

**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

Zoom Meeting

May 10, 2023

Record of the Proceedings

Table of Contents

| | |
|---|----|
| OPENING: WELCOME, ROLL CALL, AND INTRODUCTIONS | 1 |
| CDC Updates | 2 |
| Committee Chair Updates | 6 |
| ACBCYW Workgroup Reports and Open Discussion | 10 |
| Provider and Healthcare Systems Workgroup | 10 |
| Reproductive Health Workgroup | 14 |
| Genetics and Genomics Workgroup | 15 |
| Public Comment | 17 |
| Summary and Closing | 17 |
| Appendix A | 19 |
| Appendix B | 21 |

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ADVISORY COMMITTEE ON BREAST CANCER IN YOUNG WOMEN

ZOOM MEETING

MAY 10, 2023

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 May 10, 2023.

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 Zoom Meeting 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

Kimberly E. Smith, MBA, MHA

Designated Federal Officer

CDC, Division of Cancer Prevention and Control

Ms. Smith welcomed the participants to the Zoom Meeting and thanked the committee members for their time and commitment. Members of the public were also welcomed, thanked for their interest, and given the reminder that prior to the conclusion of the meeting there would be a period for public comment. Ms. Smith also instructed members of the public that if they would like to make a comment, they could email ACBCYW@cdc.gov to indicate their interest in speaking during the public comment session at the end of the meeting. She conducted roll call and confirmed 11 voting members, ex-officio members (or their proxies), or liaison representatives in attendance.

Meeting Summary

Advisory Committee on Breast Cancer in Young Women

May 10, 2023 ♦ Page 1

This constituted a quorum for ACBCYW to continue with the meeting on Wednesday, May 10, 2023. There were no publicly declared conflicts of interest by the voting members for any of the items on the published agenda (*Appendix A: Published Meeting Agenda*).

Cristina M. Checka, MD

The University of Texas MD Anderson Cancer Center
ACBCYW Committee Chair

Dr. Checka welcomed everyone and shared that she is pleased to serve as chair of the ACBCYW Committee. She then introduced herself and moved to opening the floor for members to give a brief introduction (*Appendix B: ACBCYW Public Roster*).

CDC Updates

Temeika L. Fairley, PhD

Senior Health Scientist
CDC, Division of Cancer Prevention and Control

Dr. Fairley started her presentation by briefly introducing herself and then moved into listing parts of the Division of Cancer Prevention and Control's portfolio of work on breast cancer in young women or early onset breast cancer. The portfolio includes applied public health research, funding to support organizations that serve cancer survivors (which is currently in its fifth year), the Advisory Committee on Breast Cancer in Young Women (ACBCYW), and a public health education campaign for young breast cancer survivors and health care providers. Dr. Fairley briefly discussed CDC's applied public health research work on early onset breast cancer (EOBC) survivors which includes a considerable amount of research on health economics. This is due in part to the question of, "what is the economic impact of early breast cancer on young women and their families" that was raised during the very first ACBCYW meeting. Dr. Fairley goes on to express that having some ideas about and understanding the economic burden will have an impact on decisions and possibly policies at all levels around cost. Some of the ACBCYW liaison representatives have spoken about financial toxicity so this work around health economics speaks to how the work is moving forward. Finally, she expresses how she is looking forward to hearing from the committee and hearing the recommendations that will come from the committee.

Ally Moehring

Health Communication Specialist
CDC, Division of Cancer Prevention and Control

Ms. Moehring started by giving a brief refresher on the goals of the Bring Your Brave Campaign. The objective of the campaign is to reach all women between the ages of 18

and 44 with information about risk, what raises risk, ways to lower risk, signs and symptom information, and also tools to understand the importance of knowing your family history and tools on how to have difficult conversations. As was previously stated, the campaign focuses on all women, but there is a slightly increased focus on young black women who we know have a higher risk of breast cancer at a young age and women of Ashkenazi Jewish descent to understand their unique risk of having a BRCA gene mutation. The campaign also reaches survivors and previvors or women with a known risk. Ms. Moehring expresses how these women are disproportionately affected by body image issues, financial toxicity, career disruption, relationship issues – whether dating, spousal, or friendship. Parenting, fertility preservation, and feelings of loneliness, isolation, and not feeling a strong sense of peer community are also issues that disproportionately affect this group. The campaign also seeks to reach out and address the needs of the metastatic cancer community, a community of women who sometimes feel disregarded or left behind.

Ms. Moehring shares that there are four different portfolio projects under the Breast Cancer Education and Awareness Requires Learning Young Act (EARLY Act):

Contracts

- **Main Campaign** (Bring Your Brave Campaign) – formative research, strategy development, content development, organic social media, paid media, earned media, all with a social/digital focus.
- **Entertainment Education** – storylines about breast cancer in young women in entertainment – both TV and mobile gaming.

Cooperative Agreements

- **American College of Obstetricians and Gynecologists (ACOG)** – marketing materials to promote Early Onset Breast Cancer Continuing Medical Education (CME) two-part course part of a suite of CMEs with gynecologic cancers as well.
- **National Association of Chronic Disease Directors (NACCD)** – focuses on tools to help women craft their stories and discuss genetic or hereditary risk information with family members.

