

My name is Mary and I have risky genes

Being part of an HBOC syndrome family can be a living nightmare and my own family is no exception.

I am a breast cancer survivor after being diagnosed at 41.

I am a daughter of a mother, who lost her life to ovarian cancer when she was 55.

I am a mother who lost my daughter to hereditary breast cancer when she was 34. And a mother who supported a second daughter through a preventative double-mastectomy when she was only 24 and is facing ovary/fallopian tube removal in her early thirties.

I am a grandmother helping my granddaughter navigate the world without her.

We are a family struck by hereditary breast and ovarian cancer (HBOC) syndrome. We have a BRCA1 gene mutation that has been passed down through the generations that dramatically increases our chances of getting breast, ovarian or in the case of the men, prostate cancer. We didn't know we had risky genes in the family until my cancer diagnosis.

We fear for our children, and their children

I am also the CEO of the HBOC Society, an organization that represents, educates and supports individuals, families and communities affected by this type of hereditary cancer. I knew that I needed to be part of an organization that would bring awareness and change to this issue. I originally joined the Society for myself and my family, but since the loss of my daughter my passion for this mission has grown. I now work for all families who are affected by this devastating condition.



Lianne, Mary and Janine, 2011

We are waging a war against our own bodies, and far too many risky gene carriers are losing that battle.

There are some dedicated services in place to help navigate the complexities and uncertainties of learning that you're a carrier of a mutated gene but they receive little or no funding from the government. Even with increased screening our aggressive HBOC cancers are not always caught in time. Preventative chemotherapies are available that in some cases can reduce cancer risk but as with all chemotherapy there are side effects. Preventative surgeries can reduce cancer risk up to 95% but these surgeries are drastic and cause body, relational and fertility issues. We are only just starting to see targeted treatments for HBOC syndrome cancers.

Most people have never heard of, or are misinformed about the danger and prevalence of hereditary cancer. Up to ½ million Canadians are estimated to be affected, which is several times higher than those affected by MS. Awareness is still so low that up to 80% of HBOC carriers themselves are not yet aware of that fact, so can do nothing to save their lives. It is hard enough to be an HBOC syndrome carrier but this prevailing lack of awareness means we also face discrimination. Once we have navigated our own decision-making process and many medical

hurdles, we still have to endure misconceptions, biases and incorrect assumptions from the public, within the health care system, government and sometimes even our own families.

Had Lianne the support and medical resources in place that she needed, her journey might have been very different. She was diagnosed with breast cancer at 31 years of age when her daughter was only eight months old. Although prognosis was very good, the health care system was not able to provide her with a double-mastectomy / immediate reconstruction in time to stop the cancer from spreading. Lianne suffered horribly through round after round of chemotherapy and radiation during her fight to live but her aggressive cancer won out, leaving her family devastated and a three-year old without a mother.

We are the only population that can truly get ahead of a cancer diagnosis

The dedicated services that do exist rely heavily on community involvement. For thousands of families like mine, access to these services and other supports are vital to our survival. To ensure essential resources remain available and new ones can be established, we're relying on the vision and generosity of our community and our government.

This problem will not just go away

HBOC carrier cancer rates are increasing and age at cancer diagnoses is decreasing. Due to the nature of hereditary cancer, a disproportionate number of young mothers are diagnosed with aggressive hereditary cancer. Parents are losing their children and children are losing their parents.

Why we tell our stories

It is certainly not about getting our 15 minutes of fame. It is not easy to talk about losing our loved ones or to discuss what we are going to do or have done to our private parts in public. HBOC syndrome is not well-known or understood in the public eye. We often face ridicule for the tough decisions we make to save our lives. Speaking out publicly may mean risking our jobs or relationships. So why do we do it? **Because we deserve to be understood, hereditary cancer deserves to be properly funded and each person affected deserves a fighting chance at life.**



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