

CONNECTIONS

Hard-Won Lessons

BY LACEY MEYER

Ovarian cancer survivors teach medical students how to spot the disease early.

Diagnosed with stage 3C ovarian cancer in January 2002, Diane O'Connor felt she had lost control of her body and her life. Then she found a way to give back, by helping to educate medical students about what knocked her down.

Through the Ovarian Cancer National Alliance program, “Survivors Teaching Students: Saving Women’s Lives” (STS), ovarian cancer survivors explain to the third-year students the importance of understanding ovarian cancer symptoms for early diagnosis.

“It’s a very empowering concept and feeling,” O’Connor says of the one-hour presentation to future physicians. “I’ve been doing this for three years, and each time I walk out of the boardroom where we speak, I’m excited; I want to skip down the hall.”

Director Betty Reiser, a 35-year ovarian cancer survivor, founded the STS program in New York City in 2002; today it’s presented in 46 medical schools across the U.S. and was recently expanded to Canada.

“What we are trying to do first and foremost is to reinforce the fact that symptoms exist and describe what they are. Every woman in the program has had either some or all of these symptoms that have been missed by doctors,” Reiser says. Students are looking at and listening to these women talk about their experiences—women who could be their mothers, their sisters, their wives, their cousins, or their aunts, she says.

The Silent Killer

Ovarian cancer, the fifth-leading cause of cancer death in women, has a five-year survival rate of 93 percent if detected at an early stage. Unfortunately, only 19 percent of these cancers are detected at that point, and the five-year survival rate drops to 30 percent for stages 3 and 4, when the cancer has spread beyond the ovaries.

Although survivors in the program have been talking and teaching about ovarian cancer symptoms for the past five years, national experts remained hesitant to take a stand—research was needed to verify that these symptoms were predictive of ovarian cancer.

But in June, the American Cancer Society, the Gynecologic Cancer Foundation, and the Society of Gynecologic Oncologists, having compiled conclusive research and studies over the past decade, released a consensus statement declaring a set of symptoms as possible early signs of ovarian cancer: bloating, pelvic or abdominal pain, difficulty eating or feeling full quickly, and urinary urgency or frequency.

Sherry Salway Black, executive director of the Ovarian Cancer National Alliance, says survivors in the program present the symptoms as stories based on their own experiences, not on research.

“The consensus puts strength behind the program now with evidence from research supporting what these women have been describing from their personal experiences,” says Salway Black, a five-year survivor of ovarian and endometrial cancer, both diagnosed in stage 1.

Considering Symptoms Fully

The program emphasizes that it’s important when women have these symptoms that doctors don’t just consider gastrointestinal problems, chronic fatigue syndrome or post-menopause issues, but also consider ovarian cancer as a possible cause. “In most cases it won’t be, but if they are alert to it, and they follow up, they will pick it up early,” Reiser says.

A study published in January in the journal *Cancer* helped provide conclusive evidence that early symptoms of ovarian cancer do exist, paving the way for the recent consensus. Lead researcher Barbara Goff, MD, says the symptoms are common to other illnesses, but the combination of these symptoms, with increasing severity and frequency, is more likely to occur in women with ovarian cancer than in the general population of women.

Goff, a gynecologic oncologist at the University of Washington School of Medicine, says it is vital to educate women and the medical community about these symptoms since no accurate screening test for ovarian cancer exists. “What we should do is pay attention to symptoms and then initiate diagnostic testing should somebody have those symptoms,” she says. “Ovarian cancer has historically been the silent killer, and when most physicians went through medical school, that’s what they learned—that ovarian cancer has no symptoms—which is why the program of survivors teaching medical students is a very important one.”

The majority of the women in the STS program had many or all of the early symptoms, but in most cases their cancer was diagnosed in stage 3 or 4, according to program director Reiser. O’Connor says her late diagnosis drives her commitment to pass on the signs and symptoms of ovarian cancer to medical and nursing students through the program.

Life Interrupted

Two and a half years ago O’Connor, a Vancouver, Wash., resident and member of the OCNA board of directors, started a local branch of the alliance, the Ovarian

Cancer Alliance of Oregon and Southwest Washington, with her friend and fellow ovarian cancer survivor, Diane Elizondo. O'Connor has been in public education for 30 years and describes the STS program as the most empowering thing she does in the area of ovarian cancer.

One time, she says, she presented the program with a woman who had the symptoms and whose ovarian cancer had been diagnosed in stage 1. "It was wonderful for the students to see in real life and hear not only my story in stage 3, but a woman who was diagnosed in stage 1," O'Connor says.



Volunteer ovarian cancer survivors meet with medical students at The State University of New York Health Science Center at Brooklyn to talk about symptoms of ovarian cancer. Photo by Lorraine Bajada.

The program also emphasizes important issues in doctor-patient relationships — how a doctor gives a patient bad news and hope, something students consistently ask about during the interactive dialogue at the end of the presentation. "They feel that the program is a very important adjunct to their education because it puts a face and a voice to the disease," O'Connor says. "They may not remember our names, but they will remember our stories, and they tell us that time after time."

At the conclusion of the presentation, students fill out evaluation forms. In the anonymous evaluations, students say that lectures and lessons in books and slides do not create the impact achieved by these women—they humanize the disease.

"The women who volunteer to do this, and this is volunteerism at its highest, really get so much from it because they realize that they are working for change for women will who come after them," Reiser adds. "This is a program that can be done for any disease. We chose to do it because of the urgency for early detection. The statistics are devastating for ovarian cancer. The program is an important step toward trying to change those statistics.

"The women are the essence of the program, and they are truly amazing."

For more information about the Survivors Teaching Students program and the Ovarian Cancer National Alliance, visit www.ovariancancer.org. To read the consensus statement, go to the American Cancer Society website, www.cancer.org, and search for "ovarian symptoms consensus."