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## **Supplemental Material**

### **The Sister Study Cohort: Baseline Methods and Participant Characteristics.**

Dale P. Sandler, M. Elizabeth Hodgson, Sandra L. Deming-Halverson, Paula S. Juras, Aimee A. D'Aloisio, Lourdes M. Suarez, Cynthia A. Kleeberger, David L. Shore, Lisa A. DeRoo, Jack A. Taylor, Clarice R. Weinberg, and the Sister Study Research Team

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**Table S1: Examples of environmental exposures of interest in the Sister Study<sup>1</sup>**

<b>At study initiation:</b>
Age at menarche/menopause/first birth
Alcohol: including binge drinking, ADH genotype, and BrCa subtypes
Antioxidants, carotenoids, omega-3 fatty acids
Calcium, calcium channel blockers
Childhood residential and environmental exposures
Childhood socioeconomic factors
Cigarette smoking, active and passive: including modifying effect timing of exposure
Cooking methods, heterocyclic amines
Disturbances in circadian rhythms: light at night, shift work, sleep/insomnia, melatonin
Exogenous hormones: hormone replacement therapies, contraceptive hormones
Family history of breast and other cancer
Fertility treatments, including medical hyperstimulation of the ovaries
Hormonal risk factors
Ionizing radiation
Nutritional and dietary factors
Occupational factors: solvents, solder, PAHs, paints, metals
Oxidative stress
Perinatal factors: toxemia, birth order, birthweight, soy formula, breast feeding
Personal care products: endocrine disruptors
Pesticides: home and occupational use; biological measure of organochlorine levels
Pharmaceuticals: NSAIDs, anti-depressants
Physical activity: leisure and occupational
Phytoestrogens
Reproductive history: preeclampsia, gestational diabetes, breast feeding
Steroid hormones: estrogens, androgens, progesterone, prolactin, other
Vitamin D: diet, sunlight, serum
Weight and weight change
<b>Since study initiation:</b>
Air pollution
Central adiposity
Dietary patterns
Endocrine disruptors other than those in personal care products
Epigenetic mediation
Flame retardants
Health disparities
Inflammation
Metabolic dysfunction, including metabolic syndrome and diabetes
Metalloestrogens
Metformin
Oxidative stress
Parabens
Phthalates
Stress and trauma

Thyroid dysfunction

<sup>1</sup> See the Sister Study website for data collected relevant to tabulated exposures (<https://sisterstudy.niehs.nih.gov/English/researchers.htm>), including baseline and detailed follow-up questionnaires, and biological and environmental samples

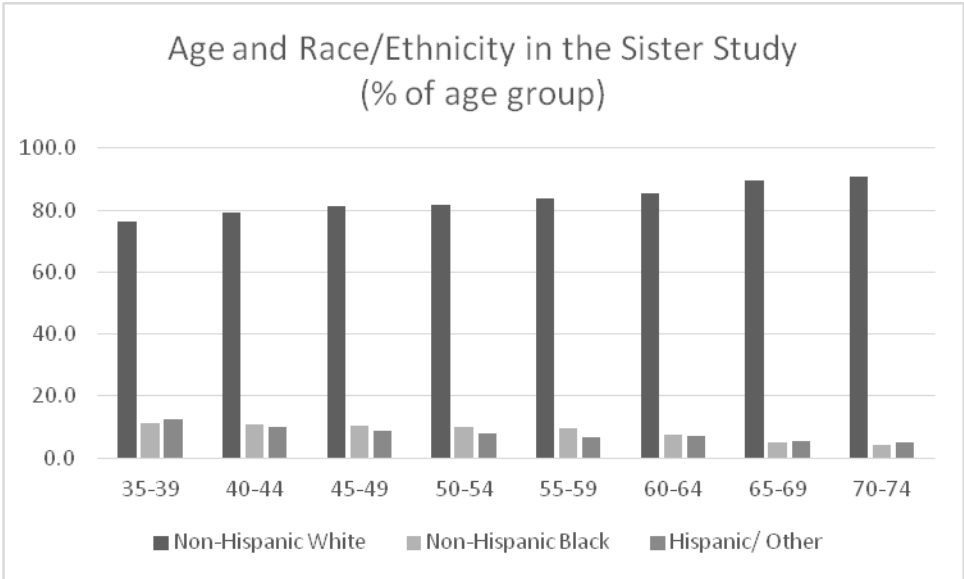
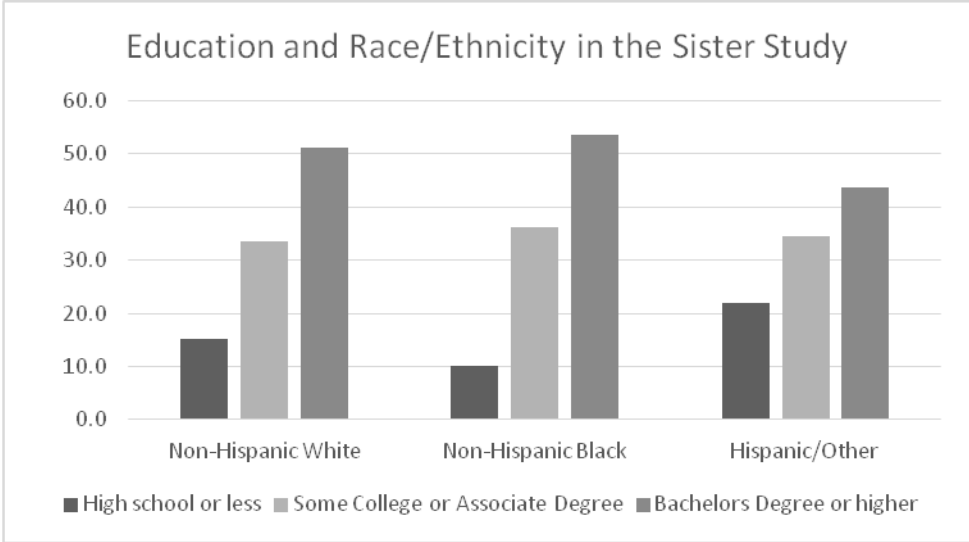


