

# Update from CDC: Overview of EARLY Act Funded Efforts

Temeika L. Fairley, PhD

Health Scientist

Designated Federal Official

Division of Cancer Prevention and Control, Centers for Disease Control and Prevention

January 28, 2016



# 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



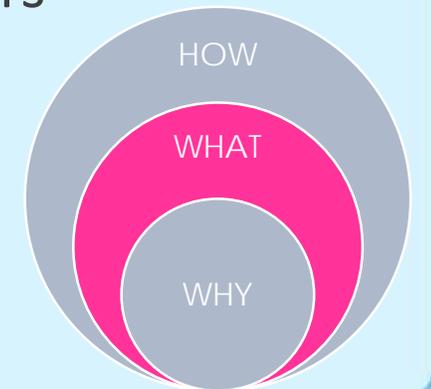
**11% OF  
WOMEN**  
DIAGNOSED WITH  
BREAST CANCER  
IN THE US ARE YOUNGER  
THAN 45 YEARS OLD.

# 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).

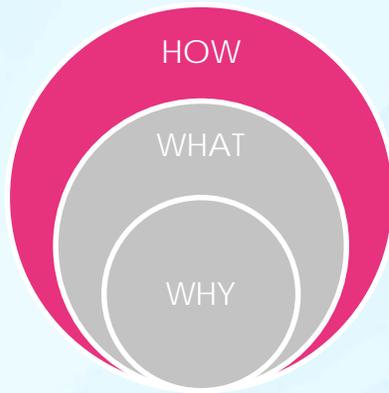
# Key Provisions

- **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

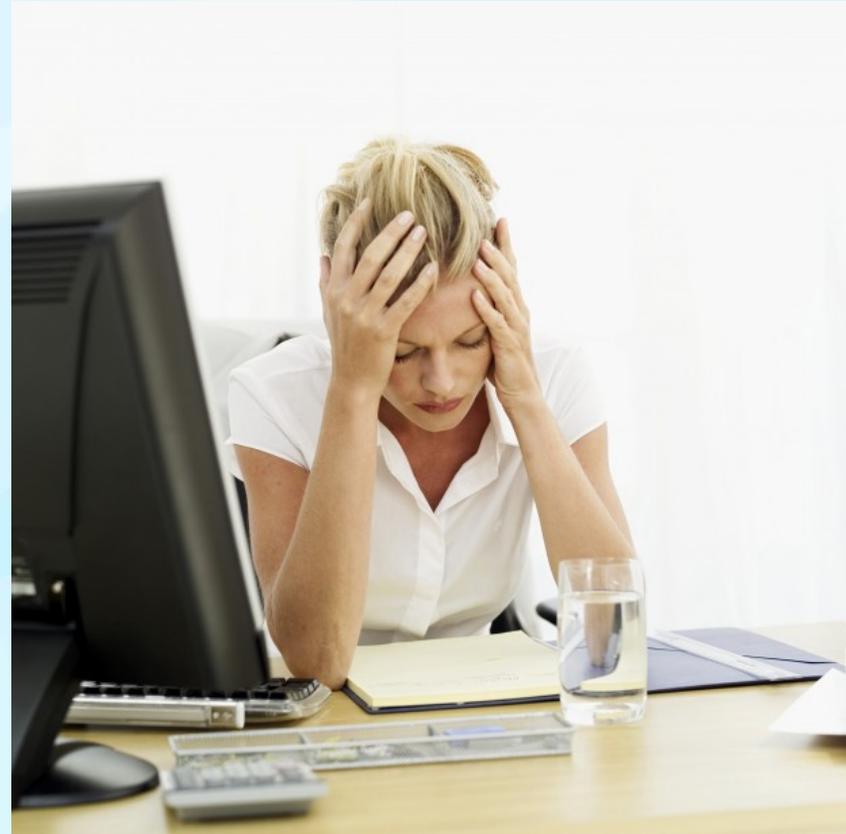


# Research/Evaluation

- **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  $\geq 45$  years.
- Work loss costs were higher per capita among younger employed women than older employed women.



