

**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**

**Teleconference**

**November 20, 2020**

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**Record of the Proceedings**

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**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**

**TELECONFERENCE**

**NOVEMBER 20, 2020**

**MINUTES OF THE MEETING**

The U.S. Department of Health and Human Services (HHS) and the Centers for Disease Control and Prevention (CDC), National Center for Chronic Disease Prevention and Health Promotion, Division of Cancer Prevention and Control (DCPC), convened the teleconference of the Advisory Committee on Breast Cancer in Young Women (ACBCYW) on November 20, 2020.

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

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

**OPENING: WELCOME, ROLL CALL, AND INTRODUCTIONS**

*Jeremy McCallister*

Designated Federal Officer, DCPC, CDC

Mr. McCallister conducted roll call and confirmed 14 voting members and *ex-officio* members (or their proxies) in attendance. This constituted a quorum for ACBCYW to conduct its business on Friday, November 20, 2020. He welcomed the participants to the teleconference. There were no publicly declared conflicts of interest by the voting members for any of the items on the published agenda (*Attachment 1: Published Meeting Agenda*).

*Elana Silber, MBA*

Sharsheret

ACBCYW Committee Chair

Ms. Silber called the meeting to order at 8:17 a.m. EST. She thanked the members for making the meeting a priority despite the challenging times the world is currently experiencing. Each member was afforded the opportunity to introduce themselves as well as their organization.

## CDC UPDATES

*Temeika L. Fairley, PhD*

Senior Health Scientist, DCPC, CDC

Dr. Fairley provided the committee with an overview of the DIVISION OF CANCER PREVENTION AND CONTROL (DCPC), and activities and national programs (<https://www.cdc.gov/cancer/dcpc/about/programs.htm>) managed by the Division.

Dr. Fairley also discussed some of the work related to breast cancer in young women, including the BRING YOUR BRAVE CAMPAIGN which was launched in 2015. This year, CDC launched a continuing medical education (CME) one-credit course on early onset breast cancer for HCPs, launched new videos featuring young women at risk for or living with breast cancer diagnoses, and launched website material to educate the public about AT-HOME GENETIC TESTING. CDC also fostered collaborations with national organizations to advance its work in breast cancer in young women. CDC co-sponsored a podcast with the National Society of Genetic Counselors (NSGC) to discuss best methods for facilitating better interactions between primary care providers and genetic counselors. CDC launched the EARLY ONSET BREAST CANCER EDUCATION PROGRAM in June 2020, in collaboration with the American College of Obstetricians and Gynecologists (ACOG). The free course offers 14 (CME) or continuing education (CEU) credits for health care providers that complete the training. So far, 837 people registered for the course, with 427 course completions. Increases in knowledge for people completing the course have been noted. The course completion demographics include 70% MDs; 10% Doctors of Osteopathy; 9% nurse practitioners; 6% physician assistants; and 5% students.

In addition to the online course, clinical guidance documents and peer-reviewed journal articles have been published and made available to persons taking this course. An executive summary from the evidence reviews conducted by ACOG on EOBC was also published in OBSTETRICS & GYNECOLOGY.

Another collaboration highlighted was one developed with the National Association of Chronic Disease Directors and several other partners. An online resource was created that utilizes virtual humans to assist patients with the screening and the diagnosis process. Segments include topics like triple negative breast cancer, prostate cancer screening, and infection control and risks.

Dr. Fairley also provided the committee with a detailed overview of the social media metrics for all its campaigns and digital resources. This included data related to the BYB campaign.

Lastly, Dr. Fairley expressed gratitude to the committee members for helping the Division advance the work of breast cancer in young women.

Before moving to the next presentation, a motion was made by Ms. Silber to invite Dr. Fairley to the committee table to serve as a subject matter expert (SME) and provide input, as necessary. The committee unanimously approved the motion.

## BARRIERS TO CARE PRESENTATION

*Lisa Schlager*

Facing Our Risk of Cancer Empowered (FORCE)

Vice President, Public Policy

Ms. Schlager's presentation focused on the cost of and access to care high-risk screening and prevention, with the goal of having a discussion with the committee regarding these barriers and share remedies to address these issues.

She began by providing some background information on FORCE. The organization is over 20 years old and has recently been rebranded. Previously, FORCE's work focused on the individuals who have breast cancer gene (BRCA) mutations, but it now also serves individuals who test positive or have a strong family history for other cancer mutations or hereditary cancer syndromes. The efforts of the organization now include support, education, research, advocacy, and public policy.

According to Ms. Schlager, data shows that patients at increased or high risk for cancer, are encountering excessive out-of-pocket costs for expert-recommended cancer screenings/surveillance related to their health status. She provided a brief overview of the various cancer gene mutations (e.g., BRCA1, BRCA2, ATM, CHEK2, etc.). She also discussed Lynch Syndrome, which is more common than BRCA mutations, and the cancers associated with it (e.g., colorectal, endometrial, and ovarian cancers). Currently, cost sharing is allowed under the Affordable Care Act (ACA) for BRCA 1 and 2, but there are other gene mutations that play a factor in hereditary cancers. Ms. Schlager noted that multigene panel testing has become a great way of addressing this issue as it allows for the testing of many more gene mutations and identification of more individuals who carry an inherited genetic risk. Multigene panel testing has become the standard of care and can be done for \$250 or less (using at-home or direct to consumer tests).

Ms. Schlager provided the Committee with a detailed overview of the National Comprehensive Cancer Network (NCCN) guidelines for genetic counseling and testing and risk and disease management. These guidelines include those with breast (including males) or ovarian cancer.

Other national guidelines exist for treatment and care of high-risk individuals (e.g., National Cancer Institute, Society of Surgical Oncology, and ACOG). Guidelines published by these organizations generally align with those published by NCCN.

Ms. Schlager provided the Committee with an overview of the recent USPSTF recommendations for risk assessment, genetic counseling, and genetic testing. She noted, while testing and the counseling may be covered at 100%, but the other interventions related to management (e.g., surveillance, risk reducing medication, and risk reducing surgeries, etc.) are often not covered. Ms. Schlager discussed the challenges faced by high risk individuals who need to cover cost for managing their care. Additionally, she discussed gaps in the USPSTF recommendation, in that they do not address the following:

- Increased screening and preventive options for high-risk women (other than chemoprevention for certain women)
- Cancer survivors in treatment
- Genetic counseling and testing for Lynch and other hereditary cancer syndromes - single gene or multigene panel
- Repeat genetic test for women who previously tested negative
- Genetic testing for men

Thus, some health plans use the absence of guidance from the USPSTF or the lack of a letter grade as justification to exclude or deny coverage for these services.

