

A Sister Story: Donna and Gail, Sisters and Best Friends

My sister Gail and I were best friends, shared a bedroom, and pretty much did everything together. After college we both moved to New York and then to Los Angeles and figured we would grow old together. That all changed in October 2001 when Gail discovered she had breast cancer. About a year later the cancer spread to her liver, which was devastating news since our father died of liver cancer. Gail was a fighter. We were together for every doctor's appointment, every chemo session, every evening walk, but her cancer was aggressive. On December 4, 2003, Gail passed away in Santa Monica. She was only 46 years old. As soon as I heard about the **Sister Study**, I knew I had to sign up. Unfortunately, breast cancer seems to be more aggressive in African American women and we need to find out why. I thank God for blessing me with my sister Gail, and I still miss her every day. I am doing this study in her honor. I know she is looking down on me, smiling, and in spirit we are still together. [To learn more about Donna and Gail, and to read other Sister Stories, see our website www.sisterstudy.org.]



Donna Castleberry (left) and sister Gail

Sister Study Spokespersons



Delores Burgess

Award-winning gospel recording artist and speaker Delores Burgess uses her music ministry to share testimony about her personal victory over breast cancer and to promote the **Sister Study**. "I'm delighted to use my ministry to help enroll more African American sisters in this landmark study. I knew I would be heavily involved in the cause of breast cancer once I was back on my feet, and I'm extremely proud of my sister Pat for participating in such important research."



Molly Ximenez (center) with sisters

Molly Ximenez is a Latina breast cancer survivor. Her sister Geri is a participant. Together, they have appeared on radio and television shows speaking about their **Sister Study** involvement. Molly has recruited women from her family and community to participate in the study. She works through her local American Cancer Society chapter and community-based organizations to help spread the word about the **Sister Study**.



Lois Catrambone

When 73-year-old Lois Catrambone lost her sister to breast cancer in 2002, she decided it was important to join "the only study that I know that focused on causes." She urges others to join the **Sister Study** by distributing study brochures, setting up tables at local hospital events, and visiting senior centers and church groups to urge other seniors to participate.

How You Can Help Spread the Word About the Sister Study

You can submit information to newsletters, bulletins, or listservs. You can become a spokeswoman for local media or events. You can distribute **Sister Study** brochures, bookmarks, and flyers or play the **Sister Study** video for groups of women.

To obtain **Sister Study** materials, contact Naomi Piserchia at 1-800-948-7552, ext. 4356 / piserchian@niehs.nih.gov. For ideas to promote the study in your local press, contact Kim Varner at (202) 842-3600, ext. 254 / kvamer@hagerssharp.com.

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 Helping Us Recruit Sisters



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

Celebrating Sister Study Participants

It's hard to believe we are almost halfway through the **Sister Study** Recruitment years! In these two years, you have sent us a clear message — that you love your sisters, you hate breast cancer, and you want to be heard. None of our scientific theories could have predicted the enthusiasm you bring to this study.

Even in our firm commitment to maintain your privacy, you have compelled us to provide ways for you to tell your stories — of your sisters and your families and your commitment to eradicate breast cancer for your daughters and granddaughters. Each day you send us Sister Stories and tell us, "Here is our story! Post it on the website ... send it to the newspaper ... use it however it will help!" In this newsletter you'll read about some sister participants, and the ways they have adopted the **Sister Study** as their mission. As Spokespersons, they talk openly wherever they can to encourage more sisters to join. Yet for every Delores, Molly, or Lois, we realize there are a thousand more women who are reminded of breast cancer when they think of their sisters. Each day your stories remind us that what we are trying to do really is important.

You are amazing women. More than 25,000 strong so far. From Anchorage to Charleston, Santa Fe to San Juan, Portland to Palm Beach. You are farmers and fishers, homemakers and house painters, doctors, dentists and daycare givers. You are Native American, Alaskan, and Hawaiian. You are Black, Latina, Asian, and White. You live in the largest cities and the smallest townships. You are very different ... yet you are all sisters. By joining the **Sister Study** you are breaking the silence that may help unlock the mysteries of breast cancer.

Message from the Principal Investigator

You are now a member of what will become the largest long-term study ever conducted in the U.S. on the potential environmental causes of breast cancer. My sincere thanks to each of you for making our first two years so successful. As I write this, we are already more than 25,000 strong.

Our first challenge is to recruit 50,000 sisters from all walks of life. The second is to keep everyone motivated to stay with the study! Study results will not come quickly, but the information you share with us over the years will greatly increase our chances of finding causes of breast cancer.

The Health Update Form is critical. This year all we are asking you to do is tell us about any changes in your overall health or your contact information, especially if you have moved. Next year you will be given an opportunity to help us explore new research topics, such as the effects of life's stresses on health.

"Keeping in touch" will continue to be an important part of your contribution to this landmark study. Our job will be to keep you well informed as the study progresses.

