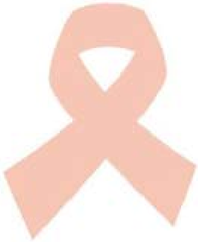
U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
CENTERS FOR DISEASE CONTROL AND PREVENTION
National Center for Chronic Disease Prevention and Health Promotion
Division of Cancer Prevention and Control



Advisory Committee on Breast Cancer in Young Women

Teleconference

February 6, 2020

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

FEBRUARY 6, 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 February 6, 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

Temeika Fairley, PhD
Designated Federal Officer, DCPC, CDC

Dr. Fairley conducted roll call and confirmed 14 voting members and *ex-officio* members (or their proxies) in attendance, which constituted a quorum for ACBCYW to conduct its business on Thursday, February 6, 2020. She called the proceedings to order at 9:10 a.m. EST and welcomed the participants to the Advisory Committee on Breast Cancer in Young Women (ACBCYW) 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

Out of all the committees Ms. Silber has worked with, she has found the ACBCYW to be the most conscientious. She thanked the members for being on time and present. For the day's agenda, workgroups will be afforded fifteen minutes to present to the committee, with a discussion period to follow. She looked forward to the meaningful conversations along with potential recommendations to CDC.

WORKGROUP REPORTS AND DISCUSSION

Genetics & Genomics Workgroup

Presenters: *Sue Friedman, DVM*
FORCE: Facing Our Risk of Cancer Empowered

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

The Genetics & Genomics Workgroup, co-chaired by Shubhada Dhage, MD, FACS and Joyce Turner, MS, CGC, consists of the following members:

- Susan Brown, MS, RN
- Sue Friedman, DVM
- Sadie Hudson, PhD, RN, WHNP, FAANP

Since it is a small group, an invitation was extended for others to join. The group has created a large outline of goals it wishes to accomplish and would welcome additional help from those interested.

The 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 group created a comprehensive list that outlines areas it felt were relevant to the charge and warranted further investigation. Some of the needs identified include:

- Defining genetic terminology
- Developing a list of categories of:
    - Genetic tests available for breast cancer
    - Genetic testing guidelines published by various organizations pertaining to cancer genetics
    - Associated breast cancer risks in one's lifetime
    - Associated management guidelines as they exist
- Examining delivery and care messages for direct to consumer (DTC) testing and genetic counseling
- Determining how genetics plays into environmental factors, lifestyle, and overall risk

The group seeks to catalog existing materials/tests for providers and patients on genetics, genomics, and pathologic risk factors for breast cancer; identify challenges and deficiencies in adequately informing the public and clinicians about genetic and genomic testing options, especially given the highly evolving field and complex information; and inform and advise the ACBCYW on prioritizing and supporting ongoing program efforts.

They noted challenges in this task which included the following:

- The terminology is confusing for the lay public and health professionals.
- There are a large number of tests available; however, knowing which test to use and when is a challenge.
- Moreover, interpreting results for untrained and trained professionals proves to be difficult.
- There is an uncertain impact of various genetic and genomic tests.
- Sometimes there is not sufficient knowledge to interpret the results and how to use the information for medical management.
- Health insurance coverage for testing is not always an option.
- DTC type screening test result oftentimes result in misinterpretations and unverified findings.
- There are various types of risk making it hard to synthesize the individual risks and provide a total risk estimate.
- Lastly, the prediction models are outdated.

The workgroup also identified gaps. There are insufficient educational materials. There are websites, such as Genetics Home Reference. However, is the terminology too high level? Is there access to the sites? Do users know how to navigate to the site? There are an insufficient number of comprehensive platforms to compare the different types of risks (genetics, genomics, epigenetic, environmental, pathologic) and tests for assessments. Finally, a complete understanding of the genes tested, results, and their impact on risk and management does not exist.

There are also several genes where there is the potential for increased risk for breast cancer susceptibility, but the specific risk is unknown and again, management guidelines cannot be made. Furthermore, there are a group of additional genes where preliminary evidence shows associated risk for breast cancer susceptibility, but those are also not well defined. If there is a mutation among those genes, there will not be a specific risk estimate or guideline to direct medical management. The National Center for Biotechnology Information's Genetic Testing Registry website (https://www.ncbi.nlm.nih.gov/guide/), made primarily for providers, allows users to access information regarding genetics, laboratories, and literature.

The workgroup also researched RNA analysis, which is a newer technology slowly emerging from the research arena to the clinical. It is normally performed in parallel to traditional genetic testing. The results from germline genetic testing can include a positive result, negative result, or variant of unclear significance (VUS). The VUS means that at the current time there is insufficient evidence to classify a gene change as positive or negative. The RNA analysis is a type of functional analysis of a gene, which aims to decrease the number of VUS and identify mutations that traditional testing cannot identify.

