U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
CENTERS FOR DISEASE CONTROL AND PREVENTION

National Center for Chronic Disease Prevention and Health Promotion
Division of Cancer Prevention and Control

Advisory Committee on Breast Cancer in Young Women
January 9, 2014 Virtual Meeting
Record of the Proceedings

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Minutes of the January 9, 2014 Virtual Meeting

The U.S. Department of Health and Human Services (HHS) and the Centers for Disease Control and Prevention (CDC), National Center for Chronic Disease Prevention and Health Promotion, Division of Cancer Prevention and Control (DCPC), convened a virtual meeting of the Advisory Committee on Breast Cancer in Young Women (ACBCYW). The proceedings were held on January 9, 2014.

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.

Information for the public to access the ACBCYW virtual meeting via teleconference or webinar was published in the *Federal Register* in accordance with Federal Advisory Committee Act (FACA) regulations. All sessions of the ACBCYW meeting were open to the public.

Opening Session

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

Dr. Fairley conducted a roll call to determine the ACBCYW voting members, *ex-officio* members and liaison representatives who were attending the virtual meeting. She announced that the voting members and *ex-officio* members constituted a quorum for ACBCYW to conduct its business.

Dr. Fairley called the proceedings to order at 9:14 a.m. EST on January 9, 2014 and welcomed the participants to the ACBCYW virtual meeting. None of the voting members declared conflicts of interest for the record for any of the items on the published agenda.

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

Dr. Partridge joined Dr. Fairley in welcoming the participants to the meeting. She thanked the ACBCYW members for their ongoing efforts and continued commitment to improve the lives of young women who are at risk of or have developed breast cancer. She announced that the next in-person ACBCYW meeting would be held in March 2014 in Atlanta, Georgia.

Dr. Partridge described ACBCYW's role and function for the benefit of the new members. ACBCYW was established to provide external advice and expertise to the CDC Director and HHS Secretary as mandated by the Education and Awareness Requires Learning Young (EARLY) Act. In this capacity, ACBCYW develops and submits formal recommendations to the HHS Secretary for CDC's consideration and action.

Dr. Partridge explained that research is critical to improve the care of persons with breast cancer, but ACBCYW is not chartered to provide guidance on bench research or clinical trials, such as studies to better understand breast cancer rates in young women with a certain gene mutation. Instead, the scope of ACBCYW's research recommendations to CDC focuses on public health studies, implementation science, and interventions to raise awareness of existing research and resources.

Dr. Partridge noted that ACBCYW meetings are structured with presentations, overviews and updates by CDC and guest speakers; ACBCYW's question/answer or discussion sessions after each speaker; and open discussions for ACBCYW to propose recommendations or concrete deliverables to CDC. In accordance with FACA regulations, ACBCYW meetings also include a public comment session.

Dr. Partridge emphasized that the major focus of the current meeting would be for ACBCYW to prepare for the in-person March 2014 meeting by identifying action steps to advance its priority topics: young women at "high risk" for breast cancer and behavior change of providers related to breast cancer in young women (BCYW). The current meeting also would be used as an opportunity for ACBCYW to propose new areas of focus or priorities for CDC.

Dr. Partridge concluded her opening remarks by asking the participants to join her in welcoming the new and reappointed ACBCYW members. To overcome visual barriers to the virtual meeting, biographical sketches and photographs were displayed on the screen as the members introduced themselves.

New ACBCYW Members

- Raquel Arias, MD: Associate Professor of Obstetrics and Gynecology, Keck School of Medicine; Clinical Associate Professor of Gerontology, University of Southern California
- Lindsay Avner: Founder, Bright Pink
- Sue Friedman, DVM: Founder and Executive Director, Facing Our Risk of Cancer Empowered (FORCE)
- Susan Kutner, MD: Breast Surgeon, Kaiser Permanente San Jose Medical Center; Chair, Kaiser Permanente Northern California Breast Care Task Force; Chair, Kaiser Permanente Interregional Breast Care Leaders Group; Board of Directors Member, Breast Cancer Fund
- Karen Meneses, PhD, RN, FAAN: Professor and Associate Dean for Research, School of Nursing, University of Alabama at Birmingham; Director, Young Breast Cancer Survivorship Network
- Jennifer Merschdorf, MBA: Chief Executive Officer, Young Survival Coalition
- Marisa Weiss, MD: Breast Cancer Oncologist, Lankenau Medical Center; Founder and President, Breastcancer.org; Founder and past President, Living Beyond Breast Cancer

Reappointed ACBCYW Members

- Otis Brawley, MD, FACP: Chief Medical Officer and Executive Vice President for Research and Cancer Control Science, American Cancer Society
- Maimah Karmo: Founder and President, Tigerlily Foundation
- Rochelle Shoretz, JD: Founder and Executive Director, Sharsheret

Panel Presentation: Updates on CDC's Breast and Ovarian Cancer Genomics Grantee Activities

The CDC Project Officer of the DP11-1114 Cooperative Agreement (CoAg) and a panel of three grantees presented a series of updates on their Breast and Ovarian Cancer Genomics activities. The updates are summarized below.

Update on CDC's Programmatic Activities in Breast and Ovarian Cancer Genomics

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

Dr. Trivers presented an update on CDC's programmatic activities in breast and ovarian cancer genomics. CDC focuses on primary prevention to identify women at high risk before cancer develops. Women with BRCA 1/2 mutations have a substantially higher cancer risk than those without these mutations. Compared to the cumulative breast cancer risk of 12% in the general population, the risk is 57% in BRCA1 carriers and 49% in BRCA2 carriers. Compared to the cumulative ovarian cancer risk of 1.4% in the general population, the risk is 40% in BRCA 1 carriers and 18% in BRCA2 carriers.

Enhanced surveillance, chemoprevention and other interventions can dramatically decrease cancer risk in BRCA 1/2 carriers. Most notably, prophylactic surgery can reduce breast cancer risk by 85%–100% and reduce ovarian cancer risk by 69%–100%. Despite the positive impact of primary prevention, however, barriers still exist to implementation of genetic services. High-risk women often are not identified due to limited knowledge and confidence about family history and genetics among healthcare providers (HCPs).

Most risk assessment tools are complex and difficult to implement in primary care settings. The development of rapid tools is underway, but further study and validation are needed to determine the best tools. Other barriers to implementation of genetic services include limited access and disparities due to the shortage of genetic experts, particularly in non-urban areas. Even with implementation of the Affordable Care Act (ACA) in January 2014, gaps still exist in health insurance coverage. Genetic testing is expensive and can range from $400 to $4,000 for BRCA 1/2 carriers.

CDC acknowledges that to address these barriers, federal funding will need to be allocated to programmatic activities to enhance breast/ovarian cancer genomic practices through policy, education and surveillance. To support this effort, CDC released a new non-research funding opportunity announcement (FOA) in 2011 to facilitate the continuation and expansion of state-based activities focused on breast/ovarian cancer genomics. CDC awarded the new FOA funds in a competitive, objective review process.

CDC awarded approximately $300,000 per year for 3 years to three grantees to conduct breast/ovarian cancer genomic activities: Georgia Center for Oncology Research and Education, Michigan Department of Community Health, and the Oregon Genomics Program. The grantees are completing their final year of funding under the FOA at this time.

CDC placed explicit limitations on applicants that would be eligible to receive funding under this breast/ovarian cancer genomics FOA. State/local governments and tribal organizations were eligible to apply and were required to demonstrate capacity in the following areas:

- Efforts to develop and expand ongoing breast/ovarian cancer genomic activities at the state level;
- Existing expertise in surveillance, policy and education;

- Ability to collaborate with state partners and inform state policies based on linkages to state cancer registries, health insurance providers and other resources; and

- The possibility of replicating the state's breast/ovarian cancer genomic activities for national implementation.

The grantees used their cooperative agreement (CoAg) funds to conduct activities in three areas required by the FOA. Examples of "education" activities included the development or expansion of public and provider education to increase knowledge of the importance of family history, genetic counseling and BRCA 1/2 testing; appropriate risk assessment and communication; and preventive services for persons identified as high risk.

Examples of "surveillance" activities included tracking of the use of genetic counseling, BRCA 1/2 testing, and follow-up procedures for persons identified as high risk. Examples of "policy/ system change" activities included the promotion of organizational, policy and system changes to increase the use of clinical best practices for genetic counseling, BRCA 1/2 testing, and preventive services for persons identified as high risk.

Update by the Georgia Center for Oncology Research and Education

Monique Martin, MPH, CHES
Health Education and Communication Specialist
Georgia Center for Oncology Research and Education (Georgia CORE)

Ms. Martin presented an update on the education, policy, and surveillance achievements that Georgia CORE has made to date with funding from the CDC DP11-1114 CoAg. The 159 counties in the state of Georgia are divided into 18 public health districts that include 42 Commission on Cancer Hospitals, 17 cancer genetic counselors, and 1 National Cancer Institute (NCI) Hospital. Despite Georgia's wide geographical spread of 159 counties, cancer resources primarily are targeted in the Atlanta metropolitan area because breast/ovarian cancer incidence rates are highest in this region compared to the remainder of the state.

Georgia CORE used its DP11-1114 CoAg funds to create the Georgia Breast Cancer Genomic Health Consortium (Consortium) as a public/private partnership with Emory University, Georgia State University and Morehouse School of Medicine. The overarching goal of the Consortium is to promote the use of evidence-based guidelines for breast/ovarian cancer genetic risk assessment, counseling and testing and also to improve the identification of young women at genetic risk of these cancers. The Consortium conducts activities in three major areas to achieve its goal.

