

**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**



**Virtual Meeting of the  
Advisory Committee on Breast Cancer in Young Women  
December 13, 2016**

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**DRAFT Record of the Proceedings**

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**ADVISORY COMMITTEE ON BREAST CANCER IN YOUNG WOMEN  
December 13, 2016**

**Minutes of the Virtual Meeting**

The U.S. Department of Health and Human Services (HHS) and the Centers for Disease Control and Prevention (CDC), National Center for Chronic Disease Prevention and Health Promotion, Division of Cancer Prevention and Control (DCPC), convened a virtual meeting of the Advisory Committee on Breast Cancer in Young Women (ACBCYW) on December 13, 2016.

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 virtual ACBCYW meeting via teleconference or webinar 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**

**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 and confirmed that the 15 voting members and *ex-officio* members (or their proxies) in attendance constituted a quorum for ACBCYW to conduct its business on December 13, 2016. She called the proceedings to order at 1:18 p.m. EST and welcomed the participants to the virtual ACBCYW meeting. None of the voting members publicly declared conflicts of interest for any of the items on the published agenda (*Attachment 1: Published Meeting Agenda*).

**Ann H. Partridge, MD, MPH, 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 extended her welcome to the participants. She was pleased that ACBCYW is continuing to make tremendous progress on its mission to improve the lives of young women who develop or are at risk of developing breast cancer. She led the members in a review of the major agenda items: updates on CDC's cancer activities, overviews of BCYW initiatives in the field, and ACBCYW workgroup reports.

Dr. Partridge announced that her extended term expired in November 2016. The new ACBCYW Chair would begin serving in this role in 2017. She thanked CDC for the opportunity to have served as the chair since ACBCYW was established in 2011.

## 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 has created an impressive portfolio of cancer survivorship activities.

*Research and Publications*

- Surveillance of Demographic Characteristics and Health Behaviors Among Adult Cancer Survivors—Behavioral Risk Factor Surveillance System, United States, 2009
- A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies
- Advancing Public Health Research, Surveillance and Programs
- Cancer Rehabilitation and Survivorship: Transdisciplinary Approaches to Personalized Care

*Programs*

- Comprehensive Cancer Control: Collaborating to Conquer Cancer

- Livestrong at the YMCA

#### *Population-Based Surveys*

- Behavioral Risk Factor Surveillance System
- National Health Interview Survey
- Medical Expenditure Panel Survey

#### *Surveillance*

- National Program of Cancer Registries

#### *Health Promotion*

- Web-based materials (e.g., cancer survivorship and approaches to care for cancer survivors who use tobacco)
- Bring Your Brave Public Health Education Campaign
- 8<sup>th</sup> Biennial Cancer Survivorship Research Innovation in a Rapidly Changing Landscape

CDC commissioned an expert committee of the National Academies of Sciences, Engineering and Medicine (formerly the Institute of Medicine) in response to a Congressional request. The committee was charged with examining and summarizing the state of the science in ovarian cancer research; identifying key gaps in the evidence base; and identifying opportunities for advancing ovarian cancer research.

The committee released a report of its findings in March 2016, *Ovarian Cancers: Evolving Paradigms in Research and Care*. The report presents a broad overview of ovarian cancer research and provides recommendations to help reduce the incidence of and morbidity and mortality from ovarian cancers. The report highlights three key recommendations related to hereditary breast and ovarian cancer (HBOC) syndrome: develop and implement strategies to increase genetic counseling and testing; evaluate the performance and utility of testing tools; and identify biologic mechanisms of new and established risk factors. (URL of the National Academies report:

<http://www.nationalacademies.org/hmd/Reports/2016/state-of-ovarian-cancer.aspx>)

CDC conducted a Public Health Grand Rounds in 2016 that was well received, “Family History and Genomics as Tools for Cancer Prevention and Control.” The presenters included DCPC, the CDC Office of Public Health Genomics, Michigan Department of Health and Human Services, and Bright Pink representatives. CDC’s Public Health Grand Rounds was published in the *Morbidity and Mortality Weekly Report (MMWR)* in November 2016.

Vice President Joe Biden announced the White House’s plan in February 2016 to increase public and private resources to fight cancer, eliminate silos, and convene all cancer fighters to collaborate, share information and end cancer. The goal of the “Cancer Moonshot” initiative is to make a decade’s worth of advances in cancer prevention, diagnosis and treatment in five years

by integrating science, technology, advocacy, social science and data to solve the greatest challenges related to cancer. The timeline of the Cancer Moonshot activities is highlighted below.

- January-February 2016: Release of the White House memorandum and announcement by Vice President Biden
- April 2016: Engagement of CDC and the Centers for Medicare and Medicaid Services
- May 2016: Launch of the Prevention and Diagnosis Workgroup
- June 2016: Moonshot Summit
- September-October 2016: Release of the Blue Ribbon Panel report and the Federal Task Force report

The organizational structure of the Cancer Moonshot initiative includes the Federal Task Force with representation by the National Cancer Institute (NCI) and the Blue Ribbon Panel. The Federal Task Force formed five workgroups: Science, Data, Therapies, Prevention and Diagnosis, and Access and Care Workgroups. Dr. Richardson represents CDC on the Prevention and Diagnosis Workgroup. The Blue Ribbon Panel formed seven workgroups to conduct specific activities: Cancer Immunology and Prevention, Tumor Evolution and Progression, Precision Prevention and Early Detection, Expanding Clinical Trials, Pediatric Cancer, Enhanced Data Sharing, and Implementation Sciences Workgroups.

The Cancer Moonshot Task Force report highlighted five priority areas: catalyze new scientific breakthroughs, unleash the power of data, accelerate the development of new therapies for patients, strengthen prevention and diagnosis, and improve patient access and care. The 2016 Cancer Moonshot Blue Ribbon Panel Report also provided a series of recommendations:

- Establish a network for direct patient involvement
- Create a clinical trials network exclusively devoted to immunotherapy
- Develop strategies to overcome resistance to therapy
- Build a national cancer data ecosystem
- Intensify research on the major drivers of childhood cancers
- Minimize the debilitating side effects of cancer treatment
- Expand the use of proven prevention and early detection strategies (CDC-led activity)
- Mine past patient data to predict future patients
- Develop a 3D Cancer Atlas
- Develop new cancer technologies

The recommendation targeted to CDC in the Blue Ribbon Panel report builds on its existing expertise and experience in translating evidence into practice. CDC has a long history of disseminating and implementing evidence-based interventions in communities. CDC and NCI recently discussed the possibility of leveraging new funding to accelerate these activities for the Cancer Moonshot initiative.

CDC and the U.S. Food and Drug Administration are collaborating on a two-year project that is funded by the Patient-Centered Outcomes Research Trust Fund. The overarching goal of the project is to develop a natural language processing (NLP) web service for structuring and standardizing unstructured clinical information. The NLP platform will be piloted to determine its utility in cancer registries (CDC) and safety (FDA) surveillance domains, but the web service ultimately will be expanded to meet other domain requirements.

The high-level conceptual design of the NLP platform includes a language model, pipeline services and taxonomy services that will support a “Clinical NLP Workbench.” The workbench will include tools for loading, parsing and annotating data, providing training, building a language model, and offering online learning.

DCPC published an *MMWR* article in October 2016, “Patterns and Trends in Age-Specific Black-White Differences in Breast Cancer Incidence and Mortality—United States, 1999-2014.” The study reported that trends in invasive female breast cancer incidence have continued to narrow between white and black women from 1999-2013. The study further showed that racial/ethnic differences in female breast cancer death rates among younger women are diminishing. Based on the study findings, DCPC is interested in identifying specific risk factors and targeting effective therapies.

CDC, the Health Resources and Services Administration (HRSA) and the National Institutes of Health participated in an engagement session with the U.S. Government Accountability Office (GAO) to answer questions on a draft report, *Breast Cancer Education: HHS Has Implemented Initiatives Aimed at Young Women*. The final GAO report was published in October 2016 and issued no recommendations to HHS (<http://www.gao.gov/products/GAO-17-19>).

