



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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Newsletter

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The Sister Study 1009 Slater Road, Suite 120, Durham, NC 27703 www.sisterstudy.org

Sister Study Enrollment

The **Sister Study** is the only long-term study of women aged 35-74 whose sister had breast cancer. It is a national study to learn how our environment and genes affect our chances of getting breast cancer. Initially open to women in Arizona, Florida, Missouri, and Rhode Island, the study is now open to women throughout the United States.

Since you joined the **Sister Study**, another 16,000 women have enrolled. The recent surge in enrollment is very encouraging, but we still have a long way to go to reach our goal of 50,000 women. Some upcoming efforts will focus on encouraging more minority and older women to join.

Diversity is important. The **Sister Study** aims for results that apply to women from all 50 states, from different generations, and from different racial, ethnic, and income groups.

Keep in touch – Every woman who joins is important. If your address or telephone number changes, please email us at update@sisterstudy.org or call our Help Desk toll-free at 1-877-4SISTER (1-877-474-7837). Also check our website www.sisterstudy.org for new features and updates.

*Woman by woman...
Sister by sister...
We can make a difference!*

Message from the Principal Investigator

Thank you for completing all of the first-year study activities and becoming one of the first 2,000 women to join the Sister Study. You are in the 'vanguard' of the study. We are interested in any comments or suggestions you have. Your feedback has already helped us refine our procedures for the many women who will join the study after you. You are now the first to participate in our annual follow-up activities. Please fill out and return the enclosed forms so we will have up-to-date information about your health and contact information.



Dale Sandler, PhD

I thought you'd enjoy knowing a little bit about our 'vanguard' participants. Some statistics are given below. Best wishes and please keep in touch.

Dale P. Sandler

Our 2000 'vanguard' Sister Study Participants

- 35% have 1 sister
 - 32% have 2 sisters
 - 17% have 3 sisters
 - 16% have 4 or more sisters
 - Some even have 10 sisters
 - 2 to 3 sisters on average
-
- 5% aged 35-39
 - 27% aged 40-49
 - 38% aged 50-59
 - 24% aged 60-69
 - 6% aged 70-74
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- 92% white
 - 3% African American
 - 2.5% Hispanic/Latina
 - <3% Asian; Pacific Islander; or Native American, Alaskan, or Hawaiian
 - *We need greater diversity!*
-
- 15% high school or GED, or less
 - 24% some college
 - 13% assoc. or tech. degree
 - 26% bachelor's degree
 - 21% advanced degree
-
- 71% married
 - 18% divorced or separated
 - 6% widowed
 - 5% never married
-
- 28% from Arizona
 - 42% from Florida
 - 25% from Missouri
 - 5% from Rhode Island
-
- 23% urban
 - 49% suburbs
 - 17% small towns
 - 11% rural
 - Average time in current home is 11 yrs
-
- 66% work full- or part-time jobs
 - 19% retired
 - 12% full-time homemakers
-
- 85% exercised regularly year before interview.
 - Walking, weightlifting, swimming, bicycling, and yoga are the most popular exercise activities reported.

Volunteers in the Spotlight:

Witness Project® Joins Sister Study in Recruiting African American Women

The **Sister Study** is coordinating recruitment activities with The Witness Project®, a program funded by the Susan G. Komen Breast Cancer Foundation that teaches medically underserved African American women the importance of early detection of breast and cervical cancer. They began in 1990 in rural delta areas of Arkansas and have grown to 32 programs in 22 states. This spiritually rich group of Witness Role Models and Lay Health Advisors visit African American churches and community centers where access to breast health education and services is minimal or non-existent. African American women often develop breast cancer at an earlier age, and are more likely than women from other ethnic and racial groups to die from breast cancer, so the Witness Project® is particularly important in breast cancer prevention.

