



THE SISTER STUDY

A STUDY OF THE ENVIRONMENTAL AND GENETIC RISK FACTORS FOR BREAST CANCER

NATIONAL INSTITUTE OF ENVIRONMENTAL HEALTH SCIENCES • NATIONAL INSTITUTES OF HEALTH • DEPARTMENT OF HEALTH AND HUMAN SERVICES

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The Sister Study

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WHY SISTERS?

The idea behind recruiting 50,000 sisters is simple. Alike in many ways, sisters share half their genes and many early and later life experiences. While the average risk of developing breast cancer for a woman whose sister had breast cancer is not large, it is about double that for a random woman from the same population. Some of this increase in risk could be genetic, some may be environmental, and some may be due to the combined effects of environment and genes. The known breast cancer genes (like BRCA1 and BRCA2) alone cannot explain the doubled risk seen in sisters, so much remains to be learned. However, we know that any gene variants that are related to risk will be more common in the sisters of women with breast cancer than they are in the general population. So a large group of sisters is ideal to study if we want to understand how genes and the environment sometimes work together to cause breast cancer.

The Sister Study was the first to use this idea for studying breast cancer. A similar approach is being proposed for a study of autism, because babies born to parents who already have an autistic child are at greatly increased risk for this problem. The design could be used to study any condition a person may have, and for which siblings are known to be at higher risk. We have a report in press in the American Journal of Epidemiology that describes the statistical advantages of this approach. When the paper comes out, we will post a link to it on the Sister Study web site, www.sisterstudy.org.

MESSAGE FROM THE PRINCIPAL INVESTIGATOR

Welcome to all of you who joined us in the past year and greetings to those who have been with us from the beginning. More than 35,000 of the 50,000 sisters needed have joined the study so far, and nearly 28,000 have completed all enrollment activities. Some of you have already completed one or more annual updates; for others, this is your first chance to tell us about changes in your lives since we last spoke with you.



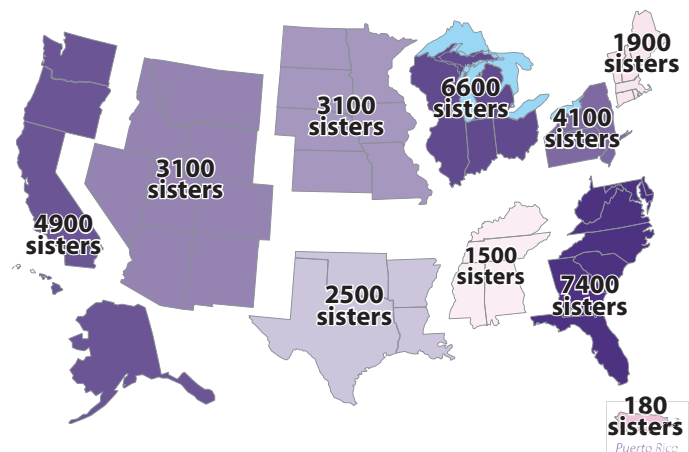
Dale P. Sandler, PhD

New this year, for those who joined before July 31, 2004, are the *Biennial Follow-up Questionnaires* that are enclosed with your newsletter. While these are more detailed than the two-page updates you are used to, it is important that we fully track changes in your health, lifestyle, and exposures over the course of the study. We hope you will find the questionnaires easy to complete and will send them back promptly, as so many of you did for the last annual update. To make it easier for you, there are two ways you can complete the questionnaires – pen and paper or by telephone. Choose the method that works best for you, and as always, let us know if you have any questions or concerns.

We hope that this mailing finds you in good health. But if there have been changes, be sure to let us know. Thank you again for your ongoing and enthusiastic support of the Sister Study. Remember, woman by woman, sister by sister, we can make a difference.

Dale P. Sandler

Sister Study Enrollment by Census Division - as of April 16, 2007



QUALITY MANAGEMENT OF SISTER STUDY SPECIMENS

Have you ever wondered what happens to your blood and urine after it is collected?