DCPC collaborated with the CDC Office on Smoking and Health to release a *Vital Signs* report in November 2016 on cancer and tobacco use. The report cited three major data points: (1) Tobacco use causes at least 12 types of cancer;(2) Cancers linked to tobacco use contribute to 40% of all diagnosed cancers;(3) Cigarette smoking causes 3 in 10 of all cancer deaths.

The *Vital Signs* report also was released to raise public awareness of the categories of activities that are conducted by 65 CDC-funded Comprehensive Cancer Control Programs in the United States, District of Columbia, U.S. territories and tribes. “Prevention” activities focus on creating tobacco-free environments to help prevent cancer. “Early detection and care activities” focus on increasing access to early detection and care for tobacco-related cancers. “Survivorship” activities focus on helping cancer survivors who use tobacco to quit. “Good health for all” activities focus on cancer outcomes for all persons, particularly communities with higher tobacco-related cancers and deaths.

Dr. Richardson concluded her update by commending Dr. Partridge for her excellent role as the ACBCYW Chair over the past five years. She confirmed that the progress and successes ACBCYW has achieved over time were a direct result of Dr. Partridge’s leadership and vision.

Dr. Fairley provided additional details on the GAO engagement process. The Education and Awareness Requires Learning Young (EARLY) Act was reauthorized in 2014 with two new provisions for GAO: (1) identify HHS activities to provide breast cancer education and (2) assess whether the HHS activities are duplicative of other federal breast cancer education efforts.

Dr. Fairley reiterated that the final GAO report was published in October 2016 and has been shared with Congress. GAO did not issue any recommendations to HHS, but the report provides an extensive overview of EARLY Act-funded initiatives over the past six years, such as BCYW projects, research, educational campaigns and partnerships. She thanked the ACBCYW members who provided thoughtful input and extremely helpful guidance to inform the GAO engagement process. She also thanked the DCPC staff for its outstanding efforts in compiling and preparing materials for this process.

### Update on 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 update on CDC's Bring Your Brave campaign. However, she first showed a photograph of Jackie, who is 39 years of age, and her young child. Jackie is a campaign spokesperson who was affected by breast cancer at a young age. CDC typically makes data-driven presentations, but Dr. Fairley showed the photograph of Jackie and her child to remind ACBCYW of the impact of breast cancer and HBOC on the actual lives of young women and their families.

CDC launched Bring Your Brave in May 2015 as a social and digital media campaign to provide information about breast cancer to women 18-44 years of age. CDC designed the campaign to achieve four key objectives.

- Encourage young women to learn their family history of breast ovarian cancer.
- Educate young women on risk factors for breast cancer before 45 years of age, particularly young African American and Ashkenazi Jewish women.
- Inspire and empower young women to engage healthcare providers/professionals (HCPs) in discussions about their potentially higher risk for breast cancer.
- Encourage young women to live healthy lifestyles and be aware of their individual breast health.

CDC conducted formative research at the outset to ensure the effectiveness of the Bring Your Brave campaign and maximize its reach to the target audience. The research showed that young women 18-44 years of age most frequently seek health information through social media and other online platforms. Personal stories were found to play an instrumental role in BCYW conversations, but stories shared via social media typically did not provide a tangible call to action related to breast cancer risks or describe concrete next steps.

Materials for young Jewish women need to be developed to “show” this population of women, cite facts and statistics specific to Jewish women, provide proactive guidance, and include messages with an upbeat and positive tone. Materials for young African American women need to be developed to “show” this population of women 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.

CDC identified several opportunities to refine the Bring Your Brave campaign based on the findings of its formative research. First, a tangible call to action related to breast cancer risks need to be provided through audience-based messaging and materials that are centered around personal stories. Second, social media channels with the most active audiences of young women need to be leveraged to broadly share the call to action. Third, supporting content need to be created and optimized for social medial channels that can extend the reach of messaging. Fourth, a platform need to be provided for previvors (persons with a known genetic predisposition for hereditary breast cancer), survivors, caregivers and supporters to share their powerful personal stories of the impact of breast cancer on their lives.

CDC agreed that an “influence the influencer” approach would be best suited for the Bring Your Brave campaign. Breast cancer is not a priority for most young women, but other young women with a personal story on this issue can serve as powerful messengers. The strategy is designed to harness the power of young women who have a strong connection to breast cancer through either a family or personal history. The “influence the influencers” approach also serves as a platform for young women to share their individual stories with online communities.

Dr. Fairley presented a series of slides to highlight key features of the Bring Your Brave campaign:

- A video of Jackie and her child in which digital storytelling was used to implement the “influence the influencers” strategy
- Digital content, such as infographics tailored to specific audiences
- Paid media
- Bring Your Brave website, including the new “Share Your Story” feature and resources for survivors, previvors, caregivers and supporters to create a campaign badge
- A note from Meagan, 22 years of age and a campaign spokesperson, who shared her personal experience regarding the power of the “influence the influencer” strategy

To date, the Bring Your Brave campaign has generated 95 million impressions across social media, blogs, search engines, digital displays and earned media; ~1.3 million video views; 826,203 social media engagements; and 132,972 visits to the website. With the exception of the Inside Knowledge gynecologic cancer campaign, the Bring Your Brave website generates more visits than any other CDC.gov/cancer website.

Other notable successes of the Bring Your Brave campaign include the CDC Award for Excellence in Communication; the Certificate of Excellence: Public Service Through the Public Relations Society of America; and the first peer-reviewed publication, *Getting Beyond Impressions: An Evaluation of Engagement with Breast Cancer-Related Facebook Content* (<http://mhealth.amegroups.com/article/view/12304>).

CDC's next steps in the Bring Your Brave campaign will be to focus on HCP outreach, partner engagement and new social media platforms. For HCP education, CDC contracted Links Media and Medscape to develop and disseminate continuing medical education (CME) on breast health and breast cancer in young women in January 2017. Existing resources, such as Know:BRCA, will be promoted to the HCP community.

CDC has taken specific actions to respond to ACBCYW's previous recommendations on Know:BRCA. Retrospective and prospective evaluations of Know:BRCA are underway and are expected to be completed in August 2017. The evaluations are designed to review de-identified data to determine the effectiveness of Know:BRCA in identifying women who potentially are at high risk for having a BRCA mutation.

CDC also has initiated a planning process for experts in the field to lead a discussion on the future direction of Know:BRCA. The key topics will include HCP engagement, dissemination and the feasibility of incorporating Know:BRCA into electronic health/medical record systems. The ACBCYW membership will be well represented on the expert panel: Drs. Raquel Arias, Ulrike Boehmer, Sue Friedman, Susan Kutner, Karen Meneses and Ann Partridge.

#### **ACBCYW Discussion: CDC's BCYW ACTIVITIES**

ACBCYW commended CDC on the extraordinary progress that has been made on its portfolio of BCYW research and activities since the previous meeting. Several members were impressed and excited that a much larger segment of the target audience is actively engaged in the Bring Your Brave campaign. Other members were pleased that the current phase of the campaign is focusing on HCP engagement and education, particularly the CME for breast health and breast cancer in young women.

During the upcoming discussion on the future direction of Know:BRCA, Dr. Dizon advised the expert panel to explore the possibility of expanding Know:BRCA to include advancements in genomics sequencing and new gene mutations. Dr. Fairley clarified that CDC is only focusing on the evaluation of Know:BRCA at this time, but Dr. Dizon's suggestions will be considered in future efforts.

## UPDATES ON BCYW ACTIVITIES FROM THE FIELD

A panel of two ACBCYW liaison representatives presented overviews of BCYW activities in the field conducted by their organizations.

