

**NAACCR Town Hall Meeting
The Sister Study
February 10, 2006
2:00 PM Eastern**

Present – Representatives from the following registries and organizations:

1 Canada: Manitoba Cancer Registry

23 U.S.: American Cancer Society, Arizona Cancer Registry, Arkansas Central Cancer Registry, California Cancer Registry, Colorado Central Cancer Registry, District of Columbia Cancer Registry, HCA, Illinois State Cancer Registry, Louisiana Tumor Registry, Maine Cancer Registry, Massachusetts Cancer Registry, Minnesota Cancer Surveillance System, Missouri Cancer Registry, New Hampshire State Cancer Registry, New Jersey State Cancer Registry, New York State Cancer Registry, North Carolina Central Cancer Registry, Oregon State Cancer Registry, Puerto Rico Central Cancer Registry, Rhode Island Cancer Registry, South Carolina Central Cancer Registry, Texas Cancer Registry, Virginia Cancer Registry

3 NAACCR Staff: Dr. Holly Howe, Moderator – Executive Director, Joellyn Ellison – Program Manager of Data Evaluation and Publication, Royale Anne Hinds – Assistant to the Executive Director

5 Sister Study Researchers: Dr. Dale Sandler, Dr. Paula Juras, Sara Williams, Debbie Bittner, Lisa Duroo

Welcome

Holly Howe

The NAACCR Town Meeting provides a forum for researchers and Central Registries personnel so issues and partnerships can be discussed. The Sister Study is a national study including female participants from United States and Puerto Rico.

Description of the Sister Study

Dale Sandler, Principal Investigator

Dale hopes that the registries can explore a partnership with the Sister Study.

Dale introduced the Sister Study staff:

Paula Juras – manages the contract and is the IRB expert.

Sara Williams – recruitment specialist

Debbie Bittner – study manager

Lisa Duroo – from NIEHS. She is responsible for the day to day operations of the study and will be doing research.

The Sister Study is about environmental and genetic risk factors particularly for breast cancer. For descriptive information, see the text from the PowerPoint Presentation on pages 3 - 5.

Questions

- 1) How is the study addressing breast cancer in rural/urban populations? Recruitment of female participants does not discern women from rural or urban populations.

- However, the researchers are interested in women who live in farming communities because of potential pesticide exposures.
- 2) How many American Indians have been recruited? 314 Native Americans have signed up so far. They are currently preparing materials for Navajo Nation IRB. Researchers are hoping that community leaders will endorse the study once they get IRB approval.
 - 3) Have the study used census tract information to identify areas with blue collar and less than a college education patients? Yes, researchers have examined demographics within census tracts.
 - 4) Will the study be prepared to accept women who only speak Spanish speaking? Yes, the study employs native Spanish-speaking examiners.
 - 5) Have researchers contacted any California organizations? The researchers partnered with organizations in California, but not with cancer registries as of yet.
 - 6) How does the study identify which women are in their target group? The age range is broad. In some states they may only want to contact minority women or older women, etc. College education is not a standard field in cancer registries.

Closing Remarks

Holly Howe

Holly thanked the registry personnel for joining the meeting and expressed that this is a wonderful opportunity to expand the uses of registry data by helping cancer epidemiologists and cancer research. Please contact Dr. Dale Sandler or her staff directly with your individual state information or questions if you are interested in participating. Dale can be reached at sandler@niehs.nih.gov.

Motivation for the Sister Study

- Concern that trends in breast cancer incidence are due to the environment
 - Known risk factors explain < 50% of breast cancer variation; ~30% among African Americans
 - Increase in chemicals in our environment
 - Limited studies
- Advocates and breast cancer survivors demand studies

Environment and Breast Cancer

Trends consistent with environment

- Rates vary with time and place
- Rates change for migrants

Genetic studies consistent with environment

- Known breast cancer genes found in <10% of cases
- Concordance rate 14-20% in monozygotic twins

Environment and Breast Cancer

Experimental studies implicate synthetic chemicals

- > 40 chemicals cause mammary gland tumors in animals
- Many chemicals weakly estrogenic
 - Mimic estrogen activity
 - Direct or indirect effects on other risk factors
- Widespread low level exposure
- Few studies in women

Environment and Breast Cancer

Epidemiologic studies

- Radiation
- Lifestyle factors
- Pesticides, solvents, PAHs, aromatic amines
 - Difficult to measure past exposures
 - Hard to interpret measurements after diagnosis
 - Occupational studies include few women
 - Cohort studies address lifestyle factors

Enhanced Power of the Sister Study

Enhanced Power

- Recessive or dominant genes
 - Gene only effects
 - Environment only effects
 - G x E without main effects
- Increased ability to detect environmental exposures when there are interactions, even when gene is not known

The Cohort

50,000 sisters of women who have had breast cancer

- Age 35-74
- Never had breast cancer
- Volunteers throughout US
 - Media
 - Community and organizational partnerships
 - Active recruitment of minorities and older women
 - Exploring ways to target key groups (e.g. women with breast cancer who may have a sister)

Extensive Data for G x E

Biological and environmental samples from all participants

- Blood, urine, toenails, dust
- Collected and stored to maximize options

Extensive data on environmental and occupational exposures

- Residential histories to link with GIS
- Exposures *in utero*, in childhood, early reproductive years, at enrollment
- Complete occupational history

Enrollment*

Year 2 Enrollment Plans (1)

▪ Actively recruit target groups

- Over 65
- Blue collar jobs or < college education
- Minority populations
- Mississippi Delta region

▪ Slow recruitment of some groups to achieve 20% nonwhite; increase overall diversity

- Reduce reliance on general media
- Selective enrollment

Year 2 Enrollment Plans (2)

▪ Focus intensive recruitment efforts on states with desired diversity

- NY, CA, AK, HI, PA, NJ, IL, DC, MS, LA, TN, TX, MI, AR, PR
- Enroll target women only in other states

▪ Well-coordinated efforts in specific cities

- Washington-Baltimore initiative

▪ Reach out to eligible women rather than women in general

NAACCR Ideas

▪ Direct mail to women diagnosed with breast cancer

- Current and past cases provided reasonable expectation of current contact information

- **Emphasis on minority or older women**
- **Emphasize states with enrollment initiatives**

NAACCR Ideas

- **Mailings from us or registry depending on requirements**
- **Different approaches possible**
 - Mail letter or informational brochure only
 - Ask cases to pass brochure on to sisters
 - Ask cases to send us names of sisters who we will contact (pending NIEHS IRB approval)
- **Registry involvement minimal**
 - Central IRB approval vs individual?
 - Options for covering costs and getting work done

Advantages of having subgroup of cohort identified through registries

- Ability to track incident cancers in future (to extent sisters live in same states)
- Good will – passing on information cases and sisters seem to want to have
- Opportunities for future collaborations built on registry subpopulations (or larger whole)

Partners

- National Center on Minority Health and Health Disparities
- American Cancer Society
- Susan G. Komen Breast Cancer Foundation
- Sisters Network, Inc.
- Y-Me National Breast Cancer Organization

Collaborators

NIEHS

Dale Sandler, PI
 Clarice Weinberg – Co PI
 Donna Baird
 Honglei Chen
 Glinda Cooper
 Jane Hoppin
 Paula Juras
 Stephanie London
 Matthew Longnecker
 Jack Taylor

Other

Christine Parks, NIOSH
 Jim Termaat, CODA
 Pam Schwingl, CODA

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