

# Addressing the health needs of young women diagnosed with breast cancer

Advisory Committee on Breast Cancer in Young Women

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# Education and Awareness Requires Learning Young (EARLY) Act History

- ❑ Sponsored by Rep. Debbie Wasserman-Schultz
- ❑ In response to initial legislation, CDC formed a workgroup that identified key areas of focus:
  - Applied research initiatives
  - Communication approaches
  - Communication messages
  - Programmatic support (e.g., young survivors)

## **EARLY Act Provisions Integrated in Affordable Care Act**

- ❑ **YOUNG WOMEN'S BREAST HEALTH AWARENESS AND SUPPORT OF YOUNG WOMEN DIAGNOSED WITH BREAST CANCER.**
- ❑ **Established under Part V, Section 399 NN of the Patient Protection and Affordable Care Act (PPACA), 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 40.**

## Key Provisions

- ❑ Establish an evidence-based education campaign
- ❑ Target women between ages 15 and 44
- ❑ Target specific at-risk populations
  - African Americans
  - Ashkenazi Jews
- ❑ Target messages to health care providers
- ❑ Prevention research
- ❑ Survivor support
- ❑ Establish a Federal Advisory Committee on Breast Cancer in Young Women (ACBCYW)

# Federal Advisory Committee on Breast Cancer in Young Women (ACBCYW)



# Advisory Committee on Breast Cancer in Young Women (ACBCYW)

- Provides advice and guidance to the Secretary, HHS, the Assistant Secretary for Health, and the Director, CDC, regarding:
  - formative research, development, implementation and evaluation of evidence-based activities aimed at prevention, early detection, and survivorship.
  
- The advice provided by the Committee will assist in ensuring scientific quality, timeliness, utility, and dissemination of credible appropriate messages and resource materials.

## ❑ **Current status:**

- Developed a list of organizations and individuals to serve on the Committee
- Contacting potential nominees regarding Committee service.
- Finalizing the committee membership and nomination package to send to HHS
- Communications

## ❑ **Future activities:**

- Preparing for the first FACA meeting to be held in early 2011 (e.g., agenda development, meeting logistics, etc.)

# Research



# Literature Reviews and Expert Panel

- **Breast Cancer in Young Women: Reviewing the Evidence and Setting the Course**
  - 3 large components to this project:
    1. Review of the scientific literature
      - Genomics and family history
      - Diagnosis and treatment
      - Survivorship
      - Patient and provider communication
    2. Media Audit and Environmental Scan
      - Reviewing messaging from print, broadcast, and internet sources
      - Reviewing social media outlets
      - Environmental scan of relevant organizations and websites
      - Review of patient and provider educational materials
    3. Expert Panel
      - Experts and advocates from several relevant disciplines
      - Working to set a research agenda for the division
- **POC: Natasha Buchanan**

# Genomics Cooperative Agreements

- ❑ The Office of Public Health Genomics (OPHG) supports cooperative agreements with Oregon and Michigan
- ❑ Increased the scope of those agreements to support additional cancer genomics related activities
- ❑ Activities include (but not limited to):
  - Working with state clinics to expand data collection on BRCA 1/2 testing and follow-up
  - Adding questions related to family history of breast cancer and genetic testing to state BRFSS
  - Data collection on follow-up procedures for those with a genetic mutation
  - Work with state insurance carriers to expand coverage of genetic services
  - Explore linkages with other state cancer programs - cancer registry data and B&C programs
- ❑ POC: Katrina Trivers

# Health Insurance Coverage of Genetics Services

- ❑ Project consists of a review of major health insurance plans (public and private) across the US
- ❑ Will provide a comprehensive view of coverage for genetic services and requirements for referral and payment
- ❑ The review seeks to assess coverage for:
  - Genetic Counseling for BRCA 1/2
  - Genetic Testing
  - For those who test positive:
    - Prevention techniques (prophylactic procedures, increased or alternative screening, chemo-preventive drugs, etc.)
    - Psycho-social services
- ❑ POC: Juan Rodriguez

# Extension to the Sisters Studies

## □ Sister Study extension

- The National Institute of Environmental Health Sciences (NIEHS) has been conducting a longitudinal, prospective cohort study on 52,000 women with a first degree relative with breast cancer to assess genetic and environmental risk factors for cancer
- CDC will be adding a short survey to their yearly follow-up (n ~ 6,000) that will assess risk perception, provider communication, and information seeking behavior
- Survey currently being finalized by CDC team should go into the field in Summer 2011