### Overview by the Patient Advocate Foundation

#### **Shonta Chambers, MSW**

Executive Vice President, Health Equity Initiatives and Programs  
Patient Advocate Foundation

Ms. Chambers presented an overview of BCYW activities conducted by the Patient Advocate Foundation (PAF) ([www.patientadvocate.org](http://www.patientadvocate.org)). The mission of PAF is to safeguard patients through effective mediation by assuring their access to care, maintenance of employment, and preservation of financial stability relative to a diagnosis of a life-threatening or debilitating disease.

PAF is a highly rated, charitable and national non-profit 501(c)(3) organization that has earned seven consecutive 4-star Charity Navigator designations and numerous case management awards. PAF employs professional case managers who have expertise and experience in coding and billing, public health and disability systems, insurance and nursing. PAF also provides case management services at no cost to patients with a chronic, life-threatening or debilitating disease. PAF is headquartered in Hampton, Virginia and celebrated its 20<sup>th</sup> anniversary in April 2016.

The diagnosis of a chronic, life-threatening or debilitating disease has a much more profound impact on fragile low-income households. Most notably, persons with annual household incomes ≤\$34,000 account for >61% of the total PAF patient population. The breakdown of the PAF patient population by key demographics is described below.

<b>DEMOGRAPHIC GROUP</b>	<b>PERCENT OF PAF PATIENTS</b>
<b>AGE (in years)</b>	
0-18	2%
19-25	3%
26-35	9%
36-45	12%
46-55	23%
56-65	26%
Over 65	17%
<b>RACE/ETHNICITY</b>	
Caucasian	57%
African American	17%
Hispanic/Latino	11%
Asian	2%
Blended Race	1%
American Indian	1%
Middle Eastern	<1%
Native Hawaiian/Pacific Islander	<1%
Caribbean Islander	<1%
<b>INSURANCE COVERAGE</b>	
Commercially Insured (29% in 2014)	32%
Medicare	26%
Uninsured (20% in 2014)	16%
Medicaid	12%
Military Benefits	1%
<b>ANNUAL HOUSEHOLD INCOME</b>	
<\$11,000	25%
\$12,000-\$23,000	23%
\$24,000-\$35,000	13%
\$36,000-\$47,000	7%
\$48,000-\$59,000	4%
\$60,000-\$71,000	3%
\$72,000-\$83,000	1%

DEMOGRAPHIC GROUP	PERCENT OF PAF PATIENTS
\$84,000-\$95,000	1%
\$96,000-\$107,000	1%
≥\$120,000	2%

PAF provides a variety of confidential and secure services, resources and assistance at no cost to fulfill its mission and meet the needs of patients, their caregivers or points of contact:

- Real-time assistance in the current environment
- Personalized assistance
- Designated case managers to provide comprehensive support
- Thorough and comprehensive case assessments to identify and resolve both short- and long-term barriers or issues for patients
- Active liaisons to advocate on the behalf of patients
- Telephone-based interaction
- Engagement within 48 hours
- Issue-specific assistance focusing on insurance, financial stability/medical debt, and employment
- Referral source for providers

The population that is eligible for PAF case management services is broad and includes persons of any age, any insurance status, any gender, any race/ethnicity or cultural heritage, any employment status, any annual household income, and residence in any state in the United States or U.S. territory. However, persons are required to have an official diagnosis or pending screening results of a PAF-defined “debilitating,” “chronic” or “life-threatening” illness.

PAF does not support local walk-in facilities or provide direct funds or grants. PAF services do not cover fraud, active court litigation, medical malpractice, disease research, accidents, injuries, non-chronic illnesses, medical or pharmaceutical advice, and emotional/mental health. Non-U.S. citizens and undocumented immigrants also are eligible for PAF case management services, but assistance and resources for these patient populations might be limited in certain jurisdictions.

PAF offers its services, resources and assistance to patients through numerous mechanisms, such as case management, co-pay relief, specialty programs, financial aid funds, educational materials and college scholarships. The PAF Co-Pay Relief (CPR) Program provides direct financial assistance to insured patients who cannot afford a co-payment or co-insurance to access their prescribed pharmaceutical therapies. Eligibility criteria for the CPR Program are based on four requirements:

- Some level of insurance coverage for needed medications (e.g., commercial insurance, military TRICARE plan or Medicare coverage)

- Diagnosis/medication for treatment matching funds related to the diagnosis
- Household income ≤400% of the Federal Poverty Level
- Current residence and receipt of treatment in the United States

Specific online portals for patients, providers and pharmacies can be rapidly accessed at any time on the CPR Program website (<https://www.copays.org>). The CPR Program also is available through a toll-free telephone number from 8:30 a.m.-5:00 p.m. EST.

PAF has impacted the lives of millions of Americans in all 50 states since its establishment in 1996. From 1996-2015, PAF served 780,000 individual patients through case management and/or financial assistance programs. In 2016 alone, 88,364 patients received direct, sustained assistance from PAF. PAF professional staff made ~1.1 million contacts on behalf of patients to relevant stakeholders to resolve healthcare access issues. PAF case managers obtained debt relief for patients valued at \$39.7 million through negotiated write-offs, charity care access and coding/billing error resolutions. The CPR Program has served 158,294 patients since its establishment and allocated >\$300 million in patient assistance. PAF allocates \$0.94 out of each \$1.00 donated to support its direct patient service program.

PAF recently analyzed its data and identified the top three priorities in its patient population: medical debt crisis (57.2%), healthcare access (40.6%), and employment (2.1%). The analysis also showed the key issues among PAF patients with a medical debt crisis: debt crisis/cost of living (25.7%), pharmaceutical co-payment (21.1%), insurance (21.1%), medical co-payment (11.2%), no insurance coverage (9.2%), disability (6.4%), education (3.9%), and employment (1.4%).

PAF has developed several web-based tools and applications to more effectively and efficiently address the needs of patients/consumers.

- The “My Resource Search” mobile phone application is available at: [www.patientadvocate.org/myresources](http://www.patientadvocate.org/myresources).
- The online National Uninsured and Underinsured Resource Directories (NURD) reflect a compilation of all resources that PAF case managers have identified across the country. For example, uninsured/underinsured persons can search the NURD websites to identify resources to address their specific needs. After users enter their age range, medical diagnosis, state of residence and categories of assistance needed (e.g., housing and lodging), the NURD websites will generate a list of relevant organizations, their contact information and descriptions of their primary functions. (URLs of the NURD websites: <http://www.patientadvocate.org/NURD/index2.php?application=uninsured> <http://www.patientadvocate.org/NURD/index2.php?application=underinsured>)
- The *Coverage Access Guide: A Consumer’s Guide to Insurance* is a user-friendly tool that is designed to answer frequently asked questions regarding access to, enrollment in, and

maintenance of healthcare coverage. The educational guide is free of charge and is based on published articles to help current and future patients overcome common healthcare barriers and enhance their overall healthcare experience. The guide is exclusively available on the iPhone App Store.

- The *Managed Care Answer Guide* was updated in the spring of 2015 to educate and empower consumers in the following areas:
  - Health insurance eligibility
  - Enrollment process, timelines and materials
  - Selection of the appropriate plan for specific medical needs
  - Essential health benefits
  - Tips to understand and navigate the structure of health plans
  - Vocabulary and terminology
  - Tips to understand out-of-pocket costs, co-payments and drug tiers
  - Insurance denial and appeal processes
  - Protections under the Affordable Care Act (ACA)
  
- *The Metastatic Breast Cancer (MBC) Insert* is a companion document to the *Managed Care Guide*. The MBC insert is available in English and Spanish and can be delivered in both print and electronic formats. The MBC insert covers the following issues:
  - Disability eligibility and compassionate allowance
  - Medication tiers and drug reimbursement in plain language
  - Clinical trial options
  - The important role of prior authorization in costs and access
  - Tips to understand the MBC treatment vocabulary
  - Options for palliative and hospice care
  - Personalized treatment
  - Genetic screening and biomarker testing
  - Strategies to reenter the workforce
  - Guidance to negotiate medical bills and seek alternate funding
  - Specific resources for MBC patientsURL of the MBC insert: [www.patientadvocate.org/publicationswww.patientadvocate.org/metastaticbreastguide](http://www.patientadvocate.org/publicationswww.patientadvocate.org/metastaticbreastguide)

Overview by Susan G. Komen® for the Cure

**Susan Brown, MS, RN**

Managing Director, Health and Mission Program Education  
Susan G. Komen® for the Cure

Ms. Brown presented an overview of BCYW activities conducted by Susan G. Komen® for the Cure (SGK). SGK was established in 1982 with a mission to save lives by meeting the most critical needs in communities and investing in breakthrough research to prevent and cure breast cancer. SGK's partnerships and collaborations with multiple organizations have led to several notable achievements over the past 34 years: decreased breast cancer mortality rates by 37%; engaged 23 million persons in SGK community events; and built a group of 3.1 million breast cancer survivors in the United States (i.e., the largest group of survivors of all cancers in the country).