Course highlights of the CDC/ACOG Early Onset Breast Cancer CME were also shared. In terms of the course registration, course completion, and CMEs awarded the goals have been exceeded. The most noted accomplishment is the pretest/posttest knowledge change. For the first part of the course there is a 21% increase in knowledge change and for the second part of the course there is a 12% increase. Of the providers who completed the entire course 57% reported an intent to change their practice as a result of taking the course.

Moving into the outreach strategies, Ms. Moehring speaks to the increase in outreach to young women who are within the survivor or previvor community. During the beginning of the COVID-19 pandemic some of the women within the survivor community were

reached out to. It was important to check on these women and keep a pulse on their thoughts and feelings during this time of isolation. She goes on to say that it was important to lead with empathy and to address issues that these women disproportionately experience. These issues are referred to as “outside of cancer” issues and include mental health issues, feelings of isolation, sexual health, financial health, career disruption, fertility, and relationships. To note, “outside of cancer” issues also affect previvors. The outreach for previvors has been providing them with the support and tools needed to help them share the information with their families. One of the avenues in which this is done is through a peer-to-peer approach that is modeled through video depictions of being the first – those who are first in their families to learn their risk. Other efforts include the production of videos that mimic posts that are found on popular social media platforms like TikTok and Instagram. Although CDC is not on TikTok it was important to have visuals that were reminiscent of the posts (the vertical format) and videos that could be attached to a TikTok trend (like closet hauls) on the platform to attract the attention of young women.

Entertainment education within the Bring Your Brave Campaign was the next topic to be explored. Ms. Moehring shares that this a space that has had great movement, which has been driven by relationship building, talking to people within the entertainment industry, and most of all leaving an indelible mark. Work has been done with the Hollywood Health and Society over the years but within the last few years there has been a concerted effort to focus on specific topics and to get into as many writer’s rooms to advise or give them information that could spark creative ideas on their end. One of the shows in which they were able to advise is the Bold Type in which the main characters mother died at a young age, resulting in the contemplation of her getting genetic testing. Other work includes panels with Hollywood Health and Society and a board meeting. At the board meeting Dr. Fairley presented on young black women and breast cancer. This meeting was attended by major writers in the industry and resulted in an immediate storyline in a show called New Amsterdam. Another panel was done with Hollywood Health and Society on fertility and family planning that was moderated by comedian and breast cancer survivor Tig Notaro. A season long story arc on the CW’s Superman and Lois was developed based off the experiences of spokespersons, Jennifer and Jay, who shared their story of Jennifer being diagnosed in her late 20’s and how that affected their family planning. There is currently a two-episode storyline on Grey’s Anatomy about a young black woman diagnosed with breast cancer. The depiction of the character in these episodes allowed for a lot of valuable information to be shared broadly. Ms. Moehring goes on to share her excitement of their presence in the mobile gaming space. Young women are very active in this space and now there is a mobile game called Insecure, The Come Up, which is a companion mobile game to the HBO hit show, Insecure. In this mobile game the characters explore their experiences and family history as it relates to the signs and symptoms of breast cancer.

Ms. Moehring wraps up her presentation with sharing what’s on the horizon with the Bring Your Brave Campaign. One of the next steps is **formative research** where there will be focus groups with previvors to learn about their care during the pandemic, where

they currently are in terms of taking of their health, and what their biggest needs are. Three new video concepts are in preproduction and are as follows: 1) Bring Your Brave spokesperson, Carletta, has reached 10 years of survivorship and will speak to her journey, feelings, attitude, and how her life has changed; 2) A Survivor will share her story and the support she received from a non-traditional caregiver; 3) Survivor and previvor series of video to encourage peer-to-peer conversation – helping “the firsts” to tell their stories. The “firsts” are those who are first in their families to learn about BRCA/genetic risks.

Q&A:

During the Q&A session, the first question was, “Can other organizations leverage the campaign’s content? Can they push this content through their channels?” Ms. Moehring replied that it would depend on how the organization would like to do this. All the videos are not available online, some of them are social media only, but they can be made available and sent to the requesting organization – the resources can be made available. The next question was regarding how feedback was retrieved from those who had viewed some of the shows and videos. A robust measurement strategy that includes qualitative work that looks at what the social conversation has been around the various videos. As it relates to the shows, like New Amsterdam and Superman and Lois, what has been a trend is an increase in google searches of the topics that were addressed. For example, the storyline in New Amsterdam revolved around breast density as a risk factor. After that episode aired there was an uptick in google searches around dense breast and breast cancer and young women. Dr. Fairley adds to the response by sharing that at the onset of the entertainment education work there was a publication that was centered around how entertainment education can be used to deliver messaging. Now that it is known that the messaging can be effectively delivered, the next phase will consist of exploring what people are doing with the messaging.

A series of questions were posed; beginning with are there any plans to expand the CME course credits to family medicine and internal medicine? Dr. Fairley responds that the marketing of the CMEs is broadly disseminated, going out to various organizations, some of whom are family practitioners, nurse practitioners, PAs, etc. She goes on to say that reaching that community of practitioners is very important because a lot of young women may be seen by their family medicine doctor and then referred out to other specialists, so this is being considered as they begin to ramp up their provider education work. Another question was asked of how can we support the work that is being done – the previvors peer-to-peer support groups, possibly providing survivor participants? Ms. Moehring shares that once the webpages are updated, they will serve as a resource page for organizations to amplify the work. As it relates to committee members/organizations providing previvor/survivor participants, the contractors working on the videos are deep within the casting cycle, but when they are casting for new projects, they will take recommendations. The next question within this series of questions is, as the work matures and becomes more finalized are there plans to present at any conferences? There is interest in presenting at national

meetings/conferences and they are looking into some this year. Lastly, are there any thoughts to including a male perspective for “the firsts”? In the last cycle of videos of “the firsts”, three videos were developed that included two male previvors and one male survivor.