Figure S1. Education, race/ethnicity and age in the Sister Study at enrollment

**Table S2. Response, Enrollment and Baseline Activity Completion in the Sister Study**

<b>Status</b>	<b>Overall</b>	<b>Web- screened (62.1%)</b>	<b>Phone- screened (37.9%)</b>
	<b>N</b>	<b>N</b>	<b>N</b>
Screened	89,428	55,502	33,926
Not Eligible	5,456	16	5,440
Eligible	83,972	55,486	28,486
Signed Up	62,813	36,570	26,243
Baseline Complete/Fully Enrolled	50,884	30,189	20,695
% of eligible fully enrolled	60.6	54.4	72.6
% of signed up who fully enrolled	81.0	82.6	78.9

**Table S3. Baseline Activity Completion: Sister Study Cohort and Passive Cohort at Baseline, 2003-2009.**

Baseline activity	Sister Study Cohort (n=50,884)		Passive Cohort (n=3,066)	
	N	(%) <sup>a</sup>	N	(%) <sup>a</sup>
<b>Baseline components completed</b>				
<i>CATI 1</i>	50,884	100.0	3064	99.9
<i>CATI 2</i>	50,884	100.0	1247	40.7
<i>Home visit</i>	50,884	100.0	642	20.9
<i>Past 24 hour questionnaire</i>	50,572	99.4		
<i>FH questionnaire</i>	50,074	98.4		
<i>FFQ &amp; supplemental questions</i>	49,741	97.8		
<i>Personal care products questionnaire</i>	49,905	98.1		
<b>Biospecimens received</b>				
<i>Blood</i>	50,433	99.1	595	19.4
<i>Saliva*</i>	354	0.7	0	0.0
<i>Urine</i>	50,705	99.7	613	20.0
<i>Toenails</i>	49,835	97.9	547	17.8
<i>Dust</i>	50,367	99.0	569	18.6

**Abbreviations:** CATI = computer assisted telephone interview; FFQ = food frequency questionnaire; FH = family history; N = number; PC = passive cohort

<sup>a</sup> Total percentages may not always equal 100% due to missing values and rounding.