SGK acknowledges that although breast cancer outcomes have improved overall, disparities have persisted over time. Most notably, 40,000 persons continue to die from breast cancer in the United States each year. SGK is placing a great deal of emphasis on disparities and established a bold goal of reducing the current number of breast cancer deaths in the United States by 50% within the next decade.

SGK is uniquely positioned to reach its bold goal with the implementation of two key programs. The Community Program will focus on early detection, access to care, patient navigation and health equity. The Research Program will focus on transformative technologies, metastasis, disparities and novel therapeutics. Ms. Brown devoted the remainder of her overview to SGK's Community Program that is designed to advance from reducing breast cancer disparities to achieving health equity among African American women (<http://ww5.komen.org/enddisparities>).

SGK has a long history of conducting community-based initiatives to improve health outcomes for low-income women, uninsured women, women of color and other underserved populations that face barriers to care. However, SGK is directly focusing on disparities at this time by partnering with the Fund II Foundation to launch the African American health equity initiative. The primary aim of this activity is to end breast cancer disparities in the African American community. Data show that African American women in the United State die from breast cancer nearly 40% more than Caucasian women; are diagnosed when treatment options are limited and costly or the prognosis is poor; and often are diagnosed younger and with more aggressive types of breast cancer.

SGK's initial target audiences for the health equity initiative to close the African American breast cancer mortality gap are the top 10 metropolitan areas in the United States with the greatest disparities. These jurisdictions were identified by community profiles that are submitted by SGK affiliates throughout the country. Community profiles are designed to determine local areas with the highest risk of triple-negative breast cancer; populations at risk of dying from breast cancer and their socioeconomic characteristics; and specific needs and disparities in these communities in terms of available resources and access to/utilization of quality care services. Community profiles also include quantitative and/or qualitative data, a health system analysis and a public policy overview.

SGK and its national network of affiliates use community profile data to inform the development and implementation of community-based activities, such as grant programs, state policy and advocacy efforts, and strategic partnerships. SGK and its affiliates also support community health programs and fund ~1,000 community grants each year.

SGK invested \$2.6 million to support a Chicago-based program that piloted a comprehensive and coordinated approach to address health disparities to achieve health equity. The program resulted in the formation of the Chicago Breast Cancer Task Force and led to a reduction in breast cancer mortality by ~33% over a five-year period. Memphis is one of the top 10 metropolitan areas with the greatest breast cancer disparities and adapted the Chicago pilot program for replication in its local communities as part of SGK’s African American health equity initiative.

To determine breast cancer disparities at the national level, SGK compiled and reviewed data from local community profiles of the 50 metropolitan areas with the largest adult female African American populations. These data were compared to breast cancer mortality rates and late-stage incidence rates between African American and Caucasian women. The concept of “where you live should not determine whether you live” served as a guiding principle in this effort.

Based on its review and comparison of local community profile data, SGK developed a national community assessment of the top 10 metropolitan areas in the United States with the greatest breast cancer disparities.

Rank	SGK Breast Cancer Disparities Cities	Black Mortality Rates (Overall Rank)	Black:White Mortality Disparity Ratio (Overall Rank)	Late-Stage Rate (Overall Rank)	Black:White Late-Stage Disparity Ratio (Overall Rank)
1	Memphis, TN	39.7 (1)	1.74 (1)	55.9 (4)	1.30 (2)
2	St. Louis, MO	33.2 (7)	1.44 (9)	61.1 (1)	1.32 (1)
3	Dallas/Fort Worth/Arlington, TX	34.2 (5)	1.62 (2)	54.1 (8)	1.24 (4)
3	Los Angeles/Long Beach, CA	34.8 (3)	1.55 (4)	54.4 (6)	1.22 (6)
4	Virginia Beach, VA	34.8 (3)	1.51 (5)	54.1 (8)	1.24 (4)
5	Atlanta, GA	31.7 (10)	1.45 (8)	56.2 (3)	1.30 (2)
5	Chicago, IL	34.1 (6)	1.48 (7)	56.6 (2)	1.20 (8)
6	Houston, TX	35.6 (2)	1.60 (3)	50.1 (14)	1.23 (5)
7	Washington, DC	32.2 (8)	1.51 (5)	53.6 (9)	1.26 (3)
8	Philadelphia, PA	31.8 (9)	1.34 (12)	55.0 (5)	1.21 (7)

SGK and its affiliates launched the African American health equity initiative in the top 10 metropolitan areas by convening roundtable discussions with community leaders in the civic, health, faith-based and government sectors. The major outcomes of the roundtables included engaging >400 experts in dialogue to establish priorities; determining best practices in all 10 metropolitan areas; developing a network of advocates to best meet the needs of their respective

communities; and exploring effective partnerships and grassroots efforts at the local level to save lives. SGK and its affiliates hosted the roundtables from March 2015-June 2016.

SGK ensured that the African American health equity initiative was informed by community needs and driven by local leaders and HCPs. As a result, community leaders played an instrumental role in identifying and implementing interventions that would be most relevant and effective for their communities. SGK established a key indicator of reducing African American breast cancer disparities by 25% in five years in the top 10 metropolitan areas.

SGK designed the African American health equity initiative with three primary methods. First, health equity will be achieved and trust will be built by ensuring access to high-quality screening, treatment, genetic testing and clinical trials. Second, barriers to quality care will be reduced through patient navigation by guiding women through the healthcare continuum. Third, communities will be empowered through advocacy to sustain local health system changes.

SGK identified several common themes and trends across all 10 metropolitan areas during the roundtable discussions.

#### *Advocacy and Policy*

- Sustainability of Breast and Cervical Cancer Program funding
- Training and resources for advocates
- Medicaid expansion/ACA
- Legislation to increase access to clinical trials
- Coalition building
- National versus state initiatives

#### *Clinical Trials, Genetic Testing and Research*

- Understanding of historical injustices
- Education and generational perspectives
- Accessibility and barriers
- Community-based participatory research
- Clinician training on cultural competency
- Fertility issues

#### *Community and Faith*

- Trusted and strategic partnerships
- Utilization of ambassadors and their networks
- Physician training on cultural competency
- The need for physicians to visit communities
- Strategies to include individuals who are not church members
- Engagement of salons, sororities and members of family reunions
- Health literacy

- Fun and socially supportive activities

*Patient Navigation and Screening*

- Confusion with guidelines
- Reimbursement and standardization
- Insufficient number of navigators to meet current needs
- Clinical trials and genetic testing education

SGK affiliates are well represented in each of the 10 metropolitan areas to achieve the goals and outcomes of the African American health equity initiative. The local impact of a few SGK affiliates is described below.

