

**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
September 21-23, 2011
Atlanta, GA**

Record of the Proceedings

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**ADVISORY COMMITTEE ON BREAST CANCER IN YOUNG WOMEN
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Meeting Minutes

The U.S. Department of Health and Human Services (HHS) and the Centers for Disease Control and Prevention (CDC), National Center for Chronic Disease Prevention and Health Promotion, Division of Cancer Prevention and Control (DCPC), convened a meeting of the Advisory Committee on Breast Cancer in Young Women (ACBCYW). The proceedings were held September 21-23, 2011, in Building 19 of the Tom Harkin Global Communications Center, CDC Roybal Campus in Atlanta, GA.

The purpose of the meeting was for ACBCYW to provide advice to the HHS Secretary and the CDC Director regarding the formative research, development, implementation, and evaluation of evidence-based activities designed to prevent breast cancer in young women, particularly those at heightened risk. All sessions of the ACBCYW meeting were open to the public.

Opening Session: September 21, 2011

Temeika L. Fairley, Ph.D.

Health Scientist, Division of Cancer Prevention and Control
Centers for Disease Control and Prevention
ACBCYW Designated Federal Officer

Dr. Fairley conducted a roll call to determine the ACBCYW voting members, *ex-officio* members, and liaison representatives who were in attendance. She verified that the voting members and *ex-officio* members in attendance constituted a quorum for ACBCYW to conduct its business on September 21, 2011. None of the voting members declared conflicts of interest for the record on any of the items in the published agenda for September 21, 2011. Dr. Fairley called the meeting to order at 9:07 a.m.

Ann Hart Partridge, M.D., M.P.H.

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

Dr. Partridge welcomed the participants to the ACBCYW meeting. She explained that a series of overviews would be presented during the meeting highlighting the exciting breast cancer in young women (BCYW) initiatives. She emphasized that the meeting would serve as a forum for the ACBCYW members to apply their perspectives and experiences to advance the important BCYW effort and improve the detection, care, counseling, and outcomes of young women who may be at risk for breast cancer.

Marcus Plescia, M.D., M.P.H.

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

Dr. Plescia joined Dr. Partridge in welcoming the participants to the ACBCYW meeting. He thanked the ACBCYW members for taking time from their busy schedules to attend the meeting, provide CDC with guidance on its important BCYW portfolio and future directions in this effort, and formulate recommendations to improve the productivity and effectiveness of ACBCYW. He was pleased to announce that since the first ACBCYW meeting in January 2011, CDC and its partners and grantees have made tremendous progress in conducting research and other activities to address BCYW.

Dr. Fairley opened the floor for introductions and reviewed the meeting agenda.

A glossary of meeting related terms is appended to meeting minutes as Attachment 1. The meeting agenda and the roster of the ACBCYW are appended to the meeting minutes as Attachment 2 and Attachment 3, respectively.

Keynote Address by Congresswoman Debbie Wasserman Schultz

Dr. Plescia announced that Congresswoman Debbie Wasserman Schultz was the primary sponsor of the Education and Awareness Requires Learning Young (EARLY) Act which created the ACBCYW, and has been a strong advocate and champion for CDC's cancer prevention and control activities.

Congresswoman Debbie Wasserman Schultz joined the meeting via teleconference and recognized the groups and individuals who played a key role in transforming her vision for the important BCYW effort into reality. She thanked CDC and its organizational partners for their diligent efforts to establish ACBCYW. She thanked Dr. Partridge for providing strong leadership and support of the BCYW effort in general and serving as the ACBCYW Chair in particular. She thanked the ACBCYW members for their continued devotion and tremendous contributions to BCYW throughout their careers.

Congresswoman Wasserman Schultz noted that the insight and dedication of the ACBCYW members have been vital in developing, nurturing, and realizing the essential tenant of the EARLY Act to empower young women to understand their bodies and speak up for their health. She was extremely pleased that the ACBCYW members dedicated themselves to achieving this goal.

Congresswoman Wasserman Schultz noted that CDC planned outstanding presentations on a diverse range of topics (e.g., new media, cultural and competent messaging and materials, and

health education and awareness) for the 3-day ACBCYW meeting. CDC also would provide overviews of its most recent comprehensive studies and projects on genetic risks for cancer, the impact of cancer on fertility, and other areas. The meeting agenda clearly demonstrates ongoing efforts throughout the country to achieve the primary goal of the EARLY Act to reach a younger generation of women in relevant settings.

Congresswoman Wasserman Schultz pointed out that her introduction and sponsorship of the EARLY Act in March 2009 were driven by her interest in applying her personal experience as a young breast cancer survivor (YBCS) to help other young women face this challenge. Since that time, her dream has been transformed into a dynamic and comprehensive initiative at CDC. The EARLY Act was one of the first provisions of the Affordable Care Act to be implemented.

Congresswoman Wasserman Schultz looked forward to hearing updates on ACBCYW's progress and exciting, new directions of the EARLY Act. She was confident that ACBCYW would recommend the best and most innovative strategies to reach and empower young women to speak up for their health.

Congresswoman Wasserman Schultz planned to continue to collaborate with her congressional colleagues to secure funding in the Labor, Health, and Human Services Appropriations Bill to support the EARLY Act provision. Congressional members were successful in securing \$5 million per year for the EARLY Act. This funding has been used to support CDC's research and initiatives as well as exciting, new grant opportunities. Most notably, CDC is funding organizations to establish or enhance existing programs for YBCS and their families and develop tools to increase patient and provider awareness of BCYW.

Moreover, CDC awarded new grants to seven organizations over the next 3 years for program development, support, education, and awareness of YBCS in the United States. CDC hopes the projects from these grants will inspire the development of new BCYW initiatives to educate and empower young women and save lives. Congresswoman Wasserman Schultz congratulated the seven grantees on their BCYW awards:

- John C. Lincoln Health Foundation
- Living Beyond Breast Cancer
- Louisiana State University Health Sciences Center
- Sharsheret
- University of California, Los Angeles
- University of North Carolina at Chapel Hill
- Washington University in St. Louis

Congresswoman Wasserman Schultz concluded her remarks by wishing the ACBCYW good luck in the important BCYW endeavor. She looked forward to reviewing ACBCYW's creative ideas and suggestions. She encouraged the ACBCYW members to share additional thoughts with her legislative assistant, Ms. Danielle Gilbert, who would attend the entire meeting. She welcomed feedback from the ACBCYW members on additional actions she could take to help amplify and continue the important BCYW effort.

Overview of CDC's Health Communication Activities

Katherine Lyon Daniel, Ph.D.

Acting Associate Director for Communication
Centers for Disease Control and Prevention

Dr. Lyon Daniel covered the following areas in her overview of CDC's health communication activities. The movie *Contagion* was an outstanding opportunity to couple CDC's public health activities with commercial marketing and entertainment education. The movie encouraged CDC to consider different and more creative strategies to promote its public health activities for a more significant impact.

Effective health communications and marketing are designed to provide health information, interventions, and products when, where, and how individuals need this information to inform health decisions. The U.K. National Social Marketing Centre designed a social marketing triangle that combines the principals of social marketing (e.g., the customer, behavior theories and goals, intervention and marketing mix, and audience segmentation).

The "4 P's" in the marketing mix are highlighted as follows. The product is the desired behavior and associated benefits of the target audience. The product can be a tangible object or service that supports or facilitates behavior change. For example, a car service was a creative product in a rural area in Wisconsin to decrease vehicle accidents and fatalities resulting from drunk driving. Wisconsin achieved a cost savings of \$70,000 in the first year of providing the car service by reducing the incidence of drunk driving and associated vehicle accidents in the State.

The price is the cost from financial, emotional, psychological, or time perspectives or barriers to the target audience making desired behavior changes. Interventions should be planned to reduce costs of desired behaviors or increase costs of competing risk behaviors. The place is a physical location, stage of life, or time when the target audience performs the desired behavior, accesses program products and services, and considers their health or safety issues. Promotion is the messages, materials, channels, and activities that reach the target audience to promote the benefits of behavior changes, including the product, price, and place features of the health communication campaign.

Health communication includes traditional media (e.g., news, outdoor advertising, or print materials), trusted peers, and social media. CDC's health communication activities involve three major tactics: being customer-centered, science-based, and high-impact. The customer-centered tactic is designed to apply data on target audiences, use a range of communication tools, assess baseline and changing needs, disseminate culturally and linguistically appropriate materials, adhere to translation standards to distribute information in multiple languages and plain language, conduct audience segment research, administer national polls and surveys, and conduct usability research.

CDC's future directions in its customer-centered tactic include applying social media to expand the delivery of messages and supporting integrated, strategic communication planning through tailored consultancy.

The science-based tactic is designed to support health communication research and health/social marketing, promulgate the state of the science with concrete actions and publications,

conduct strategic communication with brand identity marketing, focus on health literacy, and provide publication support. CDC's future directions in its science-based tactic include improving capacity to demonstrate the value of its activities and investigating cost-effective and relevant strategies to assess the changing needs of the target audience.

The high-impact tactic is designed to establish specific outcome and impact targets, evaluate activities, solicit feedback from target audiences, learn from successes and failures, improve skills, conduct media evaluations, create information technology services assessments and evaluations, compile best practices, publicize success stories, and focus on innovation. CDC's future directions in its science-based tactic include applying evidence-based practice while identifying new and creative strategies, and continuing to foster a community of practice.

CDC has developed a 5-step coordinated message approach: (1) identify the core value shared by the public; (2) develop an overarching public health message frame around the core value; (3) craft public health-specific and audience-centric messages that link to the frame; (4) build awareness using coordinated messaging across multiple channels; and (5) increase social and political will.

The message frames should be designed to appeal to the value of the target audience; connect persons to issues with new perspectives; establish new associations; unify messages to persuade a massive shift in paradigms, beliefs, and assumptions; and change media responses. For example, the key messages in CDC's "24/7 Health Communication Campaign" are to save lives, protect individuals, and save money through prevention. The campaign emphasizes CDC's value to America's health and bottom line, articulates the need to protect public health funding through CDC, and promotes a wide variety of communication deliverables.

Health communication campaigns must focus on health equity to reach groups that are vulnerable to health disparities (e.g., racial/ethnic minorities, elderly and disabled persons, persons living in rural or other geographically underserved areas, persons with low English proficiency or limited education, persons of low socioeconomic status [SES], and persons at risk due to gender or sex).

Health communication campaigns must be designed to focus on health literacy. Data show that only 12 percent of adults in the United States have proficient health literacy and 14 percent (or 30 million persons) are below the basic health literacy level. Of this subpopulation, 42 percent are more likely to report poor health and 28 percent are more likely to lack health insurance.

Efforts are underway throughout the country to address health literacy. New methods and mechanisms are being developed to more widely share information. Partnerships with providers, media, and service organizations are being formed to improve access to accurate and appropriate health information. Print documents are being simply and appropriately used to facilitate healthy decision-making. Partnerships are being formed with educators to improve health curricula with a focus on "real-life" examples for adult and young learners.

The "digital divide" must be addressed in health communication campaigns to close the gap between target audiences with and without access. Data show that 49 percent of persons have few technological assets. These audiences include persons >70 years of age, disabled persons, persons with less than a high school education, and persons with literacy issues. Health equity and health literacy experts should be engaged at the outset of developing health communication campaigns.

The 2007 Glasgow and Emmons study reported that only 50 percent of recommended healthcare practices are implemented and <50 percent of these interventions are implemented for prevention and behavior changes. Data have not been generated to date to document the percentage of health communication programs that use evidence-based practices.

The role of researchers in translating research to practice includes the completion of studies and dissemination of results. The role of practitioners includes adoption decisions, practice integration, implementation, and maintenance. However, roles have not been clearly defined for knowledge synthesis, actionable knowledge, and transfer and distribution.

Overall, health communication, marketing, and health-related social media will be ubiquitous and will continue to grow in the future. Dynamic, rich, and tailored content should be developed to counteract the overabundance of information. The credibility of information will be more difficult to assess in the future. Health communication campaigns should be designed, on a vertical axis with trusted experts and on a horizontal axis with peers, to meet this challenge.

Barriers related to health equity, literacy, and translation of research to practice must be addressed at the outset in developing health communication campaigns because most information is not accessible to most individuals. However, mobile media might serve as a mechanism to bridge this gap. Dr. Lyon Daniel encouraged ACBCYW to view CDC's "Gateway to Health Communication and Social Marketing Practice" at www.cdc.gov/healthcommunication.

Dr. Lyon Daniel provided additional details on health communication in response to ACBCYW's questions.

- Creative strategies should be developed and implemented to make health messages interesting to persons (e.g., an interactive "What Do I Know About Breast Cancer" quiz). Message bundling and integration also can be utilized because many preventive measures for overall good health are important for breast cancer prevention. These and other approaches will be important in targeting health messages without diluting other health issues that might be viewed as more important to young women (e.g., physical activity, good nutrition, folate supplementation, contraception, and protection against HIV/STDs).
- Audience research and qualitative feedback should be obtained through multiple channels (e.g., focus groups and online polls) early in the development of a health communication campaign. Emphasis also should be placed on mechanisms and locations for message delivery to improve the uptake, reception, and impact of the campaign.
- Surrogate measures can be incorporated into a health communication campaign to evaluate its effectiveness at certain points in time and make mid-course corrections and improvements as needed.

Dr. Fairley confirmed that ACBCYW would discuss methods to leverage and utilize CDC's existing resources to help the members in developing and targeting health communication messages to young women at increased risk for developing breast cancer. For example, ACBCYW might vote to establish a new workgroup to specifically address BCYW health communication.

Overview of the Importance of Health Communication

Leslie Snyder, Ph.D.

University of Connecticut Center for Health Communication & Marketing

Dr. Snyder covered the following areas in her overview of the importance of health communication. A “communication campaign” is defined as an organized set of communication activities directed at particular audiences for a certain period of time to achieve specified goals. A “communication program” has the same definition, but for a more open-ended period of time.

Health communication can identify population behavior change; determine policy change; change language to alter perceptions of problems and solutions; identify and support persons in need; provide professional training; improve patient-provider encounters; organize stakeholders through boards, coalitions, and other mechanisms; and diffuse and translate successful programs. Wellstart’s International Breastfeeding Campaign serves as a solid model of a comprehensive health communication campaign.

Several actions can be taken to increase the effectiveness and potential for success of health communication campaigns. The steps for strategic communication should be followed. Appropriate theories of behavior change and communication should be used. Attention should be paid to contextual factors, including differences among target populations and their environments.

The strategic communication protocol includes six steps:

- Step 1: conduct research to identify behaviors, resources, targets, and social, political, economic, and legal contexts.
- Step 2: develop a communication plan to determine goals, targets, persuasive strategies, channels, and behaviors.
- Step 3: develop a management plan with personnel, resources, a timetable, and an approach to integrate activities with those of other organizations and events.
- Step 4: develop and prepare messages by pretesting materials with target audiences to ensure the desired effect is achieved, conducting focus groups to test messages for the media, and training interpersonal channels.
- Step 5: implement and monitor the efficacy of the messages.
- Step 6: evaluate and adjust the communication plan, messages, or other aspects of the strategic communication protocol.

Specific and realistic goals should be established, including behavior changes for each target group. Meta-analyses have reported that of 12 major health topics, media campaigns for mammography and smoking cessation have the least effectiveness. The 2004 Snyder, *et al.* study showed that campaigns promoting the commencement of new behaviors were more effective than those promoting the cessation and prevention of existing behaviors.

Several behaviors potentially support breast cancer prevention (e.g., nutrition, exercise, smoking cessation, reduction in secondhand smoke [SHS] exposure, moderate alcohol consumption of 1 drink per day, screening behaviors, genetic testing, collection of a family cancer history, and access to support if indicated).

Identification of audiences is the first step in targeting messages. The potential target audience should be divided into segments (e.g., demographic groups). Theoretically meaningful segments of the audience should be targeted. Audience segmentation by outcomes should identify goal behaviors, current and past behaviors, needs, decision-makers, attitudes, perceptions and values, and knowledge.

BCYW target audiences can be segmented into various categories. Risk segments could include African American, Ashkenazi Jewish, and American Indian/Alaska Native (AI/AN) women; women with a family history of or genetic predisposition to breast cancer; smokers and women with SHS exposure; and overweight/obese women. Needs segments could include YBCS who need survivor support and interventions to prevent future cancers. Decision-maker segments could include healthcare providers and families of patients. The segments of the target audiences should be further broken down based on their behaviors.

Audience segmentation by communication issues should identify persons who are motivated to change and will easily change behaviors. The timing of information-seeking and decision-making should be clearly defined. The use of, and accessibility to, communication channels should be determined. Social, cultural, and linguistic communication differences should be specified. Political and organizational concerns should be addressed. The segments of the target audiences should be further broken down based on persons who need different channels and messages.

A decision should be made on whether the target audience will be narrow or broad. Messages are more effective in narrow target groups, while messages have a greater reach in broad target groups. The balance between these two options is to launch the health communication campaign to a broad target group with common message points and then design special messages and channels for populations that need further communication. Tailored or individualized messaging can be used when applicable.

The 2002 Snyder, *et al.* study reported an association between increased exposure and greater behavior change. The average exposure of U.S. health campaigns is only 40 percent of the target audience, while intensive and well-funded campaigns can achieve 90 percent exposure. Emphasis should be placed on the intensity of messages and frequency of exposure. Multiple and novel channels and formats should be utilized.

The 2004 Cheong, *et al.* study examined the sources of information for Hispanic families with children <5 years of age in Los Angeles in 2002. The top five information sources for this cohort were television, in-person and telephone conversations with family and friends, healthcare providers, newspapers, and books or magazines.

A number of important issues should be considered in determining appropriate channels for health communication campaigns (e.g., effectiveness of the channel in reaching and affecting persons, cost and cost-effectiveness of the channel, and timing of the channel in terms of readiness and ability to sustain behavior change).

The Snyder and La Croix meta-analysis is in press and includes a review of all meta-analyses of interventions that used the media through 2010. The meta-analysis showed that telephone reminders, invitation or reminder letters, and interpersonal interventions were most effective for mammography screening, while tailored interventions and media campaigns were less effective. Mobile phone reminders were highly effective as a smoking cessation and prevention

intervention targeted to adults. The meta-analysis results emphasize the need to combine various health communication approaches.

Recent data show that 95 percent of persons 18-29 years of age, 93 percent of teens, and 87 percent of persons 30-49 years of age use the Internet in general, while 75 percent of adults and 28 percent of teens search the Internet for health information. The 2008 Fox study showed that patients used Internet searches to make treatment decisions and ask their physicians new questions. However, medical professionals continue to serve as the dominant information source for patients with urgent health questions. Although individuals are aware of inaccurate information on the Internet, 75 percent do not check the source of information.

