

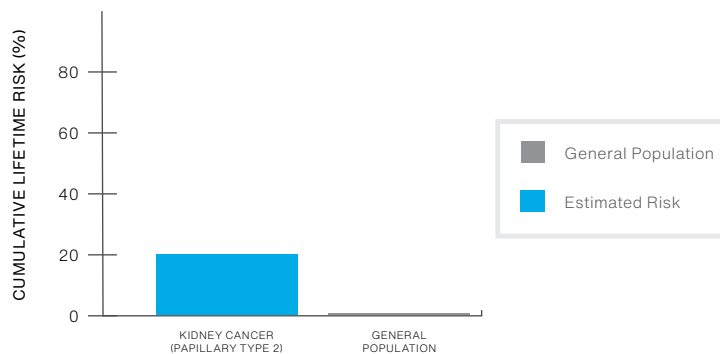
Understanding Your Positive *FH* Genetic Test Result

INFORMATION FOR PATIENTS WITH A PATHOGENIC MUTATION OR VARIANT, LIKELY PATHOGENIC

7 Things to know

1	<i>FH</i> mutation	Your testing shows that you have a pathogenic mutation or a variant that is likely pathogenic in the <i>FH</i> gene.
2	Hereditary leiomyomatosis and renal cell cancer	People with one <i>FH</i> mutation have hereditary leiomyomatosis and renal cell cancer (HLRCC).
3	Cancer risks	You have an increased chance to develop kidney (renal cell) cancer.
4	Tumor risks	<ul style="list-style-type: none"> • For women: Women with <i>FH</i> mutations have a higher chance to develop multiple uterine leiomyomas (uterine fibroids), which usually occur at a younger age compared to the general population. • For men and women: Many people with <i>FH</i> mutations develop skin leiomyomas, which appear as skin-colored or light brown bumps. • You may also have a slightly increased risk to develop paragangliomas or pheochromocytomas, which are rare tumors that affect the endocrine system (the body system that makes and controls hormones).
5	Other medical concerns	Individuals with <i>FH</i> mutations may have an increased risk to have a child with fumarate hydratase deficiency (FHD), but only if their partner also carries a mutation in the <i>FH</i> gene. FHD is a rare, severe condition of infancy that can cause abnormal brain development, weak muscle tone, and seizures.
6	What you can do	Risk management decisions are very personal. There are options to detect cancer early or lower the risk to develop cancer. It is important to discuss these options with your healthcare provider and decide on a plan that works for you.
7	Family	Family members may also be at risk – they can be tested for the <i>FH</i> mutation that was found in you. It is recommended that you share this information with your family members so they can learn more and discuss with their healthcare providers.

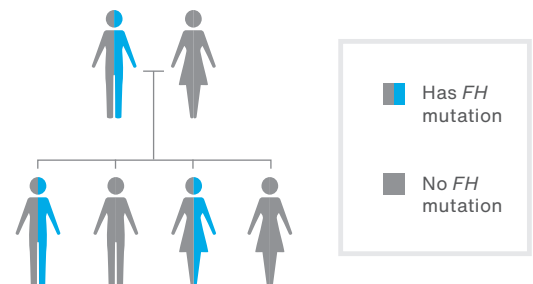
FH Mutation Lifetime Cancer Risks (%)*



* Because risk estimates vary in different studies, only approximate risks are given. Cancer risks will differ based on individual and family history.

FH Mutations in the Family

There is a 50/50 random chance to pass on an *FH* mutation to your sons and daughters. The image below shows that both men and women can carry and pass on these mutations.



Reach Out	RESOURCES	<ul style="list-style-type: none"> • HLRCC Family Alliance hlrccinfo.org • Genetic Information Nondiscrimination Act (GINA) ginahelp.org • National Society of Genetic Counselors nsgc.org • Canadian Association of Genetic Counsellors cagc-accg.ca
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Please discuss this information with your healthcare provider. The cancer genetics field is continuously evolving, so updates related to your *FH* result, medical recommendations, and/or potential treatments may be available over time. This information is not meant to replace a discussion with a healthcare provider, and should not be considered or interpreted as medical advice.