<b>KOMEN CALIFORNIA COLLABORATIVE PUBLIC POLICY COMMITTEE</b>	
Goal	Ensure that women have more timely access to receive necessary services to detect and treat cancer earlier.
Methods	Statewide partnerships: <ul style="list-style-type: none"> <li>• 7 Komen California Affiliates</li> <li>• State assembly members and senators</li> <li>• Breast cancer survivors</li> <li>• Community Health Centers (Grantees)</li> </ul>
Local Impact	The Komen California Collaborative established advocacy partnerships and sponsored legislation to end service and treatment gaps; expand screening for young women; and delete the 18-month treatment coverage limit.
<b>KOMEN ARIZONA BREAST CANCER LEARNING COMMUNITY</b>	
Goal	Decrease barriers and increase education to reduce late-stage incidence of and deaths due to breast cancer in African American females.
Methods	<ul style="list-style-type: none"> <li>• Prioritized African American females in a 2016 request for applications</li> <li>• Built relationships with African American leaders to establish statewide system change partnerships</li> <li>• Broad dissemination of the breast cancer community profile</li> <li>• Formed a partnership with the Association of State and Territorial Health Officials</li> </ul>
Local Impact	The Komen Arizona Breast Cancer Learning Community established system change partnerships with >23 organizations to create a toolkit and launch a statewide call to action. The initiative has now been expanded to include Hispanic and Native American communities.

<b>KOMEN MEMPHIS-MIDSOUTH: PINK SUNDAY/WORSHIP IN PINK</b>	
Goal	Reach women in a trusted place to provide breast health education.
Methods	<ul style="list-style-type: none"> <li>• Faith-based partnerships</li> <li>• Trusted network with a “warm handoff”</li> <li>• Culturally appropriate toolkit</li> <li>• Voluntary data collection</li> <li>• Sharing of resources</li> <li>• Data sharing with partners</li> </ul>
Local Impact	Komen Memphis-Midsouth established faith-based partnerships that have provided breast health education to 6,500-7,000 persons to date, collected screening data, expanded collaborations, promoted patient behavioral changes, and strengthened relationships in local communities.

SGK’s next steps in the African American health equity initiative will be to sponsor a national summit in Washington, DC on February 16, 2017 with representation by community leaders in all 10 metropolitan areas. SGK will use key outcomes from the 2015-2016 roundtables and the 2017 summit to develop and implement jurisdiction-specific strategic plans. Each strategic plan will include an assessment, quality review and recommendations. Community leaders will be identified to serve on an advisory group that will have oversight of local implementation efforts. These data will be used to determine services that currently are available in each metropolitan area.

Several key factors will be assessed and mapped at the neighborhood level: demographics/ relevant health data, breast cancer mortality rates, average household incomes, distribution of breast cancer screening capacity, and access to specially trained breast cancer screening radiologists and specialized treatment services. A review of screening services will be conducted to develop plans to improve the quality of screening techniques. SGK will apply lessons learned and experiences from the top 10 metropolitan areas to expand the African American health equity initiative to other jurisdictions in the United States in the future.

**ACBCYW Discussion: BCYW Activities in the Field**

Dr. Partridge encouraged the ACBCYW members to widely publicize the availability of PAF’s outstanding services and resources for patients/consumers in their networks and communities. Dr. Fairley confirmed that CDC also would include links to PAF’s resources in its BCYW activities.

In response to Dr. Fairley’s question, Ms. Brown confirmed that SGK submitted a paper for publication in December 2016 comparing African American breast cancer disparities between Chicago and the nine other metropolitan areas. SGK also is preparing a paper for journal publication regarding breast cancer disparities by age. Dr. Partridge commended SGK for its leadership in addressing breast cancer disparities at the national level.

## Ad Hoc General Risk Assessment and Management Workgroup Report

### **Susan E. Kutner, MD, Workgroup Co-Chair**

Breast Surgeon  
Kaiser Permanente

### **Tari A. King, MD, FACS, Workgroup Co-Chair**

Chief, Breast Surgery  
Dana Farber/Brigham and Women's Cancer Center

Dr. Kutner reported that during the January 2016 meeting, ACBCYW reached consensus on rebranding the previous General Population/High-Risk Workgroup as the new General Risk Assessment and Management Workgroup. Since that time, the workgroup has made progress in several areas to begin fulfilling its charge of focusing on breast cancer risk assessment and management of young women.

#### **WORKGROUP TASKS**

The workgroup initiated numerous tasks to begin fulfilling its charge. The workgroup analyzed currently available risk assessment tools and found that some models were created for specific purposes, such as genetic testing. However, family history is the cornerstone of nearly all existing risk assessment tools to identify women who are at significant risk for having a genetic mutation. The workgroup acknowledged that young women typically have limited knowledge, appreciation and understanding of the risks of breast cancer and the ability to survive the disease.

The workgroup reviewed current research on risk-based breast cancer screening, such as the time for women to initiate screening, earlier screening for specific subgroups of women, and the frequency of screening based on risk level rather than age. The workgroup also examined key outcomes from grassroots activities in its ongoing efforts to update risk-related issues for young women and enhance risk communications.

The workgroup is continuing to identify effective communication strategies to inform young women about the current state of knowledge regarding new genetic testing and panel testing. The workgroup acknowledged the complexity and controversy associated with communicating these issues, particularly the specific meaning of and types of interventions for young women with non-BRCA gene mutations. The workgroup will continue its focus in this area as the field of genetic testing and panel testing evolves over time.

The workgroup discussed the fact that mammography is an ACA-covered preventive service, but the members emphasized the need to expand this coverage to include young women with documented breast cancer genetic mutations who are recommended for magnetic resonance imaging (MRI) screening. The workgroup reviewed current research on breast cancer prevention

and modifiable risk factors, such as well-documented, evidence-based lifestyle changes for young women (e.g., smoking cessation, exercise, weight management and alcohol modification).

The workgroup discussed the critical need for ongoing monitoring to track adherence to breast cancer screening recommendations and routine provision of risk reduction education and strategies to young women who are at high risk or have a hereditary risk of breast cancer.

The workgroup is continuing to review the literature on the linkage between environmental/occupational risks and breast cancer, including landmark publications by the National Institute of Environmental Health Sciences (NIEHS), to support ACBCYW's new focus in this area. Updated messaging and recommendations are needed to help young women make lifestyle changes, reduce occupational risks, and avoid environmental exposures to decrease their environmental or occupational risks of developing breast cancer.

The workgroup likely will leverage ongoing expertise from NIEHS in the future to inform its development of recommendations to ACBCYW on the linkage between breast cancer and environmental/occupational risks. Websites of studies that the workgroup is using as data sources in this effort are referenced below.

- NIEHS: <https://www.niehs.nih.gov>
- Breast Cancer Fund: <http://www.breastcancerfund.org>
- Women Firefighters Study: <http://womenfirefighterstudy.com>

#### **WORKGROUP RECOMMENDATIONS TO ACBCYW**

The workgroup drafted preliminary recommendations to ACBCYW based on its meetings to date.

- ACBCYW should advise CDC to include key messaging in its breast cancer risk communication materials for young women:
  - The purpose of existing risk assessment tools and guidance on the most appropriate models to use
  - The availability of tremendous experience and expertise across the country to address breast cancer risks
  - Positive outcomes of early-stage breast cancer for women of all ages
  - Risk-based messaging and information disseminated to young women and HCPs by community-based organizations
- ACBCYW should go on record with its formal support of ongoing BCYW research efforts:
  - Research on risk-based breast cancer screening, such as the WISDOM Study that is being led by Dr. Laura Esserman at the University of California, San Francisco
  - New research on the linkage between breast cancer and environmental/occupational risks that is targeted to young women

- ACBCYW should recommend the development of a new national registry to determine whether the identification of young women who are at high risk or have a hereditary risk of breast cancer has an impact on their survival over time.
- ACBCYW should recommend an expansion of ACA coverage of mammography to include MRI screening of women with documented genetic mutations.

## Ad Hoc Provider Workgroup Report

### **Karen Meneses, PhD, RN, FAAN, Workgroup Co-Chair**

Professor and Associate Dean for Research

University of Alabama at Birmingham School of Nursing, Center for Nursing Research

### **Sue Friedman, DVM, Workgroup Co-Chair**

Executive Director

FORCE: Facing Our Risk of Cancer Empowered

Dr. Meneses reported that during the January 2016 meeting, ACBCYW reached consensus on retaining the Provider Workgroup. Since that time, the workgroup has made progress in several areas to begin fulfilling its charge.