Not a question but a comment was made of the sexual health group potentially collaborating with the Bring Your Brave campaign because sexual health is a part of the dialogue.

Committee Chair Updates

Cristina M. Checka, MD

The University of Texas MD Anderson Cancer Center
ACBCYW Committee Chair

Dr. Checka begins by giving an overview of the recent scientific presentations about breast cancer in young women that were given from August 2022 through the first of May 2023. She began with the abstract of Melissa Peters who presented, in San Antonio, an abstract titled “Delays in Diagnosis of Adolescent and Young Adult Breast Cancer and Lack of Breast Health Education”. The delays and diagnosis of adolescents and young adult breast cancer and the overall lack of breast health education was quantified. An online survey was sent via social media to women diagnosed younger than 40 years of age, with 455 responses. Of the respondents, 70% required extra steps to obtain a diagnosis resulting in a third of the respondents having a delay from detection to diagnosis. About two-thirds of the respondents reported that they had never received breast health education prior to the diagnosis from a physician. The findings of this study revealed a tremendous knowledge gap with about half of the respondents being unfamiliar with breast self-awareness and 54% incorrectly defining breast self-exams. These data confirm earlier findings that women under 40 face a significant rate of delayed diagnosis with patient perceptions and medical provider perceptions contributing to these delays. This is important because in earlier diagnosis of breast cancer in young women will initiate quicker treatment interventions which have been shown to increase 5-year survival rates and lower long-term mortality rates. The researchers concluded that greater efforts should be made to educate young women on breast health, and the medical community should be made aware of these challenges.

Dr. Checka discusses the findings of two groups who did presentations at two different meetings that further evaluated the outcomes of fertility preservation. She begins with the group at Mount Sinai that looked at embryo utilization in young breast cancer patients who had undergone egg harvesting for fertility preservation. The identified gap of this research is: there is limited investigation of the ultimate issue in fertility preservation, which is namely how often do women who have undergone egg harvesting actually pursue childbearing. They looked at a 10-year period from 2010 – 2020 with 316 breast cancer patients of reproductive age identified. Of these participants 53% were offered fertility referral and 38% saw a fertility specialist. Dr.

Checka noted that this is just an abstract and she is looking forward to the details in the manuscript. However, 91 patients pursued egg harvesting followed by cryopreservation in 49 cases and embryos in 41 cases. After an average of 5-year follow-up 31% of those who used egg harvesting utilized the egg or embryo to pursue childbearing with 17 undergoing embryo transfer to themselves, 11 using surrogate carriers. At the time this abstract was submitted there had been 24 pregnancies resulting in 20 childbirths with four pregnancies underway. They also looked at the proportion of their patients that had Medicaid coverage, and these were fifty-five women of reproductive age, and only 8 of them met with a fertility specialist, four harvested eggs, and none pursued childbearing. So, they found specific statistical significance that HMO and PPO insured patients were far more likely than Medicaid patients to actually pursue fertility preservation. Dr. Checka shares the conclusion of this study that these data demonstrate a low overall rate of cryopreserved egg and embryo utilization among women treated for breast cancer whose earlier pursuit of egg harvesting was evidence of a desire for childbearing. Furthermore, racial and insurance data demonstrate disparities in the pursuit of fertility treatment and utilization of preserved eggs and embryos. Further research will utilize interviews to analyze individual women's decision-making process relevant to such issues as hormone therapy utilization, concerns about breast cancer recurrence, progression of disease and restraints imposed by relationship status and finances.

The next group, investigators from the Dana-Farber Cancer Institute, looked at conception and pregnancy among young breast cancer survivors and the outcomes of those pregnancies. Over a 10-year period, 2006 – 2016, the investigators looked at young women, breast cancer stage 0 – III, less than 40 years old who reported having at least one baby after treatment. They wanted to know how these women got pregnant, and peripartum complications. They had a response rate of 77% with 92 eligible women completing the survey. The follow-up was about the same in five years; most of the women had stage II cancer, about 70% received chemotherapy and half of the respondents had never been pregnant. Overall, 61% conceived naturally, 39% of the pregnancies occurred with assisted reproductive technology (ART) – of those who received ART 74% had tried to conceive naturally. Dr. Checka goes on to report that in this study, 11% of those who had a known genetic mutation underwent testing; for those who declined testing their reasoning included having a strong belief in more effective cancer risk reduction in the future, not being offered testing, high cost associated with testing, no interest in IVF, acceptable odds for inheriting the mutation, belief in other risk reduction strategies, and it posed an ethical concern for one of the respondents. In terms of outcomes most conceived naturally with the majority of those who used ART first attempting natural conception. There was limited use of prenatal genetic testing. The rate of peripartum complications was consistent with what would be expected in the larger population. This research may drive future research to help inform the care of young breast cancer survivors pursuing pregnancy.

