

Ensuring the Participation of Educated Patient Advocates in Science Research and all Levels of Health Care Decision Making

Background

The voice of educated patient advocates must be part of all levels of health care decision making which affects their lives. This has been a tenet of the National Breast Cancer Coalition (NBCC) since its inception. NBCC continues to work to ensure that educated patient advocates who represent a constituency, have a meaningful “seat at the table” in all levels of health care decision making which affects their lives.

Why Patient Advocates are Necessary

Educated patient advocates provide a unique perspective which cannot be contributed by others. They are the ones who ultimately receive health care services and along with their families, are required to engage and navigate the complexities of the health insurance system. They have no agenda in the scientific community other than looking for the best science; they have no conflict of interest. Their perspective cannot be duplicated by the doctors who care for them or the scientists who search for answers, even if these doctors and scientists too are patients. A lay advocate perspective is key to moving forward to the end of breast cancer.

What Criteria Must Patient Advocates Meet

In order to bring the true patient advocate perspective, patient advocates must meet the following criteria:

- (1) Have a patient-led, patient-centered organization with a patient constituency to which they are responsible and accountable;
- (2) Have been personally affected by disease; and
- (2) Be knowledgeable, trained, prepared and confident in their ability to participate in the decision making process of science and medicine.

True patient advocates have an integral role to play in ensuring that the health care system is responsive to the needs of the medical and scientific communities, as well as the patient. Just as scientists, academics, economists and other participants must meet certain criteria in order to qualify for designated positions on health care boards, panels, advisory committees or commissions, it is equally important for patient advocates to meet a set of minimum requirements.

Action Requested

NBCC asks Senators and Representatives to ensure that educated patient advocates have a “seat at the table” on boards, panels and advisory committees and that those appointed to fill these important roles meet the minimum requirements listed above.