Education activities are designed to increase knowledge and awareness of the methods and benefits of identifying women at risk of hereditary breast/ovarian cancer (HBOC). The Consortium has participated in numerous conferences and meetings of state and national organizations to display posters and make presentations; disseminate information and widely publicize its state-specific grant activities in Georgia; and highlight key outcomes and successes of the Michigan and Oregon grantees.

The Consortium conducted needs assessments of its target populations of young breast cancer survivors (YBCS), primary care residents, resident directors and cancer genetic counselors. Surveys were distributed to 275 primary care providers (PCPs) licensed in the state of Georgia to rate their knowledge or confidence level of key HBOC genetic concepts. The survey showed a significant deficit in HBOC knowledge among Georgia PCPs, particularly with respect to the identification of high-risk individuals.

Based on the survey results, the Consortium will convene a conference on February 21, 2014, "The First Line of Defense: Application of Breast Cancer Genomic Standards in Primary Care." The goal of the conference will be to communicate the importance of genomics in the PCP's clinical practice and disseminate information on current cancer genomic standards and guidelines. The conference will be structured around the theme of "meeting the newest line of defense in fighting hereditary cancers."

Policy activities are designed to expand utilization and coverage of cancer genetic services in accordance with evidence-based guidelines. The Consortium included a new objective in the Georgia Comprehensive Cancer Control Plan: "By 2017, increase the number of high-risk Georgians with access to breast, ovarian and colorectal cancer genetic risk assessment (e.g., genetic counseling and testing) by 20%."

The Consortium has met with the Georgia Insurance Commissioner, medical directors of major health plans and tele-health program directors to advance these activities and improve outreach to rural areas of the state. The Consortium's analysis of 11 Georgia health plans showed the following results:

- 9 health plans have a written BRCA counseling and testing policy.
- 8 health plans include coverage for female members with a significant family history of breast and/or ovarian cancer without a personal history.
- 7 health plans "require" or "strongly recommend" counseling prior to testing.
- 7 health plans are in compliance with U.S. Preventive Services Task Force (USPSTF) recommendations.
- 3 health plans cover BRACAnalysis® Large Rearrangement Testing (BART).
- 3 health plans are in compliance with the 2012 National Comprehensive Cancer Network (NCCN) guidelines.

The Consortium intends to disseminate the results of the analysis to the 11 Georgia health plans. Due to proceeds from the Georgia license plate that is dedicated to breast cancer, the Consortium obtained approval for a $46,000 genetic testing fund. Every $22 from the purchase or renewal of the Georgia breast cancer license plate is deposited into the Indigent Care Fund for community-based breast health programs that care for underserved populations. The Consortium created a new funding stream that will allow underinsured persons in Georgia to receive genetic testing for HBOC beginning in January 2014.

Surveillance activities are designed to assess utilization of and barriers to cancer genetic services and also to promote and enhance use of assessment, screening, counseling, referral and clinical services. The Consortium has used the Breast Cancer Genetics Referral and Screening Tool (B-RST) in public health clinics since 2012. The USPSTF recommendations described B-RST as one of two tools that is the simplest and quickest to administer.

The Consortium used a portion of its CoAg funds to develop a Web-based B-RST algorithm with six simple questions that provide the user with a "negative," "moderate" or "positive" result. The Web site also includes targeted provider and public information. Traffic to the B-RST and NCI Web sites peaked after two major events in 2013: publication of Angelina Jolie's op-ed about her double mastectomy in May 2013 and release of the USPSTF recommendations in December 2013. The B-RST Web site averages about 495 unique visitors per month.

The Consortium's screening of 1,184 public users of the B-RST Web site showed that 81% were 18–49 years of age and 61% were racial/ethnic minorities: African Americans (41%) and Hispanics (20%). The location of Georgia counties with clinics using B-RST screening is aligned with the incidence rates of breast/ovarian in the state. Implementation of B-RST was based on locations of Ashkenazi Jewish populations and areas of high need.

The Consortium conducts a three-phase process before B-RST can be used in Georgia public health clinics. First, prior to the patient's visit to the clinic, the Consortium holds a three-hour session with all clinic staff that will have contact with the patient (front desk staff, medical assistants and nurses) to provide education on breast cancer, genomics, HBOC and use of B-RST.

Second, clinic staff incorporates HBOC screening into the typical process for collecting the patient's medical history using the Web-based version of B-RST. Third, patients with moderate or negative screening results are given information and encouraged to present for routine screening. Patients with positive screening results who do not opt out are contacted by a genetic service provider/professional (GSP) and referred for testing.

Ms. Martin presented the B-RST Web page with screening results and also displayed a flow chart of services that public health clinics and the Consortium's GSPs offer to patients with positive test results. To date, 2,120 women have been screened with B-RST in six public health clinics in Georgia. The tremendous diversity in the number of patients screened at the six public health clinics is due to different dates to implement B-RST, various operational structures (the absence of WiFi), and the number of providers.

Of 2,120 women who have been screened with B-RST in six public health clinics, approximately 73% were African American, approximately 88% were 18–49 years of age, and 6% had positive screening results. Of 128 patients with positive screening results, approximately 74% agreed to follow-up and approximately 70% were contacted successfully. Of 66 patients who were contacted successfully, approximately 47% met the NCCN High Risk Guidelines criteria, approximately 15% were tested, and 21% reported breast findings. The screening identified one woman under 40 years of age who was BRCA2-positive and one woman with a genetic variant of uncertain significance (VUS).

Georgia CORE's major successes with the DP11-1114 CoAg to date include collaboration with and lessons learned from the Michigan and Oregon grantees; strong partnerships with academic, public, and private institutions; the ability to work within health clinics; and new opportunities to increase its reach with the recently released USPSTF recommendation statement.

Georgia CORE's key challenges with the DP11-1114 CoAg to date include the need to initiate a learning process due to Georgia's role as a newly funded state; uncertainty about future funding opportunities and sustainability of activities over time; capacity to only serve a small population due to limited access to genetic counselors in Georgia; lack of genomic awareness among providers and the public; and policy-related uncertainties due to Georgia's decision not to expand Medicaid coverage under ACA and patent challenges that will affect pricing, coverage and counseling.

ACBCYW discussed the following topics in the question/answer session with Ms. Martin on the Georgia CORE DP11-1114 CoAg activities.

- The process for the Consortium's GSPs to refer patients with positive genetic screening results for testing.
- Plans to implement B-RST outside of Georgia public health clinics, including the Avon Breast Center at Grady Memorial Hospital and a community-based organization.
- Georgia CORE's ability to track outcomes of women with positive screening results and evaluate the level of satisfaction among women who have participated in the B-RST process.

The discussion resulted in ACBCYW advising Georgia CORE to administer a follow-up survey to determine whether implementation of B-RST had an impact on increasing the knowledge or confidence level of key HBOC genetic concepts among providers. Results of the follow-up survey could help to inform the development of additional recommendations to CDC by the ACBCWY Provider Workgroup.

Update by the Michigan Department of Community Health

Debra Duquette, MS, CGC
Genomics Coordinator and Program Manager
Michigan Department of Community Health

Ms. Duquette presented an update on the education, policy, and surveillance achievements the Michigan Department of Community Health (MDCH) has made to date with funding from the CDC DP11-1114 CoAg. MDCH's mission is to protect, preserve and promote the health and safety of Michigan residents and give particular attention to meeting the needs of vulnerable and underserved populations. MDCH's vision is to improve the experience of care, improve the health of populations, and reduce per capita costs of health care.

Based on the requirement for DP11-1114 grantees to conduct policy activities, MDCH structured its Breast Cancer Genomics Program to utilize health plan policies as the catalyst to maximize health benefits of appropriate BRCA-related services and minimize potential harms from inappropriate use. MDCH organized its BRCA counseling, testing, and clinical services into four critical phases:

1. Accurate recording of family and/or personal history of cancer;
2. Appropriate cancer genetic risk evaluation and referral to BRCA counseling for at-risk persons;
3. BRCA testing and interpretation of results based on written informed consent; and
4. Appropriate delivery of BRCA-related clinical services for persons identified with a known deleterious mutation.

MDCH engaged partners at multiple levels to implement its DP11-1114 project, "Enhancing Breast Cancer Genomics Best Practices and Policies in the State of Michigan." These partners include national, state, and local health partners; providers; family members and caregivers; 16 clinical practices; and Michigan adults at risk of BRCA. Partners at all levels are represented on the MDCH Steering Committee and are extensively involved in at least one of the project goals. MDCH prioritized specific activities and outcomes for each of the goals, but the overall impact of the project is to reduce breast/ovarian cancer death rates among young women in Michigan.

MDCH acknowledges that its partners and their strong commitments are the most important factors to the success of the DP11-1114 project. MDCH's guiding principle for the project is based on a key finding of the 2005 Marks study: "No important health problem will be solved by clinical care alone, research alone or public health alone, but rather by all public and private sectors working together."