The Genetics & Genomics Workgroup set forth the following issues as the Committee to consider:

- Providers need to have sufficient training in genetics and genomics to navigate the array of testing options and select appropriate testing
- Support studies to better understand breast cancer genes & associated mutations
- Support studies that help guide medical management that is gene specific
- Support studies to better understand additive risks – genetics + environment + pathologic risk factors
- Support efforts to adopt consistent, plain language terms to describe tumor-based and germline testing
- Synthesize evidence based (EB) information in central location and develop an educational platform on genetics and genomics for providers and the public

Comments by the ACBCYW:

- The Initiative for Consistent Testing Terminology is a multi-stakeholder effort. Possibly CDC or AHRQ could send representation to the group that meets monthly. Dr. Fairley said CDC is open to joining and asked that information be forwarded regarding joining the membership.

Mental/Behavioral Health Workgroup

Presenters: *Mylin Torres, MD*
Winship Cancer Institute

Michele Maria Cerullo, JD
DaVita Medical Group

The Mental/Behavioral Health Workgroup is co-chaired by Mylin Torres, MD and Michele M. Cerullo, JD. Group members include Shonta Chambers, MSW, Ricki Fairley, Jean Rowe, LCSW, OSW-C, CJT, and Marisa C. Weiss, MD. The workgroup's charge is to provide the ACBCYW with an overview of current issues in mental/behavioral health, including resources, gaps, and evidence-based interventions for young women facing breast cancer.

The group initially took a broad view of the landscape searching Pubmed and the web for evidence and available resources. They spoke with experts and thought leaders, who worked predominately in the space of mental health and young women with breast cancer. Suggestions came from individuals such as 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.

After the literature search and communication with experts, the group endeavored to describe the scope and the breath of mental health challenges young women with breast cancer face. A consistent finding in the literature was a fear of recurrence, which persists long after treatment. Many of the studies showed half of all patients will have a fear of recurrence that may impact their daily activities as long as five years after treatment.

Other prevalent mental health challenges included depression, anxiety, and stress. Several studies cited the number of women suffering from depression and anxiety as highest at diagnosis and through treatment. Thereafter, it tended to decline, but in many cases, the levels do not return to zero or baseline levels seen prior to diagnosis.

One study which focused on women who had gone through treatment compared to the normal population. Findings shows with time, even after treatment, levels of depression, anxiety, and stress related disorders were significantly higher than the general population of women, who were never diagnosed with breast cancer. The study suggests that up to 30% of survivors experienced persistent depression, anxiety, and stress long after treatment.

Another study by Dr. Patricia Ganz, documented an increase in rates of attempted suicide among young breast cancer patients, up to two years after completing treatment. The study authors speculated on the cause of this increase, suggesting that several factors such as financial stress from the actual cancer diagnosis and treatment, personal stress with spouses or partners, competing responsibilities, or changes in working ability after cancer treatment or diagnosis were at play. This study also noted other mental health challenges including:

- Fatigue
- Sleep Disturbances
- Non-specific pain
- Childhood trauma impacts ability to cope with diagnosis and treatment
- Cognitive dysfunction may be influenced by post-traumatic stress
- PTSD symptoms (mean of 3-4) may impact patients at diagnosis (97%), after completion of chemotherapy (62%), and up to 1 year after diagnosis (50%)

The workgroup identified the following resources for young women with breast cancer who are facing mental health challenges.

Organization	Primary Link	Services
ABCD (After Breast Cancer Diagnosis)	HTTPS://WWW.ABCDBREASTCANCERSUPPORT.ORG/	Peer Matching
American Psychological Association	HTTPS://WWW.APA.ORG/HELPCENTER/BREAST-CANCER	Reference Find a Psychologist
Association of Oncology Social Workers	WWW.AOSW.ORG	International professional society with 1400 members. OSWs are often a consistent support and contact with patients
Breastcancer.org	HTTPS://WWW.BREASTCANCER.ORG/	Go to for research, information and education
Breast Cancer Now Research and Care Charity (England and Wales)	WWW.BREASTCANCERNOW.ORG	Educational materials for Fear of Recurrence, anxiety, depression
Cancer*Care*	WWW.CANCERCARE.ORG	Education, information, support
Cancer.net	WWW.CANCER.NET	Education, information, support
Cancer Support Community	WWW.CANCERSUPPORTCOMMUNITY.ORG	Education, information, support
Triple Negative Breast Cancer Foundation	HTTPS://TNBCFOUNDATION.ORG/LIVING-WITH-TNBC/SURVIVORSHIP	Education, information
Dana Farber Young & Strong	HTTPS://WWW.DANA-FARBER.ORG/YOUNG-AND-STRONG-PROGRAM-FOR-YOUNG-WOMEN-WITH-BREAST-CANCER/	Education, information, support

Organization	Primary Link	Services
For the Breast of Us	HTTPS://WWW.BREASTOFUS.COM/	Educate, inspire, connect