[http://www.ajpmonline.org/article/S0749-3797\(15\)00751-5/abstract](http://www.ajpmonline.org/article/S0749-3797(15)00751-5/abstract)

[http://www.nwintimes.com/business/jobs-and-employment/coming-to-work-sick-can-cost-companies-in-lost-productivity/article\\_fb5a3dc3-a833-54b0-8f69-735d1fd26c81.html](http://www.nwintimes.com/business/jobs-and-employment/coming-to-work-sick-can-cost-companies-in-lost-productivity/article_fb5a3dc3-a833-54b0-8f69-735d1fd26c81.html)

# Highlights from AJPM Theme Issue: Economics Research on Breast Cancer in Young 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.:

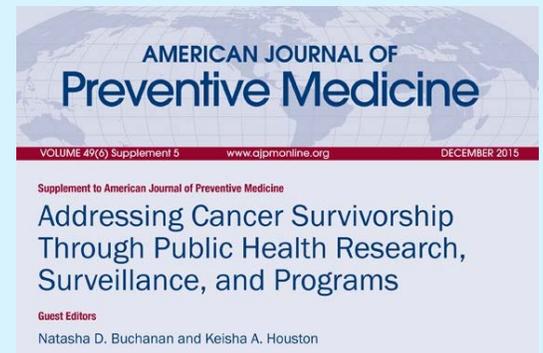
- 60% of breast cancer survivors had concerns with thinking, memory and/or attention after receiving chemotherapy and/or hormone therapy treatment for their breast cancer.
- Only 37% of women with these concerns discussed them with their doctor and only 15% reported receiving related treatment.

### Evaluation of a Web-Based Program for African American Young Breast Cancer Survivors

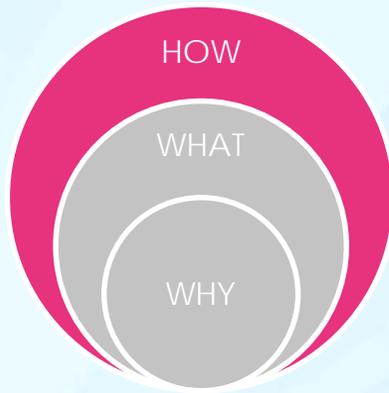
Ashani Johnson-Turbes, PhD,<sup>1</sup> Dara Schlueter, MPH,<sup>2</sup> Angela R. Moore, MPH,<sup>2</sup>  
Natasha D. Buchanan, PhD,<sup>2</sup> Temeika L. Fairley, PhD<sup>2</sup>

### Post-treatment Neurocognition and Psychosocial Care Among Breast Cancer Survivors

Natasha D. Buchanan, PhD,<sup>1</sup> Sabitha Dasari, MBBS, MPH,<sup>2</sup> Juan L. Rodriguez, MPH, MS,<sup>1</sup>  
Judith Lee Smith, PhD,<sup>1</sup> M. Elizabeth Hodgson, PhD, MSPH,<sup>2</sup> Clarice R. Weinberg, PhD,<sup>2</sup>  
Dale P. Sandler, PhD<sup>2</sup>

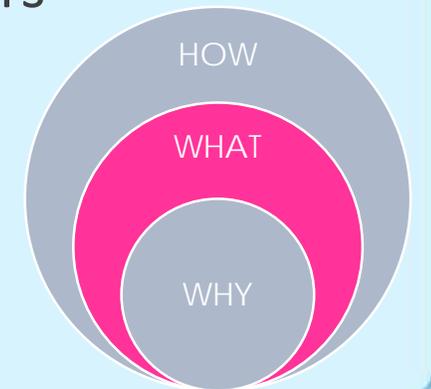


# Programmatic Support



# 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*: “Enhancing Breast Cancer Genomic Practices Through Education, Surveillance, and Policy (3 grantees; 2011-2014)”
- *CoAg*: “Developing support and educational awareness for young (<45 years of age) breast cancer survivors in the United States” (7 grantees; 2011-2014)
- *CoAg*: “Enhancing Breast Cancer Genomic Practices through Education, Surveillance, and Policy” (5 grantees; 2014-2019)
- *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: SUCSESSES