As it pertains to private or group health plans, the majority do cover genetic testing such as BRCA testing for certain women is required by law. Coverage has grown in recent years to include Lynch, multigene testing or testing for other mutations. Many plans don't cover this type of testing for men. Coverage and reimbursement for increased screening and risk-reducing surgeries also varies substantially. This includes services such as earlier mammograms; breast screening MRIs; earlier and more frequent colonoscopies; ovarian cancer screening (TVU and CA125); bilateral salpingo-oophorectomy/hysterectomy; mastectomy with reconstruction; and PSA testing. Copays or deductible and coinsurance apply to all these services except in very rare circumstances, typically when the state requires no cost-sharing. There are a few states that require insurance companies to provide coverage of ultrasound or MRI for women at increased risk of breast cancer and some cover colonoscopies for persons of any age who are considered high risk for colorectal cancer.

Ms. Schlager briefly discussed challenges with Medicare coverage for genetic counseling and testing in some states. Additional issues exist for high risk individuals who need additional care to manage their risk for hereditary cancers. For example, women with a known cancer genetic mutation are recommended to receive one mammogram and 1 MRI annually. While mammograms may be access by funded programs such as the National Breast & Cervical Cancer Early Detection Program (NBCCEDP), coverage for

MRIs may be difficult to obtain. According to Ms. Schlager, FORCE has received significantly more queries and concerns regarding these costs. In a recent survey conducted through a closed Facebook group called BRCA Sisterhood (women at high risk for HBOC, etc.), the average out-of-pocket cost from their most recent MRI ranged from \$75 to \$4,000. Individuals with increased risk of colorectal cancer are also facing similar and even worst situations. FORCE continues to explore options to find remedies to these problems. Ms. Schlager noted significant challenges with both Medicare and private insurance and believed these are not easy problems to solve given the current healthcare environment. She mentioned that the NBCCEDP might be one avenue to resolve these obstacles, at least for women who have fewer financial resources.

### **Comments from the ACBCYW:**

At the closing of Ms. Schlager's presentation, several committee members expressed their gratitude for her presentation. Ms. Chism told the group about a rapid MRI/abbreviated MRI that yields good screening images. If something is seen in the rapid MRI, a more diagnostic MRI can then be performed and possibly covered as opposed to a screening, or they will perform what is called a "second look ultrasound". The rapid MRI costs roughly \$200 out-of-pocket.

Another member said there are some concerns with the rapid MRI because it has not been validated according to the national guidelines. Dr. Mylin Torres countered by referring to an article in the Journal of the American Medical Association (JAMA) regarding a randomized trial for abbreviated MRIs with 3D mammography showing that it was better. Emory University participated in the trial. She thought it might be a delay in the process being taken up into practice, but she believes it is coming.

Ms. Shonta Chambers suggested that the issue should be examined through an equity lens. Even something that seems like a nominal cost, can be an exacerbating cost for women with limited resources. The variations in state policies have the potential to intensify some of the disparities that are already present, particularly for women of color, who are not as active in terms of genetic testing or screening. The task, in those cases, is to determine the policy activities that need to be undertaken to close the gap.

## **WORKGROUP REPORTS AND DISCUSSION**

### **Mental/Behavioral Health Workgroup**

Presenters: *Mylin Torres, MD*  
Winship Cancer Institute

*Michele Maria Cerullo, JD*  
DaVita Medical Group

The Mental Health Work Group is responsible for providing the Committee with an overview of current issues in mental and behavioral health, including resources, gaps,

and evidence-based interventions for young women facing breast cancer. The group is comprised of the following members:

- Mylin Torres, MD (subcommittee co-chair)
- Michele M. Cerullo, JD (subcommittee co-chair)
- Shonta Chambers, MSW
- Ricki Fairley
- Jean Rowe, LCSW, OSW-C, CJT
- Marisa C. Weiss, MD
- Anne Altomare
- Carletta Cunningham

The work group used a two-fold approach. It first completed a comprehensive search for evidence of mental health challenges among women with breast cancer using written evidence in primary sources of study such as PubMed and the internet. They also conducted interviews with thought leaders and experts in mental health among young women with breast cancer. Experts interviewed included Brad Zebrack, PhD, MSW, MPH, FAPOS, Professor, University Of Michigan Social Work; Patricia Ganz, MD, Professor of Medicine, Professor of Health Policy and Management, Director of Cancer Prevention and Control Research, UCLA; and Ann H. Partridge, MD, MPH, Founder and Director, Program for Young Women with Breast Cancer, Director, Adult Survivorship Program, Professor of Medicine, Harvard Medical School, Dana Farber Cancer Institute.

Mental health challenges in young women with breast cancer are not monolithic. There are several components of mental health seen in women who are undergoing treatment. One of the biggest challenges is the fear of recurrence. Approximately 50% of survivors five years after treatment experience this fear.

Depression is highest at diagnosis and through the treatment process but can even exist as late as six years out from treatment, with 30% of women still having signs of clinical depression.

Anxiety and distress seem to be highest at the beginning of treatment but can last up to five years after treatment. Roughly 50% of patients still report issues with anxiety and distress, particularly in women with chronic and metastatic disease.

Lastly, stress is a chronic issue also experienced. This comes mostly from balancing treatment schedules as well as other competing responsibilities. Even after treatment, the fear of recurrence can be felt several years after treatment.

In certain cohorts of patients, depression, anxiety, and stress-related disorders tend to increase years after diagnosis. The presence of comorbidities, like obesity, diabetes, hypertension, and cardiovascular disease are also associated with an increased risk of

depression and anxiety three years after diagnosis. They may even be exacerbated by the treatments themselves.

Dr. Patricia Ganz, in her studies, found that survivors may experience moments of depression several years after treatment. Her data even suggests that there is an increased rates of attempted suicide two years after completing treatment. This adds more credence to the fact that these issues tend to linger for a longer period of time and may worsen in the years after treatment, when patients have competing financial obligations that they may not be able to meet.

Other symptoms include fatigue, sleep disturbances, and non-specific pain. Even some childhood trauma can impact the ability to cope with diagnoses and treatment. Cognitive dysfunction may be influenced by post-traumatic stress, which could impair a person's ability to work or manage their daily affairs. Posttraumatic stress disorder (PTSD) symptoms seem to impact patients at diagnoses the most (97%), but even half of patients up to a year after diagnosis (50%) still report PTSD symptoms.

The work group compiled a list of resources that provide education regarding mental health to both patients and their caregivers. However, there are still gaps that exists such as:

- Lack of patient awareness regarding mental health resources and support services
- Lack of provider awareness regarding prevalence of mental health challenges in young women with breast cancer and available mental health resources and support services
- Use of mental health resources/support services is low, even among patients who are aware of their availability
- Difficulty finding time and to take part in such resources due to competing responsibilities
- Feelings of guilt when taking time to take care of themselves when they have children
- Research indicates that young women prefer online resources
- Unclear who needs resources and when (at diagnosis, during or after treatment)
- Under appreciation, lack of research on how many women continue to suffer from mental health issues as survivors
- Research on PTSD
- Range and variety of mental health challenges based on geographic location (urban vs. rural), race, culture
- Lack of research on other health impacts in these patients, particularly alcohol and opioid use

There are some evidence-based interventions that can be employed. Mindfulness meditation has been shown to be effective for those facing mental health challenges. A study from Julian Bower at UCLA utilizes a mindfulness awareness practice invention that

is both behavioral and physical. Data showed that it improved sleep, pain, fatigue, and positive aspects. This class was delivered in six weekly sessions that were two hours each.