Friend for Life (cancer support network)	HTTPS://WWW.FRIEND4LIFE.ORG/	Peer Matching
Gulf States Young Breast Cancer Survivor Network	HTTPS://SURVIVEDAT.ORG/HISTORY	Education, information, support
Know Cancer	HTTPS://WWW.KNOWCANCER.COM/	Portal Directory
Living Beyond Breast Cancer	HTTPS://WWW.LBBC.ORG/	Education, information, support
National Suicide Prevention Lifeline	1-800-273-8255	Crisis counseling and support
SHARE	HTTPS://WWW.SHARECANCERSUPPORT.ORG	Education, information, support
Sisters Network	HTTPS://WWW.SISTERSNETWORKINC.ORG/	Education, information, support
Stupid Cancer	WWW.STUPIDCANCER.ORG	Education, information, support
Triple Negative Breast Cancer Foundation	HTTPS://TNBCFOUNDATION.ORG/	Education, information, support
Cancer.gov	HTTPS://WWW.CANCER.GOV/ABOUT-CANCER/COPING/ADJUSTING-TO-CANCER/SPOUSE-OR-PARTNER	Education, information to address partners, relationships of cancer patients
Susan G. Komen	HTTPS://WW5.KOMEN.ORG/BREASTCANCER/ABOUTBREASTCANCER.HTML	Education, information to address partners, relationships of cancer patients

The workgroup noted that while there are numerous resources available, significant gaps are still present. There is also a lack of awareness among patients regarding available mental health resources and support services. They also noted lack of provider awareness regarding prevalence of mental health challenges in young women with breast cancer and available mental health resources and support services. The use of mental health resources/support services is low, even among patients who are aware of their availability. Experts have identified few factors to explain this issue in this population, such as:

- Difficulty finding time and resources 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.
- Preference for online resources among young women.
- Difficulty identifying which patients need supportive resources (e.g., at diagnosis, during treatment, or post treatment)
- Limited research on the breadth of mental health issues among survivors (e.g., epidemiology or surveillance by socio-demographic like age, race, culture, etc.), including limited understanding of the development and impact of PTSD in this population;
- Limited understanding of behaviors (e.g., alcohol) in this population and their impact on mental health status (e.g., contributing to or caused by substance abuse)

The workgroup also identified several evidence-based interventions (EBI). One of those involves mindfulness meditation and has shown good results. The participants take part in six-weekly two-hour classes. Findings show the women displayed lower levels of fatigue, sleep issue, depression, and stress three months after the intervention. However, after the three months and when the program was over, the effects of the mindfulness mediation did not persist. This underscores the need for a more consistent and persistent approach.

Another EBI included cognitive behavioral therapy. There are significant data that attribute greater physical health through activities such as yoga and exercise to better prospects of coping with mental health issues that may arise. Also, having a better, quality social support or larger social networks cause patients to cope easier with their treatment and thereafter. And lastly, better emotional and physical functioning is directly related to a person’s quality of life.

Educational information and support also lower anxiety, depression, and marital distress in patients, partners, and family members. There is research which suggests internet-based interactive content may be effective in providing educational interventions, as well as reach a large number of people. There is also existing research that supports the use of psychoeducational support interventions to improve symptoms and emotional wellbeing for approximately six to twelve months after treatment. Lastly, educational interventions show greater promise than relaxation-based or supportive group therapies in some studies.

One expert interviewed by the working group mentioned having visual cues during the treatment process can normalize or raise awareness around the potential side effects. They also help with communication and sets expectations. The patients are not caught off guard when symptoms such as insomnia, fatigue, or anxiety manifest. This process can help patients put their feelings in perspective and allows them to be proactive in addressing these issues when they arise.

The workgroup put forth a number of recommendations, which include the following:

- Advocate for screening method to identify high risk patients and survivors for mental health issues. “Ask, advise, refer” (AAR) is a model used by health care providers to assess tobacco use and initiate linkage tobacco cessation support
    - Use a short, validated clinical instrument to identify mental health issues in patients and survivors
    - Routine screening could enhance patient-provider communication
    - Make appropriate referrals as needed
- Funding 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)?

Comments from the ACBCYW:

- ➢ As a survivor knowing what to expect and that mental health is a part of the process was helpful. There should be thought given to educational materials that can be provided upfront.
- ➢ One member acknowledged the recommendation for the use of the AAR model, noting that it could apply to many of the issues being addressed here. They also suggested the need for an assessment that directly engaged patients and patients.
- ➢ This can be individualized by patient. Some patient may need and utilize mental health services early on, whereas others are not ready and will utilize it later in the treatment. It is up to providers and their patients to determine when it occurs.
- ➢ This could be framed as a patient journey map where providers can look at different services along the care continuum. NIH possibly has a model for this.
- ➢ Postpartum screening could be used as a model that determine when it is time to have interventions.

Provider Workgroup

Presenters: *Lindsay Avner*
Bright Pink

Kenneth Lin, MD, MPH

Georgetown University Medical Center

The Provider Workgroup has a number of assignments as a part of its charge. The first is to review activities completed by the previous provider membership. They are also tasked with 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. It is co-chaired by Kenny Lin, MD, MPH and Lindsay Avner. The group members are Nancy Mautone-Smith, Shubhada Dhage, MD, FACS, Deborah Lindner, MD, FACOG, and Claudine Isaacs, MD.