MDCH's four interconnected goals and activities for its DP11-1114 project were highlighted. The **policy** goal is designed to promote adoption of health plan policies to increase coverage of BRCA clinical services for high-risk women. To investigate insurance coverage gaps for BRCA clinical services, MDCH focused on 25 health plans with at least 1% of the Michigan market and developed formal partnerships and projects with three of the top payers in the state: Blue Cross/Blue Shield of Michigan, Priority Health, and Michigan Medicaid. MDCH also formed a relationship with the Michigan Association of Health Plans that represents 15 health plans in the state.

MDCH continued its longstanding efforts to enhance awareness, knowledge and use of BRCA clinical serves among payers in the context of USPSTF and NCCN recommendations. This activity aims to increase the number of health plans that have written policies for BRCA clinical services consistent with USPSTF and NCCN recommended practices. MDCH develops and disseminates an individualized "BRCA Policy Dashboard Report" to each of the 25 health plans. The dashboard reports are based on responses to the following questions.

- Does the health plan have a written BRCA counseling and testing policy for adults with a personal history of breast and/or ovarian cancer aligned with NCCN guidelines?
- Does the health plan include coverage for adults with a family history of breast and/or ovarian cancer aligned with USPSTF and NCCN recommendations?
- Does the health plan "require" or "strongly recommend" counseling prior to BRCA testing?
- Does the health plan have written policies that cover a variety of BRCA-related clinical services for patients with a known deleterious mutation included in the NCCN guidelines?

MDCH awards plaques to health plans that receive a "green thumbs-up" for each question in the dashboard report. Health plans that receive a "red thumbs-down" or "unknown" response for each question in the dashboard report are encouraged to improve their performance and share their newly developed policies with MDCH.

MDCH develops and disseminates a "BRCA Genetic Counseling and Testing Member Report" to all 25 health plans. The reports maintain de-identified data collected from more than 11,000 patients who were

seen for BRCA counseling by a Michigan board-certified GSP between October 2007 through December 2012. MDCH provides each health plan with the actual number of their members who received BRCA counseling and testing, had a personal or family history of breast/ ovarian cancer, and were not tested due to inadequate insurance. The reports also provide these numbers on a statewide basis for comparison among health plans.

In 2013, MDCH began monitoring the actual number of health plan members with specific types of BRCA testing ordered in 2008 versus 2012. MDCH initiated this effort due to data that showed tremendous growth in comprehensive BRCA and BART testing in Michigan and little or no growth in single-site and multi-site 3 BRCA testing. MDCH acknowledges that increased awareness, appropriate ordering and use of tests will lead to higher quality care, better interpretation of test results, and lower overall costs of BRCA testing.

MDCH's comprehensive "Resource Guide" for breast cancer genomics best practices accompanies the individualized Dashboard and Member Reports for each of the 25 health plans. MDCH uses key events, publications, media outlets and other venues to widely publicize awards and honors to health plans for their breast cancer genomics best practices. MDCH has awarded 15 health plans for aligning their written BRCA counseling and testing policies with the 2005 USPSTF Grade B recommendation. Awards also were made to 8 health plans that aligned their written policies for BRCA-related clinical services for women with a known deleterious BRCA mutation with the 2012 NCCN guidelines.

The **provider** goal is designed to increase HCP knowledge and use of BRCA clinical practices recommended by USPSTF and NCCN. MDCH focuses on three key activities to achieve this goal:

1. Assess and improve provider knowledge about the validity, utility, harms and benefits of family history, risk assessment and/or referral for BRCA counseling and testing for appropriate women.

2. Increase the number or percentage of appropriate visits for BRCA counseling.

3. Increase the number of appropriate BRCA tests and related clinical services.

MDCH is partnering with Priority Health to disseminate a variety of provider education resources that will be developed in direct response to 2012 survey results and an existing policy requiring board-certified GSPs to provide BRCA counseling and testing. MDCH and Priority Health also are investigating health plan claims for specific BRCA-related services among members who had BRCA testing. Other health plans have expressed an interest in partnering with MDCH to conduct similar activities in 2014.

MDCH established a partnership with the National Coalition for Health Professional Education and Genetics in 2011 to develop an online breast cancer genomics module with continuing medical education (CME) in order for PCPs to increase their competency in HBOC risk assessment, referral, and management.

MDCH asked the Georgia and Oregon DP11-1114 grantees and the Moffitt Cancer Center to collaborate on developing the module, including case-based presentations for PCPs to select their next steps and describe outcomes based on their choices. PCPs who achieve a post-test score of at least 70% will receive 2.0 CMEs from Michigan State University at no cost until October 2016. The module will be finalized for national dissemination in January 2014.

The **surveillance/epidemiology** goal is designed to expand surveillance of BRCA clinical practices. MDCH focuses on five key activities to achieve this goal.

- Expand a comprehensive statewide surveillance network to track the use of BRCA clinical services through board-certified GSPs.

- Describe statewide trends regarding cancer family history to inform data collection by the Michigan Cancer Surveillance Program (MCSP).

- Continue to investigate statewide cancer incidence and mortality that are appropriate for BRCA counseling and testing in accordance with NCCN guidelines.

- Increase understanding of patient and provider practices pre- and post-BRCA testing.

- Monitor Michigan's progress in achieving the Healthy People 2020 objective to increase the proportion of women with a family history of breast/ovarian cancer who received genetic counseling (Objective G-1).

MDCH uses existing state and local cancer registry data to inform its breast cancer genomics surveillance, provider/payer education activities and policy initiatives. MDCH's epidemiology activities allow trends in breast cancer genomics to be documented at a population level and over time.

MDCH's major accomplishments in breast cancer genomics were highlighted. Appropriate cancer genetic counseling and BRCA testing of persons with a personal or family history of breast/ovarian cancer have continued to grow annually. The number of cancer genetic clinics with board-certified GSPs in Michigan, including new clinics in previously underserved areas, has doubled from 8 clinics in 2010 to 16 clinics in 2013.

Barriers to appropriate BRCA testing have decreased. The percentage of persons who had genetic counseling, but were unable to pursue BRCA testing due to inadequate insurance has continued to decline from approximately 22% in 2008 to approximately 8% in 2012. Educational tools and resources have been disseminated to more than 17,000 providers to assist with appropriate breast cancer genetic counseling referrals. Written health plan policies for BRCA clinical services now cover more than 7.5 million Michigan residents. The reported incidence of breast cancer diagnoses among women under 50 years of age has continued to decrease.

The **dissemination/evaluation** goal is designed to utilize data to inform best practices, promote policy change, conduct program evaluation and disseminate findings. MDCH focuses on two key activities to achieve this goal: (1) evaluate the strengths, impact and needs of the DP11-1114 project and (2) disseminate model policies, educational resources, surveillance findings and strategies for payers and providers at multiple levels. Additional audiences of MDCH's data include other state public health departments, federal agencies, national organizations, academic institutions, local cancer registries and clinics, BRCA patients and their families, and the general public.

MDCH is aware that despite its successes in breast cancer genomics in Michigan, more efforts are needed in this area based on statewide data. In 2008–2009, more than 5,000 cases that were appropriate for cancer genetic services were diagnosed in Michigan and reported to MCSP. These cases included 3,184 cases of early onset female breast cancer, 1,680 cases of ovarian cancer, and 141 cases of male breast cancer. A previous survey showed that approximately 55% of YBCS in Michigan did not receive genetic services. The survey also reported that genetic services were not recommended for approximately 58% of these YBCS.

Data from a recent provider survey showed self-perceived confidence in breast cancer genomics, but deficits were noted in the actual knowledge and practice of providers regarding risk assessment, BRCA management, and existing federal laws related to BRCA. Of the surveyed providers, approximately 40% correctly identified autosomal dominant gene mutations as the most common mode of inheritance for most hereditary cancer syndromes; approximately 40% collected ancestry or ethnicity data when obtaining a family history for cancer risk assessment of a patient, approximately 32% correctly identified prophylactic oophorectomy as the procedure with the greatest capacity to reduce the risk of cancer in women 40 years of age with a known BRCA mutation; and approximately 32% were aware of the Genetic Information Nondiscrimination Act.

A recent population-based telephone survey showed that 11% of adult women in Michigan had a significant family history of breast/ovarian cancer, but only approximately 9% of these women reported having genetic counseling in the past. Current MCSP data show that mortality rates are relatively steady for ovarian cancer and female breast cancer diagnosed under 50 years of age. Beginning in 2014, MCDH

will prioritize these and other needs to make further progress on the overarching goal to reduce cancer mortality related to hereditary cancer syndromes. MCDH has established four Web sites and a toll-free telephone number for the public to obtain additional information on its breast cancer genomic activities.

ACBCYW discussed the following topics in the question/answer session with Ms. Duquette on the MDCH DP11-1114 CoAg activities.

- The extent to which payers were involved in the project and strategies to evolve existing relationships with payers as genetic testing becomes more widely available in the future.
- Differences between health plans with a willingness to develop their policies based on USPSTF recommendations versus NCCN guidelines.
- The most effective incentives for health plans to improve their BRCA Policy Dashboard Reports (public recognition through plaques, honors, awards, and press releases).

The discussion resulted in ACBCYW advising CDC to replicate the Michigan survey nationally. The national survey should be designed so that the total number of cases that were appropriate for cancer genetic services versus the number of persons who actually received these services could be compared. These findings would play a critical role in identifying gaps in cancer genetic services at the national level.