Samples are transported overnight to a secured laboratory, dedicated to the Sister Study. Upon arrival, each item is inspected, inventoried, and processed. A urine glucose (sugar) test is conducted and the remaining urine is stored. Blood is cryo-preserved (specially frozen), dried onto filter cards, or separated into serum and plasma.

Blood and urine are stored using state-of-the-art technology called “CryoBiosSystem” (IMV Technologies), that minimizes contamination and space requirements, and maximizes testing opportunities. Serum, plasma and urine are put into small straw-like sealed containers, loaded into color-coded cylinders, and stored in liquid nitrogen.

Each participant contributes up to 70 individual specimens stored in multiple freezers and liquid nitrogen tanks. A database details the location of each specimen, along with documentation of the condition of the samples when they arrived.

Development and maintenance of a Quality Management System is a high priority to ensure specimen quality for future work. This coincides with a larger National Institutes of Health goal to standardize specimen collection and storage protocols, improve quality, and promote timeliness. The Sister Study lab recently underwent a voluntary audit, conducted by Dr. Karen Pitt, Special Assistant for Biological Resources at the NCI Division of Cancer Epidemiology and Genetics. Dr. Pitt reported that, “future results obtained from testing Sister Study samples will benefit from the careful attention to detail and quality that has been included in the planning for this large study.”

Cynthia Kleeberger, Sister Study Laboratory Director, has been invited to speak at the International Society for Biological and Environmental Repositories (ISBER) in Singapore this Spring. Her talk is titled “Developing a Quality Specimen Collection for the Sister Study – Environmental and Genetic Causes of Breast Cancer.”

Your specimens will allow scientists to address a wide range of women’s health questions. None of this would be possible without your contributions. It is our mission to maintain your specimens in optimal conditions for long-term research use.



SISTER STUDY DATA PROVIDE CLUES ABOUT OBESITY AND POTENTIAL BREAST CANCER RISK FACTORS

As we promised when you enrolled, we are working to learn as much as we can about breast cancer and other health concerns, using the information you provided. An important first step is to better understand relationships between known or suspected breast cancer risk factors. For example, obesity and weight gain after menopause are known to be associated with breast cancer and other diseases, and obesity may be related to other factors linked to breast cancer.

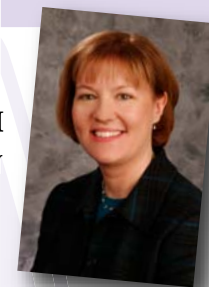
The Sister Study team is studying the impact of food deprivation in childhood on height, weight, and obesity. Our preliminary results suggest that not getting enough to eat during childhood may cause one to be shorter as an adult. Ironically, food deprivation is also associated with being overweight as a teen or adult — this may be due to differences in diet patterns, to psychological factors that cause people to eat more, or to biological changes related to not getting enough to eat in childhood.

We have also been exploring potential links between being depressed and being overweight. Women who report being depressed are more likely to be overweight and more likely to have repeatedly lost and gained 20 or more pounds. Women who exercise more are less likely to report being depressed. It is difficult to sort out what comes first – overweight or depression.

Early analyses like these will be informative when we are able to look at associations with breast cancer risk.

NEW STAFF SCIENTIST FOR THE SISTER STUDY

Greetings. My name is Lisa DeRoo. My role in the Sister Study is to help organize the wealth of information you have shared and continue to share with us, and to plan and conduct research analyses using this information. I earned a doctoral degree in epidemiology from the University of Washington in Seattle, where I conducted research at the Fred Hutchinson Cancer Research Center. Most recently, I worked at the University of Geneva in Switzerland studying risk factors for breast cancer among Geneva women. Your enthusiasm and dedication as participants have been an inspiration to me. There is so much to learn about how to prevent breast cancer, and I am excited to have the opportunity to work on such an important research study.