The Pew Internet and American Life 2011 data show that 50 percent of adults use social networking sites. For information dissemination, the Red Cross posted videos of the Haiti earthquake on YouTube only 30 minutes after the disaster occurred. YouTube serves as a valuable resource for reporters to rapidly obtain information. For message delivery, social media, social networking sites, and text and peer-to-peer messaging are extremely effective for young persons. However, mechanisms must be incorporated to prevent or correct inaccurate information in peer-to-peer messaging.

Formats should be matched for goals and target groups in selecting channels. Tailored and individualized channels are more effective than non-tailored channels. News and public relations strategies are less expensive, but a “news hook” must be utilized to obtain media attention. Advertising can include public service announcements (PSAs), informational text messages, or videos, but ~50 percent of PSAs are broadcast at poor times with limited viewers. Entertainment messages might be effective in reducing counterarguments.

The 2004 Kreuter, *et al.* study highlighted the benefits of a tailored campaign to promote childhood immunization. Parents of babies 0-1 year of age were given personalized calendars with their child’s name, age, photograph, immunization dates, and information on local health centers, child developmental status, and other health and safety issues. The study showed that 66 percent of babies in the intervention group were up-to-date on their immunization at 2 years of age compared to 47 percent of babies in the control group. Promotions with objects, contests, events, and linkages can be used to help normalize messages.

In terms of interpersonal channels, patient-provider encounters should be of high quality. The 2005 Babor study showed that brief 15-minute interventions could be effective if outreach staff is trained in both content and communication skills. The 2002 Kiwanuka-Tondo and Snyder study reported an association in Uganda between using outreach workers who are the same race/ethnicity as the target audience and improving the reach of AIDS campaign messages. Interpersonal channels may increase sustainability by institutionalizing interventions. The Broadhead and Huckathorn study showed that outreach workers were much more effective in communicating AIDS information to intravenous drug users by using a respondent-driven sampling approach.

All messages and media should be pretested and improved prior to delivery. All channels, including physicians, should share and convey consistent messages. Simple and memorable concepts should be selected to promote messages. Thoughtful consideration should be given to branding. New information should be emphasized to the target group. For example, the old “smoking kills” message should be replaced with a photograph to illustrate the effects of

smoking on facial appearance over time. The new message would have more of an impact on young persons who are concerned with their appearance.

High-quality execution and fresh messaging should be utilized to capture attention with logos, slogans, and jingles. Multiple executions, frequent updates of media messages, and celebrities, characters, babies, and animals should be used to increase attention. Explicit, entertaining, or intense messages should be delivered.

Other issues to consider in message development include the stage of behavior change of the target audience; risk-taking behaviors, psychological reactance, and other beliefs of individuals; the need for persons to know essential information; and peer norms, perceptions of the commonality of behaviors, and identification with persons who are or are not engaged in the behavior. Current messages should be analyzed to evaluate whether two-sided messages will be needed to attack incorrect messages and assess whether the credibility of misleading message sources should be undermined.

Health communication campaigns should be evaluated by monitoring adherence to the plan, checking the distribution of materials, observing interpersonal outreach, and periodically soliciting feedback from all staff. The evaluation should be designed with a pretest and a control group if possible. Efforts should be made to rule out a potential secular trend that caused the change. The 2009 Snyder, *et al.* study found an association between better evaluation designs and greater capacity to detect change. Intermediate steps to behavior change should be measured to track progress.

Overall, additional research is needed to fill gaps in the existing health communication literature. More data are needed on behavior maintenance, sustainability, cultural/belief changes, and coordination of common behavior changes. Strong partnerships should be established with the media and other organizations to leverage resources to increase the reach and impact of the health communication campaign to the target audience.

Ms. Faye Wong is Chief of the DCPC Program Services Branch and the former lead for CDC's VERB campaign. In response to ACBCYW's questions regarding the cost, reach, and impact of public health campaigns, she described CDC's national VERB™ Campaign to increase physical activity among children 9-13 years of age.

CDC was given a \$125 million congressional appropriation in Year 1 of the campaign, but funding decreased to \$50-\$70 million per year over the next 4 years. The high level of funding directly contributed to the success of the campaign. Awareness of the campaign and its messages was 74 percent among 21 million children 9-13 years of age in the U.S. A behavior change of 4-7 percent was achieved each year of the campaign in increasing physical activity in the target audience. Ms. Wong noted that traditional funding levels of ~\$1-2 million to conduct public health campaigns are not adequate to achieve expected outcomes and impact.

Overview of the "Get Yourself Tested" (GYT) Campaign

Allison L. Friedman, M.S.

Health Communication Specialist, Division of STD Prevention
Centers for Disease Control and Prevention

Ms. Friedman covered the following areas in her overview of the Get Yourself Tested (GYT) Campaign that CDC conducts in partnership with MTV, Henry J. Kaiser Family Foundation (KFF), and Planned Parenthood Federation of America (PPFA). GYT was created to address the hidden epidemic of STDs. Many STDs are asymptomatic. Of 19 million STDs that are acquired each year in the United States, 50 percent are among young persons 15-25 years of age. Estimates show that 2.8 million new cases of chlamydia occur each year.

STDs are associated with tremendous age, gender, and racial disparities among youth, women, men who have sex with men, and African American, Hispanic, and Native American populations. STD-associated stigma serves as a barrier to open discussions, prevention behaviors, information- and treatment-seeking behaviors, testing, and disclosure.

CDC, KFF, and the American Social Health Association conducted formative qualitative consumer research from 2003-2009 to fill data gaps on misconceptions, stigma, and fear that prevent persons from being tested for STDs. The research showed that many youth and young adults had no knowledge that STDs can be asymptomatic, STD testing is not a standard part of routine medical examinations, and urine tests, as well as free and confidential testing, are available. This target audience also had no knowledge of the recommendation for routine testing for certain STDs and locations to access testing.

In 2008, CDC established communication priorities to promote chlamydia screening for young women to prevent infertility, reduce STD disparities, and destigmatize and normalize STD testing. The 2009 Forhan, *et al.* study reported that 1 in 4 teen girls had an STD.

GYT was launched in April 2009 as a youthful and empowering social movement to reduce the spread of STDs among young persons 15-25 years of age through information, open communication, and testing and treatment. GYT was implemented as part of the MTV and KFF "It's Your Sex Life" Campaign.

The GYT partners established 4 key objectives for the campaign:

- present testing in a context that is familiar and relatable to young persons;
- promote an open dialogue about STDs;
- encourage testing as an act of pride rather than shame;
- and connect the target audience to testing centers in their area.

The GYT partners also clearly defined their roles in the campaign. MTV is responsible for communication assets, creative development, youth market expertise, and on-air and online promotions and programming. KFF is responsible for health communications expertise, project management, Web site design, and consumer materials. PPFA is responsible for testing services in health centers, point-of-service promotions, community outreach, and evaluation. CDC is responsible for epidemiologic and health communication technical expertise, research and evaluation, and a network of public health partners for expanded services. CDC provides an STD testing locator for the campaign.

MTV's role is critical to the success of GYT. According to the National YouthStyles Survey, 57 percent of young persons 15-25 years of age reported watching MTV in the past 7 days. The survey also showed that MTV reaches 39-60 percent of African American, Hispanic, AI/AN, and Asian Pacific Islander (API) young persons 15-25 years of age, compared to 36 percent of their white counterparts.

The major categories of GYT's coordinated response include media, health centers and clinics, Web-based and mobile resources, and community partners. Specific products in these categories include original programming, targeted PSAs, a dedicated Web site, social media, sweepstakes to promote STD testing, celebrity endorsements, and concerts and other on-the-ground events.

GYT connects youth with local testing centers through a testing locator widget on GYTnow.org and the GYTNOW SMS code. Youth can obtain a list of the closest STD testing sites by entering their zip codes on their mobile phones. From April 2009 - April 2011, ~155,000 STD clinic referrals were made. CDC's STDtest.org provides additional GYT resources as well.

PPFA health centers are prioritized in CDC's testing center database during STD Awareness Month in April. GYT toolkits are distributed to PPFA clinics, school- and college-based health centers, and other community organizations. Partner clinics offer reduced or free STD testing and special promotions to link to the national GYT media campaign.

GYT messaging is refreshed each April based on public health priorities, consumer research, and MTV's in-depth understanding of youth audiences. The Year 1 messaging focused on branding of the campaign to raise awareness and ease discomfort with STD testing in the target audience.

The Year 2 messaging focused on the slogan of "Get Yourself Talking. Get Yourself Tested," to strengthen communication with partners and providers. The Year 3 messaging focused on the slogan of "Know Yourself. Know Your Status," to promote STD testing as an act of pride, publicize GYT as a lifestyle brand, and encourage a youth movement. The overarching goal of this messaging was to increase chlamydia testing for girls. Ms. Friedman presented a sample of some of the celebrity endorsements and targeted PSAs for GYT.

From 2009-2011, MTV has broadcast 74 PSAs and 20 original programs for GYT. The GYTnow.org Web site has had 2 million visitors to date. The Web site provides STD testing facts, tips for youth to have STD-related conversations, videos, the GYT toolkit, an evaluation toolkit, youth involvement opportunities, and a testing center locator tool.

In terms of social media, the GYT Facebook page has 14,101 fans, the GYT Twitter page has 2,384 followers, and the GYT blog catalog includes 30 bloggers. The key partners allocated \$15,000 to launch a Facebook advertising campaign in April 2011 to determine, in real-time, the effectiveness of GYT messages targeted to youth, African Americans, Hispanics, and Native Americans.

Several activities are conducted to increase youth involvement in GYT (e.g., the GYT Campus Challenge, GYT Ambassador Program, and sweepstakes to promote the testing locator). "Mashable Awards" recognized GYT as one of the five game-changing social media marketing campaigns. GYT is branded and promoted at MTV concerts and mobile STD testing is offered at other on-the-ground events.

CDC's evaluation of GYT is designed to measure the reach and impact of the campaign. These indicators include tracking of online, on-air, and social media usage; the number of GYT toolkits requested and distributed; PPFA and college outreach events; STD testing locator referrals; the addition of new questions to national surveys; the demand for STD testing at PPFA clinics; and

reports and evaluations from local partners. A GYT survey is administered annually to obtain more formal feedback from partners.

The evaluation data showed an increase in the distribution of GYT toolkits from ~1,300 in 2010 to >5,000 in 2011. In addition to CDC's evaluation, PPFA also tracks on-the-ground activities of its affiliates. The evaluation data showed an increase in GYT's reach from ~20,000 youth in 2009 to ~52,000 youth in 2010.

Based on data from the National YouthStyles Survey of youth 9-17 years of age, 11.8 percent of 1,310 youth were aware of GYT in 2009, while 18.3 percent of 1,197 youth were aware of GYT in 2010. Another survey of 3,065 youth and young adults 12-29 years of age reported that 30 percent had heard of GYT.

PPFA collected STD testing data from 10 of its affiliates regarding the number of patients who received STD services during the month of April. The data showed a 70 percent increase in the number of STD testing patients from April 2008 to April 2010. The largest increases were observed in female patients, young persons <25 years of age, African American and Hispanic patients, and persons living below the Federal Poverty Level. STD positivity rates for chlamydia, gonorrhea, and HIV in these populations were comparable to or higher than the national average. Anecdotal reports from the field substantiate the success and increased awareness of GYT. For example, GYT led to the declaration of April 29 as "STD Testing Day," by the Governor of Connecticut

Overall, GYT has emphasized several important components of launching and maintaining a national media campaign (e.g., partnerships, agency endorsement, frequent updates with novel concepts, multimedia platforms, cross-promotions, incentives, tangible products, and youth advocacy).

The key partners also addressed major challenges of GYT (e.g., organizational and cultural differences, evaluation of a national media campaign without a control group, difficulties in engaging youth and celebrities due to the stigma associated with STDs, and mechanisms to meet the increasing demand for GYT materials with diminishing resources). CDC has been unable to determine the actual cost and cost-effectiveness of GYT to date.

Overview of CDC's Pre-Teen Vaccination Social Media Campaign

Jill B. Roark, M.P.H.

Project Manager, Carter Consulting
CDC Adolescent Immunization Communication Campaign

Ms. Roark covered the following areas in her overview of CDC's efforts to harness the power of social networks, "mom bloggers," and Google to launch its pre-teen vaccination social media campaign. No adolescent immunizations had been developed and approved by the Food and Drug Administration (FDA) prior to 2005. After FDA licensed the Tdap, human papillomavirus (HPV), and meningococcal conjugate vaccines (MCV4) for children 11-12 years of age, CDC launched a new communication campaign. In 2009, a second HPV vaccine was added for girls only and a permissive recommendation was made for boys.

Editorial Note: On October 25, 2011, CDC's Advisory Committee on Immunization Practices (ACIP) approved recommendations for routine vaccination of males 11 or 12 years old with 3-doses of HPV4 to protect against Human Papilloma Virus. The HPV vaccine will afford protection against certain HPV-related conditions and cancers in males, and vaccination of males with HPV may also provide indirect protection of women by reducing transmission of HPV.

Annual data collection on the HPV vaccine was initiated in 2006 through telephone surveys of parents and providers. The survey data showed that HPV vaccine coverage was lower than Tdap and MCV4 coverage. Coverage of 1 HPV vaccine dose increased by only 12 percent in 2008-2010 compared to a 29 percent increase in Tdap coverage in the same 2-year period. Disparities in HPV vaccine coverage also were observed by race/ethnicity and poverty status. HPV vaccine coverage was lower for African Americans and Hispanics compared to whites. Moreover, girls living in poverty were less likely to complete the HPV vaccine series.

CDC used \$50,000 from its fiscal year 2010 budget to launch a social media campaign. The purpose of the campaign was to increase awareness among parents of CDC's latest adolescent vaccination recommendations for HPV, MCV4, and influenza vaccines. Social media experts informed CDC that 1 word-of-mouth conversation has the impact of 200 television advertisements. CDC also learned that 3.9 million women with children write blogs in the United States, but the number of mom bloggers is expected to increase to 4.4 million by 2014.

Compared to 76 percent of women in general, 90 percent of mothers are online and 66 percent believe word-of-mouth is credible. Other data have shown that mom bloggers are vastly more likely to write about topics other than their experiences with motherhood and 55 percent of active social media moms reported their purchases were influenced by recommendations from personal review blogs.

CDC vetted and outreached to 60 online publishers and received responses from 34 publishers with an interest in blogging information on pre-teen vaccination. These initial efforts led to the placement of CDC's messages on multiple social media sites: momversation.com, Parents of Kids of Infectious Diseases, the Louis Pagan blog to specifically reach Hispanic parents, Berkeley Parents' Network e-newsletter, and GirlsHealth.gov.

CDC devoted \$15,000 to launch a blogging campaign with TwitterMoms. Of 25,000 online TwitterMoms, ~60 agreed to blog and tweet on adolescent vaccination and other health issues. Ms. Roark presented a sample of the TwitterMoms blogs. CDC also used funds to conduct mobile marketing through Google with three components: a mobile search, sponsored applications, and click-to-call advertisements. This effort included a promotion of CDC's PSA using YouTube searches.

CDC received a solid return on its \$50,000 investment. The pre-teen vaccination social media campaign resulted in 12 publishers participating in earned publisher outreach with nearly 4 million impressions; 13 publishers participating in TwitterMoms with 510,628 impressions; and ~14.7 million impressions delivered to mobile phones with 251 calls to CDC-INFO.

Publisher outreach and TwitterMoms generated positive feedback, but the pharmaceutical industry served as a significant competitor in the mobile component of the campaign. The mobile application resulted in 26,158 visitors to CDC's pre-teen Web site, but the mobile search only resulted in 162 visitors. The video search resulted in 2,150 visitors to the Web site and 747,229 views of the actual video. Overall, 25 publishers participated in the pre-teen vaccination social media campaign and ~19 million impressions were achieved.

CDC learned several valuable lessons in launching the pre-teen vaccination social media campaign in 2010. Increased funding levels would allow for more comprehensive campaigns to have greater reach and impact. Therefore, \$600,000 was allocated to address both childhood and pre-teen vaccination in 2011. Moreover, publisher outreach should be leveraged and the list of publishers for outreach should be vetted.

In 2011, CDC used the additional funds to expand the campaign with traditional media (e.g., fliers, posters, magazine and bus advertisements, and PSAs in movie theaters located in 16 cities covering 6 States with the lowest rates of pre-teen vaccination). For digital media for the 2011 campaign, CDC increased the Twitter applications, updated the Web site, and added a mobile texting pilot project and other social media features. Ms. Roark presented CDC's new PSA on pre-teen vaccination targeted to mothers and also showed samples of the traditional and digital media products for the campaign.

Latinos in Social Media sponsored a 1-hour Twitter party in July 2011, in which 20 bloggers posted information on pre-teen and teen vaccination provided by CDC. This effort led to 20 blog posts and ~1.6 million impressions. Google TV broadcast CDC's PSA during popular television shows for 12 days. The 20 broadcasts of the PSA resulted in nearly 4 million impressions.

Overall, CDC learned that the provision of detailed information to blogger groups can result in a high number of impressions and an increase in the number of Facebook and Twitter followers with only a small investment. CDC's next steps in the campaign will be to target physicians to improve capacity in addressing disparities associated with pre-teen vaccination.

ACBCYW advised CDC to engage BlogHer in its ongoing efforts with the pre-teen vaccination social media campaign because this Web site hosts and maintains a tremendous number of mom who blog.

Overview of CDC's Use of Social Media for Health Communication

Diane Brodalski

Social Media Specialist, Office of the Associate Director for Communication
Centers for Disease Control and Prevention

Ms. Brodalski covered the following areas in her overview of CDC's use of social media for health communication. "Social media" is defined as Internet-based tools for sharing and discussing information and includes activities that integrate technology and social interaction. The goals of social media are to complement traditional communication, share content in new spaces, reach new audiences, and encourage engagement and interaction with content.

Social media has allowed CDC to reach a younger audience. The age of CDC.gov consumers ranges from 35-64 years of age, while 55 percent of CDC fans on Facebook are 18-24 years of age. Data collected in 2011 showed that >250 million active Facebook users use mobile devices to access the Web site; 20 percent of Twitter users produce at least 80 percent of content on the Web site; and 15 percent of cell phone users in the United States utilize these devices to search for health information. Overall, social media accounts for 1 of every 6 minutes spent

online in the United States, while 59 percent of Internet users search for health and medical issues.

The 2011 Pew Internet and American Life Project collected data on the influence of the Internet in changing the lives of individuals. The data showed that online sources and advice from peers are significant sources of health information, but healthcare providers are still the primary choice for persons to obtain health information.

