STL Connection

Program for the Elimination of Cancer Disparities Volume II Issue II 2007

RESEARCH ON BREAST CANCER AND SISTERS NEEDS MORE WOMEN OF COLOR

August 5, 2007 **BY CECILIA OLECK** FREE PRESS STAFF WRITER

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Connie Orr and her sister, Sherrill Jackson, a member of PECaD's Disparity Elimination Advisory Committee.

Ever since they were children, Connie Orr has adored her older sister.

When the two were young, Sherrill Jackson would walk little Connie to class, bring her along on dates to the drive-in and let her tag along to sleepovers at friends' houses. They've supported each other through marriage, children, divorce, re-marriage and the deaths of both parents.

Now, they're taking on breast cancer -- together.

Jackson, 60, a 15-year breast cancer survivor and pediatric nurse practitioner in St. Louis, fought it head-on and now leads a 75-member breast cancer support group. Orr, 56, of Novi, is fighting the disease in a different way: She signed up to take part in the Sister Study, a national look at the sisters of women who have or have had breast cancer.

She's among 39,000 women who have signed up so far and one of 2,324 African Americans enrolled in the study. As the study enters its final months of recruitment, getting more women of color like Orr to participate is key.

The study's aim? Find out what causes breast cancer -- and how it varies among women of different ethnic backgrounds.

Nearly 180,000 women annually in the United States are diagnosed with breast cancer and 41,000 die from it.

As part of the 10-year-long study, Orr will answers questions every other year about her health and habits. She already filled out questionnaires when she signed up last year and has had a health professional visit her home to give her a physical.

Signing up for the study was a simple yet significant way Orr felt she could help.

"You may think you understand ... but you can't reach out to them like another survivor can," says Orr. "The Sister Study is the only meaningful thing I can do to help. I feel, in some ways, I've helped all women."

Diversity required

But in order to better understand how a woman's habits, environment and genetics contribute to her risk for breast cancer, researchers need more women like Orr to step forward.

With five months left for recruiting, the study is 11,000 women short of its goal of 50,000 participants.

More troubling to researchers is that only 12% of the 39,000 women recruited so far are minorities, 214 from Michigan.

"We really want the study to be representative of the women in the United States," says Lisa DeRoo, an epidemiologist for the Sister Study. "We do know that the incidence of the disease and survival rates vary from group to group. ... Part of the reason why it's so important to recruit a diverse group of women is that we want the results to benefit the different women across the United States."

African Americans, for example, are less likely than white women to get breast cancer, but they are more likely to die from it. Some studies suggest that this is because black women are more likely to be diagnosed when their tumors are more advanced.

Sister article contines on page 2

The Program for the Elimination of Cancer Disparities is one of 25 Community Network Programs funded by the National Cancer Institute. (Grant number 1 U01 CA 114594-01).

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Gaining a better understanding of such differences is one of the study's key aims.

Special hurdles

Getting the word out about the study has been challenging. Too often cultural inhibitions and language barriers prevent many women from learning about their cancer risk or from participating in projects like the Sister Study.

Recruiters at the national level have mostly relied on cancer registries in each state to reach breast cancer survivors.

They've also sent mailings to sororities and contacted organizations like the the Barbara Ann Karmanos Cancer Institute.

The Sister Study faces many of the same difficulties in recruiting minority women that local organizations do in preventing and treating breast cancer, says Dr. Adnan Hammad, director of the Community Health and Research Center for the Arab Community Center for Economic and Social Services in Dearborn.

When Hammad started a breast and cervical cancer screening program for Arab women in metro Detroit in 1996, health workers conducted an estimated 5,000 home visits to talk to women. Only 50 women agreed to be screened that year. Many women they talked to lacked knowledge of cancer and were hesitant to be screened for because of privacy concerns.

Now more than 2,000 women receive breast and cervical cancer exams annually through the program.

Hispanic women also visit the center, says Hammad.

"We have done tons of work in the area of cancer screening," says Hammad. "And the survivor rate is becoming so strong ... but to some cancer is a taboo, it's a curse, it's a punishment."

DeRoo says another challenge to recruiting women for the Sister Study is the 10-year commitment.

