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
January 28-29, 2016
Atlanta, Georgia

Record of the Proceedings

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ADVISORY COMMITTEE ON BREAST CANCER IN YOUNG WOMEN
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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 (NCCDPHP), Division of Cancer Prevention and Control (DCPC), convened a meeting of the Advisory Committee on Breast Cancer in Young Women (ACBCYW) on January 28-29, 2016 at the CDC Chamblee Campus, Room 1A, in Atlanta, Georgia.

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

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

Opening Session: January 28, 2016

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

Dr. Fairley conducted a roll call of the membership and confirmed that the 18 voting members and *ex-officio* members (or their proxies) in attendance constituted a quorum for ACBCYW to conduct its business on January 28, 2016. She called the proceedings to order at 9:24 a.m. and welcomed the participants to day 1 of the ACBCYW meeting. None of the voting members publicly declared conflicts of interest for any of the items on the published agenda (*Attachment 1: Published Meeting Agenda*).

Dr. Fairley announced that the four-year terms of several original members expired in 2015. Because an ACBCYW meeting has not been held since the new members were appointed in September 2015, the current meeting would serve as a comprehensive overview. The agenda items would cover ACBCYW's key accomplishments from 2011-2015; CDC's BCYW research and other activities; BCYW initiatives in the field conducted by CDC grantees; and open discussions for ACBCYW to determine its future direction over the next year.

Ann H. Partridge, MD, MPH, ACBCYW Chair
Director, Adult Survivorship Program & Founder and Director,
Program for Young Women with Breast Cancer, Dana-Farber Cancer Institute
Associate Professor, Harvard Medical School

Dr. Partridge dedicated her opening remarks to Ms. Rochelle Shoretz, who passed away on May 31, 2015. Ms. Shoretz was appointed as one of the original members when ACBCYW was established in 2011. She also served as the chair and driving force of the ACBCYW High-Risk Workgroup.

Ms. Shoretz graduated from Columbia Law School and clerked for U.S. Supreme Court Associate Justice Ruth Bader Ginsburg. After her breast cancer diagnosis at 28 years of age, she served as a brilliant and tireless advocate for young women with breast cancer. She was an orthodox Jew and founded Sharsheret as a support group for cancer patients, particularly those of Ashkenazi Jewish heritage.

Dr. Partridge encouraged the members to build on Ms. Shoretz's tremendous contributions during her tenure on ACBCYW by making further progress in providing the HHS Secretary and CDC Director with guidance to improve the lives of young women who are at risk for or have developed breast cancer. She expected ACBCYW to convene an extremely productive meeting over the next two days as a tribute to Ms. Shoretz. She concluded her remarks by asking the participants to join her in a moment of silence in honor of Ms. Shoretz's memory.

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

Dr. Richardson joined her colleagues in welcoming the participants to the meeting, particularly the new ACBCYW members. She thanked the members for continuing to commit their time,

expertise and efforts to providing CDC with excellent guidance to improve its portfolio of BCYW research and activities.

Dr. Fairley concluded the opening session by opening the floor for introductions (*Attachment 2: Roster of the ACBCYW Membership*). She noted that this session would be extended to allow the new members to describe their backgrounds, areas of expertise and interest in the BCYW field.

Overview of the Advisory Committee on Breast Cancer in Young Women: 2011-2015

Ann H. Partridge, MD, MPH, ACBCYW Chair
Director, Adult Survivorship Program & Founder and Director,
Program for Young Women with Breast Cancer, Dana-Farber Cancer Institute
Associate Professor, Harvard Medical School

Dr. Partridge emphasized that she was honored and privileged to have served as the Chair of ACBCYW since its establishment in 2011. She was proud to present an overview of ACBCYW from 2011-2015, including its key accomplishments.

ACBCYW was created pursuant to Section 399NN of the Public Health Service Act and is governed by the provisions of Public Law 92-463. The legislation establishes standards for the formation and use of Federal Advisory Committees. The legislation also provides the HHS Secretary, acting through the CDC Director, with authority in four key areas:

- Develop evidence-based initiatives to advance understanding and awareness of breast cancer among young women, particularly those at heightened high risk for developing disease.
- Establish and conduct activities for the public and healthcare professionals.
- Conduct prevention research.
- Support the dissemination of evidence-based, age-appropriate messages and materials.

The ACBCYW charter outlines the objectives, scope of activities and description of duties of the members. ACBCYW shall provide advice and guidance to the HHS Secretary, Assistant Secretary for Health and CDC Director regarding the formative research, development, implementation and evaluation of evidence-based activities designed to prevent breast cancer (particularly among those at heightened risk) and promote the early detection and support of young women who develop the disease. Advice provided by ACBCYW will assist in ensuring the scientific quality, timeliness, utility and dissemination of credible appropriate messages and resource materials.

The Affordable Care Act (ACA) calls for ACBCYW to assist CDC in creating and conducting a national evidence-based education campaign to increase awareness and knowledge among young women in the following areas:

- Breast health in young women of all racial, ethnic and cultural backgrounds
- Breast health awareness and good breast health habits
- The overall occurrence of breast cancer as well as general and specific risk factors in women who may be at high risk for breast cancer based on familial, racial, ethnic, and cultural backgrounds, such as Ashkenazi Jewish populations
- Evidence-based information that would encourage young women and their healthcare providers (HCPs) to increase early detection of breast cancer
- The availability of health information and other resources for young women diagnosed with breast cancer

During its first meeting on September 21-23, 2011, ACBCYW reviewed the existing BCYW evidence to begin meeting the objectives of its charter and addressing the ACA requirements. ACBCYW devoted a significant amount of time to highlighting areas in which breast cancer experiences between young and older women were detrimentally different. ACBCYW's key findings from its review of the BCYW evidence are summarized as follows. Young women lack awareness of or are not responsive to a personal high risk or family history of breast cancer. Young women have less capacity than older women to engage in risk reduction strategies due to their failure to understand risks and limited knowledge of testing for known high-risk genetic changes.

The rare occurrence of BCYW causes diagnostic delays due to the lack of awareness among both patients and providers that breast cancer can and does develop in young women. Issues of tremendous concern and their potential impact on young women with breast cancer (e.g., fertility, genetic predisposition and psychosocial health) are given limited attention and minimal or no support. Young women have an increased risk of dying from breast cancer due to their lack of access to care and more aggressive disease (e.g., a more advanced stage of disease at diagnosis and a worse tumor biology).

ACBCYW formally approved the establishment of two workgroups to specifically address gaps identified in its review of the BCYW evidence. The High-Risk Workgroup was charged with drafting recommendations for the high-risk population of patients and the public. The Provider Workgroup was charged with drafting recommendations for researchers and HCPs. The workgroups fulfilled their charges by holding monthly teleconferences to gather, discuss and review data to support the draft recommendations. The workgroups leveraged expertise from external sources as needed. The workgroup chairs presented the draft guidance during each ACBCYW meeting for review and comment. The workgroups continually revised the draft recommendations based on ACBCYW's suggestions and input.

ACBCYW formally approved the workgroups' revised recommendations and included the guidance for high-risk women and HCPs in a letter to the HHS Secretary in 2013.

- Identify and effectively communicate with young women at elevated risk
- Support the development and utilization of strategies to engage HCPs in identifying and communicating with young women at elevated risk
- Engage patients and HCPs in highlighting and addressing issues that are unique to young women facing breast cancer

After submitting its 2013 recommendations to the HHS Secretary, ACBCYW agreed that the High-Risk and Provider Workgroups should continue their activities. However, ACBCYW formally approved the formation of a new, separate General Population Workgroup to align the high-risk recommendations to those for women in the general population. ACBCYW formally approved the workgroup's revised recommendations and included the guidance in a letter to the HHS Secretary in 2015.

- Promote balanced messages to young women regarding their likelihood of being diagnosed with breast cancer
- Promote awareness of the fact that although breast cancer is uncommon in the general population of American women <45 years of age, the disease can happen and the signs might be subtle
- Promote the importance of young women understanding their individual risk profiles and whether the profile suggests a risk for breast cancer that is higher than in the general population of young women
- Promote awareness of the ability of young women to adopt lifestyle practices and habits that are effective in reducing their future risk of breast cancer
- Provide resources and promote research in areas that are poorly understood and/or under-funded with regard to BCYW
- Support, provide resources and promote formative research to assess the needs of various constituents of HCPs and also to identify effective strategies that allow targeting of high-risk groups by HCPs and HCP systems
- Develop, evaluate and utilize advances in healthcare and electronic health record (EHR) systems that can reach young women and HCPs
- Conduct additional research that is critical to the field of effective outreach to HCPs
- Consider further support for groups that currently are conducting activities targeting HCPs

ACBCYW's next steps to continue and advance its activities in 2016 will be to integrate the High-Risk and General Population Workgroups, retain the Provider Workgroup, and launch the new Social Justice Workgroup that was formally approved during the April 2015 meeting. During the current meeting, the workgroup charges will need to be clarified and new workgroup chairs and members will need to be designated.

Dr. Partridge concluded her overview by informing the new members that the ACBCYW website (http://www.cdc.gov/maso/facm/facmACBCYW.htm) serves as a rich source of information to familiarize themselves with ACBCYW's activities since 2011. The website includes detailed minutes of all past meetings, PowerPoint slide sets presented at meetings, ACBCYW's 2013 and 2015 recommendations to the HHS Secretary in their entirety, and other background materials and resources.

Division of Cancer Prevention and Control Director's Report

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

Dr. Richardson covered the following topics in her Director's report to ACBCYW. DCPC is housed in NCCDPHP and is responsible for CDC's cancer activities. The DCPC Office of the Director and National Comprehensive Cancer Control Branch have oversight of and are responsible for all BCYW activities. DCPC is undertaking efforts at this time to strengthen its internal partnerships with other NCCDPHP divisions. For example, DCPC's collaborations with divisions that focus on smoking and health, heart disease, diabetes and obesity will be extremely helpful in empowering persons to reduce their individual risk factors for cancer.

CDC's cancer prevention and control appropriations must be spent in accordance with their Congressional line-items. The four cancer programs that CDC funds in states, tribal organizations and U.S. territories are summarized below.

The National Breast and Cervical Cancer Early Detection Program (NBCCEDP) funds all 50 states and the District of Columbia, five U.S. territories, and 11 American Indian/Alaska Native tribes or tribal organizations. CDC established NBCCEDP in 1991 with a vision to increase population-level breast and cervical screening rates. NBCCEDP is the only public health program that has a legislative mandate to take action (e.g., diagnostic and treatment follow-up) if screening identifies an abnormal result. Medicaid expansion and patient navigation were later added to NBCCEDP as key program components.

NBCCEDP is an important safety net that has provided >12 million screening examinations, but ACA has increased access to these services. Moreover, DCPC is expanding NBCCEDP to meet the needs of new public health roles. DCPC awarded funding to the U.S. Census Bureau to estimate the NBCCEDP-eligible population and develop small area health insurance estimates (SAHIEs). SAHIEs are the only source of single-year health insurance coverage estimates for all U.S. counties. The SAHIEs showed that NBCCEDP reaches only 12% of program-eligible women.

The Colorectal Cancer Control Program (CRCCP) funds 24 state health departments, 6 universities and one American Indian tribe. CDC established CRCCP in 2009 with a vision to increase population-level screening rates. All 31 CRCCP grantees are partnering with health systems to implement priority strategies to increase and improve colorectal screening rates and encourage evidence-based interventions. DCPC also funds six of the 31 CRCCP grantees to support direct screening for low-income adults 50-64 years of age. The new CRCCP funding cycle began in FY2016.

The National Comprehensive Cancer Control Program (NCCCP) funds 50 states and the District of Columbia, seven tribal groups, and seven U.S.-Associated Pacific Islands and territories. NCCCP was established in 1998 and provides support to robust state, tribal and territorial coalitions. NCCCP grantees are funded to address six programmatic priorities:

- Emphasize primary prevention of cancer
- Support early detection and treatment activities
- Address the public health needs of cancer survivors
- Plan and implement policy, system and environmental changes to guide sustainable cancer control
- Promote health equity in the context of cancer control
- Demonstrate outcomes through evaluation

The National Program of Cancer Registries (NPCR) funds central cancer registries in 45 states and the District of Columbia, Puerto Rico and U.S. Pacific Island jurisdictions. CDC established NPCR in 1992 with a vision to increase the completeness, timeliness and usefulness of registry data. NPCR's coverage rate of the U.S. population is 96%. NPCR maintains data on 1.2 million new invasive cancer cases that are submitted to CDC each year.

DCPC is implementing several innovative methods to improve cancer prevention and control with "real-time" interventions. These methods include state Health Information Exchanges, interstate e-Path reporting, electronic diagnostic imaging, EHRs and collaboration with large pediatric hospitals. DCPC and the National Cancer Institute (NCI) jointly fund eight universities across the country as part of the Cancer Prevention and Control Research Network.

DCPC has made strong efforts over time to translate its research across the entire continuum of discovery, dissemination and adoption. For example, the "Make It Your Own" online tool helps users create individual versions of evidence-based interventions for specific populations. Users build materials by selecting from a menu of proven approaches recommended by the *Guide to Community Preventive Services*. The materials are then tailored based on a library of images, messages and graphic designs.

DCPC has closely collaborated with its federal partners over the past three years in the Surgeon General's Call to Action to Prevent Skin Cancer. The initiative calls for the establishment of community-based skin cancer prevention programs to prevent future melanoma cases and

decrease treatment costs. The Call to Action also identified skin cancer as a serious public health concern and promoted five strategic goals for skin cancer prevention:

- Increase opportunities for sun protection
- Provide information on ultraviolet exposure
- Promote policies that advance prevention
- Reduce harm from indoor tanning
- Strengthen research, surveillance, monitoring and evaluation

After the Call to Action was published, CDC published a cost-benefit analysis estimated that the prevention of 21,000 melanoma cases annually from 2020-2030 would result in cost-savings of $250 million each year over the ten-year period.

