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
April 18-19, 2012
Atlanta, Georgia

DRAFT Record of the Proceedings

DEPARTMENT OF HEALTH AND HUMAN SERVICES
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ADVISORY COMMITTEE ON BREAST CANCER IN YOUNG WOMEN
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DRAFT Meeting Minutes

The Department of Health and Human Services (HHS) and the Centers for Disease Control and Prevention (CDC), National Center for Chronic Disease Prevention and Health Promotion, Division of Cancer Prevention and Control (DCPC), convened a meeting of the Advisory Committee on Breast Cancer in Young Women (ACBCYW). The proceedings were held on April 18-19, 2012 at the Atlanta Marriott Perimeter Center Hotel in Atlanta, Georgia.

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

Opening Session: April 18, 2012

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 of the ACBCYW voting members, *ex-officio* members and liaison representatives. She verified that the voting members and *ex-officio* members in attendance constituted a quorum for ACBCYW to conduct its business on April 18, 2012. None of the voting members declared conflicts of interest for the record for any of the items on the published agenda for April 18, 2012. Dr. Fairley called the meeting to order at 12:10 p.m.

Dr. Fairley regrettably announced that Dr. Jo Anne Zujewski, the *ex-officio* member for the National Institutes of Health (NIH), would be unable to attend the meeting due to her mother's death on the previous day. A condolence card would be distributed for the ACBCYW members to sign. Moreover, Dr. Zujewski's contact information could be located on the ACBCYW roster for members with an interest in sending a personal condolence message.

Dr. Fairley announced that CDC is currently preparing nomination packets for 6 ACBCYW members whose terms would expire on November 30, 2012. She thanked the ACBCYW

members for submitting names of potential candidates to fill these vacancies. She would provide ACBCYW with more information on the nomination and appointment process during the next meeting.

Marcus Plescia, M.D., M.P.H.
Director, Division of Cancer Prevention and Control
Centers for Disease Control and Prevention

Dr. Plescia welcomed the participants to the meeting and thanked ACBCYW for making tremendous progress in the prevention of breast cancer in young women (BCYW). He was pleased that since the previous meeting, ACBCYW has started to give substantial consideration to specific topics on this issue. He was confident that the ACBCYW members would continue to make progress over the course of the two-day meeting and during their closed workgroup sessions on April 20, 2012. Dr. Plescia looked forward to ACBCYW's continued advice and guidance to CDC.

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

Dr. Partridge joined Dr. Plescia in welcoming the participants to the ACBCYW meeting. She was pleased to announce that the agenda was developed with a number of exciting items, including updates on CDC's BCYW activities since the previous meeting and overviews from several BCYW grantees.

Dr. Partridge opened the floor for introductions. The meeting agenda and the participants' directory are appended to the meeting minutes as Attachment 1 and Attachment 3, respectively.

Overview of Congressionally-Directed Medical Research Programs (CDMRP)

Gayle Vaday, Ph.D.
Program Manager, Breast Cancer Research Program/CDMRP
Department of Defense

Dr. Vaday presented an overview of the Department of Defense's (DoD) Breast Cancer Research Program (BCRP). BCRP is housed in the DoD Army Medical Command that is responsible for overseeing medical care, logistics and research for the U.S. Army. The Medical Research and Materiel Command has a long and rich history of conducting and funding biomedical research as well as developing vaccines and other biomedical products or solutions to help deployed military personnel and the public. The CDMRP Office manages all of the BCRP programs.

In 1992, advocates lobbied Congress for increased federal funding of breast cancer research. In response to this action, Congress appropriated $210 million to DoD in 1993 to administer the peer-reviewed BCRP. DoD commissioned the Institute of Medicine (IOM) to provide guidance on an investment and management strategy and an appropriate review process for BCRP.

Since that time, >20 research programs have been added to BCRP, including ovarian cancer, prostate cancer and neurofibromatosis. Each disease-focused program has distinct and individual visions, goals and budgets. However, DoD allocates funds to all of the BCRP programs to specifically identify gaps in eradicating cancer and conduct research to fill these gaps.

After receiving its Congressional appropriation for the fiscal year (FY), DoD initiates a vision setting process with an Integration Panel to determine the current goals of BCRP and identify investments that will be made to achieve the goals. Leading scientists, clinicians and breast cancer advocates in the field serve on the Integration Panel. DoD releases a funding opportunity announcement (FOA) with extensive information for applicants, including the program description, goals and vision; application review, selection and award criteria; eligibility for funding; and deadlines for the submission of applications.

DoD has implemented a two-tier review process based on the IOM recommendations. Tier 1 is a criteria-based peer review. This process identifies the most scientifically meritorious applications that best fulfill the program goals based on their individual strengths and weaknesses. Both scientific and consumer reviewers (e.g., breast cancer survivors and advocates) serve as peer reviewers and closely collaborate with the Integration Panel. Over the past 5 years, >100 representatives of advocacy organizations have served as peer reviewers. The overarching outcome of the peer review process is the production of summary statements.

Tier 2 is a comparison-based programmatic review. This process evaluates applications that are relevant to the program's mission and adhere to the intent of the award mechanism. The composition of the program's portfolio is considered during this process. Programmatic reviewers include the Integration Panel and ad-hoc reviewers. The overarching outcome of the programmatic review process is to use the summary statements and application abstracts to make funding recommendations.

The vision of BCRP is to end breast cancer by funding innovative and high-impact research through a partnership of scientists and consumers. BCRP implements 3 major approaches to achieve its vision. Scientists are allowed to propose their best ideas without being restricted by programmatic requirements. Scientists are challenged to design research that will address the urgency of the BCRP vision to end breast cancer. Award mechanisms are offered to accelerate high-impact research, encourage innovation and stimulate creativity, expand the breast cancer field with new investigators, and facilitate multidisciplinary collaborations.

The BCRP award mechanisms fall into 3 broad categories. Career development mechanisms include the "Predoctoral Traineeship Award" for promising graduate students who are studying breast cancer. The "Postdoctoral Fellowship Award" is for exceptionally talented postdoctoral fellows who are committed to careers in breast cancer research. The "Era of Hope Scholar Award" is for the best and brightest researchers who are early in their careers and have the potential for leadership and innovation in breast cancer research. The "Innovator Award" is for visionary persons with a history of innovation and leadership in novel or high-risk areas that challenge the status quo.

Research idea development mechanisms include the "Concept Award" for early and untested ideas that could reveal entirely new areas for investigation. The "Idea Award" is for innovative research with the potential for high impact. The "Impact Award" is for research that could have a revolutionary impact on understanding, preventing or treating breast cancer. The "Clinical Translational Research Award" is for the translation of promising research from the laboratory to

the clinic. The "Transformative Vision Award" is for new approaches that will transform breast cancer prevention or treatment with integral participation of consumer advocates.

Collaboration development mechanisms include the "Collaborative Option" across several mechanisms to support meaningful and productive collaborations among investigators. Multiple principal investigators submit a joint research proposal and share the funding award. The "Multi-Team Award" is for the promotion of collaboration among teams from diverse disciplines with integral participation of consumer advocates.

DoD is implementing new approaches to further transform the BCRP research process. Several of these award mechanisms do not require preliminary data. A blinded review process is conducted for smaller awards to allow investigators to focus on their research ideas. These approaches do not utilize standing peer review panels.

Communications between anonymous reviewers and applicants are prohibited to eliminate any potential bias or influence and ensure fairness and equity throughout the review process. Consumer advocates are integrated into all aspects of the BCRP program cycle, including the vision setting process, pre-application screening, peer and programmatic reviews, and the final research effort.

Overall, DoD has designed BCRP to be accountable to the public, including breast cancer consumers, advocates and survivors. The impact of the research proposal is a significant criterion for each award. Funding recommendations must consider critical needs in addition to scientific merit, but the best ideas from any location are eligible for funding. To date, DoD has awarded BCRP funds to 49 states and 17 countries.

DoD obligates funds up front to eliminate any risk to investigators completing their research projects. Over the past 20 years, DoD has maintained a low cost of ~6% to manage BCRP, including the peer and programmatic reviews. Although ~4% of BCRP funds are held by the Army for Small Business Innovation Programs and administrative issues, a total of ~90% is targeted to breast cancer research. All cost-savings are invested back into BCRP.

In addition to ensuring accountability at the federal level, DoD also requires a high standard of performance at the grantee level. Most notably, all BCRP grantees must provide DoD with written progress reports either quarterly or annually and present their research at the Era of Hope Conference every 3 years.

Dr. Vaday presented additional details on BCRP in response to ACBCYW's questions. The discussion topics included:

- DoD funding of ~$220 million for BRCA1/BRCA2 research (or ~8-10% of the entire BCRP portfolio);
- DoD funding of $500 million for research of familial breast cancer, BCYW and other topics of interest to ACBCYW (or ~20% of the entire BCRP portfolio); and
- a total of ~$108 million that will be allocated to breast cancer research in FY2012 from the entire BCRP budget of $120 million.

Several ACBCYW members who have participated in the BCRP peer review process commended DoD in two areas. First, DoD has provided a unique forum for breast cancer survivors and advocates to be extensively engaged in the federal peer review process and for their viewpoints to be fully respected and valued.

Second, DoD has a 20-year history of being visionary and providing leadership in pairing scientific peer reviewers and consumer reviewers in a true partnership during the federal peer review process. These collaborations have allowed DoD to fund exciting, innovative and novel breast cancer research ideas that would not be funded by NIH due to the absence of preliminary data.

The ACBCYW members urged their colleagues to serve as consumer reviewers themselves or nominate breast cancer patients, survivors or advocates to serve in this capacity. The members noted that similar to the ACBCYW membership, the terms of consumer reviewers for the BCRP peer review process are for a specified period of time. Application packages to become a consumer reviewer can be accessed at http://cdmrp.army.mil/bcrp.

Overview of the CDC DP11-1111 Cooperative Agreement

Angela Moore, M.P.H.
Program Evaluation and Partnership Team Lead/DCPC
Centers for Disease Control and Prevention

Ms. Moore presented an overview of the CDC DP11-1111 cooperative agreement, *Developing Support and Educational Awareness for Young Breast Cancer Survivors in the United States*. DP11-1111 is managed by a multi-disciplinary team in the Division's Comprehensive Cancer Control Branch (CCCB). CCCB administers a total of 6 cooperative agreements spanning the entire cancer control continuum from prevention to survivorship. Grantees include governmental agencies, academic institutions and national organizations. CCCB has 3 interdisciplinary working units: Program Evaluation and Partnership Team, Scientific Support and Clinical Translation Team, and Communication and Training Team. These units closely collaborate to provide quality technical assistance to all DP11-1111 grantees.

Ms. Moore described the selection and funding process for the 3 year cooperative agreement, DP11-1111 (project period: September 30, 2011-September 29, 2014):

- CDC procedures for reviewing and funding this cooperative agreement were used:
  - CDC received 53 responsive applications from several eligible entities (e.g., nonprofit and for-profit organizations; small, minority and women-owned businesses; colleges and universities; research institutions and hospitals; and community-/faith-based organizations).
  - Following the July 16, 2011 deadline for submission of applications, CDC convened an objective review panel to assess each application based on the evaluation criteria outlined in the DP11-1111 Funding Opportunity Announcement (FOA).
  - In September 2011, CDC awarded ~$1.8 million to the 7 organizations to conduct activities under the DP11-1111 FOA
    - John C. Lincoln Health Foundation (Phoenix, AZ)
    - Living Beyond Breast Cancer (Haverford, PA)
    - Louisiana State University Health Sciences Center (New Orleans, LA)
    - Sharsheret, Inc. (Teaneck, NJ)
      - University of California, Los Angeles (UCLA) (Los Angeles, CA)
      - University of North Carolina at Chapel Hill (UNC) (Chapel Hill, NC)
      - Washington University School of Medicine (St. Louis, MO)

Ms. Moore described the grantee/recipient and CDC activities associated with DP11-1111. The grantees will utilize their funds to increase knowledge and awareness of health behaviors; promote other strategies to reduce the risk of recurrences, new malignancies and chronic disease onset; and improve the overall health and quality of life of young breast cancer survivors (YBCS) <45 years of age. The DP11-1111 grantees will conduct several activities over the 3-year project period:

- Retain an individual with core public health competencies to manage the program.
- Conduct a needs and resource assessment in year 1 to identify gaps in support services and educational content for the target population.
- Utilize findings of the needs assessment to select 3-5 priorities to build program plans.
- Initiate partnership building efforts to assist program planning and implementation.
- Monitor and evaluation program implementation
- Develop sustainability plans for newly developed and implemented programs.

CDC will conduct a number of activities to guide the DP11-1111 grantees over the 3-year project period:

- Provide extensive technical assistance, training and overall guidance to the grantees, including scientific, evaluation, communication and programmatic support.
- CDC will help the grantees to develop publications that relate to the purpose and goals of the Cooperative agreement, facilitate information sharing and partnership building, and conduct program evaluation.

Ms. Moore provided brief program summaries of 3 grantees that were unable to attend the ACBCYW meeting.

- John C. Lincoln Health Foundation will build and maintain an online comprehensive database that can be accessed by patients and patient navigators. The database will be designed for users to search state resources by location and need. Educational events will be launched across Arizona to encourage breast health awareness, particularly in rural areas of the state. Survivor support groups will be formed and additional needs identified in the needs assessment will be addressed.

- Louisiana State University Health Sciences Center will conduct a literature review, survey, resource assessment and gap analysis to determine the priority needs of YBCS. A network of providers will be established to respond to the needs of this target population. A community of collaboration and engagement for learning will be developed. A system will be designed to aid in the rapid identification of YBCS and facilitate their navigation into services.

- UNC at Chapel Hill will assess the needs and utilization of structured support services. Existing barriers to routine needs assessments and use of supportive care services will be identified. Existing systems will be modified to facilitate assessment for and utilization of support services. Educational materials will be developed for patients, families and staff. Information will be disseminated via UNC's existing navigator and lay navigator network, teleconferencing system, and educational sessions at UNC and in the community.