SISTER STUDY SPONSORS STUDENT INTERNS



Last summer, the Sister Study hosted three students through the NIEHS Summers of Discovery Program, which offers NIH internships for students and teachers interested in environmental and public health. While the students broadened their research experience, they also made important contributions to Sister Study data analyses and quality management.

Jonetta Johnson (right) earned a Master's degree at the University of Minnesota School of Public Health, and is now completing a fellowship at the Centers for Disease Control and Prevention. We are delighted that she was recently accepted into doctoral programs in public health, and will be choosing from among several outstanding schools. With us, she studied the relationship between depression and obesity or weight gain (see related article).

Ashleigh May (left) is a doctoral student in Human Development and Family Studies at The Pennsylvania State University (Penn State). She recently passed her qualifying exams, and has begun her research on health disparities and the effects of early life exposures on childhood obesity. She used Sister Study questionnaire data to explore the impact of food deprivation on obesity at different periods of life (see related article).

Sara Rubin (not pictured) was a junior at Cornell University when she worked with the Sister Study. She assisted the laboratory staff, reviewed the quality of home examiners' forms, and evaluated the literature on reliability of self-reported height and weight. Sara graduated early and now works at a public health policy consulting firm in Washington DC.

Congratulations to our interns for their accomplishments!

SISTER STUDY STAFFER HONORED AS 2007 YOPLAIT BREAST CANCER CHAMPION

Sara Williams, a breast cancer survivor and member of the Sister Study recruitment staff, has devoted herself to breast cancer awareness and advocacy since being diagnosed in 1997. You can read her story and that of the other 2007 champions at http://www.yoplait.com/breastcancer_championsvideo.aspx.



The participant sisters and supporting organization featured below are special recruitment collaborators for the Sister Study. They have been involved in diverse recruitment activities and have contributed immensely to the study.

STORIES FROM THE HEART



Lyn May (right) is a participant from Connecticut: "Despite her knowledge, strength and quick action, in our female-dominated family my sister's breast cancer at 56 was a shock. When it happens to one of us, it feels like it happens to all of us. You feel powerless. You feel that you all have the cancer."

"We are fortunate that her cancer hasn't dominated our lives and that frightening time has grown fuzzy in our minds. Too many families aren't as lucky as my family has been. That is why I joined the Sister Study - to help bring attention to this death-causing, family-destroying illness."

"We must educate ourselves and others. We must learn and teach; and we must help all men and women - but especially men and women of color - understand that good care, knowledge and attention can save lives. As people of color we must believe our lives are worth saving."

Barbara Moore (left), a participant from New York, learned about the Sister Study at the *Coalition of Labor Union Women* convention in Detroit in 2005: "My sister Mary Catherine wasn't aware that she had breast cancer until it was late stage. She had a mastectomy in 2003, and on Thanksgiving of that year she passed away. I was devastated. We were so close. The Sister Study said they were looking for the causes. That really caught my attention."



VOLUNTEER SPOTLIGHT



We would like to give special recognition to the *Puerto Rico Primary Health Care Association, Inc. (PRPHCA)*, a not-for-profit organization representing agencies providing preventive and primary healthcare services to their communities. PRPHCA has been instrumental in providing us with guidance on approaching their diverse clientele. They recently coordinated a successful informational session where they graciously hosted 18 Health Center Corporations and the 37 sites the Association represents. The meeting they hosted is an example of how much our recruitment benefits from the assistance of volunteers and agencies that have direct access to women who may be eligible for the Sister Study.

WE ARE ALMOST THERE, BUT...

We have one more year to reach our goal of 50,000 women. You can help by telling everyone you know about the study. It is especially important to encourage under-represented women, including those over 65, African Americans, Latinas, and Asian women to join the study. One of our most successful methods for recruiting sisters for the study is friends telling friends and sisters telling sisters. Please call 1-877-4SISTER or email info@sisterstudy.org to find out other ways you can help.



The Sister Study is conducted by the National Institute of Environmental Health Sciences, one of the National Institutes of Health of the U.S. Department of Health and Human Services.

Partner Organizations