DCPC Works 2015 was launched and features the "Bring Your Brave" public health education campaign to educate young women <45 years of age about breast cancer. To date, Bring Your Brave has generated more than 46 million impressions on news outlets, blogs and social media platforms, including Facebook, Twitter, Pinterest and YouTube. DCPC is continuing to actively increase its presence on social media to rapidly share cancer prevention and control messages.

DCPC, its federal partners and several professional organizations are collaborating to conduct health economics research on cancer to determine human behaviors and decision-making that affect health. Health economics can be used to inform cancer control planning by estimating the cost of cancer to society; evaluating the value of cancer interventions and programs; and projecting the future cost of cancer treatment and care. DCPC and its partners recently published several manuscripts on health economics research on cancer in peer-reviewed journals.

DCPC is continuing to collaborate with multiple partners to address cancer survivorship issues through a number of activities. Cancer survivorship research and health promotion messages are disseminated. High-quality data on cancer survivorship are collected from national population-based surveys. Cancer registry data are gathered to identify and address the unique needs of cancer survivors. Technical assistance and programmatic support are provided to NCCCP and other grantees to address the needs of survivors in their communities.

DCPC awarded a cooperative agreement (CoAg) to seven grantees to develop approaches to increase awareness of and support for young women diagnosed with breast cancer. The grantees are funded to increase the availability of health information and support services for young breast cancer survivors (YBCS) and their families by supporting organizations and other entities that serve the target population.

ACBCYW DISCUSSION: DCPC DIRECTOR'S REPORT

- DCPC should conduct more outreach, research and other activities for the subpopulation of young women with breast cancer who do not self-identify as "survivors." Most notably, breast cancer conversations on social media show that young women living with chronic

cancer and metastatic disease do not feel adequately represented or supported in current BCYW resources and activities. For example, a young woman who became pregnant after her breast cancer diagnosis reported on Twitter that she was unable to locate materials on breastfeeding with breast cancer.

- DCPC's messaging to young women should place more emphasis on dispelling myths and correcting inaccurate perceptions. For example, a large proportion of young women believe that the risk for breast cancer begins at 50 years of age when mammography is initiated. Young women <45 years of age should be informed of specific factors other than lifestyle behaviors that increase their risk for breast cancer, such as race/ethnicity, place of residence, occupation, environmental hazards and genetic predisposition. However, DCPC's messaging should be framed with positive language that describes effective prevention strategies to reduce young women's risk for breast cancer and improve their health outcomes.
- DCPC should more widely promote and disseminate information on the availability of its four funded cancer programs. For example, some states are unaware that CDC funds Comprehensive Cancer Control Plans in all 50 states.
- DCPC should ensure that the "other" category of women (e.g., Asian Americans and Native Americans) is separated for full and accurate representation in breast cancer surveillance systems and other datasets. For example, the traditional approach of integrating all Asian American and Native American women into one racial/ethnic category does not allow breast cancer disparities to be identified in a particular subpopulation. Moreover, most states collect and report breast cancer data to CDC in English and Spanish only.
- DCPC should leverage its role and influence as a national public health leader to fill gaps between public health and health plan datasets. For example, health plan data are a major contributor to DCPC's surveillance, research and datasets on BCYW. Because health plans are not required to collect race/ethnicity data, DCPC's ability to accurately determine the race/ethnicity of women who are served by its breast cancer programs is uncertain.

Overview of CDC's EARLY Act-Funded 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 presented an overview of CDC's activities that are funded by the Education and Awareness Requires Learning Young (EARLY) Act. Breast cancer is the most common cancer in American women and is diagnosed in one out of every eight women. Breast cancer is the second most common form of cancer in women <45 years of age and is diagnosed in 11% of

young women in the United States. Late-stage diagnoses, poor prognoses and treatment effects typically are associated with BCYW.
Specific subpopulations of young women are at higher risk for breast cancer than others: Ashkenazi Jewish women, African American women, women with a family history or genetic predisposition, women with a personal history of breast or ovarian cancer, and women with a history of chest radiation due to childhood cancer.

Congress passed the EARLY Act in 2010 under Part V of the ACA legislation and provided CDC with authority in two key areas: (1) conduct initiatives to increase understanding and awareness of breast health and breast cancer among women at high risk for breast cancer, including those <45 years of age and (2) establish ACBCYW to provide advice and guidance at the federal level. CDC develops and implements research and activities that are aligned with the key provisions outlined in the EARLY Act.

Provision 1 requires CDC to conduct prevention research. CDC's BCYW applied research focuses on genetics, fertility, social media/communications, survivorship, population-level data collection and economics. CDC's ongoing and completed research and evaluation projects are outlined below.

- Literature Review/Subject-Matter Expert Panel on Breast Cancer in Young Women: Reviewing the Evidence and Setting the Course
- Estimating Infertility Among Breast Cancer Survivors
- Health Insurance Coverage of Genetics Services
- Economic Burden of Breast Cancer in Young Women Aged 15-44 Years in the United States, 2000-2010
- Sisters Study and Two Sisters Study: A National Survey of Young Breast Cancer Survivors and Their Sisters
- Walking Together: Making a Path Toward Healing
- Evaluation to Explore Interventions That Support, Build and Provide Legacy Awareness for Young Breast Cancer Survivors
- Developing Psychosocial and Reproductive Health Support for Young Breast Cancer Survivors in the United States: An Evaluation of Existing Survivorship Support Resources
- Impact of Genomics and Personalized Medicine on the Cost-Effectiveness of Preventing and Screening for Breast Cancer in Younger Women
- Comparative Effectiveness and Clinical Utility of Risk Assessment Tools for Hereditary Breast and Ovarian Cancer
- The Economic Impact of Late Stage Breast Cancer Diagnosis and Benefits of Reducing Alcohol Consumption Among Women Aged 18-44 Years at High Risk for Breast Cancer

The *American Journal of Preventive Medicine* published a supplement that featured five papers on BCYW economics research. The supplement highlighted the need for separate quality of life adjustments for women by age at diagnosis and race/ethnicity. Most notably, the burden of breast cancer in terms of health state utility is significantly larger for younger women compared to women

≥45 years of age. Work loss costs are higher per capita among younger employed women than older employed women. The estimated health-related quality of life effects of breast cancer are larger among women who are diagnosed at younger ages and are significantly different by race/ ethnicity.

CDC published a survivorship monograph in late 2015 that featured two BCYW studies. The Johnson-Turbes, *et al.* study reported on the development, implementation and evaluation of *A Guide to a Better You!* by the Young Sisters Initiative (YSI). The study found that the YSI program was appropriately accessed by African American women <45 years of age. The YSI program also was found to be a helpful, useful and valuable educational resource for providing reproductive and psychosocial information to African American women who are newly diagnosed, in treatment, or in post-treatment. However, the study reported that available psychosocial and reproductive health information tailored to African American YBCS is lacking overall.

The Buchanan, *et al*. study reported that 60% of YBCS had concerns with thinking, memory and/or attention after receiving chemotherapy or hormone therapy treatment for their breast cancer. Of all women who expressed concerns, only 37% discussed these issues with their physicians and only 15% reported receiving treatment related to these issues.

Provision 2 requires CDC to provide support to young women with breast cancer. CDC launches a competitive process to award CoAgs to academic institutions, national organizations and other entities that provide support to this population of women in the field. CDC's BCYW CoAgs that have been awarded to date are highlighted below.

- CoAg award to three grantees: "Enhancing Breast Cancer Genomic Practices Through Education, Surveillance and Policy" (2011-2014)
- CoAg award to seven grantees: "Developing Support and Educational Awareness for Young (<45 years of age) Breast Cancer Survivors in the United States" (2011-2014)
- CoAg award to five grantees: "Enhancing Breast Cancer Genomic Practices Through Education, Surveillance and Policy" (2014-2019)
- CoAg award to seven grantees: "Multiple Approaches to Increase Awareness and Support Among Young Women Diagnosed with Breast Cancer" (2014-2019)

CDC is extremely proud of the successes and best practices of its survivorship cancer genomics grantees. For example, Washington University's "Young Women's Breast Cancer Program" provided support services and other resources to >1,400 young women who were affected by breast cancer in the St. Louis region as well as to 2,700 YBCS through national research efforts. Living Beyond Breast Cancer's "Young Women's Initiative" expanded its Breast Cancer Helpline from 25 to 130 volunteers across the country. This initiative also was used to disseminate the "Let's Talk About It" video series that featured young women affected by breast cancer and providers discussing health topics.

Oregon developed and disseminated materials to providers and the general public. Georgia integrated a genetic risk screening protocol into nine existing public health clinics across the state. Michigan decreased inadequate insurance as a barrier to BRCA testing among women who received counseling.

Provision 3 requires CDC to establish a national, evidence-based education campaign to target specific populations at risk and direct messages and educational resources to HCPs. CDC launched the *Know*:BRCA campaign (*Knowing Your BRCA Gene Mutation Risk Can Save Your Life*) in May 2014 as an interactive, web-based resource with unique areas for consumers and HCPs. CDC designed *Know*:BRCA as a clinical decision support tool to assist young women in creating a family history to assess their risk for the BRCA gene and sharing the results with their HCPs. *Know*:BRCA also includes specific tools to help HCPs engage in BRCA-related discussions with their patients.

CDC collected data to determine the interest in and usage of *Know*:BRCA since its launch in May 2014: 41,160 visitors to the website from 166 countries with consumers representing 91% of users; the completion of 1,851 family history cancer assessments by users; and 416 users who shared their risk results with physicians. The *Know*:BRCA social media initiative that was launched on Facebook, Twitter and Pinterest won an award. CDC also was proud that *Know*:BRCA was a recipient of the 2015 Digital Health Award.

CDC launched "Bring Your Brave: It's Time to Talk About Breast Cancer Risk" to meet the requirement of Provision 3 to conduct a health communications campaign. CDC developed the public education, digital and social media campaign in direct response to ACBCYW's guidance in 2013. To support its recommendation, ACBCYW cited language from the ACA legislation that called for the members to assist CDC in creating and conducting a national evidence-based education campaign to increase awareness and knowledge among young women in the following areas:

- Breast health in young women of all racial, ethnic and cultural backgrounds
- Breast health awareness and good breast health habits
- The overall occurrence of breast cancer as well as general and specific risk factors in women who may be at high risk for breast cancer based on familial, racial, ethnic, and cultural backgrounds, such as Ashkenazi Jewish populations
- Evidence-based information that would encourage young women and their HCPs to increase early detection of breast cancer
- The availability of health information and other resources for young women diagnosed with breast cancer

CDC is responding to ACBCYW's guidance on the Bring Your Brave campaign by applying lessons learned from the *Know*:BRCA social media initiative, conducting focus group testing, and utilizing the best available evidence. The Bring Your Brave campaign was launched on several digital and social media platforms (e.g., Facebook, Twitter, Pinterest and YouTube) and includes

a number of key components: targeted messaging, metrics, partner engagement, paid digital advertisements/search engine optimization, and a campaign website.
CDC's next steps will be to refine *Know*:BRCA based on feedback provided by ACBCYW. Functionality improvements will be launched on February 1, 2016. An evaluation will be piloted in the summer or fall of 2016 to explore additional capabilities of *Know*:BRCA, such as the potential to integrate the tool into an EHR-based system. The existing *Know*:BRCA content will be analyzed, updated and improved based on the evaluation results and changes in messaging protocols that have occurred since 2014. New and innovative strategies will be implemented to more widely promote *Know*:BRCA to both young women and HCPs. Educational tools will be used to increase and improve education, engagement and outreach to multiple disciplines of HCPs, including primary care physicians (PCPs), oncologists and nurse practitioners.

ACBCYW DISCUSSION: CDC'S EARLY ACT-FUNDED ACTIVITIES

- CDC's BCYW programs, research and other activities should have a stronger focus on under-represented subpopulations, such as sexual/gender minority groups and women with mental health issues.
- CDC should explore innovative strategies to target its BCYW campaigns to the sub-population of hard-to-reach young women. For example, underserved young women who might be at risk for breast cancer are not likely to visit the *Know*:BRCA or Bring Your Brave website and create a family history if the discussion of cancer is still "taboo" in their specific cultures or families.
- CDC's BCYW messaging should be designed to educate and empower young women to ask their HCPs for referrals to experts in the field at the time of a breast cancer diagnosis. Many young women have the unrealistic expectation that any HCP (e.g., PCP, clinician or oncologist) has the necessary knowledge, training and skill set to address complex BCYW issues. Young women with a breast cancer diagnosis should be informed that a multidisciplinary team of HCPs will be required to provide optimal care and address long-term needs over the course of their breast cancer treatment. For example, behavioral health specialists will be needed to address changes in cognitive function. Genetics specialists will be needed to address BRCA-related issues. Obstetricians/gynecologists will be needed to address premature menopause, sexual dysfunction and fertility/reproductive issues.

Update on CDC's Cancer Genomics Activities

Juan Rodriguez, MPH, MS
Epidemiologist, Division of Cancer Prevention and Control
Centers for Disease Control and Prevention

Mr. Rodriguez presented a two-part update on CDC's cancer genomics activities. Part 1 of the update focused on CDC's study to evaluate the U.S. Preventive Services Task Force (USPSTF)

guidelines on referral to genetic counseling and testing for hereditary breast and ovarian cancer (HBOC). The USPSTF's first recommendations in 2005 focused on specific family history patterns that were indicative of needing a referral to cancer genetic services. However, the family history criteria included in the guidelines did not call for a personal history of cancer or specificity regarding the patient's side of the family.

The USPSTF issued a revised statement in 2013 that was fairly consistent with the previous Grade B recommendation to screen high-risk patients for referral and the Grade D recommendation to conduct population-level genetic counseling and testing. However, the major difference in the 2013 recommendation was for PCPs to use five tools rather than family history criteria to refer patients to cancer genetic services.