The availability of social media tools and an increased desire for persons living with chronic conditions to connect to, and obtain support from, other patients drive online health discussions. Social media tools have various levels of engagement that include listening, generating interest, sharing content, and building communities, but an increased level of engagement is associated with the amount of time and resources involved.

Examples of CDC's social media tools for health communication are highlighted as follows. CDC's monthly *Vital Signs* reports focus on a single, important public health topic to generate a call to action for different audiences. CDC uses social media to highlight and complement releases of the monthly *Vital Signs* reports, encourage participation, and communicate key messages to influence health decisions. A series of five to seven posts is scheduled for the launch of each *Vital Signs* report.

CDC's social media tools include informative and interactive tabs, buttons, and widgets that partners can use to directly link to the CDC.gov Web site. The Facebook posts have generated ~80,000 impressions of the *Vital Signs* reports, while the CDC.gov and CDC_eHealth Twitter accounts are used by millions of individuals, organizations, and businesses to discover and share new information. However, CDC's Spanish Facebook page for the *Vital Signs* reports that was launched in December 2010 has only generated ~7,000 fans to date.

CDC's eCards can be effectively and inexpensively distributed via e-mail to reach individuals with personalized and targeted health information. CDCStreamingHealth is CDC's YouTube channel that was established in 2007. The channel currently includes 200 videos on a variety of health topics and has generated >4 million uploaded videos to date. YouTube is an extremely powerful social media tool that has a regular audience of 490 million unique visitors per month. Data show that 25 percent of Internet users have viewed an online video of health and medical issues.

CDC also uses SMS text messaging to share information on *Vital Signs* reports because this technology is a common mobile data service. Data show that 72 percent of users utilize their mobile phones to send or receive text messages. CDC's mobile Web site is optimized for viewing on Smartphones and other devices. CDC's other social media tools to launch the monthly *Vital Signs* reports include podcasts, a content syndication digital application for partners to rapidly download up-to-date information from CDC on their Web sites, a list of GovDelivery e-mail subscribers, and digital press releases.

CDC began its social media activities by initially adopting low-risk tools; targeting health communication messages to mechanisms and locations that were relevant to, and utilized by, the intended audience; monitoring the preferences of the target audience; identifying pressing issues, knowledge gaps, and misconceptions to address; and understanding the level of effort.

CDC was particularly aware of the immense power of social media during the 2009-2010 H1N1 seasonal influenza outbreak. CDC's 32 videos that were posted on YouTube covered influenza symptoms, antiviral use, prevention tips, and other topics and were viewed >2 million times. CDC's Twitter account also facilitated rapid communication with a wide audience of engaged users. Moreover, CDC uses social media to rapidly and continuously disseminate accurate and up-to-date information during emergency events to address fears and concerns.

CDC used three Twitter profiles during the 2009-2010 H1N1 seasonal influenza outbreak: CDCFlu, CDCemergency, and CDC_eHealth. The Twitter profiles were used to provide up-to-date information on emergency events, new guidelines, the status of outbreaks, and social media tools. The Twitter profiles generated 1.28 million followers during the influenza outbreak.

CDC's Facebook fans during the influenza outbreak increased from 57,000 in July 2010 to ~1.6 million in September 2011. CDC used Facebook to post updates, provide social media tools, and promote blogs and the CDC text messaging program. At the division level, the CDC Division of Injury Prevention and Control has produced the "Heads Up: Brain Injury Awareness" and the "VetoViolence" Facebook pages.

In terms of measurement, multiple tools and resources are available to gather social media metrics at no or low costs (e.g., Facebook insights, Twitter searches, Web site analytics, and the CDC eHealth metric dashboard at www.cdc.gov/metrics). CDC uses qualitative metrics to determine the awareness, reach, and sentiment of its messages (e.g., the extent to which CDC content is shared, wall posts, additional hashtags added to posts, and the types of comments and mentions).

CDC also uses quantitative social media metrics to measure the awareness, reach, and usage of its messages and the engagement of target audiences. These measures include the number of fans or followers on Facebook or Twitter, the number of impressions for each post, the number of likes and comments, the number of re-tweets or mentions, and the number of click-throughs to the CDC.gov Web site.

Monitoring of social media activities is equally important as measurement to check usage at regular intervals, determine development or progression of the campaign, and obtain feedback on the brand and messages perceived by the target audiences. Pre-campaign environmental scanning should be conducted and real-time monitoring should be performed throughout the campaign to appropriately monitor the effectiveness of the social media activities.

CDC has compiled a number of lessons learned and best practices from its social media activities. Social media is only one part of a larger, integrated campaign. Meaningful content will continue to be a critical component of any social media campaign. Information should be collected to make strategic choices, determine resource needs, and identify target audiences and their relevant locations and mechanisms. Moreover, a social media campaign should be designed to encourage participation, set realistic goals, and develop guidance and policies.

In terms of social media trends, Facebook and LinkedIn are the most popular social media Web sites at this time. Data show that ~152 million persons in the United States are Facebook users, 92 percent of social network participants use Facebook, and 35 percent of Facebook users have a college or advanced degree. Of 750 million Facebook users, 50 percent access their accounts daily. The use of social networking sites is projected to increase among persons >35 years of age.

The use of Twitter also is expected to expand beyond sampling posting through Twitter Chat, Twitterview, Twitter Town Hall, and live tweeting. These new Twitter features include question/answer sessions with followers on general or specific topics, live tweets from conferences or other events, and interviews with short-form responses.

A significant increase has been observed in the number of social media sites accessed via mobile phones because these personal and portable devices have unique characteristics. At this time, 93 percent of Americans have a mobile device, including usage by 87 percent of African Americans, 87 percent of Hispanics, and 80 percent of whites. In terms of simplicity, mobile devices are suitable for regularly scheduled tasks with a minimum number of steps or clicks.

In terms of immediacy, users immediately can receive content on their mobile devices from virtually any location in the world. In terms of context, mobile devices can be used to deliver services that are relevant to the location of the user (e.g., flooding or power outages based on zip codes). Recent data show that 9 percent of mobile users have applications on their devices to track or manage health issues (e.g., weight loss or physical activity).

Overall, CDC has created several social media resources that are available to specific target audiences and the general public. The Health Communicator's Social Media Toolkit includes an overview of social media tools, resources, case studies, statistics and other data; guidance, lessons learned, and best practices; templates to develop and evaluate communication objectives and strategies; and examples of social media campaigns. The toolkit also provides guidance on whether a low, moderate, or high level of resources in terms of time, staff, or funding will be needed over the social media continuum from engagement to dissemination. (www.cdc.gov/healthcommunication/ToolsTemplates/SocialMediaToolkit_BM.pdf)

CDC's *Social Media Guidelines* contain best practice and policy documents in the area of social media (www.cdc.gov/SocialMedia/Tools/guidelines). The Gateway to Health Communication and Social Marketing contains information from CDC, other public entities, and private organizations to assist in building social marketing or health communication campaigns and programs (www.cdc.gov/healthcommunication).

Overview of LIVESTRONG's Social Media Campaigns

Renee Nicholas

Director of Corporate Partnerships, LIVESTRONG
ACBCYW Liaison Representative

Ms. Nicholas covered the following areas in her overview of LIVESTRONG's social media campaigns. The mission of LIVESTRONG (formerly the Lance Armstrong Foundation) is to inspire and empower persons affected by cancer by facilitating connections to other cancer patients and survivors through community building.

Nike, Inc. initially designed the yellow LIVESTRONG wristband in 2004 to link cancer patients and survivors, but the wristband eventually served as an international symbol of hope and courage. Due to Nike's major role in marketing both domestically and internationally, key

influencers and celebrities throughout the world wore the wristbands, generated interest, and minimized barriers to discussions on cancer and other health issues. As a result, LIVESTRONG is the “original” social network, well before Facebook and other social media sites.

Since that time, LIVESTRONG has dedicated a full-time staff member to social media. LIVESTRONG currently has >1.45 million Facebook friends in its community and ~2.5 million persons in its database. However, LIVESTRONG has learned that its social media activities and initiatives generate more interest and engagement with a recognized personality. For example, Lance Armstrong, the founder of LIVESTRONG, personally has >3 million Twitter followers. Doug Ulman, the President and Chief Executive Officer of LIVESTRONG, personally has >1 million Twitter followers. The LIVESTRONG organization has 100,000 Twitter followers. Women represent 56 percent of all LIVESTRONG followers on Twitter.

LIVESTRONG’s authenticity, integrity, and consistency of its brand are directly attributed to its success with social media. LIVESTRONG strategically developed a campaign to leverage social media for the United Nations Summit on Non-Communicable Diseases in September 2011. LIVESTRONG used Facebook and Twitter for persons around the world to log on its Web site and enter their name, e-mail address, country, and photograph.

The campaign led to the creation of a mosaic of all of the photographs that were submitted. The mosaic was presented to world leaders during the summit to make cancer a global fight and also was featured on a billboard in Times Square. The overarching goal of the campaign is to focus attention on global cancer survivorship to attract funding to this issue. Ms. Nicholas presented two videos of its integrated, targeted, and multi-channel “Face Up to It” campaign. Overall, LIVESTRONG’s key lessons learned in creating its social media campaigns and initiatives are to listen, develop strong partnerships, and obtain a corporate sponsor.

ACBCYW Open Discussion: Session 1

Dr. Partridge announced that she would facilitate the open discussion by soliciting input from ACBCYW in response to a specific set of questions CDC developed. ACBCYW’s comments and suggestions in response to CDC’s questions are outlined below.

1. *What lessons should CDC and ACBCYW consider in disseminating BCYW/YBCS health messages?*

- Some members found Question 1 to be premature because ACBCYW was being asked to provide advice on implementation and dissemination without clearly defining the target audience, specific products, and messages. For example, different health messages, strategies, and campaigns will be needed for at-risk young women who do not have cancer, young breast cancer patients undergoing treatment, and YBCS who are in follow-up care.
- Data should be collected to determine appropriate body image messages to deliver to young women.
- Key lessons learned from health communication and social media campaigns of CDC and its partners should be applied to the development and dissemination of BCYW/ YBCS health messages (e.g., listening, branding, and collaborating with partners).

- Dr. Snyder's data showed that telephone reminders, invitation or reminder letters, and interpersonal interventions were most effective for mammography screening, while media campaigns were less effective. Social media should be used to educate young breast cancer patients and survivors, but may not be the most effective channel in reaching at-risk young women who do not have cancer, particularly those in disparate populations. A survey should be administered to obtain direct feedback from young women on their fears, concerns, and needs regarding breast cancer.
- Health messages should be designed for young women to change behavior and take action, but the development and dissemination of breast cancer prevention and screening messages will be difficult for the target population because mammography is not recommended for women <40 years of age. Young women should be advised to know their family history of cancer, heart disease, diabetes, or other chronic conditions to facilitate behavior changes that will have positive outcomes over time.
- All health messages targeted to young women should be founded on the principle of "first do no harm." For example, young women have been diagnosed with early-stage breast cancer who did not need to be treated. However, cancer treatment severely and adversely impacted these young women throughout their entire lives.
- Creative strategies should be developed to overcome barriers to effectively reach the small BCYW/YBCS population.
- The GYT and LIVESTRONG social media campaigns should be reviewed as models in developing a simple and easy online registration method to identify the number of the BCYW/YBCS population.
- ACBCYW should take a stepwise approach to outreach to the BCYW/YBCS population. First, the types of data that need to be collected should be specified to ensure groups at highest risk and the best screening methods are identified. Second, the evidence-based recommendations should be tailored to address the unique needs of, and advocacy for, specific populations. For example, AI women typically have higher rates of late-stage breast cancer diagnoses due to limited access to screening services.
- Research should be conducted on the implications of breast cancer in young women of reproductive age in terms of their physical, emotional, and mental health. ACBCYW should use these data to make evidence-based recommendations on these issues.
- ACBCYW's health messages to young women should focus on overall good health in the context of proper diet, physical activity, and maintenance of an appropriate body mass index (BMI). General health messages would prevent more breast cancer deaths in women <40 years of age than messages on mammography or breast self-examination (BSE). However, the ACBCYW members were divided on the evidence base of general health messages for breast cancer risk. Some members noted that data collected to date have demonstrated only a weak association between breast cancer risk reduction and proper diet, exercise, and smoking cessation, whereas other members pointed out that ongoing epidemiologic research on exercise has shown an association between exercise and breast cancer risk reduction of ~20 percent. The National Cancer Institute (NCI) plans to conduct a prospective randomized trial in cancer survivors to collect more epidemiologic data on the important role of exercise in breast cancer prevention. Moreover, Dr. Leslie Bernstein at the City of Hope recently published a paper that documented epidemiologic research continues to confirm a strong inverse association between physical activity and breast cancer risk. The paper further reported that new studies emphasize the important role of physical activity during adolescence in the reduction of pre-menopausal breast cancer. Overall, the majority of ACBCYW members were in favor of disseminating broad rather than targeted messages to young women to

increase the potential for leveraging additional funding, obtaining support, and partnering with organizations that address obesity and other chronic conditions.

- CDC should provide ACBCYW with its research, literature reviews, media audits, and environmental scans on BCYW for the members to identify and make recommendations on existing data gaps.

Dr. Fairley made follow-up remarks in response to ACBCYW's concerns regarding the prematurity of Question 1. ACBCYW is not being asked to make definitive recommendations at this time. Instead, CDC posed the question for ACBCYW to engage in an initial dialogue. ACBCYW would discuss the target audience and potential methods to reach the population. The members also would be given an opportunity during the meeting to form ad hoc workgroups to focus on these issues in more detail, gather additional information, and report their findings to ACBCYW.

2. *What other programs/organizations have been successful in delivering health messages to young women? What are the target ages of these initiatives? Do these programs/organizations utilize unique media (e.g., social media and radio) to deliver messages to their target audiences? What challenges do these programs/organizations face in using these mechanisms to disseminate their messages?*

Dr. Partridge clarified that ACBCYW's responses to Question 2 should not focus on healthcare providers/organizations because an entire meeting would be devoted to this target audience in the future. Instead, she asked ACBCYW to focus its comments on direct-to-consumer/patient organizations.

- Partnership for a Drug Free America and other controlled substance abuse programs
- The GYT target audience
- Bedsider.org developed by the National Campaign to Prevent Teen and Unplanned Pregnancy (This group targets women 18-30 years of age.)
- Tigerlily Foundation, Young Survivor Coalition, and similar groups that currently utilize direct-to-consumer media to reach young women
- Organizations that successfully bundle healthy lifestyle and prevention messages (e.g., "know your body" or "take these steps to live a positive and informed life")
- School nurses and guidance counselors
- Breastfeeding promotion and advocacy organizations

3. *What strategies should be implemented to assess the effectiveness of key messages related to BCYW/YBCS? What are possible outcomes from the dissemination of these messages? Are examples of metrics used for similar efforts available?*

- The percentage of young women who receive annual physicals should be used as a metric to measure the extent to which these women receive constructive advice on general health issues.
- Findings from ongoing meta-analyses and other research on physical activity, obesity, and other chronic conditions should be compiled, packaged, and presented to the HHS Secretary to guide an evidence-based evaluation of BCYW/YCBS messages.
- The effectiveness of key messages should be measured by an increase in the number of young women who know their risk for breast cancer based on family history, take actions for early detection to avoid detection of late-stage disease, and obtain treatment and

support for breast cancer that is identified. These metrics will be more effective than measuring an increase in the number of young women who are screened for breast cancer.

- CDC should disseminate accurate information to clarify misconceptions, dispel myths, and educate young women on whether their breast cancer risk is high or low. For example, Dr. Marisa Weiss, the founder of Breastcancer.org, is currently conducting a study that shows female high school students in Philadelphia inaccurately perceive themselves to be at tremendous risk for breast cancer due to media messages.
- The poor health literacy of the American population should be addressed before efforts are made to develop and disseminate health messages to reach the BCYW/YBCS population.
- Opportunities should be provided to expose young women to breast cancer (e.g., volunteering in clinics or developing personal relationships with women who currently have or survived breast cancer). These efforts might indirectly increase knowledge and change behaviors of young women.
- CDC's messages should focus on preventive measures (e.g., healthy lifestyles, exercise, and avoidance of obesity) to reduce risks for second cancers among young women with breast cancer. However, the messages should be designed to ensure that, for example, overweight/obese women with poor diets do not blame themselves for not taking measures to prevent breast cancer.

Public Comment Session

Doryn Chervin, Dr.P.H.

ICF Macro

Dr. Chervin made the following public comments to ACBCYW. ICF was funded by CDC to conduct a study on the role of communication in the South, particularly in poor populations. ICF's research showed that individuals believed efforts to know, assess, or compare their risks were extremely burdensome in comparison to more pressing economic issues in their lives. These findings demonstrate that, in order to change behavior, target audiences must be segmented in social media and health communication campaigns by racial/ethnic groups, socioeconomic factors, access to services, and other unique needs.

Dr. Chervin urged CDC to define its goals and focus messages and recommendations on specific populations or behavior change. Messages to young women should be prioritized and simplified, particularly in the current environment of budget constraints. CDC also should develop an overarching risk communication plan for young women with specific action steps. Moreover, ACBCYW should identify and extensively engage partners in implementation of the risk communication plan.

With no further discussion or business brought before ACBCYW, Dr. Partridge recessed the meeting at 4:49 p.m. on September 21, 2011.

Opening Session: September 22, 2011

Temeika L. Fairley, Ph.D.

Health Scientist, Division of Cancer Prevention and Control
Centers for Disease Control and Prevention
ACBCYW Designated Federal Officer

Dr. Fairley conducted a roll call to determine the ACBCYW voting members, *ex-officio* members, and liaison representatives who were in attendance. She verified that the voting members and *ex-officio* members in attendance constituted a quorum for ACBCYW to conduct its business on September 22, 2011. None of the voting members declared conflicts of interest for the record for any of the items on the published agenda for September 22, 2011. Dr. Fairley reconvened the meeting at 8:04 a.m.

Ann Hart Partridge, M.D., M.P.H.

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

Dr. Partridge summarized key outcomes from Day 1 of the ACBCYW meeting. Numerous overviews were presented on health communication and social media campaigns, initiatives, and activities to provide ACBCYW with a starting point to outreach and communicate to its target audience of young women. The overarching purpose of these presentations was to inform ACBCYW of successes, failures, and lessons learned in using health communication and social media campaigns to reach a target audience with specific messages.

Based on ACBCYW's open discussion, Dr. Partridge was aware that the members emphasized the critical need to clearly define the target audience, specific messages, and appropriate mechanisms to deliver messages. She confirmed that ACBCYW would extensively discuss and address these issues during the open discussions on the remaining 2 days of the meeting.

Dr. Partridge noted that CDC, its partners, and grantees would continue to present overviews of their evidence-based programs to frame ACBCYW's discussions on the development and dissemination of messages to the BCYW/YBCS population. These presentations would position ACBCYW to apply evidence-based medicine and science-based messaging strategies in recommendations for CDC to effectively reach its target audience.

