Ambry Genetics®

Clinician Management Resource for *MEN1*

This overview of clinical management guidelines is based on this patient's positive test result for *MEN1* gene mutation. Unless otherwise stated, medical management guidelines used here are limited to those issued by the National Comprehensive Cancer Network (NCCN) in the U.S. Please consult the referenced guideline for complete details and further information.

Clinical correlation with the patient's past medical history, treatments, surgeries, and family history may lead to changes in clinical management decisions; therefore, other management recommendations may be considered. Genetic testing results and medical society guidelines help inform medical management decision but do not constitute formal recommendations. Discussions of medical management decisions and individualized treatment plans should be made in consultation between each patient and his or her healthcare provider and may change.

SCREENING CONSIDERATIONS ^,*,[1]	AGE TO START	FREQUENCY
Parathyroid		
Monitor serum calcium	8-15 years old	Annually
Pancreatic Neuroendocrine Tumors		
Follow previously elevated serum hormones or as symptoms indicate	8-15 years old	Individualized
Consider abdominal/pelvic CT or MRI* with contrast	8-15 years old	Every 1–3 years
Consider serial endoscopic ultrasound	8-15 years old	Individualized
Pituitary		
Pituitary or sella MRI with contrast of pituitary	8-15 years old	Every 3-5 years
Monitor prolactin, IGF-1, and other previously abnormal pituitary hormones	8-15 years old	Every 3-5 years, or as symptoms indicate
Bronchopulmonary/Thymic Neuroendocrine Tumors		
Consider chest CT or MRI* with contrast	8-15 years old	Every 1-3 years

^ For management of abnormal screening results or diagnosed tumors, see NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines) for Neuroendocrine and Adrenal Tumors v1. 2023.[1]

* For prolonged surveillance, studies without radiation are preferred.

1. Referenced with permission from the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines) for Neuroendocrine and Adrenal Tumors v1.2023. National Comprehensive Cancer Network, Inc. 2023. All rights reserved. Accessed December 6, 2023. To view the most recent and complete version of the guideline, go to NCCN.org. NCCN makes no warranties of any kind whatsoever regarding their content, use or application and disclaims any responsibility for their application or use in any way.

Understanding Your Positive *MEN1* Genetic Test Result

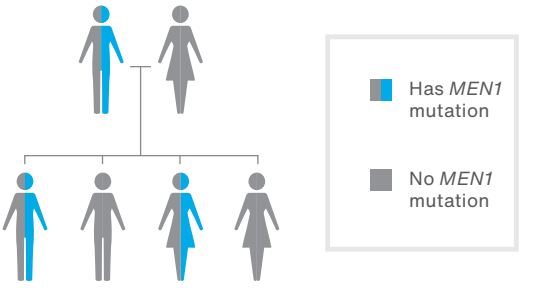
INFORMATION FOR PATIENTS WITH A PATHOGENIC MUTATION OR VARIANT, LIKELY PATHOGENIC

6 Things to Know

1	*MEN1* mutation	Your testing shows that you have a pathogenic mutation or a variant that is likely pathogenic in the *MEN1* gene.
2	Multiple endocrine neoplasia type 1	People with *MEN1* mutations have multiple endocrine neoplasia type 1 (MEN1) or familial isolated hyperparathyroidism (FIHP).
3	Non-cancerous tumor and cancer risks	You have an increased risk for various tumors of the endocrine system (parts of the body that produce hormones); over 80% of people with an *MEN1* mutation will develop symptoms by age 50. While most tumors in *MEN1* are not cancerous, some may develop into cancer. The following tumor types can occur: ▪ Parathyroid (four glands in your neck behind your thyroid) ▪ Digestive endocrine tract (most often in the intestine and/or the pancreas) ▪ Pituitary (one gland in the brain) ▪ Carcinoid (most often in the stomach, more rarely in the thymus or lung) ▪ Adrenal (two glands, one on top of each of your kidneys) ▪ Skin (growths that can occur on various parts of the body) ▪ Fatty tissue (lipomas)
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 *MEN1* 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
- International Neuroendocrine Cancer Alliance incalliance.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 *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.

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