- Ontario Family History Assessment Tool (FHAT)
- Manchester Scoring System
- Referral Screening Tool (B-RST)
- Pedigree Assessment Tool (PAT)
- Family Health Screen 7 (FHS-7)

CDC conducted a study and found limited information on referral patterns of the five tools recommended by the USPSTF versus other tools that are publicly available for use. CDC designed the study to assess referral patterns of tools that are available for use in primary care settings for the identification of patients who might benefit from cancer genetic clinical services. CDC also compared referral patterns of these tools to "gold standards" (*i.e.*, tools from other commonly used referral criteria). The overarching goal of CDC's study was to enable PCPs to better identify patients at high risk for cancer and provide greater opportunities for prevention and early detection.

CDC's study design and methodology are summarized as follows. A review was conducted to identify all tools that were available for use in primary care settings at the time of the USPSTF recommendations in 2013. A family history of cancer was assessed for referral to cancer genetic services. The following tools were selected for inclusion in the study: B-RST, BRSQ, FHAT, FHS-7, Michigan Wheel, PAT and 6-Point Scale.

The 2005 California Health Interview Survey (CHIS) and the CDC Ovarian Cancer Risk Perception (OCRP) Study were used as the datasets for the study due to their collection of both first- and second-degree family histories of cancer. The two gold standards selected for comparison were the National Comprehensive Cancer Network (NCCN) family history guidelines for genetic testing of HBOC and BRCAPro due to its mutation probability of ≥20%. Referral rates were calculated for each tool, while correlations were calculated between each tool and the two gold standards.

The study showed tremendous variation among the seven tools in terms of the percent of the population that was referred for genetic counseling and testing. Referral rates ranged from 0.4%

(BRCAPro) to 14.52% (FHS-7) in the 2005 CHIS and from 0.61% (BRCAPro) to 24.12 (FHS-7) in the CDC OCRP Study. Correlations between the ability of the tools to refer patients to genetic counseling and testing and the two gold standards greatly differed as well.

Overall, the study found wide variation among the seven tools in specific patients and the volume of patients referred for genetic counseling and testing. Referral rates ranged from 1%-24%. Differences in referral rates among the seven tools likely were due to individual characteristics, such as a focus on cancer syndromes, HBOC or BRCA; inclusion of a family history of colorectal and prostate cancers; restrictions related to the patient's side of family; and a low threshold for referrals. Differences in referral rates between the 2005 CHIS and the CDC OCRP Study likely were due to sampling of insured persons versus the general population; patient knowledge of their family histories; and missing family history data.

The study concluded that none of the referral tools are "perfect," but referrals are more likely to occur with more knowledge of the patient's family history. Results from the referral tools are informative for genetic counselors to predict their potential patient loads. The results also provide physicians with more information on selecting specific referral tools that would be most effective for their practices. Opportunities are available to improve existing tools or develop new tools for referral to genetic counseling and testing.

The limitations of the study included family history data that were missing from both the 2005 CHIS and the CDC OCRP Study. Moreover, the study design of gold standard comparisons was not ideal because the NCCN HBOC guidelines and BRCAPro are not true gold standards. The actual number of women in the study who were mutation carriers was unknown.

Mr. Rodriguez concluded part 1 of his update by emphasizing that online risk assessment tools and risk calculators are a helpful starting point in helping women to assess their individual risk of breast cancer. However, tools that cannot be easily adopted and implemented in primary care settings will not be used by PCPs to refer patients to genetic counseling and testing. Most notably, CDC conducted a qualitative analysis with a small sample of PCPs to determine the extent to which existing referral tools would be implemented in their primary care practices. The PCPs reported that their adoption, implementation or routine use of referral tools would be limited to only those with the ability to be integrated into their EHR systems.

Mr. Rodriguez focused part 2 of his update on the CDC Public Health Cancer Genomics Program. CDC initially awarded genomics program funding in 2011 with a three-year CoAg to Michigan, Oregon and Georgia. CDC released a new non-research, competitive five-year funding opportunity announcement and awarded funding to five state health departments in 2014: Michigan, Oregon, Utah, Connecticut and Colorado. The grantees are funded to conduct cancer genomics activities in three key areas: public and provider education, surveillance, and policy or systems change. The grantees also are required to develop partnerships with local organizations or health systems, collaborate with other CDC-funded cancer programs in their states, and conduct a comprehensive evaluation of their programs.

Examples of the grantees' activities in the area of education are highlighted as follows. Michigan developed an online continuing medical education module for physicians, nurse practitioners and physician assistants. Utah created Project ECHO (Extension for Community Healthcare Outcomes) as a virtual, case-based "lunch and learn" program with PCPs in rural areas of the state.

Connecticut piloted a genetic counseling mentor program to integrate genetic counselors into primary care practices. The three pilot clinics will be trained in taking a family history, conducting risk screening, and making referrals to genetic counseling and testing. Connecticut and Oregon targeted programs and educational outreach opportunities to specific sites of populations that are at higher risk for breast cancer, such as Jewish students on college campuses and African Americans in churches.

Examples of the grantees' activities in the area of surveillance are highlighted as follows. Most of the five grantees developed cancer genomics or family health history modules for their state-based Behavioral Risk Factor Surveillance Systems. The grantees collaborated with their state cancer registries to describe the burden of hereditary cancer in their respective states. Michigan and Utah assessed the feasibility of collecting BRCA testing data as part of abstracting cancer registry data. A grantee developed a database to share information among all genetic testing clinics to describe the prevalence of BRCA testing in the state.

Examples of the grantees' activities in the area of policy/systems changes are highlighted as follows. The grantees partnered with health insurance carriers in their states to ensure that coverage policies for genetic counseling, testing and risk management of high-risk patients are evidence-based. Oregon collaborated with its state Medicaid programs to ensure coverage of genetic counseling and testing. Oregon assisted in integrating and implementing HBOC risk assessment into screening programs. Georgia and Michigan collaborated with their state governments to cover the cost of genetic counseling and testing for uninsured women.

The grantees currently are in year 2 of the five-year funding cycle for the cancer genomics CoAg. Efforts are underway to foster collaboration, leverage resources and facilitate cross-cutting initiatives among the five grantees and with other CDC programs. Resources and program products will be broadly disseminated throughout the remainder of the CoAg.

CDC and the five grantees will address several emerging issues to inform the future direction of the cancer genomics CoAg. The shift from single site testing to full cancer panel testing has led to the detection of more variants of unknown significance. This change has been problematic in terms of the grantees' approaches to educating and communicating with HCPs and the public. There has been a call to action in the breast cancer genetics community for universal screening of BRCA genes, including testing of all persons of Ashkenazi Jewish descent and the general population.

Evidence from existing risk assessment models is not sufficient to develop guidelines on risk-

stratified screening among high-risk patients. The quality of laboratories to perform genetic testing is questionable. For example, two laboratories that process the same genetic test could obtain different results. Better population-based data are needed because existing cancer genomics data are based on small studies in specialized health centers or with specialized patients. The cost of surveillance is increasing as well. Access to care continues to be a challenge in several areas, such as the shortage of genetic counselors, disparities in access, and payment or coverage for services required by insurance companies.

ACBCYW DISCUSSION: CDC'S CANCER GENOMICS ACTIVITIES

ACBCYW discussed numerous user-friendly tools and calculators that are available online to help women in assessing their individual risk of breast cancer. Bright Pink developed the robust "Assess Your Risk™" tool that collects information on family and personal health histories, reproductive factors and lifestyle factors.

Washington University created a tool that gathers information on reproductive history, lifestyle factors, mammography and other factors to assess risk. NCI's risk calculator estimates women's lifetime risk of developing breast cancer, but the tool does not provide information on their potential genetic risk. ACBCYW also noted the availability of CDC's *Know*:BRCA clinical decision support tool and Kaiser's risk assessment tool.

Several ACBCYW members made suggestions for CDC to consider in refining its ongoing cancer genomics activities.

- CDC should adjust its study on referral tools to include the confounder of limited knowledge of family structures, particularly among patients who were adopted. For example, the literature reports that ~15% of women with positive screening results for ovarian cancer or a BRCA gene mutation have no family history due their adoption.
- CDC's future focus groups to obtain input on the implementation of referral tools should include a broader group of clinicians. Qualitative analyses should not be informed by feedback from PCPs only. Nurses and other types of clinicians typically are responsible for collecting family histories and would be the primary users of referral tools rather than PCPs.
- ACBCYW is aware that as a federal agency, CDC is prohibited from endorsing the use of a particular commercial product. However, CDC should develop and disseminate an evidence-based resource guide to assist clinicians in selecting the most appropriate genetic test for their patients. CDC could to describe the strengths and limitations of each genetic test and provide examples or case studies of patients who would serve as the best candidates for each test.
- CDC should conduct surveillance to identify high-risk women who have no insurance coverage or access to prophylactic surgery. Anecdotal reports from the field show that high-risk women increasingly are being denied insurance coverage for preventive services because prophylactic surgery or magnetic resonance imaging (MRI) does not have a USPSTF grade recommendation for health plans to be reimbursed.

- CDC's special emphasis on African American and Ashkenazi Jewish women in its cancer genomics activities is appropriate due to the increased risk of hereditary breast cancer in these subpopulations. However, CDC should give more attention to Asian American women as well, particularly Filipino women, due to the growing prevalence of BRCA genes in this subpopulation.

Overview of CDC's Bring Your Brave Campaign

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

Dr. Fairley presented an overview of CDC's Bring Your Brave Campaign. CDC applied several lessons learned from *Know:*BRCA to inform the development of Bring Your Brave. Most notably, the campaign is framed with a positive tone and "non-scary," informative and educational messages. Advertisements do not trivialize or oversimplify an issue as personal and important as cancer. Imagery or a logo that is instantly distinguishable with the campaign is used, such as the breast cancer pink ribbon. The campaign is targeted to high-performance venues, such as Facebook and Twitter.

CDC developed and implemented Bring Your Brave in four phases. Phase 1, the research phase, was initiated in the fall of 2014, but is still underway. Phase 2, the planning phase, was initiated in the spring and summer of 2015 and included specific actions to build the foundation of the campaign. First, the target audiences were identified: the primary audience of young women 18-44 years of age at above average risk for developing breast cancer and secondary audiences of all young women and YBCS 18-44 years of age.

Second, ACBCYW's previous input was applied to establish four major goals. Young women would be encouraged to learn their family history of breast and ovarian cancer. Young women would be educated on the risk factors for breast cancer before 45 years of age. Young women would be inspired and empowered to engage their HCPs in discussions about their potentially higher risk for breast cancer. Young women would be encouraged to live healthy lifestyles and be aware of their individual breast health.

Third, an "influence the influencer" strategy was implemented. This approach allows young women who have a strong connection to breast cancer. For example, young women with a family or personal history of breast cancer are given a platform to share their individual stories with the online community of young women who are less aware of their risk.

Fourth, the campaign name was selected based on results from research, legal searches, and

both formal and informal testing. "Bring Your Brave" resonated with young women 18-44 years of age. Moreover, the campaign name emphasized that young women can be personally affected by breast cancer. The campaign name also empowered young women to learn about their risk for early breast cancer and take action if needed. Fifth, young women who reflected the target audiences were recruited as campaign spokespersons to share their personal stories (e.g., young women with a known risk for breast or ovarian cancer, YBCS, and a young woman who experienced a "breast cancer scare").

Phase 3, the campaign rollout, occurred in two different phases in 2015. The phase 1 rollout occurred in May 2015 to launch the Bring Your Brave website with four videos on genetic counseling and testing and four videos of personal breast cancer stories by a campaign spokesperson. Other features of the phase 1 rollout included an HBOC infographic, promotion of the website and videos by CDC's partners, and paid Facebook promotion of the campaign. The campaign also is available on Twitter, Pinterest and YouTube at this time. CDC intends to include additional social media platforms in the future.

CDC learned several valuable lessons in the phase 1 rollout. The genetic counselor video was helpful in educating young women on the role and key functions of this position. Brief videos of 30-45 seconds and graphics with short, eye-catching statistics were the most successful content. Messages to initiate social media conversations increased engagement of the target audiences. Partners were critical in ensuring broad delivery of the campaign messages and increasing the number of visitors to the campaign website. The approach of leveraging health observances was useful. The incorporation of focus group findings played a significant role in research for the campaign, such as changing the black and white graphics to color and including more African American women.

Research for the campaign in the phase 1 rollout was designed to gather core insights to shape a credible and distinct digital and social media education campaign about breast cancer for effective outreach to young women 18-44 years of age. The research methods included reviews of the literature and other existing studies, key informant interviews, an audit of materials, social media analyses, and Bring Your Brave focus groups.

The research showed that audience-based messages and materials for women 18-44 years of age should be developed and centered on personal stories. For example, materials for young Jewish women should show this population, cite facts and statistics specific to this population, provide proactive guidance, and include messages with an upbeat and positive tone. Materials for young African American women should show this population in warm environments and with family members; provide substantial, simple and easily understandable information; and include messages with an empowering tone and specific action steps.

The phase 2 rollout occurred in October 2015 to introduce seven new personal stories, including six new videos of personal breast cancer stories by two additional campaign spokespersons who represented young women in the African American and Ashkenazi Jewish communities. Other

features of the phase 2 rollout included the "Brave Because" Day of Action hashtag; earned and paid media through Facebook, display advertisements, YouTube, search engine marketing and engagement of influencers; and additional promotion of the campaign website and videos by CDC's partners.

Modifications of the content, graphics and personal stories in the phase 2 rollout attracted more visitors to the campaign website. Most notably, personal stories shared on Facebook reached 21,526 individuals with an engagement rate of 19.3%. Personal stories shared on Twitter generated 14,413 impressions with an engagement rate of 2.3%. The Brave Because hashtag was launched on October 27, 2015 to encourage young women to share their personal stories based on the following tagline: "I was inspired to learn my breast cancer risk because X."