Dr. Checka goes on to explore an abstract and a poster from two bodies of work that looked at Oncotype DX (ODX) for young patients. She further explains that these are

patients who have early stage, hormone receptor-positive, HER-2 negative breast cancer. The abstract was from the Kaiser group in California. It showed a reduction in chemotherapy in patients with a low oncoprotein recurrence score. Over recent years this tool has been increasingly used in young breast cancer patients, younger than 40 years of age, a population that is underrepresented in randomized trials. From 2008-2018, 1,436 Stage I-III young breast cancer patients were diagnosed with invasive breast cancer, and 455 met eligibility criteria for ODX testing. Prior to 2018, 52% were tested, after 2017 ODX testing rate increased to 88%. Some of the conclusions from the study were that utilization of ODX testing increased after 2017; a significantly lower proportion of women who underwent ODX testing received chemotherapy compared with women not tested for ODX and a higher percent of women with T2 cancer received chemotherapy if testing was not completed, which may reflect a greater fear of recurrence in younger patients. The investigators suggest that more research is needed to better understand the potential risk of overtreatment in the young breast cancer population.

Dr. Checka then begins to examine the poster from the University of Washington where a group of surgeons looked at the impact of genomic testing on chemotherapy and survival in young patients. Their cohort of interest was devised from the National Cancer Database where they saw that about 5,600 women and of those women, 67% had undergone genomic testing, with testing increasing over time. Dr. Checka goes on to report that the researchers saw that most patients didn't receive chemotherapy with a trend towards decreasing use over time, this was especially seen as the practitioners had the more personalized genomic information. Dr. Checka pivots and brings Dr. Lustberg into the conversation by drawing attention to the fact that the researchers felt there was a need for a longer follow up. They thought that longer follow-up might generate some survival curves that could have stronger predictive value. However, Dr. Checka poses that the other competing question is the role and value of ovarian suppression in young patients and how that might impact survival. She admits that she is not as aware of trials that are going on currently but from this abstract, she can deduce that there must be a question which looks at the role of ovarian suppression in young women. Dr. Lustberg responds that the latest thinking is that a lot of chemotherapy benefit for certain types of breast cancer might be the ovarian suppressing effect of chemotherapy. Dr. Lustberg goes on to say there is a perspective study from NRG that is trying to answer that question. She addresses the idea of long-term follow-up by sharing there are several studies looking at tumor DNA as a minimal residual disease predictor.

The updates continue with Dr. Checka sharing the study "Racial/Ethnic Disparities in Overall Survival among Young Women with Triple Negative Breast Cancer and Residual Disease after Neoadjuvant Chemotherapy" by surgeons from Duke University School of Medicine. This remains a clinical challenge. It is known that pathologic complete response to neoadjuvant chemotherapy correlates to overall improved survival with patients with triple negative breast cancer. It is also known that race/ethnicity and socioeconomic variables can influence access to care and treatment. Dr. Checka notes,

what is unclear is whether these variables influence overall survival in the subset of patients that go on to have surgery after chemotherapy and are found on final pathology to have residual disease. The methods were discussed, and the results were after looking at 16,416 patients, two-thirds had residual disease after neoadjuvant chemotherapy with the rate of residual disease being highest among non-Hispanic Black patients. While most socioeconomic factors were not associated with overall survival insurance type was significant, and beyond those factors race and ethnicity remained significantly associated with overall survival in young patients with triple-negative cancer.

Dr. Checka concludes her updates with the overview of a presentation given at the Radiologic Society of North America about the imaging approach and challenges to breast cancer in young patients. The criteria for early screening were reviewed and the limitations of mammography was discussed. Dr. Saphier clarifies that ultrasounds are not necessarily the initial exam of choice in women less than 30 years of age and women who are lactating/pregnant. One of the biggest issues is doctors are trying to rely less on black and white age cut offs and rely more on ensuring younger women get risk assessments by the age of 25. Dr. Saphier goes on to impart that this needs to be the biggest messaging and goal of this workgroup – how can we capture younger patients earlier to determine their need for higher risk screening? Whether at the pediatrician' office, up until the age of 18, at the primary care doctor, or at the OB/GYN solid risk assessments before the age of 25 should be what guides future screening. From this comment sparked discussion around updated guidelines for screening, which will be discussed later in the meeting. Dr. Saphier reports that the American College of Radiation recommendations for pregnant and lactating women is routine screening with mammography, ultrasound, and MRI if high risk, even when lactating, the recommendation is not to wait.

Q&A:

During this time Dr. Saphier shares that it is important to remind people that breast cancer incidence among young women is rising. Some of the risk factors are genetic mutation, familial, environmental, but there are other factors that attribute to the rise like obesity – rising body fat is directly linked to rise in breast cancer, lower fertility rates – women having babies at older age, and fewer women are breastfeeding. These are all linked to increasing the risk of breast cancer.

Dr. Lustberg does not want the messaging of early risk assessment in young women to be muddled by the focus placed on average risk women starting at age 40. She wonders if this could be an opportunity for the ACBCYW committee to re-emphasize that screening at the age of 40 is for average risk women but some women need to start sooner or may need a different type of imaging in addition to a mammogram.

Dr. Friedman asks has there by any thought to or push to revisit the issue of breast self-exam? She feels there should more research on the topic. Dr. Checka responds that

she had the same question. She goes on to say that it feels like we have to lose momentum on what was previously taught, update the masses with the updated recommendations, and then catch them up. In this process there is a lag, this is seen in the topic of breast self-exams.

After a break and before the open discussion, roll was taken and a quorum was established to continue with the ACBCYW meeting.