### **WORKGROUP MEMBERSHIP**

The workgroup's current membership includes the co-chairs (Drs. Meneses and Friedman); two ACBCYW members (Drs. Jacquelyn Roth and Debbie Tuttle); the ACBCYW *ex-officio* member for HRSA (Ms. Christina Lachance); and two liaison representatives from Sharsheret (Ms. Adina Fleischmann and Ms. Elana Silber).

The workgroup used the Join Me and Google Docs online meeting applications to hold three meetings in July, August and November 2016. The applications are free of charge and allowed the members to generate meeting minutes, share documents and take advantage of other features to convene their meetings in an efficient and organized manner.

### **WORKGROUP CHARGE**

The workgroup established three major goals to fulfill its charge: (1) review activities completed by the previous membership; (2) gather new background information to further improve provider behavior, education and training regarding BCYW; and (3) advise ACBCYW on prioritizing and supporting ongoing programmatic efforts in the future.

## **WORKGROUP TARGET AUDIENCES**

The previous workgroup targeted its efforts to the following audiences: primary care physicians in internal medicine, family medicine and obstetrics/gynecology, nurse practitioners, physician assistants, naturopaths, insurance providers and professional societies. The current workgroup reached consensus on expanding these target audiences to include general and community oncologists, community-based breast surgeons and plastic surgeons, nurse navigators, nurses based in mammography centers and fertility counselors.

The previous workgroup primarily addressed provider education related to genetic counseling and testing of high-risk young women. The current workgroup will continue to focus on this issue, but additional topics will be included in its provider education activities: previvorship, survivorship, breast density and other risks, and breast cancer disparities.

## **WORKGROUP TASKS**

The workgroup reached consensus on conducting three major tasks to fulfill its charge. Task 1 is to compile information about existing provider education programs. CDC currently is funding Living Beyond Breast Cancer's (LBBC) webinars for social workers and other providers as well as Sharsheret's cultural competency training for HCPs. Based on Ms. Brown's presentation during the current meeting, the workgroup also would be interested in gathering information on any aspects of SGK's African American health equity initiative that relate to provider education.

The workgroup identified several provider education programs that are not supported by CDC, but warrant consideration and evaluation for broad dissemination.

- The Society of Gynecologic Oncology collaborated with other professional societies and advocacy groups to develop a genetics toolkit (<https://www.sgo.org/genetics/genetics-toolkit>).
- Bright Pink University (BPU) (<https://www.brightpink.org/get-involved/educate-your-community>) is a training program for volunteer leaders to become a certified Education Ambassador and present Brighten Up® educational workshops. BPU serves as a mechanism for providers to offer breast cancer education directly to their peers, including nurse practitioners and specialty physicians.
- The NCI Research-Tested Intervention Programs (RTIPs) (<https://rtips.cancer.gov/rtips/index.do>) are a searchable database of published, evidence-based cancer control interventions and program materials. The RTIPs have demonstrated efficacy and can be adapted for use in specific communities and populations. Of 172 RTIPs in the NCI database, 15 focus on psychosocial survivorship and supportive care. The RTIPs primarily are targeted to populations, but some interventions include provider education components.

Task 2 is to ensure that the use of existing professional guidelines for care is a key message in provider education. The major guidelines for breast cancer risk assessment and screening of high-risk young women include those published by the National Comprehensive Cancer Network

(NCCN) and U.S. Preventive Services Task Force. The major guidelines for young breast cancer survivors (YBCS) include those published by NCCN, the American Society of Clinical Oncology (ASCO) and American Society of Reproductive Medicine. These guidelines cover a wide range of topics that are helpful to provider education efforts, such as adolescents/ young adults with cancer, fertility and other reproductive health issues, and ethical principles to guide new fertility technologies.

Task 3 is to expand the existing workgroup membership to fill gaps. The current membership is limited to ACBCYW members, but the workgroup acknowledged the need to invite guest speakers to obtain additional information on other provider education efforts. The workgroup proposed several provider categories as future guest speakers, such as mammographers, radiologists, genetic counselors and geneticists. The workgroup also suggested the City of Hope as a future guest speaker to present its Cancer Genetics Education Program.

The workgroup agreed that in addition to CDC-funded providers, HRSA-funded grantees and contractors also should be included in provider education to expand dissemination channels to reach providers who work in underserved communities. Diverse mechanisms have been created to deliver education to HRSA-funded providers, such as Technical Assistance Centers and other training programs, social media platforms, e-newsletters, and partnerships with local communities in all 10 HHS regions.

#### **WORKGROUP RECOMMENDATIONS TO ACBCYW**

The workgroup drafted preliminary recommendations to ACBCYW based on its three meetings to date.

- Compile and disseminate resources of developed programs that are targeted to HCPs.
- Develop a standardized process or criteria for non-CDC programs to be formally evaluated and included in CDC's efforts for provider education of YBCS.
- Compile all approved CDC-funded and non-CDC-funded efforts for HCPs into a catalogue or resource guide for dissemination.
- Expand outreach efforts to additional target audiences of HCPs: general and community oncologists, community-based breast surgeons and plastic surgeons, nurses based in mammography centers, nurse navigators and fertility counselors.
- Expand provider education to include additional topics: previvorship, survivorship, breast density and other risks, and breast cancer disparities.
- Align and coordinate efforts to ensure that all three ACBCYW workgroups address complementary issues in parallel, leverage their activities, avoid duplication and reduce gaps.
- Expand efforts beyond the CDC network and mobilize all federal partners to enhance dissemination, such as leveraging activities with HRSA and other government agencies.
- Continue ACBCYW's important activities and efforts in some form, independent of ACA.

Dr. Friedman added that the workgroup's draft recommendation to develop a standardized process or criteria to evaluate non-CDC programs for provider education also could be applied to non-CDC programs for young women in the general population and YBCS. Non-CDC programs and resources should be assessed based on their impact, reach to the target audience and capacity to address breast cancer disparities. To support this effort, CDC should announce an opportunity for non-CDC grantees to submit applications to have their programs formally evaluated. CDC also should use RTIPs as a model for the formal evaluation.

## Ad Hoc Survivorship Workgroup Report

### **Ulrike Boehmer, PhD, Workgroup Co-Chair**

Associate Professor  
Boston University School of Public Health

### **Don S. Dizon, MD, Workgroup Co-Chair**

Director, Oncology Sexual Health Clinic  
Massachusetts General Hospital, Gillette Center for Women's Cancers

Dr. Boehmer reported that during the January 2016 meeting, ACBCYW took a vote and formally approved the establishment of the new Survivorship Workgroup. Since that time, the workgroup has convened teleconference meetings approximately every three weeks to make progress in fulfilling its charge.

### **WORKGROUP MEMBERSHIP**

The workgroup's current membership includes the co-chairs (Drs. Boehmer and Dizon); two ACBCYW members (Ms. Chien-Chi Huang and Ms. Desiree Walker); and five liaison representatives from Bright Pink (Ms. Lindsay Avner and Ms. Sarah Storey), LBBC (Ms. Arin Hanson), PAF (Ms. Shonta Chambers), and Tigerlily Foundation (Ms. Maimah Karmo).

### **WORKGROUP TARGET AUDIENCE**

The workgroup devoted a significant portion of its initial meetings to reaching consensus on defining the target audience of "young breast cancer survivors." The workgroup ultimately agreed to adopt the National Coalition for Cancer Survivorship's (NCCS) definition of a cancer survivor: "Survivorship after cancer starts at the point of diagnosis, extends to the end of life, and embraces anyone touched by the experience, including caregivers."

