

Patient Advocate Corner

Preparing for a Seat at the Research Table: The National Breast Cancer Coalition Fund's Project LEAD



Fran Visco

By Fran Visco

An economist who chairs the Integration Panel of the Department of Defense (DOD) Breast Cancer Research Program. A retired Air Force Lieutenant Colonel with metastatic breast cancer who serves as a California Breast Cancer Research Program reviewer. A founder of a state breast cancer coalition who coordinates doctor/patient

communications for Brown University oncology residents. A homemaker who created and coordinates a program for newly diagnosed African American breast cancer patients.

What do these four women have in common? They are all breast cancer survivors. And they are all prepared to help shape breast cancer research policy. How? They are graduates of the National Breast Cancer Coalition Fund's premier science training program, Project LEAD.

In 1991, determined to challenge the apathy surrounding breast cancer, breast cancer survivors created the National Breast Cancer Coalition Fund (NBCCF) with its mission to eradicate breast cancer through action and advocacy. Since then, NBCCF has forged strategic collaborations with the scientific community, improved access to care for low-income and uninsured women, and expanded the influence of trained consumer advocates at every level at which decisions about breast cancer are made. At the same time, NBCCF's lobbying arm, NBCC, made breast cancer a political priority and obtained increased federal funding for research.

Nonetheless, money alone will not end this epidemic. Advocates must make their voices heard whenever breast cancer policies are being formed and wherever decisions about research funding are made. Project LEAD was born to provide a solid knowledge base to these advocates' voices.

Launched in June 1995, Project LEAD's intense 5-day training has provided a foundation of scientific knowledge for more than 1,100 breast cancer activists, including 80 international graduates. It teaches the language and concepts

of science so they can speak up, ask critical questions and find common ground within the scientific community. For example, LEAD graduates participate at all levels of decision making in the DOD program—a model of accountable, transparent, and innovation-driven research.

Renowned scientists from leading academic and public research institutions teach the LEAD course and helped develop its curriculum, which includes clinical medicine, microbiology, genetics and proteomics, epidemiology, research design, and leadership development skills. Graduates stay current through Web-based continuing education called LEADgrads Online.

LEAD students are selected through a competitive application process based on their personal connection to breast cancer, commitment to breast cancer activism and motivation to learn scientific concepts. Some scholarships are available. Please visit NBCCF's Web site at www.stopbreastcancer.org or call 800-622-2838 if you know someone who could be a candidate for Project LEAD or if you would like a LEAD graduate to participate in one of your programs, serve on an institutional review board or join a research review committee.

Fran Visco is the first president of the NBCC, and a member of its Board of Directors and Executive Committee. Formed in May 1991, NBCC is a grassroots advocacy organization of hundreds of member organizations and tens of thousands of individual members.