The group kicked off its activities in October 2019 with dialogues over a few topics. The initial conversations were on the variety of resources that exist to educate providers. The second was to establish the “audience” for provider education. The group felt this audience could be broken into two groups:

- Providers without a baseline set of knowledge/comfort who could benefit from 101-type education and resources to refer out
- Providers with baseline knowledge who feel comfortable testing/counseling patients and need support in more nuanced, one-off cases

Also covered were the gaps in quality provider education surrounding specific topic areas including DTC genetic tests.

Between October and December 2019, the workgroup compiled existing resources from the previous committee’s work. They also reached out to their respective colleagues for additional sources. The information was compiled into a central spreadsheet, which comprised of audiences, access restrictions, and key content areas addressed. The next task was to review the resources and identify gaps in education and identify topics that are not being addressed in a meaningful way.

Below is an example of some of resources that are a part of the spreadsheet. The diversity of training of workgroup members was an asset when compiling the list. The resources listed in the example below are free and open to any provider, although registration may be required by the website. They also have current continuing medical education (CME) accreditation, which is particularly important for physicians and nurses.

EXISTING PROVIDER EDUCATION RESOURCES

- **Risk assessment**
    - o *Bright Pink https://www.brightpink.org/healthcare-providers/online-learning/*
- ***Genetic testing and counseling***
    - o *Medscape https://www.medscape.org/viewarticle/919116*

    - *The Jackson Laboratory https://www.jax.org/education-and-learning/clinical-and-continuing-education/cancer-risk-assessment-testing-and-management/bcr*
    - *American Society of Clinical Oncology ttps://elearning.asco.org/product-details/hereditary-breast-ovarian-cancer-syndrome*
- ***Breast cancer screening–general***
    - *American College of Radiology https://www.acr.org/Lifelong-Learning-and-CME/Learning-Activities/Mammography-CME-Module*
- ***Inflammatory breast cancer***
    - *American College of Surgeons/NAPBC https://www.facs.org/quality-programs/napbc/education/webinars/inflammatory-breast-cancer*

Dr. Lin tested the resources and found the only cumbersome part of using the websites was having to set up logins.

He also reviewed a story board on the American College of Obstetricians and Gynecologists (ACOG) website titled *Understanding Early Onset Breast Cancer: A review of EOBC risk factors, assessing EOBC risk in patients, and risk mitigation measures.* He found it to be very impressive and comprehensive. It covers all the issues in a way that no other existing resource does. He noted the importance of making this tool available to a variety of providers.

The workgroup then presented its recommendations. The first is to 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.

The group identified many gaps in topics and recommended the development of simple supplemental provider educational resources to address gaps in content, such as:

- Ductal carcinoma *in situ* (DCIS)
- DTC genetic testing
- Pregnant/Postpartum patients
- Pathologic High Risk
- Genetic High Risk
- Atypia

- Other cancers intersecting with breast

They again noted the importance of dissemination of these resources to health care providers. Therefore, the workgroup suggested the development of a comprehensive promotion plan to amplify the resource and drive greater provider engagement of existing resources. And lastly, as new technology and information emerge, websites will need to be updated, so, the workgroup proposed identifying a process that will ensure regular review and all timely updates are reflected including recommendations, new resources, etc.

Comments from the ACBCYW:

- FORCE will be partnering with the National Society of Genetic Counselors for a continuing education piece. It will include direct to consumer testing. They are also partnering with the Academy of Oncology Nurse and Patient Navigator for a similar module on direct to consumer testing for their conference held in May and June. It is possible that FORCE can make the content available more widely and online as well. Dr. Friedman will report back to the ACBCYW after the conference in May and June with an update.
- Behavior and mental health could be a topic to add to the FORCE continuing education piece. This would be educating providers on assessing and alerting their patients regarding the resources available for mental and behavioral health. It will also increase the uptake of mental health interventions. This will be added to the second recommendation as an additional topic area.

Sexual Health & Fertility Workgroup

Presenters: *Lisa Astalos Chism, DNP, APRN, NCMP, FAANP*
Karmanos Cancer Institute

Ellyn Davidson
Brogan & Partners

The members of the Sexual Health & Fertility Working Group are Anna Crollman, Elissa Thorner, MHS, Myrlene Jeudy, MD, along with Ellyn Davidson and Lisa Astalos Chism DNP, APRN, BC, CSC, NCMP, FAANP serving as co-chairs. The group was created to address two identified issues in the sexual health and fertility space. One was the lack of consistent acknowledgement, assessment, and interventions offered for sexual health concerns among young women with breast cancer. Although there are some current guidelines available in the National Comprehensive Cancer Network (NCCN), there are significant issues with those guidelines. After some deliberation, the guidelines seemed like a logical starting point by highlighting the accepted guideline being used and pick it apart to expose the second problem, which is the lack of consistent acknowledgement, assessment, and interventions offered for fertility concerns among young women with breast cancer.

The working group presented information from the NCCN Guidelines under Survivorship. In the ACBCYW's August 2019 meeting, it was debated if these guidelines should be under the heading of survivorship. The group suggested that support for sexual health should start at the time of diagnosis as the treatment processes can cause women to enter medical or surgical menopause, which cause sexual health concerns. Therefore, placing the subject under survivorship could be the reason providers find it difficult to find information on sexual health.

