

COMMUNITY ADVISERS AN INTEGRAL PART OF STUDY

Community advisers are key to the success of the third phase of the Carolina Breast Cancer Study, often referred to as the "Lucas Study." A 10-member advisory board includes breast cancer advocates, an assistant professor at NC State University, a registered nurse and representatives of the Sisters Network Triangle, the local affiliate of Sisters Network® Inc., a national African-American breast cancer survivorship organization.

Researchers are relying on the advisers to review all study protocols and materials to make sure they are culturally sensitive. Sisters Network Triangle President Valarie Worthy, RN, says her group also provides insight into "the unique challenges faced by African-American breast cancer survivors."

She commends researchers for their innovative approach of assessing newly diagnosed breast cancer survivors, and said the Lucas Study would help identify potential risk factors and/or barriers that women face as they battle cancer. She also says that early detection is key.

"The mortality rate is much higher for African-American women diagnosed with breast cancer partly due to diagnosis

at a later stage, younger age, and presenting with aggressive tumors," she says. "Sisters Network Triangle's message is that breast cancer does not have to be a death sentence. We are living proof that one can survive and thrive after breast cancer."

The study's principal investigator, Robert Millikan, DVM, PhD, credits the advocates with "helping us improve response rates" by revising outreach materials and developing informed consent for patients. They also helped develop the Web site (<http://cbcs.med.unc.edu>) and created a statewide, comprehensive resource directory – funded in part by the UNC Lineberger Comprehensive Cancer Center – for women who need information about breast cancer diagnosis, treatment and support in North Carolina.

"Both the study Web site and the resource directory demonstrate the important role that advocates can play in making epidemiologic research more responsive to the needs of the communities in which research studies are carried out," Millikan says. "Advocates have been with us at every step of the way." ■