Dr. Partridge pointed out that evaluation was a key component of the health communication and social media campaigns presented on the previous day. Rigorous evaluation also would play an important role in CDC's development of messages and campaigns for the BCYW/YBCS population. However, she emphasized the need for CDC to evaluate its strategies in an iterative and ongoing process to make mid-course improvements as needed, based on interim successes or failures identified. Dr. Partridge concluded her opening remarks by reviewing the agenda for Day 2 of the meeting.

Overview of the BodyTalk Decision Support Tool

Galen Cole, Ph.D., D.A.P.A., M.P.H., L.P.C.

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

Dr. Cole announced that CDC currently is developing three tools. The MessageWorks tool is being designed to craft and defend effective messages. The SocialWorks tool is being designed to effectively plan and execute social media strategies. The ProofWorks tool is being designed to evaluate communication. An adaptable and customized interface is being developed for partner agencies and organizations to tailor the three tools based on their specific needs. All three of the tools will be available on HealthCommWorks.com in the near future.

Dr. Cole provided a personal perspective of BCYW in his role as a healthcare provider and emphasized the seriousness of advising young women to receive genetic testing for BRCA1/2.

Doug George

Senior Web Designer
Oak Ridge Institute for Science and Education

Mr. George announced that CDC awarded a contract to Oak Ridge Institute for Science and Education (ORISE) to develop the BodyTalk decision support tool with four major outcomes:

- Young women and their physicians would be educated on genetic and lifestyle risk factors for breast and ovarian cancers.
- Communication between young women and their physicians would be improved.
- Special emphasis would be placed on outreach to young women 18-44 years of age who are at risk for, or have been diagnosed with, breast cancer.
- BodyTalk would be easily integrated with existing workflows of physicians.

ORISE was charged with creating BodyTalk to be easily scalable in a real-world environment; deployed on the Web, iPhone, and Android Smartphone platforms; and based on the validated “Cancer in the Family” tool developed for the Agency for Healthcare Research and Quality (AHRQ) by Research Triangle Institute (RTI). BodyTalk will provide a platform for young women at risk for developing early breast cancer to learn the facts, know their bodies, speak up for their health, and embrace support. In addition to the well-validated RTI/AHRQ tool, the design and development of BodyTalk also were based on an extensive literature review of research related to communication, patient-provider interaction, and decision-making.

BodyTalk will educate patients and their physicians about the nature and importance of four major areas:

- lifestyle and familial risk factors for breast and ovarian cancers;
- risk reduction strategies and evidence-based health lifestyles to reduce the onset, metastasis, or recurrence of disease;
- early detection and early warning signs for breast cancer; and
- screening, including genetic counseling when appropriate.

BodyTalk will facilitate communication between young women and their physicians on breast and ovarian cancer risks by allowing patient-physician data sharing. Patients will receive a detailed risk profile, including tips on speaking to their physicians regarding these issues. Physicians will have access to risk profiles shared by their patients, including reported family histories and tips for speaking with their patients.

BodyTalk's secure and encrypted database will be compliant with the Health Insurance Portability and Accountability Act and will be protected against unauthorized access. Patients will be in control of their data at all times. The data sharing functionality will not be automatic and will need to be manually enabled. Data entered into either the BodyTalk Smartphone application or the Web site will be immediately mirrored on the other platform.

BodyTalk will link to educational information or support resources for patients to share materials via Facebook and Twitter. However, confidential medical results or findings of risk will not be shared on the social media platforms. BodyTalk will not require a central system administration for clinics and patients to participate in the program. A content management system will be utilized to generate and store the Web site content.

BodyTalk will be operated with two major zones of responsibility. The patient zone will focus on learning about breast and ovarian cancer risk factors and completing the risk assessment. The clinic zone will focus on directing patients to the BodyTalk Web site and processing risk profile data of patients.

CDC will use several channels to publicize BodyTalk to primary care and obstetrics and gynecology (OB/GYN) clinics. Clinical staff will be directed to the BodyTalk Web site to obtain more information on the program and download a starter kit. The starter kit will include three key documents. The welcome letter will educate clinical staff about the mission and purpose of BodyTalk and provide a link to educational materials for physicians. The detailed set of instructions will provide guidance to clinical staff on administering BodyTalk. The customizable form letter will be available for clinics to distribute to their patients who should participate in BodyTalk.

The form letter will provide specific information (e.g., a link to the BodyTalk Web site, a unique reference number for the patient, and the clinic's e-mail address) for patients to establish their personal BodyTalk accounts and share data with the clinic. However, an account will not need to be created for patients to view the educational component. Patients will visit the BodyTalk Web site to educate themselves on breast and ovarian cancer risks in the following topical areas:

- What is cancer and who is at risk?
- How can cancer run in families?
- How can BRCA1/BRCA2 gene mutations influence cancer risk?
- How can lifestyle habits influence cancer risk?
- How can BodyTalk help me to know my risk?

Patients will be able to use the BodyTalk Web site to link to a library of references, resources, and educational materials hosted by the broader cancer community (e.g., CDC, NCI, the American Cancer Society (ACS), and GeneTests). These resources will be indexed and searchable and will be automatically tailored to a particular patient after the risk assessment is completed.

Patients will need to establish an account to take the risk assessment. Patients will enter their basic demographic information (e.g., age, gender, race and ethnicity); their lifestyle choices (e.g., tobacco use, alcohol consumption, exercise habits, and dietary tendencies); and their personal cancer history and family cancer history. BodyTalk will calculate the risk profiles of patients and generate results of their genetic or lifestyle risk in six categories: BRCA1/BRCA2 mutation risk, tobacco use, alcohol consumption, BMI, diet, and exercise.

Patients who are defined as “risky” based on the lifestyle risk results will be asked to rate their willingness to change risky behaviors. Tailored content will be presented to patients based on their willingness to change that will be determined by their choice of one of four options: “I am not ready to change,” “I am thinking about changing,” “I am planning to change,” and “I am taking action to change.”

Patients will be able to print the results of their risk profiles. The BodyTalk system will bundle the risk result sections and append a consumer-friendly discussion guide to help patients speak with their physicians during the next consultation. Patients also will be able to securely share their risk profile results electronically with the clinic. The clinic will receive a PDF file for printing and a clinical document architecture file for direct importation into an electronic medical record system.

The BodyTalk system will send an e-mail to the clinic with a link to the Web site for staff to download the patient’s shared results. Clinics will be able to access the link for 14 days only and must use the patient’s reference number as a password. The clinic will then be able to download both the PDF and clinical document architecture files. CDC and ORISE agreed on the 14-day expiration period for security purposes.

The discussion guides and other shared information will allow both patients and providers to be prepared for the next consultation, share in decision-making, enhance the efficiency of the consultation, and improve understanding of the patient’s family cancer history. Mr. George presented screen shots of the BodyTalk Web site and Smartphone application and described the key features of these tools.

ORISE conducted a cursory assessment of BodyTalk during the concept testing phase in July-August 2011. Testing focused on (1) the feasibility of implementing BodyTalk in primary care and OB/GYN settings; (2) the readability and comprehension of marketing and starter kit materials; (3) user experience of the risk assessment steps and other aspects of the Web site; and (4) the informational needs and desires of young women in the context of the BodyTalk Web site. BodyTalk concept testing was conducted with 1-hour remote sessions via Web and teleconferences, onsite sessions at the respondent’s place of business, and laboratory sessions.

Target audiences recruited for the BodyTalk concept testing included clinic administrators in large and small practices, young women with and without previous breast cancer diagnoses, and primary care physicians and OB/GYNs.

Results from the BodyTalk concept testing showed that physicians were not confident patients would be able to complete the risk assessment without assistance. Missing or inaccurate information would skew the results. Physicians also expressed concern about being reimbursed for time spent on the BodyTalk program. However, physicians were confident that their clinics

could support the BodyTalk process. The participants appreciated the inclusion of discussion guides to help frame discussions of breast and ovarian cancer risks. Mr. George played recordings of actual feedback the participants provided during the BodyTalk concept testing.

ORISE's next steps will be to launch a beta version of the BodyTalk Web site on a web development server for internal review. The BodyTalk Web site will be piloted in a small and diverse set of primary care and OB/GYN clinics across the country to evaluate the program in real-world settings and make further refinements as needed. The BodyTalk Web site will be broadly launched to the general public with a custom URL. Smartphone applications will be submitted to the iTunes application store and the Android Marketplace for approval and dissemination. A communication plan will be implemented at that time.

The ACBCYW members made a number of comments and suggestions for CDC and ORISE to consider in further refining BodyTalk before releasing the program to the general public.

- The limited functionality of BodyTalk to only gather information on risks for BRCA1/BRCA2 genetic mutations is problematic. The risk for BRCA1/BRCA2 positivity is small, but women might still be at increased risk due to a biopsy history, age of menarche, family cancer history, or other factors that are captured by the Gail model. However, other ACBCYW members noted that the Gail model is designed for women ≥ 35 years of age and is not well validated for the pre-menopausal population. The BodyTalk target population includes young women less than 35 years of age. Overall, ACBCYW advised CDC and ORISE to redesign BodyTalk to more broadly capture and quantify risk factors based on the Gail model. This approach would be particularly important in geographic locations where genetic counselors are not readily available.
- CDC and ORISE should ensure that the following issues are addressed before BodyTalk is broadly released to the general public: (1) the ability of patients to modify or include additional information to their risk assessment profiles; (2) the need to consider a time period longer than 14 days for providers to access the shared data of their patients; and (3) uninsured, underinsured, or low-income women who are found to be at risk based on their BodyTalk risk profiles, but who cannot afford genetic counseling and testing.
- The BodyTalk Web site should provide links to resources to reduce barriers to breast cancer screening and genetic counseling and testing among uninsured, underinsured, and low-income young women who need these services. These resources include CDC-funded National Breast and Cervical Cancer Early Detection Programs in each State and new healthcare exchanges under the Affordable Care Act. CDC also should outreach to screening facilities highlighted on the interactive BodyTalk map to determine whether these centers would be willing to offer free or reduced rates to this subgroup of young women.
- CDC should test the "BodyTalk" name with focus group participants who represent the target audience of young women 18-44 years of age. Some ACBCYW members did not believe the target population would associate the "BodyTalk" name as a tool to help make decisions on breast and ovarian cancer risks.
- CDC and ORISE should conduct additional testing of BodyTalk to determine the extent to which young women understand the terminology and language in completing their risk profiles. Consideration also should be given to adding a video or other interactive media to keep young women engaged in completing their risk profiles, particularly those 18-25 years of age. Moreover, the BodyTalk graphics on the Smartphone application should be redesigned to be more modern and appealing to young women.

Dr. Cole thanked ACBCYW for its constructive comments and suggestions on BodyTalk. He confirmed that ACBCYW's feedback would be considered during the beta testing of the program. He encouraged ACBCYW to provide additional input after the meeting to help CDC and ORISE in further refining BodyTalk. ACBCYW would be given a number of resources for this effort:

- The validated tool RTI developed for AHRQ that served as the model for BodyTalk
- Data to support the development of BodyTalk
- An example of the PDF file patients will give to their providers
- Access to the pilot BodyTalk Web site for the ACBCYW members to complete risk profiles as "patients"

Overview of the CDC/National Institute for Environmental Health Sciences (NIEHS) Partnership on The Sister Study and The Two Sister Study

Mary C. White, Sc.D.

Chief, Epidemiology and Applied Research Branch
Division of Cancer Prevention and Control
Centers for Disease Control and Prevention

Dr. White covered the following areas in her overview of the CDC/NIEHS partnership in conducting The Sister Study and The Two Sister Study. These studies are considered to be the premier research on breast cancer in the United States at this time. NIEHS initiated the original prospective Sister Study approximately 10 years ago to address data gaps in environmental and genetic risk factors for breast cancer.

The 2007 Weinberg, *et al.* study described the design of the Sister Study with a volunteer cohort of 50,000 women. A large group of healthy women whose sisters had developed breast cancer was followed over time to identify persons who developed disease and determine the rationale for onset of disease in these individuals. The study also analyzed factors related to prognosis and other health outcomes.

The Sister Study was designed to collect information from multiple mechanisms (e.g., baseline assessments, home visits, telephone interviews, questionnaires, and banked samples). Recruitment for the Sister Study was initiated in August 2003 and completed in March 2009 through media, previously recruited patients, and community and organizational partnerships.

The 50,884 sisters who are actively participating in the study represent ~4,400 sets of sisters 35-74 years of age. Of the entire cohort, women <50 years of age represent ~30 percent of participants and minority women (e.g., African Americans and Hispanics) represent 16 percent of participants.

Sister Study participants who develop breast cancer over time are reported through a hotline or questionnaires. Diagnoses are confirmed by telephone and efforts are made to retrieve medical records and pathology reports. Women who develop breast cancer during the study are defined as the "incident cases." Self-reported information on breast cancer diagnoses and treatment provided by patients is gathered as well. Of ~1,360 Sister Study participants who have been

diagnosed to date, ~25 percent have *in situ* disease and ~17 percent were diagnosed at <50 years of age. These women will continue to be followed after diagnosis.

NIEHS recruited affected sisters from the original Sister Study cohort to conduct the Two Sister Study. This cohort includes sisters <50 years of age who were diagnosed within 4 years of initiation of the study. Parents of these women are recruited when available. A tetrad design was used for the study to analyze gene-environment interactions with the affected sisters, their healthy sisters, and parents.

The overarching goals of the Two Sister Study are to retrospectively determine causative roles of genetic and environmental factors in onset of breast cancer in younger women, identify factors that predict health following treatment, and collaborate with other groups to conduct a pooled analysis. To date, the Two Sister Study has 1,527 active enrollees and 1,416 parents.

CDC and NIEHS entered into an interagency agreement in 2010 for CDC to use epidemiologic data NIEHS had previously collected to conduct three projects.

Project 1 was the Sister Study Cohort Survey. This project analyzed the potential for increased breast cancer risk among Sister Study participants who had at least one sister with breast cancer.

CDC designed the survey to collect additional information in three key areas: (1) knowledge and understanding of risk among women with a family breast cancer history; (2) the impact of having a family breast cancer history on primary and secondary prevention practices and medical behaviors; and (3) communication within the family about family breast cancer risk.

The survey questions addressed interaction with providers regarding family history, participation in genetic counseling and testing, performance of BSE, use of breast magnetic resonance imaging (MRI) for screening, perceived risk for developing breast and ovarian cancers, personal beliefs about breast cancer and risks from this disease, and discussions with daughters and other family members on family breast cancer history. CDC administered the survey in 2 phases to ~30,000 sisters. The survey was available in both English and Spanish and could be completed by mail, telephone, or online.

Project 2 was “Identifying Priorities in Breast Cancer Survivorship Research: A Workshop for the Sister and Two Sister Studies.” The workshop was convened in January 2011 to achieve two major goals. The state of the science was reviewed with 23 experts and gaps and limitations in the current research and knowledge were discussed. Areas of the greatest research opportunities for CDC and NIEHS to address in the context of the Sister Studies were identified.

The major discussion topics during the workshop included behavioral, psychosocial, and economic outcomes after breast cancer; occurrence and severity of breast cancer treatment related to side effects; factors affecting recurrence and survival after breast cancer; and opportunities for data pooling with other cancer cohorts.

Project 3 is the ongoing development of the Survivorship Survey based on input the experts provided during the workshop. The survey is being designed with questions in several areas: (1) the use of cancer genetic services and communication of cancer risk within families; (2) detection of breast cancer in younger women and its relationship to outcomes; (3) the impact of

breast cancer in younger women on employment, health benefits and behaviors, caregiving, and family functioning; and (4) the occurrence and impact of treatment-related side effects on YBCS. CDC expects to administer the survey in the field beginning in 2012 with a focus on prevalent and incident cases. Additional details on the Sister Study and Two Sisters Study are available at www.SisterStudy.org.

ACBCYW advised NIEHS and CDC to make stronger efforts to increase minority participation in both of the Sister Studies. The members pointed out that minorities represent only 16 percent of the cohort and these participants are limited to African American and Hispanic women. The members further noted that this cohort does not reflect the broader U.S. population.

Overview of CDC's Breast Cancer Genomics Research and Programmatic Activities

Juan Rodriguez, M.P.H.

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Mr. Rodriguez covered the following areas in his overview of CDC's breast cancer genomics research and programmatic activities. The CDC Office of Public Health Genomics (OPHG) has been collaborating with State health departments to integrate genomics knowledge and tools into State Chronic Disease Prevention Programs and core public health functions. In 2010, DCPC used the OPHG cooperative agreements to award supplemental funds to two States to expand their existing breast cancer genomics activities.

Supplemental funds were awarded to the Michigan Department of Community Health to conduct four major activities: 1) Surveillance of genetic counseling and BRCA1/BRCA2 genetic testing would be expanded; 2) The feasibility of linking BRCA-positive patients to State cancer registry data would be explored; 3) Identification of State health insurance plans would be expanded and medical policies for coverage of genetic counseling, testing, and related preventive services would be evaluated; 4) Dissemination of appropriate medical policies for genetic counseling, testing, and related preventive services to health insurance carriers would be increased.

Supplemental funds were awarded to the Oregon Division of Public Health to conduct five major activities: 1) Surveillance of genetic counseling and BRCA1/BRCA2 genetic testing would be conducted; 2) Identification of State health insurance plans would be expanded and medical policies for coverage of genetic counseling, testing, and related preventive services would be evaluated; 3) Collection and analysis of Medicaid data on BRCA testing and follow-up procedures would be expanded; 4) Questions on family history and genetic testing would be added to the Oregon Behavioral Risk Factor Surveillance Survey; 5) Collaborations would be established with CDC-funded National Breast and Cervical Cancer Early Detection Programs' to develop a conceptual model for educating and identifying high risk clients.

CDC released a new FOA in June 2011, "Enhancing Breast Cancer Genomic Practices Through Education, Surveillance, and Policy," to continue and build on the activities initiated by the OPHG cooperative agreements. The deadline for applications was July 25, 2011. State and local governments or tribal organizations were eligible to apply. CDC expects to fund up to 3 applicants at \$300,000 per year for 3 years.

Programs funded under the new cooperative agreement will be required to conduct activities in three focus areas. In terms of policy, grantees will use policy interventions to promote the use of clinical best practices for genetic counseling, BRCA1/BRCA2 testing, and preventive services for persons identified as high-risk.

In terms of education, grantees will develop or expand public and provider education programs to increase knowledge on the importance of family history, appropriate risk assessment and communication, genetic counseling and BRCA1/BRCA2 testing, and preventive services for persons identified as high-risk.