## Oregon

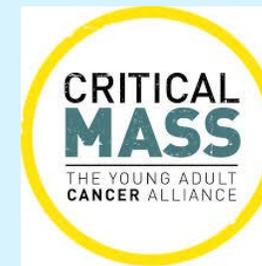
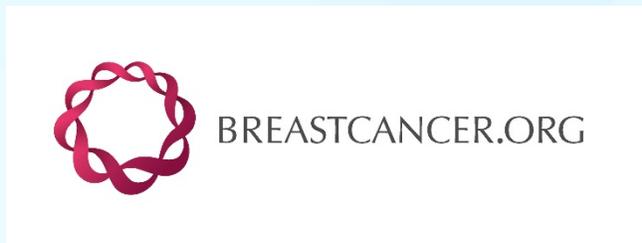
- Developed public and provider (almost 15,000) materials

## Georgia

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

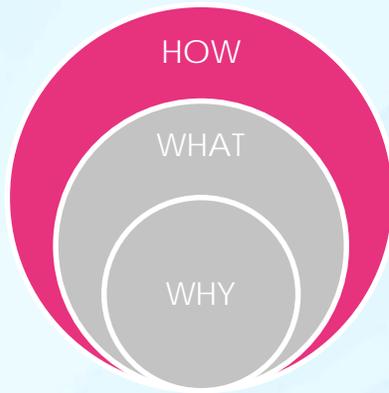
## Michigan

- Decreased inadequate insurance as a barrier to BRCA testing among women who received counseling



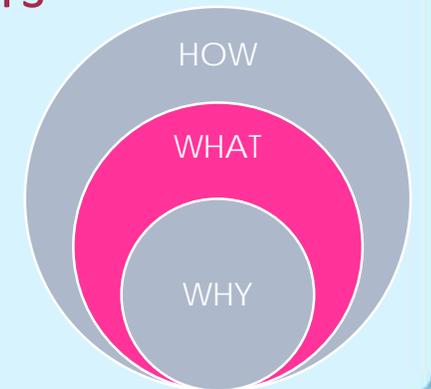
# Health Communication

---



# 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***

KNOWING YOUR BRCA GENE MUTATION RISK CAN SAVE YOUR LIFE

# 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

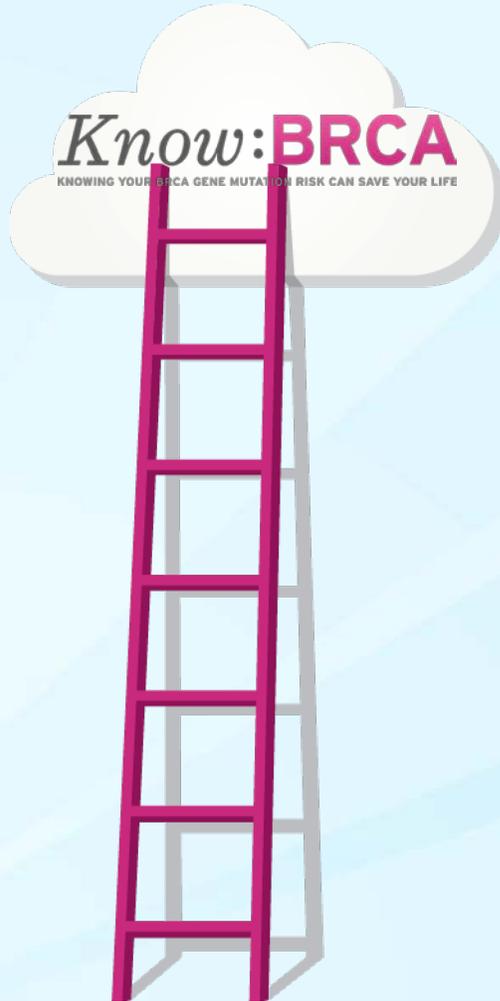
# Know:BRCA - Communications Activities

- Launched *Know:BRCA* Clinical Decision Support Tool
- *Know:BRCA* Social Media Initiative
  - Facebook
  - Twitter
  - Pinterest
- **2015 Digital Health Award Winners!!**