□ POC: Juan Rodriguez

# Extension to the Sisters Studies, cont.

## □ The Two Sister Study

- Additional NIEHS study looking at breast cancer survivors diagnosed under age 50.
- CDC is working with NIEHS to convene a workshop where experts and some advocacy organizations will discuss the state of the science and determine priorities and research questions for this project. (Projected date: Late January, Early February 2011)
- CDC heading up the development of a study questionnaire that will assess several domains of interest, including:
  - Treatment-related outcomes (including infertility, cognitive dysfunction, etc.)
  - Patient-reported outcomes (Quality of Life and well being, fatigue, pain, etc.)
  - Economic factors (employment issues, insurance issues, financial distress, etc.)
  - Psychosocial factors (family issues, health beliefs, information needs, support services, etc.)
  - Medical factors (recurrence, cancer screening, chemo-prevention, etc.)
- Survey expected to field in late 2012, early 2013

□ POC: Juan Rodriguez

# Estimating Infertility Among Breast Cancer Survivors

- ❑ **Project will identify magnitude of infertility among breast cancer survivors on national level**
  - Establish baseline number of at-risk women
  - Provide foundation to assess availability and access to infertility services
- ❑ **Based on a conceptual model including age-specific estimates of:**
  - Fertility rates, breast cancer incidence, stage distribution, expected treatment, and fertility effects of treatment
- ❑ **This project will use a variety of data sources (e.g. cancer registry, NSFG, NCCN, ASCO, NCI) to estimate the number of women diagnosed with breast cancer who will potentially have compromised fertility as a result of their treatment.**
- ❑ **POC: Loria Pollack**

# American Indian/Alaska Native (AI/AN) Project – “Walking Together: Making A Path Towards Healing”

- This project will identify and describe the barriers to care physically, psychologically and spiritually faced by young (<45 years) American Indian/Alaska Native (AI/AN) women diagnosed with breast cancer.
  - Target s young AI/AN breast cancer patients treated at the Indian Health Service (IHS) Phoenix Indian Medical Center (PIMC).
  - Focus group study to identify perceived barriers to accessing care and related services among young AI/AN breast cancer patients
  - Findings used to develop recommendations for targeted interventions that will address common concerns in these patients (e.g., development of culturally appropriate educational materials for patients and providers).

# Program Support

# Developing Psycho-Social and Reproductive Health Support for Young Breast Cancer Survivors

## □ Project Background

- Few programs, policies focus on mitigating short- and long-term effects of breast cancer in younger women
- Scarcity of evidence-based interventions for psychosocial, reproductive health issues among women under 40
- Legislation directs CDC to provide grants to organizations to provide:
  - Health information from credible sources
  - Substantive assistance directed to young women diagnosed with breast cancer and pre-neoplastic breast diseases

# Developing Psycho-Social and Reproductive Health Support for Young Breast Cancer Survivors

## □ Project Purpose:

- Provide programmatic support up to 3 national organizations that address the needs of and provide intervention programs for young survivors

## □ Project Objectives: Conduct evaluation to assess:

- Organizations' capacity to effectively develop, implement, disseminate interventions
- If current interventions and tools yield intended outcomes
- If newly-developed interventions are effective and can be applied

## Project Outcomes

- ❑ Identify core programmatic elements of organizations that provide psycho-social, reproductive support
- ❑ Identify best methods to disseminate psycho-social and reproductive health support to this age group
- ❑ Increase the use of evidence-based interventions
- ❑ Increase implementation of broader dissemination efforts

## Project Next Steps

- ❑ Establish “Centers of Excellence” or “Program Models”
- ❑ Expand partnerships with organizations doing this work
- ❑ Establish promising practices and contribute to the knowledge base