The DP11-1111 grantees currently are completing their needs assessment activities. In year 2, the grantees will develop their program plans, foster relationships with organizations that can

help with implementation, and begin to design a comprehensive evaluation plan. During future meetings, CDC will provide ACBCYW with updates on the progress of the DP11-1111 grantees.

PANEL PRESENTATION: OVERVIEWS BY THE DP11-1111 GRANTEES

A panel of 4 grantees presented overviews of the programs that were proposed in their DP11-1111 applications. The presentations are summarized below.

Overview of the UCLA-LIVESTRONG® Survivorship Center of Excellence Program

Patricia Ganz, M.D.
Director, Division of Cancer Prevention and Control Research
Director, Patients and Survivors Program/UCLA Jonsson Comprehensive Cancer Center
UCLA Schools of Public Health and Medicine

Dr. Ganz presented an overview of the UCLA Young Breast Cancer Survivorship Program that is housed in the UCLA-LIVESTRONG® Survivorship Center of Excellence (COE). Los Angeles County is the most populous and diverse county in the United States. Of nearly 10 million residents in the county, ~75% are ≥18 years of age, 50% are white, and ~36% are foreign-born. LIVESTRONG® began funding the COE in 2006.

The COE is housed in the UCLA Medical Center that is ranked fifth in the country and provides the best cancer care in the state of California. COE's internal programs at UCLA include the Patients and Survivors Program with a mission to reduce avoidable morbidity and mortality among patients with cancer, including long-term survivors. The Vital Information and Tailored Assessment Program serves as the COE's clinical arm and provides psychosocial services for cancer survivors. Overall, COE's research focuses on quality of life across the developmental life span as well as the measurement and evaluation of the quality of cancer care.

In addition to its internal programs, research and services, the COE also has developed strong affiliations with 2 hospital partners to expand outreach to uninsured, foreign-born and underserved YBCS in the broader community. First, the Torrance Memorial Medical Center is a nonprofit community hospital that is fully accredited by the American College of Surgeons Cancer Program. The full-service hospital has 376 beds and maintains a hospital cancer registry with 1,300 incident cases per year.

Second, the Olive View-UCLA Medical Center is a state-of-the-art county hospital with 377 beds. Under its Avon Breast Cancer Survivorship Program, the hospital provides a broad range of services (e.g., patient navigation, early diagnosis and treatment, survivorship and genetic testing).

The COE conducts a number of activities to outreach to teen and young adult cancer survivors. The "Healthy Lives After Cancer" Program focuses on persons 15-39 years of age and offers quarterly seminars, such as the free "Cooking After Cancer" class for young adult cancer survivors.

Moreover, the COE prioritizes fertility preservation due to its strong focus on young adult cancer survivors. The COE attended the Memorial Sloan-Kettering Cancer Center Conference in October 2011 and met with a nurse practitioner with responsibility for fertility services consultation. The COE also administered a survey to UCLA oncologists and other providers to assess their knowledge and attitudes toward these services. The COE is partnering with reproductive endocrinologists to develop an in-house referral program in addition to regional resources.

After CDC awarded the DP11-1111 funds in September 2011, the COE hired a skilled and knowledgeable health educator. Over the 3-year project period, the COE will establish priorities, foster new collaborations and expand existing partnerships, develop and implement a program plan, evaluate the overall program, and design a sustainability plan. The COE limited the scope of the needs assessment due to its existing knowledge of the needs of the patient population from a clinical perspective.

The needs assessment focused on interviewing community organizations that serve the diverse and large patient population of Los Angeles County as well as cancer patients and survivors. The 23 community organizations that were interviewed found programs targeted to young women 21-45 years of age to be the primary gap in services. Other gaps in services included fertility, early menopause and menopause symptoms, and issues related to sexual functioning, body image, and management of work and careers.

The community organizations further reported that the top recurring issues for their patients included fatigue, fear of recurrence, side effects of treatment, “chemobrain,” psychological issues, fertility and the ability to return to work.

The COE conducted 18 interviews with breast cancer patients who were 27-45 years of age at diagnosis and 29-54 years of age at the time of the interviews. The primary gaps in services reported by the patients included support groups for younger women, fertility, and mentor/buddy matching programs. The top recurring issues reported by the patients included cognitive issues (e.g., chemobrain), fatigue and fear of recurrence.

The major needs reported by the patients included skills to cope with the “new normal” post-treatment, long-term survivorship issues, healthy lifestyle changes, and support groups for younger women. The COE concluded that the gaps in services and recurring issues reported by the community organizations and breast cancer patients were strikingly similar.

The COE used the needs assessment to confirm its existing literature and clinical experiences; identify specific regional gaps in services; prioritize strategies for program development; and focus on unique needs of the target population that are difficult to address within large organizations.

The COE formed an internal advisory committee with diverse representation that will help to design a psychosocial intervention program based on the priorities identified in the needs assessment (e.g., fear of recurrence, skills to cope with the “new normal,” chemobrain, fatigue, reproductive and fertility services, early menopause and menopause symptoms, and sexuality and intimacy issues). Over the next 6 months, the COE will identify and pilot various technical modalities to best deliver the program (e.g., in-person sessions and web-based modules). As the program is refined over time, the COE will offer a Spanish version.

The COE developed a mission statement for its YBCS Program that is dedicated to enhancing the health and wellness of YBCS. The overarching goal of the YBCS Program is to address the unique gaps in services that exist for this population by providing a regionally refined community resource listing of programs and services catering to the specific challenges faced by YBCS. The YBCS Program particularly will focus on psychosocial support services and educational programs aimed at providing education on coping with various psychosocial issues.

The COE's next steps to achieve the goals of the DP11-1111 cooperative agreement will be to continue with the development of the psychosocial intervention program; use the $10,000 grant from the UCLA Clinical Translational Science Institute to create an online regional resource library with podcasts, videos and other tools; and develop additional regional resources that will specifically focus on reproductive services and fertility preservation for YBCS.

Dr. Ganz concluded her overview by announcing that the COE would host the "6th Annual Cancer Survivor Education Day" on May 19, 2012 for the entire community of Los Angeles County. During this event, she would convene a special "Ask the Doctor" session with a focus on YBCS. She presented 3 web-based and social media resources for ACBCYW to obtain additional information on the UCLA-LIVESTRONG® Survivorship COE.

- VITA Program (http://vita.mednet.ucla.edu)
- Facebook page (www.facebook.com/YBCSprogram)
- UCLA Jonsson Comprehensive Cancer Center (www.cancer.ucla.edu/YBCS)

Overview of the Washington University School of Medicine Program

Jennifer Ivanovich, M.S., M.B.A.
Program Director, Young Women's Breast Cancer Program
Washington University in St. Louis, School of Medicine

Ms. Ivanovich presented an overview of the Washington University (WU) School of Medicine Young Women's Breast Cancer Program (YWBCP). WU is building the YWBCP based on 3 principles in the "golden circle." The "why" principle is designed to achieve positive change for young adults with cancer by challenging the status quo. The "how" principle is designed to achieve positive change by persistently pursuing research, targeted education, support and advocacy and engaging YBCS as the most essential partners.

The "what" principle is designed to build diverse approaches to reach young adults and lead clinical research that is focused on aggressive disease. Overall, the 3 principles in the "golden circle" are targeted to deliver education, research, advocacy and support to BCYW.

WU initiated support and education for the YWBCP in 2001; implemented the research program in 2005; and successfully competed for CDC funding, support and educational programming in 2011 to complete the needs assessment. The YWBCP is a regional program with national outreach that reaches ~1,400 survivors in the St. Louis region and ~2,700 survivors throughout the United States.

The key findings of WU's local needs assessment are summarized as follows. The majority of women who currently are participating in the YWBCP completed their primary cancer treatment, but minority YBCS in racial/ethnic groups and women with limited financial resources are not

adequately represented. Young women who are engaged in the YWBCP expressed a strong interest in connecting with other YBCS for peer support and information and receiving targeted and easy-to-manage information on the following topics: fertility, sexual dysfunction, coping skills, body image and specific types of cancer.

YBCS reported difficulties in locating targeted programs. Most notably, targeted support programming does not exist in the St. Louis region at this time for women with metastatic breast cancer. Moreover, support and educational programming for young adults with cancer in the St. Louis region is lacking.

Prior to its DP11-1111 award from CDC, WU's support programs included a monthly BCYW network support group and a peer network to train YBCS in serving as peer-mentors to young women in treatment. WU will utilize its DP11-1111 award to expand its existing YWBCP programming. A new "Coach Program" will be implemented for a licensed clinical social worker to meet with young women soon after their breast cancer diagnoses to appropriately manage the healthcare system throughout the entire treatment process.

A new "Psychosocial Support Program" will be implemented to provide resources to women with metastatic disease. Modules for caregivers and a general psychosocial program will be available as well. Overall, the DP11-1111 award will allow WU to broaden support programs throughout the entire continuum of cancer care.

Prior to its DP11-1111 award from CDC, WU's educational activities included dissemination of a guidance journal that was written by and targeted to YBCS as well as young women who were newly diagnosed with breast cancer. WU also has published and presented 5 editions of the *Together Magazine* at its educational symposium. WU will utilize its DP11-1111 award to continue to publish the magazine and host the educational symposium. WU's upcoming symposium on May 5, 2012 will focus on survivorship.

WU will implement and target a new survivorship program to women who have completed breast cancer treatment. The new program will provide education on long-term effects from breast cancer treatment, skills to live as a YBCS, physical activities for YBCS in partnership with the local YMCA, cooking classes, and guidance on other unique issues faced by YBCS. WU will develop a genetics navigation tool to provide accurate and evidence-based information to the cancer community.

The tool will include a workbook for young women to document their family histories, better understand family-based risk, and engage in well-informed discussions with their providers to facilitate more appropriate medical screening. WU will pilot the workbook with YWBCP participants in St. Louis and YBCS across the country. After refinements are made, WU will develop the workbook as an online module.

WU recently applied for funding outside of CDC to support a new 1-year "Young Survivor Art Program," particularly to reach minority breast cancer patients and survivors. If WU successfully competes for funding, the new program will be housed in the Center of Creative Arts in St. Louis to reach a large African American (AA) population.

WU currently is using non-CDC funds to conduct a YWBCP study to answer 3 key research questions. <u>One</u>, what are the unidentified genetic factors that contribute to the risk for breast cancer, particularly breast cancer at a young age? This research will focus on laboratory/ molecular genetic studies.

Two, how common is familial breast cancer in early onset disease and among women with a positive family history? How many of these women have a BRCA1 or BRCA2 gene mutation? This research will focus on family studies. Three, what is the best approach to communicate clinical whole-genome sequencing results to individuals and families? This research will focus on communication studies.

Enrollment criteria for the YWBCP study include any woman in the United States who was diagnosed with invasive breast cancer at ≤40 years of age. The study participants must sign a consent form, provide blood specimens, and allow WU to collect their medical records and family cancer histories. Parents and sisters of patients are invited to participate in the study as well. Of 2,701 YBCS who have asked to participate in the study, WU has enrolled 1,792 to date (or 66%) with an average age of 37 years at diagnosis. The study population also includes 1,607 parents and sisters of YBCS at this time.

Of the current study population of YBCS, 91% are white, 3.5% are AA, 2.4% are Hispanic, 2.1% are "other," and 1% is Asian. WU is extremely interested in obtaining guidance from ACBCYW on increasing the proportion of minority participants in the study. WU has estimated that ~13% of the cohort is at least 10 years from the time of diagnosis and ~8% of the cohort had a second primary cancer by the time of consent.

The YWBCP research includes molecular studies to discover genes that are associated with BRCA1 approaches and examine copy number variants. The relationship between copy number variants and neuropsychiatric disorders has been well described in the literature, but this association has been poorly documented in cancer populations. As a result, WU will examine a subpopulation of the YWBCP cohort with no family history of breast cancer, but whose parents are enrolled in the study.

In addition to the copy number variant approach, the molecular studies also will include an exome sequencing approach. Studies of YBCS with strong family histories that test negative for the BRCA1, BRCA2 or TP53 gene will be examined to identify genes that are significant for this population. The overarching goal of the molecular studies will be to identify *de novo* events for BCYW. WU will test the results of the molecular studies in the broader YWBCP cohort.

The YWBCP research also includes studies that will be used to document findings on ~1,400 family histories of YBCS to determine differences among families with and without a mutation. The family history studies will allow WU to increase its knowledge of the role of family history on gene variance and gene mutation.

WU was awarded R01 funding from NIH to begin communicating sequencing results in June 2012. To bridge the gap between technology and information access, the components of this study will include provider and public genetics education, communication and outcome research, behavioral education research, clinical validation studies, and cross-discipline training.

Overview of the Living Beyond Breast Cancer Program

Arin Ahlum Hanson, M.P.H., C.H.E.S.
Manager, Young Women's Initiative
Living Beyond Breast Cancer

Ms. Hanson presented an overview of the Living Beyond Breast Cancer (LBBC) Young Women's Initiative (YWI). LBBC was founded in 1991 in suburban Philadelphia as a national nonprofit organization (NPO) with a mission to empower all women affected by breast cancer to live as long as possible with the best quality of life. LBBC is one of the first national NPOs that was established to fulfill the need for breast cancer-related information, connection and support after treatment.