In terms of surveillance, grantees will track the use of genetic counseling and BRCA1/BRCA2 testing, follow-up procedures for persons identified as high risk, and family medical history tools or family medical history based on risk assessment tools for breast and ovarian cancers. Applicants were required to propose activities in two of the three key areas, including the mandatory focus area of policy. The grantees will conduct innovative activities to effectively reach rural, disadvantaged, and ethnic/minority populations.

CDC currently is conducting a research project focusing on health insurance coverage of genetic and prevention services in populations at increased risk for breast and ovarian cancers. The increased demand for genetic testing has caused clinicians and researchers to prioritize the identification of persons at high-risk for breast and ovarian cancers. Several mathematical models have been developed to calculate the probability of an individual being a mutation carrier.

Several professional medical associations have developed clinical practice guidelines based on a personal or family history of breast or ovarian cancer. However, CDC recognizes the need to promote genetic testing with strong evidence-based medical policies, while addressing issues related to limited access, health disparities, and health equity.

In 2005, the U.S. Preventive Services Task Force (USPSTF) issued a Grade B recommendation for a referral to genetic counseling and evaluation for BRCA testing for women whose family history is associated with an increased risk for deleterious mutations in BRCA1 or BRCA2 genes. USPSTF further recommended that suitably trained healthcare providers conduct genetic counseling. Although recommendations and clinical guidelines have been developed to identify high-risk populations, several uncertainties still remain.

Uncertainty continues to be associated with insurance coverage and medical policy. Breast and ovarian cancer genetic services that generally are covered by health insurance plans and requirements for coverage faced by policyholders are unclear. Evidence or guidelines that are used to develop these medical policies have not been identified to date.

To address these issues, CDC is conducting a systematic review of health insurance medical policies that address genetic counseling and testing for BRCA1/BRCA2 mutations. Medical policies for coverage of clinical preventive services also are being reviewed. The goal of the systematic review is for CDC to answer five key questions:

1. What are the conditions or stipulations for coverage of genetic counseling and testing for hereditary breast and ovarian cancers faced by health insurance policyholders?

2. What are the conditions for coverage of clinical preventive services for persons identified as being at higher risk?
3. What evidence is being used to justify medical policy?
4. What factors affect medical policy coverage?
5. What differences exist between public and private insurance medical policies?

CDC is conducting the systematic review at the State level due to variations across States in the same national health insurance plan. A list of health insurance companies that offer health insurance coverage is compiled for each State. Criteria for inclusion in the systematic review are companies that offer comprehensive group, family, or individual health insurance coverage. Moreover, the number of covered lives within each company must be ≥ 1 percent of the market share. Public plans also are included in the systematic review.

After CDC selects a health plan, the company Web site is searched for its relevant medical policies. Search engines also are used to retrieve relevant Web sites and documents. Retrieved health plan medical policies are reviewed and abstracted into the study database. The original study methodology called for CDC to contact health insurance companies with incomplete data, but this approach was suspended because health insurance companies do not participate in research.

Medical policies are being reviewed for the following clinical services: genetic counseling for breast and ovarian cancer susceptibility, use of *BRCAAnalysis*[®] and *BRCAAnalysis*[®] Large Rearrangement Test for genetic testing of BRCA1/BRCA2, prophylactic mastectomy and breast reconstruction, prophylactic oophorectomy, chemopreventive drugs, and cancer surveillance (e.g., mammography, breast MRI, breast ultrasound, Cancer Antigen-125, and trans-vaginal ultrasound).

Preliminary results of the systematic review from September 2010 - August 2011 are highlighted as follows. Medical policies were reviewed for >200 health insurance companies in 20 States. Significant variability was observed among States in terms of requirements, conditions, and coverage. The geographic location and size of health insurance companies contributed to the variability. Criteria for genetic counseling and testing were different than criteria for surveillance. Few policies specifically identified genetic counselors, while other policies explicitly informed patients to present to their primary care providers or source of usual care for genetic counseling.

Several health insurance companies use USPSTF guidelines as the basis for their medical policies, but many policies extend beyond these recommendations. Health insurance companies that solely base their medical policies on the 2005 USPSTF guidelines potentially could misclassify women because more recent data are not reflected. Many health insurance companies lacked detailed and comprehensive medical policies for genetic counseling and testing services.

The passage of the Affordable Care Act in 2010 significantly impacted the policies. The legislation calls for all health insurance companies to provide full coverage to new policyholders with no cost-sharing for Grade A and B USPSTF recommendations. Genetic counseling is a covered procedure, but rules regarding “grandfathered” versus new policies are still being determined. The Affordable Care Act rules similarly apply to Medicare and Medicaid plans.

CDC’s next steps will be to review health insurance company medical policies in the remaining 28 States in 2012. Michigan and Oregon are excluded from the systematic review due to their recent awards to expand their existing breast cancer genomics activities. CDC will collaborate

with State health departments and comprehensive cancer programs to improve the medical policies of health insurance carriers in their respective States.

Tremendous efforts are needed at the national level to address issues related to medical policies, insurance coverage, medical billing, lack of capacity, and limited access. Most notably, private health insurance plans and public Medicaid/Medicare plans do not consider genetic counselors to be clinical providers who should be reimbursed for their services. CDC plans to make presentations to ACBCYW, Academy Health, and other groups.

ACBCYW advised CDC to analyze fertility preservation in the next steps of the systematic review. The members noted that potential infertility is a major consideration for young women and serves as a barrier to obtaining genetic counseling unless options for fertility preservation are offered.

Overview of BCYW: Reviewing the Evidence and Setting the Course

Natasha Buchanan, Ph.D.

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Division of Cancer Prevention and Control
Centers for Disease Control and Prevention

Dr. Buchanan presented an overview of the four components of CDC's new initiative, "Breast Cancer in Young Women: Reviewing the Evidence and Setting the Course."

Component 1 is the scientific literature review of younger women at risk for breast cancer, BCYW, and YBCS. The focus areas of this effort include epidemiology, family history and genomics, risk and prevention, screening, diagnosis and treatment, survivorship, social disparities, and patient-provider communication.

Criteria for inclusion in the scientific literature review are peer-reviewed studies from the United States, United Kingdom, and Canada published between January 1, 2000 and December 31, 2010 that focus on women <50 years of age. Of >38,000 publications initially abstracted, CDC determined that ~1,300 are relevant. The 2000-2010 literature primarily examines risk and protective factors related to post-menopausal breast cancer.

Risk and protective factors for BCYW documented in the literature include family history and ethnicity, the use of hormones, estrogen or oral contraceptives, age of menarche and onset of puberty, age at first full-term pregnancy, birth characteristics, parity, breast density, breastfeeding, induced abortion or miscarriage, diet and nutrition, vitamins and dietary supplements, physical activity, obesity, overweight and BMI, alcohol use, smoking and SHS exposure, radiation exposure, environmental exposures and traffic emissions, and prophylactic surgery.

Early detection of BCYW documented in the literature covers five major areas. Guidelines have been published on breast and ovarian cancer screening, criteria to assess family history and high-risk women, recommendations for genetic counseling, and testing. Screening methods discussed in the literature include BSE, clinical breast examination, mammography, and breast MRI and ultrasound.

Family history discussed in the literature focuses on using family history to determine risk and assessing family history in clinical settings. Special populations highlighted in the literature include Ashkenazi Jewish women, African American women, and survivors of Hodgkin's lymphoma due to chest irradiation. Genetic counseling and testing discussed in the literature focuses on risk assessment, referral and providers, receipt of genetic testing and counseling, and testing and clinical management decisions.

Survivorship issues for BCYW documented in the literature cover four major areas. Treatment and related side effects and late effects focus on chemotherapy, radiation, surgery, amenorrhea, fatigue, cognitive function, infertility, treatment during pregnancy, and bone mineral density. Fertility preservation and family planning options focus on referrals and decision-making.

Prevention and management of secondary malignancies focus on recurrence, regional and metastatic spread, breast-conserving therapy, and mastectomy. Psychosocial effects and quality of life issues focus on anxiety and depression, sexuality and body image, occupational functioning, coping and support, social functioning, and financial concerns.

Component 2 is the environmental scan examining policy, research, Web sites, and educational tools and materials for patients and providers developed by organizations that focus on breast cancer.

Component 3 is the media review of a sample of 17,070 messages that were published in U.S.-based print and press, and on the Internet from both urban and rural sources from June 2009 to May 31, 2011. The media sources included magazines, newspapers, television and radio news reports, and press releases. The audience and readership of the media messages ranged from 1 to 25 million persons.

Media are used to disseminate research findings and other information, present personal survivorship stories, and provide public and expert commentary on various issues (e.g., guidelines; policies with economic, healthcare practice, and coverage implications; new technology; risk and protective factors for breast cancer; epidemiology of breast cancer; and medical decision-making between providers and patients). Several events have influenced the focus of media messages in 2009-2011 (e.g., systems changes, policy, legislation, guidelines, new technologies, emerging research, advocacy discussion, conferences, and fundraising events). Dr. Buchanan provided a cursory review of the major themes identified in media review, but noted that more detailed analysis of the media messaging is underway.

Component 4 is the Expert Panel meeting CDC convened on September 12-14, 2011, in Atlanta, GA, to discuss research, messaging, and recommendations regarding BCYW with 18 nationally recognized experts and advocates from several relevant disciplines (e.g., medical oncology, genetics, behavioral science, health psychology, oncology nursing, breast cancer survivorship, advocacy, and public health policy and epidemiology).

The overarching objectives of the meeting were two-fold: (1) examine areas where scientific evidence indicates an opportunity for public health intervention, communication efforts, or a strong need for further research; and (2) review messages about risk and prevention, early detection, and survivorship issues.

Key findings from the Expert Panel meeting are highlighted as follows:

Risk and prevention.

- Women and providers may struggle with numeracy and health literacy when discussing breast cancer risk.
- Risk factors with sufficient evidence to create public health messages include family history and genomics, age, race/ethnicity, and other demographic factors, breast density, parity, age of menarche, onset of puberty, age at the first full-term pregnancy, and radiation exposure.
- Risk factors with promising evidence to create public health messages, but require additional research include birth weight, gestational age, stress and sleep, and exposure to chemicals.
- Evidence-based risk and prevention messages to communicate at this time should focus on “know your body, health history, and family history of breast and ovarian cancers.”

Early detection

- The Expert Panel discussed the current early detection as well as similarities and differences between the recommendations. Because guidelines may be outdated, before being updated the dissemination of interim recommendations is important.
- Differences between the guidelines and recommendations made by practicing physicians on BSE should be reconciled.
- MRI should be recommended as a part of screening for high-risk women.
- An adequate assessment should be performed to detect risk for breast cancer in younger women <30 years of age. The risk assessment should capture a solid family history and be conducted periodically thereafter. Issues related to insurance coverage of genetic counseling and testing should be addressed.
- Efforts should be made at the national level to train and license genetic counselors.
- Women need to be empowered with information and strategies to access genetic counseling services.

Survivorship.

- The Expert Panel emphasized that survivorship issues have been well studied, but analyses of women <50 of age have been limited. Although overlapping concerns exist for pre-/post-menopausal survivors of breast cancer, younger women have unique needs.
- Several issues are particularly important for younger women and require additional research (e.g., work and re-entry into the work force after breast cancer treatment; infertility and fertility counseling before cancer treatment; cognitive effects; psychosocial adjustment and support; decision-making and communication strategies; and lymphedema, osteoporosis, and other side effect and quality of life issues).
- Survivorship guidelines that describe the minimum standard of care are lacking, but best practices and interventions are available to guide the development of recommendations. If established, guidelines should outline services that are unique to younger women and should be provided by current providers or referral entities (e.g., a larger cancer center or specialists). They should be designed to empower women to ask about optimal services early in the process or later as a survivor. Guidelines should also help providers to offer more personalized care to younger women with breast cancer.

In terms of special populations, the inclusion of ethnic minorities and disparate populations in BCYW research trials should be monitored. Awareness of the North Carolina Breast Cancer

Directory (<http://bcresourcedirectory.org>) and other State-based breast cancer directories should be increased and updated on a regular basis.

Dr. Buchanan clarified that her overview does not represent the full range of the Expert Panel's findings and recommendations. She confirmed that the summary report of the Expert Panel meeting would be distributed to ACBCYW for review and comment.

The ACBCYW members made a number of comments and suggestions on CDC's new initiative to review the evidence and set the course for BCYW.

- Some members expressed concerns that ACBCYW was not represented at the Expert Panel meeting. The members also were concerned that the short 1-week timeline between the September 2011 Expert Panel and ACBCYW meetings did not allow ACBCYW to review the summary report of the Expert Panel and provide CDC with concrete suggestions. The members emphasized the need for CDC to solicit ACBCYW's advice on its BCYW initiatives before these activities are conducted. Alternatively, CDC should inform ACBCYW of upcoming BCYW initiatives to provide an opportunity for the members to submit specific questions or issues to be addressed during these projects.
- CDC's media audit does not address the "bias" of information targeted to young women. Because young women represent an extremely small proportion of persons who are diagnosed with breast cancer, media messages most likely overlook this population.
- The Expert Panel's findings on evidence-based messages that can be communicated at this time do not appear to focus on actual health behavior changes (e.g., exercise, weight loss, and healthy diet).
- CDC should provide ACBCYW with a list of its current and ongoing BCYW programs to guide the development of recommendations and evaluation of these initiatives.

Dr. Fairley responded to ACBCYW's concerns about not being represented at the Expert Panel meeting. She explained that CDC did not offer ACBCYW the option of attending the Expert Panel meeting to reduce the burden on the members and respect their time. She noted that this commitment would have required the members to participate in the 3-day Expert Panel meeting on September 12-14, 2011, and attend the 3-day ACBCYW meeting 1 week later on September 21-23, 2011.

Dr. Fairley emphasized that CDC tremendously values the dedication and time the members devote to serving on ACBCYW and the contribution of their expertise to the BCYW effort. She reiterated that CDC is conducting other BCYW initiatives beyond the ACBCYW, which serves as a group of experts to formally provide CDC with advice on all of these activities on an ongoing basis.

Public Commit Session

Mr. George provided additional details on BodyTalk in response to questions posed by Ms. Danielle Gilbert, Legislative Assistant to Congresswoman Wasserman Schultz. Patients who complete the BodyTalk risk assessment profile and are not found to be at risk for breast cancer will be informed that a finding of "no increased risk" is not equivalent to "no risk."

BodyTalk will be available to all women through a Google search, including those without an affiliation or relationship with a provider or clinic. However, CDC and ORISE plan to collaborate with a wide range of partners and organizations to broadly publicize the availability of BodyTalk to the general public.

Overview of the AI/AN EARLY Act Project

Kathy Evans, M.S.W.

Oncology Program Specialist, Oncology Centers of Excellence
Phoenix Indian Medical Center, Indian Health Service

Annie Fair, M.P.H.

Tribal Liaison, Division of Cancer Prevention and Control
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Cathy Witte, R.Ph., M.Div.

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Ms. Evans, Ms. Fair, and Dr. Witte joined the ACBCYW meeting by teleconference to present an overview of a project targeting young AI/AN women, "Walking Together: Making a Path Toward Healing." The Phoenix Indian Medical Center (PIMC) is an Indian Health Service (IHS) facility that serves as a referral center for 40 Tribes in southwestern States and California to provide a comprehensive range of general and specialized care. PIMC is a 60-bed hospital that is accredited by The Joint Commission. PIMC's partners on this project include CDC, the Oncology Center of Excellence (OCE), and the Native American Breast Care Clinic (NABCC).

The IHS service region in Phoenix covers Arizona, Nevada, and Utah, with Arizona representing 21 federally recognized Tribes. The travel time of patients to obtain specialized cancer care from PIMC can range from 2-5 hours. The mission of the PIMC OCE is to lessen the disparity and burden of cancer by delivering high-quality cancer prevention and treatment services. Hematology and oncology consultation services have been provided by the Mayo Clinic in Scottsdale, AZ, since 2005. An oncologist from the University of Arizona provided these services prior to 2005.

OCE primarily focuses on breast, colorectal, and lymphoma cancers. Many patients reside on remote reservations in Arizona, but patients also travel to OCE from States as far away as Alaska and Oklahoma. OCE patients represent the Navajo, Whiteriver, San Carlos, and Parker Tribes. OCE treats 18-20 cancer patients every Wednesday, but outpatient chemotherapy services are provided throughout the week. OCE also provides onsite support services to patients (e.g., a chaplain, ACS navigator, case manager, and CDC liaison).

The PIMC NABCC was created in 2005 and has provided care to 175 patients each year on average since 2006. NABCC provides services to both AI women and men with benign and malignant breast disease and has designed an innovative breast reconstruction program specifically for AI women undergoing surgical treatments for breast cancer.

CDC awarded funds to PIMC in May 2010 to conduct the "Walking Together: Making a Path Towards Healing" project. The goals of this initiative are two-fold: (1) identify and describe impediments of AI/AN women <45 years of age who are diagnosed with breast cancer and (2)

describe the experiences and impact of cancer on the physical, psychological, and spiritual well-being of AI/AN women.

An initial review of breast cancer patients treated at PIMC served as the basis for the development of the project. The 2005 retrospective Tillman, *et al.* study highlighted the breast cancer incidence and experience of AI/AN women treated at an urban-based Indian Health Referral Center in 1982-2003. The study reported that compared to national averages, AI/AN women presented for cancer care at later stages of disease, under-utilized screening, and had greater delays in treatment. The study findings led to the development of specific questions about patients' access to care, treatment choices, and follow-up, particularly for young women.

OCE, NABCC and CDC jointly developed a protocol for young women to convey their stories through conversational interviews, focus groups, and one-on-one interviews in-person or via telephone. The overarching goals of gathering information from the interviews were to understand the experiences of, and barriers to, AI/AN women obtaining care; share viewpoints about available or unavailable services for AI/AN women; and develop targeted interventions.

The project team used PIMC's breast cancer registry to identify AI/AN women ≤ 45 years of age who were diagnosed with breast cancer and received treatment at PIMC. The review of the PIMC breast cancer registry showed that of 33 AI/AN women who met the eligibility criteria, 11 could not be contacted. Of the 20 eligible AI/AN women who were contacted, 13 agreed to participate in the study. Refusals to participating in the study were due to work, school or family requirements, health issues, emotional burdens as a result of recurrence, and distance to travel.

The project team asked the following questions during the one-on-one interviews and focus groups.

1. What challenges have you faced (e.g., access to and affordability of medical care, social and emotional issues, or relational and cultural/spiritual concerns)?
2. Do you believe that some of these challenges may be different from those of older women with breast cancer?
3. What challenges are most prevalent in your life at this time?
4. What actions did you take to continue to cope with these challenges?
5. What treatment, services, and information were well-suited to your needs and those of other young women?
6. What are the methods/ways to increase awareness about breast cancer risks among young AI women?