The NCCS definition is inclusive, offers a more holistic view of a cancer survivor, and recognizes that some individuals might not choose to self-identify as a "survivor." To ensure alignment with the ACBCYW charter, the workgroup narrowed the focus of the NCCS broad definition of a "cancer survivor" to only include women diagnosed with breast cancer before 45 years of age. However, the workgroup acknowledged that some issues might occur or continue after this age.

## **WORKGROUP TASKS/RECOMMENDATIONS TO ACBCYW**

The workgroup agreed that its initial tasks would be to articulate the major concerns of YBCS and propose one overarching recommendation to address each issue. The workgroup has focused on six YBCS concerns in its discussions to date, but emphasis will be placed on other issues during future meetings.

In accordance with ACBCYW's formal consensus during the January 2016 meeting, the workgroup adopted a health equity framework to guide its activities. The workgroup's tasks and preliminary recommendations are inclusive of women who have sex with women (WSW), African American women, and women living in poverty and/or rural areas.

### *YBCS Issue 1: Sexuality and Body Image*

- Sexual dysfunction is highly prevalent in YBCS and is estimated to range from 30%-100%.
- Providers have limited knowledge of sexuality and body image issues among YBCS because key subgroups are not well characterized in the existing literature, such as women without partners, WSW and women with metastatic breast cancer.
- The 2010 Livestrong survey reported a linkage between sexual dysfunction and other issues, including depression, negative body image and couple discord.
- Workgroup Recommendation: Raise awareness of sexual side effects for both patients and providers by coordinating access to education with partners.

### *YBCS Issue 2: Fertility*

- Fertility concerns are of paramount importance and have a strong connection to a young woman's socioeconomic status and financial ability to store her eggs and preserve her fertility.
- The ASCO guidelines on fertility preservation are available, but barriers to accessing information have persisted over time.
- Workgroup Recommendation: Increase awareness of fertility needs and issues; emphasize the importance of early access; and position ACBCYW to advocate for insurance coverage of fertility preservation.

### *YBCS Issue 3: Spirituality*

- YBCS are interested in searching for meaning, purpose and transcendent experiences. However, spirituality includes, but is not synonymous with religion. As a result, YBCS should not necessarily be referred to faith-based organizations for their spirituality.
- Spirituality is a critical aspect of survivorship care. Limited research has been conducted to characterize young women with breast cancer because the disease is rare in this age group, but most YBCS have reported feeling "alone" after their diagnoses.
- Workgroup Recommendation: Integrate non-religious resources into survivorship care planning efforts for YBCS to seek spirituality.

#### *YBCS Issue 4: Mental Health*

- A breast cancer diagnosis at a young age is a known risk factor for poorer mental health compared to a diagnosis at an older age.
- Changes in the mental health status of young women diagnosed with breast cancer include heightened anxiety and distress; genitourinary symptoms of menopause due to chemotherapy; treatment-related cognitive dysfunction and neuropathy; and disruption of life goals.
- Workgroup Recommendation: Raise awareness of mental health implications related to a breast cancer diagnosis and therapy among young women and emphasize the importance of mental health treatment for this population.

#### *YBCS Issue 5: Healthy Lifestyles*

- Risky health behaviors contribute to worse breast cancer outcomes, particularly among young women, including a poorer quality of life and potentially higher relapse or secondary cancer rates.
- Smoking among young women with breast cancer remains a concern based on recent data.
- Workgroup Recommendation: Partner with other CDC centers that create and deliver messaging to decrease risky behaviors among young women (e.g., smoking cessation, obesity reduction and healthy lifestyles).

#### *YBCS Issue 6: Financial Burden*

- Emphasis on the impact of BCYW should extend well beyond “dollars and cents.” “Opportunity costs” faced by young women with breast cancer should be considered as well, such as college, work, career and other life goals that might be delayed or deferred.
- Insurance coverage and individual health plans will drive the extent to which YBCS face a financial burden, but treatment and other out-of-pocket costs will have a direct impact overall.
- Workgroup Recommendation: Identify assistance programs for struggling YBCS with a financial burden to more easily access treatment resources.

In addition to the six issue-specific recommendations for YBCS, the workgroup also drafted two cross-cutting recommendations for ACBCYW to consider. First, surveillance activities should be expanded to capture breast cancer outcomes reported by young patients. Existing partnerships and collaborations should be leveraged to achieve this goal. Second, resources across the country should be utilized to meet the needs of the diverse YBCS population.

Dr. Dizon added that the workgroup emphasized the need for CDC to leverage and promote available YBCS resources developed by its partners and advocacy organizations. For example, a paper was recently published that described social isolation as a risk factor among younger women with early-stage disease. CDC should collaborate with partners to conduct outreach to decrease the feeling of social isolation among YBCS.

## **ACBCYW DISCUSSION: WORKGROUP REPORTS**

ACBCYW commended the workgroups on their tremendous progress since the previous meeting in January 2016. The members were particularly impressed that the first workgroup reports included preliminary recommendations for ACBCYW to consider. ACBCYW provided feedback for the workgroups to discuss in their ongoing efforts.

### *Ad Hoc General Assessment and Management Workgroup*

- Risk communication messaging should be designed to inform young women <45 years of age of their potential risk for breast cancer and describe evidence-based prevention strategies to lower their risk. Because mammography guidelines now recommend screening beginning at 50 years of age, a large segment of the target audience does not associate breast cancer risks with younger women <45 years of age.
- Risk communication messaging on the linkage between environmental/occupational risks and breast cancer in young women <45 years of age should include plain public health language rather than complex numeric language on the absolute relative risk. Examples of environmental exposures could include ionizing chest radiation and potentially unhealthy hormones in milk, while an example of occupational exposures could include benzene in the workplace.
- Risk communication messaging should be carefully and thoughtfully designed to avoid the unintended consequence of “blaming” YBCS. Most notably, existing evidence should be gathered to inform the development of positive messaging that focuses on breast cancer risks and survivorship outcomes.
- NCCN (<https://www.nccn.org>) should serve as the primary resource for the most up-to-date data on breast cancer genetic testing and panel testing. NCCN convenes annual meetings to review the most recent evidence, update its consensus-based guidelines, and add new genes to the panel as appropriate.
- HCPs also should be a target audience of breast cancer recommendations, messaging and education on the risk assessment and management of young women. HCPs across the country typically deliver care and services to patients based on current guidelines and the current state of the science.
- Existing studies on lifestyle risks published by the medical community and advocacy groups should be cited to provide more explicit guidance to young women.

### *Ad Hoc Survivorship Workgroup*

- The Susan Love Research Foundation convened a conference to promote its Metastatic Breast Cancer Collateral Damage Project. The conference participants adopted “financial toxicity” and “collateral damage” as two terms to describe the impact on young persons with metastatic breast cancer who undergo continuous treatment during the most productive years of their lives. The conference participants also recognized the challenge in providing this diverse population with effective support and personalized assistance to fully address their medical, social, spiritual and other needs. The workgroup should explore strategies during its future meetings to address the complex topics of “financial toxicity” and “collateral damage” for YBCS.

Dr. Partridge pointed out that the comprehensive workgroup reports reflect a great deal of time and commitment the members have devoted to fulfilling their respective charges. She thanked ACBCYW for providing excellent feedback to assist the workgroups in their ongoing efforts. However, she reminded the workgroups that ACBCYW is formally chartered to provide evidence-based BCYW recommendations to the HHS Secretary and CDC Director. She cautioned the workgroups against drafting guidance that is not supported by robust or rigorous data or is outside the scope of public health standards.

Dr. Partridge announced that SGK previously commissioned the National Academies to develop a report with recommendations on the relationship between the internal environment and healthy lifestyles. The report is viewed as the most credible source of evidence on the impact of these factors on breast cancer risks. During the discussion, for example, a suggestion was made to describe unhealthy hormones in milk as an environmental risk factor for breast cancer in young women. However, ACBCYW will have much more public health credibility by citing the National Academies report.

