

Kate and Marie's Story

In this conversation, Kate and Marie talked with Gene Scene about how cancer has impacted their large close-knit family.

As is often the case in large families, the generations in this family have blended together. Marie is 48 years old. Her aunt Kate is 47. They have become close over the years, spending time together as children and rooming together after high school.

Cancer has followed their family from one generation to the next, striking down women in the prime of their lives. Now with the chance to have genetic testing, this family has found a way to fight back. This is their story.

THE FIRST GENERATION

Kate: My mother came from a large French Canadian family. She had five brothers and four sisters. It was in her generation that I first saw what cancer was doing to our family.

My mother had lost three of her sisters to breast or ovarian cancer before her own diagnosis at the age of 59. I remember her fear. It seemed to me that she worried a lot. One day when she received a phone call saying her youngest sister had died she collapsed on the kitchen floor; it was awful to see such grief.

A day I'll never forget was when my mother and father both returned from a doctor's appointment. I was 14 at the time. My mother was disoriented and didn't know where she was, who I was or my dad. She must have been in shock and the next day it all came out—I remember the conversation as clear as anything. She said "I have this lump in my breast and I'm going to have surgery. When I wake up I'll know I have cancer if they have removed my breast." I was devastated. I remember praying for her on my knees beside my bed every night. She died a year and a half later.

Marie: Ever since I can remember, there was a lot of death in my dad's maternal family. I was in grade 11 when my grandma, Kate's mom, passed away at age 61.

THE SECOND GENERATION

Kate: I was the youngest of the five children in my family. Ten years after we lost our mother, my sister Anne who was closest in age to me was diagnosed with breast cancer. She was 33. She passed away at 36, leaving behind three young children. I was expecting my first baby that year and didn't know if I should tell her as I knew she wouldn't live to see the baby born. However, I did share it with her and she was so happy. It was the miracle of this new life that carried me through this very difficult time.

Just months before Anne died, my sister Irene was diagnosed with breast cancer at the age of 45. The whole situation was unbelievable. She survived breast cancer but 17 years later, ovarian cancer took her life. It is not possible to describe the gap that has been left in our family with the death of these three wonderful women.

GENETIC TESTING

Kate: My sister Irene was the first in the family to have genetic testing as she had a cancer diagnosis. She really wanted to know if the cancer was hereditary and hoped there would be a clear result, BRCA1 or BRCA2. We waited for over two years for her test result. She didn't live to learn that she was BRCA1 positive. We were almost relieved to know what it was and that

we could be tested. Irene would have been so pleased that we would benefit from her testing. One of her sons has since tested negative so his daughters will not be faced with the worry of hereditary breast cancer.

Marie: My dad was the next to go for testing after that. I went with him and Mom when he got the results several months later - he had the gene mutation as well. He was devastated to know that his three daughters and his son all had a 50% chance of inheriting this curse. I felt so bad for him!

Soon after that my siblings and our spouses all went for genetic counseling together. Only the three girls provided blood for the testing right away. My brother decided to hold off for awhile since his health was not yet at risk. (He has since gone and has tested negative). My sisters and I went together with our spouses for the results three months later. Each couple was put in a separate office to get our own results. Then we reconvened in a meeting room where there were lots of tears. My youngest sister and I both carried the mutation, while my other sister did not. She, however, did not feel any relief. She was probably the most upset person there. It was incredibly awful and sad for all of us, but I'm glad we were all there together.

I remember that I was in shock for awhile. Even though I was half expecting it, I was still caught off guard. I had to go back to a meeting at work and will always remember the meeting and who was there. I somehow felt like I was a different person and would never, ever be the same again.

Kate: During this time my brother John, who was 67, was diagnosed with prostate cancer which made us think that he was probably positive as well. Later his test confirmed that he did have the mutation. We assumed that my sister Anne had been positive too so that just left me.

I was tested in 2000 at the age of 45. I thank my nieces for leading the way as they went for their testing before I did. I was still getting over the death of my sister Irene and needed the gentle pushes they provided.

I was not surprised when my result was positive too. But, it was still incredible to us. All 5 of us had the BRCA1 mutation. How unlucky could we get? I had hoped so much that my brothers would be negative as one has three daughters and the other has two.

DIFFICULT DECISIONS

Marie: The months after I got my positive test result were difficult. I went to surgeons and plastic surgeons to hear what they had to say. My sister and I accompanied each other to our various appointments and both decided to proceed with prophylactic mastectomies with reconstruction. We did not feel it was too drastic a measure. The doctors that we met with were compassionate and supportive of our decision, which really helped. I was terrified of the lengthy surgery and the significant trauma to my body but now, a year and a half later, I am very pleased with the results. The support of my husband, kids, family and friends helped me get through the physical and emotional hardships of the surgery.

Several years earlier I had undergone a prophylactic oophorectomy and hysterectomy. At that time a study had been published showing a significant reduction in breast cancer risk after oophorectomy.

Kate: I had a bilateral prophylactic mastectomy and free tram breast reconstruction. It was a huge step but the surgeons were so competent and assuring. I knew I was in good hands. I had my ovaries removed in 1999 after Irene was diagnosed with ovarian cancer. I have no regrets at all for the measures I have taken.

THE THIRD GENERATION

Kate: One of the hardest blows was when two of my nieces were diagnosed with breast cancer last year within months of each other, one at 32 and the other at 42. They had both tested positive for the gene. My younger niece had opted to have a prophylactic mastectomy but when the pathology report came back, she was told that she already had an early stage breast cancer. My other niece was doing regular surveillance and found her cancer through a mammogram. We had hoped this genetic information and the prevention and surveillance we were doing would put an end to the horrible fear hanging over our heads all the time. I realize the genetic testing has made a difference to their prognoses because they were so proactive and found the cancers early.

LOOKING AHEAD

Kate: We have an amazing family who totally support each other through this journey. My husband has supported me entirely throughout these events. We have a son 19 and a daughter 17 who are both very informed about the mutation and the risk factors. I hope and pray that they may be the lucky ones. For those of us who are positive, I hope we never feel guilty about passing this mutation on to our children. I have never for a minute had a negative thought about my mother and her BRCA1 mutation as she passed on to me so many other wonderful genes which I know have made me a better person.

Marie: I have a wonderful family – a great husband and two adult children – a boy and a girl, who I love dearly. I no longer worry about getting breast cancer. It is a relief to know that I, my sister, aunt and cousins have taken steps to be around to see our grandchildren, and each other's grandchildren. We know this is what my grandma and aunts, our three angels, would want.