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Sister Study newsletter 2009

The Sister Study is a study of the environmental and genetic risk factors for breast cancer, conducted by the National Institute of Environmental Health Sciences, one of the National Institutes of Health, of the US Department of Health and Human Services

A Message from the Sister Study

Thank you for visiting the assistive reading device version of the 2009 Sister Study newsletter. We are committed to providing access to our web pages for individuals with disabilities, and to this end, we are currently working on an html webpage that will provide a richer experience, but in the meantime, please enjoy this pdf. Thank you and please direct any questions to info@sisterstudy.org.

A Message from the Principal Investigator

Dear amazing and wonderful sisters,

You did it! Together we have successfully enrolled over 50,000 women into the Sister Study! You come from all over the United States and Puerto Rico. You are diverse in age, race, ethnicity, and education, and you each bring unique experiences that will help us to learn about potentially preventable causes of breast cancer. When we started this study in a few cities in 2003 we had a huge task ahead of us. But thanks to your efforts and the enthusiastic Sister Study team, we managed to reach out to you – a sisterhood of women who care about someone with breast cancer and want to make a difference. But now that our cohort of sisters is assembled, what's next?

I know we are all eager to learn about the causes of breast cancer., because you've asked about results. We ask for your patience and perseverance in this long term study about a difficult and complex problem. There will not be instant success in discovering the causes of breast cancer. However, we pledge to work diligently to use wisely the information you give us to study issues affecting women's health. We began conducting analyses even before the cohort was fully assembled. See articles in this issue on the results we can already report.

When you joined, we told you we would be asking every year about changes in your health. This information is vital to our ability to deliver on our promise to learn about factors that lead to breast cancer. At the start of the Sister Study, we were told that some women would not join because they thought that by signing up for a study about breast cancer they might tempt fate and get breast cancer themselves. I now worry that some women may think that by joining the study, they won't get breast cancer or other diseases. Unfortunately that is not true. During the study follow-up over ten or more years., we'll all face life's changes, opportunities and challenges. We may decide to run a marathon, we may develop a disability, we may experience job changes or even retire. And yes, some of us may be diagnosed with breast cancer and other major illnesses during our years together in this study.

While we hate to learn that any of us has had an illness, it is what we learn from comparing information from those who got sick to those that did not that will allow us to uncover factors that may someday be used to prevent breast cancer and other diseases. For this reason, we hope you will stay with us and continue to promptly return updates about your health and your experiences. We also hope you'll participate in related studies like the Two Sister Study.

As always, if you have suggestions or questions about the study, feel free to contact me.

Principal Investigator, The Sister Study

The Importance of “Sister”hood

co•hort \ kō- hort\ noun 1: a group of individuals having a statistical factor (as age or class membership) in common in a demographic study 2: COMPANION, COLLEAGUE

As a member of the Sister Study, you have joined a cohort of over 50,000 women coming together to help uncover the causes of breast cancer and other diseases. Each and every one of you contributed important information when you completed the enrollment activities. We could not have gotten this far without you and your continued participation is crucial for us to carry out the mandate of the study.

In epidemiologic terms, a cohort is a group of people followed prospectively over time in a study. In practice, that means that information about changes in your habits, lifestyle, and health over the course of the study follow-up period is extremely important. In this case, the follow-up period is ten or more years, and the information is collected with the annual updates and longer questionnaires every two years.

Our lives will change over the course of this study. Like women everywhere, some of the women in the Sister Study will develop breast cancer and other health conditions. Information about who gets these health conditions and who does not will help us to discover risk factors for disease. By continuing to follow women even after they develop breast cancer or another condition, we can also gain important information on what besides treatment affects how well women do after a diagnosis. Therefore we are asking all members of the Sister Study to actively participate in follow-up activities so that you can let us know about any changes in your lifestyle and health. For some medical conditions, including breast cancer, it will also be important for us to learn more about the specific diagnosis and treatment, so women may be asked for permission to allow the Sister Study to request relevant information from their health care providers.

The dictionary defines ‘cohort’ as companion and colleague. We view each of you as a colleague in this research effort. We hope you will continue to accompany us during the ten-year follow-up period. Thank you for joining our team and working with us for the good of women everywhere.

Photo caption: Some faces of the cohort and their sisters...

Here is a photo collage of sisters of varying ages and ethnic backgrounds.

Photos appear with permission from the Sisters who sent them to us. The Sister Study protects participants’ privacy and personal information.

Early Results Reinforce the Importance of Healthy Living

Early results from the Sister Study published in the journal *Cancer Epidemiology Biomarkers and Prevention* suggest that women who maintain a healthy weight and who have lower perceived stress may be less likely to have chromosome changes associated with aging. Two papers looked at the length of telomeres, or the repeating DNA sequences that cap the ends of a person's chromosomes.