LBBC has >15 years of experience in providing tailored programs for BCYW and extensively collaborating with partners to identify and fill gaps in information and support for all women affected by breast cancer. As the need for specialized services increased over time, LBBC expanded its focus to assist women at all stages of diagnosis, treatment and survivorship. LBBC's major activities, programs, products and services now include:

- national conferences that are held 3 times per year with a broad range of topics (e.g., BCYW, women living with metastatic breast cancer, and women of all ages who have been diagnosed with breast cancer at any stage);
- monthly teleconferences with broad participation by breast cancer patients and providers across the country;
- the *Insight Educational Newsletter* with medical updates and information on quality of life issues;
- >15 publications that have covered diverse breast cancer topics (e.g., women living with metastatic breast cancer, early-stage breast cancer, and unique issue issues faced by AA and Latina breast cancer patients);
- community meetings and outreach programs in the Philadelphia area;
- the Survivors' Helpline with peer-to-peer telephone support;
- training and resources for healthcare providers; and
- an interactive website at www.lbbc.org.

LBBC's Annual Conference for Young Women Affected by Breast Cancer (C4YW) is the only international event that is specifically dedicated to BCYW issues. LBBC and the Young Survival Coalition co-host this annual 3-day conference with attendance by ~800 individuals from the United States and international countries. The "13th Annual C4YW Conference" will be held on February 22-24, 2013 in Bellevue, Washington with 3 plenary sessions and 26 workshops.

LBBC will use its DP11-1111 award from CDC to develop and implement YWI by building on its 15 years of experience in offering tailored programs to young women. LBBC will design YWI to identify the unique needs of BCYW, create new programs, and expand existing activities for this population. In year 1, LBBC will establish an Advisory and Outreach Network with >40 members; expand online breast cancer content for young women; engage key stakeholders and community organizations that serve underserved groups identified in the needs assessment and program planning processes; and utilize the findings of the needs assessment to guide program planning efforts.

Preliminary findings of LBBC's multi-component needs assessment for YWI are summarized as follows. Component 1 is key informant interviews with diverse stakeholders. LBBC completed 12 interviews with 2 medical oncologists, a prominent cancer advocate, an oncology social worker, a leader in psycho-oncology, a reproductive endocrinologist, a breast surgeon, a breast cancer coordinator, and cancer advocates who closely collaborate with young Latina, AA and Asian women affected by breast cancer.

The interviewees were asked to identify the 3 most pressing needs of young women; resources and programs used when working with young women; and the types of programs that should be developed for this population. The primary needs the interviewees identified included the lack of social support, strain on personal relationships, tools to raise young children, financial concerns and body image. LBBC integrated the preliminary findings of the interviews into a quantitative survey tool that will be launched later in April 2012. LBBC will complete a full analysis of the interview notes and audio recordings by June 2012.

Component 2 is focus groups with young women to obtain input. To date, LBBC has completed 3 90-minute focus groups with young women who were diagnosed with early stage breast cancer <1 year ago, 2-5 years ago, and >5 years ago. LBBC will hold the fourth focus group on April 27, 2012 with 12 young women who are living with metastatic breast cancer.

During the C4YW Conference, LBBC recruited 20 women to participate in the 3 early stage breast cancer focus groups. The average age of the participants was 40 years with a range of 30-64 years. Of these participants, 85% were married or living as married, 60% had a college or graduate degree, 56% were white, 26% were AA, and 11% were Latina. The participants represented all 4 regions of the United States.

Women with early stage breast cancer who participated in the C4YW focus groups expressed concerns about the impact of their breast cancer experience on partners and children; discussed challenges in communicating with their friends and families; and noted the difficulty in locating quality survivorship programming for YBCS. The newly-diagnosed and mid-term survivor groups discussed their use of social media (e.g., Facebook and Twitter) to access health information, connect with other YBCS, and update friends and families on their treatment and overall health.

Several women in the newly-diagnosed group emphasized the need for breast cancer information to be tailored to their life stage. The lack of support and information at the end of treatment as well as the need for more information on long-term effects and other survivorship concerns were consistent themes in the mid-term and long-term survivor groups. LBBC will fully analyze the outcomes of the focus groups and compare these data with other components of the needs assessment.

Component 3 is an environmental scan and gap analysis to identify existing resources for BCYW, areas lacking in coverage and potential partner organizations. LBBC examined 29 national organizations that provide educational and support resources that are relevant to BCYW. In terms of program areas, gaps were identified in the management of short-/long-term side effects of treatment (e.g., fatigue management, premature menopause and cognitive changes) and aftercare compliance.

In terms of content delivery, gaps were identified in the provision of live conferences, online message board communities, and thematic workshops and teleconferences. In terms of tailored programming, gaps were identified in the provision of programs targeted to young women of color and young lesbian, bisexual or transgender women affected by breast cancer. LBBC will use these findings to partner with national organizations to strategically fill existing gaps.

Component 4 will be a national survey of young women to identify the unique needs of this population, the type of breast cancer information young women most desire, and the best

methods to deliver information to young women. LBBC will launch the survey by the end of April 2012 in both print and electronic formats.

The domains of the survey will cover demographic factors, breast cancer treatment, social support, ethnic identity, common side effects, use of and interest in breast cancer education programs, fertility preservation, breast reconstruction, and genetic testing decision-making. LBBC will distribute the survey via multiple venues, including an outreach network of >30 organizations, social media, Facebook advertisements, and a link to the survey for women in LBBC's database.

LBBC's next steps to achieve the goals of the DP11-1111 cooperative agreement will be to complete the needs assessment and analyze the results; develop a white paper to summarize the overall needs assessment process; collaborate with partners to convene 2-3 strategy building focus groups with underserved women; and complete program planning efforts.

In year 2, LBBC will disseminate the findings of the needs assessment; continue to expand online content for young women; enhance the capacity of the Survivors' Helpline by training 10 additional young volunteers; increase the geographic diversity and participation rates of low-income women at the C4YW Conference; and develop a new pilot program for underserved young women.

ACBCYW members made two suggestions for LBBC to consider in refining its DP11-1111 activities in year 1. First, in its activities focused on young women with early stage breast cancer, LBBC should make a clear distinction in obtaining input from women with *in situ* cancer versus those with early stage invasive cancer. The needs of women in these two subgroups are likely to differ.

Second, of participants in the C4YW focus groups, 85% were married or living as married and 60% had a college or graduate degree. These demographics do not adequately represent the needs of women who are single or those with a lower educational status. LBBC should broaden the focus groups to obtain more diverse input from young women affected by breast cancer who have a lower socioeconomic status (SES).

Overview of the Sharsheret Program

Jennifer Thompson, M.S.W.
Survivorship Program Supervisor
Sharsheret, Inc.

Ms. Thompson presented an overview of Sharsheret's DP11-1111 program, *Thriving Again: Life After Breast Cancer for Young Jewish Women*. Sharsheret's overarching objective is to develop a program that will provide culturally-relevant clinical support and educational resources for young Jewish breast cancer survivors (YJBCS) and their families. After receiving its year 1 funding of $305,049 from CDC in September 2011, Sharsheret hired a Program Supervisor and a Program Coordinator to develop and implement the program.

Sharsheret created a 5-step process to develop and implement the program: (1) identify the needs of YJBCS; (2) develop a program model that will enhance Sharsheret's current programs and include new materials to address the needs identified in step 1, identify gaps and determine

opportunities for growth; (3) solicit feedback from YJBCS on the materials developed in step 2; (4) revise the materials; and (5) launch the program in October 2012.

To better understand survivorship, Sharsheret conducted a literature review of 120 articles, studies and books with broad and diverse definitions of "survivorship" among the medical community, NPOs and breast cancer survivors. The literature review identified various needs (e.g., fertility, depression, healthy lifestyle choices and weight management), but research that was specific to Jewish women and women in other cultural groups was limited. Sharsheret designed the literature review as a living document that will change and expand over time as its program grows and as research continues to evolve.

Sharsheret conducted key informant interviews with 14 leaders from across the country that represented breast cancer NPO professionals, breast surgeons, cancer researchers, oncologists, oncology nurses, oncology social workers, and breast cancer survivors. The key informants helped Sharsheret to identify emerging trends in the field, the needs of patients and survivors, and potential advisory board members.

Sharsheret established a 12-member National Survivorship Advisory Board (NSAB) with representation by medical oncologists, breast surgeons, nurse practitioners, social workers, NPO leaders, genetic counselors, researchers and breast cancer survivors. The members will serve 3-year terms and will convene quarterly teleconference meetings. NSAB is charged with providing guidance to Sharsheret on developing the National Survivorship Survey (NSS), offering feedback on material development, assisting in launching the program, reviewing the program evaluation, and providing input and advice on the growth and expansion of the program.

To identify the needs of YJBCS, Sharsheret conducted 6 in-person and online focus groups with 45 participants who represented Jewish women across the spectrum of cultural and religious observance. Of the focus groups participants, 22% were from Los Angeles, 11% were from Atlanta, 11% were from New Jersey, and 9% were from Chicago. The remaining 47% of women participated in the online focus groups.

The participants provided feedback on existing survivorship programs and identified >100 needs of YJBCS in 8 broad categories: finances, work/employment, parenting/children, insurance, fertility/family planning, management of healthcare decisions, health/fitness, and relationships/ dating.

To prioritize the concerns of YBCS, Sharsheret and NSAB developed the NSS as a universal tool. Although the NSS is open to all YBCS, culturally-specific questions for YJBCS also are included for comparative purposes. The NSS asked YBCS to prioritize survivorship issues that were identified through the literature review, key informant interviews and focus groups.

Sharsheret administered the NSS in March 2012 in collaboration with >40 partners (e.g., NPOs, hospitals, women's groups and national Jewish organizations). The NSS was offered in written, online and telephone formats, via Facebook and QR code. Sharsheret launched a promotional advertisement campaign on Facebook as well.

Sharsheret received >1,450 responses from women representing all 50 states. Of the participants, 36% identified as Jewish and >50% were not currently in treatment. Sharsheret's next steps in the NSS will be to rigorously analyze the data in April 2012, identify nuanced survivorship needs, and complete and disseminate the formal report in June 2012.

Sharsheret has learned a number of lessons since initiating the program development and implementation process in September 2011. The amount of culturally-relevant information and research is extremely limited. Most notably, only 3 of >120 articles in the literature review addressed cultural issues. The number of programs and research on the unique survivorship needs of Jewish women and women from other cultural groups are limited. Sharsheret expects that its program will contribute to filling gaps in culturally-relevant research and program evaluation.

Sharsheret learned that women individualize and self-define "survivorship" based on their diverse responses to the following question: "When do you consider yourself a survivor?" The responses included: "at completion of treatment" (31%); "on the first anniversary with no recurrence" (22%); "at the time of diagnosis" (20%); "I do not consider myself a survivor" (18%); and "during treatment" (10%). Because women identify as survivors at various stages in their breast cancer journey, survivorship programs should be sensitive and inclusive of women at all stages of disease.

Sharsheret further learned that YBCS are in a broad range of locations, including small rural areas and large metropolitan cities. As a result, organizations should offer programs that are accessible from any location in the United States and also should create and maintain strategic outreach plans to reach YBCS through multiple channels and modalities. For example, the Facebook promotion, e-mail surveys and conferences accounted for the top 3 methods that women used to respond to the NSS.

Sharsheret's next steps in the robust analysis of NSS will be to utilize the Statistical Package for Social Sciences to help identify trends, correlations and nuances that are specific to YJBCS. The research expertise of NSAB members will be leveraged to assist in the data analysis process. The preliminary findings of the NSS will be completed in May 2012 and the formal report will be shared with partners and the broader breast cancer community in June 2012.

Sharsheret's next steps in program development will be to conduct an internal review of needs identified in the NSS and compare these findings with its current programs to identify existing gaps and new opportunities for growth. Sharsheret will identify 5-10 priority needs that are not currently addressed and develop strategies and programs for these needs. National focus groups will be convened with YBCS for Sharsheret to obtain input on its preliminary strategies and programs to guide the final development of the program before the rollout in October 2012.

Sharsheret's next steps in program evaluation will be to convene focus groups in January-April 2013 to obtain initial feedback on the platform, program materials, and ability to easily access services. Revisions to the program will be made in May-June 2013 if needed. Additional focus groups will be convened in July-September 2013 to obtain further input on the survey tool.

CDC was commended for providing outstanding technical assistance document which was helpful for the DP11-1111 grantees to begin program development in year 1 and advance to more complex activities in years 2 and 3 (e.g., program evaluation and a sustainability plan for communities).
ACBYW was impressed by the exciting YBCS programs the grantees will conduct over the 3-year project period of the DP11-1111 cooperative agreement. The members made several suggestions and comments for CDC and the grantees to consider in refining these programs.

- Specific program components, particularly the needs assessments and focus groups, have tremendous overlap across the grantees. CDC should streamline the DP11-1111 efforts by compiling the needs assessment results and focus group findings from all of the grantees. For example, CDC should create a "shared" website that would house all of the grantees' background data, research and other key outcomes. The website also should serve as a repository for all of the existing resources that are available to YBCS. Ideally, breast cancer scientists, researchers and advocates would have access to the shared website. A compilation of the DP11-1111 data across all of the grantees would be extremely useful to the general public as well.
- In further developing their DP11-1111 programs, the grantees should always be aware that the requirements of the cooperative agreement present a dilemma. On the one hand, the mandate to include women up to 45 years of age is a positive approach that will allow the grantees to reach more young women with breast cancer. On the other hand, the mandate will dilute the ability of the grantees to specifically focus on issues that are unique to or accentuated by younger women. For example, the inclusion of women up to 40 years of age would result in an average age of 37 or 38 years. Fertility and genetics are much less likely to be major concerns for this older age group compared to younger women 30 years of age.
- Several grantees noted that their needs assessments found minimal representation by minority YBCS in racial/ethnic groups and young women with limited financial resources. The grantees should revise their programs at this time to expand participation by and outreach to young AA, Latina and Asian women with breast cancer and survivors.

In response to ACBCYW's suggestion to harmonize the DP11-1111 data, Dr. Fairley noted that both CDC and the grantees have discussed this issue. CDC has discussed the possibility of developing and disseminating DP11-1111 products, such as white papers, monographs or formal reports. However, CDC is aware of the challenges in this effort due to different strategies used by each grantee to address components of the grant award.