CDC's paid media significantly increased the profile and visibility of the Bring Your Brave campaign. Outreach efforts to influencers resulted in 31 blog posts that generated ~4 million impressions. As a result of bloggers sharing posts nearly 100 times, >2.17 million impressions were generated on various social media platforms. Digital display advertising resulted in >20 million impressions with a click-through rate of 0.16%. Mobile and desktop advertisements were targeted to young women 18-44 years of age and Jewish women. Search engine marketing generated >619,000 impressions and nearly 10,000 click-throughs to the CDC.gov website at an average cost per click of $1.97. The campaign keywords of "BRCA" and "genetic testing" attracted the largest number of visitors to the CDC.gov website with the lowest cost per click of $1.74 on average.

The 15-second advertisements with the African American and Ashkenazi Jewish spokespersons that were featured on YouTube for two weeks in November 2015 generated 31,675 views with a cost per view of $0.17. The view rate of the African American advertisement (17.18%) was higher than the view rate of the Ashkenazi Jewish advertisement (14.15%). Conversely, the Ashkenazi Jewish advertisement was more effective in generating clicks from the video (498 clicks with a click-through rate of 0.49%) than the African American video (315 clicks with a click-through rate of 0.31%). Facebook advertising generated 2.5 million impressions and >348,000 total engagements.

CDC's earned media resulted in 12 placements, including *Shape Magazine*, *Washington Jewish Week* and BlackDoctor.org. These placements reached >7.5 million individuals. Promotion of the campaign by CDC's partners continued to play a significant role in the phase 2 rollout. To date, the campaign has generated 39.25 million impressions on Twitter, Facebook, Pinterest and YouTube; >454,000 views of the videos; nearly 68,000 visits to the website; >418,991 engagements on social media through retweets, shares and conversations; and >1,900 mentions of #Bring Your Brave and #Brave Because on social media.

CDC learned several valuable lessons in the phase 2 rollout. Paid media efforts accounted for 75% of impressions in the phase 2 rollout. Simple and relatable stories were more shareable, generated the highest level of engagement and reached more individuals. Of all content in the

campaign, graphics were the most successful. Most notably, the infographic was the top performing content on Twitter. Partnership was a key component in all phases of implementing and promoting the campaign and dramatically increased the success rate of the content. Ongoing evaluation of paid advertising will allow CDC to optimize a strong return on its investment in the future.

Phase 4, the outreach phase, is underway and will continue through August 2016 to expand the reach of the campaign. CDC is exploring opportunities to engage non-traditional partners outside of the breast cancer community. New spokespersons have been recruited to share additional personal stories. The new "Share Your Story" web application is being developed to create graphic content that will allow other users in the field to share their personal stories. New content will be released in the future. CDC will continue its paid media efforts with ongoing investments in digital display, Facebook and YouTube advertising as well as search engine marketing. Additional earned media opportunities will be explored as well.

ACBCYW DISCUSSION: BRING YOUR BRAVE CAMPAIGN

- CDC should explore the possibility of linking the campaign to well-publicized initiatives to further expand the reach. For example, links to the *Know:*BRCA and Bring Your Brave websites could be placed on Ancestry.com to attract the population of young women that is actively seeking more information on their family histories.
- The campaign appears to be successfully reaching young women who already are well represented on social media. CDC should expand the campaign to reach marginalized and underserved subpopulations of young women, such as women with linguistic barriers, minority women, the class of "working poor" single mothers, and women with limited or no access to social media.

In response to the suggestion to expand the Bring Your Brave campaign to reach marginalized and underserved subpopulations of women, Dr. Fairley announced that CDC would solicit guidance from ACBCYW on specific strategies to undertake this effort. She confirmed that ACBCYW's input would be considered as CDC refines the campaign over time.

ACBCYW Open Discussion: Session 1

Ann H. Partridge, MD, MPH, ACBCYW Chair
Director, Adult Survivorship Program & Founder and Director,
Program for Young Women with Breast Cancer, Dana-Farber Cancer Institute
Associate Professor, Harvard Medical School

Dr. Partridge opened the floor for the members to engage in their first open discussion. ACBCYW made several comments and suggestions on potential issues that should be considered in developing its 2016 recommendations to the HHS Secretary and CDC Director.

Request for CDC Guidance

- CDC should provide ACBCYW with a clear definition of the scope of the BCYW target audiences. For example, ACBCYW members are likely to reflect their individual interests, perspectives and constituent groups in proposing recommendations to CDC, such as young women living with metastatic disease who do not self-identify as "survivors," young women in sexual minority or racial/ethnic groups, and newly diagnosed young women <50 years of age.
- CDC should provide clear guidance on the appropriate focus and direction of ACBCYW's recommendations (e.g., education, risk communications and genetic testing versus treatment, survivorship and metastatic disease).

Emerging Community-Based Issues

- Wider availability of genetic testing has led to direct marketing and incorrect usage of generic tests by gynecologists, PCPs and other providers in the field who have limited expertise in follow-up of patients with positive test results. ACBCYW's guidance should address two issues in this regard: (1) the best genetic tests for the general population and (2) education to clinicians on using the best genetic tests and providing support to their patients with positive results.
- ACBCYW will be challenged in providing guidance to CDC on building a stronger evidence base for its BCYW activities without collecting data on a broader group of topics, such as socially disadvantaged populations and environmental issues.
- ACBCYW should identify subpopulations of young women who are not well represented in CDC's BCYW materials and activities at this time, such as women in rural areas with limited or no access to social media. The identification of gaps in the target audiences will allow ACBCYW to provide CDC with better guidance on specific subpopulations that should be addressed in the next phase of the BCYW communication campaigns.
- ACBCYW should focus on drafting recommendations to assist CDC in funding more practice-based evidence programs for young women.

Messaging and Education to the BCYW Target Audiences

- ACBCYW should draft evidence-based messaging for young women and YBCS on risk factors that can prevent breast cancer or the recurrence of disease. These prevention messages should promote decreased alcohol consumption, a healthy diet, and exercise to minimize weight gain/obesity. The prevention messages should reference studies that have documented the role of economic disparities and environmental or occupational exposures to toxic chemicals in increasing the risk for recurrence of disease in YBCS and breast cancer in young women. For example, young Vietnamese women who are employed by nail salons have daily occupational exposures to toxic chemicals that could increase their risk for breast cancer.
- ACBCYW should review findings from community-based participatory research to inform its development of messaging on cultural, linguistic and other issues that are specific to certain subpopulations. For example, a small focus group study recently was completed

in Massachusetts that showed Asian American women accounted for the highest insurance coverage rates, but had the lowest rates of mammography utilization. Although access to mammography is high among Asian American women, the study showed that cultural and linguistic issues were the major barriers to service utilization.

- ACBCYW should draft messaging to older breast cancer survivors specifically to convey to their young daughters. This approach would stimulate dialogue between mothers and daughters to ensure that discussions on family histories of breast cancer continue across generations.
- ACBCYW should draft messaging to empower young women with a BRCA mutation to fully investigate all of their options. A companion set of messages should be developed to educate clinicians. For example, many well-intentioned clinicians routinely advise a bilateral mastectomy and removal of ovaries for their young patients <30 years of age with a BRCA mutation. To assist ACBCYW in drafting these messages, CDC should convene focus groups to obtain input from clinicians who offer this type of surgical advice to young women.

New Workgroup Charges

- As of January 2015, 21 states have adopted new legislation to mandate reporting of women identified with dense breast tissue and educate women on breast density. ACBCYW should charge the newly integrated General Population/High-Risk Workgroup with reviewing the state breast density laws and drafting messaging to young women in this regard.
- ACBCYW should charge the Provider Workgroup with engaging and closely collaborating with the American Congress of Obstetricians and Gynecologists (ACOG), American Society of Clinical Oncology, Society of General Internal Medicine and other professional societies in drafting prevention and educational messages to PCPs.
- ACBCYW's current workgroups are not charged with addressing issues related to metastatic disease and survivorship. ACBCYW should consider taking three key actions to fill this gap. First, the membership of each workgroup should include at least one YBCS. Second, ACBCYW should charge a new or an existing workgroup with engaging the Metastatic Breast Cancer Network as a key partner. Third, several global efforts are underway to study metastatic disease, but biopsy results that have been collected to date do not meet the criteria to be included in Phase I/II clinical trials. Because young women are missing opportunities to be enrolled in these studies, ACBCYW should charge a new or an existing workgroup with highlighting the importance of these ongoing research efforts and educating young women on the value of biopsies.
- The EARLY Act calls for CDC to focus on young women in the general population, high-risk young women, and YBCS. ACBCYW should form workgroups to reflect these three populations of young women only.

Dr. Partridge and CDC staff made several remarks in follow-up to ACBCYW's comments and suggestions in the open discussion.

ACBCYW's Request for Guidance

- Dr. Fairley explained that the scope of the BCYW target audiences is fairly broad. The EARLY Act calls for CDC to educate and outreach to young women in the general population, young women who are at higher risk for breast cancer, and YBCS. CDC also is mandated to provide education to HCPs on all these groups of young women. Due to the broad scope of the EARLY Act provisions, sufficient flexibility exists for CDC to include subpopulations of underserved young women in its BCYW activities as proposed by ACBCYW.

- Dr. Partridge clarified that several new focus areas proposed by the members are beyond ACBCYW's purview, such as newly diagnosed women >44 years of age, clinical research on breast cancer treatment and actual treatment options. Examples of guidance that ACBCYW is chartered to provide include public health prevention recommendations, messaging to improve supportive care of young women with breast cancer, and education to survivors of metastatic disease.

- Dr. Partridge described ACBCYW's definitions of at-risk populations in response to questions by the new members. "High-risk" young women are defined as (1) young women with hereditary susceptibility to breast cancer; (2) young women with biopsy-proven atypical hyperplasia or lobular carcinoma in-situ; and (3) young women with a history of chest wall radiation during adolescence or early adult life. Young women at "higher than average risk" are defined as (1) young Jewish women (with a specific target of women of Ashkenazi descent) with a known or unknown family history or a family history that does not indicate a hereditary susceptibility of breast cancer and (2) young women with clinically-determined mammographically-dense breasts. The new members should review ACBCYW's 2013 recommendations to the HHS Secretary that are posted on the ACBCYW website to obtain additional details.

- Drs. Fairley and Richardson confirmed that efforts are underway to address ACBCYW's interest in focusing on alcohol consumption as a BCYW risk factor. Most notably, CDC recently published a policy document on the correlation between alcohol and cancer. In its ongoing efforts to refine the BCYW campaigns, CDC also will place more emphasis on delivering evidence-based prevention messaging to young women to reduce alcohol consumption and decrease their risk for breast cancer.

New Workgroup Charges

- Dr. Fairley reminded the members that ACBCYW retained the Provider Workgroup and integrated the General Population and High-Risk Workgroups. ACBCYW formally approved the establishment of a new Social Justice Workgroup during the April 2015 meeting, but the workgroup has not initiated any activities to date. After the CDC grantees present updates on their YBCS activities in the field on the following day, ACBCYW could engage in additional discussion to determine whether the formation of a new workgroup would be warranted to address issues related to survivorship and metastatic disease.

CDC also can distribute summaries of YBCS activities from all of the BCYW grantees to further aid in ACBCYW's decision-making on forming a new workgroup.

- Dr. Fairley provided details on the composition, structure and role of workgroups for the benefit of the new members. Workgroups are formed at the discretion of the parent committee and are charged with completing specific tasks. Workgroups must be represented by at least two voting members of the parent committee to serve as the chair and a member. Other workgroup members can include *ex-officio* members, liaison representatives and CDC staff for technical support. Workgroups are allowed to engage external representatives from other federal agencies, professional organizations or other groups to serve as members, provide additional expertise or make presentations when needed. Workgroups are not authorized to present their findings directly to the CDC Director or HHS Secretary because their teleconference meetings are not open to the public. Instead, workgroups must present regular updates of their draft guidance during public meetings of the parent committee for consideration, deliberation and formal action.

- Dr. Partridge returned to ACBCYW's formal approval of establishing a new Social Justice Workgroup. After the April 2015 meeting, several members expressed concern that the terminology of "social justice" would have more of a legal or political focus than a public health approach. Because ACBCYW's efforts are directed toward recommending the best supportive care for young women with breast cancer and conducting the most effective outreach to engage hard-to-reach populations, "Health Equity" might be a more appropriate name for the new workgroup.

Dr. Partridge concluded the first open discussion by confirming that an extensive amount of time would be available on the following day for ACBCYW to engage in additional dialogue. She pointed out that ACBCYW would devote the second open discussion to reaching consensus on the chairs, memberships and other aspects of the workgroups outlined below.

- The newly integrated General Population/High-Risk Workgroup will be charged with defining "risk" beyond ACBCYW's current definitions of "high risk" and "higher than average risk." The expanded definitions should account for alcohol consumption and other modifiable risk factors, environmental exposures and breast density.
- The General Population/High-Risk Workgroup will be charged with drafting guidance to reach and engage underserved, neglected or hard-to-reach young women.
- A new or an existing workgroup will be charged with drafting messaging for subgroups within the YBCS population, such as young women living with metastatic disease.
- The Provider Workgroup's next steps and future directions will be determined.
- Consensus will be reached on changing the name from the "Social Justice Workgroup" to the "Health Equity Workgroup."

Public Comment Session

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

With no further discussion or business brought before ACBCYW, Dr. Fairley recessed the meeting at 3:58 p.m. on January 28, 2016.

Opening Session: January 29, 2016

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

Dr. Fairley conducted a roll call of the membership and confirmed that the 18 voting members and *ex-officio* members (or their proxies) in attendance constituted a quorum for ACBCYW to conduct its business on January 29, 2016. She called the proceedings to order at 9:27 a.m. and welcomed the participants to day 2 of the ACBCYW meeting. None of the voting members publicly declared conflicts of interest for any of the items on the published agenda.

