

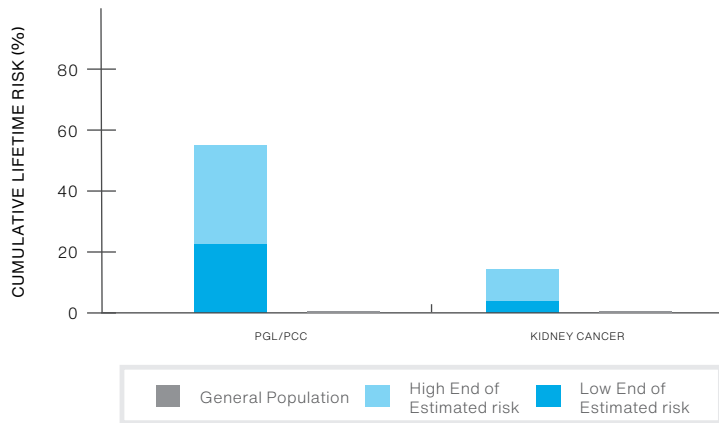
# Understanding Your Positive *SDHB* Genetic Test Result

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

## 5 Things to Know

|   |                                      |  |
|---|--------------------------------------|--|
| 1 | <i>SDHB</i> mutation                 | Your testing shows that you have a pathogenic mutation or a variant that is likely pathogenic in the <i>SDHB</i> gene.   |
| 2 | Non-cancerous tumor and cancer risks | You have an increased chance to develop paragangliomas (PGLs)/pheochromocytomas (PCCs), gastrointestinal stromal tumors (GISTs), and kidney cancer.  |
| 3 | 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 doctor and decide on a plan that works for you.  |
| 4 | Other medical concerns               | Individuals with <i>SDHB</i> mutations may have an increased risk to have a child with mitochondrial complex II deficiency, but only if their partner also carries a mutation in the <i>SDHB</i> gene. Mitochondrial complex II deficiency is a rare, highly variable autosomal recessive condition that can affect many different parts of the body, including the brain, heart, and muscles. |
| 5 | Family                               | Family members may also be at risk – they can be tested for the <i>SDHB</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.   |

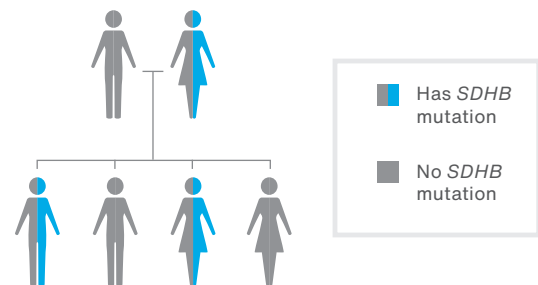
### *SDHB* Mutation Lifetime Cancer Risks\*



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

### *SDHB* Mutations in the Family

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



|           |           |  |
|-----------|-----------|--|
| Reach Out | RESOURCES | <ul style="list-style-type: none"> <li>• Pheo Para Alliance <a href="http://pheo-para-alliance.org">pheo-para-alliance.org</a></li> <li>• Pheo Para Troopers <a href="http://pheoparatroopers.org">pheoparatroopers.org</a></li> <li>• Genetic Information Nondiscrimination Act (GINA) <a href="http://ginahelp.org">ginahelp.org</a></li> <li>• National Society of Genetic Counselors <a href="http://nsgc.org">nsgc.org</a></li> <li>• Canadian Society of Genetic Counsellors <a href="http://cagc-accg.ca">cagc-accg.ca</a></li> </ul> |
|-----------|-----------|--|

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