Dr. Fairley confirmed that the DCPC would have more in-depth discussions with the grantees on potential strategies to synthesize the DP11-1111 findings of the initial needs assessment to generate a more community-oriented initiative for BCYW/YBCS.

Overview of the CDC DP11-1114 Cooperative Agreement

Katrina Trivers, Ph.D., M.S.P.H.
Epidemiologist, Epidemiology and Applied Research Branch/DCPC
Centers for Disease Control and Prevention

Dr. Trivers presented an overview of CDC's programmatic activities and research in breast cancer genomics. CDC's programmatic activities are designed to enhance breast cancer genomic practices through education, surveillance and policy. The CDC Office of Public Health Genomics (OPHG) has collaborated with state health departments since 2003 to integrate genomics knowledge and tools into state chronic disease prevention programs and core public health functions. DCPC awarded supplemental funds to 2 states in 2010 to expand their activities in breast cancer genomics. Funded efforts included: enhancing surveillance of genetic counseling and BRCA1/BRCA2 genetic testing; expanding review of state health insurance plan's policies and procedures related to genetic counseling and testing as well as preventive

services. Dr. Trivers provided the ACBCYW with a brief overview of the outcomes the funded efforts in Michigan and Oregon.

In June 2011, CDC released a new FOA, *Enhancing Breast Cancer Genomic Practices Through Education, Surveillance and Policy*, to continue and expand activities that were initiated under the OPHG cooperative agreements.

State/local governments and tribal organizations were eligible to apply for funding. The FOA criteria included: (1) necessary expertise in surveillance, policy and education; (2) capacity to develop and expand ongoing activities at the state level; (3) ability to collaborate with state partners and influence state policies through linkages with Comprehensive Cancer Control (CCC) Programs, cancer registries and health insurance providers; and (4) ability to potentially expand state models to national approaches. Applications were objectively reviewed by CDC. Georgia, Michigan and Oregon received DP11-1114 funds of ~$300,000 per year for 3 years.

The applicants were required to propose activities in 2 of 3 program components: policy interventions, education, and/or surveillance.

- Policy - utilize policy interventions to promote the increased use of clinical best practices for genetic counseling, BRCA1/BRCA2 testing, and preventive services for women identified as high risk.

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

- Surveillance - track the use of genetic counseling and BRCA1/BRCA2 testing, follow-up procedures for women identified as high risk, and family medical history tools or family medical history-based risk assessment tools for breast and ovarian cancer.

Dr. Trivers provided brief program summaries of the 3 grantees:

- Georgia will increase knowledge and awareness of the methods and benefits of identifying women at risk for hereditary breast and ovarian cancer among clinicians, public health practitioners and young women. They will assess the utilization of and barriers to cancer genetic services. Georgia will also expand coverage for genetic services for high risk women.

- Michigan will expand surveillance of genetic counseling and BRCA1/BRCA2 genetic testing. They will expand activities to identify state health insurance plans and evaluate medical policies for coverage of genetic counseling and testing as well as preventive services based on USPSTF recommendations and NCCN guidelines. Michigan will also make presentations and publish data on its accomplishments in cancer genetic counseling and testing.

- Oregon will implement a BRCA surveillance system with participation by all 5 genetics clinics in the state and 1 oncology clinic. Insurance coverage for genetic counseling and testing will be promoted for women at increased risk. Partnerships will be built and education will be provided to health professionals and the public on the appropriate use of genetic services.

DCPC is conducting a national research project to determine health insurance coverage of genetic and prevention services in populations at increased risk for breast and ovarian cancer. DCPC designed the project to answer 4 key research questions: (1) What are the conditions for stipulations for coverage of genetic counseling and testing for hereditary breast and ovarian cancer? (2) What are the conditions for coverage of clinical preventive services for women identified as higher risk? (3) What evidence is being used to justify medical policy? (4) Do medical policies and coverage vary by geographical area?

DCPC is conducting the review at the state level by compiling a list of health insurance companies in each state that offer health insurance coverage. To be included in the review, each company must offer comprehensive group, family or individual health insurance coverage. The number of covered lives within each company must be $\geq$1% of the market share. DCPC automatically included Medicare and Medicaid health plans in the review.

For the health plans that met the inclusion criteria, DCPC searched their websites to identify relevant medical policies and used search engines to retrieve additional data. Medical policies of the health plans were reviewed and abstracted into the study database. In the original study design, DCPC planned to contact health insurance companies directly if data were incomplete, but this time-consuming approach was suspended early in the study.

DCPC reviewed the medical policies of the health plans to identify the following clinical services: genetic counseling for breast and ovarian cancer susceptibility; genetic testing for BRCA1/ BRCA2 and use of the BRACAnalysis® Rearrangement Test; prophylactic mastectomy and breast reconstruction; prophylactic oophorectomy; cancer screening with mammography, breast magnetic resonance imaging (MRI), breast ultrasound, cancer antigen-125 screening test, or transvaginal ultrasound; and chemopreventive drugs.

DCPC reviewed medical policies for >200 health insurance companies in 38 states in the September 2010-February 2012 time period. The preliminary review found significant variability in requirements for conditions for coverage. Although several health insurance companies are using USPSTF recommendations as the basis for their medical policies, some health plans are making efforts beyond these guidelines. Overall, many health insurance companies lacked detailed and comprehensive medical policies for these services.

DCPC's next steps in the research project are to complete the data analysis and present the results at the CDC National Cancer Conference in August 2012. Collaborations will be formed with state health departments and CCC Programs to improve the medical policies of health insurance carriers in their respective states. DCPC is aware that significant efforts will be required at the national level to address medical policies and insurance coverage, medical billing, lack of capacity, issues related to access, and the limited number of certified genetic counselors in the country to meet the possible increased demand for services.

Dr. Trivers provided additional details on CDC's programmatic activities and research in breast cancer genomics in response to ACBCYW's questions. The discussion topics included:

- the need for all 3 DP11-1114 grantees to reach consensus on and utilize the same definition of "high-risk" before the national rollout of these programmatic activities;
- the serious problem of <30% of PCPs who use family history information to determine if a patient needs a referral to genetic services;
- the critical need to educate providers and women on Affordable Care Act coverage of genetic counseling and testing with no cost-sharing for women;

- the need for states to identify, track and monitor health insurance companies that are not complying with the Affordable Care Act legislation for coverage of genetic counseling and testing; and
- similarities and differences between Georgia's Breast and Ovarian Cancer Genetics Referral Screening Tool for PCPs and CDC's BodyTalk Decision Support Tool for providers and the public.

Update on CDC's BCYW Research, Program and Communication Activities

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 presented an update on CDC's BCYW research, program and communication activities.

CDC has launched a number of projects in accordance with the EARLY Act mandate. The goal of the "Social Media Usage for Breast Cancer Awareness and Survivors" Project was to provide a research background, strategy and recommendations for social media educational materials and interventions for young women 15-44 years of age who are at risk for breast cancer and survivors.

CDC conducted several activities to achieve the project goal. A literature review and environmental scan were conducted from November 2011 to January 2012 to identify evidence-based and peer-reviewed publications. CDC found no studies that evaluated the use of social media to disseminate health information to young women at high risk for breast cancer. CDC found only 1 peer-reviewed study that evaluated the use of social media to support young women with breast cancer.

The literature focused on social media habits of older women with breast cancer and underrepresented minority populations. CDC's broader literature scan found several campaigns that targeted young adults for public health purposes, but these studies could not be generalized. Based on the results of the literature scan, CDC acknowledged the need for more formative research in this area.

CDC contracted an organization with extensive expertise in engaging the target population through social media. This research was conducted in February-March 2012 with the "social listening" technique. With this strategy, computer software was programmed with specific parameters to listen for certain topics and conversations across multiple platforms that occurred in the social media community from February 2011 to February 2012.

Clearly defined search terms (e.g., "BCYW" and "hormone therapy") were used to collect data and metrics from conversations on the use of social media by 8 organizations and their members. Researchers quantitatively and qualitatively analyzed the conversations and social media strategies used by cancer organizations to identify "successful" campaigns with broad reach, determine the best venues, evaluate effective messaging of popular topics, and identify and verify new and existing trends and patterns.

A broad range of social media platforms were analyzed for the project, including Facebook, Twitter, blogs and micro blogs, forums, message boards, Usenet newsgroups, social networking sites, consumer review and shopping sites, news and traditional media sites, and video and photo sharing sites.

CDC convened an expert panel to discuss social media as a tool for disseminating health information and psychosocial interventions and make recommendations on sharing the study results with various programs and stakeholders. The expert panel advised CDC to conduct 3 specific activities in developing its social media strategy: (1) increase awareness among young women at high risk for breast cancer; (2) provide support to YBCS early in their diagnosis, during treatment and post-treatment; and (3) address prevention and treatment myths with scientific evidence.

Based on guidance from the expert panel, CDC revised the tasks of the project to conduct additional social media monitoring research, develop social media campaign strategies, test these approaches with the target audience, and engage partner organizations and experts in reviewing and revising the campaign strategies.

CDC launched the "Developing Psychosocial and Reproductive Health Support for YBCS in the United States" Project in September 2010 to identify, strengthen and promote real-world and evidence-based interventions that provide psychosocial and reproductive health support to YBCS. CDC awarded funds to 2 national organizations to address the needs of and provide psychosocial and reproductive health-related intervention programs for YBCS. Sisters Network, Inc.® (SNI) and Sharsheret were funded to target program activities to AA women and women of Ashkenazi Jewish descent, respectively.

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

SNI and Sharsheret completed a number of tasks to fulfill the project goals. The capacity of selected organizations to effectively develop, implement and disseminate interventions that provide psychosocial and reproductive health support for YBCS was assessed. The utility of existing programs that support YBCS was identified, evaluated, modified and implemented as needed.

A plan was prepared to conduct a process and/or outcome evaluation for the programs that SNI and Sharsheret modified and implemented. Evaluations were conducted to determine if the modified YBCS programs yielded the intended outcomes, were effective, and had the capacity to be amplified and applied to YBCS in other groups.

Dr. Fairley provided an update on Sharsheret's program activities since the previous ACBCYW meeting. Sharsheret received Institutional Review Board (IRB) approval to conduct focus groups with YJBCS to test its Peer Support Network (PSN) and Genetics for Life (GFL) Programs. Based on input provided by the focus group participants, Sharsheret currently is making program modifications to improve the provision of psychosocial and reproductive health support to YJBCS. After receiving an Office of Management and Budget (OMB) exemption, Sharsheret created PSN and GFL logic models that will serve as the foundation of outcome evaluations for these programs.

In November 2011, Sharsheret conducted 4 focus groups with YJBCS to gain a deeper understanding of the health information needs and concerns of this population and gather feedback on the PSN and GFL Programs. Sharsheret's analysis of the qualitative focus group data included thematic notes and Excel spreadsheets to examine demographics and other pre-discussion information.

The key focus group findings are highlighted as follows. YJBCS are interested in connecting with a peer supporter immediately after diagnosis for guidance, validation, comfort and hope. Information that is provided on the physical and emotional expectations following diagnosis should be tailored to YBCS to avoid an overload of information. YJBCS need information about the hereditary risk of breast cancer and related cancers, timely information about the impact of treatment on fertility, fertility preservation options, and the cost of these services prior to treatment.

YJBCS need information regarding the impact of treatment on and skills to cope with early menopause, body image, and issues related to sexuality and intimacy. YJBCS are interested in psychosocial and reproductive health information in multiple formats (e.g., print, online and in person) and organizations that are culturally relevant to Jewish women.

Sharsheret applied the findings from the focus groups to modify the PSN and GFL Programs in several areas. Organizational materials will be placed in locations that attract younger women to expand outreach efforts. The PSN and GFL Programs and resources will be delivered through multiple channels, including telephone and online formats, live chats, and online intake forms through the Sharsheret website.

Teleconferences will be offered to PSN and GFL participants to discuss financial and insurance concerns of YJBCS and management of symptoms related to early onset menopause. The GFL Program will offer family conference calls to provide reproductive health support to women. During the first contact with single women, Sharsheret will direct this population to its online transcript of the "Dating and Disclosure" teleconference.

Dr. Fairley provided an update on SNI's program activities since the previous ACBCYW meeting. SNI held focus groups to obtain input on information AA women are interested in receiving regarding their breast cancer diagnoses. The focus group participants reported that limited information is available on breast cancer treatment specifically tailored to young AA women.

In response to this feedback, SNI completely revamped its existing "Sisters Peer Counseling in Reproductive Issues after Treatment" (SPIRIT) Program that is targeted to older breast cancer survivors. SNI's modified program is the Young Sisters Initiative (YSI) that is specifically for young African American breast cancer survivors (YAABCS).

The key feature of YSI is *A Guide To A Better You!* This resource is based on the principles of unity, strength, power and change and provides YAABCS with comprehensive information on genetic testing for breast cancer, the types of and treatment for breast cancer, skills to cope with emotional issues related to cancer diagnosis and treatment, sexual health and fertility, and guidance on communicating with healthcare providers on these issues.

SNI created a mock-up of the new YSI website that will contain background information on the program; a 5-minute demographic screening tool for YAABCS to access the website and for SNI

to track users and evaluate the tool; video testimonials from YAABCS; a program workbook with 8 chapters; helpful websites and other resources; and frequently asked questions.

SNI's next steps in the rollout of YSI will be to obtain OMB approval, disseminate resources to the target audience of YAABCS, initiate the evaluation component by analyzing data and reviewing findings, and sharing the findings of the study in appropriate venues. SNI expects to complete the study in the 2013-2014 time frame.

CDC awarded a contract to Oak Ridge Institute for Science and Education to design the "BodyTalk Decision Support Tool" to help facilitate communication and interaction between providers and patients regarding BRCA1/BRCA2-related risk. From December 2010 to September 2011, the beta version of the website was released internally to CDC subject-matter experts for review and comment; the BodyTalk website and concept were presented to the ACBCYW members; the user experience and concept testing of web pages as well as supporting documents were completed; and a prototype of the website was completed.