Research also shows an increase in education to patients and caretakers causes lower anxiety, depression, and marital distress. Internet-based interactive content may be effective in providing educational interventions and reach many people. The existing research supports the use of psychoeducational support interventions to improve symptoms and emotional wellbeing for six to twelve months. Educational interventions show greater promise than relaxation-based or supportive group therapies. Enhanced communication visual tools are available that could help with educating patients on the onset of certain side effects that could be experienced in treatment (hair loss, diarrhea, nausea, mouth sores, neuropathy, cognitive problems, fatigue, anxiety, and insomnia), through years 1 – 3 afterwards, years 3 – 5, and 5 years and beyond from treatment. Neuropathy, cognitive problems, fatigue, anxiety, and insomnia can persist from years 1 – 5 and beyond after treatment.

The workgroup presented three potential recommendations to the Committee for discussion:

1. Support screening method to identify high risk breast cancer patients and survivors for mental health issues
  - Use a short, validated clinical instrument to identify mental health issues in patients and survivors at all visits (i.e. Patient Health Questionnaire-9 (PHQ-9) is more sensitive and specific for detecting depression in young cancer survivors including those with breast cancer than the NCCN distress thermometer)
  - Routine screening will enhance patient-provider communication
  - Make appropriate referrals as needed (PHQ-9 score >4 prompts referral to established mental health social work/psychiatric services)
2. Provide funding to clinics/healthcare systems to support mental health services for cancer patients
3. Allocate resources for dedicated research on mental health in young women with breast cancer
  - Why are mental health issues underutilized?
  - When is the best time for intervention and what are the best interventions?
  - What is the best medium for providing help (in-person, online, support groups?)
  - What is the most effective communication strategy in routine discussions about treatment risks and potential impact on quality of life?
  - What are long-term outcomes related to treatment effects and accurate post-treatment expectations (need for large, longitudinal studies)?

## **Recommendations and Comments from the ACBCYW:**

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- There needs to a dedicated governmental effort or mandate that will allocate funding to provide every clinic or cancer center with a social worker or a telehealth social work access line. This may even assist with some of the time constraints many patients have.
- Leverage advocacy organizations that have social workers on staff that can be utilized. Train organizations on where to find these resources at no cost and who may have telehealth options.

### Provider Workgroup

Presenters: *Lindsay Avner*  
Bright Pink

*Kenneth Lin, MD, MPH*  
Georgetown University Medical Center

The Provider Work Group is tasked with reviewing activities completed by the previous membership; gathering new background information to further improve provider behavior, education and training regarding breast cancer in young women; and advising the ACBCYW on prioritizing and supporting ongoing programmatic efforts in the future. The work group members are:

- Kenny Lin, MD, MPH; Co-Chair
- Lindsay Avner; Co-Chair
- Nancy Mautone-Smith
- Shubhada Dhage, MD, FACS
- Deborah Lindner, MD, FACOG
- Claudine Isaacs, MD

The work group's prior potential recommendations from the February 2020 meeting were reviewed and approved by the Committee. The group's only update their previous suggestions was made as a result of challenges the pandemic has presented.

The JAMA NETWORK provided a study on the changes in U.S. patients with newly identified cancer before and during the pandemic. The data shows a decline in newly identified diagnoses in all areas, particularly breast cancer, but unfortunately, this does not mean that cancer has disappeared. These are mostly delayed diagnoses.

Also observed was a significant decrease in mammogram screenings from March 2020 to July 2020 compared to the previous year likely due to the pandemic. Some practices did see a slight increase in screenings over the summer of 2020, but there still is a significant decline overall.

Many procedures, treatments, and surgeries were deferred as a result of the pandemic. A STUDY which survey 607 U.S. breast cancer patients and survivors, there were reported

delays in care: 79% in a routine or follow-up clinic appointment, 66% in breast reconstruction, 60% in diagnostic testing and imaging, and 50% in lab testing. Although these numbers are from spring 2020, there is a sense that this is still the case. These delays have the potential to setback progress garnered over the years.

Given the current environment, the workgroup updated the previously suggested Recommendation 2 was updated. The message to women is not to delay care, particularly if they have been diagnosed with breast cancer or are at high risk of being diagnosed and require more frequent check-ins. It was suggested to have more supplemental educational resources on which screenings could be deferred and what markers, in terms of community COVID-19 risk, might cause changes over time. The work group felt that CDC could serve as the source of relaying such information. The work groups suggested the following to address these issues:

1. Create a "one-stop shop" repository\* on the CDC website that houses:
  - All of the current, evidence-based, medically-sound provider educational online learning modules that exist
  - Searchable FAQ with links to medical journals included
  - User-friendly comparison of different tests (provider-initiated and direct-to-consumer (DTC))
  - Connections to referrals for genetic counseling, specialists for patients requiring more in-depth review
  - Recommend one login to access all modules; the current need to set up different logins is cumbersome.

\* Strong user experience necessary to meet the needs of providers with varying needs and must acknowledge inconsistencies (i.e. because each resource was uniquely authored, different sources informed output)

2. Develop simple supplemental provider educational resources to address gaps in content:
  - DCIS
  - DTC genetic testing
  - Pregnant/Post-partum patients
  - Pathologic High Risk
  - Genetic High Risk
  - Atypia
  - Other cancers intersecting with breast
  - COVID-19 and screening, testing & care (new)
3. Develop comprehensive promotion plan to amplify the resource and drive greater provider engagement of existing resources.
4. Identify process to ensure regular review and all timely updates are reflected including recommendations, new resources, etc.

## Recommendations and Comments from the ACBCYW:

- Dr. Chism appreciated the data regarding delay in breast cancer treatment. Back in March of 2020, she had to close her clinic due to pandemic. She found it heartbreaking that women had to wait to come in for mammograms when they were breast cancer survivors. She hopes to share the data with the new facility, where she works, and with her contacts at the Karmanos Cancer Institute. She feels people need to be aware of how much delay of diagnosis is occurring, as well as delay of treatment.
- Ms. Anna Crollman liked the information dissemination and marketing of resources. Information may be present, but if it is not marketed correctly, people will not be aware of it. From the patient side, in the spring of 2020, there was a lack of information, guidance and messaging regarding delaying of treatment and screening. Dr. Shubhada Dhage concurred with those thoughts and added the variation state by state and urban versus rural regarding screening further worsened the problem. It is important to disseminate this data so that people understand if they may or may not be impacted by delays in screening and treatment.
- There is amazing information available, but burdensome steps such as creating logins and passwords make it difficult to access. Information should be consolidated and easily obtainable. Hopefully, bringing such a platform to life will be an easy solution for the Committee.

