

ABOUT CNETS

CNETS is the only Canadian charitable organization supporting the neuroendocrine cancer patient community. Our free patient specific services include:

- Live patient support over the phone or via email
- In person patient support groups in many regions across Canada
- Free patient education sessions across Canada featuring Canada's top NET cancer medical professionals
- Free information sent directly to your door about NET cancer, latest diagnostics, and treatment options available in Canada and where to find Canadian NET experts
- One-on-one connection with another patient who has the same specific type of NETs
- We can connect you with other support resources available in your region

NET REFERENCE GUIDE

Request a copy of our comprehensive NET Reference Guide for Patients and Families, or download a soft copy from our website.



We're
here for
YOU!



CONTACT US

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Facebook Support Forum

Canadian Neuroendocrine Zebras -
CNETS Community Support Group



**NEUROENDOCRINE
TUMOURS
(NETs)**



**CANADIAN
NEUROENDOCRINE
TUMOUR SOCIETY**

NeuroEndocrine Tumours (NETs) are a broad group of complex tumours that arise from neuroendocrine cells.

The most common types occur in the lungs, bronchi, thymus, pituitary, thyroid, adrenals, small intestine, pancreas, appendix and rectum.

Less frequently NETs may occur in the parathyroids, ovaries, cervix, testicles, spleen, skin and breast, but these are considered very rare.



60 - 80%
of NET cancer patients
are diagnosed with
advanced disease.

NET Cancer is often **misdiagnosed**

as something else and by the time a patient is correctly diagnosed the cancer has often spread to other parts of the body.

Early, accurate diagnosis is the first step towards successful and better outcomes.

DIAGNOSING NEUROENDOCRINE TUMOURS

NeuroEndocrine Tumours (NETs) can be difficult to diagnose because symptoms can be vague. They often metastasize (cancer spreads) to the liver and bone before showing any symptoms.

When symptoms are present (dependent on the type of NET tumours), they're often unclear and similar to common health problems like Irritable Bowel Syndrome, Crohn's disease, asthma or menopause.

As a result, NETs are often misdiagnosed, and the average time to proper diagnosis is between five to seven years.

Symptoms depend on the type of tumour, but can include:

- Diarrhea
- Abdominal cramps
- Flushing of the skin
- Wheezing or shortness of breath
- Pounding of the heart

Important tests are:

Blood: Chromogranin A (CgA), Hormones

Urine: 5-HIAA

Scans: Ga68 PET, CT, MRI, Octreoscan

WHAT CAUSES NEUROENDOCRINE CANCER?

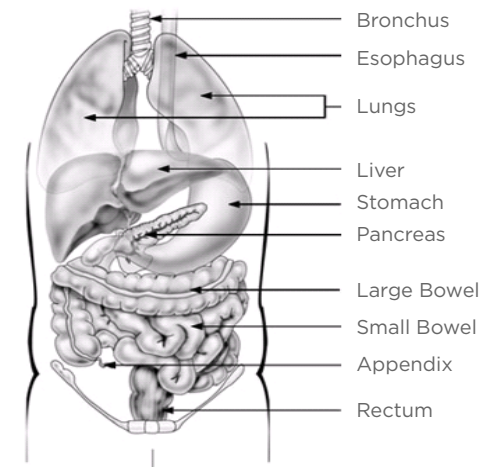
Most NETs have no known cause, but are almost always malignant (cancerous).

STAGING & GRADING

The **stage** of NETs depends on the tumour size, spread to the lymph nodes or other organs.

The **grade** of NETs is based on whether they are **well differentiated** (look close to normal cells) or **poorly differentiated** (abnormal looking cells), and how fast they grow (proliferative index, G1, G2, G3).

SITES WHERE NEUROENDOCRINE TUMOURS CAN APPEAR



PLUS: Hypothalamus, Pituitary Gland, Adrenal Glands, Parathyroid Glands, Thyroid Gland, Thymus Gland and Skin.

TREATMENT OPTIONS

NET treatment plans depend on the stage and grade and the type of hormones (if any) secreted.

There are many treatment options available and surgical removal of very small, localized tumours is the only curative therapy.

Generally, the goals of treatment are to eliminate the tumour or reduce its size, control the effects of hormones produced by the tumour; manage complications and symptoms caused by the disease itself or hormone secretion.

Ideally, a multidisciplinary team of specialists will work with the patient to determine the best treatment plan.