After the project team received Institutional Review Board (IRB) approval of the project in September 2010, the participants were identified, contacted, and recruited. The focus groups and one-on-one interviews were conducted from November 2010 to April 2011. Audio recordings and transcriptions of the focus group and one-on-one interviews were used to produce narrative entries of responses to each question and group the responses into common themes and sub-topics. Summaries and interpretations were independently generated, compared, and validated.

The cohort included 13 AI women representing reservations and urban areas who participated in 3 focus groups and 6 one-on-one interviews. The project team identified 216 narrative entries for inclusion in the database as either assigned themes or sub-topics. Narrative comments and themes based on the preliminary data are highlighted as follows. Previous cancer experiences

with family and friends significantly impacted the participants. Family dynamics changed and were challenged.

Cancer education at the early stages of care was essential for patients to empower themselves and learn about their options. The participants realized that all cancers, including breast cancer, are not the same. The participants noted that some healthcare staff needed cancer care education as well.

Education via multiple channels was extremely helpful (e.g., radio, billboards, demonstrations, presentations, health fairs, and pictures to increase understanding among women with low literacy levels). The ability to obtain centralized, specialized, and comprehensive cancer care services in one location was tremendously appreciated, particularly among women who traveled long distances.

The opportunity to have conversations with young women who had similar experiences with breast cancer was helpful, but only one study participant attended a support group outside of her Native community or social circle. The availability of support groups on Indian reservations was emphasized as a critical need, particularly for the women to engage their spouses/partners and children; address stigma that is strongly prevalent in families and communities; and serve as an agent for change in their communities.

The project team will complete the data analysis to produce a report with quantitative and qualitative information describing the understanding and experiences of young women with breast cancer. A copy of the final report with recommendations will be given to each participant.

Overview of the Development of Survivorship and Reproductive Health Resources

Temeika L. Fairley, Ph.D.

Health Scientist, Division of Cancer Prevention and Control
Centers for Disease Control and Prevention
ACBCYW Designated Federal Officer

Dr. Fairley covered the following areas in her overview of the development of psychosocial and reproductive health support resources for YBCS in the United States. The key provisions of the BCYW section of the ACA are to establish an evidence-based education campaign, target women 15-44 years of age, target specific at-risk populations (e.g., African American and Ashkenazi Jewish women), target messages to healthcare providers, conduct prevention research, provide survivor support, and establish ACBCYW.

Breast cancer survivors face a myriad of medical, physical, psychological, cognitive, social, practice, and economic issues that impact the quality of their lives. CDC commissioned a literature review in 2009 to more closely examine breast cancer survivorship issues. This effort led to CDC launching a project in September 2010, "Developing Psychosocial and Reproductive Health Support for YBCS in the U.S."

The overarching purpose of the project is to identify, strengthen, and promote real-world and evidence-based interventions to provide psychosocial and reproductive health support to YBCS. CDC provided programmatic support to two national organizations that currently address the

needs of, and provide psychosocial and reproductive health-related intervention programs for, YBCS. The project targets the populations of African American and Ashkenazi Jewish women.

The goals of the project are to:

- identify core programmatic elements of organizations that provide psychosocial and reproductive health support to YBCS,
- identify the best methods and practices to disseminate psychosocial and reproductive health support to YBCS,
- increase the use of evidence-based interventions,
- increase implementation of broader dissemination efforts.

The funded organizations are required to complete several tasks for the project. The capacity of selected organizations to effectively develop, implement, and disseminate interventions providing psychosocial and reproductive health support for YBCS would be assessed. Existing programs that support survivors would be identified, tested, and modified for implementation if needed. A plan would be prepared to conduct a process or outcome evaluation for the modified and implemented programs.

Project tasks that were completed in Year 1 in 2010-2011 include conducting organizational case studies, testing the selected interventions, obtaining IRB approval and developing the evaluation design and protocol. In Year 2 of the project in 2011-2012, OMB approval will be obtained and the selected programs will be modified for implementation. In Year 3 of the project in 2012-2013, the tailored programs will be implemented, the selected programs will be evaluated, and the evaluation report will be prepared.

CDC established a specific process to identify and select organizations for the project. An initial list of organizations that serve YBCS was created and an environmental scan was conducted to identify other potential organizations. CDC funded Sharsharet and Sisters Network, Inc. (SNI) to undertake this project.

CDC conducted organizational case studies to understand the process each organization utilizes to develop, disseminate, strengthen, and evaluate programs that provide psychosocial and reproductive health support to its target audience. Data were collected for this effort by reviewing documents and conducting five to six in-depth interviews with organizational staff and organizational partners. A thematic analysis of the data was performed using the Atlas.ti software.

After the organizational case studies were completed, a process was implemented to select the programs in the organizations for inclusion in the project. Sharsheret's programs were reviewed to select those that provide psychosocial and reproductive health support to YBCS, serve Ashkenazi Jewish YBCS and women diagnosed with breast cancer before 45 years of age, have the potential to be "scaled up" to serve more women, have existing core elements (e.g., counseling and Web support), have modifiable key program characteristics, and have a history of some level of monitoring and evaluation. Based on these criteria, 2 of Sharsheret's 11 programs were selected for inclusion in the project: The Link Peer Support Network (LPSN) and Genetics for Life (GFL). LPSN is Sharsheret's foundational program that serves as a matched peer-support network to connect YBCS and women at elevated risk for breast cancer with other Jewish women for support and encouragement. GFL serves as a safe and confidential mechanism for women at risk, those newly diagnosed, and survivors to receive genetics counseling. Focus groups will be conducted in the fall of 2011 to test the two Sharsheret

programs. The purpose of the focus groups will be to gain a deeper understanding of the health information needs and concerns of Jewish YBCS and gather their feedback on the LPSN and GFL Programs. Data will be collected from four focus groups of Jewish YBCS. A thematic note-based analysis will be performed of the qualitative focus group data and pre-focus group questionnaires. Sharsheret will convene both in-person and online focus groups of Jewish YBCS <45 years of age in New Jersey and other States.

A plan will be developed to conduct a mixed-methods outcome evaluation of the modified LPSN and GFL Programs. The outcome evaluation questions will focus on the impact of the programs in terms of changes in the knowledge, attitudes, skills, behavioral intentions, or behaviors of Jewish YBCS. Implementation and evaluation of the newly modified programs will be conducted in Year 3 of the project.

SNI's programs and resources were reviewed to select those that provide psychosocial and reproductive health support to YBCS, serve African American YBCS and women diagnosed with breast cancer before 45 years of age, have the potential to be "scaled up" to serve more women, have existing core elements (e.g., counseling and Web support), have modifiable key program characteristics, and have a history of some level of monitoring and evaluation.

Based on these criteria, SNI's Sisters Peer Counseling in Reproductive Issues after Treatment (SPIRIT) was selected for inclusion in the project. Dr. Leslie Schover (University of Texas M.D. Anderson Cancer Center) developed SPIRIT in partnership with SNI. The overarching objective of SPIRIT is to improve knowledge and reduce symptoms related to sexual dysfunction, menopause, and distress about infertility among African American breast cancer survivors.

Focus groups were conducted to test SPIRIT to gain a deeper understanding of the health information needs and concerns of African American YBCS and gather their feedback on tailoring the SPIRIT workbook for a general African American breast cancer survivor audience.

Findings from the focus groups are highlighted as follows. The participants need information about breast cancer types, treatment, and sources to obtain reliable and up-to-date information about recent advances in breast cancer research. The participants did not trust healthcare providers and were skeptical of the ability or willingness of providers to meet their needs for reproductive health information. The participants believed that providers do not discuss reproductive health issues with African American YBCS due to their perception that this population lacks insurance or other resources to obtain services to preserve their fertility. The participants believed that minimal information on breast cancer and treatment is tailored for African Americans. Existing materials targeted to African Americans were perceived to be of lower production quality than those for general audiences. The participants need more information about early menopause, impact of treatment on intimacy and sexual function, fertility, and mental health issues. The participants desired information about breast cancer directly from other African American breast cancer survivors, particularly YBCS. All of the participants, particularly YBCS, expressed an interest in accessing psychosocial and reproductive health information through diverse channels, particularly via Internet sources and from peer groups of all ages.

The participants suggested including the following content in the SPIRIT program workbook: more information on coping with breast cancer symptoms and treatment; testimonials from YBCS; and a frequently asked questions/answers section. The participants suggested the following changes to the graphics of the SPIRIT program workbook: photographs of African American YBCS; bright colors to offset the text; and more tables and textboxes to present

textual information. The participants also recommended the availability of the SPIRIT workbook through multiple channels, particularly online.

The next steps with SNI will be to completely revamp and modify SPIRIT as a program that specifically serves African American YBCS in Year 2. SPIRIT will be delivered as an online program to provide psychosocial and reproductive health support to African American YBCS. The process evaluation plan for the new online program will be developed in Year 2. Implementation and process evaluation of the new program will be conducted in Year 3 to answer three key questions: (1) Was SPIRIT implemented as planned? (2) Did SPIRIT reach the intended audience? (3) What are the barriers to the implementation of SPIRIT?

The ACBCYW members made a number of comments and suggestions on CDC's new initiative to develop psychosocial and reproductive health support resources for YBCS.

- Additional focus groups should be convened to determine whether the race/ethnicity of healthcare providers of patients plays a role in the extent to which providers offer fertility treatment options and patients feel comfortable in discussing this issue. CDC should focus on developing interventions to build trusting relationships between patients and healthcare providers.
- Some ACBCYW members were concerned about the potential bias of data collected from the African American YBCS focus groups. A high percentage of the participants had a high school diploma or more education, were married, and employed full-time. These demographics may not represent average African American women <45 years who are diagnosed with breast cancer. More focus groups should be held or the new SPIRIT online program should be piloted in a population of African American YBCS that more accurately reflects the target audience. Overall, survivorship and reproductive health resources should not be developed and disseminated to the general public without first making efforts to outreach to, and collect data from, disenfranchised and isolated women and those who face discrimination and stigma. These subgroups include unemployed and unmarried women, women on public assistance, women with a low educational status, and poor women of all racial/ethnic groups in urban and rural areas.
- Data should be extracted from State cancer registries to identify and reach hard-to-reach target audiences by race and age. Although cancer registries do not maintain SES data, addresses of cancer patients could be matched with Census data as an SES surrogate. CDC should explore the opportunity of engaging a partner in the project with access to global patient data that can be cross-sectioned and available in real-time reports. Ms. Beth Patterson, the ACBCYW liaison representative for Patient Advocate Foundation, offered her organization's rich data set in this effort.

ACBCYW Open Discussion: Session 2

Dr. Partridge facilitated an open discussion for ACBCYW to make comments and suggestions on CDC's BCYW and YBCS research, projects, and other activities that were presented. The comments of the Committee are summarized here.

- More emphasis should be placed on Hispanic women in all of CDC's BCYW and YBCS initiatives.

- ACBCYW’s target audience should be clearly defined as “an underserved population” (e.g., young women at risk for, diagnosed with, or surviving breast cancer) that needs tailored resources and targeted services.
- Interventions and health messages should be specifically developed to increase the current mammography screening rate from ~60 percent to 90 percent and address studies that document 33 percent of women across all racial/ethnic groups receive “sub-optimal” breast cancer treatment and care. Health messages should emphasize the need for women to obtain “high-quality” mammograms and breast cancer treatment.
- The Grady Center in Atlanta, GA, recently reported results that showed its navigator program increased compliance with treatment recommendations from ~70 percent to >90 percent in underserved patients. CDC and ACBCYW should conduct implementation research to highlight patient navigators as an additional resource to help young women complete breast cancer treatment.
- Standards established by the Federal Government for proper diet, nutrition, physical activity, and BMI should be communicated in BCYW health messages to young women.
- Young women should be advised to “know their bodies” and “be aware of changes in their breasts” instead of performing a monthly BSE.

Dr. Fairley led ACBCYW in a discussion of potential audiences for BCYW messages that will be developed. She proposed four potential audiences to initiate the discussion:

1. Young women at average risk for developing breast cancer (e.g., healthy young women)
2. Young women at increased risk for developing breast cancer (e.g., high-risk women)
3. YBCS (CDC’s definition of a “survivor” is all women from the point of diagnosis to the end of life. Survivors also can include families, friends, caregivers, and other members of young women’s health network.)
4. Providers (e.g., clinicians who make the diagnosis and oncologists who provide care and treatment)

ACBCYW’s comments and suggestions on potential target audiences are outlined below.

- Emphasis should be placed on educating providers to recognize signs and symptoms of high-risk women to achieve the greatest impact. These providers include primary care providers, internists, OB/GYNs, family medicine practitioners, nurse navigators, nurse practitioners, Planned Parenthood, clinical providers, mental health providers, and community health outreach workers.
- ACBCYW was divided on prioritization of the four proposed target audiences.
- CDC’s definition of “survivors” should be reconsidered to make a clear separation between “breast cancer patients” who are newly diagnosed or undergoing treatment and “breast cancer survivors” who have completed their treatment. Patients and survivors will need different messages, resources and education.
- YBCS should be used as a resource to help identify high-risk women (e.g., their sisters).

At the conclusion of the discussion, Dr. Fairley noted that the majority of ACBCYW members were in favor of providers and high-risk women as the top two target audiences. She explained the process for FACs to establish ad hoc workgroups.

Workgroups must be charged by the parent Committee. Workgroup members must include at least two voting members of the parent Committee with one voting member serving as the chair.

Other workgroup members can include two to three *ex-officio* members and two to three liaison representatives. Workgroups must report and present all of their findings to the parent committee for review, comment, and formal approval. Workgroups are disbanded after fulfilling their charge.

In terms of ACBCYW, CDC will provide staff support for teleconferences, subject matter-expertise, and other resources as needed. However, the workgroups will be responsible for developing reports and recommendations as ACBCYW products. Dr. Fairley led ACBCYW in a discussion to draft the preliminary charges of the new workgroups.

The Provider Ad Hoc Workgroup will focus on message development to educate and change the behaviors of healthcare professionals regarding breast cancer risks to young women and also to help providers educate their patients on breast cancer risks. Messages will be designed to improve patient-provider education.

The following ACBCYW members volunteered to serve on the Provider Workgroup: Brandon Hayes-Lattin (chair), JoAnne Zujewski, Renee Nicholas, Generosa Grana, Karen Kelly Thomas, Laura Tillman (proxy for IHS), and Wendy Susswein.

The High-Risk Ad Hoc Workgroup will define “high-risk” for breast cancer in young women. An initial focus will be placed on message development for the populations described in the EARLY Act, but the potential to add other high-risk groups will be explored (e.g., African American women, Ashkenazi Jewish women, women with a family breast cancer history, and women with a lump in their breast or suspicious BSE). A process to identify high-risk women will be clearly defined.

The following ACBCYW members volunteered to serve on the High-Risk Workgroup: Rochelle Shoretz (chair), Marc Hurlbert, Ngina Lythcott, Maimah Karmo, Kelly Hodges, Morrisa Rice, Mavis Nitta, and Padmini Jagadish.

Dr. Fairley confirmed that the draft workgroup charges would be typed and presented during the open discussion on the following day for ACBCYW’s further review, comment, and revision. Dr. Partridge thanked the ACBCYW members for volunteering to chair and serve on the new ad hoc workgroups. She confirmed that ACBCYW looked forward to hearing their findings during future meetings.

With no further discussion or business brought before ACBCYW, Dr. Partridge recessed the meeting at 4:10 p.m. on September 22, 2011.

Opening Session: September 23, 2011

Temeika L. Fairley, Ph.D.

Health Scientist, Division of Cancer Prevention and Control
Centers for Disease Control and Prevention
ACBCYW Designated Federal Officer

Dr. Fairley conducted a roll call to determine the ACBCYW voting members, *ex-officio* members and liaison representatives who were in attendance. She verified that the voting members and

ex-officio members in attendance constituted a quorum for ACBCYW to conduct its business on September 23, 2011. None of the voting members declared conflicts of interest for the record for any of the items on the published agenda for September 23, 2011. Dr. Fairley reconvened the meeting at 8:05 a.m.

Dr. Fairley announced that Dr. Plescia was unable to attend Day 3 of the ACBCYW meeting. Mr. Mike Mizelle, the DCPC Associate Director for Policy, would represent the DCPC Office of the Director in Dr. Plescia's absence.

Ann Hart Partridge, M.D., M.P.H.
Clinical Director, Breast Oncology Center
Dana-Farber Cancer Institute
ACBCYW Chair

Dr. Partridge focused her opening remarks on addressing concerns ACBCYW raised during the meeting. In terms of uncertainty regarding ACBCYW's role, responsibilities, and future direction, ACBCYW is charged with providing CDC with strong guidance and concrete recommendations on its research, projects, and other activities funded by EARLY Act dollars. As a formal FAC, ACBCYW will have an opportunity to shape CDC's BCYW portfolio.

In terms of concerns regarding meeting agendas, the ACBCYW members are welcome to submit comments to Dr. Fairley when the draft agenda is circulated 2-3 months in advance of the meeting. CDC leadership is extremely open to receiving input from the members on agendas and any other aspects of ACBCYW's meetings.

In terms of the structure of meetings, all sessions of all FAC meetings must be open to the public and the deliberations of the FAC must be made on the record. A FAC must operate with a quorum. These rules apply to both face-to-face public meetings and teleconferences of the entire FAC, but do not apply to workgroups. As a result, the two new ad hoc workgroups formed on the previous day will serve as a solid mechanism to continue ACBCYW's activities in between meetings. Dr. Partridge concluded her opening remarks by reviewing the agenda for Day 3 of the meeting.

Dr. Fairley added that CDC values the input, time, effort, and expertise of each ACBCYW member. She emphasized that both CDC and ACBCYW are learning important lessons of collaborating as a group to address the important issue of BCYW. She reiterated Dr. Partridge's comments for the members to feel free to express their concerns to CDC via e-mail to address any issues within the rules and regulations of the Federal Advisory Committee Act.

**CULTURALLY APPROPRIATE
HEALTH COMMUNICATIONS FOR WOMEN AT INCREASED RISK**

A panel of speakers presented a series of overviews on culturally-appropriate health communication activities conducted by their organizations to reach women at increased risk for breast cancer. The presentations are summarized below.

Culturally Appropriate Communication for the Asian Americans, Native Hawaiians and Pacific Islanders (AANHPI)

Mavis M. Nitta, M.P.H., C.H.E.S.

Chronic Disease Program Coordinator
Asian & Pacific Islander American Health Forum
ACBCYW Member

Ms. Nitta covered the following areas in her overview of Asian & Pacific Islander American Health Forum's (APIAHF) health communication activities for AANHPIs. APIAHF is a national nonprofit health and advocacy organization that focuses on the AANHPI population. APIAHF is not a direct service organization, but several partnerships have been established with the U.S. Pacific Island Nation, diverse organizations, health departments, and cancer advocacy and survivor groups across the country.

