

NET cancer: Understanding a rare disease

A guide to understanding neuroendocrine tumors (NETs) and the role of imaging



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Rare, but you're not alone

Because it's considered a rare disease, **NET cancer has not been top of mind for many doctors.** This has prevented it from being more prioritized for medical research. However, as awareness increases, diagnoses are increasing too, showing that **this disease is not as rare as once thought.**

Although awareness is increasing, medical students are typically taught that when they hear hoofbeats, they should think horses, not zebras. In other words, they should expect more common conditions before a rare disease like NET cancer. That's why **the NET cancer community has adopted the zebra as a symbol.** And since no 2 zebras have the same coat pattern, they represent the fact that each person living with NETs will have their own unique journey.

NET cancer explained

When the cells of your neuroendocrine system grow abnormally, it can lead to **neuroendocrine tumors, or NETs.** Your **neuroendocrine system is made up of a combination of neurological (nerves) and endocrine (glands) processes throughout your body, and it regulates the release of hormones into your blood.** Some areas are more common for NETs, but they can occur in many parts of the body.

Some facts about NETs

- i** NET cancer is **often treatable**, and **many patients survive years after diagnosis**
- i** NETs often start in the **digestive tract** and develop most commonly in the **stomach, small intestine, pancreas, rectum, colon, and lungs**
- i** Although rare, NETs are the **second most common type of identified gastrointestinal cancers** after colon cancer
- i** While considered slow growing, **the rate at which they may grow or spread is unpredictable**
- i** NET cancer diagnosis has been on the rise, which could be due to **better diagnostic tools and an increasing awareness**
- i** Sometimes NETs can be more aggressive and **spread to other parts of the body**. This is called **metastasizing**
- i** For this reason, it is important that a medical team performs a **full diagnostic workup** and **continues to monitor the disease**
- i** **Survival for NET cancers has improved** due to more effective therapies and earlier diagnosis, and is determined by the location of NETs and whether they have spread

YOUR DIAGNOSTIC JOURNEY

What to expect

Every person's path to receiving or confirming a NETs diagnosis is different. The example on the next 2 pages can help give you an idea of what to expect, so you can plan and make the most of appointments with your healthcare team.

1

Start of symptoms

What might happen

- Getting your symptoms evaluated
- Getting medication prescribed to you if needed
- Setting up follow-up appointments
- Getting referred to a specialist if symptoms haven't improved on follow-up

Who you might see

- Primary care physician
- Gynecologist

You can find definitions for each of these specialists in the glossary of healthcare professionals on [page 23](#).

2

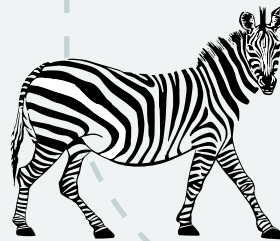
Seeing a specialist

What might happen

- Having a focused discussion about your symptoms
- Getting additional medication prescribed if needed
- Going through diagnostic tests to check for tumors
- Getting referred to cancer specialists if tumors are found or suspected

Who you might see

- Gastroenterologist
- Endocrinologist
- Pulmonologist



3

Cancer care

What might happen

- A review of your previous test results and additional tests if needed
- Imaging of tumors
- Creation of a treatment plan
- Ongoing care

Who you might see

- Oncologist
- Nuclear medicine physician
- Radiation oncologist
- Interventional radiologist
- Surgeon

Why NETs can be hard to find

NETs don't always immediately cause symptoms. The presence and type of symptoms depend on where the tumor is located and whether the tumor is functional or nonfunctional.

- **Functional NETs** cause symptoms because they produce too much of a hormone
- **Nonfunctional NETs** may not cause symptoms because they either don't make hormones or don't make enough for symptoms to occur

NET symptoms may include:



Diarrhea



Feeling more tired than usual



Abdominal pain



Skin reactions like flushing



Sweating, dizziness, headaches, or nausea



Anxiety



Feeling breathless



Changes in blood pressure



Heartburn



Weight loss

It's important to keep track of your symptoms, including when and how often you experience them and their severity. Doing so will help you have more productive discussions with your healthcare team.

Download a helpful tool you can use to keep track of symptoms, doctor's visits, and other important information at www.lacnets.org/netvitals.

You can learn more about this resource on [page 26](#).

An accurate diagnosis is crucial



Because these symptoms are nonspecific and other diseases can cause similar symptoms, people with NETs may be misdiagnosed. It may take many doctor visits over several years to receive an accurate diagnosis. Meanwhile, people might continue to live with it without realizing. Doing so can potentially allow NETs to spread, or metastasize.