At this time, the ACBCYW members are reviewing and testing an updated beta version of the BodyTalk website and will submit comments to CDC by the April 24, 2012 deadline. The structural and functional components of both the iPhone and Android applications of BodyTalk are scheduled to be completed by the end of April 2012. In the near future, the BodyTalk website and smartphone applications will be re-branded with a new name, logo and color scheme. Dr. Fairley thanked the ACBCYW members for contributing a significant amount of time to review, test and provide comments to CDC on the BodyTalk tool.

ACBCYW commended CDC on the tremendous progress that has been made since the previous meeting on the BCYW research, program and communication activities. The members made several comments and suggestions for CDC to consider in their ongoing efforts to refine these projects.

- SNI should change the photographs of the YSI women before the mock-up of the website is approved by OMB, finalized and rolled out to the public. For example, the happy and smiling women have professional makeup and hairstyles and do not appear to be "true" breast cancer survivors. The photographs do not accurately represent contemplative women with a new breast cancer diagnosis or women in treatment who are depressed about their hair loss and other side effects. Moreover, all of the women are at the younger age of the spectrum and do not adequately represent the entire BCYW/YBCS population of women up to 45 years of age.
- SNI should truncate the extensive amount of information on each page of the YSI website to no more than 5 bullet points per page. Most notably, the genetics section is entirely too sophisticated for the general public.
- Efforts should be made to compile core information that is applicable to all young women with breast cancer and survivors, provide the resources in a centralized location, and update the materials over time. For example, "breast cancer 101" templates should be developed to address basic issues (e.g., breast cancer risk factors, diagnosis, treatment and after-care). The templates also should include culturally-specific data for certain groups. Overall, a compilation of Sharsheret's basic information for women of Ashkenazi Jewish descent and SNI's basic information for AA women would be extremely valuable, useful and helpful to the entire target population of BCYW/YBCS.
- Sharsheret and SNI should ensure that their programmatic activities are developed to be both linguistically appropriate and culturally appropriate. To address the reading level of

the entire target population of BCYW/YBCS, printed materials, websites and other resources should be designed with pictures/drawings, plain language with monosyllabic words and "white spaces."

Ms. Kelly Hodges is the SNI National Program Director and an ACBCYW liaison representative. She thanked the ACBCYW members for their feedback on YSI and made some clarifying remarks. The mock-up of the YSI website was for the sole purpose of presenting an update to ACBCYW. Before the YSI website is rolled out to the public, the "placeholder" photographs would be replaced with pictures of young AA women up to 45 years of age who are actual breast cancer patients and survivors.

In terms of truncating the YSI content, Ms. Hodges confirmed that each section of the website would have bulleted highlights for users to easily determine their interest in further reviewing the information.

Public Comment Session

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

With no further discussion or business brought before ACBCYW, Dr. Partridge recessed the meeting at 4:36 p.m. on April 18, 2012.

Opening Session: April 19, 2012

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 of the ACBCYW voting members, *ex-officio* members and liaison representatives. She verified that the voting members and *ex-officio* members in attendance constituted a quorum for ACBCYW to conduct its business on April 19, 2012. None of the voting members declared conflicts of interest for the record for any of the items on the published agenda for April 19, 2012. Dr. Fairley called the meeting to order at 9:09 a.m.

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

Dr. Partridge noted that based on the discussions on the previous day, the ACBCYW members were extremely impressed by the BCYW/YBCS programs, research and other activities of CDC and its grantees. She announced that day 2 of the meeting would be devoted to the ACBCYW workgroup reports and overviews of ongoing activities across the country to improve patient-provider communications. Dr. Partridge yielded the floor to the first presenter.

Update by the ACBCYW Ad Hoc High Risk Workgroup

Rochelle L. Shoretz, J.D.
Executive Director and Founder, Sharsheret, Inc.
ACBCYW Member & High Risk Workgroup Chair

Ms. Shoretz presented an update on activities by the Ad Hoc High Risk Workgroup. During the September 2011 meeting, ACBCYW established and formally charged the workgroup with gathering initial background information to provide advice on (1) developing an understanding of the meaning of "high risk" for BCYW and (2) identifying potential evidence-based messages to disseminate to this population. The workgroup members include ACBCYW members, liaison representatives and clinical advisors.

The workgroup conducted research in 2 phases to fulfill its charge. In phase 1, the workgroup defined "high risk" by examining data from cancer organizations and professional societies, research articles, scientific studies and major media publications. Preliminary findings of the workgroup's literature review showed that "high-risk populations" typically are defined as:

- young women who are known carriers of hereditary susceptibility mutations (e.g., BRCA1/BRCA2 gene mutations and TP53 or PTEN gene mutations that lead to Li-Fraumeni or Cowden syndrome);
- young women with a strong family history of breast or ovarian cancer;
- young women with a history of chest wall radiation; and
- young women with pathological indices of high risk (e.g., a personal history of breast cancer or atypical hyperplasia).

The workgroup's literature review further showed that high-risk populations also include young women who are referred for genetic counseling and testing, referred for more intensive breast or ovarian cancer screening, or are eligible for chemoprevention or chemoprevention clinical trials. Based on these data, the workgroup concluded that young women at "higher risk" of breast cancer than the general population include women of Ashkenazi Jewish descent and AA women. However, the workgroup noted that these subgroups of women do not necessarily fall into the "absolute high-risk" category.

The workgroup conducted extensive research and reviewed several resources to fulfill its charge of defining "average risk," "higher risk" and "high risk" for BCYW and presenting its findings to ACBCYW for review, comment and consensus:

- www.cdc.gov/genomics/resources/diseases/breast_ovarian (risk factors as defined by CDC);
- www.cancer.gov/bcrisktool/breast-cancer-risk.aspx (risk factors as defined by NCI);
- www.cancer.gov/bcrisktool (National Cancer Institute (NCI) Breast Cancer Risk Tool); and
- websites of professional associations.

The workgroup devoted a considerable amount of time in reviewing the NCI Breast Cancer Risk Tool. The tool calculates a woman's relative risk for breast cancer compared to the general population based on responses to the following questions:

- the woman's medical history of any breast cancer, ductal carcinoma *in situ* or lobular carcinoma *in situ*;
- the woman's age;
- the woman's age at the time of her first menstrual period;
- the woman's age at the time of her first live birth of a child;
- the number of the women's first-degree relatives (e.g., mother, sister or daughter) with a history of breast cancer;
- the woman's history of having a breast biopsy (e.g., the number of positive or negative biopsies and a history of at least 1 breast biopsy with atypical hyperplasia); and
- the woman's race/ethnicity and her sub-race/ethnicity. (The workgroup acknowledged that Ashkenazi Jewish women are not included in the pull-down menu of the NCI Risk Calculator.)

In phase 2, the workgroup identified effective messaging strategies for diverse populations based on content and delivery. The workgroup agreed that 3 guiding principles should be applied to deliver messages to all young women in the target population: (1) craft positive messages, (2) develop messages at appropriate reading levels, and (3) include images of individuals who resemble the target audience.

In addition to the general population, the workgroup also proposed strategies for effective messaging to specific subpopulations at high/higher risk of breast cancer. For young AA women, messaging should include celebrities, other influential persons and text messages. "Dry" and "data-heavy" messages with statistics should be avoided.

For young women with a family history of breast or ovarian cancer, messaging should include visual images to clearly articulate and define "high/higher risk," emphasize the need to understand their health history, and provide guidance on gathering and regularly updating their health history during holidays and other family celebrations. The workgroup noted that certain populations do not openly discuss cancer and may use other terms to refer to "breast cancer."

For young Jewish women, messaging should include core community, parenting and family values and address generational issues that may be inherent in the family history of disease. The workgroup extensively discussed using Sharsheret's successful "Have the Talk" Campaign as a model to effectively deliver high-risk breast cancer messages to young Jewish women and men.

Ms. Shoretz concluded her update by informing ACBCYW that the workgroup's next steps would be to continue to develop the risk communication campaign. To assist in this effort, she asked ACBCYW to provide input on 4 key questions.

1. What core information should be communicated to young women at high risk of breast cancer?
2. How should the content and delivery of messaging vary for women in different age groups (e.g., 15-20, 20-30 or 30-45 years)?
3. How should the content and delivery of messaging vary for women in different high-risk groups?
4. What are the best methods to utilize findings from CDC's "Social Media Usage for Breast Cancer Awareness and Survivors" Project?

Ms. Shoretz provided additional details on the activities of the Ad Hoc High Risk Workgroup in response to ACBCYW's questions. The discussion topics included:

- the rationale for excluding Ashkenazi Jewish women and other subpopulations from the NCI Risk Calculator;
- the need to distinguish between the level of risk of Jewish women developing hereditary breast cancer or carrying "high-risk" mutations;
- the need for messaging to inform women with a genetic history of breast cancer of the importance seeing a trained genetic counselor/professional; and
- the need to strike an appropriate balance in delivering "positive," "realistic" and "fearless" messages in order for the target population of BCYW to have meaningful conversations with their providers and make informed choices.

ACBCYW applauded the workgroup on developing a thoughtful, comprehensive and thorough approach to fulfill its charge. In response to Ms. Shoretz's request for feedback, ACBCYW proposed a number of suggestions to assist the workgroup in answering the 4 key questions.

- ***Question 1-Core Information:*** Messages to the target population should make a clear distinction among young women at "average," "higher" and "high" risk of breast cancer. Visual images should accompany these messages, particularly to reach young women at a lower educational status. For example, a "ladder" should be designed as one of the visual images in the risk communication campaign. Each rung of the ladder should describe concrete action steps for young women in all 3 risk categories and all 3 age groups to minimize fear, promote prevention, and eliminate the myth of breast cancer being equivalent to death.
- All messages to the target population should be both positive and realistic. Moreover, messages that include "risk reduction," "prevention," "risk perception" and similar terms should be carefully and thoughtfully crafted with sensitive language. The workgroup should engage outside experts to help identify appropriate messages for young women from both clinical and public health perspectives.
- Basic and simple messages should be targeted to all young women regardless of their age and level of risk: "Understand your risk." "Talk to your doctor about your family history and personal health history." "Know your options." "Get support."
- Focus groups should be convened with young women in various age, risk, racial/ethnic and SES groups to develop and pilot a mockup of the risk communication campaign in the field. The focus group questions should be designed to obtain input on the best core messages to deliver to the entire target population and the most effective messages to reach young women in specific age and risk groups.
- ***Question 2-Messaging by Age Group:*** Messages to young women in the 3 age groups should take into account a variety of demographics (e.g., married versus single or higher versus lower SES).
- Messages to young women in the age group of 15-20 years should be designed to provide education on healthy living and other lifestyle strategies that can have a positive impact on their lives. These women should be informed of the multiple benefits of a healthy lifestyle over the lifespan, such as reducing the risk of breast cancer, heart disease and bone loss. Moreover, studies have shown that even in women with a BRCA mutation, oral contraception can suppress the risk of breast and ovarian cancer. Because these women are too young for genetic counseling and testing, mammography or MRI to determine their level of risk of breast cancer, more thoughtful and careful attention will be needed to develop messages for this subgroup. However, the 2

overarching messages to this subgroup should be "knowledge is power" and "options are available."

- The workgroup should conduct research to determine the most effective formats and venues to reach, provide accurate information to, and communicate with young women in different age groups (e.g., Facebook for women 15-20 years of age, "risk level" quizzes in *Cosmopolitan* and other women's magazines for women 20-30 years of age, and informative materials in physicians' offices for women 30-45 years of age).
- Messages to young women in the age group of 15-20 years should be designed to encourage this subgroup to collect their family history while family members are still living. To assist young women in this effort, a parent/child communication tool should be developed and Sharsheret's "Have the Talk" Campaign should be tailored to the broader non-Jewish population. Moreover, schools should provide students with a brief family history questionnaire to be completed with their parents and/or other family members. Because school health classes begin to educate sixth-grade students on HIV, reproductive health and other health topics that are relevant to young persons, schools could play an important role in empowering young persons to initiate family history discussions with their family members.
- ***Question 3-Messaging by Risk Group:*** Short, simple and clear messages should be developed for and targeted to each high-risk subgroup (e.g., young AA women, young Jewish women, and young adults with a history of radiation treatment). The messages should include language and images that are culturally appropriate to the specific risk group.
- The race/ethnicity questions on the NCI Risk Calculator are based on federal OMB requirements and U.S. Census data and would be extremely difficult and time-consuming to modify. To overcome this barrier, the workgroup should explore the possibility of including additional questions (e.g., "Are you of Ashkenazi Jewish descent?").
- ***Question 4-Use of Social Media:*** The workgroup should utilize findings from CDC's "Social Media Usage for Breast Cancer Awareness and Survivors" Project as the basis for creating the risk communication campaign.

In response to ACBCYW's suggestion to convene several focus groups to obtain input on designing and piloting the risk communication campaign, Dr. Fairley provided the Committee with a brief overview of CDC's process for conducting research projects that involve direct contact with the public. Research involving human subjects must be done in a way to ensure the protection of human subjects, and validate the scientific merit of the proposed research (e.g., securing IRB and OMB approvals). Dr. Fairley encouraged the Committee to consider conducting an inventory of published research, activities, projects and campaigns that have successfully communicated with young women in the same age and risk groups.

Dr. Fairley also provided an example of efforts that are currently underway to address breast health in young women. Zero Breast Cancer is an NPO that is funded by the National Institute of Environmental Health Sciences to deliver breast cancer-related messages to adolescents and young persons in the field. Zero Breast Cancer has conducted extensive research and evaluation of existing tools and other resources to support this effort.