ACBCYW Workgroup Reports and Open Discussion

Cristina M. Checka, MD

The University of Texas MD Anderson Cancer Center
ACBCYW Committee Chair

Dr. Checka begins by introducing the agenda item of committee workgroup presentations. During this time there will be some report outs and open discussion. The workgroups that will present are the **Provider and Healthcare Systems Workgroup**, the **Reproductive Health Workgroup**, and the **Genetics and Genomics Workgroup**. The **Mental Health Workgroup** will not present at this meeting, as it has been a little more difficult to launch this workgroup. However, this workgroup will come up to speed by the Fall ACBCYW meeting. Dr. Checka shares that Maimah Karmo has graciously volunteered to chair this workgroup and she welcomes others to volunteer for the co-chair position. Dr. Checka states that this is the interactive part of the meeting so all comments and questions are welcomed.

Provider and Healthcare Systems Workgroup

Dr. Heller begins the report out by sharing some of the workgroup ideas that they thought would be really helpful to address. These ideas were divided into buckets with the first being early risk assessment. Under the **early risk assessment** bucket Dr. Heller shares the following ideas:

- Promote national campaign for early risk assessment
- Promote understanding of factors contributing to increased risk of breast cancer in adolescent and young adult women
- Identify genetic links sooner
- Promote understanding of mutations including and in addition to BRCA that confer an increased risk of breast cancer
- Include resources for black, indigenous, people of color (BIPOC) women and rural communities
- Address cultural issues that may prohibit women from acting even when educated

Bucket 2 - **Education in terms of provider awareness** which included:

- Provide data-driven updates regarding rising incidence of breast cancer in young women, presentation of disease in young women, incidence in young women without known genetic mutations
- Prevalence and incidence update – providing numbers that will prompt groups to act
- Make providers aware of the difficulties young women face seeking a prompt diagnosis/address provider bias
- Consider focusing education and resources by type of provider (develop in partnership with patients for maximum patient-friendly and effective materials)
 - PCPs* (largest impact/greatest focus)
 - OB/GYNs
 - Radiologists
 - Pediatricians
 - Breast Surgeons
 - Oncologists
 - Reconstruction/Plastic Surgeons
 - Genetic Counselors
 - Nurse Navigators
- Improve patient education regarding signs, symptoms, and risks of breast cancer
- Examine sources and resources for awareness of breast cancer— can we target parents, physicians, schools [high school-sex ed curriculum]; can we target college-public health groups, student activity groups?

Bucket 3 - Resources to address barriers to breast cancer prevention, diagnosis, and treatment:

- Identify social determinants of health
- Identify potential barriers to care
- Identify resources to overcome barriers to care as well as means of reaching populations at high risk for cancer and for poorer outcomes

Bucket 4 – Screening in Pregnancy/Lactation

- Background: Persistent widespread confusion about screening in this setting
- Goal: Dispel common misconceptions about safety of mammography in pregnancy
- Provide clear recommendations for both patients and providers regarding modality specific screening recommendations during lactation and pregnancy

Ms. Muñoz continues the conversation by discussing resources for reconstruction. She explains that there has been a change in DIEP flap support but she poses the questions of what does these changes look like for not only the patient but for the providers as well. How are providers staying up to date? From a call she learned that the insurance carrier Cigna is going to delay the change in DIEP flap support but she is unaware if other insurance carriers will also delay the change. Ms. Muñoz continues that breast reconstruction is a very important aspect of breast cancer care for young women so her

workgroup wants to discuss within this meeting setting the options and opportunities to support DIEP flap reconstruction access. Next she spoke of long-term support because of the longer survivorship rates for young women with breast cancer. There is a need for ongoing treatment like the resources for survivors to keep up with new advances that might be beneficial for screening and proactive breast health even after the acute treatment phase is past. Long-term support also addresses the needs and provides support to the caregivers of previvors and survivors. Ms. Muñoz moves into how the workgroup can “plug in” to some of the movement around the Bring Your Brave campaign. Some suggestions include sharing stories and narratives which may encourage awareness for both patients and providers. For example, ensuring representation and bringing a wide range of stories like young women under the age of 18 who have been diagnosed and exploring the duality of being under the care of parents and navigating a school setting. Also, representation of minority groups to show a full representation and wider range of women that get affected by breast cancer. Additionally, it was suggested that patient influencers should be engaged to promote various programs and the Bring Your Brave campaign. Ms. Muñoz concludes with acknowledging there is overlap between the Provider and Healthcare Systems Workgroup and the Mental Health Workgroup. Providers are often the facilitators of have those discussions and making the referral so it is important to work in partnership with that workgroup.

Dr. Friedman kicks off the discussion with announcing that CMS is revisiting the decision to go away with the code for DIEP flap. On June 1st there will be a public meeting where they are accepting public commentary and she invites the committee members to be present so that their voices can be heard. Another comment by Dr. Friedman is related to an issue that was raised earlier which is, is there a role, especially within the provider workgroup, to revisit conversations around breast awareness/breast health exam? She went on to make one more comment around long-term survivorship – there are some long-term outcomes and guidelines that have changed. Therefore, there should be a role in the Provider and Healthcare Systems Workgroup that ensures that people who were young when they were diagnosed are receiving updates on care, especially those who are no longer being followed by their oncologist.

