



**OUR MISSION** is to optimize the care of those with neuroendocrine cancer through the education of and collaboration among physicians, health care providers, patients, and caregivers.

## PROGRAMS/RESOURCES

Learn more at [www.thehealingnet.org](http://www.thehealingnet.org)

### Navigating the NET Patient Journey

A publication and an evolving online hub of information and resources by and for patients and caregivers.

### High-Grade Neuroendocrine Cancers

*A Guide for Patients and Caregivers*

Request a print copy or download a PDF.

### Neuroendocrine Tumors:

*A Primer for Healthcare Professionals*

Downloadable PDF and online content for providers caring for patients with neuroendocrine cancer.

### Healthcare Provider Education

Learning opportunities for healthcare providers in neuroendocrine cancer care.

### Patient Education, Awareness & Support

Vetted information, shared experiences, and links to other resources via the website, newsletter, and social media.

### International Healing NET Summit

A meeting of invited NET experts who collaborate to envision the future of patient care.

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*“The right treatment  
by the right team  
at the right time”*

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# 10 NET FACTS

Why education and raising awareness of neuroendocrine tumors is so critical.

- 1. YES, IT'S CANCER** The older term for neuroendocrine tumors (NETs) is carcinoid (meaning carcinoma-like), which can create confusion that the tumors are benign.
- 2. HOW RARE IS IT?** Neuroendocrine cancer is considered rare, but a recent study in the U.S. showed an increase in the incidence from 1 in 100,000 in 1973 to 7 in 100,000 in 2012, possibly due to better diagnosis.
- 3. DIFFERENT IN EACH PATIENT** The cancer can arise anywhere there are endocrine or hormone-producing cells, such as the lung, small intestine, rectum, pancreas, or other sites. Some patients are asymptomatic, but others may have significant symptoms.
- 4. DIFFICULT TO DIAGNOSE** Patients often go 5-7 years without a correct diagnosis. Symptoms, such as diarrhea and flushing, can mimic other common diseases like asthma or inflammatory bowel disease. Medical students are taught to think *horses*, or typical diseases, when they hear hoofbeats, rather than to think *zebras*, or exotic diseases.
- 5. MANAGED BUT RARELY CURED** NETs often metastasize to sites such as the liver, lungs, bone or lymph nodes. Because many are slow-growing, they can take years to show on scans. There is a risk of under-treating the disease by not recognizing its full extent and over-treating where tumors are growing slowly.
- 6. NOT ALL ARE SLOW-GROWING** Some types of neuroendocrine cancer, high-grade NETs and poorly differentiated neuroendocrine carcinomas, grow more quickly and require timely assessment and treatment.
- 7. MULTIDISCIPLINARY TEAM** Patients benefit the most from a multidisciplinary care team, ideally with a “quarterback” who has NET expertise.
- 8. NEW TREATMENTS AND DIAGNOSTIC TOOLS** In recent years the FDA has approved new diagnostic tests, medications and therapies, which have led to better diagnosis and treatment of NET cancer.
- 9. NEW CLINICAL TRIALS** Trials are ongoing and actively recruiting patients. You can search [trialstoday.com](http://trialstoday.com), [ancora.ai](http://ancora.ai), or [clinicaltrials.gov](http://clinicaltrials.gov). Talk to your physician to understand if any trials are suitable for you.
- 10. INSURANCE REIMBURSEMENT** Like anyone with a rare or chronic disease, NET patients often find themselves battling for coverage because of the newness and expense of some tools and treatments.