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Profile

Susan Beausang

With Three Generations Affected by Breast Cancer, a Woman Takes Action Against Her Genetic High Risk

By Robin Warshaw, for LBCC

As a child, **Susan Beausang** wondered about the odd way her grandmother's clothes hung on one side of her body.

"It was totally sunken down," she says. "I don't remember it being explained to me."

When Susan was a bit older, her aunt—her grandmother's daughter and her mother's younger sister—was diagnosed with breast cancer. Soon, her aunt's body had the same sunken appearance as her grandmother's.

Thirty years later, those childhood recollections came flooding back when Susan's mother was found to have breast cancer. Surgical techniques had improved in that time, and her mother underwent a modified mastectomy. By that point, Susan and her sisters (there were nine children in her family) had become concerned that they, too, might someday receive a breast cancer diagnosis.

That day arrived far sooner than expected, when Susan's 29-year-old sister felt an odd sensation in her breast. Cancer was confirmed. She decided to have a mastectomy with reconstruction instead of removing both breasts, as the doctor advised.

Discovering Genetic Links

These events happened before the introduction of testing for the BRCA1 and BRCA2 gene mutations linked to family susceptibility to breast cancer.

After genetic testing for BRCA began, Susan, three of her sisters and three of her brothers chose to be tested. However, since the sister who had been treated for breast cancer decided she was not ready to hear her results, all the other siblings could not get their findings. (When families are tested, the person with cancer is considered the patient. All other family members fall under the umbrella of her patient confidentiality.)

When a second sister was diagnosed with breast cancer in 1999, the first sister agreed to hear the results and release her siblings' results to help her sister with treatment decision-making. The testing showed that all four sisters (including Susan) and one brother tested positive for the BRCA2 genetic mutation. The sister who had recently been diagnosed had both breasts removed, a procedure known as *bilateral mastectomy*.

It was time for Susan to consider what to do about her own risk.

"Up until then, I had had suspicious lumps and needle biopsies [to evaluate the lumps]," Susan says, but no breast cancer had been found. She heard about *prophylactic bilateral mastectomy*—the removal of both healthy breasts in women who test positive for BRCA1 or BRCA2—but that had seemed too radical a step at the time.

"After my second sister was diagnosed, it was so different," says Susan. "I didn't even think about prophylactic mastectomy as a decision [to consider pro and con]. I immediately started making appointments to see a surgeon."



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Taking a Big Step for Risk Reduction

Things did not go smoothly in Susan's quest to outmaneuver her family breast cancer legacy.

Because Susan had had her children already, she first had *oophorectomy* surgery to remove her ovaries and fallopian tubes, lowering her risk of both breast and ovarian cancers. But the surgery left Susan with an infection that needed treatment with antibiotics. Those medicines produced a side effect, a ruptured Achilles tendon. Susan had to wear a cast on her leg. She became "a little gun-shy" of further surgery, so she delayed having the voluntary breast removal surgery for months.

Finally, at age 52, she went through with the prophylactic mastectomy. When she awoke from the anesthesia, she had only one emotion: relief.

"To me, it was a painless and simple surgery," Susan says. "Maybe because I was so sure it was the right thing to do [to reduce my inherited breast cancer risk], I never looked back."

Her only regret was choosing silicone implants, a decision she says she reached because of her doctor's strong support for the idea. She soon began having medical problems and became concerned these symptoms were caused by the implants. She had the gel sacs removed seven months after receiving them. Two years later, Susan decided to put in saline implants. She led an active life in Florida and believed that implants would help her feel more comfortable when wearing tank tops and other hot-weather clothing.

Before her silicone implants were removed, another strange problem began. Susan's hair started falling out.

"I can remember standing in the shower, washing my hair, and having clumps of hair in my hands and thinking, 'What is this?'" she recalls. "This" turned out to be *alopecia*, an autoimmune skin disease that causes hair loss. In just six months, Susan lost all her hair, including her eyelashes and eyebrows.

It was a hard reality to adjust to: Susan had taken strong steps to combat her inherited risk of breast cancer, only to develop a disease that mirrored one of the devastating side effects of breast cancer treatment—yet had nothing to do with breast cancer. Her doctors didn't know if her hair would ever grow back.

"Believe me, having alopecia and having cancer are *not* on the same planet!" Susan says, emphatically. "Yes, it's only my hair. But I did not come to that acceptance initially. There's such an emotional side to losing your hair."

Experience Brings a New Direction

From the challenge of total hair loss, Susan got an idea that eventually would benefit women affected by breast cancer.

Because she didn't like wigs and found head scarf options limited and cumbersome, Susan—who had studied fashion design in college—came up with an alternative. She created a comfortable, attractive, pre-tied head covering that she began selling through cancer boutiques and online. There's now a patent pending on her design, which can be seen at her company Web site, 4women.com.

As for her breast cancer risk, Susan feels she has done the best she can to reduce it significantly. Research shows that women with an inherited high risk of breast cancer lower that risk by up to 90 percent when they choose to have prophylactic bilateral mastectomy. It's not the choice every woman makes, but Susan feels at peace knowing the surgery lowered her risk.

"I'm monitored the same way anyone is—I go to the gynecologist and I do self-exams," she says. "I just don't worry about it."

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Be gentle, but firm, with your parents. This is hitting them hard, too.