Update from CDC: Public health’s response to early onset breast cancer

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Background

• Breast cancer is the most commonly diagnosed cancer among women

• About 10% of invasive breast cancer cases occur among women younger than age 45.

• These women often face difficult medical, psychosocial, financial, and health issues related to their diagnosis and treatment for breast cancer.

• Nearly 30% of women diagnosed with early breast cancer develop metastatic breast cancer (mBC) with an expected median survival between two to four years.
The Breast Cancer Education and Awareness Requires Learning Young Act (EARLY Act): the first piece of legislation related to breast cancer in young women, enacted in 2010. The EARLY Act authorizes CDC to:

- Develop initiatives to increase awareness of breast health and breast cancer risk among young women.
- Establish a Federal Advisory Committee on Breast Cancer in Young Women (ACBCYW).
- Establish applied public health research program about breast cancer in young women.
- Establish a program to provide support to young women living with breast cancer.
Grantees and Programs

Partnering to support young women at risk for or living with breast cancer
Programmatic Support

CDC currently funds 7 grantees through the *Multiple Approaches to Increase Awareness and Support among Young Women Diagnosed with Breast Cancer* five year cooperative agreement (2014-2019).
Johns Hopkins Medical
Young Women’s Breast Cancer Program

- Enhancing delivery of care and wellness first visit through continuum of care
  - One-on-one patient navigation: 425 young women/year

- Multiple psycho-educational peer support groups for early stage and metastatic young women

- On-line nutrition course with accompanying recipe booklet: 200 participants

- Access to fitness and wellness with gym partnerships and online programming that reduces barriers to exercise

Figure 1: Experiences of YBCS
Johns Hopkins Medical
Young Women’s Breast Cancer Program

2018 -2019 DP-1408 Successes
A multi-disciplinary program that meets the unique medical, emotional and practical needs of young women living with and surviving breast cancer.

Education for patients, survivors and providers through print materials, in-person events and technology

• Binder for young women: 150-200 distributed/year

• 3 Webinars with global reach (600 real-time participants; 1200 archived webinar views)

• 70 website videos with distinct topics in our library; viewed 600 x/mo

• Mobile App for patients: tools for scheduling, education, navigation, and treatment
Sharsheret
*Thriving Again Survivorship Program*

- During the 2018-2019 grant year:
  - Disseminated 154 updated *Thriving Again* wellness kits to YBCS
  - Presented BRCA genetics webinar for 400+ participants, featuring updated information on new recommendations in genetic testing.
  - Implemented online, patient navigation resources for YBCS and caregivers.
  - Conducted 2 peer support and story sharing training webinars for 112 YBCS
  - Established partner network of 90 agencies providing YBCS support in local communities.
FORCE XRAYS Program

• During the 2018-2019 grant year:
  • FORCE's eXamining the Relevance of Articles for Young Survivors (XRAYS) program, helps young breast cancer survivors and high-risk women to better understand breast cancer research and news that is relevant to them.

• XRAYS allows users to submit articles for review and subscribe to an XRAYS quarterly digest.

• XRAYS Metrics:
  • 38 XRAYS article reviews published.
  • 10 blog posts about the XRAYS program
  • Reached 140,000 readers
Gulf States Young Breast Cancer Survivor Network (GSYBCSN)

- An online health resource for young breast cancer survivors (YBCS) living in Louisiana, Alabama, and Mississippi.
  - Digital platforms:
    - SurviveDAT in Louisiana;
    - SurviveAL in Alabama;
    - SurviveMISS in Mississippi.

- Purpose of the GSYBCSN is to increase the availability of and access to services and support for YBCS including those with metastatic cancer, and their caregivers and families in the gulf states region.
Gulf States Young Breast Cancer Survivor Network (GSYBCSN)

During the 2018-2019 grant year:

• Developed a video-based psycho-social support series with a board certified oncology counselor, which will be rolled out over the next 5 months.

• Disseminated educational information to 852 physicians across the three states to update them on concerns important to YBCS.

• Developed and leveraged a new partnerships:
  • Collaboration with Komen affiliates on a metastatic Breast Cancer Conferences in Louisiana and Mississippi.
  • Participated in Alabama’s annual Women’s Cancer Survivor’s Workshop
  • Young Survival Coalition’s Annual Summit for YBCS, as well as FORCE’s annual conference
**Young Survival Coalition**

- **Reach and Impact in 2018**
  - 10,000 survivors supported
  - 3627 co-survivors supported
  - 285,000 visitors to younsgsurvival.org
  - 1900 educational Navigators ordered
  - 100+ State Leader volunteers who serve young adults affected by breast cancer
  - 170+ Face 2 Face in-person support groups across the U.S.