### Sexual Health & Fertility Workgroup

Presenters: *Lisa Astalos Chism, DNP, APRN, NCMP, FAANP*  
Oakland Macomb Obstetrics & Gynecology Associates

*Ellyn Davidson*  
Brogan & Partners

The Sexual Health and Fertility Work Group is comprised of the following members:

- Anna Crollman
- Elissa Thorner, MHS
- Myrlene Jeudy, MD
- Ellyn Davidson
- Lisa Chism DNP, APRN, BC, CSC, NCMP, FAANP

When the work group was formed, there were two problems to be solved. The first was the lack of consistent acknowledgement, assessment, and interventions offered for sexual health concerns among young women with breast cancer, and the second was the lack of consistent acknowledgement, assessment, and interventions offered for fertility concerns among young women with breast cancer.

The group's last presentation in February 2020 focused on the current state of the NCCN guidelines, which the group found to be insufficient. Moreover, the guidelines lacked advice that would address the nuances of young women with breast cancer or women with breast cancer in general. Below are the issues the work group found with the NCCN guidelines:

- Sexual Health
  - Listed under “survivorship”
  - Not specific to young women in breast cancer
  - Treatment options not FDA Approved; Requires extensive counseling
  - Not consistently used according to the literature/practice
  - Sexual minorities not addressed
- Fertility
  - Listed under “adolescent and young adult”
  - Not specific to young women and breast cancer
  - Not consistently used according to the literature/practice
  - Sexual minorities not addressed

In response to the findings, the group presented the following:

1. Sexual health should not be listed under survivorship but instead have its own CDC guidance area. For example, organized on CDC website with breast cancer and young women and not under survivorship.
2. Experts in the field (sexual health and fertility) developing specific content for CDC to include on its website, etc.:
  - Extend information on CDC website and patient education to include young women
  - Include information regarding sexual health and fertility for sexual minorities (LGBT)
  - Move fertility information to breast cancer information not only adolescent and young adults

### **Recommendations and Comments from the ACBCYW:**

- Dr. Tara Sanft is a part of the NCCN Guideline committee. She will present the recommendations to her colleagues. She also suggested to move the recommendations into the breast cancer guidelines as well. She agreed that it is not appropriate for the sexual health component to be placed under survivorship.
- Guidelines take time and are garnered from evidence-based data. Perhaps look to CDC to shift how information is disseminated on their end and recommend that recommendations should be organized with an awareness of the topics to be brought to light at the time of diagnosis. Providers need more tools and resources to do that. Perhaps a task force is needed to come up with more readily available information for both consumers, patients, and providers.

- There cannot be enough redundancy for where information regarding fertility is included. Sexual health should be included in all aspects of survivorship as well as up front in a diagnosis. Life changes. Treatment change. Choices differ. This information should be available for wherever the patient is in their life's journey.
- For many physicians, the question is not only what the right resources are but also how to initiate the conversation with the patients about sexual health. There should be possibly some prompts that will help providers begin engaging on this topic.
- Perhaps a template or a survey could be created to help providers with having these discussions. This could be done in collaboration with the Provider Work Group.

Dr. Fairley, for clarification, asked if the recommendation was to add this information to the Breast Cancer in Young Women's pages like the way it is listed in the survivorship section, as well as in the provider component. The group confirmed the ask including establishment of a task force who can compile the information for providers, patients, and consumers. It takes expertise in the area of sexual health and fertility to home in on disseminating the finest and most accurate information. Dr. Chism would welcome the opportunity to be a part of such an effort. Dr. Fairley suggested refining the potential recommendations to include the language of "the creation of a task force by CDC" since these are formal recommendations that will be given to U.S. Department of Health and Human Services (HHS).

It was also discussed in the work group that it may not be practical for all providers to have these in-depth discussions in clinic. The hope is that providers at least asks these questions and then have the resources available that can be provided to patients. The resources utilized should come from individuals who are experts in sexual health. These resources should be more readily available and organized appropriately even if it is through the CDC website.

#### Genetics & Genomics Workgroup

Presenters: *Shubhada Dhage, MD, FACS*  
NYU Perlmutter Cancer Center

*Joyce Tannenbaum Turner, MS, CGC*  
Children's National Medical Center

Genetics & Genomics Workgroup's charge is to provide the committee with an overview of utilization of genetic and genomic testing in interpreting risk outcomes for young women facing breast cancer. The members are as follows:

- Shubhada Dhage, MD, FACS Co-Chair
- Joyce Turner, MS, CGC, Co-Chair
- Susan Brown, MS, RN
- Sue Friedman, DVM

- Sadie Hudson, PhD, RN, WHNP, FAANP

Since the meeting in February 2020 the group, unfortunately, has not had a chance to reconvene as a full unit, however, comments from the last meeting were reviewed and taken into consideration for their recommendations. Some of the gaps the work group identified have been addressed by the CME and a podcast event, but more work is needed.

The group has cataloged existing materials/tests for providers and patients on genetics, genomics, and pathologic risk factors for breast cancer. They are still working on the pathologic risk factors portion at this time. They also identified challenges and deficiencies in adequately informing the public and clinicians about genetic and genomic testing options, especially given the highly evolving field and the complex material. These activities were conducted with the intent of informing and advising the ACBCYW on ways to prioritize and support ongoing program efforts.

The group identified several challenges that providers and the public may face with regard to genetic and genomic testing. They include the following:

- Terminology is confusing
- Large number of tests-knowing which test to use when and how to interpret results can be challenging to untrained professionals
- Uncertain impact of various genetic and genomic tests
- Health insurance coverage for testing
- Consumer genetics-testing kits
- Different types of risk and hard to synthesize the individual risks to provide a total risk estimate; prediction programs outdated

There is insufficient educational material on genetics and genomics in particular. There is also a lack of a comprehensive platform to compare the different types of risks side by side as it pertains to genetics, genomics, epigenetic, and environmental and pathologic risk factors. There is also confusion around which tests are appropriate to assess which risk. In addition, there exists an incomplete understanding of genes tested, interpretation of results, and their impact on risk and management.

In the February 2020 presentation, the work group presented two multi-organizational studies that were conducted by various organizations to better understand terminology, genetics, and patient experiences. The studies validated several findings:

- Terminology is confusing.
- Most patients do their own research and use the information to help guide their decisions regarding treatment and interventions.
- Genetics and genomics does not refer to one tests in particular and is beyond BRCA 1 and 2.

The work group found the most comprehensive guideline is the NCCN Guidelines.

