Update from CDC: Overview of EARLY Act Funded Efforts

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Breast Cancer in Young Women

• Breast cancer is the second most common form of cancer in women.
• Late stage diagnosis, poor prognosis, treatment affects
• Some women are at higher risk
  • Ashkenazi Jewish women
  • African American women
  • Family history/Genetic predisposition
  • Personal history of breast/ovarian cancer
  • Chest radiation for childhood cancer
The Legislation

• Breast Cancer Education and Awareness Requires Learning Young (EARLY) Act
  • Established under Part V, Section 399 NN of the Patient Protection and Affordable Care Act, Public Law 111-148.
  • Authorizes CDC to work on initiatives to increase the understanding and awareness of breast health and breast cancer among women at high risk for breast cancer, including those under 45, and establish a Federal Advisory Committee on Breast Cancer in Young Women (ACBCYW).
Key Provisions

- Conduct prevention research
- Provide support to young women with breast cancer
- Establish a national, evidence-based education campaign
  - Target specific populations at risk including
  - Target messages and educational resources to health care providers
- Establish a Federal Advisory Committee
Applied Research
Focus Areas

- Genetics
- Fertility
- Social Media
- Survivorship
- Economics
- Population Level Data Collection
Research/Evaluation

- 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
- Sisters Study and Two Sisters Study: national survey of young breast cancer survivors and their sisters
- Walking Together: Making a Path toward Healing
- Evaluation to Explore Interventions that Support, Build, and Provide Legacy Awareness for Young Breast Cancer Survivors
- Developing psychosocial and reproductive health support for young breast cancer survivors (YBCS) in the United States: an evaluation of existing survivorship support resources.
- Impact of Genomics and Personalized Medicine on the Cost-effectiveness of Preventing and Screening for Breast Cancer in Younger Women
- Comparative Effectiveness and Clinical Utility of Risk Assessment Tools for Hereditary Breast and Ovarian Cancer
- The 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
Highlights from AJPM Theme Issue: Economics Research on Breast Cancer in Young Women

• Burden of breast cancer in terms of health state utility is significantly larger for younger women compared with women aged >45 years.

• Work loss costs were higher per capita among younger employed women than older employed women.

Estimated HRQoL effects of breast cancer are larger among women diagnosed at younger ages.

Significant differences in the HRQoL effects of breast cancer by race/ethnicity

Highlights the need for separate quality of life adjustments for women by age at diagnosis and race/ethnicity.
Survivorship Monograph

Johnson Turbes et al.:  
- Lack of available psychosocial and reproductive health information tailored for Young African American breast cancer survivors.  
- The Young Sisters Initiative: A Guide to a Better You! Program (YSI) was developed, implemented, and evaluated.  
  - appropriately accessed by African American women under the age of 45 years  
  - “helpful, useful and valuable” educational resource for providing reproductive and psychosocial information to African American YBCSs who are newly diagnosed, in treatment, and post-treatment.

Buchanan et al:  
- 60% of breast cancer survivors had concerns with thinking, memory and/or attention after receiving chemotherapy and/or hormone therapy treatment for their breast cancer.  
- Only 37% of women with these concerns discussed them with their doctor and only 15% reported receiving related treatment.
Programmatic Support
Key Provisions

• Conduct prevention research

• **Provide support to young women with breast cancer**

• Establish a national, evidence-based education campaign
  • Target specific populations at risk including
  • Target messages and educational resources to health care providers

• Establish a Federal Advisory Committee
Programmatic Support


- **CoAg**: “Developing support and educational awareness for young (<45 years of age) breast cancer survivors in the United States” (7 grantees; 2011-2014)


- **CoAg**: “Multiple Approaches to Increase Awareness and Support among Young Women Diagnosed with Breast Cancer” (7 grantees; 2014-2019)
Survivorship Grantee Successes

Washington University
Young Women’s Breast Cancer Program

- Resources and services have been provided to over 1,400 young women affected by breast cancer in the St. Louis region, and 2,700 survivors through national research efforts.