- **2019 YSC Summit**
  - 507 attendees including 86 co-survivors and 67 YMBC
  - 81% of attendees agreed or strongly agreed they learned something new
  - 89% of attendees agreed or strongly agreed the co-survivor hangout enabled them to meet and form connections with fellow co-survivors
  - 200+ registrations for Continuing Education livestream for healthcare providers
Dana Farber
Young and Strong Survivorship Program

• Completed fall 2018 **Forum for Young Women with Breast Cancer**: 95 attendees

• 105 YBCS Navigated to Survivorship Visit

• 3 Phone Support Groups with YBCS

• 2 Sexual Health Workshops for Couples and YBCS

• 4 Webcasts on topics relevant to YBCS

SoulMates offers peer support for breast cancer patients.
Living Beyond Breast Cancer

- Implemented the *Survivorship Series for Young Women* to be delivered by trained professionals within cancer centers that serve *underserved YBCS*.
  - Collaboration with medical centers nationwide building on LBBC’s extensive engagement with the medical community
  - 15 nurse navigators trained
    - 7 navigator led sessions have engaged 126 YBCS
  - Anticipate up to 200 additional YBCS reached in 2019
- Current program is being evaluated by CDC for utility and scalability
Applied Public Health Research

Economic impact of early onset breast cancer diagnosis
EA Activities: Research

Completed Activities

- Walking Together: Making a Path toward Healing
- Literature Review/SME Panel: Breast Cancer in Young Women: Reviewing the Evidence and Setting the Course
- Estimating Infertility Among Breast Cancer Survivors
- Health Insurance Coverage of Genetics Services
- Economic Burden of Breast Cancer in Young Women Aged 15-44 Years in the United States, 2000-2010
- Economic Impact of Late Stage Breast Cancer Diagnosis and Benefits of Reducing Alcohol Consumption Among Women Aged 18-44 Years at High Risk for Breast Cancer
- Sisters Study and Two Sisters Study: national survey of young breast cancer survivors and their sisters
Economic Impact Studies

• Study to assess the lifetime economic burden in younger, midlife, and older women with metastatic breast cancer
  • Ongoing study estimating economic factors related to mBC: lost productivity, direct costs, years potential life lost, and cost of care per population;
  • Literature Review published in *Breast Cancer Research and Treatment* in January 2019
  • Additional findings anticipated in early 2020

• Economic Wellbeing of Young Women with Breast Cancer: Insurance, Employment and Financial Experiences
Health Care Provider Education
Supporting Medical Education for PCPs Regarding Early Onset Breast Cancer
Project Overview

• Funded by CDC Cooperative Agreement OT18-1802

• Provider-focused branch of CDC’s Bring Your Brave patient education campaign

• Goal is to develop innovative, evidence-based provider education materials on early onset breast cancer with input from stakeholders
Bring Your Brave - Campaign Metrics & Progress

CDC-developed tools and outreach programs for young women and health care providers
Know:BRCA: an interactive online tool that estimates a woman’s chance of having a BRCA gene mutation based on her personal and family history of breast and ovarian cancer.

- 2014-2018, more than 122,000 users have visited the site, with 4,200 users/month visiting the site in 2017

- >77,000 views of the Know:BRCA’s Learn the Facts pages

- 4,072 women have completed the Know:BRCA assessment and learned their risk for a BRCA gene mutation

- 581 providers have downloaded a starter kit to explore using Know:BRCA in their practice
  - More than 15 starter kits downloaded each month on average
Bring Your Brave Campaign

Multi-media storytelling campaign targeting young women and health care providers, with an emphasis on young women at higher risk for early onset breast cancer (including HBOC).

Platforms and methods:
- Facebook, Twitter, YouTube, Tumblr, LinkedIn, & Instagram
- CDC website with resources for young women and health care providers
- Medscape - Continuing Medical Education (CME) training
- Paid Media
Bring Your Brave Campaign

The campaign objectives are to reach young women and:

**Encourage**
- Them to learn their family history.

**Educate**
- On the risk factors for breast cancer before age 45.

**Inspire**
- Women to talk to their health care providers if they think they may be at a higher risk for breast cancer.

**Incite**
- To live a healthy lifestyle and be aware of their own breast health.
Cumulative Results

In total, the *Bring Your Brave* campaign has generated:

- 114 million impressions across social media, blogs, search engines, digital display, and earned media;
- 2.28 million video views;
- 1.4 million social media engagements; and
- 337,000+ visits to CDC’s *Bring Your Brave* website.

The campaign has also received a CDC Award for Excellence in Communication and a Certificate of Excellence: Public Service through the Public Relations Society of America.

Most importantly, campaign efforts have encouraged thousands of women to learn their family history of breast cancer and be aware of their own breast health.
Bring Your Brave Campaign
Health Care Provider Outreach

CDC Initiated Health Care Provider component of the campaign in 2017

- **Formative Research:**
  - CDC fielded a DocStyles survey of doctors regarding HBOC
  - Literature review
  - Medscape survey of internal user needs

- **CDC launched the Bring Your Brave Health Care Provider website with:**
  - Risk assessment tools and screening guidelines
  - Tailored, downloadable fact sheets
  - Access to a CME training course

- **Launched Medscape CME training for HCPs and reviewed CME metrics.**

- **Developed Provider Education training videos in 2018**
Bring Your Brave
Health Care Provider Outreach

Since the Medscape CME launch in late January 2017, the Bring Your Brave health care provider CME has resulted in:

- 14,849 learners
- 7,328 test-takers
- 7,174 CME certificates issued
- 10,738.75 CME credits
- Positive feedback from those who completed the CME training
What’s Next: Research and Results

Filling the Knowledge Gaps

Direct-to-Consumer Genetic Testing Awareness

Provider Education