Information regarding RNA analysis was also reviewed with the Committee. Results from germline genetic testing can include a positive result, negative result, or variant of unclear significance (VUS). VUS means that at the current time there is insufficient evidence to classify a gene change as positive or negative. This term is confusing. What does the provider do with that term? What is the next step with the patient? When does it become significant?

The speaker noted that RNA analysis may help decrease the number of VUS and aid in the interpretation of what a VUS means as most providers and patients neither understand this information nor are aware that it can be added to genetic testing.

The work group felt it may be an opportune time to capitalize on educating providers and the public on disease issues being affected by the pandemic, such as deferment of screening, treatment, and care.

The Genetics & Genomics Work Group put forth the following potential recommendations:

- Support and provide educational materials for understanding terminology related to:
  - Genetics and Genomics
  - Various Types of Testing
    - Translate into improving the ability to navigate the array of testing options and select appropriate testing
- Synthesize available and reliable information in central location and develop an educational platform on genetics and genomics for providers and the public
- Should we explore education regarding pathologic risk?

Dr. Fairley asked the group to clarify if the last potential recommendation was a question or a directive. The group clarified it was not a question, but more of a directive to explore pathologic risk' to align with intent stated during open discussion. A lot of focus is put on BRCA 1 and 2, but the public has not been provided sufficient information regarding the other pathologic risk factors, and there are not any comprehensive websites that explain those factors.

### **Recommendations and Comments from ACBCYW:**

- The Consistent Terminology Work Group continues to meet. They have also expanded their members, and welcome new stakeholders, including professional societies and government agencies. There would be value in the CDC participating in that effort to align terms being used to describe genetic and genomic testing.

## ACBCYW OPEN DISCUSSION

Elana Silber, MBA

Sharsheret

ACBCYW Committee Chair

During the open discussion, the ACBCYW reviewed and discussed the potential recommendations from each of the workgroup.

### Genetics & Genomics Workgroup Recommendations (Original Version)

1. Support and provide educational materials for understanding terminology related to :
  - Genetics and Genomics
  - Various Types of Testing
    - Translate into improving the ability to navigate the array of testing options and select appropriate testing
2. Synthesize available and reliable information in central location and develop an educational platform on genetics and genomics for providers and the public
3. Should we explore education regarding pathologic risk?

### Comments and Revisions:

- Add a fourth recommendation that reads “CDC join the Consistent Testing Terminology Working Group to stay apprised of and participate in ongoing discussions to develop specific language around “genetics” and “genomics”.”
- Remove “translate into improving the ability to navigate the array of testing options and select appropriate testing.”
- Change Recommendation 2 to read “Synthesize reliable information regarding genetics and genomics in a central educational platform.”
- Change Recommendation 3 to read “Explore education regarding pathologic risk factors.”

### Mental/Behavioral Health Workgroup (Original Version)

1. Support screening method to identify high risk breast cancer patients and survivors for mental health issues
  - Use a short, validated clinical instrument to identify mental health issues in patients and survivors at all visits (i.e. Patient Health Questionnaire-9 (PHQ-9) is more sensitive and specific for detecting depression in young cancer survivors including those with breast cancer than the NCCN distress thermometer)
  - Routine screening will enhance patient-provider communication

- Make appropriate referrals as needed (PHQ-9 score >4 prompts referral to established mental health social work/psychiatric services)
2. Provide funding to clinics/healthcare systems to support mental health services for cancer patients

### Comments and Revisions:

- Revise first sub-bullet under Recommendation 1 to read “Use short, validated clinical instrument shown in young women with breast cancer to identify mental health issues in patients and survivors at all visits (e.g., Patient Health Questionnaire-9, PHQ-9).”
- The funding referred to in Recommendation 2 is not in CDC’s purview. Dr. Marisa Weiss added it is important to make the full range of appropriate therapeutic services available for each individual facing mental health challenges including the utilization of telehealth. Therefore, Recommendation 2 was changed to “Support breast cancer patients with individual mental health services through all available channels including telehealth.”

### Provider Workgroup (Original Version)

1. Create a "one-stop shop" repository\* on the CDC website that houses:
  - All of the current, evidence-based, medically-sound provider educational online learning modules that exist
  - Searchable FAQ with links to medical journals included
  - Democratic, user-friendly comparison of different tests (provider-initiated and DTC)
  - Connections to referrals for genetic counseling, specialists for patients requiring more in-depth review
  - Recommend one login to access all modules; the current need to set up different logins is cumbersome.

\*Strong user experience necessary to meet the needs of providers with varying needs and must acknowledge inconsistencies (i.e. because each resource was uniquely authored, different sources informed output)

2. Develop simple supplemental provider educational resources to address gaps in content:
  - DCIS
  - DTC genetic testing
  - Pregnant/Post-partum patients
  - Pathologic High Risk
  - Genetic High Risk

- Atypia
  - Other cancers intersecting with breast
  - **COVID-19 and screening, testing & care (new)**
3. Develop comprehensive promotion plan to amplify the resource and drive greater provider engagement of existing resources.
  4. Identify process to ensure regular review and all timely updates are reflected including recommendations, new resources, etc.

The Committee agreed with the recommendations submitted by the work group. No changes were made.

#### Sexual Health Workgroup (Original Version)

Some changes were already made to the recommendations as a result of the previous presentation from the work group. The recommendations before modifications read as follows:

1. Sexual health should not be listed under survivorship but instead have its own CDC guidance area. For example, organized on CDC website with breast cancer and young women and not under survivorship.
2. Experts in the field (sexual health and fertility) contribute to information available more widely in CDC materials such as the website, patient education materials.
  - Extend information on CDC website and patient education to include young women
  - Include information regarding sexual health and fertility for sexual minorities (LGBT)
  - Move fertility information to breast cancer information not only adolescent and young adults

#### Comments and Revisions:

- There was some discussion about adding “not just survivorship” to Recommendation 1 since information should be accessible throughout the whole journey.
- Ms. Crollman suggested breaking Recommendation 1 into two components: one that would speak to the creation of a singular source specifically focused on sexual health within the CDC website, and the second would recommend ensuring content is also linked within all sections of the cancer journey before and during survivorship. The goal is to have a single source of truth related to sexual health and breast cancer while also ensuring that it is noted and linked in the other sections.
- It was also decided that the sexual health aspects would be applied to fertility as well.

- As per the previous presentation the workgroup added “Form a “task-force” of individuals with expertise in sexual health to develop content regarding sexual health assessment and interventions. This content should be developed for both consumers/patient and providers.”
- A second addition, as a result of the presentation, was the wording “Form a 'task-force' of individuals with expertise in fertility preservation to develop content regarding fertility preservation and interventions. This content should be developed for both consumers/patients and providers.” There was some disagreement as to whether a taskforce would be necessary but something similar would suffice and provide flexibility. Therefore, taskforce or similar was added into the recommendation.
- Dr. Dhage felt sexual health and fertility should be addressed separately given that sexual health is behavioral and lifestyle, whereas fertility is more about intervention. Sexual health is complex and very specific and is not the expertise of many providers.
- Dr. Weiss felt contraception should be added to the fertility section since it involves reproduction. Many questions surface regarding the use of contraceptives in light of breast cancer risks. She felt it was an unmet need that could be tied to fertility. Dr. Chism was not in agreement. In her previous training, contraception was addressed with sexual health, and the use of contraceptives should be fleshed out through the taskforce or a group of experts.

