



***MEN1* gene: What You Need to Know**

What does it mean to test positive for an *MEN1* gene mutation?

Mutations in the *MEN1* gene cause a condition known as Multiple Endocrine Neoplasia Type 1 (*MEN1*) syndrome.

Do I have an increased risk for cancer if I have an *MEN1* gene mutation?

If you have a *MEN1* gene mutation, you have a greater risk of developing certain types of benign tumors. Benign tumors are not cancerous and do not spread whereas malignant tumors are cancerous and can invade nearby healthy tissue and organs. Cancerous cells also have the potential to spread (metastasize) to other sites of the body. Benign and malignant tumors are often treated in different ways. In patients with *MEN1* syndrome, cancer can occur, but your likelihood of developing a cancer due to a *MEN1* gene mutation is low.

What type of tumors am I at risk for if I have an *MEN1* gene mutation?

All individuals with *MEN1* syndrome have an increased risk of developing tumors in the endocrine system as compared to the general population. The endocrine system is made up of endocrine glands, which secrete hormones to control important functions in the body such as mood, growth and development, and metabolism.

Three major endocrine systems are involved in *MEN1* syndrome:

- *Parathyroid glands*: About 95% of individuals with *MEN1* will develop a symptom called primary hyperparathyroidism by the age of 50. This means that the parathyroid glands are overactive, causing high calcium level in the bloodstream (hypercalcemia).
- *Pituitary gland*: A benign tumor occurs in the pituitary gland in about 10-60% of individuals with *MEN1*. This benign tumor can cause the pituitary gland to overproduce hormones or cause symptoms, such as vision changes or headaches.
- *Tumors of the gastro-entero-pancreatic (GEP) tract*: Up to 40% of individuals with *MEN1* develop benign growths in their pancreas or elsewhere in the glands of the gastrointestinal tract. Sometimes, these neuroendocrine tumors can become malignant (cancerous).

Another distinguishing feature of *MEN1* is the presence of tumors in the thymus gland, lung, small intestine and stomach called carcinoids. Carcinoids are endocrine tumors and are most often benign, but some can become cancerous. Individuals with *MEN1* can also develop adrenocortical tumors.

What is the chance that my family members will have an *MEN1* gene mutation if I test positive?

There is a 50% chance that a person with a mutation will pass it on to each of his/her children. In most cases, brothers and sisters of a person with a mutation have a 50% chance to have the mutation. Additionally, other family members are at risk to have the mutation.