Telomere length is one of the many measures being looked at in the Sister Study. Telomeres protect the ends of chromosomes and buffer them against the loss of important genes during cell replication. Over the course of an individual's lifetime, telomeres shorten, gradually becoming so short that they can trigger cell death. Shorter telomere length is seen with aging and has been associated with early mortality and some chronic diseases.

One of the papers reported on the association between telomere length and perceived stress levels in 647 women. The researchers extracted DNA from blood drawn during initial enrollment to estimate telomere length and measured levels of several stress hormones in urine samples collected at the same time. The researchers used a standardized scale to characterize levels of perceived stress based on answers to questions about how stressful participants perceived their life situations to be. In general, women in the Sister Study typically reported low levels of perceived stress.

"Even so, women who reported above-average stress had somewhat shorter telomeres, but the most striking difference was when we looked at the relationship between perceived stress and telomere length among the women with the highest levels of stress hormones," said Christine Parks, PhD, an NIEHS epidemiologist and lead author on the paper. Among women with both higher perceived stress and elevated levels of the stress hormone epinephrine, the difference in telomere length was equivalent to or greater than the effects of smoking or 10 years of aging. The researchers also found that the effects of stress also may be stronger in older women.

The other paper reported that women who were overweight or obese for a long time had reduced telomere length. The researchers found that women who were overweight or obese both in their 30's and after age 40 had shorter telomeres than either those who were overweight or obese only after age 40 and those who maintained a normal body mass index (BMI) in both time periods. "This suggests that duration of obesity may be more important than weight change, although other measures of overweight and obesity were also important" said Dr. Sangmi Kim, epidemiologist and lead author on the paper. "Our results support the hypothesis that obesity accelerates the aging process," said Kim.

More research is needed to determine if the shortening of telomeres is directly related to aging, but these papers remind us that there are things people can do to modify their behavior and live healthier lives, such as maintain a healthy weight.

Kim S, Parks CG, DeRoo LA, Chen H, Taylor JA, Cawthon RM, Sandler DP. Obesity and Weight Gain in Adulthood and Telomere Length. *Cancer Epidemiology Biomarkers & Prevention* 2009;18:816-20.

Parks CG, Miller DB, McCanlies EC, Cawthon RM, Andrew ME, DeRoo LA, Sandler, DP. Telomere Length, Current Perceived Stress, and Urinary Stress Hormones in Women. *Cancer Epidemiology Biomarkers & Prevention* 2009;18:551-560.

We Did It! 50,000 Women Strong...

When the Sister Study began years ago, many people thought it would be impossible to enroll 50,000 participants. There were no lists from which to recruit women who had never had breast cancer but whose sister had. In addition to the large number of women needed, the study had a strong commitment to ensuring participants were diverse in race, ethnicity, age and background. "People didn't think we could do this. It was a tall order but we believed in the power of sisters affected by breast cancer and their desire to help us find the causes of this disease," said Dr. Sandler, Principal Investigator of the Sister Study.

In addition to these special women, it took many volunteers, organizations and tailored campaigns to accomplish all the successes we have seen. We would like to give special thanks to some individuals, organizations and our national partners without whom we may not have completed recruitment as successfully. Please know that if you helped us by distributing materials and telling others about the study, we truly appreciate it. Most of all, we would like to sincerely thank each and every Sister Study participant! Woman by woman, sister by sister, we are 50,000 strong!

Some publications and websites we'd like to thank include BlackAmericaWeb.com, Houston Chronicle, Chicago Women in Trades Magazine, United Auto Workers' Solidarity Magazine, A A R P Magazine, and Oprah.com.

Also,

Actress Sylvia Pasquel endorsed the study on television and radio and in print.

Thousands of women joined thanks to radio features by Tom Joyner, Michael Baisden and Dr. Elmer Huerta.

Dr. Susan Love and the Love/Avon Army of Women referred over 3000 women!

Actress Adamari Lopez's sisters Adilsa and Adaline joined and made numerous media appearances.

Bishop Vashti Murphy McKenzie challenged faith leaders and AME church members to get involved!

Former First Lady of Puerto Rico, Luisa Gándara encouraged Latinas to join!

Robin Roberts and her sisters Sally-Ann and Dorothy promoted the study on ABC's Good Morning America, and in Essence and People magazines.

Laboratory Research is Fundamental to Sister Study Success

Photo caption: Members of the Molecular and Genetic Epidemiology Group

Back row: Karen Baldwin, Zongli Xu. Front row: Sophie Bolick, Jack Taylor, Gleta Carswell

The Sister Study team includes scientists from many disciplines working together to better understand factors that lead to the development of breast cancer and other diseases. Study co-investigator Jack Taylor, MD PhD brings valuable expertise in molecular genetics and epidemiology. He heads both the Molecular & Genetic Epidemiology Group in the Epidemiology Branch and a laboratory within the Laboratory of Molecular Carcinogenesis at NIEHS. His research focuses on how exposures to chemicals or other environmental agents impact genes and also how our genetic make-up affects the likelihood of developing cancer. He is especially interested in exposures that cause DNA damage and how individual differences in the ability to repair DNA damage influence the risk for developing cancer.