Ms. Peters addresses Dr. Friedman’s question around breast awareness/breast health exams, she spoke with the primary investigator of the Shanghai study and he divulges that he never intended the consequences that came out of the study. Ms. Peters goes on to impart that the you cannot compare the Shanghai medical system to the American medical system or non Communist socialized medical systems which is one of many holes found within the study. So, what has happened as a consequence of the Shanghai study is denial of education, to those of high school age, of breast self-exams and breast self-awareness which poses long-term repercussions to an entire population. Ms. Hurst rounds out the topic by stating that she heard from many women, as a result of a lack of education around breast self-exams and breast self-awareness, that they don’t need to do breast self-exams, they don’t need to know their bodies, and their

biggest fear is that they will do the self-exams wrong. Dr. Friedman states that as a committee, recommendations should be made to HHS while inquiring is there a pathway for revisiting this issue? Dr. Fairley answers that written recommendations to HHS and writing of a white paper are within the purview of this committee. Just to note, at CDC, there is a requirement to follow the USPTF guidelines. Dr. Checka reiterates Dr. Lustberg's suggestion that this might be an opportunity for a editorial to summarize some of the thoughts about officially making recommendations. There is also an opportunity for academic throughput – an investigation of some of these questions that leads to work that should be considered for publication. A few committee members expressed interest in assisting with writing the paper while Ms. Peters narrowed the purview to who are we asking to provide the education on breast self-exams and breast self-awareness. Dr. Lustberg and Dr. Checka commented that this should be a quick project, possibly completed by the Fall ACBCYW meeting. Another research opportunity would be to collect data on what is happening in schools. Is there variability across types of school, the states the schools reside in?

Dr. Checka refers back to the workgroup's ideas surrounding education in terms of provider awareness. Just as she inquired about any upcoming plans to expand the CME course credits to family medicine and internal medicine in the Bring Your Brave campaign presentation, she comments at this juncture of the discussion about what group of practitioners do you target to make sure young women are taught about their risk and that a proper risk assessment is done. She notes that during the presentation Dr. Heller listed a number of specialties that speak to providing proper risk assessments, but Dr. Checka is curious about the role that subject matter experts (SMEs), mid-level providers or advanced practice providers, will assume. Nurse practitioners and physician assistants are becoming more specialized. She wonders if they could be a target population to engage? This group is also in need of CME credits, could it also be considered to extend CME courses to them? Dr. Heller agrees that including SMEs is a great idea and makes the suggestion to reach out to these SMEs to determine what would have the highest yield in terms of a website, a society page, a journal, etc.

A question comes from Dr. Heller to CDC staff regarding next steps in the process – how are the ideas moved into action? After gaining clarity around the question posed by Dr. Heller, Dr. Fairley shares that CDC staff works with the Committee on the feasibility of implementing their ideas or recommendations. The committee workgroups are supported by CDC staff, who work to provide context on certain EOBC-related activities or recommendations (current and proposed). Dr. Checka shares that there might be access to graduate students and residents who can serve as a resource. Ms. Smith confirms that workgroups can reach out to students so they can engage with the workgroups; although, they would not be ACBCYW committee members.

Dr. Checka goes on to solicit the members on suggestions of where they think the earliest opportunity for educational intervention might be, whether it's middle school, high school, or college. Middle school was offered as an early opportunity because this

is the time where kids are taught about their bodies. Another thought was to integrate the conversation with their PCP – teens having the conversation with their doctor about breast health and body health awareness. More campaigns with moms and daughters talking about their breasts and bodies as a way to be proactive would be a way to propel awareness. Partnering with sororities, other women’s groups, community advocacy groups can be a viable component of sharing messaging. Another possible audience could be authors of puberty books. Dr. Fairely shared that the group could reach out to an organization that connects health centers on college campuses to disseminate messaging. Other organizations were also shared like the American College Health Association and two other student affairs professional organizations that may have this type of information which could be a starting point to understand what is happening in this area.

Reproductive Health Workgroup

Dr. Checka transitions to the Reproductive Health Workgroup where Dr. Lustberg begins with identifying the topic centers of the workgroup, which are pregnancy and reproductive health in younger women with breast cancer and overall sexual health. She felt the latter topic had a great deal of gaps that could be explored as a topic area but suggests that she and her workgroup members landed on a broader sexual health focus. Once the focus area was established, the question then became how would they approach this topic. After discussion and exploration of different resources a group member asked if there was an option to synergize and build on the efforts of the Bring Your Brave campaign. The idea was not to “re-invent the wheel” but to contribute to what had already been developed. Ms. Hanson adds that young women experiencing sexual health impacts can feel really isolated especially when no one in their peer group is experiencing the same challenges. This can then become an opportunity for those women to find CDC resources and to see themselves in content developed by CDC. For the workgroup, the question then became how can their work advance the goals. Ms. Hanson shared that their first step was to review the recommendations of the previous working group which they found to be very strong but there was a need to go deeper and expand what had been presented. The next phase would consist of more conversation and refinement. After hearing the information from the Provider and Healthcare Systems Workgroup, Ms. Hanson shares that education of providers is a key strategy to improving this issue of sexual health and reproductive health.

Dr. Lustberg and Ms. Hanson opened the discussion to ideas and suggestions from the committee. Dr. Friedman starts the conversation by mentioning that it has been her experience that if healthcare professionals do not have any options to offer, they tend not to validate the experience of early menopause. She goes on to say this might be an issue that can be addressed within the Reproductive Health Workgroup. Dr. Jeudy expresses the importance of multidisciplinary teams in situations where the oncologist might not have all of the answers. When an issue or concern is beyond the scope of

one practitioner that patient can be referred to a practitioner that has a greater level of understanding.

