

#AskMeAboutNETs



Good afternoon,

I'm reaching out to you because someone close to me was diagnosed with neuroendocrine tumor (NET), also known as neuroendocrine cancer. In hopes of educating healthcare professionals and raising awareness about this disease, I'd like to share some information and resources with you.

Neuroendocrine tumor (NET) or neuroendocrine cancer is a rare disease that affects 6.98 in 100,000 people in the U.S. Most patients are misdiagnosed for years before they are diagnosed with NETs, but with continuous advances in imaging, genetics and research, we are now moving toward earlier detection and diagnosis - and this is where I can use YOUR expertise and help!

Attached to this note, I've included:

- Facts about NET
- Resources for healthcare professionals
- Resources for patients and caregivers
- Information about NET Cancer Day (a day dedicated to increasing awareness of NET)

In an effort to raise awareness about NETs in the healthcare community, would you please share this information with at least two of your colleagues and community members? Together, we can raise awareness for this disease and strive for accurate and early diagnosis.

Thank you for taking the time to read this letter and attached information.

We are stronger together. #AskMeAboutNETs

FACTS ABOUT NET

Neuroendocrine Cancer is often referred to as NET (neuroendocrine tumor). Other terms commonly used refer to the primary tumor site (e.g. PNET or pancreatic NET) or the hormone that the tumor secretes (e.g. Insulinoma or VIPoma)

The terms “carcinoid” or “carcinoid cancer” is generally considered obsolete. Neuroendocrine neoplasm (NEN) is another term sometimes seen in medical literature such as the World Health Organization (WHO) classification of NEN.

Did you know?

NET is not cancer-like; it is cancer. Though some are benign, most are malignant.

NET is a rare cancer that affects about 6.98 in 100,000 people in the U.S.

NET affects neuroendocrine tumor cells, which are hormone-producing cells most commonly found in the gastrointestinal system (stomach, small intestine, large intestine, rectum, the lung, and pancreas. It often spreads to the lymph nodes, liver, and bones.

Patients diagnosed with NET should be seen by a multidisciplinary team which includes a NET specialist.



Symptoms

Less than half of all NET patients will be symptomatic, which hinders diagnosis. When symptoms are present, they are typically caused by functional (hormone-producing) tumors. These symptoms include:

- Flushing
- Bloating/gas
- Diarrhea
- Shortness of breath
- Nausea
- Low blood pressure
- Abdominal cramping
- Hypertension.

Carcinoid Syndrome

When not caused by functional pheochromocytoma/paraganglioma, this constellation of symptoms is referred to as “carcinoid syndrome.” More information about carcinoid syndrome may be found at www.carcinoidsyndrome.org.

Genetic Link

Although some NETs have a genetic link, most have no known cause. Pheochromocytoma and paraganglioma are two types of NETs which are strongly associated with inherited genetic mutations.

SYMPTOMS

Symptoms caused by NET can mimic those attributable to other, more common diseases like asthma, IBS, or Crohn's. The following represents a list of possible symptoms caused by neuroendocrine tumors:

- Dry Flushing (redness, warmth) of the face and neck
- Diarrhea
- Rapid heartbeat/palpitations
- Damage of the heart valves
- Abdominal Cramping/Pain
- Blood pressure changes (High or low)
- Urgency to defecate
- Unexplained weight loss
- Unexplained weight gain
- Skin rash or discoloration
- Fatigue or weakness
- Joint pains
- Wheezing
- Coughing
- Shortness of breath
- Anxiety
- Swelling in feet and ankles
- High glucose levels
- Low glucose levels
- Heartburn
- Indigestion
- Pain in the chest
- Bowel blockages
- Chronic pancreatitis



Resources for Health Care Providers



Note: The terminology on this page (Neuroendocrine Tumor/Neuroendocrine Cancer/Carcinoid) varies by organization but are all applicable to this family of cancers.

The Healing NET Foundation - (www.thehealingnet.org)



CME credit offered

The Healing NET Foundation 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.

The Healing NET Foundation offers a FREE NET Boot Camp for healthcare professionals to:

- help assess disease using appropriate diagnostic and imaging tools to build a sound treatment plan
- understand the role of surgery and other local interventions to treat neuroendocrine neoplasms
- discern the appropriate use of systemic therapy for these tumors

To learn more and attend the next NET Boot Camp, visit netbootcamp.pathable.co.