The **Sister Study** and Witness Project® Witness Role Models and Lay Health Advisors understand the importance of ensuring that African American women participate in breast cancer studies for future generations. We will work together to promote the **Sister Study** with African American women. Deborah O. Erwin, Ph.D., a medical anthropologist at the Arkansas Cancer Research Center and the University of Arkansas for Medical Sciences (UAMS), is the central player in bringing these two projects together.

We are proud to shine a bright spotlight on the Witness Project®. Thanks to Dr. Erwin, the Susan G. Komen Breast Cancer Foundation, and the Witness Project® for their commitment to the **Sister Study**.

Millions Learn of Sister Study Following National Launch

Without a doubt, the **Sister Study** made an impressive national debut at a press conference in Washington, DC, on October 18, 2004. Representing the National Institute of Environmental Health Sciences were NIEHS Director Dr. Kenneth Olden and **Sister Study** Principal Investigator Dr. Dale Sandler. Also there were representatives from the study's partners, including Jennifer Cawley from the Susan G. Komen Breast Cancer Foundation; Dr. Roshini George from the American Cancer Society; and Margaret Kirk, Chief Executive Officer of Y-ME National Breast Cancer Organization. Other attendees included **Sister Study** representatives Lourdes Suarez, Vernal Branch, and Dr. Paula Juras; participant spokespersons Patricia Bango and Anne Raffaelli; breast cancer survivors Darlene Nipper, Wish Martin, and Eugenie Thompson; and members of Alpha Kappa Alpha Sorority, Inc.



*Pictured left to right are **Sister Study** volunteer Wish Martin, NIEHS Director Dr. Kenneth Olden, and Dr. Sandler at the national launch press conference.*

Reporters from Black Entertainment Television (BET), CBS, Univision, Telemundo, and *U.S. News & World Report* were in attendance. With additional coverage by the Associated Press (AP), the Cable News Network (CNN), and National Public Radio (NPR), as well as by local newspapers, television and radio stations, and web sites, people across the nation heard and read more than 140 million mentions of the **Sister Study** through the first week of December. Since then the study has been highlighted in a variety of media outlets such as *ELLE Magazine*, *Komen Maryland*, the *Chicago Tribune*, and *Coping with Cancer*. The national launch was a tremendous success, causing an immediate surge in enrollment.

Woman by woman...Sister by sister...We can make a difference!

A Sister Story: Olivia and Cruz

You might think that in a family of seven sisters and one brother the odds of one of us getting a serious illness are pretty high yet that thought never entered my mind. After all, longevity runs in the family; our parents are healthy, and we are all active and try to eat the right things.

In July of 1994, we had just celebrated Olivia's fortieth birthday (sixth child) with a big party. Then in October she surprised me by calmly saying, "By the way, I'm going to the doctor tomorrow, because I found a lump in my breast." My first reaction was, "How can this be? There is no history of breast cancer in the family. Why is this happening to the princess of the family?"

Our entire family was very supportive and encouraging. Olivia's attitude was that she would beat this disease, fight it with all she had, especially her faith. I offered to do anything! It helped that I live close by, that my children were grown, and that we have a close relationship. I have been with her through the lumpectomy, radiation, chemo treatments, hair loss, emotional ups and downs, support group meetings, and fundraising events.

I joined the **Sister Study** because I want to do my part in getting the word out about this dreadful disease and to find a cure for it. As a Latina I feel even more responsibility to participate because I want the risk factors for breast cancer in my specific Latina community to be studied. Five of the six sisters are participating in the **Sister Study** because all of us want to help prevent future generations from going through what Olivia did.



Olivia Hernandez, breast cancer survivor, (L)
and sister Cruz Mireles (R)

Please tell us your Sister Story, and share your unique, personal perspective about how you came to be a part of the **Sister Study.**

For guidelines and more information, please call Lourdes Suarez at 800-948-7552 x 366.

Organic Style Magazine Names Dr. Dale Sandler to "Environmental Power List"

NIEHS' own Dale Sandler, Chief of the Epidemiology Branch and the Principal investigator of the **Sister Study**, was selected for *Organic Style* magazine's Environmental Power List, a list of "50 heroes" who are doing their part to make the planet a better place.