From both sexual health and fertility, the workgroup raised the following issues associated with using the NCCI guidelines.

<u>Sexual Health</u>

- 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

<u>Fertility</u>

- 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

The workgroup also provided its findings from a literature search of prevalence and incidence of women with a history of breast cancer who suffer from sexual health concerns. According to World Health Organization (WHO) data from 2018, there are 2.1 million breast cancer diagnoses each year worldwide, with 4-6% of those cases being women under the age of 40. Some of the information is not specific to young women, but more than likely, a temporary menopause may be induced. This brings about many of the issues experienced by post-menopausal women or women with a history of breast cancer across the lifespan experience.

The treatments in the literature require discussion and can be controversial at times. The data shows 68% of women treated for breast cancer experience sexual function issues and 45% will still experience issues once treatment is completed. Most of the issues are caused by premature ovarian failure as a result of treatment leading to genitourinary syndrome of menopause (GSM), vaginal dryness, pain with intercourse, decreased desire. Other issues that can occur as a result of treatment are self-image related, like weight gain, loss of breast, and hair loss. Fatigue and pain are also associated with treatment.

According to the literature, treatment options for GSM and decreased desire include the following:

GSM Treatments

- Vaginal moisturizers (hyaluronic acid) and lubricants
- Local estrogen that requires risks and benefits discussion
- Local DHEA-requires discussion
- Vaginal dilators
- Vaginal stimulation
- CO2 vaginal laser therapy
- Local Lidocaine

Decreased Desire Treatments

- Sexual health counseling/therapy
- Flibanserin
- Bremelanotide

This information is widely available in the literature; however, there are more treatment options available now. The workgroup can share additional information it has as well.

A search was also conducted with regards to fertility. Teresa Woodruff from Northwestern University is currently engaging in some work known as Oncofertility, which is a term Dr. Woodruff coined. This is a new branch of medicine, which examines embryo cryopreservation, cryopreservation of ovarian tissue, transplantation of ovarian tissue, and ovarian suppression. There is a YOU TUBE video presentation available about this cutting edge work, which helps young women suffering from any type of cancer diagnosis that is interfering with fertility.

The workgroup concluded their presentation by engaging the ACBCYW in determining its future steps and recommendations with regards to sexual health and fertility for young women with breast cancer.

Comments from the ACBCYW:

- ➢ This critique has been raised by other institutions as well and committee members from the annual Survivorship Meeting are committed to helping NCCN better address the issues that span the continuum. A lot of elements of survivorship start at diagnosis. NCCN leadership is also considering how to resolve these gaps.
- ➢ There has been some conversations regarding the lack of information for the LGBTQ population. This is also an issue that has been raised to NCCN. Consensus from the meeting was there is a lack of evidence-based guidelines for certain approaches. There are groups that are always sending in

recommendations to the NCCN, and if this group feels strongly that changes need to be made related to different issues identified, recommendations would be welcomed.

- NCCN does have a statement across guidelines about clinical trial participation, so maybe a comment could be added to treatment guidelines about gender minorities and reference to other guidelines, such as fertility and sexual issues with the breast cancer and other guidelines that says, "Here is where these guidelines live," so viewers of the site can find those topics. We can also ask providers to query their patients about these topics.

ACBCYW OPEN DISCUSSION

Elana Silber, MBA
Sharsheret
ACBCYW Committee Chair

During the open discussion, the ACBCYW reviewed the recommendations set forth by the workgroups. A nomination will be made to consider the recommendations made by the workgroup as formal recommendations. After the nomination, one of the committee members will second, and then the floor will be open for discussion. At the end of the discussion, there will be a vote to forward the formal recommendation to CDC.

Starting with the Genetics & Genomics Workgroup, the following recommendations were put forth:

1. Providers need to have sufficient training in genetics and genomics to navigate the array of testing options and select appropriate testing
2. Support studies to better understand breast cancer genes & associated mutations
3. Support studies that help guide medical management that is gene specific
4. Support studies to better understand additive risks – genetics + environment + pathologic risk factors
5. Support efforts to adopt consistent, plain language terms to describe tumor-based and germline testing
6. Synthesize EVB information in central location and develop an educational platform on genetics and genomics for providers and the public

Dr. Saphier proposed that the recommendations be accepted for discussion. Ms. Crollman seconded. Below are the comments made in regard to the recommendations:

- The first recommendation is vague. Providers, in general, need to have enough training. Does refer it to training from a medical school or specialist training? It is not practical to think every MD will undergo specific training for this population.
- The first recommendation sort of parlays into the Provider Workgroup's recommendations and maybe it could be tabled and held for that workgroup's discussion.

- Different types of providers will encounter this area in some way or fashion, and they need to have some sort of general more comprehensive understanding of genetics and genomics. This would include even nurse practitioners, genetic counselors, and clinicians that touch the patient along the way will come from different specialties.
- With regard to Recommendation 5, CDC has an opportunity because of the plain language initiative to help remove the jargon, which are a barrier to patient understanding and informed medical decision making.