Healing NET's Publication Neuroendocrine Tumors: A Primer for Healthcare Professionals - The Healing NET Foundation's Medical and Scientific Advisory Board wrote a booklet that summarizes our understanding of NET cancer and ways to recognize and treat it. The booklet serves healthcare professionals of many disciplines and is also useful to patients and caregivers. Their goal is to positively impact the quality of life and improve outcomes for NET patients. Download the booklet here:

www.thehealingnet.org/neuroendocrine-tumors-a-primer

NANETS - (www.NANETS.net)



CME credit offered

The North American Neuroendocrine Tumor Society's (NANETS) mission is to improve outcomes for patients with neuroendocrine tumors through multidisciplinary medical education, NET related medical research, publication of guidelines and the exchange of knowledge and innovation.

NET medical educational programming is designed exclusively for medical professionals, by leading medical professionals in the field. All members of NANETS benefit from the on-going sharing of medical knowledge and experience and the constant exchange of the very latest information in NET disease diagnosis, treatment and supportive care.

NANETS is a 501(C)3 non-profit medical society that hosts regional NET education conferences and an annual symposium that features sessions on the latest NET disease diagnosis, treatment and management presented by well-known leaders and experts in the field. The annual symposium is also an opportunity to recognize outstanding work being done in NET research through the call for abstracts. Abstracts are compiled in a yearly publication and serve as a comprehensive guide to the latest in NET research. Visit www.NANETS.net to learn about upcoming conferences and events.

Resources for Health Care Providers



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NCCN Guidelines - (www.NCCN.org)



Over the past 25 years, the National Comprehensive Cancer Network (NCCN) has developed an integrated suite of tools to improve the quality of cancer care. The NCCN Guidelines® document evidence-based, consensus-driven management to ensure that all patients receive preventive, diagnostic, treatment, and supportive services that are most likely to lead to optimal outcomes.

The NCCN Guidelines® are the recognized standard for clinical direction and policy in cancer care and are the most thorough and frequently updated clinical practice guidelines available in any area of medicine. The intent of the NCCN Guidelines is to assist in the decision-making process of individuals involved in cancer care—including physicians, nurses, pharmacists, payers, patients and their families—with the ultimate goal of improving patient care and outcomes.

To download the NCCN Guidelines for Neuroendocrine Tumors, go to bit.ly/nccnguidelines.

NETRF - (www.NETRF.org)



The mission of the Neuroendocrine Tumor Research Foundation (NETRF) is to fund research to discover cures and more effective treatments for neuroendocrine cancers. NETRF is committed to improving the lives of patients, families, and caregivers affected by neuroendocrine cancer by providing information and educational resources.

NETRF is committed to improving, extending, and saving the lives of those affected by neuroendocrine cancer by providing information and educational resources:

- Online resources to help newly diagnosed patients chart their course and practical information to help NET survivors live their best life.
- Searchable databases of NET specialists and patient support groups in the U.S.
- Regional patient and caregiver conferences bring together patients and providers to discuss the latest tests and treatments.
- Multimedia library of the latest information on treatment and disease management approaches.

To learn more about NET research and view the NETRF database, visit www.netrf.org.

Patient Resources

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LACNETS - (www.LACNETS.org)



The mission of the Los Angeles Carcinoid Neuroendocrine Tumor Society (LACNETS) is to provide a community of support and education for patients/those with neuroendocrine cancer and to advocate for all people impacted by this rare disease by expanding awareness and by voicing the patient's perspective in collaborative dialogue with healthcare professionals.

LACNETS programs are free to patients and caregivers. LACNETS programs include webinars, virtual support groups, conferences, and supportive resources. To view the full list of LACNETS resources, go to www.LACNETS.org/resources.

Carcinoid Cancer Foundation - (www.carcinoid.org)



The Carcinoid Cancer Foundation is the oldest nonprofit carcinoid/and related neuroendocrine tumor organization in the United States, founded in 1968. The mission of this foundation is to increase awareness and educate the general public and healthcare professionals regarding carcinoid and related neuroendocrine tumors (NETs), to support NET cancer patients and their families, and to serve as patient advocates. To learn about upcoming webinars and events, visit www.carcinoid.org.

The Healing NET Foundation - (www.thehealingnet.org)



The Healing NET Foundation mission: To optimize the care of those with neuroendocrine cancer through the education of and collaboration among physicians, health care providers, patients, and caregivers.

Navigating the NET Patient Journey: Peer-to-peer publication for patients and caregivers - Navigating the NET Patient Journey was written by a group of support group leaders, patients, and caregivers, who are on the NET journey themselves, so that fellow patients and caregivers can benefit from their observations of the roads they have traveled. They also invited some experts who are dedicated to the care of people with neuroendocrine cancer to share their perspective. To download the booklet, go to www.thehealingnet.org/navigating-nets.

