



THE SISTER STUDY BREAST CANCER RESEARCH

WOMAN BY WOMAN, SISTER BY SISTER, WE CAN MAKE A DIFFERENCE!

2012

Sisters –

Let me start by saying to each of you: “You amaze us.” Your commitment to the Sister Study is incredible. It is hard to miss, especially when our databases fill rapidly with your responses to the online questionnaires and the post office delivers boxes full of your written questionnaires. The collective information and experience that you so generously share with us each and every year provide us with what is needed to move forward in our understanding of breast cancer and other aspects of women’s health. You can learn about some of the results in this newsletter – results we have because of you.

Also in this newsletter, we introduce new fellows and other scientists working with the Sister Study. The information you provide not only helps answer many important research questions, it also provides scientific opportunities for the next generation of breast cancer researchers.

So what’s next? This year and next, many of you will complete your second major follow-up questionnaire about changes in your health and experiences. This time we have included additional questions on quality-of-life, family and friend support, stress, sleep, diet, and use of supplements – factors that may contribute to general well-being. Your response to the questionnaires in the past has been fantastic and we hope that you will continue to be generous in sharing your time and information.

In April 2012 the Sister Study Scientific Advisory Board convened to help us prioritize our research using this valuable resource. Now that we have fully enrolled the Sister Study cohort and completed the first cycle of detailed follow-up questionnaires, we are poised to address many important questions related to the role of environment and genes in breast cancer. We asked the Board to help us identify questions that can best be answered using Sister Study data with the technology and tools that are currently available to us. Research such as ours is not done overnight. It is important to proceed carefully with environmental questions and ensure the wisest use of the limited biological samples you shared. At the Board’s suggestion we will be assembling a working group to evaluate chemicals of current interest and suitable measurement techniques. We appreciate your patience and dedication all these years and are looking forward to future discoveries and successes together.

We wish you and your family well in the coming year. Thank you once again for being a part of our team. We couldn’t do it without you.

Yours,

Dale P. Sandler PhD
Principal Investigator
The Sister Study





RESEARCHERS

MAKING A DIFFERENCE



Dr. Sandra Halverson

Dr. Sandra Halverson is the new Sister Study Director at Social & Scientific Systems, Inc. Dr. Halverson joins us from Vanderbilt University Medical Center, where she was an Assistant Professor of Medicine and Project Director of the Nashville Breast Health Study. As a cancer and molecular epidemiologist, Sandy has spent the majority of her career engaged in breast cancer research.

I am thrilled to be a part of the Sister Study team. The amazing Sister Study participants contribute such an incredible wealth of information. These data provide the opportunity to investigate many new hypotheses to help us better understand the underlying environmental and genetic causes of breast cancer with the goal of reducing the burden of this disease on future generations. I really couldn't be more excited.



Dr. Sophia Harlid recently joined NIEHS from Sweden after finishing her PhD in molecular epidemiology at Lund University. As a graduate student, Sophia published several papers on familial breast cancer and genetic polymorphisms. She is also interested in epigenetic factors and breast cancer, which she will be studying in the Sister Study.



Dr. Sophia Harlid

Congratulations to...

Sangmi Kim, PhD, former NIEHS research fellow, on her new position as an Assistant Professor in the Department of Medicine at Georgia Health Sciences University in Augusta, Georgia. Sangmi will continue to collaborate on projects related to the Sister Study.

Chunyuan Fei, PhD, NIEHS postdoctoral fellow, on her new position at the American College of Surgeons in Chicago, Illinois.



Dr. Hazel Nichols

Dr. Hazel Nichols joined the NIEHS Sister Study research team last year after graduating from the Johns Hopkins Bloomberg School of Public Health where she received her PhD in cancer epidemiology. Hazel's research focuses on the role of reproductive and hormonal factors in the development of breast cancer, and on survivorship after a breast cancer diagnosis.



