Hayes-Lattin, M.D. ★ •

**Sharsheret**

Rochelle Shoretz, J.D. ★

**Sisters Network Inc.**

Kelly Hodges ★ •

**Susan G. Komen for the Cure**

Susan Brown, M.S., R.N. ★

**Tigerlily Foundation**

Maimah Karmo ★ •

**University of Michigan Breast Care Center**

Lisa Newman, M.D., M.P.H. ★

**Yale University School of Medicine**

Jeanne Steiner, D.O. ★

**Young Survival Coalition**

Jennifer Merschdorf, M.B.A. ★

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★ Advisory Committee Member, *Ex-Officio* Member, or Liaison Representative

♦ Pre-Registrant

• Virtual Attendee

## Attachment 2: Glossary of Acronyms

ABIM.....	American Board of Internal Medicine
ACA.....	Affordable Care Act
ACBCYW.....	Advisory Committee on Breast Cancer in Young Women
ACOG.....	American Congress of Obstetricians and Gynecologists
AHRQ.....	Agency for Healthcare Research and Quality
BCYW.....	Breast Cancer in Young Women
CBOs.....	Community-Based Organizations
CBWW.....	Center for Black Women’s Wellness
CDC.....	Centers for Disease Control and Prevention
CDS.....	Clinical Decision Support
CME.....	Continuing Medical Education
CoAg.....	Cooperative Agreement
DCPC.....	Division of Cancer Prevention and Control
EARLY Act.....	Education and Awareness Requires Learning Young Act
EMRs.....	Electronic Medical Records
FOA.....	Funding Opportunity Announcement
FORCE.....	Facing Our Risk of Cancer Empowered
HBOC.....	Hereditary Breast/Ovarian Cancer
HCP.....	Healthcare Provider
HHS.....	U.S. Department of Health and Human Services
HRSA.....	Health Resources and Services Administration
LBBC.....	Living Beyond Breast Cancer
LSUHSC.....	Louisiana State University Health Sciences Center
MDCH.....	Michigan Department of Community Health
NCI.....	National Cancer Institute
NIEHS.....	National Institute of Environmental Health Sciences
NPOs.....	Non-Profit Organizations
OB/GYNs.....	Obstetricians/Gynecologists
PCP.....	Primary Care Provider
TA.....	Technical Assistance
USPSTF.....	U.S. Preventive Services Task Force
YAP.....	Young Advocate Program
YBCS.....	Young Breast Cancer Survivors
YJBCS.....	Young Jewish Breast Cancer Survivors
YWI.....	Young Women’s Initiative