Breast Cancer and the Environment Research Centers

Community Outreach and Translation Cores

Fox Chase Cancer Center (FCCC)
Michigan State University (MSU)
Bay Area (BA)
University of Cincinnati (UC)
COTC Objectives

• Ensure community voice is incorporated
  – Foster collaboration and trust between scientists and community groups

• Dissemination of research
  – Translate findings into meaningful information for the public and policymakers
  – Develop educational key messages based on research findings

• Evaluation of community involvement in BCERC
COTC Collaborations With Biology and Epidemiology Projects

• Community input on selection and framing of research agenda
  – Prioritization of environmental exposures and input into questionnaire development

• Nine fact sheets on environmental exposures

• Advocates co-authored scientific publications

• Lay abstracts of scientific publications
COTC Collaborations With Biology

- Hands-on Laboratory Training for Advocates
- DVD “Of Mice and Women”
COTC Collaborations With Epidemiology

- **Recruitment and retention of study participants**
  - More than 90% retention at sites with heavy advocate involvement

- **Communicate results and other health and chemical data to participants’ families**
  - PFOA
  - PBDEs
  - Phthalates/1,4-dichlorobenzene (moth balls)
Recruitment and Retention
Tools/Activities

A Project of the Bay Area Breast Cancer and the Environment Research Center
CYGNET Taking Flight
Cohort Study of Young Girls Nutritional, Environment, and Transitions

Summer 2006

The CYGNET Study: Part of a National Research Effort

WELCOME BACK!

It’s been a delight and pleasure meeting each of you throughout the year, and we look forward to seeing you again. To keep you informed of our program, we currently have 367 girls and their families enrolled in the study and hope to reach our study goal of 400 participants in the next couple of months.

With your enthusiastic participation, we’ve held CYGNET Study Tea Talks in Oakland and San Rafael, where participants learned about the purpose of the study and the broader implications. CYGNET girls had their own set of activities, which included a novo research project, college preparation activities, and a “Big Hop class. Each girl also wrote a reflection and her own essay on “The Care and Keeping of You: The Body Book for Girls,” published by American Girls.

For participants unable to attend the Tea Talk, the discussion revolved around the normal variations in development of girls and what needs to be done at a young age to prevent obesity and breast development. It also explained the CYGNET Study’s relationship with the Bay Area Breast Cancer and the Environment Research Center. After meeting with leaders in the breast cancer advocacy community and scientists at the National Institutes of Health (NIH), it becomes clear that development of the breast, as a molecular or tissue level, and its response to various environmental, lifestyle, and genetic exposures, are not well understood. Thus, the NIH, through the National Institute of Environmental Health Science (NIEHS) and the National Cancer Institute (NCI), funded the Breast Cancer and the Environment Research Centers (BCERCC). Please see the map on page 4 for center locations and other collaborating institutions.

Each center includes three key components: an animal study; an epidemiology study, in which girls will be followed over the next 30 years to investigate what factors influence age at onset of puberty; and a community outreach and translation core, which ensures that research activities in these centers are responsive to community concerns. The CYGNET Study is one of the epidemiology studies. These Centers are organized to promote interactions among the investigators, the community members, and scientists at NIEHS and NCI.

This study is a cooperative effort, and your role is one of a projected 1,200 participating families nationwide. In the overall success of this research program, the importance of the CYGNET study has been recognized by the media. In late March, a photographer from National Geographic...
Community Participation
Annual Conference:
Early Environmental Exposures

PROGRAM
THURSDAY, NOVEMBER 8, 2007

7:00-7:30 Reference Breakfast & Registration

8:30-9:00 Welcome & Opening Remarks (Presidential Ballroom)

Session I: Puberty and Normal Mammary Gland Development: Understanding Windows of Exposure Susceptibility and Opportunities for Intervention [ABSTRACTS]

Moderator: Paul Yacw, MD, Lawrence Berkeley National Laboratory
9:00-9:15 Variations on a Common Theme: Progesterone Regulation of Normal Mammary Gland Development in Humans, Rats and Mice
Sandra Z.邀请, MD, Michigan State University
9:15-9:45 Effects of Environmental Exposures on Mammary Stem Cells
Mary Helen Barcellino-Hoff, PhD, Lawrence Berkeley National Laboratory

10:00-10:30 Break

10:30-11:10 Puberty: as a Window of Susceptibility to Environmental Toxins
Frank Baro, MD, Cincinnati Children’s Hospital Medical Center [video] and Mary Wolff, PhD, M. Sinai School of Medicine

11:00-11:30 Unlocking the Laboratory: Introducing Breast Cancer Advocates to Bench-Top Research
Kathy Balf (UC) [video], Janice Barlow (UCSF) [video] & Ann Fonta (UC) [video]

11:30-12:00 Q & A
12:00-1:30 Lunch - Lunch with the Experts (Fountain Room, second level)

Session II: Impacts of Everyday Stressors on the Development of Young Girls [ABSTRACTS] (Presidential Ballroom)

Moderator: Robert A. Hiatt, MD, PhD, University of California San Francisco
1:30-1:45 Psychosocial Studies of Girls and their Families in the Cincinnati Breast Cancer and the Environment Research Center
Kim Dietrich, PhD, University of Cincinnati [video]
Psychosocial Studies of Girls and their Families in the Cincinnati Breast Cancer and the Environment Research Center
Juliana Deardorff, PhD, University of California San Francisco [video]

1:45-2:15

website: www.bcerc.org
Dissemination of Educational and Outreach Materials
Communicating the Research

• Dissemination Research
  – News media and website analysis
  – Focus groups with mothers and daughters
  – Message testing
  – Survey of study families

• Key Targeted Audiences

• Strategies for Dissemination
Evaluation of Community Involvement in BCERC

Positive Effects of Community Involvement:

• **Increased community understanding and support of the scientific process**

  “I could really see the community benefit from what was found. What did they discover? Is it something we can work on, something that can be utilized for generations to come?”
  —Community Member

• **Heightened sensitivity and propriety of the research**

  “Is this appropriate for a 7-year-old girl? What’s a mother going to think?”
  —COTC Member
Evaluation of Community Involvement in BCERC

Positive Effects of Community Involvement:

• Improved communication and sharing of knowledge between scientists and community advocates

“The truth is scientists have expertise and skill that advocates don’t. But advocates have insight and a perspective that scientists don’t. And, it’s really about mutual understanding. Having both perspectives is really valuable.” -- BCERC researcher
Going Forward

• Serve as a model for continued community involvement in research

• Keep study participants and their families informed

• Expand local targeted community dissemination to a national focus

• Strengthen relationships with local, regional, and national advocacy organizations
“If you want to go quickly
   go alone;
if you want to go far
   go together.”

African Proverb