Update by the Oregon Genetics Program

Summer Lee Cox, MPH
Genetics Program Coordinator, Public Health Division
Oregon Health Authority

Ms. Cox presented an update on the education, policy and surveillance achievements the Oregon Genetics Program (OGP) has made to date with funding from the CDC DP11-1114 CoAg. OGP's mission is to promote the health, well-being and quality of life of all Oregon residents using up-to-date knowledge of genomics, evidence-based interventions and a public health model. Funding from the CDC DP11-1114 CoAg assists OGP in fulfilling its genetics mission. In addition to OGP, the Genetics Manager also oversees the Breast and Cervical Cancer Program (BCCP) and WISEWOMAN Program.

OGP implements a three-prong approach with education, surveillance and policy components to safeguard the public from detrimental use of genomics information, while promoting the application of genomics information in areas with a clear benefit. OGP collected data from multiple sources and showed that 1,222 BRCA-related breast/ovarian cancers potentially were preventable in Oregon in 2005–2009 through appropriate referrals to genetic services.

OGP estimates that of Oregon's population of nearly 3 million adults, 20,500 are BRCA carriers and approximately 154,000 are candidates for BRCA testing due to their increased risk. Knowledge of BRCA status is important for both carriers and non-carriers. Based on Oregon State Cancer Registry (OSCaR) data, approximately 800–1,150 Oregon women who are diagnosed with cancer each year are estimated to have a BRCA mutation.

The vast majority of genetic clinics in Oregon are located in the metropolitan Portland area, but an additional clinic is located in Eugene and a new tele-medicine cancer clinic is located in Medford. The concentration of clinics in one major area of the state has left approximately 33% of Oregon's population with limited access to cancer genetic services.

OGP administered a statewide quantitative survey to assess the clinical practices of HCPs. Because HCPs were found to lack knowledge and confidence about family history and cancer genetics, OGP reiterated the need for trained GSPs to perform genetic testing in a genetic counseling setting only. OGP is making strong efforts to link HCPs, particularly those in primary care settings, to educational opportunities to improve their cancer genetic knowledge.

OGP estimates that providers with no specialized training in genetics perform approximately 60% of BRCA testing in Oregon and typically do not offer genetic counseling. Gaps in provider knowledge and the provision of genetic counseling and testing by non-geneticists could result in persons at increased risk not being identified; adversely impact the patient's decision-making process; and lead to variations in the quality of counseling, interpretation of test results and development of personalized cancer screening plans. OGP urges Oregon providers to establish relationships with cancer geneticists and become knowledgeable of the appropriate time to refer patients.

OGP's **surveillance** goals are designed to collect and utilize population-level data to identify and evaluate the use of evidence-based breast cancer genomic applications, current gaps in knowledge and services, and opportunities for change. These data assist OGP in developing strategies and obtaining endorsement from stakeholders on early identification, screening, prevention, treatment and referral to genetic services.

OGP's surveillance goals are the foundation of its genetic activities and facilitate the creation of interventions that are specific to the needs of Oregon residents. However, OGP makes strong efforts to ensure that other public health genomic programs can replicate its surveillance achievements as model initiatives. OGP aims to develop systematic approaches to identify and care for high-risk populations.

OGP serves as an information clearinghouse by gathering, analyzing and tracking data from eight major sources. OGP's combined dataset maintains information on persons who do and do not seek genetic services to better understand the barriers, facilitators and health outcomes of persons who receive genetic services; enhance planning of necessary interventions; and identify gaps in knowledge and services. OGP applies surveillance data to directly support its policy and educational activities.

OGP has continued to analyze Oregon Behavioral Risk Factor Surveillance System (BRFSS) data on an ongoing basis. OGP established a strong collaboration with the state Medicaid program due to its long history of including BRCA counseling and testing in the prioritized list of health services in accordance with NCCN guidelines. OGP's analysis of Oregon Medicaid claims data showed a steady increase in BRCA testing since 2007, but significant under-utilization of genetic counseling and testing was observed statewide.

OGP's evaluation of state health insurance plan policies identified 2,801 cases that were appropriate for BRCA counseling based on 2009–2011 OSCaR data. OGP created and implemented its BRCA Surveillance System that includes data from all Oregon Cancer Genetic Clinics, a patient follow-up survey, and the Genetic Information System (GenIS) database.

OGP conducted the BRCA Testing Study to create a limited dataset with patient-level data on all patients who sought HBOC counseling from one of the six cancer genetic clinics in Oregon (first arm) and to survey patients who received BRCA testing (second arm). The clinics used GenIS to store, record and manage their study data. OGP noted that clinical capacity in terms of providing patient-level data widely varied from collecting data from electronic medical records (EMRs) to gathering data from manual chart reviews. Patients who agreed to BRCA testing in the first arm were invited to participate in the second arm of the study.

Preliminary results of OGP's follow-up survey of the BRCA Testing Study were highlighted. Of 15 patients with negative results, the suggestion to undergo BRCA testing was first made by an HCP (69%), the patient (19%), or a family member (12%). Of 14 patients with positive or VUS results, the suggestion to undergo BRCA testing was first made by a family member (64%), an HCP (29%), or the patient (7%).

Of 15 patients with negative results, 14 strongly disagreed or disagreed that increased anxiety occurred after being informed of their test results. Of 14 patients with positive or VUS results, responses to the same question were relatively similar across three categories: strongly agree or agree, neither agree nor disagree, and strongly disagree or disagree.

BRCA testing had an enormously positive effect on increasing the peace of mind of most patients with negative results, but the impact was less significant for patients with positive or VUS results. Of 15

patients with negative results, 14 strongly agreed or agreed that BRCA testing was beneficial overall.

OGP's **education** goals are designed to promote and increase the use of clinical practices and evidence-based interventions recommended by USPSTF and NCCN for BRCA testing. OGP implements a variety of methods to increase provider understanding and public knowledge of risk assessment, appropriate genetic services, the importance of family history and HBOC. OGP collaborates with partners at multiple levels to leverage resources and expertise to develop and implement its educational activities. These partners include other CDC grantees, the Ashkenazi Jewish population, cancer survivors, public health professionals, PCPs/HCPs, health insurance companies, and the general public.

OGP uses community presentations and booths at community events, train-the-trainer events, magazine articles, Web sites, OSCaR letters, and the "Family Health History Challenge" as opportunities to establish strong linkages in communities and raise public awareness of cancer genetics. OGP routinely disseminates information to health insurance companies about genetic conditions, genetic counseling and testing, evidence-based guidelines, and resources. OGP also uses partnerships and journal publications to educate health professionals on the appropriate use of genetic services.

OGP and BCCP maintain close collaborations, but the two programs are not formally integrated due to their focus on different objectives and target populations. For example, BCCP is required to provide access to breast cancer services for low-income, uninsured and underinsured women over 40 years of age and also to offer breast cancer diagnostic services to low-income, uninsured and underinsured women under 40 years of age who are symptomatic.

Benign breast conditions have been detected in many BCCP clients over 40 years of age over the past few years. These conditions are common in young women and mimic true cancer symptoms. Due to this increasing trend, BCCP has questioned whether provider knowledge and confidence in differentiating between breast cancer and benign breast disease had maintained pace with public awareness of breast cancer.

BCCP increased program costs and the number of young women who received unnecessary invasive treatment by providing diagnostic services to asymptomatic young women who were more likely to be diagnosed with benign breast disease than cancer. To correct this flaw, BCCP developed and implemented a checklist in 2012 for provider liaisons to complete before enrolling young women into the program. Provider liaisons now use the checklist to characterize symptoms reported by potential BCCP clients to determine their enrollment eligibility. A family history is taken only after breast cancer symptoms are suspected.

OGP evaluated the effectiveness of the checklist. The checklist was found to be beneficial in improving provider knowledge and confidence and decreasing BCCP enrollment rates among asymptomatic young women (a reduction in young women from 3,958 in 2007 to 2,798 in 2013). However, the evaluation also showed an increase in the rate of breast cancer among young BCCP clients since the checklist was implemented in June 2012. Based on 2011 OSCaR data, the ratio of invasive breast cancer diagnoses in Oregon between young women and women 40 years of age or older is 1:29. Moreover, BCCP's more rigorous enrollment process has required young women to obtain treatment from other sources.

To address these issues, OGP and BCCP will jointly develop and disseminate provider educational materials to increase their understanding of benign breast conditions, breast malignancy and risk factors (family history and HBOC syndrome). OGP also is exploring the possibility of piloting a study that would make screening available to unaffected young women, assess family history, and evaluate other known breast cancer risk factors in this population.

The pilot study could play an important role in increasing enrollment of high-risk young women. However, the study population of low-income, uninsured and underinsured women most likely would encounter economic and other barriers to genetic counseling and testing. OGP is exploring options to ensure that genetic services would be available to all appropriate candidates.

OGP used BRFSS data to determine that 9% of all adult women in Oregon had an increased family

history risk of breast/ovarian cancer in at least one of four categories defined by USPSTF. Of these women, 96% had been specifically asked about a family history of breast/ ovarian cancer by their HCPs, 10% had received genetic counseling, and 70% had never heard of BRCA testing. To increase awareness, OGP compiled a summary that emphasized the importance of referral to a GSP and provided Oregon-specific data, USPSTF recommendations and available resources. CDs of the summary were distributed to more than 10,000 licensed physicians, local health departments, media outlets, state policymakers, and other interested groups.