**Know:BRCA**  
KNOWING YOUR BRCA GENE MUTATION RISK CAN SAVE YOUR LIFE



# 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.*

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

Metrics

Partner  
Engagement

Paid digital  
ads/SEO

Campaign  
Website

**BREAST CANCER**  
is the most common cancer in  
**AMERICAN WOMEN**



**11% OF WOMEN**  
**DIAGNOSED WITH BREAST CANCER**  
**IN THE US ARE YOUNGER THAN 45 YEARS OLD.**

**1 IN 8**  
women will be diagnosed with breast cancer during her life.



### 3 Steps Young Women Can Take to Understand their Hereditary Breast and Ovarian Cancer Risk

- 1**  
Learn your family history of breast or ovarian cancer.  
It may indicate you are at a higher risk.
- 2**  
Talk to a doctor if you are at a higher risk.  
Your doctor can help you make a plan for managing your risk.
- 3**  
Know how your breasts normally look and feel.  
Talk to your doctor right away if you notice changes in the size or shape of your breast, pain, or nipple discharge.

ourBrave



U.S. Department of Health and Human Services  
Centers for Disease Control and Prevention

BRING YOUR *brave.*

## What Every Young Woman Needs to Know About Hereditary Breast & Ovarian Cancer



### Breast Cancer in Young Women Can be Hereditary

Breast cancer is less common in younger women than in older women, but young women are more likely to have hereditary breast cancer. Hereditary cancers run in your family and are caused by an inherited change in your genes.



**BRCA** stands for the **BR**east **CA**ncer gene. You have two **BRCA** genes—one from your mother and one from your father—which help the body prevent breast cancer.

Everyone has **BRCA** Genes

Some people have mutations—or changes in their **BRCA** genes—which increase their risk for breast, ovarian, and other cancers.

**1 IN EVERY 500**  
women in the US has either a **BRCA1** or **BRCA2** gene mutation.

**50%**  
If one of your parents carries a **BRCA** gene mutation, you have a **50%** chance of also having the mutation.

### You May Be at a Higher Risk



- You—or any family members—had breast cancer before **age 50**
- Multiple **relatives** have had breast cancer, or a male relative has had breast cancer
- You—or any family members—have had **ovarian cancer**
- You and you or any family members have had breast or ovarian cancer
- A family member has a known **BRCA** mutation

### Why BRCA Mutations Matter

<p><b>50%</b></p> <p><b>BREAST CANCER</b> 50% of women with a <b>BRCA1</b> or <b>BRCA2</b> gene mutation will develop breast cancer by the time they turn <b>70 years old</b>, compared to <b>7%</b> of women in the general US population.</p>	<p><b>30%</b></p> <p><b>OVARIAN CANCER</b> 30% of women with a <b>BRCA1</b> or <b>BRCA2</b> gene mutation will develop ovarian cancer by the time they turn <b>70 years old</b>, compared to <b>less than 1%</b> of women in the general US population.</p>
-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------	-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------



## 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](http://www.cdc.gov/BringYourBrave)

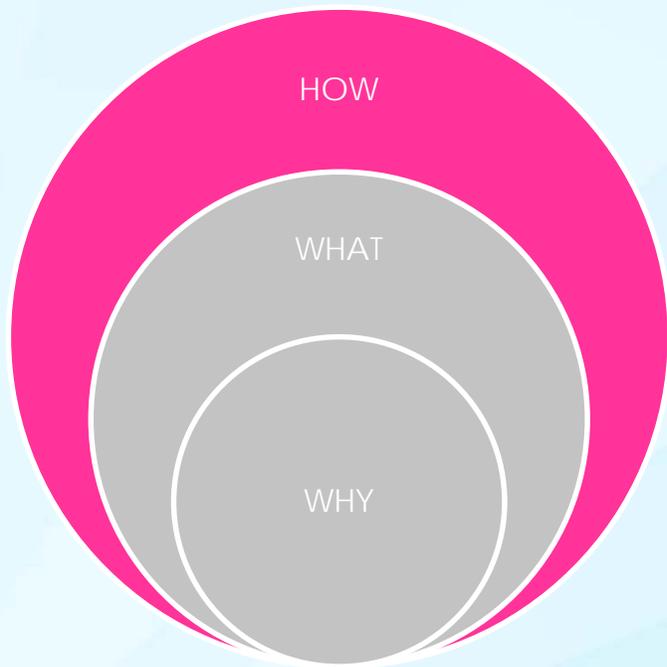
-  [facebook.com/CDCBreastCancer](https://facebook.com/CDCBreastCancer)
-  [pinterest.com/CDCgov/breast-cancer/](https://pinterest.com/CDCgov/breast-cancer/)
-  [@CDC\\_Cancer](https://twitter.com/CDC_Cancer)