ACBCYW made several follow-up comments and suggestions based on Dr. Fairley's clarifying remarks:

- Before engaging in a lengthy formal research process, cervical cancer campaigns that are targeted to young women should be reviewed and tailored for BCYW.

- The ACBCYW workgroups develop an inventory of activities (national or federally supported) that have been successful in reaching the target population of BCYW.
- Findings from the ACBCYW workgroup should be used to identify messages and delivery mechanisms through social media or other venues.

Ms. Shoretz thanked ACBCYW for providing insightful and thoughtful comments to assist the "high risk" workgroup in answering the 4 key questions. During the Friday workgroup meeting, they would review ACBCYW's input and begin to compile a list of agencies and organizations with successful risk communication models to the target population of young women in the same age and risk groups. If time permitted, the workgroup also would use the workgroups session to propose strategies and explore funding mechanisms for the potential partners to add BCYW to their existing portfolios.

Overview of Health Communication and Provider Behavior Change

Jennifer Nichols, M.P.H.
Research Supervisor
Porter Novelli

Ms. Nichols presented an overview of health communication campaigns to change the behavior of healthcare professionals (HCPs). HCPs can play an important role in health communication, but an extensive amount of their time is devoted to issues outside of patient care (e.g., healthcare reform, billing and insurance). As a result, health communication and social marketing campaigns are extremely useful tools to reach and engage the target audience of HCPs.

Health communication campaigns have 6 major functions: (1) increase the target audience's knowledge and awareness of a health issue, problem or solution; (2) influence perceptions, beliefs and attitudes that may change norms; (3) prompt action; (4) reinforce knowledge, attitudes or behaviors; (5) show the benefits of behavior change; and (6) refute misconceptions and myths. However, a health communication campaign alone cannot achieve a full system or environmental change.

The 4 steps in the health communication program cycle include planning and developing a strategy; developing and pre-testing concepts, messages and materials; implementing the program; and assessing the effectiveness of the program and making refinements. Campaigns are planned in various phases with specific strategic communication approaches.

The "listening" phase involves identifying health issues and the general audience, performing an environmental scan, and conducting background and secondary research. The "planning" phase involves establishing goals and objectives, identifying behavior change theories, and segmenting the audience. The "structural" phase involves determining strategies and messaging.

The "pre-testing" phase involves conducting formative research with key audiences and restructuring the campaign as needed. The "implementation" phase involves devising tactics, developing a work plan and launching the campaign. The final "listening" and planning" phases involve redesigning the product and conducting an evaluation to determine the impact of the health communication campaign.

Developers of health communication campaigns should be able to quickly explain the purpose and intent of the campaign by briefly describing the target audience, intended behavior changes, goals, objectives and stakeholders. However, health communication and social marketing campaigns should include more tools and outreach approaches than brochures and public service announcements (e.g., curricula, strategic partnerships, public relations, media relations, education, advertising, digital tools and spokespersons).

Porter Novelli administers an annual quantitative survey to a broad range of ~2,000 HCPs, including PCPs, nurse practitioners, OB/GYNs, registered dieticians and pharmacists. The most recent survey showed that 83% of physicians were aware of health-related information offered by CDC, but only 23% of HCPs used CDC as a primary source of information for breaking news on health. Of these physicians, 93.2% were pediatricians and 81% were PCPs. HCPs reported that medical websites, medical journals and physicians were their top 3 sources to obtain patient health information.

HCPs ranked government health agencies as the second most trusted source for patient information, but their usage among HCPs was low. Medical journals, medical websites and physicians were the most trusted and frequently used sources among PCPs. The survey showed that 42% of HCPs, 37% of OB/GYNs, 36% of nurse practitioners and 24% of pediatricians reported at least 50% of their patients had difficulty understanding health information provided.

The survey further showed that 72% of OB/GYNs, 71% of nurse practitioners, 68% of PCPs and 62% of pediatricians reported at least 50% of their patients depended on HCPs to obtain all aspects of their personal health information. Of the PCPs, 84% expressed concern about the quality and accuracy of health information their patients obtain from the Internet. In terms of continuing medical education (CME), 64% of HCPs often or always use medical journals and 59% of HCPs often or always use the Internet.

CDC and the Health Resources and Service Administration (HRSA) awarded a contract to Porter Novelli to conduct the "Learn the Signs. Act Early." Autism Awareness Campaign that includes *Autism Case Training: A Developmental-Behavioral Pediatrics Curriculum*. The key target audiences of the campaign were parents of young children, HCPs and early childhood educators. The 7 case studies of the curriculum were written by 23 authors, reviewed by 17 expert developmental-behavioral pediatricians, and include 33 handouts and 27 videos.

The curriculum modules cover early identification and screening, diagnosis and the care of children with autism. The facilitator guide includes case narratives, handouts, PowerPoint presentations and videos and is designed for in-class, resident-driven learning. However, an online CME version of the curriculum has been developed for practicing physicians. The evaluation demonstrated the success of the campaign in changing the knowledge of medical residents.

CDC awarded a contract to Porter Novelli to conduct the "HIV Screening. Standard Care." Campaign. The basis of the outreach campaign was CDC's publication of its revised recommendations for HIV testing of adults, adolescents and pregnant women in healthcare settings. Data show that physicians play a critical role in HIV testing. Private physicians or health maintenance organizations perform ~53% of HIV tests in the United States. Of these tests, ~17% are positive. Of Americans who have never been tested for HIV, 27% reported that their physicians had never recommended testing.

The campaign was launched in June 2010 and was targeted to PCPs. The materials for patients and providers include an annotated guide to CDC's revised recommendations, a resource guide, a coding guide, guidance statements, and a flier from the National HIV/AIDS Clinicians' Consultation. The campaign was rolled out in close collaboration with several medical association stakeholder groups and a 12-member clinical workgroup to provide advice and guidance to other PCPs.

Overall, successful communications must be flexible, sustainable and "evaluation-friendly" with a primary focus on the target audience. Communications also must be informed by market research; driven by creative, distinct and realistic strategies and tactics; and include tailored messages that are fun, easy and popular.

Ms. Nichols provided additional information on health communication and social marketing campaigns for provider behavior change in response to ACBCYW's questions. The discussion topics included:

- barriers to a formal evaluation and effective metrics or indicators to assess the impact and reach of a health communication campaign;
- the need to develop better measures to determine provider behavior change;
- the impact of massive "calls to action" on provider behavior change; and
- the need to integrate health communication campaigns into practices with electronic medical records (EMRs).

ACBCYW made several comments and suggestions for CDC to consider in developing health communication campaigns to promote provider behavior change.

- *The Guide to Community Preventive Services* should be reviewed because it includes detailed, extensive and rigorous literature reviews on interventions that have changed the behavior of medical providers.
- CDC should collaborate with its federal partners, particularly HRSA and NIH, to leverage funds for health communication campaigns for provider behavior change. Moreover, the Agency for Healthcare Research and Quality has conducted numerous projects to educate providers on hepatitis C and other public health issues.
- CDC should partner with the Association of American Medical Colleges, schools of nursing, professional societies and bioethicists to include health communications in curricula for medical and nursing students, engage nurse practitioners in broadly disseminating health communication materials, and clearly articulate the ethical and legal aspects of provider behavior change.
- CDC should review and replicate existing medical malpractice models that have been quite successful in changing the behavior of providers.

LCDR Morrisa Rice (HRSA) confirmed that she would convey ACBCYW's comments and suggestions on health communication and social marketing campaigns to promote provider behavior change, during the upcoming expert panel meetings for the HRSA Office of Women's Health and Bureau of Health Professions.

Overview of Provider Education and Behavior Change

Michael Wilkes, M.D., Ph.D.
Professor of Medicine and Medical Education
University of California

Dr. Wilkes presented an overview of education to change the behavior of HCPs. The major problems in provider education and behavior change are a proliferation in the volume and complexity of biomedical knowledge and technology; increased clinical pressures (e.g., patient volume, documentation and monitoring); and the lack of knowledge among physicians to remain current. In the needs assessment model, a gap exists between the "actual" and "optimal" knowledge and actions of physicians.

Instructional design should be based on 4 guiding principles. "Effective" instruction facilitates the learner's acquisition of the prescribed knowledge, skills and attitudes. "Efficient" instruction requires the least possible amount of time that is necessary for learners to achieve the objective. "Appealing" instruction motivates, interests and encourages learners to persevere in the learning task. "Enduring" instruction remains encoded in the learner's long-term memory and is accessible and applicable in the future.

Facts are important to achieve the goal of learning, but usable knowledge and disconnected facts are not the same. Instead of memory alone, organization and connections also are needed to promote the transfer of information to other contexts. Humans are goal-directed, seek information, and approach education with prior experiences, knowledge and beliefs. These factors impact an individual's views, ability to organize information, and capacity to remember, reason, solve problems and acquire new knowledge.

Live conferences are the most common format for providers to earn CME. Other formats include in-person courses, in-hospital programs, pharmaceutical-sponsored meetings, enduring materials (e.g., DVDs and journals), online CME courses with both synchronous and asynchronous learning, and "just-in-time" applications.

The National Training Laboratories designed the Learning Pyramid to illustrate the average learning retention rates of various teaching methods: lectures (5%), reading (10%), audiovisual materials (20%), demonstrations (30%), discussion groups (50%), practice by doing (75%), and teaching others (90%). Examples of 3 teaching methods are described below.

Teacher A encourages students to use shared decision-making skills by overseeing and monitoring the student's work with a focus on the product and process. In this "hospital system" scenario, students learn to complete tasks and submit materials in a timely fashion, but the timeline and task may serve as a barrier.

Teacher B assumes responsibility for learning by lecturing students, giving examinations, attending to information the students are learning, monitoring test scores, and changing the content of lectures based on test scores. In this "CME" scenario, the teacher attempts to provide information to students through lectures and document recall, but the students are not trained to learn and change their individual behaviors.

Teacher C gives students objectives and competencies, leaves learning to students to self-assess, and is available for feedback and consultation. In this "adult learning" scenario, learning

is an outgrowth of knowledge the students need. The vast majority of work is completed before the exercise.

Several principles must be applied in order for andragogy (e.g., adult learning) to be effective. Adults should be involved in the planning and evaluation of their individual instruction. Adults should have knowledge of the need to know certain information. Adults learn best through self-discovery with real and simulated experiences. Motivation is greatest when it is internal and when an activity presents new knowledge that is applicable to real life. Adults should be self-directed, have an independent self-concept and a deep need to control learning, and take responsibility for their lives.

A number of principles are important for experiential learning. Significant learning occurs when the subject matter is relevant to the personal interests of the student. Learning that is threatening to the individual (e.g., new attitudes or perspectives) is more easily assimilated when external threats are minimized. Learning proceeds faster when the threat to the individual is low. Self-initiated learning is the most lasting and pervasive.

Several principles are critical to cognitive learning. Learning activities must provide multiple representations of the content. Instructional materials should avoid oversimplifying the content domain and support content-dependent knowledge. Instruction should be case-based and emphasize the construction of knowledge rather than transmission of information. Knowledge should be highly interconnected rather than compartmentalized.

Bloom's Taxonomy has been revised since its original publication in the 1950s, but the key principles of learning in this model are to create, evaluate, analyze and apply knowledge. The ability to understand by describing and explaining and the capacity to retain knowledge by remembering are not promoted in this model.

Several approaches can be taken to assess the impact of information given to providers. The provider's "footprints" can be evaluated based on EMR documentation, the number of mammograms performed, or the number of BRCA tests ordered. The provider's "knowledge" can be evaluated based on multiple-choice questions. The provider's "attitudes" can be evaluated based on surveys, objective structured video exercises, or 360-degree evaluations. The provider's "behaviors" can be evaluated based on objective structured clinical examinations.

The provider also can complete a self-assessment, but the ability of persons to evaluate themselves typically is poor based on data from multiple articles and literature reviews. In the key patterns of data, little or no relationship exists between externally generated scores and self-assessed scores. With the exception of the very highest performers, all persons tend to overestimate their ability. The worst offenders of this practice typically are in the lowest quartile of performance.

Adult education literature promotes expertise as a process of effective self-reflection among lifelong and self-directed learners. The health professions have embraced a philosophy of professional autonomy and self-regulation, but this practice demands competent and trustworthy self-assessment by members. The 1999 Kruger and Dunning study reported that the skills required for persons to verify a high level of performance for themselves are the same skills needed to actually perform well.

The new technology of "eDoctoring" allows students, residents, physicians, patients and hospital administrators to use electronic devices to remain connected to the human network from any location at any time. Online education provides numerous opportunities to address the challenge of limited time among physicians, promote behavior change in addition to knowledge, and showcase "best" and "poor" practices. Online education also provides a safe environment to engage physicians through active involvement and self-managed learning.

CDC and NIH funded the eDoctoring online educational tool to provide physicians with interactive and video-based medical education. The course includes 30 individual case studies, a shared decision-making tutorial, and a Learning Community that serves as an online discussion forum for physicians. CDC also funded a project to determine the actual practices of physicians with their patients. Physicians reported their individual behaviors, but their patients reported that these practices did not actually occur. The data further showed that physicians overrated their engagement compared to feedback from patients.

To determine the effectiveness of the program in changing provider behavior, knowledge acquisition, knowledge retention, practice improvement and enhanced patient outcomes were measured. A baseline assessment of physicians was conducted that asked questions regarding their personal and professional experiences, knowledge and shared decision-making. The control group received written information, while the intervention group received physician education. A patient post-visit assessment was performed immediately after the visit; an announced standardized patient visit was conducted at 3 months; and a physician post-study assessment was performed 3 months later.

The post-study assessment was evaluated based on whether the physician asked open-ended questions, engaged the patient in a balanced and appropriately framed discussion, used simple and understandable language, verified the patient's understanding, clarified the patient's individual values, shared decisions with the patient, provided information that was factually accurate and truthful, and clearly articulated the medical topic in terms of risks versus benefits, confidentiality, cost, and implications of a positive versus a negative result.

