

Chronicles of Hope: Terri Swain

The Chronicles of Hope are the *real life* stories of those helped by Susan G. Komen for the Cure's commitment to the care, research and understanding of breast cancer. These are their—and our—stories.

When Terri Swain was diagnosed with Stage IIB ductal carcinoma in January of 2002, her oncologist told her that she had “garden variety breast cancer” and they proceeded to discuss treatment options. She also spoke with her oncologist and surgeon about genetic testing for the breast cancer genes 1 and 2 (BRCA1 and BRCA2), gene mutations that are linked to greatly increased risk of breast and ovarian cancers.

“Initially, I didn’t want to get the genetic test because it wasn’t going to change what I did for my treatment,” Terri said. But her mother, who had ovarian cancer, and younger sister, who had a recurrence of breast cancer, both opted for testing. The results revealed that Terri’s mother was not a carrier of either BRCA1 or 2, but that her sister was positive for BRCA2.

Shortly thereafter, these two important women in Terri’s life passed away. Devastated, Terri began to feel that her family was being overshadowed by a “cancer cloud.” At the advice of a genetic counselor, Terri was tested and found out that she had a BRCA2 gene mutation. She says, “The reason I did it was because my sister passed away and had three daughters and my other sister has a daughter she was really concerned about.” She wanted to do whatever she could to help her nieces make informed choices about their health.

After receiving the test results, Terri decided to have her ovaries removed. “Finding out nailed that decision for me – I had been thinking about it and then when I got the results I thought that was something I could do.” Terri also has changed a lot about her lifestyle, including her diet, exercising more and utilizes complementary therapies in addition to medical treatment.

Nine years after her breast cancer diagnosis, Terri cautions people considering BRCA testing to really think about the reasons for testing and what impact the results may have on them and their families. She recommends that patients consider how the test results may change the treatment plan. She also feels that it is important to find out if the family really wants to know if the genes run in the family, because some people don’t want to know.



Survivor Terri Swain

Diagnosis BRCA2 Carrier

Years of Survivorship 9

“I think some people might think that because they have the gene, they are just going to get cancer again, but I think a positive attitude and eating right increase your odds of staying healthy.”

INVOLVEMENT WITH KOMEN

Terri felt compelled to do something to honor her sister and her mom. She considered starting a trust in her sister's name, but ultimately decided against doing that "when there is this great organization out there that I can attach to and keep my sister and mom's memories alive." Ultimately, Terri felt that her experience allowed her to see how fortunate she and her family really were. "We had health insurance, access to the internet, good family and friend support systems and when I thought about all of the people who don't, it propelled me into action."

"If you do get tested and find that you carry one of the genes and the family doesn't want to know, it can become a real Pandora's box."

Terri has been involved with the Susan G. Komen Race for the Cure® since 1992, long before her own cancer diagnosis, when her employer paid the entry fees for staff. Since committing to honor the women in her family, she has

become a member of the Komen Dallas County Affiliate Board of Directors. Terri has also chaired the Komen Dallas Race for the Cure®, helped identify a new Executive Director for the Affiliate and recently raised nearly \$22 thousand for the 2010 Dallas Race.

KOMEN'S BRCA RESEARCH INVESTMENT

Komen for the Cure® has been on the front lines of BRCA research. To date we've funded 82 grants totaling more than \$24 million in BRCA gene research. Our earliest grant, in 1993, supported Dr. Mary-Claire King in identifying the specific DNA sequence of the BRCA1 gene. In the mid-90s Komen continued to support Dr. King's work with two additional grants that helped further characterize BRCA1 and its role in hereditary breast cancer.

Other key focus areas of Komen grants include studying BRCA mutations in populations at greater risk for breast cancer, such as African-Americans and Latinas, the interaction of the BRCA genes and the environment and hormones, the role of BRCA genes in DNA repair and locating other genes and proteins that might interact with BRCA genes and contribute to breast cancer. For more information about Komen for the Cure's investment in BRCA, read Research Fast Facts: BRCA1 & 2 and to learn more about breast cancer risk, including BRCA1 & 2, visit the Understanding Breast Cancer section on www.komen.org.

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