\*obtained only if blood collection not feasible

**Table S4. Impact of Recruitment Methods <sup>a</sup>**

Recruitment method	Screened and Eligible					
	Signed Up <sup>b</sup> n=62,813		Did Not Sign Up <sup>c</sup> n=21,159		Enrolled <sup>d</sup> n=50,884	
	N	%	N	%	N	%
Sister with BrCa	13,656	21.7	4,201	20.0	11,319	22.2
Friend or Family	11,073	17.6	3,865	18.4	9,151	18.0
Newspaper	9,248	14.7	2,195	10.5	7,930	15.6
Magazine	7,984	12.7	2,320	11.1	6,503	12.8
TV	6,217	9.9	1,974	9.4	4,904	9.6
Other	4,290	6.8	1,295	6.2	3,440	6.8
Website	3,408	5.4	2,263	10.8	2,604	5.1
Radio	3,167	5.0	1,221	5.8	2,354	4.6
Doctor	3,027	4.8	717	3.4	2,426	4.8
Flyer or Brochure	2,516	4.0	543	2.6	2,014	4.0
Email	1,825	2.9	1,034	4.9	1,325	2.6
Newsletter <sup>e</sup>	1,624	2.6	409	1.9	1,417	2.8
American Cancer Society	1,217	1.9	527	2.5	931	1.8
Komen	1,041	1.7	503	2.4	834	1.6
Event	660	1.1	212	1.0	527	1.0
Postcard	430	0.7	67	0.3	287	0.6
Study Recruiter	405	0.6	228	1.1	306	0.6
Advocates <sup>f</sup>	337	0.5	152	0.7	264	0.5
Cancer Registry	252	0.4	9	0.0	197	0.4
Y-Me <sup>g</sup>	200	0.3	102	0.5	158	0.3
Sisters Network	170	0.3	98	0.5	123	0.2

<sup>a</sup> Women surveyed could give more than one answer so percents do not sum to 100%

<sup>b</sup> Signed Up = Completed enrollment call and signed up to participate in study

<sup>c</sup> Did Not Sign Up = completed screener and were eligible but did not sign up for study

<sup>d</sup> Enrolled = Completed required baseline activities (i.e. the Sister Study cohort)

<sup>e</sup> Organizations with newsletters (paper or electronic) were asked to run articles or short announcements about the study

<sup>f</sup> Local advocates (e.g. community leaders)

<sup>g</sup> Previously National Breast Cancer Network of Strength

## **Appendix A. Examples of Recruiting Sources and Strategies**

Recruitment for the Sister Study was done over a five year period using strategies ranging from community-based efforts to nationally endorsed campaigns. These multi-faceted efforts ensured that the Sister Study included women from diverse backgrounds – women of ethnicities other than non-Hispanic white, women of varying educational levels and occupations, as well as older women. Although the Sister Study’s cohort is comprised of women who have never been diagnosed with breast cancer, recruitment strategies targeted both women in the general population and breast cancer survivors.

Mainstream and general audience efforts were explored the first years of recruitment. As enrollment progressed and it was evident minorities, older women and women with less education were not enrolling at the same rate as Caucasians 35-55 years of age with a college degree or higher, more tailored recruitment efforts were pursued to reach women not well represented in the Sister Study. To that end, aggressive efforts to recruit African Americans, Latinas, seniors, women with high school degrees or less and other minority groups were implemented. The following are examples of the many approaches and strategies used to recruit women for the Sister Study.

### **Focus Groups**

Between September 1999 and February 2000, focus groups were held to better understand to what extent women in the target population (i.e. women at higher risk of breast cancer due to a full or half sister having the disease), both non-minority and minority women, might be willing to participate in a study requiring a long-term commitment. Focus group feedback was also used to help shape recruitment strategies and questionnaire content. Groups included unaffected sisters of women with breast cancer (general population, African American, Latina, or lesbian women) and women with breast cancer who had unaffected sisters. Topics included sources of health information, how the sister’s diagnosis had affected the cancer-free sister, reactions to Sister Study descriptions, perceived barriers and incentives to study participation, and ideas for recruitment and messaging.

### **Pilot Phase**

At the recommendation of focus groups and minority advisory panels, during the pilot phase of the study, we established strong relationships with community gatekeepers who helped publicize the study and cultivated a diverse network of proactive recruitment volunteers.

Throughout recruitment, the PI and study team members maintained a presence at relevant conferences and meetings. This included talks by the PI at these meetings:

- National Medical Association annual meeting, 2005
- National Black Nurses Association annual meeting, 2005
- National Breast Cancer Coalition Fund Annual Meetings, 2002, 2005
- Office of Minority Health (OMH) Summit 2006 – Eliminating Racial and Ethnic Disparities in Health, Washington DC, 2006

### **Partner Organizations**



In order to create a strong cadre of volunteers, nationally known and respected organizations such as the following became partners of the study and used their own networks to help recruit for the Sister Study.