The question of the availability of resource hubs that focus on sexual health was posed by Dr. Fairley. She imparts that it might be beneficial to find a group or resource hub that has effectively addressed sexual health; any suggestions of known resources, places, or people would be helpful. Living Beyond Breast Cancer, where Ms. Hanson serves as Director of Outreach, is a “resource hub” that Dr. Fairley is speaking of. They are in the process of developing a comprehensive toolkit that will have a directory of resources. Other organizations provide patient materials as well as provider resources. However, one the goals of this workgroup is to ensure that the information is accessible and inclusive.

During the discussion attention was drawn to large prospective studies that are looking at the removal of the fallopian tubes, in mostly women with mutations, as a fertility sparing and menopause sparing method of lowering the risk of ovarian cancer. These studies and specifically the study referenced by Dr. Friedman will not reach completion soon, but bringing awareness to these studies could assist in getting more answers and essentially helping women with mutations by informing them of this option.

The discussion morphed into a consideration for the Reproductive Health Workgroup and the Genetics and Genomics Workgroup. The topic of potential legal legislative avenues for insurance to help pay for fertility treatments to not pass on genetic risks was raised. The question becomes, who is pioneering avenues to help women with these physically demanding decisions on motherhood? Moreover, which group would assume the responsibility of exploring this topic because it is not either or, rather it falls within both workgroups. It was suggested that the Reproductive Health Workgroup could connect with the Genetics and Genomics Workgroup to develop a recommendation around expanding insurance and financial coverage for these very expensive tests and procedures. These workgroups could possibly lend their voices, as experts in the field, about how it is impacting those who have genetic risks and those who have been diagnosed.

[Genetics and Genomics Workgroup](#)

At the onset of the update, Dr. Friedman shares that goals were established by the workgroup that would improve collaboration and documentation towards assessment and recommendations related to genetic and genomic testing in young women with breast cancer and offer recommendations to improve value and service for the ACBCYW committee. Previous recommendations, from several years ago, that were made from the last iteration of this workgroup were reviewed as a reminder for the committee members. They include support and provide educational materials for understanding terminology related to genetics and genomics and various types of testing; synthesize information regarding genetics and genomics in a central

educational platform; explore education regarding pathologic risk factors; CDC to join the Consistent Testing Terminology Working Group to stay apprised of and participate in ongoing discussions to develop specific language around "genetics" and "genomics." Some of the topics the current workgroup decided to address overlap some of the recommendations from the previous iteration. These topics include understanding of genetic testing and (genomic) biomarker testing, providing guidance on tests being marketed directly to patients or to providers outside of guidelines, and access to care (genetic counseling/testing and guideline-recommended risk management/care). Dr. Friedman shares the desire to do a deep dive into the genetic and biomarker testing through uncovering the gaps in patient's understanding of tests and results as well as exposing the gaps in the provider's understanding. She was mindful to address the need for an updated landscape scan on issues with people using ancestry/DTC testing for hereditary cancer risk. Is this an issue? Is it causing harm to patients. Just as in the previous presentations by the other two workgroups the topic of education for both patients and providers was considered.

Dr. Friedman went on to explore access to care as it relates to genetic counseling and testing and guideline-recommended risk-management. There are many options for low-cost genetic counseling and testing but are people aware of this and do they know how to access this testing. Guideline-recommended risk-management includes MRIs which is associated with a large out-of-pocket cost that must be absorbed by the patient. FORCE teamed up with Susan G. Komen on a project to go state-by-state to try to get laws passed that would cover 100% of the cost of guideline recommended MRIs and ultrasounds. Their efforts have resulted in New York, Arkansas, Texas, Connecticut, Georgia, Oklahoma, and Maryland passing laws covering 100% of breast MRIs and ultrasounds. However, this state-by-state approach compounds health disparities.

One suggestion to address access to care was a national scan to measure the scope of the issue. There is a lot of documentation on disparities in genetic counseling and testing but very little data on who is getting guideline-recommended screening and how much they are paying. Another suggestion by Dr. Friedman was to explore if there are opportunities as a group to advocate for expansion of CDC's National Breast and Cervical Cancer Early Detection Program (NBCCEDP) to cover more high-risk patients, especially in states without laws about coverage. She also suggests that more awareness is created around CDC's NBCCEDP program and new state-level laws about no out-of-pocket costs for MRI screening for high-risk individuals. The update was concluded by providing the workgroup's next steps.

Transitioning into the discussion of this workgroup's recommendation it was expressed that prioritization of tests and the education of providers is essential. There are different types of tests but knowing which tests to order and then the provider being able to effectively interpret those results is paramount. The question is then asked are gaps between the providers being seen depending on the institution and the area? What are the resources available for high-risk patients? The response from Dr. Friedman is that there are a lot of groups coming at it often through research and alternate ways for

providing genetic information. The goal has always been to educate providers although the sentiment is that there is always room for more provider education. However, it wasn't clear that there was a role for this workgroup or CDC to address access to genetic testing but these issues and gaps in knowledge can be revisited.

It was acknowledged that there is a lot of overlap with the workgroups, but the overlap might help to focusing the strategies to determine which are solely a part of this workgroup and which are crosscutting.