Ann H. Partridge, MD, MPH, ACBCYW Chair
Director, Adult Survivorship Program & Founder and Director,
Program for Young Women with Breast Cancer, Dana-Farber Cancer Institute
Associate Professor, Harvard Medical School

Dr. Partridge also welcomed the participants to day 2 of the ACBCYW meeting. She was extremely pleased with ACBCYW's high level of productivity and tremendous progress on the previous day. She confirmed that ACBCYW is now well positioned to formulate clear plans for the future direction of its workgroups. She concluded the opening session with a brief summary of the day 2 agenda items.

UPDATES ON BCYW ACTIVITIES FROM THE FIELD

A panel of CDC grantees presented updates on their ongoing BCYW activities in the field.

Update by the Black Women's Health Imperative

Valerie Rochester, MPA
Director of Programs and Training
Black Women's Health Imperative

Ms. Rochester presented an update on ongoing BCYW activities conducted by the Black Women's Health Imperative (BWHI). BWHI was founded in 1983 (formerly the National Black Women's Health Project) on the campus of Spelman College in Atlanta, Georgia. BWHI is the only national non-profit organization (NPO) dedicated to improving the physical, emotional and financial health and wellness of 21 million Black women and girls in the nation.

BWHI's activities are based on its organizational principle that the health of black women matters and is critically important to the wellness of the country. BWHI also operates from a position of the inherent resiliency, power and strength of black women. Although health data show that black women account for the highest rates of many diseases and conditions in the United States, BWHI takes a positive approach to promote and improve the health and wellness of this population.

BWHI defines "health equity" as the state of health that exists when social, political and economic barriers are removed to allow all black women and girls to choose behaviors and services to promote their optimum physical, emotional and financial health. BWHI's activities are guided by several important words, including access, choices, ability and empowerment.

On the one hand, BWHI recognizes that data are used to accurately describe the demographics of populations, but statistics do not provide a full representation of positive outcomes. In the African American population, for example, black women account for 66% of bachelor's degree recipients, 71% of master's degree recipients, and 65% of doctorate degree recipients. Black women lead all women in labor force participation rates and overwhelmingly are likely to work, including those with small children. Black women represent the fastest growing market segment in start-up businesses. Black women have a higher life expectancy (78 years of age) than both white men (76.5 years of age) and black men (72 years of age).

On the other hand, BWHI acknowledges that black women account for the leading health indicators in several chronic diseases. Overall breast cancer incidence rates are lower in black women >45 years of age, but are higher in their younger counterparts <45 years of age. Black women are 40% more likely than white women to die from breast cancer. Of all black women, 46% ≥20 years of age have hypertension, 4 out of 5 are overweight, and 16% have extreme obesity.

BWHI identified breast cancer as one of its organizational priorities because data have shown persistently high breast cancer incidence and mortality rates among black women in the United

States from 1999-2011. However, BWHI is continuing to promote positive trends. For example, CDC's 2010 data showed that black women 50-74 years of age had the highest mammography screening rate within the past two years compared to women in all other racial/ethnic groups.

BWHI is focusing on three key areas to address its breast cancer priority. To advocate for policy changes, BWHI and its partners actively promote new laws and review existing legislation, including the EARLY Act and the new state breast density laws. BWHI closely collaborates with a coalition of other national NPOs that serve women of color to improve access to breast cancer screening among young black women. BWHI disseminates data to educate legislators on Capitol Hill on breast cancer in black women. BWHI also takes legislative actions to ensure that black women are fully represented in decision-making processes on breast cancer screening and the development of federal guidelines.

To implement structural changes, BWHI programs in ten cities partner with community-based organizations (CBOs) across the country. For example, BWHI previously launched the "Moving Beyond Pink to End Breast Cancer Disparities" Campaign to provide a more accurate representation of breast cancer programs and services that were available to black women in the ten cities. This initiative led to an increase in the number of digital mammography units placed in hospitals, health centers and clinics in the city of Chicago. Black women previously were required to travel to suburbs outside of their communities to obtain access to this new breast cancer screening technology. The structural change ultimately shortened the timeline from black women receiving a breast cancer diagnosis to initiating treatment and engaging in patient navigation services.

To promote individual changes, BWHI is designing initiatives specifically for black women that focus on self-empowerment as a healthcare consumer, patient education, knowledge of personal and family histories, lifestyle changes and other strategies to mitigate risks for breast cancer, and available benefits through ACA. For example, BWHI's "Access. Coverage. Action." health insurance literacy initiative aims to help black women understand their new health insurance and its role in achieving and maintaining good health.

BWHI is aware that breast cancer continues to be sensitive topic in the African American culture. As a result, BWHI's approach of fully integrating breast cancer awareness and breast health information into all of its other organizational priorities, such as diabetes and HIV, has reached more black women than an initiative with a sole focus on breast cancer.

For example, breast health is a key component of BWHI's "My Sister's Keeper" Program. This sexual health and reproductive justice initiative was launched on the campuses of five Historically Black Colleges and Universities to educate young black women on the importance of having control of their contraceptive and reproductive decisions. The program also mobilizes young black women to advocate for their rights in this regard. The breast health component covers breast self-examination (BSE), clinical breast examination (CBE), and the importance of early discussions with providers to identify potential risks for breast cancer.

Breast health also is a major topic in BWHI's "Grab Your Girls & Go" Program. This mammography screening initiative was launched in six cities across the country to dispel myths and minimize fear associated with mammography. The program provides a platform for black women to engage in discussions with their female family members, peers or members in their community networks and share their experiences related to mammography screening, a breast cancer diagnosis or survivorship of the disease. The program also encourages black women to increase their knowledge and understanding of wellness and participate in activities to achieve optimal health.

BWHI initiated "IndexUS: The Black Women's Health Index" to determine key health outcomes, behaviors and risk factors that are specific to black women by geographic and economic factors in the United States. To support this initiative, BWHI partnered with Boston University to reanalyze data from the Black Women's Health Study that has been conducted over the past 20 years with a cohort of 59,000 black women. To maintain BWHI's positive approach, the reanalysis of data will focus on specific characteristics, behaviors and factors (e.g., routine screening, lifestyle changes, the built environment and socioeconomic factors) that have caused women to remain healthy over the 20-year study period.

BWHI will use the reanalyzed data to develop profiles and predictive models to address breast cancer and other chronic conditions in black women. BWHI will release the "2020: The New State of Black Women" Index later in 2016 and advocate for a $25 million investment to increase the number of healthy black women from 9 million in 2014 to 12.5 million in 2020.

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 ongoing BCYW activities conducted by Living Beyond Breast Cancer (LBBC). LBBC was founded in 1991 with a mission to connect women with trusted breast cancer information and a community of support. LBBC is one of the first national NPOs that was established to meet the need for breast cancer-related information, connection and support after treatment. LBBC has expanded its activities to assist women at all stages of diagnosis, treatment and survivorship as the need for specialized services has increased over time.

LBBC programs reach >500,000 persons affected by breast cancer and their families each year. LBBC also has tailored initiatives and resources for specific subpopulations, including young women, women diagnosed with triple-negative breast cancer, women living with metastatic breast cancer and African American women. LBBC ensures that its programs and services are available

in different formats (e.g., online, in print, by telephone and in person) to accommodate the individual preferences of users.

LBBC's programs include two national conferences that are held each year. The "Thriving Together: 2016 Conference on Metastatic Breast Cancer" will be held on April 8-10, 2016 in Philadelphia. The "2016 Annual Fall Conference: Breast Cancer Today" will be held on September 23-24, 2016 in Philadelphia and will include tracks on metastatic and triple-negative breast cancer. LBBC also convenes webinars throughout the year that focus on various medical and psychosocial topics.

LBBC's Breast Cancer Helpline offers peer-to-peer telephone support and online chat support. LBBC redesigned its interactive website (www.lbbc.org) in September 2015 to include additional resources. Twitter chats are held every other month on a variety of breast cancer-related topics. LBBC convenes its in-person "Breast Cancer 360" Program with live web streaming of the panel discussions to a national audience.

LBBC's publications include the *Insight* quarterly newsletter, the *Guide to Understanding* series on both early-stage and metastatic breast cancer, and a series of guides focusing on breast cancer in specific populations (e.g., lesbian/gay/bisexual (LGB) persons, pregnant women and men). LBBC's publications also cover general topics of interest for women with breast cancer, such as intimacy and sexuality, insomnia and fatigue, the benefits of yoga, lymphedema, bone health and financial concerns.

LBBC has targeted programs and services to young women since its establishment in 1991 and launched the Young Women's Initiative (YWI) after CDC awarded a three-year CoAg in 2011. The new funding allowed LBBC to expand and strengthen its existing programs and services for young women and develop new resources for this population. To date, YWI has reached >100,000 young women and their families. CDC awarded a second CoAg to LBBC in October 2014 to expand YWI.

LBBC conducted a multi-method needs assessment in 2012 after the first CoAg was awarded to evaluate the information and support needs of young women. LBBC selected four program priorities based on input submitted by >1,500 young women across the country:

- Develop tailored online resources for young women
- Increase opportunities for young women to receive peer support through the Breast Cancer Helpline
- Educate HCPs about the unique needs of young women affected by breast cancer
- Expand existing programming and resources for key subpopulations of young women who are underserved and have unique needs

YWI's online resources include a webpage on the LBBC website that is solely dedicated to young women. To date, >120 website articles, including easily readable summaries of recent breast

cancer studies and profiles, have been published that are specific to young women (e.g., breastfeeding after breast cancer for young mothers and family-building strategies for young women living with metastatic breast cancer). A webinar was held in January 2015 to review findings of the ovarian suppression clinical trial. The May 2016 Twitter chat will focus on young women living with metastatic breast cancer. The Breast Cancer 360 Program will be held in July 2016 in Denver focusing on sexual health and dating issues for young women. The program also will be available nationally via live web streaming.

The "Let's Talk About It" video series was launched on the LBBC website for young women to share their personal experiences regarding metastatic breast cancer and general issues, such as the impact of breast cancer, early menopause, body image, financial issues, sex and breast cancer, communications with the healthcare team and bone health. Ms. Hanson presented a segment from the video series.

YWI's telephone resources include 45 young women who have been trained to serve as new Breast Cancer Helpline volunteers. Of all 128 volunteers, 58 (or 45%) were diagnosed before 45 years of age. The volunteers also have been providing peer support through online chats since September 2015. The YWIConnect text messaging service was launched in June 2015 that enables young women to receive three texts per month on new programs, updated online content and guidance. LBBC currently has 134 subscribers and expects to reach its goal of 300 subscribers by June 2016.

YWI's in-print resources include publications on topics that are of tremendous interest to young women: intimacy and sexuality, hormonal therapy, genetics and family risk, complementary therapies, financial concerns, care to LGB persons, and pregnancy and breast cancer.

YWI's in-person resources include additional programming and connections for young women at LBBC's annual conferences and other events, such as a happy hour, workshops that focus on the needs of young women, and symposiums conducted in collaboration with regional partners (e.g., the Breast Cancer Breakthroughs Symposium with the Abramson Cancer Center Hospital at the University of Pennsylvania). Moreover, young women who were diagnosed with breast cancer before 45 years of age account for 33% of LBBC conference participants.

The Young Advocate Program is designed to help young women use their personal experiences to make a difference in their communities. The program is targeted to young women with limited incomes at or below 200% of the Federal Poverty level and who are within three years of a breast cancer diagnosis or are living with metastatic breast cancer. Young women from across the country who meet these criteria are invited to attend an 8- to 14-hour in-person session and receive training on advocacy, breast cancer disparities, and strategies to effectively share personal breast cancer stories.

Young Advocate Program participants are required to complete two activities and share LBBC's resources with at least one contact within six months of completing training. Key milestones of

the program in 2015 included 127 applicants; provision of training to 29 new young women for a total of 76 young advocates across 28 states; and completion of >50 outreach activities and distribution of 5,295 LBBC educational materials by the young advocates.

YWI's resources for HCP education include programs to help HCPs develop the necessary skills to address the unique needs of young women; educational programs targeted to oncology nurses and oncology social workers; four webinars with participation by >1,000 HCPs to date; and two half-day in-person symposiums for HCPs that were held in conjunction with the Association of Oncology Social Work Annual Conference. A new one-hour webinar will be broadcast for HCPs in March 2016, "Understanding the Unique Needs of Your Metastatic Breast Cancer Patients."

LBBC provides a number of opportunities to engage young women in YWI activities. Several organizations are partners in the YWI Outreach Network to assist LBBC in disseminating program announcements to young women. The series of "Let's Talk About It" videos are shared on social media and linked to the websites of various organizations. Hospital systems and HCPs order LBBC's publications for distribution to young women. Ongoing efforts are made to recruit external experts to serve in a variety of roles, such as speakers, medical reviewers, consumer reviewers and Twitter chat participants.

Update by Sharsheret

Elana Silber, MBA
Executive Director
Sharsheret, Inc.

Ms. Silber joined the meeting via teleconference to present an update on ongoing BCYW activities conducted by Sharsheret. Sharsheret was founded in 2001 as a national NPO to support young Jewish women and their families who face breast cancer or are at increased genetic risk of breast cancer, ovarian cancer or related hereditary cancers.

Sharsheret, the Hebrew word for "chain," was selected as the name of the organization to ensure that young Jewish women with breast cancer and their families are provided with strong linkages, connections and networks over the course of their diagnoses, treatment and survivorship. Sharsheret's 12 programs are available to national audiences in multiple formats to meet the needs of all of its target audiences. For example, the LINK Program includes a diverse group of activities to provide support to young Jewish women and their families who are directly affected by cancer. Education and outreach programs are targeted to the broader Jewish community, including women and men at various ages.