Dr. Fairley was extremely pleased that the Survivorship Workgroup adopted a health equity framework to guide its activities. Although the Bring Your Brave campaign is targeting young African American and Ashkenazi Jewish women, she confirmed that other subgroups of the BCYW target audience are represented as well.

Dr. Fairley responded to Dr. Dizon's comments regarding CDC's use and promotion of BCYW resources developed by partners and advocacy groups. CDC has awarded funding to several organizations (e.g., Sharsheret and Young Survival Coalition) that have expertise in conducting outreach, delivering supportive services and directly addressing the concerns of YBCS. However, she acknowledged that CDC could increase its efforts to widely publicize the availability of its funded programs and resources.

Dr. Fairley responded to Dr. Friedman's comments regarding a standardized evaluation process or criteria for non-CDC BCYW programs. The original ACBCYW membership advised CDC to conduct an environmental scan of non-CDC BCYW programs and evaluate these existing resources. CDC acted on ACBCYW's recommendation, but the evaluation was not a rigorous study and only included BCYW programs of CDC grantees.

Dr. Fairley agreed that CDC could now conduct a more formal and systematic evaluation of non-CDC BCYW programs, but she noted a limitation about using RTIPs as a model in this effort. RTIPs reflect published, evidence-based cancer control interventions with demonstrated efficacy, but this level of rigor would exclude evidence-informed programs that are designed for specific BCYW audiences. She confirmed that this issue would be placed on the next meeting agenda for ACBCYW's continued discussion.

Dr. Fairley responded to Ms. Tuttle's question regarding the process to prioritize or "rank" the workgroup recommendations. ACBCYW formally approves workgroup recommendations for submission to CDC. CDC takes action on ACBCYW's guidance as staff and/or financial resources become available or based on the level of public interest in a particular BCYW topic. To date, CDC has made only a few presentations to ACBCYW on formative research findings that guide the development and implementation of its BCWY activities. She confirmed that CDC would present more of its formative research findings during future meetings.

### Public Comment Session

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

### ACBCYW Open Discussion

Dr. Partridge thanked the ACBCYW members for their tireless commitment to improving the lives of young women with breast cancer. She thanked the workgroup chairs and members for their outstanding efforts and tremendous progress over the past year. She reiterated that she was honored and privileged to have served as the ACBCYW Chair over the past five years. The participants joined Dr. Partridge in applauding Dr. Fairley and Ms. Carolyn Headley, DCPC Management and Program Analyst, for their excellent leadership and support of ACBCYW.

Dr. Fairley announced that in addition to Dr. Partridge, the terms of five other members also expired in November 2016: Drs. Raquel Arias, Ulrike Boehmer, Sue Friedman, Susan Kutner and Karen Meneses. A certificate of appreciation, signed by CDC leadership, will be mailed to each of the outgoing members in January 2017 in recognition of their service. The participants joined Dr. Fairley in applauding the outgoing members for contributing their time, commitment and expertise to ACBCYW.

Dr. Fairley was pleased to announce that Dr. Meneses's term has been extended to serve as the new ACBCYW Chair for two years. Dr. Partridge confirmed that she would be available as a resource to Dr. Meneses to ensure a seamless transition to ACBCYW's new leadership.

Dr. Fairley encouraged ACBCYW to submit topics for the next meeting to her ([tff9@cdc.gov](mailto:tff9@cdc.gov)) and Dr. Meneses ([menesesk@uab.edu](mailto:menesesk@uab.edu)), but she noted three future agenda items based on the discussions during the current meeting: (1) standardized process/criteria to evaluate non-CDC BCYW programs; (2) CDC's formative research findings of BCWY activities; and (3) final recommendations by the workgroups (if completed).

In terms of action items, Dr. Fairley will follow-up with the ACBCYW members who were selected to serve on the Know:BRCA expert panel. After the new ACBCYW members have been officially appointed, Ms. Headley will circulate a Doodle poll with potential dates for the next in-person meeting in Atlanta.

### Closing Session

With no further discussion or business brought before ACBCYW, Dr. Fairley adjourned the virtual meeting at 4:27 p.m. EST on December 13, 2016.



Centers for Disease Control and Prevention

# ADVISORY COMMITTEE on **BREAST CANCER** in YOUNG WOMEN

December 13, 2016 Virtual 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).

## Tuesday, December 13, 2016

1:00 P.M. – 1:30 P.M.

### **Opening: Welcome, Roll Call, and Introductions**

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

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

*Lisa Richardson, MD, MPH*  
Director, DCPC, CDC

1:30 P.M. – 1:50 P.M.

### **Update on CDC's Cancer Activities**

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

1:50 P.M. – 2:20 P.M.

### **Updates on BCYW Activities from the Field**

*Shonta Chambers, MSW*  
Executive Vice President, Health Equity  
Initiatives and Programs  
Patient Advocate Foundation

*Susan Brown MS, RN*  
Managing Director, Health & Mission Program Education  
Susan G. Komen for the Cure

2:20 P.M. – 4:20 P.M.

**ACBCYW Workgroup Reports and Open Discussion**

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

*Tari A. King, MD, FACS*  
Dana-Farber/Brigham and Women's Cancer Center  
*Susan E. Kutner, MD*  
Kaiser Permanente  
Ad Hoc General Risk Assessment & Management Workgroup

*Sue Friedman, DVM*  
FORCE: Facing Our Risk of Cancer Empowered  
*Karen Meneses, PhD, RN, FAAN*  
University of Alabama at Birmingham  
Ad Hoc Provider Workgroup

*Ulrike Boehmer, PhD*  
Boston University School of Public Health  
*Don S. Dizon, MD*  
Massachusetts General Hospital  
Ad Hoc Survivorship Workgroup

4:20 P.M. – 4:40 P.M.

**PUBLIC COMMENT**

4:40 P.M. – 5:00 P.M.

**Summary and Closing**

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



Centers for Disease Control and Prevention

**ADVISORY COMMITTEE** on  
**BREAST CANCER** in **YOUNG WOMEN**

**December 13, 2016 Virtual Meeting**



**Attachment 2: Roster of the ACBCYW Membership**

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## **U.S. Department of Health and Human Services, Office on Women's Health**

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Centers for Disease Control and Prevention

# ADVISORY COMMITTEE on **BREAST CANCER** in YOUNG WOMEN

December 13, 2016 Virtual Meeting



## Attachment 3: Participants' Directory

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**FORCE: Facing Our Risk of Cancer  
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Centers for Disease Control and Prevention

# ADVISORY COMMITTEE on **BREAST CANCER** in YOUNG WOMEN

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## Attachment 4: Glossary of Acronyms

ACA	Affordable Care Act
ACBCYW	Advisory Committee on Breast Cancer in Young Women
ASCO	American Society of Clinical Oncology
BCYW	Breast Cancer in Young Women
BPU	Bright Pink University
CDC	Centers for Disease Control and Prevention
CME	Continuing Medical Education
CPR	Co-Pay Relief
DCPC	Division of Cancer Prevention and Control
EARLY Act	Education and Awareness Requires Learning Young Act
GAO	U.S. Government Accountability Office
HBOC	Hereditary Breast and Ovarian Cancer
HCPs	Healthcare Providers/Professionals
HHS	U.S. Department of Health and Human Services
HRSA	Health Resources and Services Administration
LBBC	Living Beyond Breast Cancer
MBC	Metastatic Breast Cancer
MMWR	<i>Morbidity and Mortality Weekly Report</i>
MRI	Magnetic Resonance Imaging
NCCN	National Comprehensive Cancer Network
NCCS	National Coalition for Cancer Survivorship
NCI	National Cancer Institute
NIEHS	National Institute of Environmental Health Sciences
NLP	Natural Language Processing
NURD	National Uninsured/Underinsured Resource Directories
PAF	Patient Advocate Foundation
RTIPs	Research-Tested Intervention Programs
SGK	Susan G. Komen® for the Cure
WSW	Women Who Have Sex With Women
YBCS	Young Breast Cancer Survivors

