

# Understanding Your Moderate Risk *RET* Genetic Test Result

## INFORMATION FOR PATIENTS WITH A MODERATE RISK MUTATION

### 6 Things to Know

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|---|--------------------------------|---|
| 1 | <i>RET</i> mutation            | Your testing shows that you have a moderate risk mutation in the <i>RET</i> gene.   |
| 2 | <i>RET</i> -related conditions | People with <i>RET</i> moderate risk mutations have multiple endocrine neoplasia type 2 (MEN2) or a variant of MEN2 called familial medullary thyroid carcinoma (FMTC).   |
| 3 | Cancer Risks                   | You may have an increased chance to develop medullary thyroid cancer, but lower than that of typical <i>RET</i> mutations. You may also have an increased risk for pheochromocytoma (PCC). Some people with <i>RET</i> moderate risk mutations never develop cancer.  |
| 4 | Other medical concerns         | You may have an increased risk for parathyroid overgrowth that can cause hyperparathyroidism and a rare skin condition known as cutaneous amyloidosis lichen.   |
| 5 | What you can do                | The specific <i>RET</i> moderate risk mutation you have may provide you more information about your specific tumor/cancer risks. Talk to your healthcare provider about which cancers you may be at risk for.<br><br>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>RET</i> moderate risk 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.   |

### *RET* Moderate Risk Mutations in the Family

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



Medullary thyroid cancer (MTC) lifetime risk is 95-100% in typical *RET* mutation carriers; however, you carry a moderate risk *RET* mutation. Risk for MTC in **moderate risk *RET* mutation** carriers is known to be **lower** than this and varies by the specific mutation. Your specific report will have details about your mutation. Talk with your provider for more information.\*

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

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| Reach Out | <b>RESOURCES</b> | <ul style="list-style-type: none"> <li>▪ Association for Multiple Endocrine Neoplasia Disorders (AMEND) <a href="http://amend.org.uk">amend.org.uk</a></li> <li>▪ Thyca: Thyroid Cancer Survivors' Association <a href="http://thyca.org">thyca.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> <li>▪ American Multiple Endocrine Neoplasia Support <a href="http://amensupport.org">amensupport.org</a></li> </ul> |
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Please discuss this information with your healthcare provider. The cancer genetics field is continuously evolving, so updates related to your *RET* 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.