Data show that 1 in 40 Ashkenazi Jewish women and men carries a BRCA gene mutation. Because this rate is nearly 10 times higher than in the general population, Jewish women are

significantly more susceptible to HBOC. Sharsheret's overarching goal is to educate all 5 million Jews in the United States on this increased risk and distribute information on prevention strategies to protect their health. Sharsheret is aware of several HBOC-related concerns that are common in the Jewish community, including genetics, culture, spirituality, values, holidays, dating, marriage, and the tension between privacy and community knowledge of a cancer diagnosis.

Ms. Silber presented a case study of Sharsheret's services that have been available to a young, BRCA-positive Ashkenazi Jewish woman who was diagnosed with early-stage breast cancer at 39 years of age. After contacting Sharsheret, the client obtained comprehensive support from the trained clinical staff of three social workers, one genetic counselor and one psychotherapist to meet her individual needs: confidentiality/privacy issues, fertility concerns, fears of passing the BRCA gene to her existing child and/or future children, and breast cancer treatment options. Examples of some of Sharsheret's 12 support and education/outreach programs that are available to young Jewish women with breast cancer are highlighted below.

In terms of Sharsheret's support programs, the Patient Navigation Program provides culturally- and age-appropriate psychosocial and reproductive resources to young Jewish women who are breast or ovarian cancer survivors. Sharsheret support staff and clients closely collaborate to develop a comprehensive, personalized navigation plan. The Peer Support Network of ~5,500 women facilitates one-on-one peer connections for young women who are newly diagnosed or are at increased risk of hereditary cancers. The tailored matches are based on the woman's individual diagnosis and life experiences.

The Genetics for Life® Program disseminates culturally-relevant resources to Jewish women and their families who are at high risk due to a strong family history of cancer or a BRCA gene mutation. The *Your Jewish Genes: Hereditary Breast Cancer and Ovarian Cancer* booklet is the leading publication distributed through this program. The issue of genetics also is addressed through healthcare symposiums and guided conversations between Sharsheret support staff and clients.

The Thriving Again® Program was launched after the CDC CoAg was awarded to Sharsheret in 2011. The program provides Jewish YBCS with professional and peer support, access to educational teleconferences, a tailored survivorship care plan, and a personalized survivorship kit to address individual issues (e.g., fertility concerns, genetic issues, and healthy lifestyles with both kosher and non-kosher cookbooks).

In terms of Sharsheret's education and outreach programs, services are delivered to address the needs of young Jewish women and their families who are directly affected by cancer. Outreach is targeted to the broader community to provide education and other resources on genetics, the incidence of cancer and the risk for HBOC in Jewish families. Tools are scaled-up to increase awareness of Sharsheret's programs.

Outreach and education are delivered through various platforms and events: "Sharsheret Pink Shabbat" in temples and synagogues; a strong presence on multiple social media platforms; wide dissemination of educational booklets (e.g., *Facing Breast Cancer as a Jewish Woman*); and implementation of the "Sharsheret on Campus" Program on 150 colleges and universities across the country.

Outreach and education also include onsite cultural competency training provided to medical professionals at major medical centers. The topics of training sessions for HCPs include the increased risk for HBOC in Jewish women, psychosocial issues specific to Jewish women, strategies to meet the needs of Jewish women at high risk for breast or ovarian cancer who refuse testing due to their orthodox religious beliefs, and the referral of patients to Sharsheret.

Sharsheret currently is focused on using its CDC CoAg to scale-up existing support programs and build capacity through a five-year strategic plan. The strategic plan will be targeted to three key areas over the next five years: (1) a comprehensive evaluation of all Sharsheret programs, services and resources; (2) collaboration with the Georgetown Lombardi Comprehensive Care Center to obtain external evaluation expertise and partnerships with >40 national Jewish-serving organizations and CBOs to increase utilization of Sharsheret's support programs for young Jewish women; and (3) nutrition, exercise and genetics.

The key findings of Sharsheret's preliminary evaluation are outlined as follows. Sharsheret administered a 30-day post-intervention satisfaction survey to obtain input from its clients in the following areas: demographics, psychosocial health, referral sources, and satisfaction with Sharsheret overall and its individual programs (e.g., Patient Navigation Program, Peer Support Network, Genetics for Life® Program and Thriving Again® Program).

Of the 24 survey respondents, 25% were 25-34 years of age and 75% were 35-45 years of age; 100% were female; 87.5% were white; 70.8% were of Jewish descent; 70.8% were married or with partners; and 20.8% were single/never married. All of the survey respondents reported being "very satisfied" (79.2%) or "satisfied" (20.8%) with Sharsheret and its programs.

Of 10 Peer Support Network participants, 100% agreed that the "peer supporter offered help I could not find from others." Of 5 Genetics for Life® Program participants, 100% agreed that the program "helped identify what I needed to make decisions about genetic issues." Of 19 Thriving Again® Program participants, 89% agreed that the "survivorship kit addressed my concerns." Health and nutrition, healthy living and a calendar were ranked as the top three most useful program components.

Sharsheret developed its five-year strategic plan to achieve four key strategic imperatives: enhancements to its national and regional infrastructure; cultivation of medical partnerships to support the expansion; sustainable fundraising and marketing initiatives; and responses to developments in technology and social media. Sharsheret's national impact at this time includes

>5,500 Jewish YBCS in its Peer Support Network and service delivery to >54,500 women and their families, community leaders, HCPs and college students.

Sharsheret made a number of notable accomplishments in 2015, including the publication of its first journal manuscript in *Healthcare* and the submission of five abstracts to professional healthcare conferences. Sharsheret also presented at three national healthcare symposiums to address clinical trial cancer screening updates and genetics. Moreover, culturally-relevant resources were shared with >3,300 HCPs in the Sharsheret database and >7,300 educational resources were disseminated to women, families and HCPs nationwide in multiple formats.

Ms. Silber concluded her overview by thanking ACBCYW and CDC for setting aside time during the meeting on day 1 to present a touching tribute to Ms. Shoretz. She confirmed that the Sharsheret staff is committed to honoring Ms. Shoretz's legacy in 2016 and beyond with its ongoing roles as an ACBCYW liaison representative and a CDC grantee. She announced that Sharsheret will convene its next healthcare symposium on February 2, 2016, "Take Control: Navigating the Emotional Roller Coaster of Cancer."

ACBCYW DISCUSSION: BCYW ACTIVITIES IN THE FIELD

The panel of CDC grantees provided additional details on the following topics in response to ACBCYW's specific questions and comments.

- BWHI's strong opposition to the USPSTF recommendation to initiate mammography screening at 50 years of age due to the historical exclusion of black women from research and increased rates of more virulent forms of breast cancer among young black women.
- The lack of a solid screening test to detect virulent forms of breast cancer in young women <40 years of age.
- The need to provide a clear explanation to HCPs and the general public on the meaning and rationale of the USPSTF breast cancer screening guidelines.
- Uncertainties regarding whether breast density should be measured by mammography or other imaging modalities.
- LBBC's next steps to evaluate its programs, publications and other resources.

Overview of Breast Cancer Screening of Young Women

Maxine Jochelson, MD
Director of Radiology, Breast and Imaging Center, Memorial Sloan Kettering Cancer Center
Associate Professor of Clinical Radiology, Weill Cornell Medical School

Dr. Jochelson joined the meeting via teleconference to present an overview of breast cancer screening of young women. The current screening guidelines are associated with a high level of

controversy regarding the frequency of screening (e.g., annually or biennially) and the age to initiate screening (e.g., women younger or older than 50 years of age).

- The Society of Breast Imaging, American College of Radiologists and ACOG endorse 2016 guidelines that serve as the current standard. Average-risk women should be screened annually beginning at 40 years of age until the life expectancy is <5 years. Annual CBE is recommended.
- The American Cancer Society (ACS) issued new guidelines in the fall of 2015. Average-risk women 45-54 years of age should be screened annually, but a shift should be made to biennial screening after 55 years of age until the life expectancy is <10 years. The guidelines also recommend initiation of screening at 40 years of age as an option. CBE by physicians and BSE by women are not recommended.
- The USPSTF reissued its 2009 guidelines with no changes. Average-risk women 40-49 years of age should discuss the potential need for screening with their physicians. The guidelines also recommend biennial screening of women 50-74 years of age. BSE is not recommended.

Several studies have demonstrated mortality-related benefits of screening, but the USPSTF cited a number of factors as its rationale to not recommend mammography for women <50 years of age. For example, dense breasts of younger women cause cancers to be missed or cancers to present as palpable masses between screenings. Recalls due to false-positive results are more frequent in young women and have led to their anxiety. The reduction in breast cancer mortality is lower in young women. Young women typically are "over-diagnosed."

Despite the current USPSTF guidelines, both mortality and morbidity data have been collected to support screening of young women. Dr. Jochelson presented findings from a series of U.S. and international studies on screening of young women for breast cancer at various levels of risk as well as different screening modalities.

SCREENING OF AVERAGE-RISK WOMEN: The 2010 Hellquist, *et al.* study reported screening results of average-risk women 40-49 years of age who were and were not invited for screening in 1986-2005. Over the 16-year follow-up period, the mortality reduction was 26%-29% higher in women who were actually screened compared to those who were only invited for screening. Women 45-49 years of age accounted for the highest reduction in mortality.

The 2012 Malmgren, *et al.* longitudinal prospective cohort study compared cancers detected by mammography versus those detected by a patient or physician in a cohort of 1,977 average-risk women 40-49 years of age. The study reported that women with mammography-detected cancers were significantly more likely to conserve their breasts, significantly less likely to need chemotherapy, and more likely to be relapse-free at five years post-survival (92% versus 88%).

The 2013 Arleo, *et al.* study reported results of 43,351 mammograms that were performed in New York City from 2007-2010. Of this cohort, 33% of women were 40-49 years of age. Of the 205

cancers detected by mammography, 20% were in women 40-49 years of age. Of the cancers detected in women 40-49 years, >50% were invasive.

The 2014 Plecha, *et al.* retrospective study reported results from 2008-2011 of 149 screened breast cancer patients and 81 non-screened breast cancer patients who presented with clinical symptoms. Compared to the non-screened cohort, the screened cohort had significantly higher rates of early-stage disease, negative nodes and smaller tumors; a lower rate of mastectomy (30% versus 48%); and a significantly lower rate of chemotherapy (44% versus 66%).

The Cancer Intervention and Surveillance Modeling Network compared screening results using the USPSTF guidelines (biennial screening of women 50-74 years of age) versus the standard guidelines (annual screening of women 40-84 years of age) among six of the "best" screening institutions. The analysis showed that for 25,000 more mammograms per 1,000 women, the standard guidelines increased mortality reduction by 16.3% on average over the USPSTF guidelines among the six institutions.

The 2014 Hendrick, *et al.* study reported that the addition of annual mammography of women 40-49 years of age to biennial screening of women 50-74 years of age would increase lives saved by 27% and increase life-years gained by 47%. Annual mammography was found to save 42% more lives and life-years than biennial mammography. The study also found that in this age group, 588 women would need to be screened with annual digital mammography to save one life. Overall, the studies demonstrated that average-risk women <50 years of age should be annually screened to reduce both mortality and morbidity.

SCREENING OF HIGH-RISK WOMEN: ACS published guidelines in 2007 that called for annual screening of high-risk women with both MRI and mammography. ACS defined "high-risk women" as women with a BRCA 1 or 2 mutation, women with an untested first-degree relative of a BRCA carrier, women with a ≥20% lifetime risk as defined by BRCAPro or other models dependent on family history, and women with a history of chest radiation at 10-30 years of age.

The rationale for ACS's guidelines is that breast MRI is the most sensitive imaging test to detect breast cancer. The sensitivity of breast MRI is due to imaging of enhancing neovascularity. MRI can identify leakages in the breast from cancerous tumors even before the detection of a discrete mass. However, the limitations of MRI include a high cost of >$4,000, the onset of claustrophobia among many women, weak detection capacity in women with metallic breast implants, and limited availability.

The 2010 Kuhl, *et al.* study compared different imaging methods that were used alone or in combination with MRI in a cohort of women at high and intermediate risk for developing breast cancer. The study demonstrated that MRI had a significantly higher detection rate compared to other modalities: 5.4 cancers/1,000 women screened with mammography, 6 cancers/1,000 women screened with ultrasound, and 14.9 cancers/1,000 women screened with MRI. The

cancer detection rate further increased to 16 cancers/1,000 women screened when MRI was added to mammography alone or an ultrasound/mammography combination.

The 2011 Warner, *et al.* study followed 1,275 BRCA 1 and 2 patients who were and were not screened with MRI. The study reported significantly better outcomes among 445 MRI-screened patients compared to 830 non-MRI-screened patients: a detection rate of 13.8% versus 7.2% for stage 1 ductal carcinoma in situ (DCIS) and a detection rate of 1.9% versus 6.6% for stage II-IV cancers.

The 2010 Rijnsburger, *et al.* study screened a cohort of 2,157 women at high and intermediate risk for developing breast cancer. Of the BRCA 1 patients, 58% were <40 years of age and 9.7% were <30 years of age. More interval cancers were detected in younger patients. MRI alone detected 43% of cancers in high-/moderate-risk women and women with a BRCA 1 or 2 mutation. The median size of the tumors was 9 mm with 62% of the tumors being ≤1 cm. MRI increased the overall survival rate to 93% in the study population compared to 74.5% in 26 historical cohorts.

The 2012 Heijnsdijk, *et al.* study examined mortality reductions among 1,275 BRCA 1 and 2 patients. The study demonstrated significant mortality reductions in the use of mammography plus MRI compared to the use of mammography alone: 50.1% versus 41.9% in BRCA 1 patients and 61.6% versus 46.8% in BRCA 2 patients. The mortality reductions remained high with the use of MRI alone: 49% in BRCA 1 patients and 61% in BRCA 2 patients. Mammography alone detected only one invasive cancer in women <40 years of age.