OGP used 2009–2011 OSCaR data to identify potential candidates for genetic services based on NCCN guidelines. OGP sent educational letters to 2,801 persons diagnosed with breast cancer, triple-negative breast cancer, ovarian cancer and male breast cancer at 50 years of age or younger. OGP also sent letters to 634 physicians who reported the 2,801 cases and an additional 619 physicians who reported other breast cancer cases in the 2009–2011 time period. The letters included $2 and an invitation to complete a brief survey. OGP has collected more than300 surveys to date. OGP hopes its simultaneous dissemination of information will promote in-depth provider/patient discussions on genetic services.

OGP's **policy** goals are designed to promote public policies that improve access to and coverage of genomic services for hereditary breast cancer recommended by USPSTF and NCCN. OGP is collaborating with the Medicaid Health Evidence Review Commission, health insurance companies and other partners to achieve the objectives of its policy goals and conduct specific activities.

- Enhance alignment between private health insurance coverage and guidelines.
- Improve the capacity of Oregon Medicaid Programs to comply with guidelines.
- Educate stakeholders to increase their knowledge of licensure for certified genetic counselors.
- Collaborate with partners to incorporate genomic information and activities into the Oregon Comprehensive Cancer Plan.
- Promote the use of evidence-based guidelines and policy-related activities by HCPs and healthcare systems.
- Establish new and maintain existing partnerships to promote cancer genetic services.

OGP administered a survey in 2012 to seven major health insurance companies in Oregon that represented 90% of approximately 1.1 million lives covered across the state. The key findings of the survey are highlighted below.

- 6 health plans have written breast/ovarian cancer policies.
- 7 health plans cover BRCA testing for persons with and without cancer.
- 7 health plans cover pre- and post-BRCA counseling.
- 7 health plans use guidelines to determine coverage (screening, counseling and testing, and prophylactic measures).
- 7 health plans cover increased breast cancer screening, bilateral mastectomy, salpingo-oophorectomy, and hysterectomy for women with cancer.

The survey identified several notable gaps. Coverage for ovarian cancer screening and chemoprophylaxis was inconsistent for women with cancer. Coverage for increased breast cancer screening, bilateral mastectomy, salpingo-oophorectomy, hysterectomy ovarian cancer screening and chemoprophylaxis was inconsistent for women without cancer. In developing policies, only one plan used USPSTF recommendations and only 4 health plans used NCCN guidelines.

OGP distributed a report of individualized survey findings to each medical director of the seven health plans. OGP is scheduling meetings with medical directors and policy staff of each of the seven health plans to provide an information packet about HBOC, evidence-based guidelines and other resources. The 2014 policies also will be reviewed during these meetings. OGP hopes the health plans will better align their coverage with evidence-based guidelines after ACA is fully implemented. OGP's next steps to advance genomic service policies will be to meet with the Oregon Insurance Commissioner and participate in upcoming local and regional health insurance meetings.

OGP learned several valuable lessons in surveillance, education and policy as a result of the DP11-1114 CoAg. Surveillance played a critical role in better understanding the local landscape and identifying the needs of Oregon residents. Surveillance was the best approach to demonstrate the impact of interventions. Surveillance is an expensive activity, but OGP staff time was the only cost involved in analyzing insurance claims and cancer registry data.

The strategy of targeting educational interventions to a broad spectrum of stakeholders promoted cohesive dialogue among diverse groups, including providers, insurers, policymakers and the general public. The establishment and retention of partnerships was a key factor in OGP's success, particularly opportunities to apply experiences and lessons learned from the Georgia and Michigan DP11-1114 grantees. OGP was able to leverage resources and broaden its reach due to collaborations with other state public health programs and non-profit groups that had similar objectives.

ACBCYW discussed the following topics in the question/answer session regarding activities conducted by all three of the CDC DP11-1114 grantees.

- Potential reasons for the surprising result of only one health plan in Oregon using the USPSTF recommendations to guide the development of policies.
- Plans by OGP, Georgia CORE, and MDCH to publish survey results, research outcomes, case studies or other key findings of their DP11-1114 grant activities in peer-reviewed journals.
- Laboratories that tested genetic samples for the DP11-1114 studies and the proportion of laboratory testing paid for by health plans, public funds or other sources in the three states.

The discussion resulted in ACBCYW making two key suggestions. First, ACBCYW should explore the possibility of forming a new workgroup to review best practices, lessons learned and areas of improvement from all three of the DP11-1114 grantees. If approved, the new workgroup could be charged with formulating recommendations to CDC to further advance breast cancer genomics research.

Second, ACBCYW should issue a formal resolution to emphasize the value of activities conducted by the three DP11-1114 grantees. ACBCYW's resolution also could be used to advise CDC to scale up the screening and prevention strategies developed by the DP11-1114 grantees. This approach would allow other state programs to take advantage of these successful breast cancer genomic tools and other resources at a national level.

Overview of Emerging Topics in Breast Cancer Genetics and Genomics

Robert Cook-Deegan, MD
Research Professor, Institute for Genome Sciences and Policy
Sanford School of Public Policy, Duke University

Dr. Cook-Deegan presented an overview of gene patents and genetic testing that is available for persons with an inherited risk of cancer. The number of DNA patents that have been granted in the United States has tremendously increased from 11 in 1971 to 4,094 in 2012. Of approximately 60,000 DNA patents that have been granted over this 41-year time period, most were not gene patents. BRCA 1/2 patents were initially filed in 1994–1995 and issued in 1997–1998.

Myriad Genetics directly owns or exclusively licenses all 24 BRCA 1/2 patents that have been granted to date in the United States. Myriad has made more than 500 claims in its patents, but claims in two of its BRCA1 patents have been the subject of recent litigation: DNA molecules and a method to detect variations in BRCA1. In 2012, courts lower than the U.S. Supreme Court invalidated Myriad's method to detect variations in BRCA1. The method was characterized as a "law of nature" and was determined to be too broad and abstract for a U.S. patent to be granted.

In May 2009, the case of the *Association for Molecular Pathology, et al. v. Myriad Genetics* was filed due to concerns by advocates regarding medical decision-making of gene patents, access to and costs of care, and Myriad's service monopoly business model. In 2010–2012, the New York City Federal District Court ruled that all challenges to the claims were invalid. The Court of Appeals for the Federal Circuit upheld the invalidation of method claims, but reversed the decision on the DNA molecule claim. The claim was allowed as "patentable subject matter."

Several major developments occurred in cancer genetics in May–June 2013. Angelina Jolie's op-ed was published in *The New York Times* and emphasized the importance of genetic testing to detect HBOC risks. The U.S. Supreme Court invalidated Myriad's genomic DNA molecule claim, but upheld its complementary DNA claims. However, litigation is ongoing because only 7 of Myriad's 24 patents were included in the recent lawsuits and only 15 of Myriad's more than 500 claims in its patents have been challenged to date.

Myriad filed lawsuits against six competitor companies that announced their intentions to offer BRCA testing. Although all six cases have been consolidated into one case, a Salt Lake City, Utah court primarily will focus on the major issue of whether Myriad has legal authority to eliminate competition by other laboratories. Some of the six competitor companies have filed countersuits against Myriad based on their claims of illegitimate monopoly, violation of antitrust laws and jurisdictional issues. Requests for declaratory judgment of non-infringement have been submitted to the court by two companies in California.

The underlying factors for the recent litigation on BRCA testing include control of access to care, optimal technical approaches related to the number of genes tested, and historical distrust of Myriad's service monopoly business model of patenting genes for testing to identify risks of HBOC and other cancers.

The early history of commercial BRCA testing in 1996–1999 allowed for competition between Oncormed and Myriad. Oncormed obtained the first BRCA 1 patent that required breast cancer testing to be conducted with a strong evidence base and protocols approved by an Institutional Review Board. Because Myriad disagreed with Oncormed's business model, the two companies reached an out-of-court settlement after lawsuits were filed.

The 2006 Cook-Deegan, *et al.* study reviewed policy documents and media coverage of various gene patent controversies over the 2002–2006 time period. The study showed that Myriad's BRCA testing has accounted for the overwhelming majority of controversial cases. Moreover, the media has negatively covered Myriad's breast cancer patent policies in Australia, Canada, the United Kingdom and United

States. Preliminary research suggests that Myriad might not have discovered BRCA2 and would have no rights to a U.S. patent for this gene mutation.

Despite controversies related to its service monopoly business model, Myriad performs well in several areas of genetic testing: rapid turnaround time for test results, accurate testing, clarity of reporting, third-party reimbursement, marketing, free family testing for VUS, data pooling, and robust generation of revenues ($520 million in 2012–2013 from BART testing). However, the collection and retention of Myriad's data from approximately 1 million BRCA tests by one laboratory is unprecedented in the United States. This infrastructure does not allow for the interpretation of gene variations that are discovered *de novo* each day.

Several factors have contributed to persistent ill will for Myriad over time. Companies that previously were invested in the BRCA gene discovery effort continue to view themselves as strong competitors of Myriad. The initial business model that Myriad adopted did not comply with evidence-based guidelines for breast cancer testing in the late 1990s. Myriad filed lawsuits and distributed a series of enforcement letters to universities and competitors.

Beginning in November 2004, Myriad no longer shared its data with the Breast Cancer Information Core (BIC) or other public databases. Myriad claimed to be a main contributor to the BIC database, but did not publicly announce its decision to withhold data from this source. Myriad still maintains its information and algorithms in a proprietary database. Myriad's continued practice of direct marketing to consumers, oncology clinics and general practitioners instead of GSPs to order genetic testing has been problematic for nearly 10 years.