Family project

For many, it takes watching a loved one deal with breast cancer to spur interest in a long-term endeavor like the Sister Study.

That was the case for Ursula Powell, a 37-year-old African-American woman from Rochester Hills.

She has watched two great-aunts die from breast cancer and her mother's sister struggle with it. That was enough to put her on a mission to increase awareness of the Sister Study, which she hopes will be a step toward preventing cancer.

She keeps stacks of Sister Study brochures in her van, ready to hand out wherever she goes -- doctors' offices, church and community health fairs, pharmacies, beauty shops and makeup stores.

It's something she's done for more than a year, even though Powell herself can't sign up for the study because none of her sisters has had breast cancer.

Perhaps her biggest outreach, however, has been to her mother and four aunts living in metro Detroit, all of whom were shaken when their sister Twila Sneed, who lives in Pennsylvania, was diagnosed with breast cancer four years ago.

Powell urged them to join the Sister Study.

The women hope the study will be a breakthrough in understanding why some families are especially hard hit.

Powell's aunt Tamara Jackson says she signed up not only because of the family's history, but also for its future. The more that is known about breast cancer, the better younger generations will be equipped to deal with it.

"I have a 12-year-old daughter," says Jackson, 43, of Waterford. "If I can do something to prevent it for her, I'm going to."

Sisterhood is powerful

While joining the study is one way for many women to show love and support for their sisters, it's also a sign of solidarity with other women.

"It's bigger than me and it's bigger than my sister," says Orr. "My sister has already gone through the experience of breast cancer. Her attitude and my attitude is this is for women who don't yet have cancer, and maybe this will shed some kind of light that they never will get cancer."

PECaD in the Spotlight

Julie Margenthaler, M.D., Assistant Professor of Surgery, is the Principal Investigator for PECaD's Susan G. Komen for the Cure St. Louis Affiliate grant to study system delays in cancer diagnosis in the St. Louis public safety net system. This project is identifying and addressing specific barriers to timely diagnosis and care for women referred from Connectcare to Siteman's Joanne Knight Breast Health Center with abnormal mammograms.

Dr. Margenthaler completed her general surgery residency training in 2005 and a breast surgery fellowship at Washington University in 2006. In addition to her interest in timely diagnosis for underserved women, Dr. Margenthaler's current research focuses on minimally invasive staging procedures for breast cancer and factors that may predict why some women under forty develop contralateral breast cancer.

Rose Robins Troupe, SBN, RN, MPA is a Health and Wellness Educator working to increase awareness and access to care for minorities and underserved populations. Her weekly talk show, "Health Connections" is heard on Hallelujah 1600 AM. PECaD partners with Rose each month to focus on cancer education, screening, diagnosis and treatment.

Ms. Troupe also consults on community health education events such as Anthem Blue Cross/Blue Shield's Annual Health & Wellness Church Tour and the Congressional Black Caucus' Black Health Empowerment Project. As a member of PECaD's Prostate Cancer Community Partnership, Rose was a key part of our team's successful Wellpoint Foundation grant submission. This grant will fund a comprehensive prostate cancer awareness campaign for the region.

BRINGING RESEARCH TO THE COMMUNITY

A recent University of Chicago Medical School study looked at the anxiety levels of men with suspected prostate cancer. 243 patients were interviewed at urology clinics; 40 percent of them were African American. All the men were about to have biopsies because they had been told they may have prostate cancer (mainly through blood tests).

The men were asked what they felt was the chance they would have the disease. Though all the men were having biopsies because they were at higher risk of having prostate cancer, 55 percent of the African Americans said they had a zero percent chance of having the disease (that is, it was impossible). In contrast, 20 percent of Caucasians said their risk of having the disease was zero.

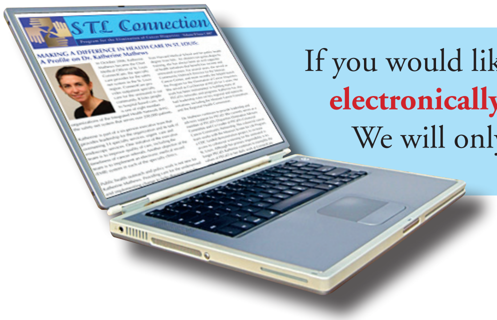
The biopsy results later showed that 70 percent of the African Americans had prostate cancer. Fifty percent of Caucasians had the disease. "A group that underestimates the risk of having cancer is likely to underestimate the value of early detection and thus skip the whole process… which may explain, in part, why African-American men are so often diagnosed later and thus have worse outcomes" said study author William Dale, MD, PhD.