JOIN THE CONVERSATION: [#BringYourBrave](https://twitter.com/BringYourBrave)



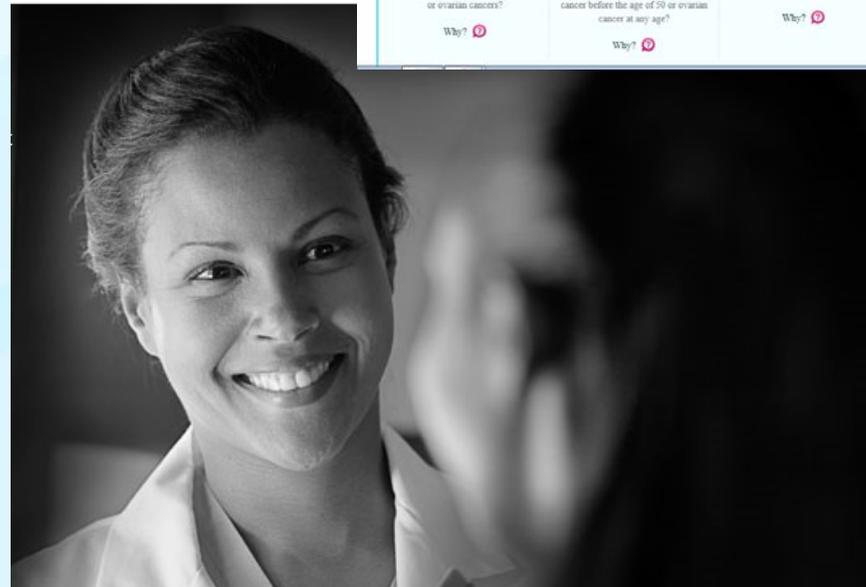
U.S. Department of  
Health and Human Services  
Centers for Disease  
Control and Prevention

# What's Next



# Projects Underway

- Provider Education & Outreach
- Know:BRCA Enhancements & *Pilot* Evaluation



Know:BRCA (beta)  
KNOWING YOUR BRCA GENE MUTATION RISK CAN SAVE YOUR LIFE

Log in Register for an Account

Assess Your Risk | Learn The Facts | Support Center | Glossary | Healthcare Provider Center

## Do You Know:BRCA?

Did you know BRCA gene mutations can be inherited from either your mother or father? Did you know that BRCA gene mutations greatly increase your risk of developing breast and ovarian cancers?

The Know:BRCA Assessment can help you assess your risk of having a BRCA mutation. Learning your risk can help you and your doctor make important decisions for your health.

[Take the Assessment](#)

or

[Learn More about BRCA](#)

### What does a BRCA gene mutation mean?

[Click Here to Get the Answer](#)

## Is This Assessment for Me?

DETERMINE IF THE ASSESSMENT IS RIGHT FOR YOU

Can you answer Yes to any of these questions?

<b>1</b>	<b>2</b>	<b>3</b>
<b>Personal and Family History</b>	<b>Age</b>	<b>Ethnicity</b>
Have you or any of your family members been diagnosed with breast or ovarian cancers?	Have you or any of your family members been diagnosed with breast cancer before the age of 50 or ovarian cancer at any age?	Are you of Ashkenazi Jewish descent?
<a href="#">Why?</a>	<a href="#">Why?</a>	<a href="#">Why?</a>

### Healthcare providers

Know: BRCA can help you collect detailed family history information and determine whether referral to genetic services is needed.

Find out how you can use Know:BRCA in your practice.

- Download our Starter Kit
- Learn about Hereditary Breast and Ovarian Cancer

[Visit the Healthcare Provider Center](#)



**Temeika L. Fairley, PhD**

**CDC/Division of Cancer Prevention and Control**

**[tfairley@cdc.gov](mailto:tfairley@cdc.gov)**

**[www.cdc.gov/cancer](http://www.cdc.gov/cancer)**

## www.KnowBRCA.org

helps women with a family history of breast and ovarian cancer:

- 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