In light of time, Dr. Fairley proposed some revisions to the process. The ACBCYW will review the recommendations from the workgroups today and decide those that are ready to move forward and those that need more development and deliberation. Therefore, a discussion will occur on the recommendations that are ready to move forward. A separate meeting will be convened to cover the remaining recommendations. Ms. Silber was in agreement.

The conversation resumed on the recommendations made by the Genetics & Genomics Workgroup. A few questions were posed. Are there pieces missing? Do the recommendations cover all of the areas the workgroup would like to see and hear about? Are they at the point of meeting their initial charge?

- The workgroup recommended studies because of the need for research, but maybe this could be rephrased to make a recommendation to take some of the work that has occurred and extend it or expand it.

Several members agreed this would be a good next step. Dr. Fairley said there are a host of mutations that could be included and asked if there were any specific ones to focus on in the initial piece. Quite a few years have been spent on BRCA 1 and 2. These are the comments and recommendations in response to Recommendation 2 put forth by the workgroup.

- From the traffic seen at FORCE, ATM, PALB2, CHEK2, PTEN, and TP53.
- Ones that have medically actionable gene mutations; all of those that have risk reducing mastectomy as an option and consideration
- CDH1 and NBN
- Use language that is flexible and not make it limited or imply endpoints. Perhaps the language could be “including but not limited to” and also include medically actionable mutations.
- There should be two bullets from this: to support studies and to expand CDC’s already existing efforts.
- More women are presenting in the same family with breast cancer with no known genetic mutation. This issue should be highlighted. Is there a place when this can be mentioned? A workgroup member responded Recommendation 4 was created

to address those scenarios, but perhaps it can be changed to include those that may not have known genetic but other unknown risk.

- There is a large effort in the genetics community for undiagnosed disease exploration, and this recommendation can expand that. Perhaps it can read "support efforts to investigate and further research for families with breast cancer but no known genetic mutation." It can be an undiagnosed category.
- Design additional videos for the Bring Your Brave Campaign that address next phase, beyond BRCA1 and 2, and potentially the need for retesting after a certain period of time.

The role of retesting was not discussed. There may be an important role for retesting of people who have been tested five years ago and have a strong family history of cancer. The committee felt there should be verbiage that conveys that genetics and genomics warrant dynamic, ongoing conversations in which the role of updated genetic testing are addressed. Genetic testing is an area with rapid advances, and given that patients can have evolving family histories, it is important for providers to again question if someone else in the family has been diagnosed with cancer, age of diagnosis, etc. and to revisit the role of updating genetic testing. A suggestion was made to roll this into another bullet which recommends updating the current efforts; however, Dr. Fairley felt this recommendation will require more discussion. There is rollover testing for women diagnosed and women from families with a strong history but no mutation. The identification of audience would require more thought. It was suggested the priority should be people who have been diagnosed and their family members at risk.

Another solution proposed was to include this into the expansion of work being conducted for BRCA1. It can be updated since there is the ability to test for more genes and tests can find mutations that were missed before. This could be an update to the qualifications for testing, test components, and the new technologies. It was proposed to conduct an environmental scan on retesting language used to date with patients and the materials available regarding retesting. Dr. Friedman asked if this should be added to the Genetics & Genomics Workgroup's tasks, and Dr. Fairley affirmed and asked for information to be presented to the ACBCYW at a later date.

Dr. Toedt remembered, at the last meeting, the committee opted not to have a health inequity and health disparities workgroup because the understanding was every workgroup would address the topics in their recommendations. He asked, of all the workgroups, how their recommendations can help in terms of accessibility, affordability, and the assurance that research will include underrepresented racial and ethnic groups with an aim of ending health inequity and health disparities. Dr. Friedman said in their literature review very little was found regarding BRCA prevalence among Native populations. There has been some work on different Latino groups, but overall, there is not much available across various racial populations. She agreed the Genetics & Genomics Workgroup should go back and locate the gaps in those areas as well. Dr. Fairley asked the workgroup to be mindful of the space of health inequity and health disparities in their recommendations, especially considering the changes made in the

BRCA testing guidelines to include founder mutation language and populations that may be at high risk for those mutations. Dr. Fairley asked committee members to feel free to reach out to the leaders of the workgroups with additional thoughts or suggestions.

The Mental/Behavioral Health Workgroup proposed the following recommendations:

1. Advocate for screening method to identify high risk patients and survivors for mental health issues. "Ask, advise, refer" (AAR) is a model used by health care providers to assess tobacco use and initiate linkage tobacco cessation support.
    a. Use a short, validated clinical instrument to identify mental health issues in patients and survivors
    b. Routine screening could enhance patient-provider communication
    c. Make appropriate referrals as needed
2. Funding for dedicated research on mental health in young women with breast cancer
    a. Why are mental health issues underutilized?
    b. When is the best time for intervention and what are the best interventions?
    c. What is the best medium for providing help (in-person, online, support groups?)
    d. What is the most effective communication strategy in routine discussions about treatment risks and potential impact on quality of life?
    e. What are long-term outcomes related to treatment effects and accurate post-treatment expectations (need for large, longitudinal studies)?

