



May 28, 2010

Dear Survey Participant,

In December, I sent a letter asking for your help with a survey I was conducting about breast cancer organizations in the United States. I wanted to learn more about the kinds of activities organizations like yours were engaged in and services you provide.

The results of the survey show that breast cancer organizations do a lot, and I appreciate the time you took to complete the survey. With your assistance, we were able to put together the attached report on the state of breast cancer organizing in the United States. I hope you find it informative and useful.

If you have any questions, feel free to contact me at 617-496-6075 (direct) or by e-mail (pstrach@rwj.harvard.edu).

Again, thank you for your help.

Sincerely,

A handwritten signature in black ink, appearing to read 'Patricia Strach'. The signature is fluid and cursive, with a long horizontal stroke at the end.

Patricia Strach
Robert Wood Johnson Scholars in Health Policy Research
Harvard University
1730 Cambridge Street, S412
Cambridge, MA 02138

Patricia Strach, RWJ Scholar in Health Policy Research

1730 Cambridge Street, 412
Cambridge, MA 02138
pstrach@rwj.harvard.edu

Breast Cancer Organizing in the United States

*An executive report for participants in the 2009-
2010 Breast Cancer Organization Survey*

Overview

Even though there are hundreds of breast cancer organizations across the United States, researchers and even other organizations do not have an overall picture of exactly what these groups do. For example: How many provide support? How many fund research? We fielded a survey in 2009-2010 to learn more about the landscape of breast cancer organizing. After contacting nearly four hundred organizations, we were pleased that 175 took the time to complete the survey. This report provides a summary of our findings.

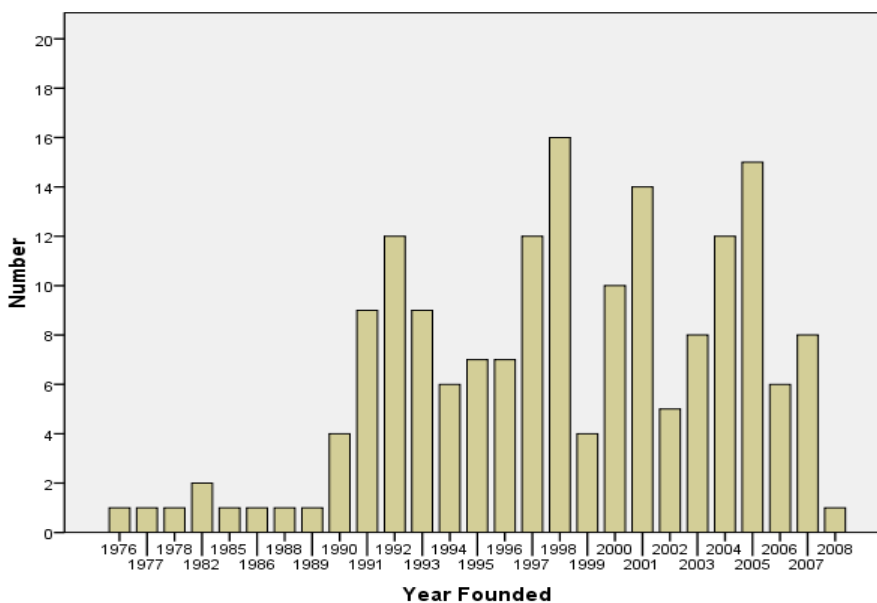
About the Organizations

Location

Breast cancer organizations are headquartered (not including chapters) in 43 states and Puerto Rico. California (54) and New York (47) have the most organizations.

Founded

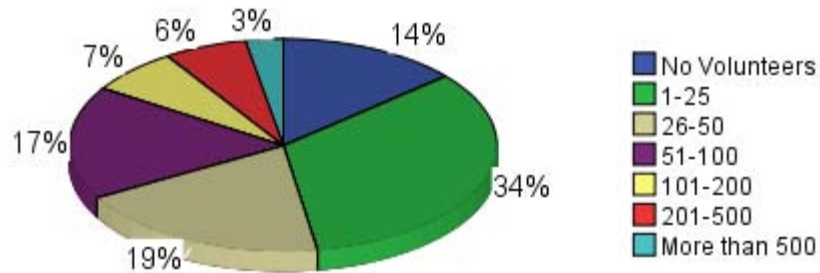
The vast majority of breast cancer organizations (93%) were founded after 1990, compared to a dozen that were formed in the 1970s and 1980s.



Volunteers and Staff

Breast cancer organizations vary in size. Most organizations (59%) have no staff and when they do, it is usually 1 person. However, the largest organizations in this sample have between 48 and 200 full-time employees. About one-third of organizations in this sample reported having individual or organizational members. The number of individual members ranged from 5 to 30,000, the average was about 145. The number of organizational members ranged from 1 to 112, the average was about 9.