Dr. Taylor played an important role in designing the Sister Study and developing procedures for the collection, storage, and handling of biological samples donated by participants. He now helps to make sure that the laboratory tests and technologies the Sister Study uses are the most current and scientifically valid. His laboratory group is developing and evaluating new assays that will be used to test hypotheses in the Sister Study. Dr. Sophie Bolick, a molecular biology postdoctoral fellow in his lab is working on assays to measure methylation changes in DNA that may be linked to environmental exposures and may be associated with risk of developing cancer. Biologist Gleta Carswell is measuring the length of telomeres, which cap the ends of chromosomes, and the number of mitochondria, which produce energy for the cell, as the laboratory investigates whether these two measures are associated with cancer risk. Dr. Zongli Xu, a statistical geneticist, is evaluating the latest results from genetic studies of breast cancer and helping to incorporate these findings with measurements made in the laboratory. Together, these investigators are making use of the samples Sister Study participants provided to gain new insight into the cause and prevention of breast cancer.

The Two Sister Study Moves Forward!

Thanks to funding from Susan G Komen for the Cure the innovative Two Sister Study of young-onset breast cancer is underway. We are sending letters to some Sister Study participants asking them to help us enroll their sister who was recently diagnosed with breast cancer and was under age 50 at diagnosis. Sisters who participate complete the Sister Study questionnaires and provide saliva (for DNA), dust, and toenail samples. We also ask them to send their parents a letter from us inviting them to provide a saliva sample. "We have sent invitations to over two thousand families so far and more than 800 have said 'Yes!' so we are now over halfway to our goal of enrolling 1600 families!", reported Dr. Clarice Weinberg, Principal Investigator of the Two Sister Study.

If you have already gotten an invitation for this important effort, and did your part by mailing our letter to your sister, we thank you for your help. Remember that we have no way to reach your sister except through you, so we appreciate your efforts to make this study work! If you think you got the letter but have misplaced it, or have any other questions, please give us a call (1-877-4SISTER). Thanks again for all you are doing to help identify risk factors for breast cancer in young women!

www.sisterstudy.org/2sister

Baseline information guides future research on breast cancer

...this long-term observational study will focus on uncovering important gene and environment interactions that influence breast cancer risk...

We've just finished enrolling the Sister Study cohort, and over the next five to ten years, this long-term observational study will focus on uncovering important gene and environment interactions that influence breast cancer risk. You've read in this issue how Sister Study researchers have already started using the information you provided to examine various lifestyle factors and environmental exposures thought to be associated with breast cancer, and to explore their possible role in other health conditions important to women.

These first studies allow us to prepare for later analyses related to breast cancer, while they also provide important information on other health conditions. For example, the scientific literature suggests that women who started their menstrual periods at a young age have a small increased risk for breast cancer and for other conditions like uterine fibroids. Dr. Aimee D'Aloisio, a postdoctoral fellow in our group, is using the questionnaire data you provided to learn what, if any, early life exposures affect age at menarche. We have also looked at the possible link between early life exposures and the development of obesity or uterine fibroids in later life.

The work described in this newsletter on a marker of chromosome aging is another example of how we use the baseline information you gave us to better understand women's health. We are building on these findings to see if this and other genetic biomarkers are related to breast cancer risk in a study of women who developed breast cancer shortly after joining the study.

Recruitment: Passion, Dedication, Commitment

The Sister Study recruitment efforts have been led by a core group of talented professionals based in North Carolina. These women share a strong commitment to public health research. It is their passion and belief in what we are doing that made it possible for us to reach women who historically have not been well represented in research. We extend our deepest appreciation to this amazing group of dedicated women.

Lourdes Suárez has led the recruitment team by managing recruitment and helping to shape special campaigns. Her prior experience working with community health organizations, combined with her commitment and enthusiasm were the heart and soul of our efforts.

Mary Quezada's networking skills helped make key linkages among the Hispanic community. Most notably, Mary developed special relationships with the First Lady of Puerto Rico and actress Sylvia Pasquel whose public endorsements inspired many Latinas to join the Sister Study.

Cat Andrews is a 17 year breast cancer survivor who has tirelessly worked as an advocate for people with cancer. Cat was especially helpful in efforts to improve representation of older women.

Carrissa Dixon has a special interest in improving African American representation in research. She has brought great knowledge on ways to engage African American women.

Suzie Dollar (left) and Naomi Piserchia (right) have remained behind the scenes, artistically and creatively designing all recruitment materials including the website, brochures, print ads and newsletters. Their skills in graphic design have been a tremendous asset to the "face" of the Sister Study.