

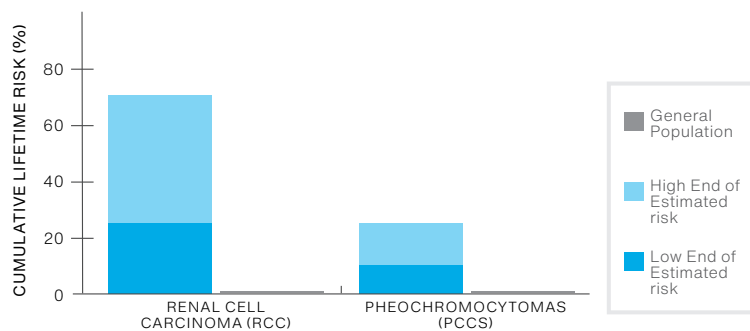
Understanding Your Positive *VHL* Genetic Test Result

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

6 Things to Know

1	<i>VHL</i> mutation	Your testing shows that you have a pathogenic mutation or a variant that is likely pathogenic in the <i>VHL</i> gene.
2	von Hippel-Lindau disease	People with <i>VHL</i> mutations have von Hippel-Lindau (VHL) disease.
3	Cancer risks and noncancerous tumor risks	You have an increased chance to develop kidney cancer, pheochromocytomas (PCCs), and neuroendocrine tumors of the pancreas (PNETs), as well as other noncancerous tumors or cysts in the eyes, ears, brain, spine, pancreas, and reproductive system.
4	Other Information About VHL	<p>There are different subtypes of VHL. Each type has different cancer and tumor risks:</p> <ul style="list-style-type: none"> • VHL type 1: kidney cancer, PNET, noncancerous tumors of the eyes, brain, spine, and pancreas • VHL type 2A: PCC, noncancerous tumors of the eyes, brain, and spine • VHL type 2B: PCC, kidney cancer (high risk), PNET, and noncancerous tumors of the eyes, brain, spine, and pancreas • VHL type 2C: PCC only <p>Your specific mutation may help clarify which type of VHL you have. It is important to talk to your healthcare provider about which tumors and cancers you are at risk for.</p>
5	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.
6	Family	Family members may also be at risk – they can be tested for the <i>VHL</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.

VHL 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.

VHL Mutations in the Family

There is a 50/50 random chance to pass on a *VHL* mutation to each of your children. The image below shows that everyone can carry and pass on these mutations, regardless of their sex at birth.



RESOURCES

- VHL Alliance vhl.org
- National Society of Genetic Counselors nsgc.org
- Canadian Society of Genetic Counsellors cagc-accg.ca

Please discuss this information with your healthcare provider. The cancer genetics field is continuously evolving, so updates related to your *VHL* 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.