Regardless of staff size and membership, breast cancer organizations rely on the hard work of their volunteers and board members. Though some groups have no volunteers, the majority of groups have between 1 and 50.



Almost all of the organizations have a board of directors (90%). Boards are most commonly comprised of breast cancer survivors (or their friends and family), business leaders, and doctors/medical experts. The table below shows the breakdown of the people who are active on these boards.

Board Members	Percent
Breast cancer survivors	89%
Business leaders	64%
Doctors/ Medical Experts	62%
Activists	52%
Community organizers	49%
Academics	48%
Attorneys	39%
Political leaders	16%
Celebrities	12%

Partnerships

The majority of breast cancer organizations partner with other breast cancer groups (80%). High level of partnering was also reported with other general health organizations (76%), women's organizations (71%), and cancer organizations (65%). Clearly cooperation with other groups is important.

Mission, Challenges, and Solutions

Type of Organization

Breast cancer organizations get involved in a number of activities across a range of arenas. Reflecting the complexity of what they do, organizations both described themselves and actively participated in a wide-range of activities (see section below for more on activities). When groups were asked how they would characterize their organization, on average they chose three of the following five descriptions: education, support, advocacy, service provider, foundation, or professional association. They most often described themselves as education or support organizations and least often as foundations or professional associations.

Type of Organizations	Percent
Education	75%
Support	75%
Advocacy	53%
Service providers	44%
Foundation	25%
Professional association	6%

Mission

Each of the groups that filled out the survey had a unique mission. However, when we grouped mission statements by theme, we found that groups most commonly described their mission as education and raising awareness (53%) followed by providing medical and other forms of support (50%), funding general research and services (31%), advocacy (17%) and promoting research (17%).

Most Important Challenge and Solution

Groups described the most important challenge facing breast cancer as empowering patients and they most often said that government agencies and charitable organizations were important in addressing the challenges (however defined) they were facing.

Most Important Challenge	Percent	Actors to Meet Challenges	Percent
Empowering patients	43%	Government agencies	37%
Providing access to medical and other treatment	30%	Charitable organizations	31%
Advancing research	21%	Non-governmental actors	31%
Getting general funding	14%	Breast cancer patients and families	28%
Outreach	7%	Private corporations	18%
Competing with other organizations	4%	Mass media	18%
Fighting the political battle	3%	Elected government officials	14%

Activities and Fundraising

Activities

Breast cancer groups reported getting involved in a range of activities in the past year. Groups report far more involvement in education, research, and support than public affairs or medical concerns. At least three-quarters of the groups report speaking engagements to the general community, press releases and mass media appearances, reading current research, running support groups and providing online resources. Less than one-third of the organizations, however, were involved in reviewing research, funding research, encouraging individuals to vote, providing medical information, or holding marches/protests.

The table below summarizes the results for the general categories education, public affairs, research, medical, support (shaded in gray) as well as individual activities within these categories.

Breast Cancer Activities	Percentage of Groups
Education/Awareness Total	98%
Speaking engagements to general community	86%
Press releases and mass media appearances	83%
Online resources	77%
Workshops and outreach to Survivors	58%
Research Total	90%
Read, participate in current research	81%
Disseminate research	70%
Meet with medical researchers	47%
Review research	29%
Fund research, research-related activities	28%
Support Total	87%
Support groups (meetings, online)	79%
Support services	65%
Public Affairs Total	73%
Contact agency heads	54%
Contact legislators	52%
Encourage individuals to contact legislators	49%
Encourage individuals to contact agencies	43%
Encourage individuals to vote	25%
Hold march, protest, demonstration	6%
Medical Total	59%
Provide medical service or funding for medical services	46%
Provide general services or medical information	21%

Fundraising

Breast cancer organizations raise money from a number of sources, most commonly individual donations (87%), corporate donations (84%), and annual appeals (57%). The least common sources of fundraising were investments (26%) and government sources (20%).

Cause-Marketing

Of particular interest to the media has been the role of cause-marketing for breast cancer. Organizations believe that as a result of cause-marketing, Americans, local communities, media, and business (but not government) raise their level of attention to the disease. Organizations that engage in cause-marketing get more recognition and more resources than organizations that do not.

Conclusion

Breast cancer organizations in the United States vary in terms of size, resources, and activities. In other words, on the ground these groups may look very different from one another. For example, one organization runs a store where the proceeds go to breast cancer research while another organization puts on sporting events to provide services in the local community. But for all the differences on the ground, there are similarities between the groups. As a whole, groups report their main goals are to raise awareness and to promote research for better detection and ultimately a cure. They seek their goals often without paid staff or formal members, and they rely on active and engaged volunteers and board members.