Below is a complete list of all the recommendations after the modifications. Each group’s recommendations were read aloud before a vote was conducted among the Committee to determine if recommendations would be forwarded to HHS for adoption.

### **Genetics and Genomics Workgroup**

1. Support and provide educational materials for understanding terminology related to :
  - Genetics and Genomics
  - Various Types of Testing
2. Synthesize reliable information regarding genetics and genomics in a central educational platform
3. Explore education regarding pathologic risk factors
4. CDC join the Consistent Testing Terminology Working Group to stay apprised of and participate in ongoing discussions to develop specific language around "genetics" and "genomics"

Committee unanimously voted to approve the recommendations.

### **Mental/Behavioral Health Workgroup**

1. Support screening method to identify high risk breast cancer patients and survivors for mental health issues
  - Use a short, validated clinical instrument shown in young women with breast cancer to identify mental health issues in patients and survivors at all visits. CDC should make available a list of the various tools and their origins. (For example, Patient Health Questionnaire-9 (PHQ-9) is more sensitive and specific for detecting depression in young cancer survivors)
  - Routine screening will enhance patient-provider communication
  - Make appropriate referrals as needed (PHQ-9 score >4 prompts referral to established mental health social work/psychiatric services)
2. Support breast cancer patients with individual mental health services through all available channels including telehealth

Committee unanimously voted to accept the recommendations.

### **Provider Workgroup**

1. Create a "one-stop shop" repository\* on the CDC website that houses:
  - All of the current, evidence-based, medically-sound provider educational online learning modules that exist
  - Searchable FAQ with links to medical journals included
  - Democratic, user-friendly comparison of different tests (provider-initiated and DTC)
  - Connections to referrals for genetic counseling, specialists for patients requiring more in-depth review
  - Recommend one login to access all modules; the current need to set up different logins is cumbersome.

\*Strong user experience necessary to meet the needs of providers with varying needs and must acknowledge inconsistencies (i.e. because each resource was uniquely authored, different sources informed output)
2. Develop simple supplemental provider educational resources to address gaps in content:
  - DCIS
  - DTC genetic testing
  - Pregnant/Post-partum patients
  - Pathologic High Risk
  - Genetic High Risk
  - Atypia
  - Other cancers intersecting with breast

- **COVID-19 and screening, testing & care (new)**
- 3. Develop comprehensive promotion plan to amplify the resource and drive greater provider engagement of existing resources.
- 4. Identify process to ensure regular review and all timely updates are reflected including recommendations, new resources, etc.

Committee unanimously voted to accept the recommendations.

### **Sexual Health**

1. Create a singular source of sexual health content that is available for access throughout the cancer journey
2. Information regarding fertility and breast cancer should be accessible and located under CDC breast cancer content, including clarity that awareness that alterations in fertility may occur during and after treatment.
3. Form a “task-force” of individuals with expertise in sexual health to develop content regarding sexual health assessment and interventions. This content should be developed for both consumers/patient and providers.
4. Form a 'task-force" (or similar) of individuals with expertise in fertility preservation to develop content regarding fertility preservation and interventions. This content should be developed for both consumers/patients and providers.

Committee unanimously voted to accept the recommendations.

### **PUBLIC COMMENT**

There were no public comments during the meeting. There was one email submission.

From jeanpublic1@gmail.com: “The fact is all age women get breast cancer and i dont think this change to specifically only help young women helps any of us. where is the group set up for old women and their breast cancer. teyd desrve their own group now that you are separting into different groups based on age of the victim. what needs to be done is to find out what is causing all breast cancer to stop it all at all ages. this is stupidity at work in setting up seperate gropus. i see no need for this. it increases costs too and does not bring about any better work for the american people. is ssex involved in this change, perversion, etc?”

### **SUMMARY AND CLOSING**

*Elana Silber, MBA*

Sharsheret

ACBCYW Committee Chair

Ms. Silber thanked the Committee for conducting a productive meeting and providing their valuable input. She also acknowledged the members who will be completing their terms this year: Ms. Lindsay Avner, Ms. Michele Maria-Cerullo, Ms. Anna Crollman, Ms. Ellyn Davidson, Dr. Shubhada Dhage, Dr. Tara Sanft, as well as herself. She said it was a privilege to serve on the Committee. She thanked the members for their time and participation. Their valuable contributions have help to further the work of the Committee and will lead the way for new committee members, who will continue the task. She hopes that everyone will stay connected.

Ms. Carolyn Headley joined in thanking and showing appreciation to the retiring members. Those members will receive letters and certificates of appreciation. Once they have been mailed, she will update the members. She also provided her contact information should there be any further questions and comments.

Ms. Silber thanked Ms. Headley for all of her work and for coordinating the meeting. She also was thankful that Dr. Fairley was able to join the meeting. Before closing, she wished everyone a Happy Thanksgiving.

With no further comments, the meeting was adjourned at 11:47 a.m. EST.

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

\_\_\_\_\_  
Date

\_\_\_\_\_  
Elana Silber, MBA, Chair  
Advisory Committee on Breast Cancer in  
Young Women



## ATTACHMENT 1: PUBLISHED MEETING AGENDA

### MEETING OBJECTIVES:

To advise the Secretary of the Department of Health and Human Services (HHS) and the Director of the Centers for Disease Control and Prevention (CDC) regarding the formative research, development, implementation, and evaluation of evidence-based activities designed to prevent breast cancer in young women (particularly among those at heightened risk).