The 2016 Krammer and Jochelson study followed 516 women with breast cancer and BRCA 1 and 2 mutations, including 159 who were <40 years of age. MRI detected 97% of all cancers, while mammography detected 79% of cancers in BRCA 1 patients and 87% of cancers in BRCA 2 patients. Mammography only detected cancer in one BRCA 1 patient <40 years of age that was not detected by MRI. Both studies indicate that mammography might not be needed in the younger population of women <40 years of age.

The clinical community has not yet reached consensus on the frequency of screening for mutation carriers. However, early data suggest that alternating between mammography and MRI at six-month intervals is a better screening protocol than performing both modalities at the same time annually.

SCREENING OF INTERMEDIATE-RISK WOMEN: No data have been collected to date to guide decision-making on the best tests to screen intermediate-risk women. This group includes women with a ≥15% lifetime risk for developing breast cancer: a personal or family history of breast cancer, atypical ductal hyperplasia, lobular carcinoma in situ or dense breasts. Uncertainty regarding screening women with dense breast presents a two-fold problem. First, the risk for breast cancer increases by four- to six-fold in women with extremely dense breasts compared to those with fatty breasts. Second, the lower sensitivity of mammography in women with dense breasts leads to missed and interval cancers, particularly in young women.

The 2014 Sprague, *et al.* study examined national legislation that was being considered to require women with mammographically-dense breasts to be informed of their breast density and encouraged to discuss supplemental breast cancer screening with their HCPs. The study estimated that the extremely high prevalence of dense breasts includes 27.6 million women in the United States 40-74 years of age. Young women 40-49 years of age were estimated to account for 44.3% of this population and might need additional screening.

ULTRASOUND SCREENING: Most women are screened by ultrasound at this time because the test is inexpensive, readily available and provides no radiation exposure. The 2002 Kolb, *et al.* study evaluated mammography screening results of 4,897 women with dense breasts. Mammography detected 31 cancers for a detection rate of 3 additional cancers/1,000 women screened. The 2008 Berg, *et al.* prospective study evaluated ultrasound screening results of 2,637 women with dense breasts plus one additional risk factor. Ultrasound detected ~3.7 additional cancers/1,000 women screened. The cancers primarily were invasive. Biopsy was recommended for 8% of women and short-term follow-up was recommended for 9% of women. However, only 7.4% of the biopsies were positive.

The 2015 Ohuchi, *et al.* study randomized 72,998 average-risk Japanese women 40-49 years of age with dense breasts to either ultrasound or no ultrasound after mammography. In the ultrasound group, sensitivity to detect cancer was significantly higher (91.1% versus 77%); specificity to detect cancer was significantly lower (87.7% versus 91.4%); a significantly larger number of cancers were detected (184 versus 117); and stage 0/1 cancers were more frequent. The cohort will be followed to determine the advantages of ultrasound post-survival.

The 2012 Weigert, *et al.* study examined the cost of ultrasound based on data from 72,030 mammograms and 8,647 ultrasounds performed by six private practice groups in Connecticut. The detection rate of 3.25 additional cancers/1,000 women screened was consistent across the six practices. However, the positive predictive value of 6.7% was poor and the recall rate of 9% for "probably benign" results was high. Of a total of $110,241 billed, the practices were paid $60,000 per breast cancers detected rather than per lives saved.

The 2012 Hooley, *et al.* study examined the cost of ultrasound in a cohort of 935 women with a variety of risks and breast densities. The results were remarkably similar to the Weigert study findings. The detection rate was 3.2 additional cancers/1,000 women screened and the positive predictive value of 6.5% was poor. Of the cohort, 187 women were recalled for "probably benign" results and biopsy was recommended for 47 women due to "suspicious abnormalities." A total of $60,267 was paid per breast cancers diagnosed, but this figure might be higher because some women in the study were diagnostic patients. These studies demonstrate that ultrasound actually is not an inexpensive modality because a large number of false-positive results leads to biopsies.

The 2008 Berg, *et al.* prospective study evaluated ultrasound screening results of 2,637 women. In the 2012 follow-up study, MRI detected 16 additional cancers in 612 women. Ultrasound and mammography were unable to detect 9 of the 16 additional cancers. Of the 9 additional cancers

that could only be observed on MRI, 8 were invasive. The study dispels the common belief and false sense of security that women with a negative mammogram or ultrasound result are cancer-free.

DIGITAL BREAST TOMOSYNTHESIS (DBT) SCREENING: DBT is based on anatomy and uses 3D imaging technology. Because DBT peels away overlying tissues, the sensitivity and specificity of mammography are greatly improved in both dense and fatty breasts. DBT likely will replace mammography in the future.

The 2012 Skaane, *et al.* study reported the results of 12,631 women in a prospective clinical trial in Oslo, Norway. The cancer detection rate was significantly higher with the DBT/ mammography combination compared to mammography alone (8 additional cancers/1,000 women screened versus 6.1 additional cancers/1,000 women screened). The DBT/ mammography combination also detected 40% more invasive cancers and led to 15% fewer false-positive results. However, no change was observed in the DCIS detection rate.

The 2013 Rafferty, *et al.* study reported significant decreases in recall rates among women with benign disease with the DBT/mammography combination compared to mammography alone: from 55.1% to 16.7% in reader study 1 and from 48.8% to 30.1% in reader study 2. The 2013 Screening with Tomosynthesis or Standard Mammography (STORM) prospective comparative trial demonstrated an improvement in cancer detection rates with the DBT/mammography combination compared to mammography alone. In the STORM cohort of 7,292 women who were screened from August 2011 to June 2012, the cancer detection rate was 5.3/1,000 with mammography alone versus 8.1/1,000 with the DBT/mammography combination.

The 2013 Haas, *et al.* study reported results from four sites in Connecticut among 7,058 women who were screened with mammography alone and 6,100 women who were screened with the DBT/mammography combination. The recall rate significantly declined in the group of women who were screened with the DBT/mammography combination (8.4% versus 12%). The reduction was observed among women with all breast densities and in all age groups. The cancer detection rate also was higher in the DBT/mammography combination group: 5.7/1,000 women screened versus 5.2/1,000 women screened.

The 2014 Friedenwald, *et al.* retrospective multi-center trial reported results from both academic and private practices among 281,187 women who were screened with full-field digital mammography (FFDM) and 173,663 women who were screened with the DBT/FFDM combination. Improvements with the DBT/FFDM combination were all significant: a decrease in the recall rate from 10.7%-9.1%; an increase in the cancer detection rate from 4.2/1,000 women screened to 5.4/1,000 women screened; and an increase in the positive predictive value of the recall rate from 4.3%-6.4%.

On the one hand, DBT detects ~1-2 additional cancers/1,000 women screened, results in fewer recalls that lead to anxiety in young women, improves the positive predictive value of breast

cancer screening, and might replace FFDM as the modality for routine screening. On the other hand, DBT delivers two times more radiation than mammography, but the exposure is still within current guidelines. Moreover, DBT is more expensive and requires more time to read compared to mammography.

ABRIDGED BREAST MRI SCREENING: The abridged breast MRI screening protocol potentially could make MRI more accessible by decreasing the cost, reading time, and number of magnetic sequences and technologist hours. The 2014 Kuhl, *et al.* prospective study read 606 screening MRIs in 443 women. Reading of MRIs was completed in three minutes with the abridged protocol versus 17 minutes in a full examination. Reading of MRIs was completed in 28 seconds with the fully abbreviated protocol at a 100% sensitivity rate and a 94.3% specificity rate. Reading of maximum intensity projection images only was completed in 2.8 seconds at a 90.9% sensitivity rate.

The 2014 Mango, *et al.* blinded study used the abridged breast MRI screening protocol to read the results of 100 patients with known cancers. The three sequences evaluated in the study required 15 minutes to perform. The mean time to complete reading was 59 seconds. The readers visualized >95% of cancers in a single MRI sequence. The sensitivity rate increased to 100% with knowledge of the patient's history and prior examinations.

Overall, the same limitations of breast MRI persist even in an abridged screening protocol. Most notably, MRI is extremely expensive, not universally available, leads to numerous false-positive results, and cannot be used in subgroups of patients who have metallic implants, claustrophobia or allergies to gadolinium.

CONTRAST ENHANCED SPECTRAL MAMMOGRAPHY (CESM): CESM involves the administration of computed tomography (CT) contrast that is injected via a power injector. After two different types of images are generated, the images are processed by removing background tissue. The major risk of CESM is the administration of iodinated contrast that leads some patients to have reactions to gadolinium. Moreover, the radiation dose from CESM is ~20% higher than routine mammography screening (or the equivalent of one additional image).

At this time, 44 CESM units have been installed in the United States and >100,000 CESM tests have been performed worldwide. For example, the volume of CESM tests performed by the Memorial Sloan Kettering Cancer Center Breast and Imaging Center has increased from 110 in 2013 to 652 to 2015. The 2011 Dromain, *et al.* study used unilateral CESM to review abnormal mammography results of 120 women in France. The sensitivity rate for detecting cancers was significantly higher with CESM (93%) compared to mammography (78%). The specificity of detecting cancer was significantly more accurate with the CESM/mammography combination compared to the mammography/ultrasound combination.

The 2013 Jochelson, *et al.* study reported results of the first bilateral CESM in a cohort of women with known cancer. The cancer detection rates were 96% with CESM, 96% with MRI and 81%

with mammography. The 2011 Diekmann, *et al.* multi-reader study compared CESM and mammography in 70 women with dense breasts in Germany. The sensitivity rate for detecting cancers was significantly higher with CESM (59%) compared to mammography (35%).

The 2014 Cheung, *et al.* study used CESM in 89 patients with dense breasts in Taiwan. Compared to mammography, CESM improved sensitivity to detect cancers from 71.5%-92.7% and specificity from 51.8%-67.9%. The 2014 Lobbes, *et al.* study reported differences between the use of CESM in normal-risk patients screened and 113 patients with abnormal mammography screening results in the Netherlands. The improved performance of CESM over mammography was significant: an increase in the sensitivity rate from 96.9%-100%; an increase in the specificity rate from 42%-87.7%, an increase in the positive predictive value of screening from 39.7%-76.2%, and an increase in the negative predictive value from 97.1%-100%.

Dr. Jochelson concluded her overview by describing the current landscape of breast cancer screening of young women based on results of the U.S. and international studies. Annual mammography in average-risk women 40-49 years of age significantly reduces both morbidity and mortality. Average-/intermediate-risk women 40-49 years of age should undergo annual screening. Intermediate-risk women with dense breasts may benefit from additional imaging. High-risk women 40-49 years of age benefit from screening with mammography and MRI every six months.

The 2015 Oeffinger, *et al.* study reached the following conclusion: "Given the weight of the evidence that mammography screening is associated with a significant reduction in the risk of dying from breast cancer after 40 years of age, a more productive discussion should be focused on how to improve the performance of mammography screening."

Ultrasound, DBT, MRI and CESM detect more cancers than mammography alone and generate other benefits as well. MRI detects ~97% of cancers. DBT reduces the rate of recalls that lead to anxiety in young women. CESM improves the sensitivity and specificity of detecting cancers. Prospective trials are underway to compare the efficacy of these screening modalities, but physiology will have more weight than anatomy in cancer detection and patients with metastatic disease. Additional time is needed to confirm the clinical advantages of these screening modalities. Breast cancer screening of women 40-49 years of age should be improved, but not discontinued.

ACBCYW DISCUSSION: BREAST CANCER SCREENING OF YOUNG WOMEN

ACBCYW proposed several next steps in response to Dr. Jochelson's comprehensive and extremely informative presentation.

- CDC should invite a USPSTF representative to a future ACBCYW meeting to present the evidence review that served as the basis of its current guidelines for women 40-49 years to discuss screening with their physicians and for women 50-74 years of age to be screened biennially. Most notably, the current USPSTF guidelines do not address

morbidity-related issues, such as the high cost of and side effects from chemotherapy, when breast cancer is detected later in women ≥50 years of age.

- The Provider Workgroup should draft clear guidance to assist HCPs in screening young women with dense breasts. Because Asian American women have the densest breasts of any other racial/ethnic group, specialized messaging should be developed for HCPs who serve this population.
- The General Population/High-Risk Workgroup should draft messaging to compare the cost of breast cancer screening and the value of young women who die from breast cancer, such as the loss of their legacies, knowledge, incomes, and future impact on children and other family members.

ACBCYW Open Discussion: Session 2

Ann H. Partridge, MD, MPH, ACBCYW Chair
Director, Adult Survivorship Program & Founder and Director,
Program for Young Women with Breast Cancer, Dana-Farber Cancer Institute
Associate Professor, Harvard Medical School

Dr. Partridge facilitated the second ACBCYW open discussion for the members to reach consensus on the chairs, memberships and other aspects of the workgroups. To guide the discussion, she reviewed the original charges and tasks that ACBCYW approved for the four workgroups established in 2011-2015.

ACBCYW Workgroup	Workgroup Charge/Tasks
Provider Workgroup	Gather initial background information to advise ACBCYW on changing the behavior of providers in the context of: • Enhancing provider knowledge regarding breast cancer in young women. • Assessing gaps, guidelines and issue-based messaging regarding breast cancer in young women. • Improving the skills of providers regarding delivery of care to young women at average and high risk of and/or facing breast cancer (e.g., survivors).
High-Risk Workgroup	Gather initial background information to advise ACBCYW in the following areas:

ACBCYW WORKGROUP	
	• Developing an understanding of the meaning of "high risk" for breast cancer in the context of young women. • Identifying potential evidence-based messages to be disseminated to these populations.
General Population Workgroup	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 the 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. • Develop 3-5 key messages regarding breast health awareness that CDC should promote to the general population of young women.

ACBCYW WORKGROUP	
Social Justice Workgroup	Focus on social justice issues that have an impact on increased awareness, early detection and care of young women who are at risk for or develop breast cancer.

Dr. Fairley informed the members that the workgroups could take no further action without ACBCYW's consensus at two levels. First, consensus is needed on the next steps for each workgroup in terms of its retention, dissolution or revision of the charge/tasks. Second, consensus is needed on the composition of each workgroup in terms of its chair and membership.