The authors found that men who were more worried about having prostate cancer were less likely to have it. Though many of the African Americans felt they were at no risk or low risk, members of this group were actually much more likely to have the disease.

"With this data, we can't say why the estimates are so low. We want to conduct more research to better understand the reasons…[which will] hopefully lead to greater attention to prostate cancer for those at highest risk such as African Americans" said Dale.

In partnership with Lane Tabernacle CME Church, PECaD has created a Lay Educator Speakers Bureau for prostate cancer. This effort trains prostate cancer survivors to share insights from their experience with the disease. By speaking at health fairs, churches and agencies, these lay educators encourage individuals to get screened and seek additional information. They are helping PECaD to increase our community outreach tremendously.

Two of our lay educators, **Dewey Helms** and **Ray Waligurski**, are shown participating in "Take a Loved One to the Doctor" health fair at the St. Louis Science Center in September. The event attracted several hundred visitors. PECaD received media exposure courtesy of Clear Channel Radio when Mr. Helms spoke on local radio station 100.3 The Beat to promote PECaD's exhibit at the fair.



If you would like to receive **PECaD's newsletters (STL Connection and Updates) electronically** in the future, please **send an email to pecad@ccadmin.wustl.edu**. We will only use your email to share information about our programs and events.

PECaD Profile

One of PECaD's goals is to increase the number of minority patients who participate in clinical studies at Siteman Cancer Center. To improve the quality of cancer care for patients of all backgrounds, it is important that research studies include participants who represent our diverse community. By enrolling more racial and ethnic minorities, Siteman researchers will be better able to assess how well new diagnostic tests, screening methods and treatments work for these groups.

To help meet this goal, PECaD works with the Center's Protocol Review and Monitoring Committee. First, investigators provide target goals for minority enrollment when they submit new studies. Second, PECaD periodically reviews our researchers' enrollments to insure they reflect our patient population. Researchers receive a commendable review when their minority enrollment rates exceed 10% of their initial targets.

One investigator who recently received such a review is: Jeff Michalski, MD, MBA Professor of Radiation Oncology, Washingthon University School of Medicine.

Researchers have speculated that prostate cancer responds differently to radiation than other types of cancer. One radiation technology, 3D-CRT/IMRT, allows oncologists to shape radiation doses to match the target tumor. This method increases patients' ability to tolerate radiation therapy.

The current standard for prostate cancer radiation treatment runs for 8 to 9 weeks. **Dr. Michalski** is studying the use of 3D-CRT/IMRT to give higher daily radiation doses and shorten the course of treatment to 5 ½ weeks for certain patients. Early results using this new treatment plan at other medical centers suggest it is at least as effective as the longer treatment course without any worse side effects.

In this type of study, a so-called "Phase III" trial, patients are randomly given either the 1) current standard of care treatment for a disease or 2) the new treatment plan being researched. Neither the patients nor their doctor get to choose the treatment plan. In this case, while the shorter treatment is appealing, randomized studies are needed to determine whether there is a benefit to a new approach.

Thank you Dr. Michalski for your excellent work!

PECaD
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Bringing Research to the Community

According to research by the Cincinnati Children's Hospital, African American children may be highly susceptible to secondhand smoke exposure. Possible problems from such exposure include asthma, sudden infant death syndrome and serious coughs. Our last newsletter summarized findings from this study which found significant amounts of nicotine byproducts in African American children who live with smokers.

To help increase awareness about the dangers to children from secondhand smoke, PECaD worked with community members and the Saint Louis University Health Communications Research Laboratory to develop an "action card" to be given out at community centers and health fairs.