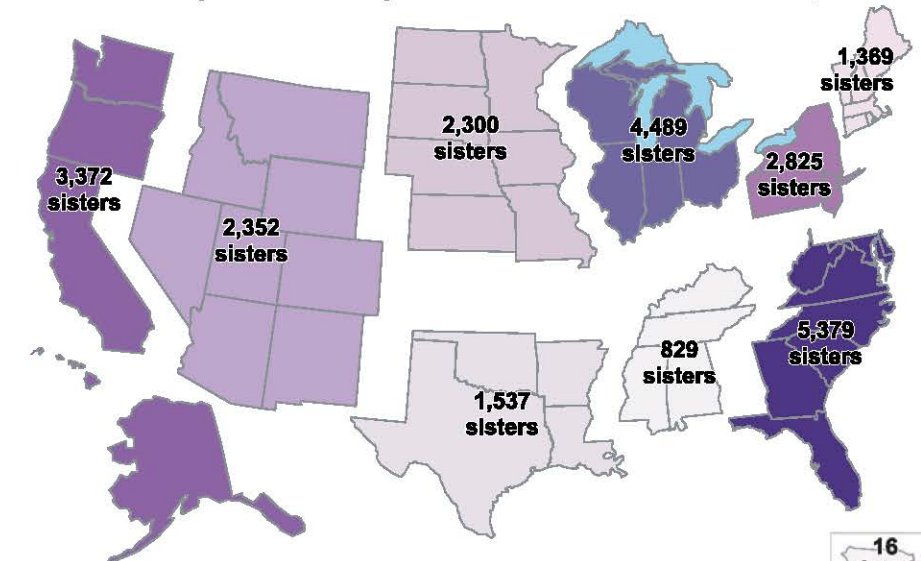
Best wishes, and please keep in touch. We are just a phone call away.

Dale P. Sandler



Dale Sandler, PhD

Sister Study Enrollment by Census Division - as of March 1, 2006



Sister Study Team at Work

Since 2003 **Sister Study** staff have worked diligently to enroll eligible sisters, prepare SISTER STUDY KITS, complete telephone interviews, perform home examinations, process laboratory specimens and questionnaires, respond to Helpdesk inquiries, and conduct periodic follow-ups. Below are some snapshots of our team at work.



The **Sister Study** team includes 50 telephone interviewers located in Durham, NC, and Merced, CA, who help sisters complete their 2-part telephone interviews. Some interviewers also answer calls and emails to the Helpdesk and answer calls to help women determine if they are eligible. Here, several of our staff assist a participant by researching a Helpdesk question.



Our team includes members who work on issues related to the home examinations (top) and prepare SISTER STUDY KITS for delivery, carefully checking each one for accuracy (bottom).



The **Sister Study** laboratory team currently includes a lab director, a lab supervisor, and 6 biologists. They carefully unpack blood and urine samples as they arrive, dividing tubes of blood into smaller containers. The team also analyzes urine samples for glucose (sugar) reports.



The **Sister Study** data processing team handles an average of 160 completed questionnaires a day. Questionnaires are reviewed and processed through our scanners, which automatically tabulate and store data.



Finally, after processing, blood and urine samples are placed in a central repository for safekeeping.

Preliminary Sister Study Data

Study Progress
<ul style="list-style-type: none"> 25,941 SISTER STUDY KITS delivered Over 40,000 sisters screened for eligibility 20,311 sisters completed both parts of the telephone interview Nearly 14,000 Sister Study Helpdesk calls and emails answered 21,143 home examinations performed Nearly 106,000 questionnaires processed and scanned 1,276,032 blood, urine, toenail, and dust samples handled and stored for later analysis

Sister Study Participants – Who You Are
<p>You are busy and accomplished women</p> <ul style="list-style-type: none"> 67% currently work full-time 20% work irregular hours or rotating shifts 32% ever worked as a teacher 16% ever worked as a nurse 14% ever worked in a factory 13% ever worked on a farm 3% ever worked in building construction <p>You come from all walks of life</p> <ul style="list-style-type: none"> 81% had routine physical in the last year 68% went through menopause or had a hysterectomy 47% ever smoked 74% married 41% live in a suburban setting 3% currently live on a farm; 14% lived on a farm as a child 14 years average length of current residence 2.3 sisters on average <p>You have strong family connections to breast cancer</p> <ul style="list-style-type: none"> 34% have a sister diagnosed before she was 45 years old 31% have a sister diagnosed within the past 2 years 19% have a mother diagnosed with breast cancer 12% have 2 or more sisters affected by breast cancer

Meet Your Recruitment Team
<p>These are the women who maintain the spirit behind the study, reaching out to women from all walks of life to Spread the Word about the Sister Study.</p> <p>Team members Catherine and Sara (front, L to R) are both Breast Cancer Survivors and speak convincingly to all women on why this study is so important for future generations, including their daughters. Team members also conduct special outreach to African Americans, Latinas, Asians and Pacific Islanders, Native Americans, Seniors, and to sisters who work in trades and blue collar jobs.</p> <p>We give TV, radio and print interviews, design graphics and ads, travel to events, work the phones endlessly, and send out materials to volunteers. Our job is not complete until we have 50,000 committed sisters. Please help us Spread the Word!</p>



<p>Sister Study En Español</p> <p>The Sister Study is now available in Spanish. Women who prefer to use Spanish may initiate enrollment by calling toll-free 1-877-474-7837. The Spanish website is available at www.estudlodehermanas.org.</p> <p>If you can help spread the word to Latinas or want to learn more about our Spanish initiative, please contact Lourdes Suárez at 1-800-948-7552, ext. 4366.</p>
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Lourdes Suárez

<p>Study Opens in PUERTO RICO</p> <p>Researchers and sisters in Puerto Rico are very excited that their island is now part of the Sister Study. Since women in Puerto Rico have higher rates of breast cancer compared with women in the U.S., Puerto Rican participation will enrich what we can learn about the causes of breast cancer in Latinas.</p>