Myriad's trade secrets are another source of tremendous concern for genetic testing. For example, Myriad's proprietary database of approximately 1 million BRCA tests leverages its role as the sole provider of BRCA testing and the primary interpreter of test results in the United States. Exclusivity of Myriad's database does not expire with its patent. Myriad claims that VUS accounts for only 2% of its genetic testing results compared to 30% among European laboratories, but data show that this rate is inflated and actually is approximately 12%. The commercial value of Myriad's proprietary database would be virtually useless if other avenues were available to effectively pool and collectively interpret breast cancer genomics information.

BRCA 1/2 genes have been applied to more than 1 million commercial tests over the past 20 years and have undergone the most rigorous study as any other two genes in the human genome. Although new mutations in BRCA genes are still being discovered, BRCA genes provide the best opportunity to detect variations in the human genome. BRCA 1/2 genes have been joined by approximately 20 other genes in conferring breast/ovarian cancer risks.

The 2002 National Research Council report and two 2012 Institute of Medicine reports emphasized the importance of obtaining independent verification in genomics apart from the testing laboratory. The reports recommended that "neutral," "deleterious" or "VUS" testing results should be claimed in the scientific literature or in clinical settings only if independent experts reviewed and agreed with both the data and the algorithm to interpret data.

In addition to the absence of an independent genomics verification system in the United States, other critical issues also need to be addressed to advance breast cancer genetics/genomics. An infrastructure is needed to share data, particularly for BRCA 1/2 testing data that are captured and maintained in proprietary databases. Proprietary databases do not allow data to be reproduced or verified for objective, scientific or clinical claims.

An infrastructure is needed to pool and link genotype, phenotype and clinical outcome data in order to reliably interpret genomes from a clinical perspective. Most notably, existing databases that track human mutations, clinical/population data and clinical outcomes of persons who receive genetic testing are extraordinarily inaccurate for clinical interpretation. An infrastructure is needed to improve and widely share algorithms for interpreting the clinical significance of variants.

ACBCYW discussed the following topics in the question/answer session with Dr. Cook-Deegan on gene patents and available genetic testing.

- The implications of Myriad's service monopoly business model on the high cost of BRCA 1/2 testing; limited access for persons who need BRCA 1/2 testing; and the inability of non-Myriad scientists and researchers both domestically and internationally to conduct independent studies on BRCA 1/2 test results.

- The potential need to identify and encourage individuals and their families with negative results to obtain additional genetic counseling and testing due to the exclusion of certain gene mutations from Myriad's commercial BRCA 1/2 tests.

Update by the ACBCYW Ad Hoc High-Risk Workgroup

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

Ms. Shoretz covered the following topics in her workgroup report to ACBCYW. The workgroup was formally charged with gathering initial background information and advising ACBCYW 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. In the course of fulfilling its charge, the workgroup agreed to advise CDC to craft messages that would educate young women about their potentially increased risk of breast cancer and the need to seek care without causing undue fear in the target audience.

The workgroup focused on answering three key questions to fulfill its charge: (1) What are the definitions of "average risk," "higher risk," and "high risk" in the context of young women at risk of breast cancer? (2) What should ACBCYW consider when exploring components of effective health messages targeting young women? (3) What should ACBCYW consider when exploring components of evidence-based or evidence-informed messages targeting young women?

In response to the workgroup's request for input, ACBCYW provided thoughtful guidance and helpful suggestions in the following areas: research gaps and data to inform the development of recommendations to CDC about messages to high-risk young women; appropriate content of breast cancer messages targeting young women; and effective methods to deliver breast cancer messages targeting young women.

Ms. Shoretz reminded ACBCYW that the workgroup presented its draft recommendations during the December 2012 meeting. Based on ACBCYW's extensive comments, the workgroup revised its recommendations for formal adoption by ACBCYW and inclusion in Dr. Partridge's letter to the HHS Secretary on May 13, 2013. The letter is available for review on the ACBCYW Web page of the CDC.gov Web site. Ms. Shoretz summarized ACBCYW's final recommendations to the HHS Secretary on actions that CDC should take to increase awareness of young women at high risk of breast cancer.

CDC should hold focus groups and/or administer Web-based surveys to gather additional data on appropriate messaging for high-risk young women. CDC should extensively engage and collaborate with the target population to develop effective messaging. CDC should target messaging to three audiences of high-risk young women: (1) young women with hereditary susceptibility of breast cancer, (2) young women with biopsy-proven atypical hyperplasia or lobular carcinoma *in situ*, and (3) young women with a history of chest wall radiation during adolescence or early adult life.

If funding is available, CDC also should craft messages to target the following audiences of young women at higher than average risk: (1) young women of Ashkenazi Jewish descent with an unknown family history or a family history that does meet "high risk" criteria, (2) young women with mammographically dense breasts as documented by a breast radiologist, and (3) young women of non-Ashkenazi Jewish descent and a family history that does not meet "high risk" criteria.

CDC's messages should include robust, evidence-based recommendations on activities with demonstrated efficacy in reducing breast cancer risks. To assist CDC in this effort, the workgroup applied findings from its literature review and other research to describe several activities that most likely would be well received by young women.

- Encourage young women to become familiar with their bodies—and specifically their breasts—to report abnormal conditions to their medical providers.

- Encourage young women to make healthy lifestyle choices (maintenance of a balanced diet and proper weight, smoking cessation, adequate exercise, and limited alcohol consumption) as healthy lifestyle choices may reduce breast cancer risk and risk of other diseases.

- Encourage young women to breastfeed because breastfeeding may reduce breast cancer risk.

CDC's messages should not cause undue fear in the target audience of young women and should be aligned with the interests of young women. The workgroup's literature review and research indicated that positive messages were much better received than negative or "fear-based" information. For example, messages that explicitly link healthy lifestyle choices to overall health and wellness may have a greater impact than those with a correlation between healthy lifestyle choices and a reduction in cancer or other diseases. Moreover, messages evoking images of exercise, fitness and beauty may have a greater impact than those evoking images of illness and disease.

CDC's messages should communicate clear information about breast cancer risk and encourage the target audience of young women to take specific actions ("Talk to your family" or "Talk to your doctor"). CDC should be mindful of health literacy issues when creating message content for young women. Based on the workgroup's literature review and research, an appropriate reading level should not exceed that of a sixth-grade to eighth-grade student.

CDC should create the text and images of messages to reflect the unique needs of diverse populations of young women. CDC should design messages to address stigma associated with breast cancer in some communities, particularly the Ashkenazi Jewish community, Orthodox community, and some parts of the African-American community.

CDC should replicate existing messages targeted to the population of high-risk young women that have been developed by other organizations for scale-up and implementation at the national level. CDC should make full use of various social media platforms to deliver messages to young women, such as Facebook, Twitter, Instagram, and Snapchat. Text messaging and other communication strategies that are effective among young women should be utilized as well. However, CDC should explore alternative methods to reach young women who do not have access to these communication portals.

Update by the ACBCYW Ad Hoc Provider Workgroup

Generosa Grana, MD, FACP
Director, Cooper Cancer Institute
ACBCYW Member & Provider Workgroup Member

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

As part of its charge, the workgroup agreed to clearly define "providers" and determine the patient population that should be targeted: women of reproductive age up to 45 years, pre-diagnosis women at average or high risk (including those at risk of relapse or second primary breast cancer), and post-diagnosis women.

In defining "providers" for breast cancer pre-diagnosis, early diagnosis and post-diagnosis women, the workgroup included all professionals who would provide services to or act as an information source for young women: general practice, family practice, and internal medicine physicians; obstetricians/gynecologists; physician assistants; primary care nurse practitioners; oncology, college and high school nurses; medical, surgical, and radiation oncologists; and PCPs who provide care to cancer survivors.

The workgroup identified several professional societies and networks that potentially could be engaged to effectively outreach and deliver messages to providers: 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, American College of Surgeons, American Society for Radiation Oncology, Oncology Nursing Society, and NCCN. Many of these organizations already have created guidelines and could serve as strong partners in assessing the current state of the field and developing and implementing strategies targeted to providers.

A review of the existing literature and relevant strategies resulted in the workgroup identifying three opportunities that potentially could impact HCPs with regard to providing BCYW care. First, training should be provided to students, physicians and other HCPs, including nurse practitioners, physician assistants, residents and trainees. Specific modules should be created and disseminated to medical schools and schools of nursing to provide training on genetics, communication skills and clinical skills.

Second, training should be provided to practicing clinicians at three key intervention points: the initial certification process, maintenance of certification and licensure, and ongoing CME. Training materials should cover BCYW in order for practicing clinicians to build expertise in this area. Third, EMRs should play a critical role in HCP education for knowledge, clinical practice and the development of benchmarks for service.

In terms of ongoing activities targeted to HCPs, the workgroup discussed tools and resources that have been developed by federal agencies and potentially could be adapted, tested and disseminated with appropriate funding. Based on the updates presented during the current meeting, Dr. Grana confirmed that the workgroup would formulate guidance for two new issues to improve the impact on provider behavior change.