### Friday, November 20, 2020

<p><b>8:00 A.M. – 8:15 A.M.</b></p>	<p><b>Opening: Welcome, Roll Call, and Introductions</b></p> <p><i>Jeremy McCallister</i>  <b>Designated Federal Officer, DCPC, CDC</b></p> <p><i>Elana Silber, MBA</i>  <i>Sharsheret</i>  <b>ACBCYW Committee Chair</b></p>
<p><b>8:15 A.M. – 8:30 A.M.</b></p>	<p><b>CDC Updates</b></p> <p><i>Temeika L. Fairley, PhD</i>  <b>Senior Health Scientist, DCPC, CDC</b></p>
<p><b>8:30 A.M. – 9:15 A.M.</b></p>	<p><b>Barriers to Care Presentation</b></p> <p><i>Lisa Schlager</i>  <b>Facing Our Risk of Cancer Empowered (FORCE)</b>  <b>Vice President, Public Policy</b></p>
<p><b>9:15 A.M. – 10:45 A.M.</b></p>	<p><b>Workgroup Reports and Discussion</b></p> <p><b>Genetics &amp; Genomics Workgroup</b>  <i>Shubhada Dhage, MD, FACS</i>          NYU Perlmutter Cancer Center</p> <p><i>Joyce Tannenbaum Turner, MS, CGC</i>          Children's National Medical Center</p> <p><b>Mental/Behavioral Health Workgroup</b>  <i>Mylin Torres, MD</i>          Winship Cancer Institute</p> <p><i>Michele Maria Cerullo, JD</i>          DaVita Medical Group</p>

	<p><b>Provider Workgroup</b>  <i>Lindsay Avner</i>  Bright Pink</p> <p><i>Kenneth Lin, MD, MPH</i>  Georgetown University Medical Center</p> <p><b>Sexual Health Workgroup</b>  <i>Lisa Astalos Chism, DNP, APRN, NCMP, FAANP</i>  Oakland Macomb Obstetrics &amp; Gynecology Associates</p> <p><i>Ellyn Davidson</i>  Brogan &amp; Partners</p>
<p><b>10:45 A.M. – 11:00 A.M.</b></p>	<p><b>Break</b></p>
<p><b>11:00 A.M. – 12:15 P.M.</b></p>	<p><b>ACBCYW Open Discussion</b></p> <p><i>Elana Silber, MBA</i>  <i>Sharsheret</i>  ACBCYW Committee Chair</p>
<p><b>12:15 P.M. – 12:30 P.M.</b></p>	<p><b>PUBLIC COMMENT</b></p>
<p><b>12:30 P.M. – 1:00 P.M.</b></p>	<p><b>Summary and Closing</b></p> <p><i>Elana Silber, MBA</i>  <i>Sharsheret</i>  ACBCYW Committee Chair</p>



## ATTACHMENT 2: ROSTER OF THE ACBCYW MEMBERSHIP

### Advisory Committee on Breast Cancer in Young Women

#### CHAIR

**Elana Silber, MBA**

Executive Director  
Sharsheret  
1086 Teaneck Road  
Site 2G  
Teneck, NJ 07666  
PHONE: 201-833-2341  
FAX: 201-833-25025  
E-mail: [esilber@sharsheret.org](mailto:esilber@sharsheret.org)  
Term: 1/17/2017 - 11/30/2020

#### EXECUTIVE SECRETARY

**Jeremy McCallister**

Designated Federal Official (DFO)  
Office of Policy, Partnership and Communication  
Division of Cancer Prevention and Control  
Centers for Disease Control and Prevention  
4770 Buford Highway NE., Mailstop S107-4  
Atlanta, GA 30341  
Phone: 404-639-7989  
Fax: 770-488-4760  
E-mail: [isn8@cdc.gov](mailto:isn8@cdc.gov)

#### MEMBERS

**Lindsay Avner**

Founder and Chairman of the Board  
Bright Pink  
670 N. Clark Street  
Chicago, IL 60654  
Phone: 312-787-4412  
E-mail: [LINDSAY@BRIGHTPINK.ORG](mailto:LINDSAY@BRIGHTPINK.ORG)  
Term: 1/18/2017 - 11/30/2020

**Michele Maria Cerullo, JD**

Assistant General Counsel  
Optum  
10051 5<sup>th</sup> Street North, Suite 200  
St. Petersburg, FL 33702  
PHONE: 727-828-8910  
FAX: 727-258-0536  
E-mail: [MMCERULLO@ICLOUD.COM](mailto:MMCERULLO@ICLOUD.COM)  
TERM: 4/01/2019 - 11/30/2020

**Lisa Astalos Chism, DNP, APRN, NCMP, CSC, FAANP**

Clinical Director, Breast Imaging Services  
Certified Menopause Practitioner  
Certified Sexuality Counselor  
Oakland Macomb Obstetrics & Gynecology Associates  
Assistant Adjunct Professor University of Tennessee Memphis, School of Nursing  
1701 South Boulevard East  
Rochester Hills, MI, 48307  
Phone: 248-218-4084  
E-mail: [lchism@oamaobgyn.com](mailto:lchism@oamaobgyn.com)  
Term: 4/04/2019 - 11/30/2021

**Anna Crollman**

Breast Cancer Advocate  
5021 Holly Brook Drive  
Apex, NC 27539  
Phone: 828-712-3706  
E-mail: [mycancerchic@gmail.com](mailto:mycancerchic@gmail.com)  
Term: 4/08/2019 - 11/30/2020

**Carletta Cunningham**

Breast Cancer Survivor  
P.O. Box 102  
Clarkdale, GA 30111-9998  
Phone: 770-635-7489  
E-mail: carlycunn@yahoo.com  
Term: 4/02/2019 - 11/30/2021

**Ellyn Davidson**

CEO  
Brogan & Partners  
535 Woodward Heights  
Ferndale, MI 48220  
PHONE: 248-341-8211  
FAX: 248-854-2318  
E-mail: EDAVIDSON@BROGAN.COM  
TERM: 1/18/2017 - 11/30/2020

**Shubhada Dhage, MD, FACS**

Associate Director of Diversity in Cancer  
Research  
NYU Perlmutter Cancer Center  
462 First Avenue-NB/15S  
New York NY 10016  
Phone: 212-263-6509  
Fax: 212-263-8640  
E-mail: shubhada.dhage@nyumc.org  
Term: 1/20/2017 - 11/30/2020

**Kenneth Lin, MD, MPH**

Professor of Family Medicine  
Georgetown University Medical Center  
3900 Reservoir Road, NW  
Pre-clinical Science GB-01A  
Washington, DC 20007  
Phone: 202-687-8040  
Fax: 202-687-7277  
E-mail: kwl4@georgetown.edu  
Term: 4/08/2019 – 11/30/2021

**Rachel M. Mayo, PhD, MA**

Professor  
Clemson University  
Department of Public Health Sciences  
519 Edwards Hall  
Clemson, SC 29634  
Phone: 864-656-7435  
E-mail : rmayo@clemson.edu  
Term : 04/17/2018 - 11/30/2021

**Tara Sanft, MD**

Assistant Professor of Medicine  
Director, Adult Survivorship Program  
Yale Cancer Center  
300 Georg Street, Suite 12  
New Haven, CT\_06511  
PHONE: 203-785-2876  
FAX: 203-785-5792  
E-mail: tara.sanft@yale.edu  
Term: 1/23/2017 - 11/30/2020

**Nicole B. Saphier, MD**

Director of Breast Imaging  
Memorial Sloan-Kettering, Monmouth  
Department of Radiology  
480 Red Hill Road  
Middletown, NJ 07748  
Phone: 848-225-6000  
E-mail: nbsaphier@gmail.com  
Term: 5/14/2018 - 11/30/2022