Dr. Fairley opened the floor for discussion. The comments were as follows:

- With regard to Recommendation 1, in primary care most practices screen universally for depression and anxiety. So, is this sufficient? Is it the general screening given no matter what the person's past medical history may be? Those simple screening questions will not be enough to elicit the kind of issues specific to this population. In addition, there is an assumption the questions are asked among the population of women who may be uninsured or underinsured or those on public insurance program, and that is not necessarily true.
- People exchange significant high-end information on BreastCancer.org. This may be a place to share information that needs to be spread.
- CDC should generate a repository of the resources.
- What other key recommendations would the committee like to set forth for the mental health and behavioral health provider community, even if their work is not specifically carved out for young women with breast cancer? What are the critical and most valuable elements for that network of providers who may be interfacing with young women, who also many have breast cancer?
- Think of tactics and approaches that inform this population of women of the mental and behavioral health services available to them.

Ms. Shonta Chambers probed if the mental and behavioral health components could be potential springboards for interaction with other federal agencies who may address mental health or behavioral health type issues. SAMSHA is a federal organization who specializes in this area. Dr. Fairley said there has not been significant outreach to work with them in this capacity. She felt it was a good idea and is something CDC would consider if it was recommended. Therefore, the recommendation put forth was for CDC to consider aligning with other efforts or coordinating a joint effort with other federal agencies or operating units to leverage efforts and promotion for the scope of work being undertaken across all the workgroups.

The Provider Workgroup made the recommendations listed below:

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 since 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
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 felt the recommendations were straightforward. Ms. Crollman motioned to put the recommendations forward as formal recommendation. Dr. Saphier seconded. The floor was open for discussion.

- Financial toxicity and the reimbursement code for testing were brought up, so additional resources should be added to Recommendation 2 to address the gaps around financial toxicity.
- Also, for Recommendation 2, decisions made from the Sexual Health & Fertility Workgroup should be included in the provider recommendations as well for consistency. Make it more general in terms of pregnant and postpartum and consider adding another bullet for sexual health and fertility or something along those lines.

Dr. Fairley reviewed each of the recommendation before calling for a vote from the voting members only. For Recommendation 1, Ms. Elana Silber, Ms. Lindsay Avner, Ms. Michele Maria Cerullo, Ms. Lisa Astalos Chism, Ms. Anna Crollman, Ms. Carletta Cunningham, Ms. Ellyn Davidson, Dr. Kenneth Lin, Dr. Rachel M. Mayo, Dr. Tara Sanft, Dr. Nicole B. Saphier, Ms. Elissa Thorner, Dr. Mylin A. Torres, and Ms. Joyce Tannenbaum Turner, all voted to approve the formal submission of Recommendation 1 to HHS.

Recommendation 2, with the proposed revisions, reads as follows:

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
    - Mental and behavioral health
    - Financial toxicity
    - Fertility and sexual health

Ms. Silber, Ms. Avner, Ms. Cerullo, Ms. Chism, Ms. Crollman, Ms. Cunningham, Ms. Davidson, Dr. Lin, Dr. Mayo, Dr. Sanft, Dr. Saphier, Ms. Thorner, Dr. Torres, and Ms. Tannenbaum Turner, all voted to approve the formal submission of Recommendation 2 to HHS.

For Recommendation 3, Ms. Silber, Ms. Avner, Ms. Cerullo, Ms. Chism, Ms. Crollman, Ms. Cunningham, Ms. Davidson, Dr. Lin, Dr. Mayo, Dr. Sanft, Dr. Saphier, Ms. Thorner, Dr. Torres, and Ms. Tannenbaum Turner, all voted to approve the formal submission of the recommendation to HHS.

For Recommendation 4, Ms. Silber, Ms. Avner, Ms. Cerullo, Ms. Chism, Ms. Crollman, Ms. Cunningham, Ms. Davidson, Dr. Lin, Dr. Mayo, Dr. Sanft, Dr. Saphier, Ms. Thorner, Dr. Torres, and Ms. Tannenbaum Turner, all voted to approve the formal submission of the recommendation to HHS.

CDC staff will work closely with the Chair, Ms. Silber to prepare and submit the approved recommendations. The committee will be able to view the submission as well.

There were no formal recommendations put forward by the Sexual Health & Fertility Workgroup; therefore, an open discussion proceeded regarding this topic and the information presented.