The conversation simulation was referred to as an interactive resource to assist with having the conversation around diagnosis. It is resources/tools like this that should be shared by all of the workgroups to expand its reach. It was suggested that an assessment is done of the resources that are available. Also, because of the overwhelming amount of work identified and the short time frame, Dr. Checka suggests that the workgroup considers working on just a couple of topics as opposed to all of them.

Cultural tendencies and what I don't know won't hurt me ideology was brought up relating to genetic testing on embryos and children. Ms. Karmo suggests that having testing done on an embryo could be perceived as a sign of admission for those who subscribe to the faith-based component of "I will not claim it", with the "it" being the disease or mutation for which the testing is being done. This is deeply rooted in the black community and oftentimes it is not addressed in campaigns or messaging. Some formative research was done on this topic to look at who was driving the conversations and who was the holder of all the family medical history and had the most influence on health decisions being made in the family. Once that person was identified messages trended towards that person as being the one to get the medical history from.

Public Comment

No written or public comment.

Summary and Closing

Cristina M. Checka, MD

The University of Texas MD Anderson Cancer Center
ACBCYW Committee Chair

Dr. Checka thanked all of the members and expressed that it was a fantastic start. She acknowledges that the challenges are very unique to the group in that they met virtually. While the virtual setting effectively bridges some distance it is hard in a collaborative group to have robust discussion and interaction but that was not a challenge for this

workgroup. In preparation for the next meeting Dr. Checka covered a couple of topics. The first topic was the Mental Health Workgroup, Ms. Karmo will be chairing this workgroup and Dr. Checka asked for new members or those who are interested to participate in the workgroup. The second topic was the fall meeting. As of May 30th five members will be replaced. The new members will have to go through HHS vetting and there may be a bit of a time lag for that. The other issue is there needs to be 60 days notice in advance of the next meeting. Once the go ahead is given there might be a tight turnaround as the logistics are confirmed and a date is determined that suits the group to have a quorum in person. Dr. Checka concluded by thanking everyone for the work and effort that went into the meeting.

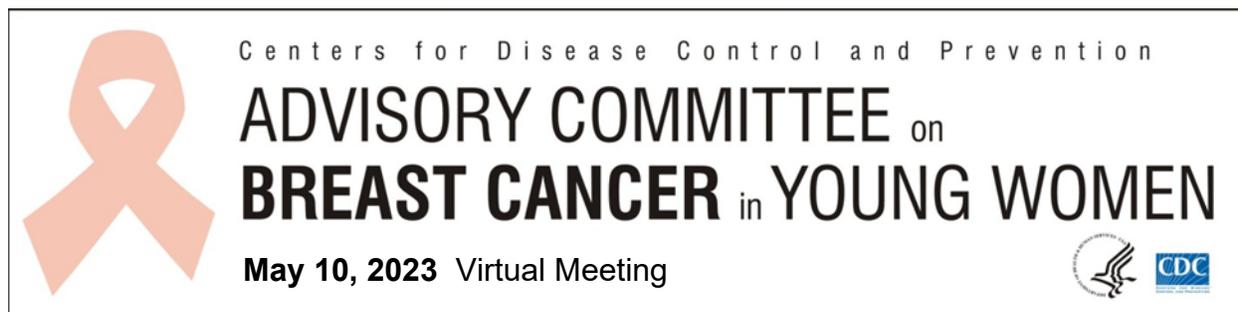
With no verbal comments or questions the meeting adjourned at 3:57 p.m. EST.

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

Date

Cristina M. Checka, MD, Chair
Advisory Committee on Breast
Cancer in Young Women

Appendix A



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).

***All times are in Eastern Time**

Wednesday, May 10, 2023

11:00 A.M. – 11:30 A.M.

Opening: Welcome, Roll Call, and Introductions

Kimberly E. Smith, MBA, MHA

Designated Federal Officer

CDC, Division of Cancer Prevention and Control

Cristina M. Checka, MD

The University of Texas MD Anderson Cancer Center

ACBCYW Committee Chair

11:30 A.M. – 12:15 P.M.

CDC Updates

Temeika L. Fairley, PhD

Senior Health Scientist

CDC, Division of Cancer Prevention and Control

Ally Moehring

Health Communication Specialist

CDC, Division of Cancer Prevention and Control

12:15 P.M. – 12:45 P.M.

Committee Chair Updates

Meeting Summary

Advisory Committee on Breast Cancer in Young Women

May 10, 2023 ♦ Page 19

Cristina M. Checka, MD
The University of Texas MD Anderson Cancer Center
ACBCYW Committee Chair

12:45 P.M. – 1:15 P.M.

Break

1:15 P.M. – 3:15 P.M.

ACBCYW Workgroup Reports and Open Discussion

Cristina M. Checka, MD
The University of Texas MD Anderson Cancer Center
ACBCYW Committee Chair

Provider and Healthcare Systems Workgroup

Reproductive Health Workgroup

Genetics and Genomics Workgroup

3:15 P.M. – 3:30 P.M.

Public Comment

3:30 P.M. – 3:45 P.M.

Summary and Closing

Cristina M. Checka, MD
The University of Texas MD Anderson Cancer Center
ACBCYW Committee Chair

Appendix B



Advisory Committee on Breast Cancer in Young Women

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Meeting Summary
Advisory Committee on Breast Cancer in Young Women
May 10, 2023 ♦ Page 24

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Meeting Summary
Advisory Committee on Breast Cancer in Young Women
May 10, 2023 ♦ Page 25

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