Dr. Christine Ekenga

Dr. Christine Ekenga joined the NIEHS Sister Study in the Fall of 2011 as a postdoctoral research fellow. Christine earned her doctorate in Epidemiology from New York University School of Medicine. Christine previously worked at the Centers for Disease Control and Prevention and the New York City Department of Health and Mental Hygiene, where she studied physical and mental health outcomes among survivors of the 9/11 World Trade Center disaster. Christine will investigate environmental and occupational risk factors for breast cancer among women in the Sister Study.



Dr. Aimee D'Aloisio

Aimee D'Aloisio, PhD, previously an NIEHS postdoctoral fellow with the Sister Study, has taken a new position as Senior Research Analyst at Social & Scientific Systems, Inc. in Durham, North Carolina. As a continuing member of the Sister Study team, Dr. D'Aloisio's work will focus on early life factors, uterine fibroids and breast cancer risk and she plans to collaborate in new research related to environmental factors and breast cancer.



RESEARCH

MAKING A DIFFERENCE



Sister Study Papers 2011

Eating patterns and nutritional characteristics associated with sleep duration.

Kim S, DeRoo LA, Sandler DP. *Public Health Nutr* 2011; 14(5):889-895.

Lifestyle behaviors in black and white women with a family history of breast cancer.

Spector DJ, DeRoo LA, Sandler DP. *Prev Med* 2011; 52(5):394-397.

Employment and work schedule are related to telomere length in women.

Parks CG, DeRoo LA, Miller DB, McCanlies EC, Cawthon RM, Sandler DP. *Occup Environ Med* 2011; 68(8):582-589.

Telomere length in peripheral blood and breast cancer risk in a prospective case-cohort analysis: results from the Sister Study.

Kim S, Sandler DP, Carswell G, DeRoo LA, Parks CG, Cawthon R, Weinberg CR, Taylor JA. *Cancer Causes Control* 2011; 22(7):1061-1066.

Reliability and short-term intra-individual variability of telomere length measurement using monochrome multiplexing quantitative PCR.

Kim S, Sandler DP, Carswell G, Weinberg CR, Taylor JA. *PLoS One* 2011; 6(9):e25774.

Family-based gene-by-environment interaction studies: revelations and remedies.

Shi M, Umbach DM, Weinberg CR. *Epidemiology* 2011; 22:400-407.

Accuracy and reliability of self-reported weight and height in the Sister Study.

Lin CJ, DeRoo LA, Jacobs SR, Sandler DP. *Public Health Nutr* 2011; Epub 09 December.

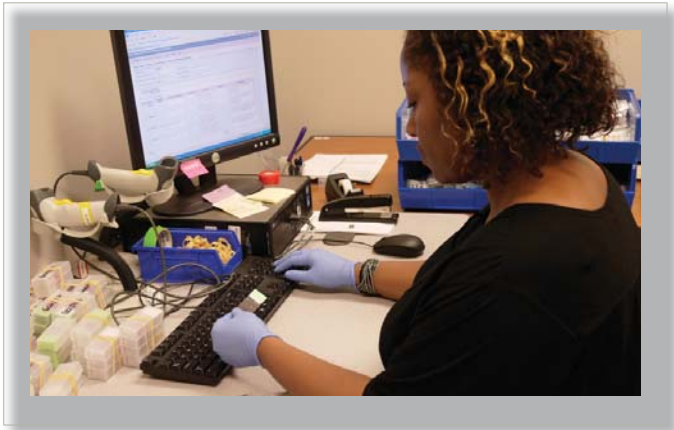
Early Life Exposures and Early Onset Uterine Leiomyomata in Black Women in the Sister Study

The Sister Study previously reported that early life factors were associated with increased risk for uterine fibroids. Uterine fibroids (also known as uterine leiomyomata) are the most common pelvic tumors in US women. Black women are at greater risk of developing fibroids and having more severe symptoms. Now that the Sister Study cohort is fully enrolled, we had enough women to be able to examine associations between early life factors and fibroids diagnosed before age 30 in black women. Fibroids were more common in black women reporting that they were fed soy formula as an infant, born at least one month early, or taller or thinner than peers at age 10. Black women with fibroids also were more likely to report having a mother who had diabetes before or during pregnancy, had pre-eclampsia or high blood pressure related to her pregnancy, or took diethylstilbestrol (DES) during pregnancy. While many of the findings were similar to those reported previously for white women in the Sister Study, differences in the frequency of the factors associated with fibroids could contribute to the higher prevalence of fibroids in black women.