Overall, messages to HCPs should be different than those to the general public. Most notably, competency-based teaching is the most effective method for HCPs. Competencies should be clearly defined and effective tools should be provided to HCPs. Provider behavior change requires the presentation of both good and bad models, coaching and monitoring of physicians in a non-threatening manner.

Dr. Wilkes provided additional information on provider education and behavior change in response to ACBCYW's questions. The discussion topics included:

- the need to incorporate specific information on provider behavior change into medical school curricula;
- tools and resources for providers to institutionalize shared decision-making; and
- differences in adult learning outcomes based on specific disciplines of providers (e.g., surgeons versus family physicians).

Overview of Health Literacy and Patient-Provider Communication

Ronne Otsby, M.A.

Principal, Strategic Communications and Marketing Division
ICF International

Ms. Otsby presented an overview of health literacy and patient-provider communication. Physicians will more readily engage with and provide more information if patients are confident, assertive, knowledgeable and skillful in asking appropriate questions. The 4 driving factors of behavior change include benefits, barriers, social norms and self-efficacy. Health literacy is a powerful tool to build self-efficacy in patients.

Healthy People 2010 defined "health literacy" as the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions. Health literacy tools for patients include prescription drug bottles, appointment slips, educational brochures, directions by the physician, consent forms, and systems and processes.

Health literacy involves confidence, assertiveness and multiple skills (e.g., reading, listening, analyzing and decision-making). Davis, *et al.* reported the following findings in *Health Literacy and Cancer Communication*: "Patients with poor health literacy have a complex array of difficulty with written and oral communication that may limit their understanding of cancer screening and symptoms of cancer and adversely affect their stage at diagnosis. In addition, these barriers impair communication and discussion about risks and benefits of treatment options and patient understanding of informed consent for routine procedures and clinical trials."

Chastity Burrows Walters reported the following findings in *Health Literacy: Strategies for Avoiding Communication Breakdown*: "Patients with cancer are particularly vulnerable to the effects of low health literacy owing to the complicated treatment regimens they receive. Oncology nurses can help by identifying patients who may be at risk and implementing strategies that can be used to help patients understand the information they receive." However, more research is needed on health literacy and its role in patient outcomes.

The skills needed for health literacy include evaluating information for credibility and quality, analyzing relative risks and benefits, calculating dosages, interpreting test results, and locating health information. The 4 types of health literacy include visual literacy by understanding charts and graphs; computer literacy by operating a computer; information literacy by obtaining and applying relevant information; and numerical or computational literacy by numerically calculating or reasoning.

Several populations are particularly vulnerable to a low health literacy level, including elderly persons $\geq$65 years of age, minority groups, immigrant populations, low-income persons, persons with chronic medical or physical health conditions, and individuals in crisis. A number of strategies can be applied to improve health literacy, such as the provision of simplified information, technology-based communications, counseling, one-on-one treatment planning and assistance, and community-based support.

The steps involved in creating simplified information are to develop the content, organize the publication, write the content, develop the design, and test the publication. In developing the content, the simplified information should clearly describe the specific behavior in a positive manner, articulate the benefits of performing the behavior, determine key messages, include only necessary information, use lay terms, provide relevant illustrations to convey behaviors and processes, and create opportunities to interact with the reader. The number of messages should be limited to 3-5.

In organizing the publication, the simplified information should describe the benefits the reader will gain, begin and end with the most important information, present content in a spatial manner, use headings that express a complete idea or reinforce a behavior, and summarize the main points.

In writing the content, the simplified information should include language at an appropriate reading level for a broad audience (e.g., 3rd to 5th grade), an active voice, a friendly and conversational tone, short and declarative sentences, familiar examples to convey concepts, and simple and consistent wording. The content should limit the use of statistics and avoid abbreviations and acronyms. Sentences should be limited to 8-10 words, while paragraphs should be limited to 3-5 sentences.

In developing the design, the simplified information should include relevant and easily readable images, adequate white space, appropriate fonts and typefaces, boldface or underline to emphasize important points, a layout and color that aid readability, and carefully selected illustrations. The design should avoid using text as an element

Update by the ACBCYW Ad Hoc Provider Workgroup

Brandon Hayes-Lattin, M.D.
Associate Professor of Medicine, Oregon Health and Science University
ACBCYW Member & Provider Workgroup Chair

Dr. Hayes-Lattin presented an update on activities by the Ad Hoc Provider Workgroup. During the September 2011 meeting, ACBCYW established and formally charged the workgroup with gathering initial background information and advising ACBCYW regarding behavior change of providers as relates to (1) enhancing provider knowledge regarding BCYW by assessing gaps, guidelines and issues related to messaging of BCYW and (2) improving the skills of providers regarding the delivery of care to young women at average and high risk of and/or facing breast cancer (e.g., survivors). As part of its charge, the workgroup would define "providers."

The workgroup agreed to target the patient populations of women of reproductive age up to 45 years, pre-diagnosis women at average or high risk (including those at risk for relapse or second primary breast cancer), and post-diagnosis women. In its definition of "providers" for pre-diagnosis and early diagnosis women, the workgroup included general practice, family practice and internal medicine physicians, OB/GYNs, physician assistants, and primary care nurse practitioners. In its definition of "providers" for post-diagnosis women, the workgroup included medical, surgical and radiation oncologists, oncology nurses, and PCPs for the care of cancer survivors.

The workgroup agreed to engage a number of professional societies and networks to effectively outreach and deliver messages to providers (e.g., American College Health Association, American Academy of Family Practice, American College of Physicians, American Congress of Obstetricians and Gynecologists, American Academy of Nurse Practitioners, American Academy of Physician Assistants, American Society of Clinical Oncology (ASCO), American College of Surgeons (ACoS), American Society for Radiation Oncology (ASTRO), Oncology Nursing Society, and National Comprehensive Cancer Network).

The workgroup assessed several factors that play an important role in provider behavior change, including knowledge through training and continuing education; guidelines, materials and other resources; communication and other skill sets to deliver messages; access to patients through utilization of care and opportunities for engagement; and accountability through quality assurance and quality improvement.

The workgroup reviewed guidelines that have been developed by several professional societies for provider screening, practice and quality assurance of BCYW. The workgroup reviewed the 2012 Ozer, *et al.* study, *Young Adult Preventive Health Guidelines: There But Can't Be Found*. The study was designed to achieve 3 important outcomes: (1) identify adolescent and adult clinical preventive services guidelines that are relevant to the young adult age group; (2) review, compare and synthesize these guidelines with an emphasis on the extent to which professional guidelines are consistent with USPSTF evidence-based guidelines; and (3) recommend next steps in the establishment and integration of preventive are guidelines for young adults.

The workgroup agreed that providers have several opportunities to engage the target patient populations and incorporate breast cancer messages. These opportunities include providing care to sexually active, pregnant and breastfeeding women, taking a family history, and assessing chronic medical conditions (e.g., high blood pressure, diabetes and hyperlipidemia).

The workgroup determined that 21 USPSTF A/B recommendations are relevant to the target patient populations. In these recommendations, USPSTF recommends screening of pregnant women, adults $\geq$18 years of age, women with a family history of BRCA1/BRCA2 genes, women at high risk for breast cancer, women $\geq$40 years of age, sexually active and breastfeeding women, women 20-45 years of age, and all women who are planning or capable of pregnancy.

Key findings of the workgroup's literature review of existing guidelines are summarized as follows. The NCCN Clinical Practice Guidelines provide recommendations to providers on breast cancer screening and diagnosis. The relevant sections cover normal risk and the modified Gail Model, increased risk, and management of positive physical findings based on a palpable mass in women >29 and <30 years of age. The section on breast cancer risk reduction covers familial risk assessment and risk reduction therapy.

The NCCN Clinical Practice Guideline for adolescent/young adult (AYA) oncology advises providers to deliver age-appropriate information, discuss fertility risks and fertility preservation options, take a psychosocial assessment, discuss genetic and familial risk assessment (e.g., BRCA1/BRCA2, Li-Fraumeni syndrome or Cowden syndrome), provide online resources to AYA patients, and discuss screening.

The NCCN Clinical Practice Guideline for breast cancer covers screening for patients with prior chest radiation; workup, treatment, surveillance and follow-up; fertility and birth control after adjuvant breast cancer treatment; and breast cancer during pregnancy.

ASCO developed an asynchronous online CME course that includes the "Focus Under Forty" series with an emphasis on patients diagnosed with cancer 15-39 years of age. The relevant modules cover cancer care, clinical trials, diagnosis and treatment of cancer, survivorship, fertility preservation issues for women, the role of primary care, supportive care, and breast cancer as a second malignancy.

The primary care role module discusses unique challenges facing AYA patients; emphasizes the importance of appropriate referrals; underscores the value of shared care between PCPs and oncologists; and lists potential causes of delayed diagnosis and key presenting symptoms, such as access, awareness of symptoms, family and social dynamics, lack of insurance, awareness, experience and time of PCPs, and psychosocial factors (e.g., fear, embarrassment and invincibility).

The primary care role module informs PCPs that in the United States, the incidence of breast cancer per million is 216 in the 15-19 age group, 365 in the 20-24 age group, 662 in the 25-29 age group, 983 in the 30-34 age group, and 1,462 in the 34-39 age group. Note: The source of this data is unknown.

The breast cancer as a second malignancy module is designed to increase awareness of disease chronicity and recurrences of both primary and secondary cancers; identify breast cancer treatments that have a significant impact on quality of life; assess the potential for alternative options as appropriate for AYA patients; and discuss unique issues related to body image and sexuality.

The module also describes various levels of risk for breast cancer after Hodgkin's lymphoma (e.g., mediastinal radiation, prior breast biopsy with proliferative findings, secondhand smoke exposure, mild alcohol use, maternal aunt with breast cancer, menarche at 12 years of age, and breastfeeding).

In addition to its online CME course, ASCO also has published guidelines that are relevant to the target patient populations: *Breast Cancer Follow-Up and Management Guidelines in the Adjuvant Setting* and a guideline that endorsed Cancer Care Ontario's *Practice Guideline on Adjuvant Ovarian Ablation in the Treatment of Premenopausal Women With Early-Sage Invasive Breast Cancer*.

The ACoS Commission on Cancer published the 2012 Cancer Program Standards. This effort is an accreditation of hospital systems that includes quality measures and performance standards for providers in several relevant categories, including risk assessment and genetic counseling, patient navigation, psychosocial distress screening, survivorship care plans, prevention, primary and secondary screening, and screening after Hodgkin's lymphoma.

The workgroup extensively discussed access to patients, utilization of care of the target patient populations and quality improvement. The workgroup reviewed the 2009 Fortuna, *et al.* study that was based on 1996-2006 data from the National Ambulatory Medical Care Survey and the National Hospital Ambulatory Medical Care Survey.

The study concluded that young adults use less ambulatory medical care relative to other age groups and infrequently receive preventive care directed at the greatest threats to their health. The study emphasized that efforts are needed to ensure appropriate preventive care to this population. The study reported that the annual number of ambulatory care visits per capita among females were lowest in young adults compared to children and older persons.

The 2010 Survey on the Utilization of Student Health Services showed that Student Health Services were utilized for medical issues, health promotion and counseling. The survey further showed that only 43% of eligible female students used Student Health Services at their academic institutions.

In terms of incorporating quality improvement into BCYW messages for providers, the workgroup discussed the ASCO Quality Oncology Practice Initiative (QOPI). Of the 89 QOPI measures, 14 specifically target breast cancer in the areas of family history, genetic counseling and testing, and therapy.

The workgroup determined that 34 additional QOPI measures are relevant to the target patient populations. The 25 core measures cover pain, chemotherapy treatment, tobacco use and emotional well-being. The 9 symptom measures cover provider discussions with patients of reproductive age on infertility risks prior to chemotherapy, fertility preservation options, and referral to a specialist.

The Commission on Cancer National Quality Forum has published *Quality of Cancer Care for Breast and Colorectal Cancer Guidelines*, while ASTRO has developed the "Performance Assessment for the Advancement of Radiation Oncology Treatment" that includes components of relevance to BCYW.

Based on the findings of its literature review, the workgroup reassessed the factors that are important for provider behavior change. Resources for providers to attain knowledge on BCYW and interact with patients are increasingly available and of high quality. However, these resources typically are expert-driven best practices rather than actual evidence-based medicine. More research is needed on skills that providers have to deliver resources and knowledge to patients. Access to patients is a challenge, but opportunities for improvement are available. Quality improvement initiatives to strengthen accountability are increasingly available and provide powerful opportunities for integration.

Dr. Hayes-Lattin concluded his update by asking ACBCYW to provide input to the workgroup in response to the following questions.

1. What steps can be taken to better assess the knowledge base of providers?
2. What steps can be taken to assure available resources are used? What steps can be taken to integrate with ongoing quality assessment and quality improvement efforts?
3. What steps can be taken to better assess provider skills in resource utilization and communication?
4. What steps can be taken to improve patient access and utilization?

Dr. Hayes-Lattin provided additional details on the activities of the Ad Hoc Provider Workgroup in response to ACBCYW's questions. The discussion topics included:

- strategies to improve knowledge and change behaviors of PCPs outside the oncology field (e.g., providers in pediatric clinics, adult internal medicine clinics and Student Health Services);
- approaches to incorporate provider behavior change data into medical school curricula;
- systems issues beyond the provider's control, particularly problems in caring for patients in remote or rural areas; and
- the need to utilize professional societies to reach a broader group of providers.

ACBCYW commended the workgroup for conducting an impressive literature review and completing an extensive amount of work since the September 2011 meeting. Due to time constraints, ACBCYW was unable to provide input in direct response to the questions Dr.

Hayes-Lattin posed. However, several members made comments and suggestions for the workgroup to consider and discuss during its closed session on the following day.