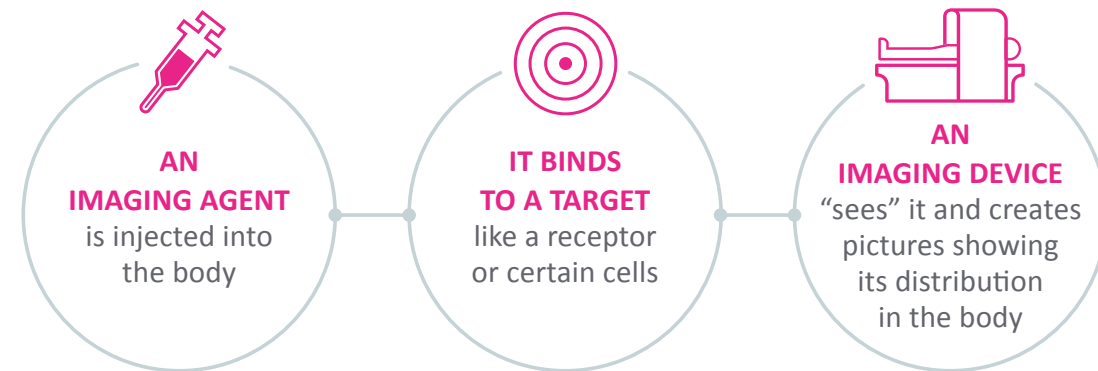
Diagnostic testing

NETs can also be quite small, so it's important to receive the right kind of diagnostic testing to make sure they can be seen. Diagnostic tests can include biopsies, blood tests, urine tests, and other procedures such as conventional or molecular imaging.

What is molecular imaging?

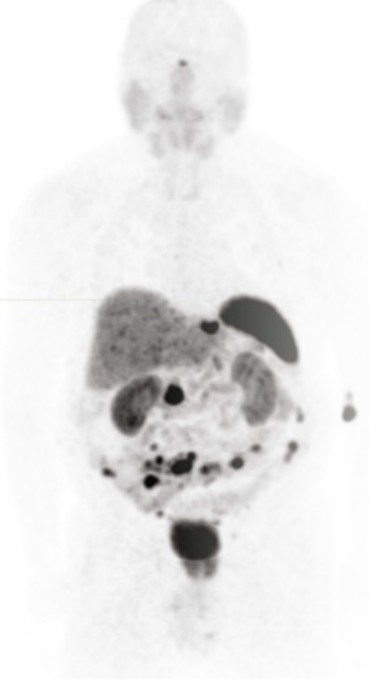
Molecular imaging, such as positron emission tomography (PET) scans, is a type of diagnostic testing. It provides detailed pictures of what is happening inside the cells that make up the tissues in your body and how those cells are working. **It can detect changes that occur early in a disease, often well before these changes can be seen on computed tomography (CT) or magnetic resonance imaging (MRI) scans.**

How molecular imaging provides doctors with important information



Doctors examine the distribution patterns of the imaging agent to better understand how organs and tissues are functioning.

- Determine how serious the disease is and if it has spread to other parts of the body
- Choose an appropriate treatment option
- Assess disease progression over time
- Identify if the disease has come back (recurred) after treatment



SSTR PET image of patient with metastatic tumors in the small-bowel region.

Why get a somatostatin receptor (SSTR) PET scan?

PET scans can help locate possible NETs, which can pose serious health risks. **They can identify NETs in their early stages, often before symptoms start or before other tests detect them.** Specifically, SSTR PET scans are able to target somatostatin receptors, which are found in higher-than-normal amounts on cancer cells like the ones that make up NETs.

The information provided by an SSTR PET scan can help determine whether certain advanced treatments should be used.

If you suspect you may have NETs, SSTR PET scans can help detect them. If you have already been diagnosed, SSTR PET scans can help determine the extent of the disease.

SSTR PET scans can help determine the extent of the disease so your doctor can develop a treatment plan.

Available treatment options for NETs

A treatment plan for NETs is primarily based on the size and location of the tumor, whether the cancer has spread, and your overall health. The goal of treatment is to improve and reduce your symptoms, control the growth of the tumor, and help you maintain a good quality of life.

Several treatment options are available, and your healthcare team will work closely with you to determine which is best. It's important to discuss what's right for you with your healthcare team.

A few treatment options include:

Surgery and interventional radiology

- Ideal for tumors with limited or no spread
- Can be used in combination with other therapies

Somatostatin analogs (SSAs)

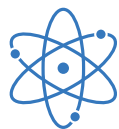
- Injections that can help stop overproduction of hormones that cause flushing, wheezing, diarrhea, and other NETs symptoms
- May also control tumor growth

Targeted therapy

- Uses drugs to identify and attack cancer cells
- Can be used in combination with other therapies

Liver-directed treatment

- Radiofrequency ablation (RFA) uses an electric current to heat and destroy tumors
- Hepatic artery embolization seals off the blood vessels leading to the tumor to block its blood supply



Radionuclide therapy or peptide receptor radionuclide therapy (PRRT)

- By using an imaging agent that binds to somatostatin receptors (SSTRs), SSTR PET can help identify the location, size, and extent of tumors. PRRT can target SSTR to treat the tumors
- Radiation specifically binds to cancer cells while minimizing damage to surrounding healthy tissue



Chemotherapy

- May be used to treat pancreatic and lung NETs, as well as NETs that grow more quickly than normal
- Primary site for NETs can help determine if chemotherapy is appropriate or not

Find your herd

Having a strong support system is important when living with a rare disease. Many organizations offer support, education, and resources for those living with NETs and their care partners at no cost and without the need for additional doctor's visits. You can read about a few on the pages ahead.



incalliance.org



lacnets.org



netcancerawareness.org



thehealingnet.org



netrf.org



norcalcarcinet.org

This is not a comprehensive list of NET advocacy organizations. You can ask your healthcare provider about additional local organizations.