The AANHPI population includes ~80 distinct ethnic and cultural groups. Census data show that 72 percent of AANHPIs in the United States were foreign born in 2009. Of >2,000 distinct AANHPI languages and dialects, >100 are commonly spoken in the United States. The U.S. Census defines "Asians" as persons having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent. Asians account for 17.3 million of the U.S. population.

The U.S. Census defines "Native Hawaiians and Pacific Islanders" as persons having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands. NHPIs account for 1.2 million of the U.S. population. In 2000-2010, both the NHPi and Asian populations in the United States increased by 46 percent.

APIAHF must consider several important factors when developing health messages for AA NHPIs. Immigrant populations are more likely to be socially isolated by retaining their native cultures and language, not speaking English, and having limited English proficiency. Immigrant populations also are socioeconomically disadvantaged due to high rates of poverty and medical insurance despite being employed full-time or working ≥ 2 full-/part-time jobs.

Culture has a tremendous impact on the development of health communication messages for this AANHPI communities. For example, physical illness or ailments could be caused by their sins or those of their ancestors in a past life, or the "supernatural." The use of home and folk remedies is common and includes herbal and plant medicines and massages. Many AANHPIs do not use Western medicine and rely on faith for assistance, pray for a cure, and seek medicine healers to treat illness. The stigma of cancer, fatalism, fear of knowing, and social and cultural obligations are extremely important in the AANHPI culture. Many AANHPIs do not take preventive measures and seek care from physicians only after the illness is present.

Structural challenges faced by AANHPIs include lack of health insurance, undocumented status, low SES, limited AANHPI interpreters, the need for health navigation, lack of culturally competent healthcare providers, and distorted conclusions from being categorized with API in terms of the data and cultural beliefs of this population. Disaggregated data show that Japanese Americans have high rates of breast cancer that are nearly comparable to rates in non-Hispanic whites. Breast cancer mortality rates in the Filipino population are rapidly increasing.

APIAHF includes several components in its culturally and linguistically appropriate materials for the AANHPI population (e.g., eye-catching photographs, positive messages, a connection to stories by cancer survivors, and a respectful tone). Colors used in materials also must be thoughtfully considered. For example, red symbolizes circulation of blood for health, good fortune, and purity, while white symbolizes death and misfortune. The positive and happy messages are designed to eliminate fear and avoid placing blame on the individual.

APIAHF convened three breast cancer focus groups with Filipino women 40-70 years of age who did not have cancer. All of the focus group participants were born in the Philippines and immigrated to the United States after 18 years of age.

The participants made several recommendations during the focus groups:

- Messages should affirm the belief that mammograms can be lifesaving and encourage responsibility to take care of personal health to be able to care for families.
- This message should be delivered with a family photograph.
- The frequency to obtain a mammogram should be clearly stated.
- Messages should strike an appropriate balance between being direct without providing too many details.

Language issues and terminology should be key factors in developing messages and materials:

- the use of Mandarin versus Cantonese and simplified versus traditional writing in the Chinese language;
- the use of Tagalog, English, or Ilocano in the Filipino language; and
- laymen's terms versus medical terminology. Most notably, the word for "cancer" might not exist in the API language.
- Moreover, the word "mammogram" must be described in no more than two sentences due to difficulties with translation in various API languages.

Ms. Nitta presented examples of various educational materials APIAHF has developed, designed, pre-tested, and evaluated in collaboration with community members and experts in the field to ensure that cultural, linguistic, and other important factors of AANHPIs were taken into account.

Ethnic and mainstream newspapers, television and radio shows, lay community health workers, church leaders, and AANHPI community-based organizations were extensively engaged to broadly disseminate the breast cancer materials to the AANHPI population. However, APIAHF is aware that social media can be used to reach and educate AANHPI women <45 years of age, but the ability of social media to change behavior in this population is unknown.

Materials for the Tongans breast cancer awareness project were developed with three simple and effective messages: "Life is a gift. Take good care of it. Get a mammogram." "A woman's good health is her most precious gift to her family. Remember your annual mammogram." "Educate and motivate. Screening saves lives."

Materials for the Filipino breast cancer project were developed with five print media messages using family, individual Filipina, health provider images, and messages: "Do it for yourself. Do it for your family." "Taking care of yourself is showing love to your family." "Take care of your health now so you can be there for your family later." "Mammograms...not just once, but for a lifetime." "Ate...get your mammogram. It could save your life." Overall, messengers to AANHPIs

must be trusted members of the community (e.g., a physician, nurse, public health navigator, lay health worker, or minister/minister's wife). The gender, age, generation, skin color, and cancer survivorship also must be considered in identifying effective, culturally-/linguistically-appropriate, and trained messengers of information to AANHPIs. Multiple approaches should be designed to address the diversity of the AANHPI population. Feedback should be obtained from the target community on an ongoing basis to tailor, adapt, and evaluate the effectiveness of materials and messages.

Sisters Network Inc.

Kelly P. Hodges

National Program Director
Sisters Network, Inc.
ACBCYW Liaison Representative

Ms. Hodges covered the following areas in her overview of Sisters Network, Inc.'s (SNI) culturally-appropriate health communication activities for African Americans. SNI is a national African American breast cancer survivorship organization that was founded in 1994 in Houston, TX, by Ms. Karen Jackson who is a breast cancer survivor. Ms. Hodges presented a moving and inspirational video to highlight SNI's outreach activities.

SNI was formed to address the lack of sisterhood and culturally-sensitive materials for African American women developed by traditional organizations. Since 1994, SNI has grown to include >43 affiliate chapters in ~22 States. New SNI affiliate chapters will be established in New York City, NY; Birmingham, AL; and Houston by the end of 2011. Ms. Hodges presented photographs and described the roles and responsibilities of the six-member SNI Board of Directors, the seven-member SNI Medical Advisory Committee, and the five-member SNI staff. She also showed a photograph of the building SNI purchased in 2008 as its headquarters in a historic community in Houston.

SNI's goals are four-fold: 1) Strategic alliances and partnerships are created to maximize the impact of SNI's activities in breast cancer research; 2) SNI's significant reach and impact include ~4.3 million African American households per year; 3) Innovative strategies are implemented to build a well-trained proactive advocacy movement; 4) New communication and social networking skills are developed and implemented to increase awareness. The year 2020 is adapted as a new vision to end breast cancer through awareness and education.

SNI's national programs include the Gift for Life Block Walk Program that distributes door-to-door breast cancer information, including a manual of local resources, to women in low-income communities. Because all SNI affiliate chapters are required to implement the program, the reach of this intervention includes >44 communities across the United States. Some SNI affiliate chapters also provide onsite screening by leveraging partnerships with local mobile mammography units.

The Pink Awareness Campaign is a faith-based educational outreach program that provides breast health education and information on available local resources. All SNI affiliate chapters are required to deliver the intervention to 12 churches per year. The Breast Cancer Assistance Program provides support to women facing financial challenges after a breast cancer diagnosis.

The financial support covers mammograms, medical-related lodging, co-pays, office visits, prescriptions, and transportation regardless of the income status of the women.

Enrollment in the program is a simple process in which the breast cancer survivor contacts SNI and receives a 3-page packet of materials (e.g., cover letter, physician verification form, and application), submits the completed forms to SNI for verification, and submits bills to SNI for direct payment to the provider.

SNI recently developed two new programs. The purpose of “Tweens in Pink” is to educate girls 12-16 years of age about the importance of breast health and provide girls with skills to become breast health ambassadors for their family members with a pre-tested, piloted and validated booklet. SNI is still attempting to leverage funding, but expects to launch the program in 2011. The development of a social networking component of the program is underway.

The purpose of the “Young Sisters Initiative” is to target activities, outreach to, and maintain engagement of younger African American women ≤ 45 years of age diagnosed with breast cancer. SNI held its first biennial National African American Breast Cancer Conference in 1999 to provide a broader scope of knowledge and address the cancer survivorship crisis affecting African American women. Conference participants typically represent >500 breast cancer survivors and healthcare professionals across the United States.

“Stop the Silence” is a national breast cancer walk that is an effort to counteract the traditional African American culture of not discussing breast cancer or any life-threatening diseases. SNI hosted the last walk in April 2011 with >6,500 participants and will sponsor the next walk in April 2012 in Houston. SNI allocated \$50,000 to its affiliate chapters to provide mammography screening to women in their local communities.

The “First Ladies Prayer Brunch” is designed to inform local churches in the community of their role in increasing awareness of breast cancer and survivorship in African American women. The program includes presentations on SNI’s services, triple-negative breast cancers, and other types of breast cancers. The program has significantly increased SNI’s reach and impact in the faith-based community.

SNI formed a national coalition in 2006 with a diverse group of African American organizations to establish “one voice” in the effort to win the fight against breast cancer and more effectively leverage resources for the same population. The coalition members include Alpha Kappa Alpha Sorority, Oncology Nursing Society, Congressional Black Caucus Foundation, International Black Women’s Congress, Association of Black Cardiologists, Delta Sigma Theta Sorority, Jack and Jill of America, The Links, and Top Ladies of Distinction, Black Women’s Health Imperative, and National Medical Association.

Ms. Hodges presented SNI’s national brochure that was developed with tailored and culturally appropriate messages and photographs for the target audience of African American women. SNI’s “Key Questions” brochure is an extremely popular resource that helps African American women who are diagnosed with breast cancer to engage in discussions with their providers.

SNI’s “Breast Health Awareness” brochure provides information that is specifically targeted to African American women (e.g., breast cancer facts, risk factors, signs and symptoms, early detection, an illustration of the monthly BSE, and survival rates). Ms. Hodges presented

examples of outreach materials of special events that were developed by its chapter affiliates across the country (e.g., Baltimore, MD; Memphis, TN; and Tupelo, MS).

In terms of SNI's breast cancer social networking site, African American YCBS are the largest users of this resource. The site features chats with breast cancer survivors, videos, and blogs. SNI also maintains a Facebook page, Twitter site, and YouTube page. SNI has observed a tremendous increase in its Facebook fans and Twitter followers since the social networking site was launched. In the future, SNI will increase its focus and efforts in webinars, blogging, "Ask the Doctor" online chats, Skype national conferences, program evaluation, and statistical analysis.

Culturally Appropriate Health Communications for Women at Increased Risk

Rochelle L. Shoretz, J.D.
Executive Director and Founder
Sharsheret

Ms. Shoretz covered the following areas in her overview of Sharsheret's culturally appropriate health communication activities for Ashkenazi Jewish women. However, she clarified that the messages and tools Sharsheret has developed over the past 10 years can be applied to young women in groups well beyond the Ashkenazi Jewish population.

Sharsheret is the Hebrew definition of "chain" and was established is a national nonprofit organization supporting young women and their families of all Jewish backgrounds who face breast cancer due to BRCA1/BRCA2 genetic mutations. Sharsheret's mission is to offer a community of support to women diagnosed with breast cancer or at increased genetic risk by fostering culturally-relevant individualized connections with networks of peers, health professionals, and related resources.

Sharsheret supports young Jewish women and their families facing breast cancer before, during, and after diagnosis. Sharsheret helps women and families connect to their communities with methods that feel most comfortable. The stage of life, diagnosis, treatment, and connection to Judaism of these young women are taken into consideration. Sharsheret also provides educational resources; offers specialized support to women facing ovarian cancer or those who are at high risk for developing cancer; and creates programs for women and families to improve their quality of life.

Sharsheret takes a three-pronged approach to craft culturally appropriate messages for women at increased risk for breast cancer: (1) understand the culture and background of the target audience; (2) assess health and risk messages that are traditionally communicated to the audience; and (3) tailor the content and delivery of risk messages to the audience.

To achieve these goals, Sharsheret conducts a qualitative analysis of the target audience through focus groups, surveys, and personal interviews with affected women and also develops strong partnerships with non-traditional experts, consultants, and community-based healthcare workers within the target community and relevant cultural resource organizations.

Sharsheret assesses health and risk messages that are traditionally communicated to the target audience by asking three key questions in the qualitative data collection process. Question 1 is "What is the current level of understanding of risk among the target audience?" Sharsheret's

qualitative data show the following responses: “Jewish women seem to have a lot of breast cancer.” “I have heard of breast cancer genes.” We do not talk about cancer in our community.”

Question 2 is “What barriers might exist in communicating additional risk information? Sharsheret’s qualitative data show the following responses in terms of religious, cultural, historical, and psychosocial barriers: “It is all in God’s hands.” “Modesty is a religious value.” “Spiritual leaders have an important role in sanctioning messages.” “We do not discuss cancer publicly.” “Breast cancer is not a ‘Jewish’ issue.” “Breast cancer has implications on marriage for single women.” “I have no knowledge of my family history because my family did not survive the Holocaust.” “I do not like to read about issues that scare me or those for which I cannot do anything.”

Question 3 is “What steps can be taken to overcome communication barriers?” Sharsheret’s strategies have been to respect and not attempt to change cultural and religious boundaries. The content of messages should be tailored to be specific to the needs of specific audiences. “Content” includes text, images, and language (e.g., word choices and tone to resonate with the target audience, images to adhere to acceptable standards of modesty, and translation of messages into the most relevant language).

The delivery of messages should be adapted to respond to cultural or religious concerns. “Delivery” includes methods, tools, and timing (e.g., the best communication with the target audience in print, online, by telephone, or word-of-mouth; social media, blogs, or the most appropriate tools to communicate; doctors, spiritual leaders, or the most appropriate messengers to assist in communication; and consideration of religion and culture in timing the delivery of messages).

Ms. Shoretz presented examples of educational materials Sharsheret developed based on responses to questions regarding content and delivery. One brochure asks an uncomfortable question, “What’s Jewish about breast cancer?” The brochure responds to the question by stating that 1 in 40 Ashkenazi Jews carries a BRCA gene mutation, nearly 10 times the rate of the general population, making Jewish families significantly more susceptible to hereditary breast cancer and ovarian cancer.

The Sharsheret Web site provides a wealth of information and concrete action steps for persons who identify themselves as being at risk for breast cancer or BRCA-positive. Opportunities are provided on the Web site for persons to communicate with other women at risk or a genetic counselor, attend a genetics seminar, or read genetics booklets.

Messages on genetic testing for a number of health issues are being published in Jewish weekly newspapers along with images that resonate with Jewish families. Data-driven content and statistics also are being delivered to emphasize the need for screening in a different subpopulation of the Jewish community.

Sharsheret has learned several valuable lessons in producing culturally sensitive materials for the Jewish community. For example, photographs of women in low-cut or sleeveless shirts in Sharsheret’s educational booklet series, *Your Jewish Genes: Hereditary Breast Cancer and Ovarian Cancer*, had to be Photoshopped to be more modest and acceptable to the Jewish community. Sharsheret translated its breast cancer booklet into Yiddish to reach the orthodox Hasidic Jewish community, but the materials had no reach or impact because the target audience desired information in English.

Sharsheret will soon launch the “Have the Talk” campaign to at-risk populations. The campaign provides sample dialogue, specific action steps, and empowerment tools for young Jewish women and men to eliminate barriers to discussing their family history with family members. Campaign messages will be delivered via multiple channels (texting, a Web site, Facebook, and print media). The campaign is not limited to women because both males and females of Ashkenazi Jewish descent carry BRCA gene mutations that are linked to breast, ovarian, and other cancers.

In terms of provider outreach and education, Sharsheret’s message of “1 in 40 Jewish patients are at risk” has appeared to be much more effective than traditional or subtle messages. Timing also is an important component in message delivery. Sharsheret sends e-mail messages to rabbis near the time of the High Holy Day season because these events call for the Jewish community to consider life, death, and health. Rabbis are more likely to convey Sharsheret’s at-risk messages to their congregations during this time.

Sharsheret’s Genetics for Life Program addresses hereditary breast cancer and ovarian cancer through an on-staff genetic counselor, topical teleconferences (e.g., “Breast Cancer Genetics and the Sephardic Jewish Woman” and “Breast Cancer Genetics: Impact on the Jewish Woman and Her Family”), and the educational booklet series.

ACBCYW applauded the outstanding efforts and activities of APIAHF, SNI, and Sharsheret to reach women at increased risk for breast cancer in specific ethnic/minority populations. Several members noted that it would be useful to further discuss the organizations’ strategies, best practices, and lessons learned in overcoming barriers to reach these populations, measure outcomes, and evaluate the impact of activities during the workgroup meetings.

Developing Psychosocial and Reproductive Health Support Resources for Young Breast Cancer Survivors in the United States

Ingrid Hall, Ph.D., M.P.H.

Epidemiologist & Team Lead, Epidemiology and Applied Research Branch
Division of Cancer Prevention and Control
Centers for Disease Control and Prevention

Dr. Hall covered the following areas in her overview of CDC’s development and evaluation of a community-based intervention to increase breast cancer screening and early detection among low-income, African American women. DCPC administers CDC’s National Breast and Cervical Cancer Early Detection Program (NBCCEDP) to provide breast and cervical cancer screening, diagnosis, and treatment to low-income, medically underserved, and uninsured women in all 50 States, the District of Columbia, 12 Tribes or Tribal Organizations, and 5 Territories.

Because African Americans accounted for only 14 percent of women who were screened by NBCCEDP in 2002-2007, CDC piloted a project in Georgia to raise awareness of the State BCC program at the local level and increase mammography utilization among African American women. The target audience was NBCCEDP-eligible African American women 40-64 years of age.

Phase 1 was the formative research phase of the study. Focus groups were held to identify factors that influence NBCCEDP-eligible African American women to obtain breast cancer screening and also to determine the most viable media outlets to reach NBCCEDP-eligible women with breast cancer screening messages. The formative research phase was designed to answer four key questions:

1. What factors influence NBCCEDP-eligible African American women to participate in NBCCEDP?
2. Why do NBCCEDP-eligible African American women not participate in the NBCCEDP?
3. What are viable methods (e.g., messages, sources, channels) to disseminate information about NBCCEDP services to NBCCEDP-eligible African American women?
4. What are the differences between NBCCEDP-eligible African American women 40–49 and 50–64 years of age that may have implications for development and dissemination of health messages to these populations?

CDC conducted focus groups in Macon and Savannah, GA, while Columbus, GA, served as the control group. These cities were selected to use black radio to communicate health messages to the African American community. The focus group participants included women who had been screened in the past 24 months by their local BCC programs and NBCCEDP-eligible women who had not been screened in the past 3 years. In these 2 categories, the focus group participants were divided into 40-49 and 50-64 year age groups to facilitate dialogue.

