

Introduction

This entire issue of *Breast Disease* is devoted to the subject of breast cancer advocacy. In it you will read about science, power, politics, legislation, egos, careers, publicity, and of course money. But, to truly understand breast cancer advocacy you need to put a face on it. It is really about people — people with cancer, their families, friends, and caretakers. For this reason I would like to dedicate this issue of *Breast Disease* to two remarkable women who are each in their own way tireless breast cancer advocates: Pat Barr and Eleanor Nealon. While once again fighting their cancers, they continue to inspire the rest of us to work even harder to eliminate this horrible disease.

As surely as scientific advances have changed how breast cancer is detected, treated, potentially prevented, and certainly studied, breast cancer advocacy has changed how we think about the role of the breast cancer patient in the entire cancer research process. Once thought of as a passive participant in the treatment process, the breast cancer patient, or consumer as we are now called, has evolved into an important and influential partner. As is true in most partnerships, the relationship between the advocacy and scientific communities has sometimes been one of excitement and success but at times has also seen the frustration of fundamental disagreement. While breast cancer advocacy has been a movement that has substantively changed the medical research process, even now it is frequently misunderstood. This edition of *Breast Disease* is not so much an attempt at “setting the record straight” as it is an opportunity for many of the key players and observers in this transition to tell their own stories.

This collection of articles represents the viewpoints of the two largest breast cancer advocacy organizations, the leadership of the National Cancer Institute, the first Director of the DOD Breast Cancer Research Program, a basic scientist/researcher, two breast cancer clinician/researchers, and two members of the pharmaceutical/biotechnology industries. While each writer has his/her own unique experience and perspective, collectively they tell the story of how breast cancer advocacy has evolved to what it is today.

As someone who has been involved in breast cancer advocacy almost from the beginning, I found the different perspectives revealing. While opinions vary on why advocacy is the way it is today and where it is likely to go next, there does seem to be a consensus that some parts of the breast cancer advocacy movement have become mainstream. From the very beginning, the advocacy community realized if they were to have any real input into the decision making processes related to breast cancer, they would have to be viewed as legitimate and respected members of the decision making processes. For that reason, the advocacy community is always demanding a “seat at the table.” In the eyes of many, breast cancer now has a seat at the table. Breast cancer advocates are on many, if not all, of the most powerful decision making boards and committees: the NCI’s National Cancer Advisory Board, the President’s Cancer Panel, the NCI’s Board of Scientific Advisors, most study sections, the DOD Breast Cancer Research Programs’ Integration Panel, and many Pharmaceutical boards and oversight committees to name a few. The full participation of advocates in the research process has become commonplace.

So where is breast cancer advocacy likely to go next? Over the past few years, more and more agenda-specific breast cancer groups have begun to spring up (e.g. bone marrow transplant groups, breast cancer & the environment groups, etc.). Although these groups usually participate in broader, national breast cancer events, each has a specific agenda and seeks individual recognition. From the general public's viewpoint, many of the breast cancer advocacy groups can appear to have similar messages; yet, in direct mail and telemarketing efforts, the public is being asked to join and give money to seemingly many different breast cancer groups. This proliferation of breast cancer groups, combined with the recent addition of other disease specific cancer groups (e.g. National Prostate Cancer Coalition, Ovarian Cancer Alliance, etc.), has become confusing. It will be interesting to see in the coming years if the advocacy groups will begin to reverse the existing trend of splintering into more and more groups and actually start to combine their resources and coalesce back into fewer organizations. From my perspective, this would be the most rational approach. Is the market for breast cancer advocacy really any different than other markets that can only tolerate a finite number of competitors in existence at any one time? Will the major advocacy groups continue with different agendas or will they begin to converge? When the plethora of cancer advocacy groups disagrees, whom will we listen to? Who will we support financially? What groups will survive and what will their agendas be?

Where do the advocates and researchers go next? Do the breast cancer advocates and the research community work toward developing new, more collaborative working relationships? Do they find new ways to work together to improve the research process or do they struggle over who is in control and who decides on the priorities? Now that they have a seat at the table, will the advocates begin to think just like the researchers? Can we only get the rich diversity of thought and ideas when the relationship is adversarial as some have suggested, or can we truly be partners in the research process?

These are just a few of the challenges facing the advocacy and research communities as we look toward the new millennium. One wonders as the breast cancer advocacy movement grows and matures, does it have a life span? If so, what will replace it? No matter what comes next, there is no doubt that the meaningful inclusion of people with cancer in the process of prioritizing resources and setting the cancer research agenda is forever changed. There is no going back.

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