- The fact that the issues with the NCCN guidelines is being moved also to the Provider Workgroup as an education item is very significant. If nothing else comes out of this workgroup, that recommendation speaks very strongly and makes a great starting point. There may not be a way of influencing the NCCN guidelines and maybe that is not the role of the committee, but what is important are the patients and providers understanding that the guidelines do not adequately address these issues and more work needs to be done to change that.
- Part of the role for changing the guidelines can be consumer education. Consumers can drive change. If women are demanding that this be addressed and assessed because they are more educated in that aspect and have access to more tools, it will help move the conversation forward.
- Providers often comment that they were not trained to talk about sexual health and fertility, and they do not know how to do it. They know it is in the NCCN guidelines, but they still feel uncomfortable with the subject and would rather wait until their patient brings it up. Therefore, educating consumers that this should be a two-way dialogue that should be addressed from the beginning would be beneficial. The consumers should be told to make sure they bring it up to their providers, and the providers need to know that the patients are waiting for them to bring it up. This is a really important part of the share-care model and can move the sensitivity down so that the dialogue can continue.
- As work is occurring on the provider side, maybe some type of patient education piece can be designed that will provide them with additional information. Something as simple as, “Here are some questions that you can ask your doctor.”
- Patient navigators do engage in this space. Looking at the literature, in general, sexual health for women is not addressed, breast cancer related, or otherwise. Multiple surveys with providers and consumers show that it is not addressed. It comes back to engaging consumers. For example, the landscape of male sexual health changed when direct to consumer advertising for erectile dysfunction was utilized. Male consumers begin to walk into their doctors’ offices and specifically requested the blue pill. So, it drove the hallmark, awareness, and the acceptance that this was a problem. There are some campaigns that are trying to empower women in the sexual space, some driven by pharmaceutical companies. The landscape is wide open, so anything the committee can establish with regard to consumer education is going to be received, necessary, and has the potential to impact.

- Sexual health is being addressed haphazardly and is not addressed universally by frontline providers and attendees. Nurse navigators, lay navigators, and community health workers are doing it, but not consistently. Also, midlevel providers do not have great training in this area and may be using their personal instincts or experiences. There is no ideal outlet available to train the providers on how or when to have the conversations. The conversation needs to be revisited constantly and not a one-time checkbox activity. It needs to happen consistently along the continuum of care.
- Sexual health education is not a reimbursable service, so mechanisms to ensure the conversation takes place and reimbursement is made available are critical.

Dr. Fairley will set up another call with the committee in or around May 2020 very similar to the day's teleconference. This will allow the committee to discuss the sexual health and fertility piece further and any additional recommendations that result from the call. It was suggested to put a focus on formulating the consumer recommendations for the next three months because it will push the work forward with the providers. Simultaneously, education can occur. Also, sexual health and fertility will be kept together because of the overlap in the subjects. Ms. Arin Hanson will share the Living Beyond Beast Cancer resources for healthcare provider regarding sexual health and fertility, as well as their consumer resources. Formal recommendations voted on during the day's meeting will move forward to HHS.

PUBLIC COMMENT

There were no public comments.

SUMMARY AND CLOSING

Elana Silber, MBA
Sharsheret
ACBCYW Committee Chair

Ms. Silber commended Dr. Fairley for being a great facilitator for today's teleconference. The conversations were vibrant, and she thanked the committee members for their valuable comments and recommendations. She enjoyed having the opportunity to flesh out these important topics with other experts in this space to bring about critical solutions for young women living with breast cancer.

With no further comments, the meeting was adjourned at 12:36 p.m. EST.

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

05.13.2020_________
Date

/Elana Silber/_______________________
Elana Silber, MBA, Chair
Advisory Committee on Breast Cancer in Young Women

Centers for Disease Control and Prevention

ADVISORY COMMITTEE on BREAST CANCER in YOUNG WOMEN

February 6, 2020 Teleconference

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).

Thursday, February 6, 2020

9:00 A.M. – 9:15 A.M.	**Opening: Welcome, Roll Call, and Introductions** ***Temeika Fairley, PhD*** **Designated Federal Officer, DCPC, CDC** ***Elana Silber, MBA*** ***Sharsheret*** **ACBCYW Committee Chair**
9:15 A.M. – 10:50 A.M.	**Workgroup Reports and Discussion** **Genetics & Genomics Workgroup** *Shubhada Dhage, MD, FACS* NYU Perlmutter Cancer Center *Joyce Tannenbaum Turner, MS, CGC* Children's National Medical Center **Mental/Behavioral Health Workgroup** *Mylin Torres, MD* Winship Cancer Institute *Michele Maria Cerullo, JD* DaVita Medical Group **Provider Workgroup** *Lindsay Avner* Bright Pink *Kenneth Lin, MD, MPH* Georgetown University Medical Center **Sexual Health Workgroup** *Lisa Astalos Chism, DNP, APRN, NCMP, FAANP* Karmanos Cancer Institute

	Ellyn Davidson Brogan & Partners
10:50 A.M. – 11:00 A.M.	**Break**
11:00 A.M. – 12:10 P.M.	**ACBCYW Open Discussion** *Elana Silber, MBA* *Sharsheret* *ACBCYW Committee Chair*
12:10 P.M. – 12:20 P.M.	**PUBLIC COMMENT**
12:20 P.M. – 12:30 P.M.	**Summary and Closing** *Elana Silber, MBA* *Sharsheret* *ACBCYW Committee Chair*

ATTACHMENT 2: ROSTER OF THE ACBCYW MEMBERSHIP

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