ABOUT US

Our Organization

The Risky Genes Society, formerly known as the HBOC Society, is a charitable organization incorporated in 2002 and the only of its kind in Canada. Our founder created the Society after she searched for information and support during her own hereditary cancer prevention journey and found none. Our goal is to prevent cancer in those where that is possible and to create better outcomes for those affected by hereditary cancer.

Our Cause

The term risky genes is defined as **the presence of proven inherited gene mutations that greatly reduce a carrier's ability to ward off or fight breast, ovarian, prostate, and related types of cancer such as pancreatic, OR where a family history of these cancer types exists potentially due to a mutation that has not yet been discovered.**

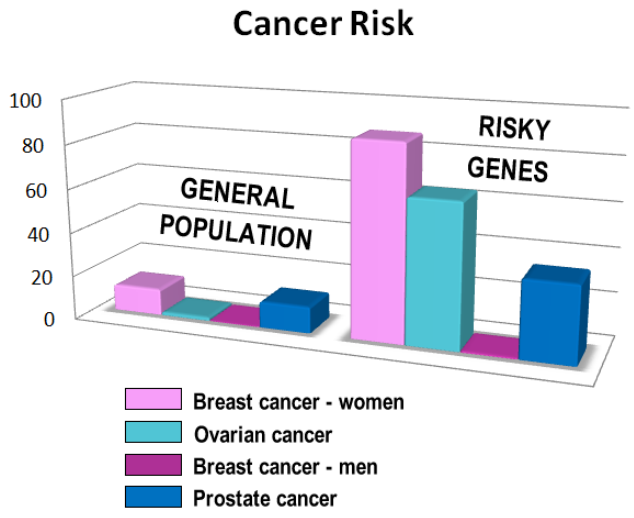
Hereditary cancer is more dangerous than the same types of spontaneous cancer. Hereditary cancer is diagnosed far more often in affected families, at younger ages, has a higher rate of recurrence or a second primary site and tends to be more aggressive, making it harder to treat. Both males and females can carry and pass down their inherited mutations to biological children, who have a 50% chance of also being affected.

RISKY GENES

Hereditary breast and ovarian cancer genes cause additional types of cancer

GENE	CANCER TYPE							
	Breast	Ovarian	Prostate	Pancreatic	Colorectal	Stomach	Uterine	Melanoma
BRCA1								
BRCA2								
MLH1								
MSH2								
MSH6								
PMS2								
EPCAM								
TP53								
PTEN								
STK11								
CDH1								
PALB2								
CHEK2								
ATM								
NBN								
BARD1								
BRIP1								
RAD51C								
RAD51D								

SOURCE: 2020 Color Genomics



At least 10% of all breast and prostate cancer and 15% of all ovarian cancer is known to be due to risky genes. Statistics vary, but average hereditary cancer risk is reported to be as high as 88% for breast, 65% for ovarian and 35% for prostate cancer, as compared to 12%, 1% and 11% respectively for their spontaneous counterparts.

Since its discovery in 1995, knowledge about this type of hereditary cancer has progressed from one type of cancer caused by mutations in one gene, to several types of cancer caused by mutations in any of many different genes, and researchers will continue to learn more. All labels used today as descriptors are based on old research and have become outdated. These include, but are not limited to, 'the breast cancer gene', 'hereditary breast and

ovarian cancer syndrome', the acronym, 'HBOC' and the acronym for the first gene discovered, 'BRCA,' which stands for 'breast cancer.' This fragmentation into cancer type and/or gene created a disconnect between later discoveries that dramatically, negatively affects patient identification and care. **The future forward label 'risky genes,' bridges all gaps between gender, cancer type and gene involved.**

The Patient Group

This is a still evolving, complex, high-needs patient group that includes those who have developed hereditary cancer and those who are at high risk to do so but have not yet had a diagnosis, known as previvors. All patients require genetic testing and/or counselling to be identified and for every newly identified patient, any number of biological family members may also be similarly affected. **Of the more than 1.3 million Canadians estimated to carry risky genes, more than 90% remain unaware.**

Treatment

The type(s) of hereditary cancer and level of cancer risk for individual patients varies, depending on which gene is mutated, the type of mutation within it and several other factors. Previvors gain access to **increased cancer screening at early ages**, and in the case of hereditary breast and ovarian cancer, **chemoprevention and surgical risk-reduction options** that have been proven to be highly effective. For those diagnosed with some types of hereditary cancer, **a promising new class of drugs is now available for those who qualify**.

The Current Environment

If identified through genetic testing, risky gene carriers have the advantage of being able to find cancer early, when most treatable, in many cases to be able to drastically reduce their risk of ever developing hereditary cancer and, in the case of a hereditary cancer diagnosis, to obtain more effective treatment options. That being the case, one would assume governments and the large cancer organizations would have done everything possible to identify risky gene carriers to provide them with those opportunities and cancer organizations would have provided proportionate funding for the various hereditary cancer components. Instead, these entities provided no public awareness programs to actively search out those affected, nor did they fund organizations like ours to do so. They also left the medical community ill-equipped to identify or treat those affected and underfunded research. As a result, **most risky gene carriers remain unaware or misinformed, the true danger and incidence continues to be downplayed and misunderstood in media and medical community and specialized services, resources, and research remain fragmented and limited.** Fragmentation into cancer type also created what is by far the largest barrier to our ability to draw funding to this cause, the widespread misperception it already exists.

Inattention to hereditary cancer has already cost countless lives unnecessarily, many at a young age when still raising families and without financial security, further exacerbating the already enormous effect on caregivers and other loved ones left behind, especially children. Ultimately, all Canadians pay a socio-economic cost for each preventable death. Risky gene carriers are known to be more likely to develop hereditary cancer at even earlier ages than in previous generations, for some by nearly a decade. **There is no more time to lose.**

ANYONE can carry risky genes, but it is more likely if you have a family history of the cancer types involved or are of a certain ethnic background. Please share the link to our website with your others. You may save a life!

To donate or for
more information visit riskygenes.org