

Today, 5 years later, Swerdlow has done better than that: her DeWitt, N.Y.-based non-profit Families Against Cancer Terror, Inc., publishes a regular newsletter; has been featured on network television and in syndicated newspaper columns, and claims more than 100,000 members.

"Cancer has always been a skeleton in the closet, but we who know and understand cancer have a responsibility to educate our elected officials and make them more responsive to our needs. Unless we demand it, it's not going to happen," Swerdlow said.

"I can call out hundreds of volunteers at any one time who are ready to bring about a new and reinvigorated national cancer policy," Swerdlow added.

FDA Targeted

For Beverly Zakarian, founder of the Brooklyn, N.Y.-based Cancer Patients Action Alliance, the target is the Food and Drug Administration, which controls both approval of and access to new drugs and therapies.

"Cancer patients are members of a special interest group by definition, and of an advocacy group out of necessity. AIDS patient groups were the first to bring life-threatening diseases out of the closet. Cancer patients comprise a very large and influential group, and we, too, are learning to act like one," Zakarian said.

Likewise, National Kidney Cancer Association President Eugene Schoenfeld, Ph.D., — who is himself battling kidney cancer — pointed out that recent advances in cancer prevention and treatment are fueling rising expectations from cancer patients and their families who are now more likely to "demand" that their physicians help them "survive cancer, cure it, or live with it for a much longer time."

"The children of the 1960s are now older and are entering the cancer

patient population. These same people who protested the Vietnam war are now getting cancer and they are much more likely to challenge the status quo of both cancer care and cancer politics," Schoenfeld asserted.

Founded by families in 1970, the Washington, D.C.-based Candlelighters Childhood Cancer Foundation initially functioned as a "self-help" group lobbying federal lawmakers for increased childhood cancer research funding.

Today, with more than 400 chapters and 33,000 members nationwide, the group is often called on to provide congressional testimony and has been active in the Family and Medical Leave Act and legislation dealing with insurance discrimination. It is also in the process of forming a "long-term cancer survivor" network.

"We realized that we could only make a tremendous difference if we gathered together and were more vocal," said Candlelighters Executive Director Julie Sullivan. "Those who yell loud and long have set the example for many cancer groups to get out there and say we want our share too," Sullivan added.

Even the American Cancer Society — the nation's oldest and best established non-profit cancer group — sees the changing course of cancer activism as "a healthy thing."

Requires Vigor

"We'd all like to see more money going into cancer research and there are a variety of approaches serving to attract attention to the issue. Our job as proponents of this cause requires us to be as vigorous and forthright as we can be," said Alan Davis, ACS vice president for public affairs.

"This change in tactics and strategy is a good thing and a very important development," said Fitzhugh



Julie Sullivan

Mullan, M.D., president of the National Coalition for Cancer Survivorship. "The key issue is consumerism in healthcare."

But will so many fragmented groups focusing their efforts on specific cancers or specific cancer issues be less effective than a unified front with a consensus on both agenda and strategy? The answer may lie with veteran AIDS activists who continue to test the limits of "disease advocacy."

Coalitions Are the Key

"Coalitions are the key, and it's important to be consistent with tactics," said New York City playwright and AIDS activist Larry Kramer, who founded the AIDS Coalition to Unleash Power (ACT-UP).

"Whether it's one person or a thousand, any pressure is useful. You should never worry about diluting the message because often one person can accomplish what a thousand can't," Kramer said.

— By Lou Fintor