

# Understanding Your Positive *MEN1* Genetic Test Result

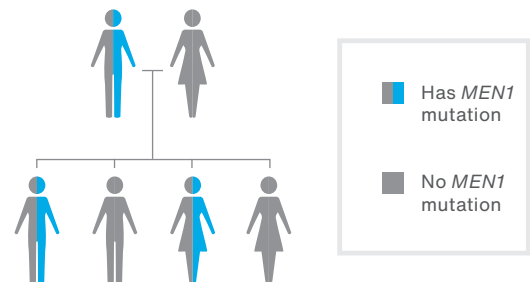
INFORMATION FOR PATIENTS WITH A PATHOGENIC MUTATION OR VARIANT, LIKELY PATHOGENIC

## 6 Things to Know

1	<i>MEN1</i> mutation	Your testing shows that you have a pathogenic mutation or a variant that is likely pathogenic in the <i>MEN1</i> gene.
2	Multiple endocrine neoplasia type 1	People with <i>MEN1</i> mutations have multiple endocrine neoplasia type 1 (MEN1) or familial isolated hyperparathyroidism (FIHP).
3	Non-cancerous tumor and cancer risks	<p>You have an increased risk for various tumors of the endocrine system (parts of the body that produce hormones); over 90% of people with an <i>MEN1</i> mutation will develop symptoms by age 50. While most tumors in MEN1 are not cancerous, some may develop into cancer.</p> <p>The following tumor types can occur:</p> <ul style="list-style-type: none"> <li>Parathyroid (four glands in your neck behind your thyroid)</li> <li>Digestive endocrine tract (most often in the intestine and/or the pancreas)</li> <li>Pituitary (one gland in the brain)</li> <li>Carcinoid (most often in the stomach, more rarely in the thymus or lung)</li> <li>Adrenal (two glands, one on top of each of your kidneys)</li> <li>Skin (growths that can occur on various parts of the body)</li> <li>Fatty tissue (lipomas)</li> </ul>
4	FIHP	Individuals with familial isolated hyperparathyroidism (FIHP) only have symptoms caused by parathyroid tumors, but they are not observed to have any other features of MEN1.
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>MEN1</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.

## *MEN1* Mutations in the Family

There is a 50/50 random chance to pass on a *MEN1* mutation to each of your children. The image to the right shows that everyone can carry and pass on these mutations, regardless of their sex at birth.



### RESOURCES

- Association for Multiple Endocrine Neoplasia Disorders (AMEND) [amend.org.uk](http://amend.org.uk)
- International Neuroendocrine Cancer Alliance [incalliance.org](http://incalliance.org)
- Genetic Information Nondiscrimination Act (GINA) [ginahelp.org](http://ginahelp.org)
- National Society of Genetic Counselors [nsgc.org](http://nsgc.org)
- Canadian Society of Genetic Counsellors [cagc-accg.ca](http://cagc-accg.ca)

Please discuss this information with your healthcare provider. The cancer genetics field is continuously evolving, so updates related to your *MEN1* 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.