Dr. Partridge clarified that although ACBCYW is responsible for establishing the workgroup charges, each individual workgroup is allowed to identify specific tasks to fulfill its charge. For example, one of the original Provider Workgroup tasks was to assess BCYW gaps, guidelines and issue-based messaging, but this effort was initiated in 2011 with background information that was available at that time. If ACBCYW approves the retention of this workgroup, the new members could continue this task, but with an assessment of more recent data.

ACBCYW Consensus	**Retain the Provider Workgroup**
Workgroup Membership	Dr. Sue Friedman, Co-Chair Dr. Karen Meneses, Co-Chair Ms. Sarah Storey, Member
Draft Charge/Tasks Proposed	*Draft Charge:* Review activities completed by the previous membership; gather new background information to further improve provider behavior, education and training regarding breast cancer in young women; and advise ACBCYW on prioritizing and supporting ongoing programmatic efforts in the future. *Tasks Proposed for Data Collection:* • Program outcomes and evaluation results from newer initiatives conducted by Bright Pink and other national organizations • Newer technologies to improve the care of young women with breast cancer • Newer YBCS data • New state breast-density laws that require reporting and providing education to women • Updated guidelines on genetic testing, referral to genetic counseling and interpretation of laboratory reports

ACBCYW Consensus	**Rebrand the newly integrated General Population/High-Risk Workgroup as the new "General Risk Assessment and Management Workgroup"**
Workgroup Membership	Dr. Tari King, Co-Chair Dr. Susan Kutner, Co-Chair
Draft Charge/Tasks Proposed	*Draft Charge:* The workgroup will use the first teleconference to draft its charge in collaboration with ACBCYW and CDC. Several ACBCYW members proposed tasks for the workgroup to consider in the interim. *Tasks Proposed* • Draft messaging to inform the public that no modality exists at this time to screen young women in the general population for breast cancer • Gather compelling data to present a strong evidence-based case to the HHS Secretary to recommend changes to the current USPSTF guidelines that call for biennial screening of women 50-74 years of age. For example, the $14.1 million WISDOM Study, led by Dr. Laura Esserman at the University of California, San Francisco, would serve as an excellent data source to include younger women <50 years of age in the current USPSTF breast cancer screening guidelines. The five-year study began in 2015 with a cohort of 100,000 women 40-80 years of age to evaluate whether a personalized approach to breast cancer screening is as safe and effective as annual mammography. • Collect data to demonstrate the heavy weight of international studies reviewed for the current USPSTF breast cancer screening guidelines that do not reflect the diversity of young women in the U.S. population • Expand the traditional focus on evidence-based programs with broader data collection efforts to include practice-based evidence on BCYW in the general population. For example, guidance should be drafted to support, promote and evaluate effective grassroots, community-based programs in the field. • Propose more strategies to deliver messages and distribute information via cell phones to increase access to breast cancer services, support and other resources. For example, the subpopulation of underserved young women (e.g., women in rural areas or hard-to-reach women) is more likely to have easier access to a cell phone-based BCYW campaign than a web-based social media campaign.

DFO's call for a vote	The DFO entertained a motion for ACBCYW to formally approve the establishment of a new "Survivorship Workgroup" that would include young women living with metastatic disease.
Outcome of vote	**Motion unanimously passed by 12 ACBCYW voting members**
Workgroup Membership	Dr. Ulrike Boehmer, Co-Chair Dr. Don Dizon, Co-Chair
Draft Charge/Tasks Proposed	*Draft Charge:* Review and identify the current state of affairs regarding breast cancer survivorship care for young women, to include all stages of disease, and give special attention to patient-centered care and healthy equity. Advise ACBCYW on needs and gaps that should be prioritized. *Tasks Proposed:* • Review current surveillance, management and evaluation data on the side effects of breast cancer treatment in YBCS/ young women living with metastatic disease and the potential for recurrence of disease in these populations • Collect data on issues related to quality of life, mental health, and access to screening and treatment for YBCS, family members of YBCS who also are breast cancer survivors, and young women living with metastatic disease • Gather surveillance data on adherence to hormonal therapies over time among YBCS and young women living with metastatic disease • Identify needs of and gaps in service for YBCS and young women living with metastatic disease to ensure the continuum of care to these populations and optimize their physical, psychosocial and other health outcomes • Compile best practices that promote culturally and linguistically responsive care, support and services for YBCS and young women living with metastatic disease

ACBCYW Consensus	**Dissolve the new Social Justice Workgroup**
Next Steps	Each workgroup will include health equity as an overarching theme and a guiding principle in its activities. All three workgroups will determine the role of health equity for their specific target audiences: providers, young women at various levels of risk for breast cancer, and YBCS/young women living with metastatic disease.

Dr. Fairley described the next steps in terms of CDC providing the workgroups with logistical, administrative and technical support to initiate their activities. CDC will circulate an e-mail over the next few days to solicit other ACBCYW members to serve on the Provider, General Risk Assessment and Management, and Survivorship Workgroups. CDC will consult with the new chairs to schedule their initial teleconferences and provide contact information for all workgroup members. CDC will draft the agenda of the next ACBCYW meeting to include the first updates by the workgroups, including revisions to refine their draft charges and preliminary tasks.

Dr. Partridge added that efforts would be made to engage former ACBCYW members to serve on the workgroups on an ongoing or ad hoc basis for institutional memory.

- Dr. Generosa Grana, former chair of the Provider Workgroup
- Dr. Lisa Newman, former chair of the General Population Workgroup
- High-Risk Workgroup member in place of Ms. Shoretz as chair

Public Comment Session

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

Closing Session

Dr. Partridge thanked the ACBCYW members for continuing to provide excellent advice and guidance to improve CDC's portfolio of BCYW research and other activities. She particularly thanked the new members for their innovative recommendations and creative strategies to guide ACBCYW's future direction in 2016 and beyond. She also thanked the ACBCYW members who volunteered to serve on the workgroups as chairs and members.

Dr. Partridge's position was that the draft charges and proposed tasks of the workgroups would tremendously improve ACBCYW's advisory role to HHS and CDC in the future. She reminded the new members to visit the ACBCYW website to review the previous meeting minutes, recommendations to the HHS Secretary, archived presentations and other materials: (http://www.cdc.gov/cancer/breast/what_cdc_is_doing/young_women.htm).

With no further discussion or business brought before ACBCYW, Dr. Fairley adjourned the meeting at 2:25 p.m. on January 29, 2016.

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

_____
Date

_____
Ann H. Partridge, MD, MPH, Chair
Advisory Committee on Breast Cancer in Young Women

Centers for Disease Control and Prevention

ADVISORY COMMITTEE on BREAST CANCER in YOUNG WOMEN

January 28-29, 2016 Meeting

Attachment 1: Published Meeting Agenda

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

Day 1: Thursday, January 28, 2016

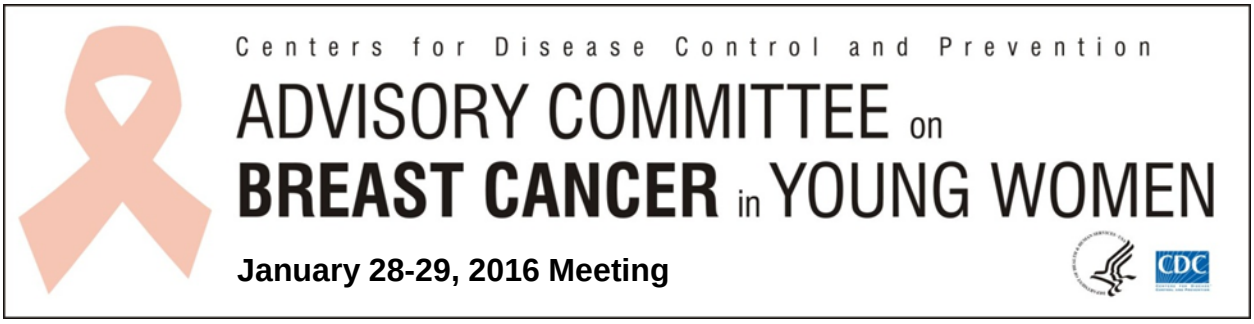
9:30 A.M. – 9:45 A.M.	**Opening: Welcome and Roll Call** *Temeika L. Fairley, PhD* Designated Federal Officer, DCPC, CDC *Ann H. Partridge, MD, MPH* Dana-Farber Cancer Institute ACBCYW Committee Chair *Lisa Richardson, MD, MPH* Director, DCPC, CDC
9:45 A.M. – 10:00 A.M.	**Introduction of ACBCYW Members** *Ann H. Partridge, MD, MPH* Dana-Farber Cancer Institute ACBCYW Committee Chair
10:00 A.M. – 10:30 A.M.	**Overview of the ACBCYW: 2011-2015** *Ann H. Partridge, MD, MPH* Dana-Farber Cancer Institute ACBCYW Committee Chair

10:30 A.M. – 11:00 A.M.	**Breast Cancer in Young Women: The Role of Public Health** *Lisa Richardson, MD, MPH* Director, DCPC, CDC
11:00 A.M. – 11:30 A.M.	**Update from CDC: Overview of EARLY Act Funded Efforts** *Temeika L. Fairley, PhD* Designated Federal Officer, DCPC, CDC
11:30 A.M. – 12:45 P.M.	**Lunch**
12:45 P.M. – 2:15 P.M.	**Updates from CDC: Genomics and Communications** *Juan Rodriguez, MPH, MS* *Epidemiologist, DCPC, CDC* *Temeika L. Fairley, PhD* Designated Federal Officer, DCPC, CDC *Sunita Theiss* Health Communications Specialist, DCPC, CDC *Junia Geisler* Vice President, Ogilvy Public Relations, Washington DC
2:15 P.M. – 2:30 P.M.	**Break**
2:30 P.M. – 3:30 P.M.	**Open Discussion**
3:30 P.M. – 3:45 P.M.	**Public Comment**
3:30 P.M. – 4:00 P.M.	**Wrap-Up/Announcements/Adjourn** *Ann H. Partridge, MD, MPH* Dana-Farber Cancer Institute ACBCYW Committee Chair

Day 2: Friday, January 29, 2016

9:30 A.M. – 9:45 A.M.	**Opening, Highlights, and Review** *Temeika L. Fairley, PhD* Designated Federal Officer, DCPC, CDC *Ann H. Partridge, MD, MPH* Dana-Farber Cancer Institute ACBCYW Committee Chair
9:45 A.M. – 10:30 A.M.	**Updates from the Field** *Valerie Rochester, MPA* Director of Programs, Black Women's Health Imperative *Arin Ahlum Hanson, MPH, CHES* Young Women's Initiative Manager, Living Beyond Breast Cancer *Elana Silber, MBA* Executive Director, Sharsheret
10:30 A.M. – 11:00 A.M.	**Emerging Topics in Early Breast Cancer** *Maxine Jochelson, MD* Director of Radiology, Breast and Imaging Center Memorial Sloan Kettering Cancer Center
11:00 A.M. – 12:00 P.M.	**Open Discussion (1)**
12:00 P.M. – 1:15 P.M.	**Lunch**
1:15 P.M. – 2:30 P.M.	**Open Discussion (2)**
2:30 P.M. – 2:45 P.M.	**Public Comment**
2:45 P.M. – 3:00 P.M.	**Wrap Up/Announcements/Adjourn** *Temeika L. Fairley, PhD* Designated Federal Officer, DCPC, CDC

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



Attachment 2: Roster of the ACBCYW Membership

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Centers for Disease Control and Prevention

ADVISORY COMMITTEE on BREAST CANCER in YOUNG WOMEN

January 28-29, 2016 Meeting

Attachment 3: Participants' Directory

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Attachment 4: Glossary of Acronyms

ACA	Affordable Care Act
ACBCYW	Advisory Committee on Breast Cancer in Young Women
ACOG	American Congress of Obstetricians and Gynecologists
ACS	American Cancer Society
BCYW	Breast Cancer in Young Women
BSE	Breast Self-Examination
BWHI	Black Women's Health Imperative
CBE	Clinical Breast Examination
CBOs	Community-Based Organizations
CCCP	Colorectal Cancer Control Program
CDC	Centers for Disease Control and Prevention
CESM	Contrast Enhanced Spectral Mammography
CHIS	California Health Interview Survey
CoAg	Cooperative Agreement
CT	Computed Tomography
DBT	Digital Breast Tomosynthesis
DCIS	Ductal Carcinoma In Situ
DCPC	Division of Cancer Prevention and Control
DFO	Designated Federal Officer
EARLY Act	Education and Awareness Requires Learning Young Act
EHR	Electronic Health Record
FFDM	Full-Field Digital Mammography
FHAT	Family History Assessment Tool
FHS-7	Family Health Screen 7
HBOC	Hereditary Breast and Ovarian Cancer
HCPs	Healthcare Providers
HHS	U.S. Department of Health and Human Services
LBBC	Living Beyond Breast Cancer
LGB	Lesbian/Gay/Bisexual
MRI	Magnetic Resonance Imaging

NBCCEDP	National Breast and Cervical Cancer Early Detection Program
NCCCP	National Comprehensive Cancer Control Program
NCCDPHP	National Center for Chronic Disease and Health Promotion
NCCN	National Comprehensive Cancer Network
NCI	National Cancer Institute
NPCR	National Program of Cancer Registries
NPO	Non-Profit Organization
OCRP	Ovarian Cancer Risk Perception Study
PAT	Pedigree Assessment Tool
PCPs	Primary Care Physicians
Project ECHO	Extension for Community Healthcare Outcomes
SAHIEs	Small Area Health Insurance Estimates
STORM	Screening with Tomosynthesis or Standard Mammography
USPSTF	U.S. Preventive Services Task Force
YBCS	Young Breast Cancer Survivors
YSI	Young Sisters Initiative
YWI	Young Women's Initiative