Living Beyond Breast Cancer
Young Women’s Initiative

- Breast Cancer Helpline expanded from 25 volunteers to 130 volunteers from across the country.
- Dissemination of “Let’s Talk About It” video series that presents young women affected by breast cancer and providers discussing health topics.
Promoting Cancer Genomics Best Practices: SUCCESSES

Oregon
- Developed public and provider (almost 15,000) materials

Georgia
- Integrated genetic risk screening protocol (B-RST) into 9 existing public health clinics across the state

Michigan
- Decreased inadequate insurance as a barrier to BRCA testing among women who received counseling
Health Communication
Key Provisions

• Conduct prevention research

• Provide support to young women with breast cancer

• Establish a national, evidence-based education campaign
  • Target specific populations at risk including
  • Target messages and educational resources to health care providers

• Establish a Federal Advisory Committee
What is Know:BRCA?

An interactive web resource with unique areas for consumers and healthcare providers

Launched on May 8, 2014
Know:BRCA - Vital Statistics

Since the May 2014 launch:

- **41,160** users (91% consumers) from **166** countries have visited the site
- Users completed **1851** assessments
- **416** users shared their risk results
Know:BRCA - Communications Activities

• Launched Know:BRCA Clinical Decision Support Tool
• Know:BRCA Social Media Initiative
  • Facebook
  • Twitter
  • Pinterest
• 2015 Digital Health Award Winners!!
Know:BRCA – Next Steps

- Functionality improvements to launch February 1, 2016
- Pilot evaluation beginning in Summer/Fall 2016 that will assess tool
- Content analysis and improvement (following evaluation)
- Promotion to women and healthcare providers
BRING YOUR BRAVE
IT'S TIME TO TALK ABOUT BREAST CANCER RISK
Behind Bring Your Brave

• ACBCYW 2013 Recommendation:
  • “Specifically, the Affordable Care Act calls for the ACBCYW to assist the CDC in creating and conducting a national evidence-based education campaign to increase awareness and young women’s knowledge regarding:
    • A) breast health in young women of all racial, ethnic, and cultural backgrounds;
    • B) breast awareness and good breast health habits;
    • C) the occurrence of breast cancer and the general and specific risk factors in women who may be at high risk for breast cancer based on familial, racial, ethnic, and cultural backgrounds such as Ashkenazi Jewish populations;
    • D) evidence-based information that would encourage young women and their health care professionals to increase early detection of breast cancer; and
    • E) the availability of health information and other resources for young women diagnosed with breast cancer.”

• Focus group testing and lessons learned from Know:BRCA social media initiative
• Evidence availability at the time
Bring Your Brave - Campaign Methods

Social and Digital Media: Facebook, Twitter, Pinterest, YouTube

Targeted messaging - focus group testing

Partner Engagement

Paid digital ads/SEO

Metrics

Campaign Website
YOUNG WOMEN CAN, AND DO, GET BREAST CANCER

Breast cancer is the most common cancer among women in the United States. Although most breast cancers are diagnosed in women over age 50, breast cancer does affect younger women. About 11% of all breast cancer cases in the United States are found in women younger than 45 years of age.

REAL WOMEN, REAL STORIES

CDC launched Bring Your Brave in 2015 to provide information about breast cancer to women younger than age 45. The campaign uses stories from real women whose lives have been affected by breast cancer. These stories about prevention, personal and family history, risk, and talking with health care providers bring to life the idea that young women can be personally affected by breast cancer.

Through these testimonials, Bring Your Brave aims to inspire young women to learn their risk for breast cancer, talk with their health care provider about their risk, and live a breast healthy lifestyle.

LEARN MORE: www.cdc.gov/BringYourBrave

JOIN THE CONVERSATION: #BringYourBrave

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What’s Next
Projects Underway

• Provider Education & Outreach
• Know:BRCA Enhancements & Pilot Evaluation
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www.KnowBRCA.org

LEARN about the BRCA gene mutations
TALK to relatives about family history for breast and ovarian cancers
ASSESS their risk for a BRCA mutation based on personal and family cancer history
ACT by sharing results with their doctor and discussing ways to reduce risk for breast and ovarian cancer

www.KnowBRCA.org/provider

educates providers on:
cancer genomics
clinical guidelines for BRCA risk assessment and referral
how to use Know:BRCA to enhance their practice