

In the Family

Isabelle Simons

It's so strange to think that the thing that can make you dangerously sick or even kill you was in you when you were first born. It just sits there. Deep inside your body, waiting to someday take hold of your life. As a young and healthy teenager, it's hard for me to wrap my brain around this. That I can have something waiting, sitting dormant inside me that someday can turn into ovarian cancer or breast cancer and turn my life upside down. But that's the reality when you have BRAC 2 in your family.

Cancer is such a scary word. It's even scarier when you grow up listening to the stories from many women in your family. The fear. The worry. The many tears cried. Hearing about the genetic testing. Talking about MRI's and mammograms. And for some of the women in in my family - the treatments and surgeries.

I will say, for the younger generation of girls and women, although it's overwhelming and scary, we do feel grateful to the older generations that we even have the knowledge we have today, so we can do something about BRAC 2 if we test positive. A couple of generations ago, our family didn't have that luxury, and it turned out to be fatal.

Three generations ago, my great-grandmother immigrated to the United States from Druogno, Italy, not knowing that she carried the BRAC 2 gene inside her. She and my great-grandfather, settled in Northern California and raised a family, having six children. It was after their last child was born, that my great-grandmother noticed a lump in one of her breasts. She didn't speak English or go to the doctor often. By the time she saw a doctor about the lump, her cancer was very advanced, and she died of breast cancer, leaving her family without a mother. Her youngest child just three years old.

I know from the family stories that this was devastating to the whole family, but especially to her three daughters, who watched cancer take her life, and had to raise their tree-year old little brother who was so young. Growing up without a mother was sad and difficult for him, and all my aunts worried about someday getting cancer.

One aunt did. She was diagnosed with breast cancer in the 90's. After a lumpectomy, treatment, and many medicines, she was declared cancer free, and her own four daughters all breathed a sigh of relief, thinking it was over. Nope. Not over. A few year later, her youngest daughter also found a lump in her breast. She went to her doctor to have it looked at, only to be told she was way too young to worry about breast cancer, all was fine. A year later the lump was bigger. A biopsy came back stage four breast cancer, and my cousin lost her life to it, after a long battle.

She left behind a loving husband and a 7-year-old son. That's when the family started wondering, can the breast cancer be genetic?

A few years later, my aunt's cancer came back, and this time the BRAC gene had been discovered by a researcher in Seattle. The whole family wanted my aunt tested. The next obstacle was that insurance wouldn't pay for genetic testing back then. But the women in our family were so determined to get the test, that everyone who could help pitched in to pay for it. It came back positive for a BRAC 2 gene mutation. The good news is that after our family knew the chromosome to test, other women in the family paid less to be tested for BRAC 2.

Today our large family is spread out all over the west coast. Of the family members I know who have been tested, 27 have tested positive for a BRAC 2 gene mutation, and have a higher risk of getting breast and ovarian cancer. To me 27 sounds like a lot.

Our family has learned a lot about the nature of genetic testing. Mainly, that there are differences in how people feel about having it done. Some of the women in our family have had testing, and if they were positive for the gene, they've made decisions to have children early so they can have surgery to reduce their risks. Some have had hysterectomies, some have had ovaries removed, and some have had preventative mastectomies to reduce their risk of cancer.

Remember how I said it's strange to think about being born with something inside you that may someday kill you? Well, some in our family just don't want to know. They have made a choice not to get BRAC 2 testing. What I've come to understand is that genetic testing is a very personal choice, and we have to learn to support the women who decide they don't want to know, as much as we have supported the ones who do want to know and choose preventative surgery. What I've decided is that either way, it's a hard thing to decide.

Probably like a lot of students entering this cancer essay contest, there's a lot I just can't say. The fear is so big, and the hurt of seeing someone you love go through cancer treatment is just so painful - it's hard to put into words.

I will say this. I know there is going to be more awfulness in my future because of having BRAC 2 in my family. I know for a fact there will be more tears, more suffering, more hard decisions, and more grieving. But I also know that cancer has a hidden gift. It makes you see what truly matters most, and makes you think differently about how you don't want to waste any of your time while on earth. The drama, the pettiness, or the inconsequential stuff that can suck away too much of your attention, is just not important. The hidden gift of cancer is that it shows you what matters most, and it makes you incredibly aware of one thing - time.

I for one, will not waste it.