The magazine editors identified people they consider "eco-superstars" from a variety of fields, and looked for specific, concrete achievements by each. Those achievements range from sponsoring environmental legislation, fighting legal battles, protecting children's health, raising or contributing money, and taking action that influences others.

The power players are ranked according to the scope and impact of their achievements and their ability to activate change in the world around them. The list was published in the November 2004 issue of *Organic Style*.

Sandler is ranked 18 for her work with the **Sister Study**. Also on the list are Nancy Pelosi, Democratic representative from California and House minority leader; Robert F. Kennedy, Jr.; Teresa Heinz Kerry; and Chicago Mayor Richard Daley. A number of celebrities who either donated large sums of money for environmental causes or have been active in environmental foundation activities appeared much lower on the list. Among them are Angelina Jolie, Leonardo DiCaprio, Bette Midler, and Cameron Diaz.

Organic Style notes that "No matter where they fall on the list, all 50 crusaders are dynamos. Their stories prove that one person really can make a difference – all it takes is that first step."

Source:

<http://www.niehs.nih.gov/factor/2004nov/home.htm#news3>

Sisters "Star" in Study Video

How do you make an 11-minute video that will touch the lives of thousands of sisters from all backgrounds, ages and races? This was the task given to **Sister Study** staff and the production company, Double R Productions. To create the video, we visited several sisters in North Carolina and in the Washington, DC, area. The passion of the sisters interviewed brought tears to our eyes and gave deeper meaning and reality to why the **Sister Study** is so important. Double R Productions president Rosemary Reed is also a breast cancer survivor and is the video narrator. She brought experience, spirit and great ideas to the film.

Our special thanks to the participants and their sisters who are the featured video stars and heroines: participants Patricia Bango and Marcia Plater; and sister pairs Barbara Parker and Heather Ward, Tina Hall and Wanda Willis, Denni Peebles and Sara Williams, and Olivia Hernandez and Cruz Mireles. Thanks to Dr. Sandler, also, who explains the scientific basis of the study and makes a personal appeal to women of all races and ethnicities to join.

View the video on our web site, www.sisterstudy.org. From the home page, click on link "Watch the Video." Video copies will be distributed to organizations who are helping recruit women.

Fitting in Fitness: The 10-Minute Solution

A Special Message from our partners at the American Cancer Society

Did you know you benefit from even small amounts of moderate activity throughout the day? Regular physical activity is easier to fit in than you may realize and can significantly lower your lifetime risk for cancer—and heart disease and diabetes, too.

The American Cancer Society recommends that adults engage in at least moderate activity for 30 minutes or more on 5 or more days of the week; 45 minutes or more of moderate to vigorous activity on 5 or more days per week may further reduce the risk of breast and colon cancer.

On those especially busy days, try working in 10 minutes of activity three times a day. For example, you can do some simple exercises for 10 minutes in the morning before everyone gets up, take a 10-minute walk during lunch, and another 10-minute walk after dinner. It's that simple to work in 30 minutes of activity.

Moderate Activity is anything that makes you breathe as hard as you do during a brisk walk. During moderate activities, you'll notice a slight increase in heart rate and breathing, but you may not break a sweat. **Vigorous Activities** are performed at a higher intensity. They produce an increased heart rate, sweating, and increased breathing rate. Other beneficial activities include those that improve strength and flexibility such as weight lifting, stretching, or yoga.

Whether you set aside time to exercise or do short bursts of activity throughout the day, the most important thing is to get up and get moving.



The Susan
G. Komen
Breast Cancer
Foundation



The **National Center on Minority Health and Health Disparities (NCMHD)** provides additional funding for the **Sister Study**. Our partnering organizations such as **The American Cancer Society**, the **Susan G. Komen Breast Cancer Foundation**, **Sisters Network, Inc.**, and the **Y-ME National Breast Cancer Organization** help us recruit women for the **Sister Study**.