

Phyllis' Story

Over a cup of coffee on a snowy winter day Phyllis tells her story. *It's not the story she ever thought she would be telling.*

Last February Phyllis had surgery hoping to prevent cancer. What she got instead was a cancer diagnosis.

Her hair has grown back now and her voice is strong, but the tears come when she talks about the struggle of the last year and the memories of her two younger sisters who both lost the fight to cancer.

Phyllis' family has seen more than their share of cancer. Genetic testing showed that the family carried a BRCA2 gene mutation and Phyllis also tested positive for it. That's when she decided to have the surgery.

She doesn't hesitate for a second when she talks about her decision to have the test and then go ahead with surgery. "I honestly think that genetic testing saved my life....and likely my girls' too."

When asked what has been the hardest part, she says, "I don't know if it's thinking about what I've been through or about what could have been."

GROWING UP

I grew up in the country where there was no power or telephone. Everyone in our community was very close and we always looked out for each other. Helping your neighbour was a joy. We attended a small one room school which accommodated everyone from Grade 1 to Grade 8. Most of the students were my relatives. We were all neighbours and very close friends. When we grew older we left the farm and most of us moved to the city.

CANCER IN MY FAMILY

My aunt died of breast cancer in 1973. We've lost so many on my Dad's side of the family to cancer, my aunt, and then her son, my uncle and two of his four children. Another aunt had thirteen children and nine of them were taken by cancer. It was all so overwhelming that this could happen to so many of my relatives. But then it occurred to me. Could I be next? Could this happen to my siblings, or heaven forbid, my children?

LILA AND KAY

In 1980 my younger sister Kay was diagnosed with breast cancer. She was just 33 years old. She found a lump and had a mastectomy, chemotherapy and radiation.

Then in 1995 my sister Lila was also diagnosed with breast cancer. She was 50. She didn't have a lump but she knew something was wrong. She kept going back to the doctors and they couldn't find anything. Her breast was absolutely red and the nipple was turned inward already. But the doctors still said they had done mammograms and there was no cancer there. By the time they told her it was cancer, I think we all knew.

In 1998 Lila's cancer came back and it was then that we talked with her about having genetic testing done. She had the test done and that's how we found out that our family carried a BRCA2 gene mutation. It was passed down through our father. Lila died that year at the age of 53.

Kay was the second one in the family to have the genetic test and, as we expected, she was positive too. But that didn't help her. We lost her in 2002, not of the breast cancer that she'd been diagnosed with 22 years earlier, but of ovarian cancer.

KAY'S FAMILY DOCTOR

We were all very angry. Since she carried the gene mutation she was at high risk for ovarian cancer but her doctor refused to remove her ovaries. He knew that Kay had the gene mutation and he knew she'd had breast cancer. The doctors at the cancer clinic had written a letter suggesting that she have her ovaries removed but her family doctor didn't think it was a good idea. We even suggested she change doctors but she lived in a small town. The diagnosis of ovarian cancer wasn't made until she was very, very ill and had been transferred to a city hospital and nothing more could be done. She died of ovarian cancer at 55.

MY GENETIC TEST

By this time I was 61, older than both my sisters when they were diagnosed. I thought I had beat cancer. I was just so sure that it wasn't going to happen to me. I decided to be tested to prove to my children that I didn't carry the gene, and they had nothing to worry about.

To my shock and surprise, my test came back positive. All my children went for testing right away. It was devastating to learn that four of my five children were positive too.

My daughters and I consulted with various doctors about what the options were to reduce our risk for cancer. After many consultations and family discussions I decided to have prophylactic surgery. First I had a bilateral mastectomy and began breast reconstruction. Five weeks later I had my ovaries, fallopian tubes and uterus removed. The surgery went well and I was looking forward to a quick recovery so I could get out to the lake to go camping.

MY DIAGNOSIS

I'll never forget the day I got the phone call from my doctor who told me that I had been diagnosed with cancer! I was very upset. The pathology report had come back and said that I had Stage 2 cancer in the fallopian tube.

My oncologist recommended that I undergo chemotherapy. Chemo was a long, hard, frustrating and emotional struggle, but I certainly don't regret my decision to go through the treatment.

The doctors were amazed that the cancer was there. They had done all kinds of testing before the surgery and nothing had showed up.

MY FAMILY DOCTOR

Everybody should have a family doctor like mine because he cares and is willing to learn. When I first told him that my two sisters had tested positive for the gene mutation, he had never heard of BRCA2. I brought him the papers from my sisters' testing and he contacted the genetic counsellor right away. Now he knows about hereditary cancer and he's pleased because he has another BRCA family who can benefit from what he's learned.

HOPE

I suppose I will always wonder if I am cancer free. I can only hope that I am. And I hope that my children and grandchildren will never have to face cancer. Most of all, I hope that, in our family, cancer stops here.