D'Aloisio AA, Baird DD, DeRoo LA, Sandler DP. *Environmental Health Perspectives*. 2012 Mar; 120(3):406-12. [Epub 2011 Nov 2]

Update on the Two Sister Study

We have completed enrollment for the Two Sister Study. Thanks to all of our sisters and parents who have generously donated their time (and saliva!) to make this study a success. We now have extensive environmental data and DNA samples for about 1400 families with young-onset breast cancer, and analyses have begun. The first paper from the Two Sister Study has been accepted for publication. We found that overall, women who took fertility drugs like Clomid have reduced risk of breast cancer. However, conceiving a pregnancy with the help of these drugs may undo some of that "protection." Women who got pregnant with fertility drugs had the same breast cancer risk as women who never took these drugs.



Medical Records and Tumor Tissue— Important Keys to Understanding Breast Cancer Characteristics

When a woman in the Sister Study develops breast cancer, we ask permission to contact her doctors for tumor tissue samples and medical records related to her breast cancer. These materials provide important details on cancer cell type, behavior, size, location, and other factors that may hold clues to understanding causes. Breast tissue samples collected during biopsy or surgery are also critical to understanding features of breast cancer that may be related to causes or treatment outcomes.

After a biopsy, breast tissue samples are embedded in paraffin (wax) blocks by the pathologist who then takes a thin slice of the tumor tissue and places it on a slide. The slide is then stained and examined for features that characterize the tumor. After the diagnosis is made, the remaining tissue blocks are stored at the medical institution. The blocks the Sister Study obtains from pathologists are used to create what are called tissue microarrays or TMAs. Our study pathologist takes multiple small samples from the tumor tissue in the blocks and places them in a new wax block which can later be sliced very thinly and stained for biological markers. The TMAs can be used to carry out many studies simultaneously from a single micro slice. This allows us to answer many research questions while preserving the original tissue sample.

Institute of Medicine Report Urges Life-Course Approach to Study Breast Cancer

The Institute of Medicine is an independent nonprofit organization that provides evidence-based advice to policy makers and the public. Their report, funded by Susan G. Komen for the Cure® and released in December 2011, can be downloaded at www.iom.edu/BreastCancerEnvironment.

In their recent report, the Institute of Medicine (IOM) urges a life-course approach to studying the environment and breast cancer because new information suggests women and girls might be more vulnerable to some exposures during certain life stages. A life course research approach would focus on experiences at different stages of life and take into account, where possible, the totality of exposures over a lifetime.

Avoiding unnecessary or inappropriate exposure to radiation, limiting how much alcohol you drink, avoiding certain kinds of hormone therapy, and minimizing weight gain are steps that might reduce [breast cancer] risks for some women.

Defining the “environment” broadly to include a range of factors women encounter in their daily lives as well as chemicals and pollutants, the IOM panel found consistent evidence linking breast cancer to some factors, but concluded there was limited or no evidence for many others.

The IOM panel also noted that, in many cases, the factors contributing to the development of breast cancer are unknown, and there is not enough information about many of the chemicals we encounter in everyday life to figure out if they are connected to breast cancer.

As the Sister Study progresses, it is poised to make important contributions to life-course research using information participants shared on exposures during different periods of life. We will also examine exposures to chemicals in the home and workplace using data and samples you have provided as well as using databases on pollutants, such as air pollution, collected nationwide.

