

Having the "talk"

Posted At : June 22, 2010 6:29 PM | Posted By : Kathy LaTour

Related Categories: Featured

My daughter Kirtley was only 13 months old when I was diagnosed with breast cancer in 1986 at age 37. By fall 1991 I was healing emotionally, and Kirtley was a happy, healthy 6-year-old who had inherited my stubborn nature and love of books. Even after the first of the BRCA genes was discovered in 1990, I knew my risk was low. I was the first in my family to get cancer. It was stroke or cardiac issues that removed my family tree limbs. Then my mother was diagnosed with stage 4 breast cancer in the fall of 1991; she died six months later. It was a difficult time for me and became even more difficult as I began to worry about whether I now needed to worry about passing on more than a love of books to my daughter. As I celebrated survivorship and Kirtley grew, I constantly scanned information about genetic testing for breast cancer, feeling sure that we would know more before I should worry.

In 1994 the BRCA2 gene was identified, and in 1996 came the first commercial test that could identify the mutated genes. I knew that if I tested positive, Kirtley had a 50 percent chance of carrying the gene. This was a terrifying thought for two reasons: Kirtley might be positive, and she was too young for either of us to do anything about it; Kirtley might be negative and stop worrying about her risk of developing breast cancer.

I applied what we knew about breast cancer prevention, keeping Kirtley active and healthy. She ice skated every day after school, but I'll take odds that I was the only mother at rink side watching her daughter jump and spin while at the same time thinking of a study that showed exercise during adolescence was an important factor in staving off breast cancer.

Then, in 2002 my brother was diagnosed with early stage prostate cancer at age 48. OK, so it was time that I requested the packet of information about genetic counseling from my local cancer center. After reading it, I was still reassured that my risk was small.

Kirtley graduated from high school in 2004 and left for college. But on the way to my next cancer maintenance check up, I ran into the oncologist who specialized in hereditary breast cancers. I asked her opinion about being tested -- not liking her response.

"You were under 40 when your breast cancer was diagnosed," she said. "All women diagnosed under age 40 should be tested."

I decided to wait until Kirtley graduated from college in 2008 to be tested, knowing that she would be well educated on breast cancer and old enough that we could have a meaningful discussion about options.

But I moved the testing date up after receiving a second breast cancer diagnosis in 2007. Since this diagnosis was DCIS and I wasn't facing chemotherapy again, my biggest fear was that it raised my risk of being positive for one of the two gene

mutations we have identified, BRCA1 and BRCA2.

I was finally tested in spring 2008, two months before Kirtley graduated from college. I was negative, something I saw as my graduation present for her -- but nothing I talked about with her. My second cancer diagnosis had scared her enough. I could put this discussion off for a while, but the genetic counselor's parting words meant it was still something we needed to talk about.

The counselor said that, while I didn't test positive for the BRAC 1 or 2 gene, there was something going on in my family as it had more than its share of cancer. We needed to be aware.

Kirtley is now an insured member of the work force in New York City and a few months ago she called to ask me if I had been tested for the the breast cancer genes. I said I had and that I was negative and asked her why she was asking. Seems that at her gynecology appointment, her new doctor read through her family history and asked if I had been tested. Kirtley needed to know.

When Kirtley relayed the information, the doctor did the best thing possible.

She told Kirtley that being negative didn't mean she could stop worrying about getting breast cancer. Her risk was still the same as any other American woman, and, as we learned more about genetics, she needed to stay aware since there could be more mutated genes found in the future.

Kirtley took it in stride, and I felt pride that she has taken control of her own health. But, like any mother who has had breast cancer, I'll always worry.

To read more on sharing genetic information with children, read CURE's Summer 2010 article, ["The Genes That Bind."](#)