

Patient Advocate Corner

The Sisters Network: A National African American Breast Cancer Survivor Advocacy Organization

By Lisa A. Newman, MD, MPH, and Karen E. Jackson

Two of our most powerful weapons in the battle against breast cancer mortality are screening programs for early detection and clinical trials for the development of improved treatments. Optimal utilization of both strategies mandates that we work closely with survivor advocacy organizations. Survivor advocates are powerful and trusted members of the oncology patient population, and this is particularly true in the field of breast cancer. They serve as ambassadors to promote mammographic surveillance in the workplace, in churches, and through print and broadcast media. Survivor advocates have been essential partners in breast cancer research fundraising efforts. They have provided guidance to investigators by ensuring that issues of survivorship and quality of life are appropriately prioritized. They have also become active in the legislative arena as their influential voices can be heard on Capitol Hill calling for the protection of and an increase in government funds for research.

The oncology community is therefore extremely fortunate to partner with the power and strength of the Sisters Network, the only national African American breast cancer survivor advocacy organization. The mission of the Sisters Network is based on a commitment to increasing local and national attention to the devastating impact that breast cancer has in the African American community. The Sisters Network was founded by Karen E. Jackson in October 1994. Jackson is an African American woman who was diagnosed with breast cancer only a few months earlier. Her experiences and observations while undergoing treatment for breast cancer motivated Jackson to create an advocacy organization dedicated to addressing the unique needs of African American women. The scope of these needs is broad, ranging from increasing the availability of hairpieces and mastectomy prostheses compatible with African American appearance to increasing breast health awareness and treatment opportunities among the general African American community. Jackson's efforts began with a meeting of 15 women in 1994. Today, the Sisters Network has evolved into a national organization of nearly 3,000 members in 43 cities throughout the United States.

"Stop the Silence" is the national slogan for the Sisters Network. This is quite appropriate, because it acknowledges the historical inclination of many African Americans to mistrust and avoid the medical establishment, coupled with the socioeconomic disadvantages that promote neglect of

health care needs. Because of this neglect, even though lifetime incidence rates of breast cancer in African American women are lower than those in white women, the mortality rates are paradoxically higher. But with regional as well as national outreach programs, the Sisters Network members invest their personal resources and energies into their commitment to improving early breast cancer detection among African American women. They also devote substantial efforts to encouraging investigators and funding agencies to strengthen the research agenda directed at evaluating breast cancer in African American women.

The Sisters Network membership enthusiastically counsels new members and newly diagnosed patients with breast cancer to empower them with all of the prevention, early-detection, and multidisciplinary treatment options that are available, including participation in clinical trials. The



Karen E. Jackson (left), founder of the Sisters Network, and Lisa A. Newman, MD, MPH, at the organization's annual conference in 2008.

organization has actively participated in a variety of multicenter research programs related to breast cancer pathogenesis and survivorship. Members of the Sisters Network serve on advisory boards for Susan G. Komen for the Cure, the National Cancer Institute, and the American Cancer Society.

One of the many highlights of the Sisters Network activities is the annual Gift of Life Block Walk, in which members walk door to door in neighborhoods composed predominantly of African American residents and inform women in these communities about breast cancer surveillance. The various Sisters Network chapters also conduct health fairs, mammography screening programs, and church-based breast health awareness programs. Other services focus on support for the individual. For example, newly diagnosed African American women can receive personalized assistance in navigating the health care system, and women seeking baseline breast evaluation can be referred to either public mammography screening programs or major cancer centers, depending on their needs.

The Sisters Network recently celebrated the 10th year of its annual conference series. This national program is another high-profile aspect of the organization's efforts to educate the public and draw widespread attention to the issue of breast cancer and its impact on African American women. This 3-day conference is continuing medical education accredited and features presentations and panel discussions by renowned

breast cancer experts. The audience includes several hundred breast cancer survivors and advocates, legislators, health care professionals, and leaders of community-based professional organizations. These meetings have presented wonderful opportunities for the Sisters Network membership to partner with public officials and local communities. The annual conference—as well as other Sisters Network activities—has been covered by many media outlets, including CNN, Lifetime TV, TNT, and *Essence* magazine.

For additional information regarding the Sisters Network, please visit www.sistersnetworkinc.org; contact the organization at 2922 Rosedale St, Houston, TX 77004; call 713-781-0255 or 866-781-1808 (713-780-8998 fax); or e-mail infonet@sistersnetworkinc.org.

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