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# The Oncology Nurse-*APN/PA*<sup>®</sup>

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***Breast Cancer Awareness Month***

## From Survivor to Teacher

By Cindy Silver

After a long series of treatments for stage IV ovarian cancer, I finished my last chemotherapy session in March 2010. About 2 months later, I realized I missed the camaraderie and friendships I had developed during the hours of waiting for the chemotherapy to be administered. I looked for a support group and soon joined the Scripps GYN Support Group that meets twice monthly. By that point, I had started sharing the story of my journey with ovarian cancer, finding that others were helped when they heard it.

Like so many others, my journey started with a doctor completely ignoring my symptoms and ended with me being treated professionally by a gynecologic oncology team. In telling my story, I found myself becoming more passionate about sharing that part of my journey, because I didn't want other women to go through what I went through, especially the part where my primary care doctor ignored and patronized my symptoms, even though I sensed something was very wrong.

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**"That was an excellent educational presentation. We are very thankful of your time and commitment to bring awareness of the existence of such a silent killer. It should not take a celebrity to make that stride. You all did it in such a very classy, heart-warming, and passionate fashion."**

—Lourdes Deperio, MSN, RN, Adjunct Nursing Instructor, Azusa Pacific University

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At the support group, I realized that most women who shared their stories had encountered a similar journey. I just couldn't imagine how to get that message where it would really matter.

In the support group, I learned about a group of survivors who talked to medical students about their experiences. I was fascinated immediately and excited about the idea, as medical students would be the future doctors who cared for women like me. One member of

Survivors Teaching Students (STS): Saving Women's Lives informed me that she not only shared her story with medical students but also spoke at CME Grand Rounds, where her story was shared with practicing medical doctors in major hospitals. I couldn't wait to make contact to see if I could be a part of the group. I thought this might be the perfect situation to get my message to future doctors.

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**"I didn't have very much background knowledge, which this presentation certainly provided."**

—Second-Year Nursing Student, Azusa Pacific University's School of Nursing

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In early September, I exchanged e-mails with the group's leader, Peg Ford, expressing my interest in joining. During a long phone conversation/interview about what her group does, we shared personal things about our lives and our cancer journeys. Definitely wanting to be part of the program, I attended the next STS training session. At Peg's suggestion, I prepared by writing the story of how I was diagnosed and what happened next.

While awaiting the training session, I had an appointment with my gynecologic oncologist, at which I informed him that I had contacted STS and would be attending the training class. He was thrilled and gave me a big hug. He talked about doing Grand Rounds with Peg and the importance of the STS message.

In January 2011, a group of survivors met for our training session. There were 8 trainees, plus Peg and Naomi Whiteacre, a fellow presenter, who was preparing to become an onsite facilitator. Peg shared the story of STS, what the group stood

for, what it hoped to accomplish, and was accomplishing. It was very inspirational. She had us read our personal stories. I volunteered to be first, just to get it over with. When I finished she gave me some great feedback. In a wonderful supportive way, she told me how to reduce the story so it would fit into a 5-minute timeframe.

After tightening my story, I was thrilled to be chosen to present it at the next STS session at the University of California San Diego. I felt somewhat desperate about wanting the main point of my story to be heard and understood. I wanted these medical students to be so moved that they literally would remember the gist of my story as they became practicing doctors. I hoped they would be inspired to really listen to their patients and understand that they know when something is wrong. As the time approached for our presentations, I felt a little calmer. I thought to myself, "look what you've overcome the last few years, this will be a piece of cake." I was very grateful to be able to read my story though, and not have to memorize it. I thought I managed to get through it pretty well. I got emotional near the end, but didn't lose control. When I finished, I looked over at Peg. I think she gave me a thumbs up, and I relaxed. It was over.

I was surprised that after our presentations there didn't seem to be questions from the students. But then after they turned in their questionnaires and some left, others made a real point to come back and thank us for sharing with them. A couple actually came up to me with tears in their eyes (one young lady was really crying) telling me how touched they were by my story. We talked more in depth with a couple of the students about our experiences. In reading the comments about our presentations, I realized that many were moved, indicating that what they saw and heard would make a difference in the way they would one day treat their patients. This is exactly what I hoped this experience would be like. My message was heard. It had to have been one of the most rewarding days of my life.

Meanwhile, over the past few months, our group of STS presenters lost 2 members. Their ovarian cancer recurred, and they lost their courageous battles. Two wonderful women whose courage took my breath away. Although it's been devastating and heartbreaking losing these wonderful women, it has made us realize even more how important a program like STS can make a difference to save more women's lives. ●

## Breast Cancer

### Patients Discovering... *Continued from page 39*

appropriate for their disease and can view research site information, including the closest research site and distance from the patient's home.

The trial portfolio includes 450 trials, including 275 treatment trials, 84 psychosocial/supportive trials, 32 evaluating diagnosis/screening, 22 assessing preventive approaches, and 37 in other categories.

"Trials are for all patients," Cohen stressed. "There is a big myth that they are only for patients who run out of options, but 40% of our trials are in the neoadjuvant and adjuvant setting. Wherever you are on the cancer journey, there is an opportunity to participate in a clinical trial. We want patients to consider trials as a routine option for their breast cancer care."

Users can share their BreastCancerTrials.org history with participating research sites through the Secure Connect message service. This enables the first screening interview to be simplified as well as efficient, and the user can leave a personal message for the research site, such as, "I don't have health insurance. Can I still enroll?"

The website now also has a weekly trial alert service that informs users when newly listed trials match their health his-

tory. The service has more than 1600 subscribers, and 85% of users who have a BreastCancerTrials.org history sign up for these alerts, she said.

"The trial alert service has been responsible for a 68% increase in users," according to Cohen. "It's prompting users to log in and view newly posted trials."

During the first year, there were 4587 returning users and this increased to 7736 in year 2 after the trial alert service was launched.

#### Who Is Using BreastCancerTrials.org?

By disease stage, 440 of 1814 users (who saved their history) were stage 0 to III and recently diagnosed; 746 had completed treatment for stage 0 to III disease; and 628 were living with metastatic disease.

Most current users are 50 to 69 years of age, with women aged 40 to 49 a close second. Most users have been white (non-Hispanic) women with some college education. Fewer than 10% have no more than a high school degree. "Our early adopters are educated and white, but we hope to change this through outreach to underserved populations," Cohen said. ●