- American Cancer Society
- Susan G. Komen for the Cure
- National Breast Cancer Network of Strength (previously Y-ME)
- Sisters Network, Inc.
- Intercultural Cancer Council
- National Center for Minority Health and Health Disparities
- AARP, under a “Joint Research Collaboration”
- Alpha Kappa Alpha (AKA), African American national sorority, Washington, DC chapter

The Sister Study reached out to women in trades and various industries through unions and their publications. Direct email appeals were sent through the unions; appeals also appeared in their electronic and print newsletters. Some of the trade groups and unions who supported the Sister Study were:

- Amalgamated Transit Union
- American Postal Workers Union
- AFL-CIO
- Coalition of Labor Union Women (CLUW)
- Glass, Molders, Pottery, Plastics and Allied Workers
- Hard Hatted Women

In several cities community-based groups were contacted for help distributing recruitment materials and to solicit volunteer recruiters. Groups included:

- Hospitals and mammography centers
- Breast cancer support groups
- Oncologists, radiologists and breast surgeons
- Women’s health centers
- Minority-focused groups

### **Events and Recruitment Materials**

Study recruiters and volunteers attended a wide range of local and national conferences, distributing promotional materials. Recruitment materials included:

- Brochures/ Flyers (See Appendix Figure 1)

- Informational DVD
- Fans with Sister Study logo and contact information
- Notepads
- Bookmarks
- Breast cancer ribbons impregnated with birdseed
- Magnets with Sister Study logo and contact information

Team members went to these events:

- sorority conferences
- women in government conferences
- national hair care conference
- breast cancer meetings
- health fairs

### **Media Campaigns**

A media relations company and staff from the NIEHS Office of Communications employed a number of strategies to promote the Sister Study. A B-Roll Video Feed with pre-recorded messages from the Sister Study PI, including state-specific information, was created for distribution and promotion to TV stations in ~40 local and regional markets. There were satellite radio tours where multiple stations could call in together or in sequence to interview the PI and other Sister Study representatives. A New York Media tour featured desk-side interviews at consumer magazines and network TV programs. Extra effort was devoted to media 'pushes' during key periods of increased media interest: National Women's Health Week (in May), Sister's Day (in August), and Breast Cancer Awareness Month (October). Radio tours by the PI, the project officer (Dr. Paula Juras, NIEHS) and a Sister Study participant were conducted during these and other times. Another study participant wrote articles that were included in media packages. Media kits were created for partner organizations that included talking points, sample press releases, pre-recorded radio ads and print-ready text for easy insertion. A more tailored media approach was taken to recruit underrepresented groups.

General:

- Magazines including *Woman's Day*, *Better Homes and Gardens*, and *Ladies Home Journal*.
- National celebrity Robin Roberts of *Good Morning America*. Other national media stories and articles spun from the Roberts' family endorsement.
- Web-based paid campaign on Oprah.com featuring rotating web banners and a banner ad on her weekly e-newsletter "Live Your Best Life".
- Local news anchor in New Orleans did a story on the Sister Study, announcing that she was eligible and would join the study
- Public Service Announcements

- Local TV and radio appearances by study investigators or participant volunteers

Targeted (non-white women, Latinas, seniors, women with less than a college degree, and women in non-traditional jobs):

- *Tom Joyner Morning Show*, a popular nationally-syndicated radio show and personality in the African American community, including live on-air mentions by Tom Joyner encouraging African American women to join; a web campaign on his *Black America Web* site; monthly blast emails to the site's members.
- Mr. Joyner's *Take a Loved One to the Doctor Day* yearly campaign.
- *The Michael Baisden Show*.
- *The Yolanda Adams Show* and *The Mo'Nique Show* – on-air mentions and interviews
- Spanish magazines *Vanidades*, *TV y Novelas*, and Walmart's bilingual magazine *Viviendo*
- Spanish public service television announcement – played in NC and Spanish network Univisión in Puerto Rico
- Media tours with Sylvia Pasquel, a Mexican actress and the sister of a famous singer and breast cancer survivor, endorsed the study on a variety of popular media outlets
- Sisters of international Puerto Rican actress Adamari Lopez, joined and publicly encouraged Latinas to join.
- Luisa Gándara, wife of the former Governor of Puerto Rico actively participated with a call to action that influenced the American Cancer Society of Puerto Rico use their volunteers and include media and promotional materials at their events.
- A "Joint Research Collaboration" was approved by AARP which allowed permission to print in the organization's high circulation magazines and bulletins (English and Spanish) - *AARP Magazine*, *AARP The Bulletin* and *AARP Segunda Juventud*.
- Radio ad campaigns in country stations with high blue collar audiences

### Contact Sources

The recruitment staff used lists from a numerous sources to contact women in different ways, including:

- Postcard with tailored messaging sent to a roster of African American females in select states. List purchased from Guaranteed Lists.
- Email efforts via *Essence.com*, and *Blacks N LA*
- Direct appeal to Historically Black Colleges and Universities (HBCUs) alumni networks. Schools were called, then were encouraged to send emails and distribute materials at events.

### Appendix Figure 1

Tailored Study Brochures