First, the DP11-1114 grantees reported that genetic counseling and testing are not provided to more than 50% of women who are candidates for these services. Second, the DP11-1114 grantees emphasized that health plans can play a valuable role in strengthening efforts to outreach and disseminate information to both their member providers and insured patients. The workgroup will place emphasis on crafting recommendations for CDC to scale up the three DP11-1114 projects for national implementation. The

workgroup explored the possibility of integrating CDC's BodyTalk Clinical Decision Support Tool into office practice and EMR settings. BodyTalk is designed to enhance communication between providers and patients.

The National Institutes of Health developed the eDoctoring Program as an interactive online educational tool that covers ethics, genetics, clinical management, epidemiology and communication skills. Potential users of the tool include medical and nursing students, residents and PCPs, but credentialing bodies could be additional users of the program for certification and licensure.

The Agency for Healthcare Research and Quality (AHRQ) developed the Effective Healthcare Program as an initiative to create educational materials for patients and HCPs. The AHRQ Accelerating Change and Transformation in Organizations and Networks (ACTION) is used to test and disseminate defined strategies. The workgroup agreed that CDC should closely collaborate with AHRQ due to its role as the major innovator in the development of EMRs and health information technology.

The workgroup reached several major conclusions based on its literature reviews and research to date. Guidelines have been developed to guide HCPs on issues related to genetic testing, risk assessment and chemoprevention strategies for young women at increased risk of breast cancer. Significant gaps persist and more research is needed to assess the current level of knowledge of PCPs, determine their utilization of existing guidelines, and fill gaps in current research. Information learned from additional research should be used to develop focused strategies to target HCPs. However, updates presented by the DP11-1114 grantees during the current meeting showed that these projects had an impact in filling some of these gaps.

The workgroup's five draft recommendations to ACBCYW are highlighted below.

1. A more detailed assessment should be conducted to determine the current level of knowledge and practice among PCPs regarding BCYW. To achieve this goal, collaborations should be established with medical and nursing primary care societies to develop and disseminate a survey instrument. The eDoctoring tool should be used to assess both provider knowledge and practice and evaluate the impact of these educational strategies. The use of tools that are available to CDC should be assessed as well (the "DocStyles" survey of PCPs and the DP11-1114 breast cancer genomics CoAg).

2. The development of educational tools that are targeted to HCPs at various points in training should be fostered. To achieve this goal, the potential use of certification and re-certification requirements should be assessed for their use in medical training, medical schools, nursing schools and residency programs. The eDoctoring module and other existing tools should be evaluated and expanded to examine the needs of providers and devise strategies to meet these needs.

3. The analysis of BodyTalk as a tool that focuses on both patients and HCPs should be continued. To achieve this goal, the potential efficacy of the AHRQ ACTION Network in both provider and patient populations should be evaluated. Effective dissemination strategies also should be explored (the AHRQ Effective Healthcare Program).

4. Ongoing EMR initiatives should be broadly expanded and evaluated through a CDC/AHRQ collaboration to focus on BCYW.

5. Collaborations should be established with ongoing national initiatives (the Tigerlily Foundation and Planned Parenthood) that provide education to PCPs on BCYW and develop new risk assessment tools.

Update on CDC's Breast Cancer in Young Women Activities

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

Dr. Fairley covered the following topics in her update to ACBCYW on CDC's BCYW activities. The EARLY Act authorized CDC to conduct initiatives to increase understanding and awareness of breast health and breast cancer among young women at high risk, including women under 40 years of age. The EARLY Act further authorized CDC to provide support to young women with breast cancer, launch a national evidence-based education campaign targeted to certain populations to conduct BCYW prevention research, and establish ACBCYW as its formal advisory committee.

ACBCYW is chartered to provide advice to the HHS Secretary and the CDC Director regarding the formative research, development, implementation, and evaluation of evidence-based activities aimed at prevention, early detection and survivorship. ACBCYW's charter also calls for the provision of guidance to assist in ensuring the scientific quality, timeliness, dissemination and utility of credible and appropriate messages for resource materials. ACBCYW was formed in July 2011 and convened the first of its five meetings to date in October 2011.

CDC uses its EARLY Act authority to fund and conduct numerous BCYW projects in three major categories. **Category 1** is CDC's completed and ongoing BCYW applied research activities. The "Walking Together: Making a Path Toward Healing" Project was designed to examine issues related to breast cancer diagnosis, treatment and survivorship among young Native American women and identify barriers to this population obtaining diagnoses and accessing post-diagnosis care and support.

The "Breast Cancer in Young Women: Reviewing the Evidence and Setting the Course" informal meeting of experts was specifically tasked with reviewing the broad spectrum of evidence and providing CDC with advice on particular research areas that should be considered. The report was published in the *Journal of Women's Health* and publication of its literature review is underway. The "Estimating Infertility Among Breast Cancer Survivors" Study was the first research project to estimate infertility among YBCS and is expected to be published in 2014.

The "Health Insurance Coverage for Genetic Services Across the United States" Study was designed as a review and analysis of health insurance policies that cover genetic and follow-up services. The data analysis and report are being finalized for publication. The "Economic Burden of Breast Cancer in Young Women Aged 15–44 Years in the United States, 2000–2010" study was initiated in response to ACBCYW's previous suggestion to better understand the economic impact of disease in this population. The study generated a paper that focused on breast cancer mortality in young women and the loss of income/wages due to their disease. The citation will be posted on the CDC.gov/cancer Web site in the near future.

CDC's ongoing BCYW research activities are highlighted as follows. The Sisters Study and Two Sisters Study are designed to answer fundamental public health questions about the BCYW population and young women who might be at increased risk of developing breast cancer because their siblings or first-degree relatives were diagnosed with the disease. The population-level studies will help to guide decision-making on appropriate communication messages for these populations. Data show a persistent lack of knowledge of genetics and genetic testing among young women with breast cancer and their siblings/first-degree relatives. Updates on the studies will be presented to ACBCYW on an ongoing basis.

The "Impact of Genomics and Personalized Medicine on the Cost-Effectiveness of Preventing and Screening Breast Cancer in Young Women" study will be important for decision-makers so that resources could be allocated appropriately nationally at both policy and health care system levels. The new "Comparative Effectiveness and Clinical Utility of Risk Assessment Tools for Hereditary Breast and Ovarian Cancer" study is designed to identify the most appropriate, accurate, and simple risk assessment

tools for young women with HBOC. Once identified, they could be promoted and further advanced.

A new economic study is examining the impact of late-stage diagnoses in young women to determine cost savings with earlier detection in this population. Another new study is focusing on the correlation between reducing alcohol consumption in young women and decreasing breast cancer risks.

Category 2 is CDC's BCYW program support activities. Funding of the DP11-1114 CoAg, "Enhancing Breast Cancer Genomics Practices Through Education, Surveillance and Policy," will end in September 2014. Cancer Survivorship CoAg funding was awarded to seven grantees to provide support and education/awareness resources to YBCS in the United States. The funding will end in September 2014.

The "Developing Psychosocial and Reproductive Health Support for Young Breast Cancer Survivors in the United States" study was designed to engage partners in the field that currently had resources in this area and were willing for their resources to be reviewed by two grantees: Sisters Network, Inc. (SNI) and Sharsheret, Inc. The grantees tailored the resources to meet the specific needs of their target populations (African-American and Jewish women, respectively) and evaluated the adapted tools and other materials. Findings from the recently completed study will be applied to support the development of additional messages for YBCS.

CDC rigorously evaluates its program support activities to assess the performance of internal staff and grantees and also to review key outcomes. The Cancer Survivorship CoAg is being evaluated at this time. Manuscripts of major findings from the most recent studies are expected to be published in 2014–2015.

Category 3 is CDC's BCYW communication activities. A CoAg was awarded to Hollywood Health and Society, "Using Entertainment Indication to Reach Women Regarding Breast Cancer Risk Factors." CDC collaborated with writers and producers of the *Beverly Hills 90210* television program to develop storylines related to BRCA 1/2. The television episodes described risk factors and specific actions for young women to take in seeking care. A social media evaluation showed that television programs are extremely effective in conveying health messages to young women.

The BodyTalk Clinical Decision Support Tool is designed to increase the ability of young women to communicate with their providers about their HBOC risk based on having BRCA 1/2 gene mutations. BodyTalk aims to facilitate dialogue from the provider's perspective, but also has the capacity to strengthen awareness, share educational information and provide background materials. BodyTalk was revised and re-branded based on input from ACBCYW, genetic counselors and researchers regarding the visual appeal and scientific features of the tool. The updated and newly-named tool will be launched on March 31, 2014 and targeted to HCPs and young women.

The "Social Media Usage" project is underway to monitor conversations related to breast/ ovarian cancer and breast cancer genetics among young women. This project was used as a foundation to develop new activities, including several initiatives that responded to ACBCYW's recommendations to HHS on young women at high risk of breast cancer. Funds were awarded to Hollywood Health and Society to conduct the new "Education, Awareness, and Support for Minority and High-Risk Women Who Are Living With or at Increased Risk for Breast Cancer" project. Collaborations will be established with television program producers to develop storylines that will convey health messages to these target populations.

A new social media campaign with evidence-based or evidence-informed messages will be targeted to and rapidly deployed for young women at high risk of developing breast cancer. ACBCYW's high-risk recommendations and existing research will be used to guide its development.