**Elissa Thorner, MHS**

Director, Breast Cancer Survivorship  
Co-Director, Young Women with Breast Cancer  
Program  
Sidney Kimmel Comprehensive Cancer Center  
at Johns Hopkins  
Skip Viragh Outpatient Cancer Building  
201 North Broadway, Room 10287  
Baltimore, MD 21287  
Phone: 410-502-3472  
E-mail: EBANTUG1@JHMI.EDU  
Term: 4/16/2019 – 11/30/2021

**Mylin A. Torres, MD**

Co-leader Cancer Prevention Control Research  
Program  
Winship Cancer Institute  
Associate Professor  
Department of Radiation Oncology  
Emory University School of Medicine  
1365 Clifton Road NE  
Building A, 1st Floor, Room 1307A  
Atlanta, GA 30322  
Phone: 404-778-3473  
E-mail: matorre@emory.edu  
Term: 4/08/201 – 11/30/2021

**Joyce Tannenbaum Turner, MS, CGC**

Director, Cancer Genetic Counseling Program  
Children's National Medical Center  
111 Michigan Avenue, NW  
Washington, DC 20010

Phone: 202-476-4685  
Fax: 202-476-2390

E-mail: [jturner@childrensnational.org](mailto:jturner@childrensnational.org)  
Term: 04/20/2018 - 11/30/2022

## EX OFFICIO MEMBERS

### Agency for Healthcare Research and Quality

#### **Camille Fabiyi, PhD, MPH**

Senior Advisor for Women's Health and Gender  
Research  
Office of Extramural Research, Education, and  
Priority Populations  
Agency for Healthcare Research and Quality  
5600 Fishers Lane  
Rockville, MD 20857  
Phone: 301-427-1559  
Fax: 301-480-0785  
Email: [camille.fabiyi@ahrq.hhs.gov](mailto:camille.fabiyi@ahrq.hhs.gov)

### Department of Health and Human Services Office on Women's Health

**Vacant**

### Health Resources and Services Administration

#### **Nancy Mautone-Smith, MSW, LCSW**

Deputy Director  
HRSA Office of Women's Health  
5600 Fishers Lane, Room 11N-05  
Rockville, MD 20857  
Phone: 301-945-5146  
Email: [NMAutone-Smith@hrsa.gov](mailto:NMAutone-Smith@hrsa.gov)

### Indian Health Service

#### **Michael Toedt, MD**

Chief Medical Officer  
Indian Health Service  
5600 Fishers Lane  
Rockville, MD 20857  
Phone: 301-443-1083  
Fax: 301-443-4794  
Email: [michael.toedt@ihs.gov](mailto:michael.toedt@ihs.gov)

### National Institutes of Health

#### **Jung-Min Lee, MD**

Investigator  
Lasker Clinical Research Scholar  
Women's Malignancies Branch  
Center for Cancer Research  
National Cancer Institute  
10 Center Drive, MSC 1906, Rm 4B54  
Bethesda, MD 20892  
Phone: 240-760-6128  
Fax: 240-541-4546  
E-mail: [LEEJ6@MAIL.NIH.GOV](mailto:LEEJ6@MAIL.NIH.GOV)

## Liaison Representatives

### American Cancer Society

Vacant

### American College of Obstetrics and Gynecology

#### Myrlene Jeudy, MD

Assistant Professor in Obstetrics and Gynecology  
American College of Obstetrics and Gynecology  
1250 East Marshall Street, 6<sup>th</sup> Floor  
P.O. Box 980034  
Richmond, VA 23298  
Phone: 804-828-7877  
Fax: 804-628-3585  
E-mail: myjeudy@gmail.com

### Avon

Vacant

### Black Women's Health Imperative

#### Ngina Lythcott, PhD

Black Women's Health Imperative  
8 Somerset Road  
Provincetown, MA 02657  
E-mail: nlythcott@me.com

### Breastcancer.org

#### Marisa C. Weiss, MD

President and Founder  
Breastcancer.org  
120 East Lancaster Avenue  
Suite 201  
Ardmore, PA 19003  
Phone: 610-642-6550  
Fax: 610-642-6559  
E-mail: mweiss@breastcancer.org  
Term: 9/22/2015 - 11/30/2018

### Bright Pink

Current Committee Member

### FORCE: Facing Our Risk of Cancer Empowered

#### Sue Friedman, DVM

Executive Director  
FORCE: Facing Our Risk of Cancer Empowered  
16057 Tampa Palms Boulevard, W., PMB #373  
Tampa, FL 33647  
PHONE: 954-255-8732  
FAX: 954-827-2200  
E-mail: suefriedman@facingourrisk.org

### LIVESTRONG, The Lance Armstrong Foundation

Vacant

### Living Beyond Breast Cancer

#### Arin Ahlum Hanson, MPH, CHES

Manager, Young Women's initiative  
Living Beyond Breast Cancer  
354 West Lancaster Avenue, Suite 224  
Haverford, PA 19041  
Phone: 610-645-4567  
Fax: 610-645-4573  
E-mail: ARIN@LBBC.ORG

### The National Patient Advocate Foundation

#### Shonta Chambers, MSW

Executive Vice President, Health Equity Initiatives and Programs  
Patient Advocate Foundation  
421 Butler Farm Road  
Hampton, VA 72366  
Phone: 757-952-2544  
Fax: 757-952-2533  
E-mail: Shonta.Chambers@patientadvocate.org

### Sharsheret

Current Committee Member

### Sisters Network, Inc.

Vacant

## **Susan G. Komen**

### **Susan Brown, MS, RN**

Sr Director, Education & Patient Support  
Susan G. Komen  
5005 LBJ Freeway, Suite 526  
Dallas, TX 75244  
Phone: 972-855-1635  
E-mail: sbrown@komen.org

## **Tigerlily Foundation**

### **Maimah S. Karmo**

Chief Executive Officer  
Tigerlily Foundation  
11654 Plaza America Drive, #725  
Reston, VA 20190  
Phone: 888-580-6253  
Fax: 703-663-9844  
E-mail: maimah@tigerlilyfoundation.org

## **Young Survival Coalition**

### **Jennifer Merschdorf, MBA**

Chief Executive Officer  
Young Survival Coalition  
80 Broad Street, Suite 1700  
New York, NY 10004  
Phone: 646-257-3001  
Fax: 646-257-3030  
E-mail: jmerschdorf@youngsurvival.org

## **COMMITTEE MANAGEMENT SPECIALIST**

### **Carolyn P.R. Headley, MSPH, CGMP**

Public Health Analyst  
Office of Policy, Partnership, and  
Communication  
Division of Cancer Prevention and Control  
Centers for Disease Control and Prevention  
4770 Buford Highway NE., Mailstop F-76  
Atlanta, GA 30341  
Phone: 770-488-4237  
Fax: 770-488-4760  
E-mail: ihg6@cdc.gov