LaVonne Boyd, a lung cancer survivor and former nurse, and Veronica Richardson, a former lung transplant nurse and the current director of community programs at Grace Hill, worked with PECaD staff on this effort. They helped develop key messages and suggested target audiences. In addition, the group reviewed the cultural sensitivity and readability of the card. Saint Louis University Health Communications Research Laboratory then wrote and produced the action card.

Using our experience with the development and distribution of this card, PECaD will next work on similar action cards for prostate, colorectal and breast cancer. These cards will be specifically tailored to individuals who use community healthcare centers and attend fairs.

They smoke what you smoke

what's in your smoke?

Cigarette smoke is toxic.

It contains **over 4,000 chemicals**, more than 250 of them **cancer-causing.** Smoke-filled air hurts kids' health. Kids who breathe cigarette smoke have more ear infections, asthma, serious coughs, and poor lung function. **Even if you smoke cigarettes...**

don't make kids breathe your smoke.

Don't smoke around kids, in your home or in the car.

Call 1-800-QUIT-NOW for help quitting smoking.
If you are a Medicaid patient or don't have insurance, you may be able to get free nicotine patches and gum to help you **stop smoking.**

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COMMUNITY CALENDAR

October 6
Event: Empowering Health Families Community Fair
Sponsor: People's Health Centers
Location: 5701 Delmar Blvd.
St. Louis, MO 63112
Time: 9:00 am – 3:00 pm
Contact: 314-367-7848

October 13
Event: Sharing Our Stories 2 Save Our Sistahs Seminar
Sponsor: Witness Project
Location: Herbert Hoover Boys & Girls Club
2901 N. Grand Blvd.
St. Louis, MO 63107
Time: 10:00 am – 2:00 pm
Contact: 314-286-0052

October 27
Event: Partners in Survival Workshop
Sponsor: Siteman Cancer Center, Men Against Breast Cancer
Location: Center for Advanced Medicine, Farrell Conference Room 1
4921 Parkview Place
St. Louis, MO 63110
Time: 9:00 am – 11:30 am
Contact: 314-747-7222 or
800-600-3606
Registration for this event is required.

October 28 through November 19
Event: Display of HIV-Aids Memorial Quilt
Sponsor: Lane Tabernacle, Faith Communities United, & Williams & Associates
Location: 910 N. Newstead Avenue
St. Louis, MO 63108
Time: Sunday thru Friday, 10am-3pm
Contact: Del Doss-Hemsley
314-533-0534

November 4
Event: Flu Clinic
Sponsor: Lane Tabernacle Health Ministries
Location: 910 N. Newstead Avenue
St. Louis, MO 63108
Time: 1:00-2:00PM
Contact: Del Doss-Hemsley
314-533-0534

Examples of professional development classes at the George Warren Brown School of Social Work at Washington University. For complete descriptions and to register, go to http://gwbweb.wustl.edu/careerdevelopment and select "Professional Development Program".

Finding Needles in the Haystack
(3 CEUs)
Friday, October 12, 2007
8:30 a.m. - 11:30 a.m.
Sylvia Toombs, PhD, *Library Director, Brown School*

This workshop introduces databases that index evidence-based articles. Learn how to phrase and develop search strategies to find articles. There will be sufficient time for questions and answers to ensure that basic skills for finding evidence-based literature are developed.

Understanding Change: An Introduction to System Dynamics and Group Model Building (3 CEUs)
Friday, October 26, 2007
8:30 a.m. - 11:30 a.m.
Peter Hovmand, PhD, MSW, *Assistant Professor, Brown School*

This workshop introduces participants to the basic concepts of system dynamics and group model building. The approach provides a way for groups to work collaboratively to solve complex problems in organizations and communities. The resulting models can be used for problem solving, strategic planning, grant applications, and research.

Growing a Group: A Facilitation Process that Works (3 CEUs)
Friday, November 16, 2007
8:30 a.m. - 11:30 a.m.
Claire Wyneken, *Chief Program Officer, Wyman Center*

Group facilitation is a reality for many professionals – whether facilitating a committee, a staff work team, an after-school group, or an actual clinical group. From a broad perspective, this workshop examines the following: stages of group development, effective engagement of group members, group participants' learning and information processing needs, and a variety of hands-on activities that can be used to further group development.

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