Key findings of the focus groups in the formative research phase are highlighted as follows. A family history of cancer motivated participants to obtain a mammogram. Unscreened women who had not received a mammogram were unaware that the BCC program offers no- or low-cost mammograms. Reasons women did not obtain screening included concerns about discomfort, embarrassment, radiation that may cause cancer, and uncertainty about next steps or lack of insurance for treatment if cancer was detected.

Unscreened women were less trusting of the medical system and low-cost services, were more likely to view mammograms as painful, and questioned the accuracy of results. All participants reported frequently listening to the radio >4 times per week. The participants commonly responded that radio as a health communication tool is a viable channel for delivering health messages.

Phase 2 of the study was the development and testing of communication concepts, radio messages, and materials based on the Phase 1 findings. CDC learned valuable lessons during testing of the preliminary print materials. The brochure's black-and-white layout and undetermined race of the woman were not acceptable to the test audience.

The revised brochure with smiling women in three generations was more acceptable to the test audience, but the message of "think about what you're not doing" was found to be vague and generic. This feedback was applied to the images and color of the final community awareness brochure with the direct message: "Haven't had a mammogram?"

CDC took the same approach of testing and revising the images, text, and messages in its other print materials based on feedback. Dr. Hall played the radio messages CDC developed based on feedback provided during the focus groups. Final versions of the 6 brochures and the 29 radio messages are available on the CDC.gov/cancer Web site.

Key findings of the concept and materials testing are highlighted as follows. The participants commonly focused on images more than on text and emphasized the need for concise and directive phrases (e.g., “Go get a mammogram!”). Images of smiling, happy, and healthy African American women and families were more acceptable to the participants.

The participants were pleased to hear African American voices on the radio. However, the participants noted that the print and radio messages should be acceptable and ideally appeal to all audiences beyond African American women. The participants reported that African American women do not discuss their breasts with medical professionals, doctors, and nurses. As a result, providers fail to inform African American women about their eligibility for services (e.g., low- or no-cost mammograms).

Phase 3 was the implementation and evaluation phase of the study. The African American Women and Mass Media (AAMM) Intervention was launched in August 2008 - July 2009. The multimedia component in Savannah and Macon included 30- and 60-second radio broadcasts of survivors’ testimonies and monthly 60-minute public affairs shows with breast cancer providers and medical professionals. The public was able to call the show and obtain answers to their questions. CDC launched a community presence component in Savannah for radio stations to place the print media in local businesses and community events frequented by African American women.

The evaluation plan was designed to monitor changes in telephone calls to 1-800-4CANCER and the number of callers who reported radio as an information source to determine increased awareness. The number of African American women screened through the local BCC program in Georgia was monitored to determine changes in behavior. New radio messages were broadcast each month of the 12-month campaign.

The evaluation data showed that no calls were made to 1-800-4CANCER from the control site (Columbus), while the percentage of callers increased each month from the intervention sites (Savannah and Macon). Of 1,019 calls, the control site accounted for 184 and the intervention sites accounted for 835.

The percentage of African American callers was 44 percent in the control site compared to 57 percent and 60 percent in the intervention sites. The callers represented more of the general public than cancer patients, their family members, and friends. The percentage of uninsured callers was 20 percent in the control site and 41 percent and 44 percent in the intervention sites.

African American callers who were directly linked to local health departments were more likely to report that the AAMM radio broadcasts, print materials, or public affairs shows, 1-800-4CANCER, and word-of-mouth communication from families and friends prompted their calls. Overall, the radio broadcasts accounted for no callers from the control site, but led to more calls from young, uninsured African American women 40-49 years of age in the general public in the intervention sites.

In terms of behavior change, the slight increase of 22 percent of African American women who received mammograms from the Columbus BCC program in April-September 2009 was not statistically significant. However, the increase of 36 percent of African American women who received mammograms from the Savannah BCC program beginning in March 2009 was statistically significant. The increase of 37 percent of African American women who received mammograms from all three sites before and during the intervention was statistically significant.

Overall, the AAMM campaign resulted in increased calls to 1-800-4CANCER in intervention sites compared to the control site. An increasing number of callers in the intervention sites reported radio as their source of information. African American callers to health departments reported radio, print, and 1-800-4CANCER as information sources more often than other groups of women.

The average number of African American women who obtained a mammogram through the BCC program increased in the intervention sites during the campaign period compared to the control site. A community-based radio and print materials public health campaign appeared to be a viable communication method to reach and change knowledge, awareness, and behavior among African American women. The campaign ideally can be used to reduce health disparities in breast cancer.

In response to ACBCYW's questions, Dr. Fairley confirmed that an update would be placed on the next agenda for Dr. Hall to present data to show the impact of the updated USPSTF breast cancer screening recommendations in November 2009 on utilization of BCC program services in the control and intervention sites in Georgia.

Dr. Fairley also confirmed that she would contact Ms. Faye Wong, Chief of the DCPC Program Services Branch, to provide ACBCYW with information in response to questions raised about NBCCEDP (e.g., program reach, monitoring, impact, expenditures, and quality and performance measures of CDC-funded BCC programs). Dr. Fairley was aware that some ACBCYW members were interested in using the NBCCEDP during their workgroup discussions.

Dr. Partridge was in favor of the members reviewing the NBCCEDP data, but she cautioned the workgroups against using the information to formulate recommendations. She explained that NBCCEDP's provision of mammography services would not apply to ACBCYW's target audience of younger women with breast cancer.

Public Comment Session

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

ACBCYW Open Discussion: Session 3

Dr. Fairley presented the charges for the new ad hoc workgroups ACBCYW drafted on the previous day. The members had an extensive discussion on the draft charges and proposed a number of revisions. **ACBCYW reached consensus on the following workgroup charges.**

PROVIDER AD HOC WORKGROUP

Charge: To gather initial background information and to advise the Committee regarding behavior change of providers* as relates to the following:

1. Enhancing provider knowledge regarding breast cancer in young women

- Assessing gaps, guidelines, and issues messaging regarding breast cancer in young women
2. Improving skills of providers regarding delivery of care to young women at risk (average risk and high risk) of, and/or facing, breast cancer (e.g., survivors).

The Ad Hoc Workgroup will define “providers.”

Membership

- *Brandon Hayes-Lattin, M.D. (Chair)
- *Generosa Grana, M.D., FACP
- *Karen Kelly Thomas, Ph.D., R.N., FAAN
- *Wendy Susswein
- JoAnne Zujewski, M.D.
- Renee Nicholas
- Laura Tillman, M.D. (proxy for IHS)
- *ACBCYW Voting Members

HIGH-RISK AD HOC WORKGROUP

Charge: To gather initial background information and to advise the Committee regarding the following:

1. Developing an understanding of what it means to be at “high risk” for breast cancer as it relates to young women
2. Identifying potential evidence-based messages to be disseminated to these populations

Membership

- *Rochelle Shoretz, J.D. (Chair)
- *Maimah Karmo
- *Mavis Nitta, M.P.H., CHES
- Marc Hurlbert, Ph.D.
- Ngina Lythcott, Dr.PH
- Kelly Hodges
- LCDR Morrisa Rice, M.H.A., REHS, RS
- Padmini Jagadish, M.P.P.

Clinical Advisors

- *Lisa Newman, M.D., M.P.H., FACS
- *Otis Brawley, M.D., FACP
- *ACBCYW Voting Members

Dr. Fairley addressed questions the members raised during the meeting related to process issues. At the committee level, ACBCYW’s 4-year charter is from 2010 to 2014. At the individual member level, CDC will publish a *Federal Register* notice to solicit applications from potential candidates when the terms of current members are due to expire. However, CDC will attempt to achieve an appropriate balance between continuity of ACBCYW (e.g., extending the terms of some current members) and fairness (e.g., recruiting new members to obtain different perspectives and views).

In terms of disclosure of conflicts of interest for the record, this issue only relates to items on the published agenda. CDC has and will continue to develop agendas to ensure that BCYW grant opportunities are not discussed during ACBCYW meetings. This caution is taken to ensure that

ACBCYW members are not deemed to be ineligible to apply for future grant opportunities as a result of obtaining advance information during meetings.

In terms of the next meeting dates, the ACBCYW reported various conflicts for the February/ March and September 2012 meetings. Dr. Fairley confirmed that she and Ms. Carolyn Headley would circulate a Doodle poll as soon as possible after the current meeting for the members to indicate their dates of availability. She explained that CDC is attempting to find the appropriate balance between the “too short” first meeting of 1.5 days and the “too long” second meeting of 3 days. Consideration is being given to holding future ACBCYW meetings for 2 days.

In terms of meeting content, Dr. Fairley explained that the theme of the next ACBCYW meeting potentially would focus on providers. She encouraged the members to contact her via e-mail at tff9@cdc.gov to propose specific agenda items.

Dr. Fairley was aware that ACBCYW made several requests for materials over the course of the meeting (e.g., BodyTalk information and access to the new beta Web site; NBCCEDP data; and CDC’s BCYW research, literature reviews, media audits, and ongoing projects). She confirmed that CDC would respond to these requests.

Closing Session

Dr. Fairley confirmed that all of the presentations would be available after the meeting on the ACBCYW Web site at CDC.gov. She encouraged ACBCYW to contact her or Ms. Headley at tff9@cdc.gov or theadley@cdc.gov. On behalf of DCPC leadership and staff, she again thanked the ACBCYW members for attending the meeting and serving on the new workgroups.

The participants joined Dr. Partridge in applauding the outstanding efforts of Dr. Fairley, Ms. Headley, and other DCPC staff for planning and organizing the meeting.

With no further discussion or business brought before ACBCYW, Dr. Partridge adjourned the meeting at 12:11 p.m. on September 23, 2011.

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

Date

Temeika L. Fairley, Ph.D.
Designated Federal Officer,
Advisory Committee on Breast
Cancer in Young Women (ACBCYW)



Centers for Disease Control and Prevention

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

SEPTEMBER 21–23, 2011 • ATLANTA, GA



Attachment 1 **Glossary of Acronyms**

AAMM	African American Women and Mass Media
AANHPI	Asian American, Native American, and Pacific Islander
ACBCYW	Advisory Committee on Breast Cancer in Young Women
ACS	American Cancer Society
AHRQ	Agency for Healthcare Research and Quality
AI/AN	American Indian/Alaska Native
API	Asian Pacific Islander
APIAHF	Asian & Pacific Islander American Health Forum
BCC	Breast and Cervical Cancer
BCYW	Breast Cancer in Young Women
BMI	Body Mass Index
BRFSS	Behavioral Risk Factor Surveillance Survey
BSE	Breast Self-Examination
CDC	Centers for Disease Control and Prevention
DCPC	Division of Cancer Prevention and Control
EARLY	Education and Awareness Requires Learning Young (Act)
FAC	Federal Advisory Committee
FDA	Food and Drug Administration
FOA	Funding Opportunity Announcement
GFL	Genetics for Life
GYT	Get Yourself Tested
HPV	Human Papillomavirus
IHS	Indian Health Service
IHS	Indian Health Center
IRB	Institutional Review Board
KFF	Henry J. Kaiser Family Foundation
LPSN	Link Peer Support Network
MCV4	Meningococcal Conjugate Vaccine
MRI	Magnet Resonance Imaging
NABCC	Native American Breast Care Clinic
NBCCEDP	National Breast and Cervical Cancer Early Detection Program
NCI	National Cancer Institute
NIEHS	National Institute of Environmental Health Sciences
OCE	Oncology Center of Excellence
OMB	Office of Management and Budget
OPHG	Office of Public Health Genomics

ORISE	Oak Ridge Institute for Science and Education
PIMC	Phoenix Indian Medical Center
PPFA	Planned Parenthood Federation of America
PSAs	Public Service Announcements
RTI	Research Triangle Institute
SES	Socioeconomic Status
SHS	Secondhand Smoke
SNI	Sisters Network, Inc.
SPIRIT	Sisters Peer Counseling in Reproductive Issues after Treatment
USPSTF	U.S. Preventive Services Task Force
YBCS	Young Breast Cancer Survivors



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Attachment 2 **Published Meeting Agenda**

MEETING OBJECTIVES:

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

Day 1: Wednesday, September 21, 2011

- 9:00 A.M. – 9:15 A.M. Opening: Welcome and Introductions**
Ann H. Partridge, M.D., M.P.H.^a
Dana-Farber Cancer Institute
ACBCYW Committee Chair
- Marcus Plescia, M.D., M.P.H.*
Director, DCPC, CDC
- 9:15 A.M. – 9:30 A.M. Opening Remarks**
Representative Debbie Wasserman Schultz
- 9:30 A.M. – 9:45 A.M. Committee Introductions (New Members)**
Temeika L. Fairley, Ph.D.
Designated Federal Officer, DCPC, CDC
- Ann H. Partridge, M.D., M.P.H.^a*
Dana-Farber Cancer Institute
ACBCYW Committee Chair
- 9:45 A.M. – 10:15 A.M. CDC's Role in Health Communication**
Katherine Lyon Daniel, Ph.D.
Acting Associate Director for Communication
Office of the Director, CDC
- 10:15 A.M. – 10:30 A.M. BREAK**

- 10:30 A.M. – 11:30 A.M.** **Importance of Health Communication**
Leslie Snyder, Ph.D.
University of Connecticut
- 11:30 A.M. – 12:30 P.M.** **CDC Real World Health Communications**
Get Yourself Tested (GYT) Campaign
Allison Friedman, M.S.
Health Scientist
National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention, CDC
- Harnessing the Power of Social Networks, Mommy Bloggers, and Google (and Improving HPV Vaccination Awareness at the same time)**
Jill B. Roark, M.P.H.
Carter Consulting, Inc.
National Center for Immunization and Respiratory Diseases, CDC
- 12:30 P.M. – 1:30 P.M.** **LUNCH**
- 1:30 P.M. – 3:00 P.M.** **Using Social Media Examples**
Social Media for Health Communication
Diane Brodalski
Social Media Specialist
Office of the Associate Director for Communication, CDC
- LIVESTRONG & Social Media: Timing Is Everything**
Renee Nicholas^c
Director of Corporate Partnerships
LIVESTRONG
- 3:00 P.M. – 3:15 P.M.** **BREAK**
- 3:15 P.M. – 4:15 P.M.** **Open Discussion**
Ann H. Partridge, M.D., M.P.H.^a
Dana-Farber Cancer Institute
ACBCYW Committee Chair
- Temeika L. Fairley, Ph.D.*
Designated Federal Officer, DCPC, CDC
- 4:15 P.M. – 4:45 P.M.** **PUBLIC COMMENT**
- 4:45 P.M. – 5:00 P.M.** **Wrap-Up/Announcements**

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

Day 2: Thursday, September 22, 2011

- 8:00 A.M. – 8:20 A.M. Highlights and Review**
Ann H. Partridge, M.D., M.P.H.^a
Dana-Farber Cancer Institute
ACBCYW Committee Chair
- 8:20 A.M. – 9:15 A.M. CDC Projects Update: Body Talk**
Galen Cole, Ph.D., M.P.H., LPC
Associate Director for Communication Research and Evaluation,
DCPC, CDC

Doug George
Senior Web Designer
Oak Ridge Institute for Science and Education
- 9:15 A.M. – 10:00 A.M. CDC and NIEHS: Partnership on The Sister and Two Sister Study**
Mary C. White, Sc.D.
Chief, Epidemiology and Applied Research Branch, DCPC, CDC

CDC Research and Program Activities in Breast Cancer Genomics
Juan Rodriguez, M.P.H., M.S.
Epidemiologist, DCPC, CDC
- 10:00 A.M. – 10:15 A.M. BREAK**
- 10:15 A.M. – 11:00 A.M. Breast Cancer in Young Women: Reviewing the Evidence and Setting the Course**
Natasha Buchanan, Ph.D.
Behavioral Scientist, DCPC, CDC
- 11:00 A.M. – 11:30 A.M. Developing Survivorship and Reproductive Health Resources**
Temeika L. Fairley, Ph.D.
Designated Federal Officer, DCPC, CDC
- 11:30 A.M. – 12:30 P.M. LUNCH**
- 12:30 P.M. – 1:00 P.M. Public Comment**
- 1:00 P.M. – 1:30 P.M. Walking Together: Making a Path Toward Healing**
Annie Fair, M.P.H.
Tribal Liaison, DCPC, CDC

Cathy Witte, R.Ph., M.Div.
Pharmacist and Chaplain
Oncology Centers of Excellence, Phoenix Indian Medical Center, IHS

Kathy Evans, M.S.W.
Oncology Program Specialist
Oncology Centers of Excellence, Phoenix Indian Medical Center, IHS

1:30 P.M. – 1:45 P.M. BREAK

1:45 P.M. – 4:00 P.M. Open Discussion

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

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

4:00 P.M. – 4:30 P.M. Wrap-Up/Announcements/Adjourn

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

Day 3: Friday, September 23, 2011

8:00 A.M. – 8:20 A.M. Highlights and Review

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

8:20 A.M. – 9:45 A.M. Culturally Appropriate Health Communications for Women at Increased Risk

Mavis M. Nitta, M.P.H., C.H.E.S.^a
Chronic Disease Program Coordinator
Asian & Pacific Islander American Health Forum

Kelly P. Hodges^c
National Program Director
Sisters Network® Inc.

Rochelle L. Shoretz, J.D.^a
Executive Director and Founder
Sharsheret

9:45 A.M. – 10:00 A.M. BREAK

- 10:00 A.M. – 10:45 A.M.** **Development and Evaluation of a Community-Based Intervention to Increase Breast Cancer Screening and Early Detection among Low-Income, African American Women**
Ingrid Hall, Ph.D., M.P.H.
Epidemiologist/Team Lead, DCPC, CDC
- 10:45 A.M. – 12:00 P.M.** **Open Discussion**
Ann H. Partridge, M.D., M.P.H.^a
Dana-Farber Cancer Institute
ACBCYW Committee Chair

Temeika L. Fairley, Ph.D.
Designated Federal Officer, DCPC, CDC
- 12:00 P.M. – 1:00 P.M.** **WORKING LUNCH**
- 1:00 P.M. – 1:30 P.M.** **PUBLIC COMMENT**
- 1:30 P.M. – 2:00 P.M.** **Wrap Up/Announcements/Adjourn**
Ann H. Partridge, M.D., M.P.H.^a
Dana-Farber Cancer Institute
ACBCYW Committee Chair

^a *Voting Committee Member, Advisory Committee on Breast Cancer in Young Women*

^b *Ex-Officio Member, Advisory Committee on Breast Cancer in Young Women*

^c *Liaison Representative, Advisory Committee on Breast Cancer in Young Women*



Centers for Disease Control and Prevention

ADVISORY COMMITTEE on BREAST CANCER in YOUNG WOMEN

SEPTEMBER 21–23, 2011 • ATLANTA, GA



ATTACHMENT 3 Roster of the ACBCYW Membership

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