
Patient Activism: Cancer Groups Become Vocal and Politically Active

Political and social forces are shaping a new breed of cancer activist.

Groups that earned their reputations for passive, measured, and cooperative approaches are taking a cue from more aggressive special interest groups and evolving into vocal and politically astute constituencies. How influential they become remains to be seen.

Where a decade ago fewer than a half dozen organizations composed of cancer patients and their families existed to provide emotional support and lobby for funding, today there are more than 15 national groups.

Aggressive Tactics

Their demands are strikingly similar to those of the activist groups that have rallied behind AIDS patients. They want increased research funds, expedited drug approvals, expanded access to experimental treatments, and protection from insurance and employment discrimination.

Their tactics for achieving those goals are also similar.

- In 1990, for example, some activists planned to draw together cancer patients, their families, and members of the research community for a march and rally on the steps of the U.S. Capitol, hoping to draw media attention to their demands by having participants lie on the steps of the building. The plan was ultimately aborted.

- On Mother's Day, a coalition of three San Francisco-area breast cancer groups plan to march on the state

capitol in Sacramento to demand that lawmakers focus their attention on support for breast cancer research and related social initiatives.

- A "summit" was held last month in New York City drawing together women representing breast cancer groups and feminist organizations.

Coalition Building

This summit, the third meeting of its kind, was held to lay the groundwork for building a "cancer advocacy coalition" replete with a Washington, D.C., office equipped to organize marches and demonstrations, issue nationwide "calls to action" involving media and political lobbying, and create a network



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that can "get the word out fast" when funding and legislative issues arise.

"We've seen these tactics work for other people. We've seen that AIDS activists are getting things done. Now, cancer patients are becoming aggressive consumers and demanding to be part of the decision-making process," said Sharon Green, executive director of "Y-ME," the Homewood, Ill.-based National Organization for Breast Cancer Information and Support.

"There is no question that there is going to be a more extreme form of advocacy; the question is what form and to what extent it will take. These events are no longer designed solely to raise funds; we are out there to make a strong public statement," Green added.

Growing frustration with the pace, nature, and extent of federal support for research is prompting relatives, friends, and in many cases, cancer patients themselves to build large national organizations out of what often begins as living room meetings between a handful of like-minded individuals.

Shocked

Such was the case with Gertrude Swerdlow and Irving Swerdlow, Ph.D., both retired economics professors who, after losing their son Paul to adult undifferentiated leukemia, were shocked that cancer research was being allocated only a fraction of 1% of the federal budget.

Five months after forming a local cancer support group, Gertrude Swerdlow made a trip to Capitol Hill to secure support from a leading member of Congress — who had been instrumental in garnering federal support for AIDS research — to help build a nationwide network.

She left the lawmaker's office with "no money, just moral support and advice to come back when we could muster a list of 10,000 members."