# Communications

# Research-Based Development Process

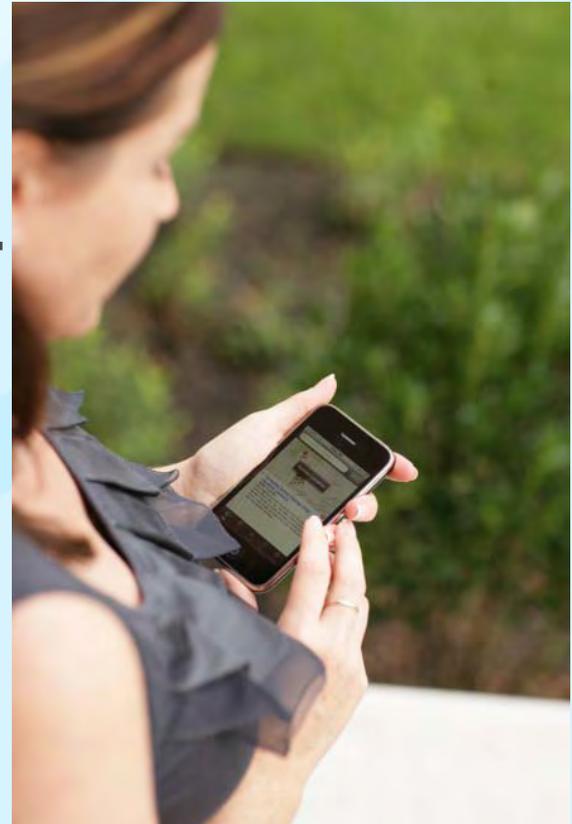
- ❑ Literature review
- ❑ Market research
- ❑ Requirements gathering
- ❑ Design concepts
- ❑ Prototype(s)
- ❑ Testing
- ❑ Delivery
- ❑ Evaluation

# Product Development

- ❑ In development by Oak Ridge Institute for Science and Education (ORISE)
  
- ❑ **Two communication products:**
  - “Body Talk” Smartphone application
  - Clinic Decision Support Tool for women and their providers

## BodyTalk: Opportunity

- ❑ More Americans have the convenience of a handheld computer integrated within their mobile telephone (or a *smartphone*).
- ❑ There is a growing market for applications designed to support and engage people in managing their health.



## BodyTalk: Objectives

- To create a smartphone application that will help educate young women about:
  - 1) Lifestyle: don't smoke, exercise, healthy diet, moderate alcohol,
  - 2) Family history: genetic and familial risk factors,
  - 3) Where women with breast cancer can go for support

## BodyTalk: Features

- BodyTalk will be designed for the iPhone® and Android operating systems – capturing the majority of the smartphone market.
- BodyTalk could:
  - Disseminate campaign messages
  - Direct to family history tools
  - Provide location-based information to the user
  - Utilize user profiles to generate specific plans to healthier living, i.e., health risk appraisals
  - Allow offline abilities through tailored support documents and/or downloaded educational videos

# Decision Support Tool: Opportunity



- ❑ The literature suggests that Clinical Decision Support (CDS) tools can enhance...
  - practitioner performance
  - patient decisions

Whitehead NS, Squiers L, Massoudi B, and McClure C. Computer-based Clinical Decision Support Tools for Gene-based Tests Used in Breast Cancer: Literature Review. RTI International DEcIDE Center, Contract No. HHS29020050036I, Task No. 8

## Decision Support Tool: Objectives

- ❑ To improve communication between women and their providers during the primary care office visit.
  
- ❑ Specifically, it is intended to:
  - Increase the use of family history by women (patients) to assess their risk for breast and ovarian cancer.
  - Increase the occurrence of patient/provider counseling sessions regarding BRCA1/2 genetic testing and breast and ovarian cancer risk factors in general.
  - Direct patients who need further support to appropriate care
  - Promote a healthy lifestyle

## Decision Support Tool: Features

### The tool will:

- ❑ Exist in a clinic and be accessible via the web
- ❑ Produce tailored information, for both patient and provider
- ❑ Leverage the existing “The Cancer in the Family” Clinical Decision Support Tool successfully piloted by the Agency for Healthcare Research and Quality (AHRQ) and Research Triangle Institute (RTI).

# Next Steps



# Next steps

## □ Planning for 2011

### ▪ Strategic planning session

- Assessment of research/program gaps
  - Economic issues
  - Connections to ovarian and/or adolescent/young adult cancer population
  - Genomics
  - Message development
  - Monitoring/evaluation
- FY 2011 funding

## □ ACBCYW meeting

- Engagement of experts

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# Questions?