WHERE CAN I LEARN MORE?

International Neuroendocrine Cancer Alliance (INCA) | incalliance.org

- Umbrella organization that represents 34 patient advocacy and research groups worldwide
- Patients and HCPs can access a wealth of resources, including NET info packs, advocacy toolkits, and much more
- Provides information on research and clinical trials

Learn, Advocate, Connect: A Neuroendocrine Tumor Society (LACNETS) | lacnets.org

- Advocacy- and education-focused organization that provides webinars, patient education conferences, video library, a podcast, and a blog dedicated to the latest medical information and research studies
- Patients and caregivers can connect with a mentor for support through NETCONNECT

Neuroendocrine Cancer Awareness Network (NCAN) | netcancerawareness.org

- Plans and hosts numerous year-round fundraising and awareness events throughout the United States
- Resources include a YouTube channel that features past patient conferences and informational videos on NETs, a toll-free hotline for patients and caregivers, support group information, and much more

Healing NET Foundation | thehealingnet.org

- Patients, caregivers, and doctors can access online hubs that cover a range of topics, including self-care, insurance, Medicare, and more
- Zebra Stories provide an opportunity for patients and their families to share their unique stories and experiences living with NETs

Neuroendocrine Tumor Research Foundation (NETRF) | netrf.org

- Comprehensive website features a robust patient section with information on the different types of NETs, diagnostic testing, finding the right care team, and more
- Patients can stay connected and learn more about their disease through a monthly podcast, YouTube channel, newsletter, and patient stories

NorCal CarciNET | norcalcarcinet.org

- Patients and their doctors can access the first NETs trial finder tool (ancora.ai/neuroendocrine) to locate and access suitable clinical trials
- Offers virtual, live, and recorded Yoga for NET Cancer classes for all levels

Glossary of healthcare professionals

Endocrinologist: A doctor who specializes in the endocrine system, which creates and releases your body’s hormones

Gastroenterologist: A doctor who specializes in the digestive system

Gynecologist: A doctor who specializes in the female reproductive system

Interventional radiologist: A doctor who diagnoses and treats disease using medical imaging, or viewing the inside of the human body

Nuclear medicine physician: A doctor who specializes in imaging or treating disease with radioactive agents

Oncologist: A doctor who specializes in diagnosing and treating cancer

Primary care physician: A doctor who practices general medicine, typically your first point of contact when symptoms begin

Pulmonologist: A doctor who has special training in diagnosing and treating diseases of the lungs

Radiation oncologist: A doctor who specializes in treating cancer with radiation therapy, which is the targeted use of high-energy particles to kill cancer cells

Surgeon: A doctor who treats disease by performing surgery

Early and accurate diagnosis is key



NETs MAY SPREAD IN THE BODY

SSTR PET SCANS CAN LOCATE NETs

YOUR HEALTHCARE TEAM WILL MAKE A PLAN

Because NETs may spread, it's important that you receive thorough diagnostic testing and be continually monitored by your healthcare team

SSTR PET scans, a type of molecular imaging, can identify NETs even before you notice any symptoms and help determine which treatments are right for you

Your healthcare team will determine the best treatment option based on the size and location of the tumor

PET scans are an important part of the diagnostic process. Talk to your healthcare team to learn if a PET scan is right for you.

Explore pages [26](#) to [28](#) for **resources** that may help you stay organized during treatment.



Keep track of your health

Keeping track of your health over time is important but isn't always simple to do.

The tracker tool at www.lacnets.org/netvitals can help by providing a place to record:

- Symptoms
- Treatments you've received
- Upcoming appointments
- General information

Or, for a quick way to track doctors' appointments, refer to the next page.

Track your appointments

You may find it helpful to keep track of your doctors' names and questions to ask at your next appointment here or on the notes app of your phone.

DATE: ___/___/_____

DATE: ___/___/_____

TIME: ___:___ _____

TIME: ___:___ _____

FACILITY NAME: _____

FACILITY NAME: _____

FACILITY PHONE NUMBER: (____)____-____

FACILITY PHONE NUMBER: (____)____-____

FACILITY ADDRESS: _____

FACILITY ADDRESS: _____

SCAN: yes no

SCAN: yes no

TYPE OF IMAGING USED: _____

TYPE OF IMAGING USED: _____

NOTES: _____

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DATE: ____ / ____ / _____

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FACILITY NAME:

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