

FLaNET

Clarity. Connection. Hope.



Volume 1 | NET Genetics

FLaNET Discusses

Could Your Neuroendocrine Tumor Be Genetic?

Neuroendocrine tumors (NETs) can develop sporadically, but others are connected to inherited genetic syndromes such as MEN1, MEN2, or Von Hippel-Lindau (VHL). Understanding whether a NET may have a genetic component can help patients and their families make more informed decisions about screening, treatment, and long-term care.

For many patients, genetic information can also provide clarity during an overwhelming and uncertain time by connecting symptoms, family history, and treatment options in ways that can influence care decisions for themselves and for future generations.

COMMON REASONS *for Genetic Testing*

Family history of NETs or unusual tumors

Diagnosis at a younger age

Multiple tumors or recurrent tumors

Pancreatic neuroendocrine tumors

Pheochromocytoma or paraganglioma diagnoses

Multiple family members with endocrine-related cancers

NET Genetics

What Does it Mean for a NET to Be Hereditary?

While most cancers are caused by genetic changes that occur during a person's lifetime, some NETs are linked to inherited genetic mutations passed down through families. These inherited conditions are often called **hereditary cancer syndromes**.

Did You Know?

50%

Chance of passing an inherited mutation to a child

20%

of VHL cases occur with no known family history

10%

of cancers are inherited mutations

Knowledge of inherited risk, advances in genetic testing, and earlier screening are helping families navigate hereditary cancer syndromes with greater clarity and proactive care.

During FlaNET's [NET Genetics Webinar](#), NET specialists discussed several hereditary syndromes associated with neuroendocrine tumors, including:

Multiple Endocrine Neoplasia Type 1 (MEN1)

MEN1 is one of the most common hereditary syndromes associated with NETs. It can affect the pancreas, pituitary gland, and parathyroid glands, and may increase the risk of developing pancreatic neuroendocrine tumors.

Multiple Endocrine Neoplasia Type 2 (MEN2)

MEN2 is associated with medullary thyroid cancer, pheochromocytomas, and other endocrine tumors. Some forms may require very early screening or preventive intervention.

Von Hippel-Lindau Syndrome (VHL)

VHL is a hereditary condition associated with both benign and malignant tumors, including pancreatic neuroendocrine tumors, kidney cancers, adrenal tumors, and tumors affecting the brain and spinal cord.

Living with VHL

Lupe's Story

Lupe was diagnosed with Von Hippel-Lindau syndrome (VHL) at age 24 after doctors discovered a tumor on her spinal cord. Although her father had passed away young with a history of tumors, her family initially knew very little about VHL or how inherited syndromes worked.

Over time, Lupe experienced additional tumors affecting her spine, kidney, and pancreas. Years later, she was diagnosed with a pancreatic neuroendocrine tumor that was difficult to detect and eventually required extensive treatment and surgery.

Today, Lupe continues treatment while advocating for the importance of persistence, screening, and patient education.

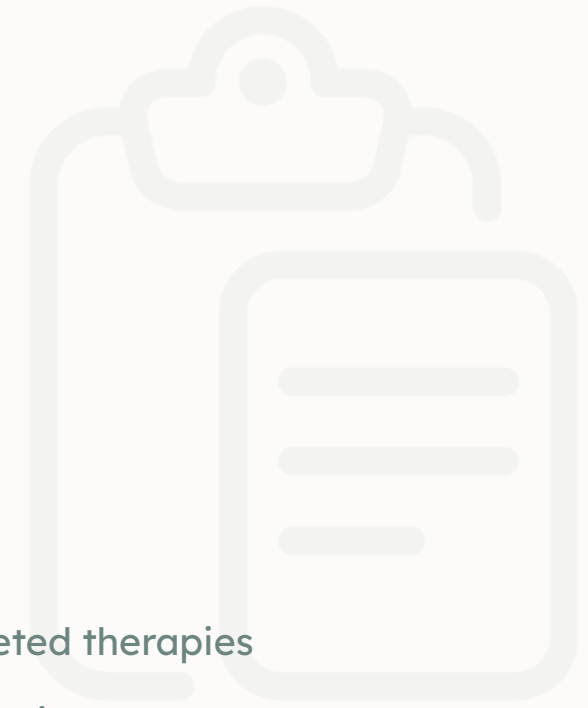
"If you feel that something's not right, keep pushing to get scans because your body's trying to tell you something."

— Lupe (patient with NETs)

HOW GENETIC INFORMATION CAN Influence Treatment

Genetic information may help physicians:

- Recommend earlier screening
- Monitor family members appropriately
- Guide treatment decisions
- Identify patients who may benefit from targeted therapies
- Reduce unnecessary procedures in some situations



WHY GENETIC

Counseling Matters

Genetic counselors can help patients:

- Understand testing options
- Interpret results
- Navigate family communication
- Understand screening recommendations
- Connect with specialists and support Resources



For many families, access to clear explanations and trusted guidance can reduce fear and confusion during an already difficult time.

Connected Care

FLaNET: Neuroendocrine Cancer Community

At FLaNET, we believe patients and caregivers deserve access to clear, compassionate, and trustworthy information about NETs.

Whether you are newly diagnosed, supporting a loved one, or exploring genetic testing options, you do not have to navigate the process alone.



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