

# **Neuroendocrine tumors (NETs)**

Through the science of targeted therapies, our goal is to reduce the global disease burden and extend the lives of patients with neuroendocrine cancer.

Neuroendocrine tumor, or NET, is a rare type of cancer that originate in neuroendocrine cells throughout the body. They are often found in the gastrointestinal tract, lungs, or pancreas. The annual age-adjusted incidence of NETs was 6.98 per 100 000 persons by 2012. NETs can be defined as functional or nonfunctional. Functional NET are characterized by symptoms caused by the over-secretion of hormones and other substances, while nonfunctional NETs may be clinically silent.

Symptoms may appear if the tumor produces hormones or grows into surrounding tissues and organs. Non-specific signs and symptoms of NET include, but are not limited to, abdominal pain, diarrhea, flushing.<sup>4</sup>

NET tend to grow slowly and can have no symptoms or vague symptoms that can be mistaken for other conditions. As a result, NET is often diagnosed at an advanced stage.<sup>5</sup>



## **NET Cancer Day**

We recognize NET Cancer Day on November 10 to raise awareness of neuroendocrine tumors. NET Cancer Day was founded by the International Neuroendocrine Cancer Alliance (INCA). We are joining forces with NET patient advocates to shed light on this rare, often misdiagnosed form of cancer.

Learn more

NET Cancer Support Groups help many people cope with the emotional aspects of cancer by providing a safe place to share their feelings and challenges and learn from others who are facing similar situations.



## Find a support group

There are NET Cancer Support Groups for patients and their caregivers all over the world.



### Gastroenteropancreatic neuroendocrine tumor

If you've been diagnosed with a gastroenteropancreatic neuroendocrine tumor (GEP-NET), InsideNETdisease.com is here to help.

## **Patient stories**

Without realizing, I had probably symptoms for about 18 months before I actually had a diagnosis. The initial diagnosis from the doctor looking at the mass wasn't the tumor that I had. Her initial diagnosis was prostate cancer.

#### Roy

#### Watch the video

I first started to feel pain probably about 10 years before my diagnosis. I had sharp dull ache in my abdomen, the pain wasn't going away. After several visits to the doctors, I was sent off for an ultrasound and CT scan: there was a suspicious mass that was a neuroendocrine tumour.

#### Rachael

#### Watch the video

It's hard to actually say when I first experienced my first symptoms. At no point had I even considered that I might have cancer.

#### Carolyn

#### Watch the video

I was tired all the time. It impacted on my social life. My journey was up and down, I would call it a roller-coaster ride.

#### Kath

Watch the video

## Related links

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#### References:

- 1. Neuroendocrine tumor: Genetic and Rare Diseases Information Center (GARD). Available at https://rarediseases.info.nih.gov/diseases/13445/neuroendocrine-tumor [Accessed Feb 2023]
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- 3. Cancer.Net. Available at <a href="https://www.cancer.net/cancer-types/neuroendocrine-tumors/introduction">https://www.cancer.net/cancer-types/neuroendocrine-tumors/introduction</a> [Accessed Feb 2023]
- 4. Cancer.Net. Available at <a href="https://www.cancer.net/cancer-types/neuroendocrine-tumors/symptoms-and-signs">https://www.cancer.net/cancer-types/neuroendocrine-tumors/symptoms-and-signs</a> [Accessed Feb 2023]
- 5. Capdevila et al. Meta-Analysis of Randomized Clinical Trials Comparing Active Treatment with Placebo in Metastatic Neuroendocrine Tumors. 2019; e1315-e1320; doi: 10.1634

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