- The workgroup should conduct a literature review to determine existing provider behavior change guidelines that have been published by professional societies and are relevant to breast cancer.
- The workgroup should identify 3-5 priority BCYW messages that should be delivered to providers. For example, key messages to PCPs would be to take a family history to determine the woman's risk for breast cancer, learn to identify and manage a palpable breast mass with well-established interventions, offer risk reduction strategies to patients, conduct surveillance, and identify and refer high-risk women to a specialist. Key messages to oncologists would be to engage in shared decision-making regarding options for women who have an interest in reducing their risk for breast cancer and conduct appropriate surveillance of high-risk patients.
- The psychosocial oncology literature contains limited data on breast cancer in young women compared to older women, particularly their unique developmental needs. In addition to the 3-5 priority BCYW messages, PCPs, nurse practitioners and other providers outside of the oncology field also should be given guidance on assessing the level of psychological distress after a young woman is diagnosed with breast cancer.
- The Workgroup should incorporate the same 3 key messages from the High Risk Workgroup into its BCYW campaign: "Understand your risk." "Know your options." "Get support."
- The workgroup should give PCPs a bundle of messages for the broader population of young women who are at risk for breast cancer (e.g., exercise, eat a healthy diet, and maintain a healthy body mass index). PCPs would more readily convey risk reduction messages to their patients that can be applied to other health issues in addition to breast cancer (e.g., heart disease and colon cancer).
- The workgroup should contact professional societies to discuss the possibility of developing accreditation and CME modules that are similar to those created by ASCO University. The ASCO modules have been developed for clinical oncologists, but the new modules could be created for providers in other disciplines (e.g., family medicine and OB/GYN).
- The workgroup should develop educational messages for community health outreach workers, particularly to reach underserved, uninsured/underinsured and hard-to-reach women.
- CDC recently awarded funds for its existing cancer screening programs to focus on genetic education. CDC should utilize this existing infrastructure to reach PCPs and women at high risk for breast cancer.
- CDC should explore the possibility of replicating the grassroots effort by the Young Survival Coalition at the national level. This organization created and disseminated a BCYW brochure to OB/GYNs in the New York tri-state area.

Dr. Fairley made follow-up remarks in response to some of ACBCYW's suggestions. In terms of utilizing CDC's existing infrastructure to reach PCPs and high-risk women, she confirmed that she would provide the workgroup with slides, website links and other information on CDC's existing programs (e.g., the National Comprehensive Cancer Control Program) to assist the members in formulating recommendations in this area.

In terms of the discussion about expanding the Young Survival Coalition's work at a national level, CDC encourages its grantees and other organizations to become involved with their state

Comprehensive Cancer Control (CCC) Program, interact with other groups and networks in the field, and emphasize partnerships. This would afford these organizations the opportunity to network and share their work with others in the cancer control community.

Public Comment Session

Michael Wilkes, M.D., Ph.D.
Professor of Medicine and Medical Education
University of California

Dr. Wilkes made several comments in response to the update by the Provider Workgroup. The workgroup plans to engage professional societies to outreach and deliver messages to providers, but this approach will overlook an entire sector of physicians who serve poor and underserved women. In terms of legal and social issues, many women and providers are extremely reluctant to document a breast cancer family history or risk factors in the medical record due to the potential for the patient to be denied health insurance coverage in the future.

In terms of college health systems, Vice Chancellors of Student Affairs can require providers at these institutions to discuss breast cancer risks with all women who present for any type of service. In terms of Student Health Services, most campuses offer peer support services and train advocates who have an interest in health and health counseling. Because advocates engage students in discussions about high-risk behaviors, this model could be expanded to easily include breast cancer.

In terms of reaching medical school and nursing students, no organization provides medical schools with information or guidance on specific topics that should be taught. Instead, faculty and administrators of the institution make these decisions. Collaborative efforts should be undertaken with the National Board of Medical Examiners to attempt to include other clinical topics in medical school examinations.

Susan Brown, M.S., R.N.
Health Educator
Susan G. Komen for the Cure®

Ms. Brown informed ACBCYW that Komen has developed educational materials for women with 4 basic and simple messages: (1) “Know your risk.” (2) “Get screened.” (3) “Know what is normal for you and immediately take action if you notice a change.” (4) “Make healthy lifestyle choices.” Message 1 clearly articulates action steps (e.g., discuss your family medical history with your family members and discuss your family history and personal medical history with your provider). Message 4 also includes 5 action steps. Ms. Brown noted that ACBCYW is free to use Komen’s educational materials as a starting point in developing its BCYW campaigns.

Ms. Brown underscored the importance of CDC and ACBCYW pilot testing educational materials and messages to the target audience and making changes to materials based on feedback prior to broad dissemination.

Closing Session

Dr. Plescia thanked DCPC staff for its outstanding efforts in planning and overseeing all aspects of the ACBCYW meeting. He recognized Dr. Fairley, Ms. Carolyn Headley (Management and Program Analyst), and Ms. Jameka Blackmon (Acting Associate Director, Office of Program Development). He also thanked staff in the DCPC CCC Branch for its administration of the EARLY Act funds.

Dr. Partridge thanked the workgroup members for their hard work since the September 2011 meeting. To inform the further development of the BCYW campaigns, she encouraged the members to apply lessons learned from the presentations on provider education, provider behavior change, health literacy, health communication, and patient-provider communication.

With no further discussion or business brought before ACBCYW, Dr. Fairley adjourned the meeting at 4:22 p.m. on April 19, 2012.

Centers for Disease Control and Prevention

ADVISORY COMMITTEE on BREAST CANCER in YOUNG WOMEN

April 18-19, 2012 ■ Atlanta, GA

Attachment 1
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, April 18, 2012

12:00 P.M. – 12:10 P.M. **Opening: Welcome and Introductions**

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

Marcus Plescia, M.D., M.P.H.
Director, DCPC, CDC

12:10 P.M. – 12:15 P.M. **Committee Updates/Announcements**

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

12:15P.M. – 12:45P.M. **Federal Activities Related to Breast Cancer in Young Women**

Gayle Vaday, Ph.D.
Program Manager, Breast Cancer Research Program
Congressionally Directed Medical Research Programs
Department of Defense

12:45 P.M. – 2:45 P.M. **Updates from CDC**

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

Angela Moore, M.P.H.
Lead Public Health Advisor, DCPC, CDC

DP11-1111 Survivorship Support
Patricia Ganz, M.D.
Professor, UCLA Schools of Medicine and Public Health
UCLA LIVESTRONG Survivorship Center of Excellence

Jennifer Ivanovich, M.S.
Research Assistant Professor
Hereditary Cancer Core &
Young Women's Breast Cancer Program
Washington University School of Medicine

Arin Ahlum Hanson, M.P.H., C.H.E.S.
Manager, Young Women's Initiative
Living Beyond Breast Cancer

Jennifer Thompson, M.S.W.
Survivorship Program Supervisor
Sharsheret

2:45 P.M. – 3:00 P.M. **BREAK**

3:00 P.M. – 4:15P.M. **Updates from CDC (continued)**

DP11-1114 Genomics
Katrina Trivers, M.S.P.H., Ph.D.
Epidemiologist, CDC, DCPC

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.
Dana-Farber Cancer Institute
ACBCYW Committee Chair

Day 2: Thursday, April 19, 2012

9:00 A.M. – 9:15 A.M.	**Highlights and Review** *Ann H. Partridge, M.D., M.P.H.* Dana-Farber Cancer Institute ACBCYW Committee Chair *Temeika L. Fairley, Ph.D.* Designated Federal Officer, DCPC, CDC
9:15 A.M. – 10:45 A.M.	**ACBCYW Workgroup Report and Open Discussion** *Rochelle Shoretz, J.D.* Sharsheret Ad Hoc High Risk Workgroup
10:45A.M. – 11:00A.M.	**BREAK**
11:00A.M. – 11:45A.M.	**Health Communication, Education, and Provider Behavior Change** *Jennifer Nichols, M.P.H.* Research Supervisor Porter Novelli
11:45A.M. – 1:00 P.M.	**LUNCH**
1:00P.M. – 1:45 P.M.	**Provider Education and Behavior Change** *Michael Wilkes, M.D., Ph.D.* Professor UC Davis School of Medicine
1:45 P.M. – 2:30 P.M.	**Health Literacy and Patient-Provider Communication** *Ronne Otsby, M.A.* Principal Strategic Communications & Marketing Division ICF International
2:30 P.M - 2:45 P.M.	**BREAK**

2:45 P.M. – 4:15P.M. **ACBCYW Workgroup Report and Open Discussion**

Brandon Hayes-Lattin, M.D.
Oregon Health and Science University
Ad Hoc Provider Workgroup

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

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

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

4:30 P.M. – 5:00 P.M. **Wrap-Up/Announcements/Close**

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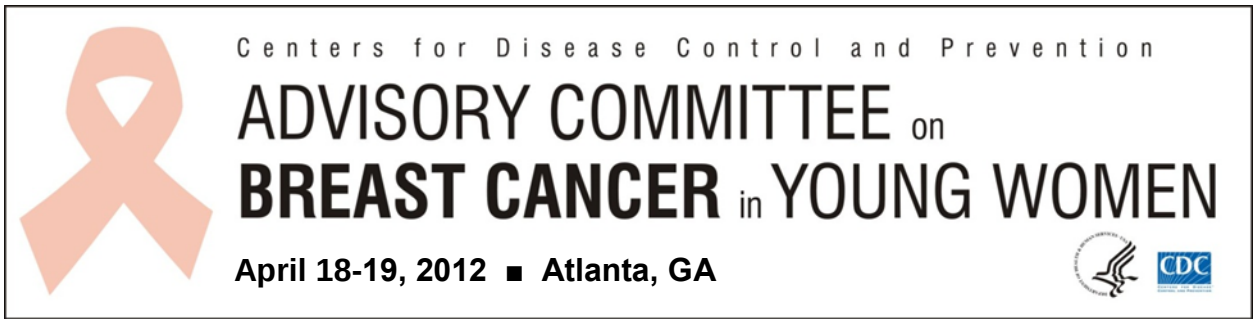

ATTACHMENT 2
Roster of the ACBCYW Membership

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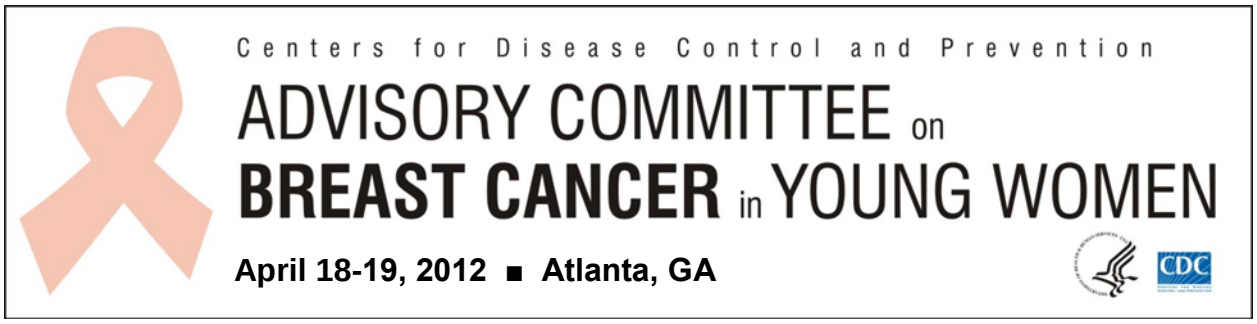

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Attachment 4
Glossary of Acronyms

AA	African American
ACBCYW	Advisory Committee on Breast Cancer in Young Women
AcoS	American College of Surgeons
ASCO	American Society of Clinical Oncology
ASTRO	American Society for Radiation Oncology
AYA	Adolescent/Young Adult
BCC	Breast and Cervical Cancer
BCRP	Breast Cancer Research Program
BCYW	Breast Cancer in Young Women
BMI	Body Mass Index
BRFSS	Behavioral Risk Factor Surveillance Survey
C4YW	Conference for Young Women (Affected by Breast Cancer)
CCC	Comprehensive Cancer Control
CDC	Centers for Disease Control and Prevention
CDMRP	Congressionally Directed Medical Research Programs
CME	Continuing Medical Education
COE	Center of Excellence
DCPC	Division of Cancer Prevention and Control
DoD	Department of Defense
EARLY	Education and Awareness Requires Learning Young (Act)
EMRs	Electronic Medical Records
FOA	Funding Opportunity Announcement
FY	Fiscal Year
GFL	Genetics for Life
HCPs	Healthcare Professionals
HRSA	Health Resources and Service Administration
IOM	Institute of Medicine
IRB	Institutional Review Board
LBBC	Living Beyond Breast Cancer
MRI	Magnetic Resonance Imaging
NBCCEDP	National Breast and Cervical Cancer Early Detection Program
NCCN	National Comprehensive Cancer Network
NCI	National Cancer Institute
NIH	National Institutes of Health

NPO	Nonprofit Organization
NSAB	National Survivorship Advisory Board
NSS	National Survivorship Survey
OB/GYNs	Obstetricians/Gynecologists
OMB	Office of Management and Budget
OPHG	Office of Public Health Genomics
ORISE	Oak Ridge Institute for Science and Education
PCPs	Primary Care Physicians
PSN	Peer Support Network
QOPI	Quality Oncology Practice Initiative
QR	Quick Response (Codes)
SES	Socioeconomic Status
SNI	Sisters Network, Inc.
SPIRIT	Sisters Peer Counseling in Reproductive Issues after Treatment
USPSTF	U.S. Preventive Services Task Force
WU	Washington University
YAABCS	Young African American Breast Cancer Survivors
YBCS	Young Breast Cancer Survivors/Survivorship
YJBCS	Young Jewish Breast Cancer Survivors
YSI	Young Sisters Initiative
YWBCP	Young Women's Breast Cancer Program
YWI	Young Women's Initiative