Making Your Data Go Further

The Sister Study was designed to address a wide range of women's health concerns in addition to breast cancer. With every survey, Sister Study participants provide information on a variety of health conditions, including some cancers that are so rare that it is difficult for any single cohort study to examine them. The National Cancer Institute's Cohort Consortium is an effort that allows cohort studies to work together and pool their data to create the large sample sizes that are necessary to study these rare cancers. The Sister Study is making your data go further by contributing to Cohort Consortium studies on head and neck, gallbladder and ovarian cancers. The Sister Study reviews the scientific merit of all collaborative studies and does not share any personal identifying information. Your data is making a difference in these important efforts to study scientific questions that the Sister Study could not address on its own.

Early Life Exposures Study Completed

The Early Life Exposures Study was completed in 2011. The study aimed to learn how well women were able to report information about their early life experiences, including their mother's pregnancy with them. Early life factors may influence health later in life. Some Sister Study participants were invited to forward a questionnaire to their mothers. The mother's questionnaire covered some of the same early life information that daughters provided when they joined the Sister Study, allowing us to directly compare how well mothers' responses agreed with those from their daughters. We received over 1,800 completed questionnaires. Early results suggest that there was good agreement between Sister Study participants and their mothers for many early life experiences although agreement was less good for uncommon health conditions in mothers such as diabetes, pre-eclampsia, and pregnancy-related hypertension. This information will improve our ability to study the relationship between early life factors and health in adulthood, including the potential relationship of these factors to breast cancer risk.

Update on EARLY Act Surveys

Last year the Sister Study partnered with the Centers for Disease Control and Prevention (CDC) to help advance EARLY Act goals. The EARLY Act is legislation passed by Congress in 2010 to advance the awareness and understanding of breast cancer in young women. As part of this effort, approximately 20,000 Sister Study participants completed a special questionnaire on breast cancer screening, family communication about cancer, and how having a sister with breast cancer has affected them and their families.

We are also on track for launching a special survey of breast cancer survivors that will focus on quality-of-life and other areas of concern for women who have experienced a breast cancer diagnosis and treatment. Together, these surveys will allow us to study topics of interest to women with breast cancer and their families including quality of life, work-life balance, barriers to care or healthy behaviors, and medical decision-making. We appreciate your participation when asked to take part in these activities, and we look forward to sharing results with you in future newsletters.



*Researchers at the Sister Study Scientific Advisory Board Meeting
April 17-18, 2012*



COMMUNICATION

MAKING A DIFFERENCE

I filled out some, but not all, of the past questionnaires. Do you still want me to fill out the current questionnaire?

Yes. Please do. Even if you missed a questionnaire, the information you can provide now is still important and will help us fill in the gaps.

Is my response to the questionnaire important?

Yes, your responses are what keep the study on track for learning about the environmental and genetic risk factors for breast cancer. We value your continued participation – together we can make a difference.

Nothing has changed in my health since last year. Why do I need to answer the same questions again?

We would like to hear from you, whether you have had changes or not. For the Sister Study to be successful, we need to check in with participants on a regular basis. If we don't hear from you, we have no way of knowing for sure that nothing has changed. We ask for a short update on your health every year. Every two to three years we will ask you to complete more detailed questionnaires. By completing these questionnaires, you help maintain our partnership in this important research.

Did you know...?

The Sister Study periodically contacts participants via email. We want to be sure you receive the latest updates from the Sister Study! Please be sure to add our email addresses to your email contacts or approved senders list.

update@sisterstudy.org
info@sisterstudy.org

You can update your current email address and other contact information anytime by emailing the study at any of the addresses above or calling toll-free **877-4-SISTER (877-474-7837)**.

How can I find a low- or no-cost breast exam or mammogram?

The Centers for Disease Control and Prevention's (CDC) National Breast and Cervical Cancer Early Detection Program (NBCCEDP) provides access to breast and cervical cancer screening services to underserved women. To find out where you can get a free or low-cost mammogram or Pap smear and learn more about CDC related cancer programs you can visit

[apps.nccd.cdc.gov/
cancercontacts/nbccedp/contacts.asp](http://apps.nccd.cdc.gov/cancercontacts/nbccedp/contacts.asp)

or contact them toll-free at **800-CDC-INFO** or email cdcinfo@cdc.gov.

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