

become an advocate:

HOW TO MAKE CHANGE HAPPEN

BY KRISTINE COLLINS

Breast cancer—a disease once kept hidden by women afraid to expose their private battles—has a strong voice thanks to people unwilling to accept the status quo. People like Joy Simha, breast cancer survivor and Co-Founder/Co-Chair of the **Young Survival Coalition**, who didn't have time to wait.

Diagnosed in 1994 at age 26, Simha realized breast cancer resources for young women were largely nonexistent. Empowered by this sad fact, she took action. And YSC—a nonprofit organization that educates the medical, research, and legislative communities on breast cancer in women 40 and younger—is the only network dedicated to the issues and concerns of young survivors.

If you think breast cancer advocacy is up your alley, there are many opportunities—large and small. To get started, simply let your interests guide the way.

WHAT WORKS FOR YOU?

Begin by asking yourself how advocacy matches your personality. Do you like fund-raising? Education? Are you interested in preventing breast cancer or in the research end of things? How about writing letters to political representatives or distributing educational material? Could you organize a community meeting or participate in a public demonstration? Any of these efforts can make an imprint on the future of breast cancer.

To Simha, who also serves on the YSC Advocacy and Research Committee, advocacy means seeking answers to tough questions, understanding complex issues, and choosing battles carefully. Right now, she is concerned about access to quality health care and is working to solve the problem with the **National Breast Cancer Coalition**, the nation's largest breast cancer advocacy group.

"Advocates should want to make the greatest change happen," she says. "I don't call my congressman for every piece of legislation concerning breast cancer. I pick and choose the ones that I believe will make the greatest impact and fight for those issues."

LEARN ALL YOU CAN

Simha's advice for advocates-to-be is this: jump in with both feet and gather information on the various levels of advocacy. She recommends attending a four-day conference—called **Project LEAD**—offered by the NBCC. Designed to train activists about the scientific and political issues that surround breast cancer, there is no substitute for this life-altering experience, Simha says.

She also suggests picking up *Breast Cancer Wars: Hope, Fear, and the Pursuit of a Cure in Twentieth-Century America* by Barron H. Lerner (Cahners Business Information, Inc., 2001), a book Simha says is a must-read for any patient or breast cancer advocate who feels called.

If a four-day commitment doesn't fit on your calendar, consider joining a local or national advocacy organization. Volunteer your time at a local hospital, cancer center or university. Or spearhead your own initiative. It might just make a world of difference.

Becoming an advocate is something that can be fulfilling and meaningful. Let your knowledge build and slowly reveal your strengths. Go in the direction that best suits your interests, talents, and lifestyle. Know that no matter the size of your contribution, your commitment will be appreciated and met with open arms from the advocacy community.

And remember the words of Robert F. Kennedy, who said: "Few will have the greatness to bend history itself; but each of us can work to change a small portion of events, and in the total of all those acts will be written the history of this generation."

GET INVOLVED

- Call your local **Susan G. Komen for the Cure** office (www.komen.org). They have several initiatives that depend on grassroots advocacy.
- The **Y-Me National Breast Cancer Organization** monitors federal breast cancer legislation and works with patient advocacy groups to affect breast cancer policy as it develops. Y-ME also publishes recent and pending federal legislative activity in its national newsletter, *Lifeline*, available in e-mail format.
- The **American Cancer Society Cancer Action Network** (www.acscan.org) is the nonprofit, nonpartisan sister advocacy organization of the American Cancer Society. Dedicated to eliminating cancer as a major public health problem, this group offers tried-and-true steps for spreading critical messages—such as meeting face-to-face with lawmakers, writing letters to newspaper editors, and calling talk shows.
- Volunteer for the **Young Survival Coalition**. To learn more, visit www.youngsurvival.org.