



## FACTS ABOUT RISKY GENES

### What are risky genes?

- The term "risky genes" is a more inclusive way of referring to hereditary breast and ovarian cancer (HBOC) syndrome, which is an inherited predisposition to a **high risk of breast, ovarian and prostate cancer**, and slightly increased risk of some other types of cancer, including skin and pancreas.

### What is the difference between hereditary and spontaneous cancer?

- Hereditary cancer is **diagnosed much more often** in affected families and at younger ages. Average cancer risk in a risky gene carrier is up to 88% for breast, 65% for ovarian, and 35% for prostate vs 12%, 1.5% and 11%, respectively, in the general population.
- Hereditary cancer tends to be **more aggressive**, making it harder to treat.
- Hereditary cancer tends to **recur more often**.
- There is a **greater chance of a second primary** hereditary cancer.
- The gene mutations that cause hereditary cancer **can be passed down in the family** by both a female or male carrier.
- Hereditary cancer is **more prevalent in certain ethnic groups**, such as the Ashkenazi Jewish.
- Hereditary cancer is **not yet well-funded**, resulting in less funding for services and research.
- Awareness **for hereditary cancer** is so low that most people with risky genes don't know it yet, so can do nothing to reduce their risk of cancer.

### How common are risky genes?

- An estimated **5-20% of all breast, ovarian and prostate cancer** is hereditary. This translates to a shocking 3-5 times more people who risky genes than are affected by multiple sclerosis.
- **This is not a small problem**, despite often being downplayed in the media and even the medical community.



## FREQUENTLY ASKED QUESTIONS

### I'm a male carrier. Am I at higher risk for breast cancer?

**Yes.** Male risky gene carriers are at risk for hereditary breast cancer, but their risk is not nearly as high as for female carriers.

### According to the internet, hereditary cancer risk stats and medical recommendations vary. Why?

**This science is still relatively new**, with hereditary breast cancer having only been discovered in the 1990's with mutations in the BRCA1 and BRCA2 genes. It later became apparent other cancers were also involved, as were other genes. There has not been enough research done to pinpoint cancer risk for the many different mutations that can happen within each of the risky genes that have been identified to date. As such, cancer risk is reported in averages and each region develops their own recommendations, based on the information they choose to use as a basis.

### I'm a risky gene carrier. What can you do for me?

Leading up to and learning one is a risky gene carrier, and then facing the difficult choices as a result, can be very traumatic. We can provide you with the **supportive connections and leading-edge information** you need to see you through any point of your wellness journey, or in the event of a cancer diagnosis.

### Why would I support the HBOC Society and not the larger cancer organizations?

Our primary purpose is to **prevent hereditary cancer**, whereas the larger cancer organizations are primarily concerned with post-diagnosis. Risky gene carriers require specialized services and resources that often fall outside the funding eligibility criteria of the larger cancer organizations. By far, the largest barrier to funding to search out carriers and provide them with the tools they need to save their lives is the misperception funding already exists. If we don't do something, who will?

### Do you hold educational events?

**Yes!** Don't miss our annual **OUR GENES** Conference held each fall, which is of interest to risky gene carriers, their friends and family, the medical community and the public.

## MORE INFORMATION