Existing partnerships with SNI and Sharsheret will be utilized to conduct the new "Breast Cancer Genetics and Family History for Women at Higher Risk for Developing Breast Cancer" project. The project will feature a campaign with both traditional and social media to increase the national dialogue on "higher risk" in the context of breast cancer genetics and family history. Many of these projects include communication research to provide support to young women with breast cancer and identify the most appropriate approaches to develop the education campaign and craft messages.

CDC anticipates launching new activities in FY2015 pending funding availability and contract approval. The "National Breast Cancer in Young Women Multimedia Campaign" will target young women at high and higher risk as well as to YBCS. Input will be solicited from ACBCYW on effective approaches to target messages to young women at "average" risk in the multimedia campaign without causing fear.

Dr. Fairley concluded her update by summarizing CDC's responses to the three categories of ACBCYW's recommendations that were outlined in the letter to the HHS Secretary.

1. *Identify and communicate effectively with young women at elevated risk (including high-risk and higher-risk women)*. CDC fully accepts the recommendation for implementation. CDC already has initiated new projects in this area and plans to conduct additional activities in the future to the extent that funding and staff time permit.

2. *Support the development and utilization of strategies to engage providers in identifying and communicating with young women at elevated risk.* CDC fully agrees with the recommendation. However, CDC needs further discussion with ACBCYW on strategies to facilitate provider engagement and communication, particularly among PCPs with busy clinical practices who have limited time to spend with patients and might be reluctant to undertake an additional task.

3. *Engage patients and providers to highlight and address issues unique to young women facing breast cancer.* CDC fully agrees with the recommendation and will continue to conduct public health research in this population, such as basic surveillance studies. However, CDC's public health mission is limited in responding to ACBCYW's strong recommendation for continued support of basic, translational, clinical and epidemiologic research aimed at improving the understanding, risk reduction and treatment of women with breast cancer in general.

Open ACBCYW Discussion

Dr. Partridge opened the floor for ACBCYW to revisit any issues raised during the virtual meeting. Key comments and suggestions raised during the open discussion are highlighted below.

- CDC expects to scale up the DP11-1114 projects beyond the three funded states. If resources are not available for broad expansion, however, CDC will utilize existing mechanisms to widely disseminate the breast cancer genomics tools, research findings and other components of the projects for replication and implementation at the state level. For example, CDC's Office of Public Health Genomics is developing toolkits with evidence-based materials and other resources to assist states in conducting public health genomics activities even with limited budgets.

- ACBCYW should not cite breast density as a risk factor for developing cancer to the same degree as other issues due to inconsistent evidence in this area at this time.

- ACBCYW will view its existing recommendations on high-risk and provider issues as "living" guidance that can be revised and updated over time as new data are generated. However, ACBCYW should now begin to shift its focus to three areas.

    - Develop a set of new recommendations over the next year based on CDC's new, ongoing, and pending BCYW activities.

    - Describe concrete action steps for CDC to advance initiatives for high-risk women and providers and fill gaps in these areas.

    - Retire or continue ACBCYW's two existing workgroups with clear priorities and expanded charges or decide whether new workgroups should be formed to focus on new tasks:

        - Further define and illustrate "average risk" of breast cancer among young women for both providers and patients.

        - Focus on young women with a strong family history of breast cancer, but who believe their risk is low based on a negative genetic test result.

        - Explore strategies to capitalize on media attention to increase the public's substantive knowledge of breast cancer genomics and genetics.

        - Scale up the Michigan model of educating payers on the importance of adhering to evidence-based guidelines in order to improve access to genetic services.

        - Identify measurable indicators to assess behavior change among the target population of young women over time.

        - Develop messages on environmental risks to young women.

        - Clarify the definition of "primary prevention" in the context of breast cancer to clearly distinguish between prevention of a new primary diagnosis of breast cancer versus recurrence of breast/ovarian cancers.

        - Facilitate the continuum of care in terms of follow-up, primary care, survivorship and secondary prevention when young women with breast cancer shift their care from oncologists to PCPs. Key results from projects conducted by the seven cancer survivorship grantees should be used to inform this effort. Updates by some of these grantees will be placed on the March 2014 ACBCYW meeting.

        - Establish a minimum level of knowledge that providers (PCPs, internists, gynecologists and adult/adolescent physicians) should have to screen young women for breast cancer.

Existing resources should be used to inform this effort: EMR technology and Michigan's online breast cancer genomics module with CME for PCPs to increase their competency in HBOC risk assessment, referral and management. Consideration also should be given to formulating guidance specifically for major EMR centers. Potential partners to engage in this activity include the American Academy of Family Physicians due to its creation of an excellent online CME program and the Association of Community Health Centers as a source to broadly reach PCPs.

- Engage the three DP11-1114 grantees in discussions to determine the provider outreach, educational tools and resources that were developed with their CoAg funds. The cancer survivorship grantee that has conducted systems-level activities at the University of North Carolina-Chapel Hill should be involved in these discussions.

The open discussion resulted in ACBCYW reaching agreement in the following areas. ACBCYW agreed to continue the High Risk and Provider Workgroups with expanded charges to focus on evaluation and the need to fill gaps between awareness and increased knowledge. Both workgroups will continue to craft guidance for CDC to develop communication messages, campaigns and other activities targeted to young women and providers.

The High-Risk Workgroup will be restructured as a broader "Risk Workgroup" with an additional charge of developing messages to clearly define and illustrate "average risk" of breast cancer among young women for both providers and patients. Dr. Marisa Weiss volunteered to lead this new effort for the Risk Workgroup.

The new ACBCYW members were asked to send e-mail messages to the following persons regarding their interest in joining either one of the workgroups:

- Dr. Ann H. Partridge, ACBCYW Chair (ahpartridge@partners.org)
- Dr. Temeika Fairley, ACBCYW Designated Federal Official (tff9@cdc.gov)
- Ms. Rochelle Shoretz, Risk Workgroup Chair (rshoretz@sharsheret.org)
- Dr. Generosa Grana, Provider Workgroup Chair (grana-generosa@cooperhealth.edu)

For the new charge of filling gaps between awareness and increased knowledge, the workgroups will focus on adherence to and gaps in evidence-based guidelines in order for payers to improve access to care and coverage of services. CDC will make efforts to invite Dr. Jeanne Conry, President of the American Congress of Obstetricians and Gynecologists, and representatives of other medical professional societies to make presentations during future ACBCYW meetings to assist the workgroups in fulfilling this new charge.

ACBCYW agreed to delay establishing an additional workgroup until the March 2014 meeting. If approved, the new workgroup will be charged with formulating guidance to address unique issues of women diagnosed with breast cancer (fertility, metastatic impacts, and survivorship).

Public Comment Session

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

Closing Session

Dr. Partridge thanked the ACBCYW members for their thoughtful advice over the course of the meeting and CDC for developing an extraordinarily productive meeting agenda. She particularly recognized Dr. Fairley, Ms. Carolyn Headley—the ACBCYW Committee Management Specialist—and other DCPC staff for their continued stewardship and management of ACBCYW. She reminded ACBCYW that CDC would circulate an e-mail message with the exact date of the March 2014 in-person meeting.

Dr. Fairley thanked the ACBCYW members for continuing to contribute their valuable time and expertise to assist CDC in developing, implementing and advancing activities to improve the lives of young women with breast cancer. She confirmed that the March 2014 ACBCYW meeting would be available by teleconference and webinar for persons who would be unable to attend in person. The participants joined Dr. Fairley in commending Dr. Partridge for her outstanding leadership as the ACBCYW Chair.

With no further discussion or business brought before ACBCYW, Dr. Partridge closed the virtual meeting at 2:42 p.m. EST on January 9, 2014.

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

◆ Pre-Registrant

Glossary of Acronyms

ACA.....Affordable Care Act
ACBCYW.....Advisory Committee on Breast Cancer in Young Women
ACTION.....Accelerating Change and Transformation in Organizations and Networks
AHRQ.....Agency for Healthcare Research and Quality
BART.....BRACAnalysis® Large Rearrangement Testing
BCCP.....Breast and Cervical Program
BCYW.....Breast Cancer in Young Women
BIC.....Breast Cancer Information Core
BRFSS.....Behavioral Risk Factor Surveillance System
B-RST.....Breast Cancer Genetics Referral and Screening Tool
CDC.....Centers for Disease Control and Prevention
CME.....Continuing Medical Education
CoAg.....Cooperative Agreement
Consortium.....Georgia Breast Cancer Genomic Health Consortium
DCPC.....Division of Cancer Prevention and Control
EARLY Act.....Education and Awareness Requires Learning Young Act
EMRs.....Electronic Medical Records
FACA.....Federal Advisory Committee Act
FOA.....Funding Opportunity Announcement
GenIS.....Genetic Information System
Georgia CORE.....Georgia Center for Oncology Research and Education
GSP.....Genetic Service Provider/Professional
HBOC.....Hereditary Breast/Ovarian Cancer
HCPs.....Healthcare Providers
HHS.....U.S. Department of Health and Human Services
MCSP.....Michigan Cancer Surveillance Program
MDCH.....Michigan Department of Community Health
NCCN.....National Comprehensive Cancer Network
NCI.....National Cancer Institute
OGP.....Oregon Genetics Program
OSCaR.....Oregon State Cancer Registry
PCPs.....Primary Care Physicians
SNI.....Sisters Network, Inc.
USPSTF.....U.S. Preventive Services Task Force
VUS.....Variant of Uncertain Significance
YBCS.....Young Breast Cancer Survivors