NCAN (www.netcancerawareness.org)



The Neuroendocrine Cancer Awareness Network (NCAN) is a non-profit organization dedicated to raising awareness of Neuroendocrine Cancer, providing support for caregivers and people with NETs, and funding for NET cancer research. Since 2003, it has been their mission, or as they like to say, their passion, to educate and support the NET community as a whole. To learn about upcoming NCAN conferences and events, visit www.netcancerawareness.org/upcoming-events.

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The NCCN Guidelines® are the recognized standard for clinical direction and policy in cancer care and are the most thorough and frequently updated clinical practice guidelines available in any area of medicine. The intent of the NCCN Guidelines is to assist in the decision-making process of individuals involved in cancer care—including physicians, nurses, pharmacists, payers, patients and their families—with the ultimate goal of improving patient care and outcomes. Download the NCCN Guidelines for Neuroendocrine and Adrenal Tumors here: bit.ly/nccnguidelines

NETRF - (www.NETRF.org)



The mission of the Neuroendocrine Tumor Research Foundation (NETRF) is to fund research to discover cures and more effective treatments for neuroendocrine cancers. To achieve rapid discovery of cures, the NET Research Foundation directs its donations to fund breakthrough scientific research of neuroendocrine cancers.

In addition to hosting in-person and online educational events, the NETRF web site contains a wealth of information for patients and healthcare professionals alike. Some notable offerings are listed below:

- **Neuroendocrine Cancer: A Guide for Patients and Families** - NETRF created an easy-to-understand neuroendocrine cancer guide for patients, family members, and caregivers. This helpful 64-page guide is essential for those newly diagnosed with neuroendocrine tumors and a handy reference for neuroendocrine tumor survivors. Packed with illustrations, definitions, and fast facts, this neuroendocrine cancer guide is the ideal starting point for the person who wants to play an active role in their care and learn to manage their symptoms. Order your FREE guide here: www.netrf.org/for-patients/guide
- **NETwise Podcast** - NETRF hosts NETwise, a podcast about neuroendocrine cancer to help patients and caregivers navigate the world of NETs. NETRF speaks with experts and patients who will help us to understand NET diagnosis, treatment, and everything in between. NETwise is for everyone, from newly diagnosed patients to longtime survivors as well as caregivers and family members. Listen to the available NETwise episodes here at www.netrf.org/podcast, or subscribe through the link at the bottom of the webpage.

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NorCal CarciNET - (www.norcalcarcinet.org)

NorCal CarciNET is a patient support group in Northern California. Their mission is to help those with neuroendocrine tumors and carcinoids to share challenges and experiences, learn about prognosis and treatments, find information, and improve communications between the medical community, patients and caregivers. To learn about upcoming events and support groups, visit www.norcalcarcinet.org.



Pheo Para Alliance - (www.pheopara.org)

Founded in 2007, the Pheo Para Alliance mission is to empower patients with pheochromocytoma or paraganglioma, their families and medical professionals through advocacy, education and a global community of support, while helping to advance research that accelerates treatments and cures. In support of its mission, the PPA offers online peer support meetings, regularly produces educational webinars, and helps connect patients with specialists in their area. To learn more, visit www.pheopara.org.



Triage Cancer - (www.triagecancer.org)

Triage Cancer provides education on legal and practical issues that may impact individuals diagnosed with cancer and their caregivers. Triage Cancer provides education on issues related to work, insurance, disability benefits, finances, estate planning, medical decision-making, and more. Offers free in-person and online educational events, materials, animated videos, and state-specific resources. Provides free one-on-one help to assist individuals understand their options and possible next steps, as well as CancerFinances.org, which helps people navigate finances after cancer. To learn about upcoming webinars and events, go to www.triagecancer.org/webinars.

For more patient resources,
visit www.lacnets.org/resources





BACKGROUND

Who is behind NET Cancer Day?

NET Cancer Day is coordinated by the International Neuroendocrine Cancer Alliance (INCA) – the home of NET Cancer Day. INCA is the global voice in support of patients with neuroendocrine cancer and multiple endocrine neoplasia syndromes.

INCA's mission is to: raise awareness about all types of NETs; push for scientific advancements with a focus on identified unmet needs; and to provide a platform for global collaboration to address the many challenges NET patients and the medical community face, in securing a timely diagnosis and accessing optimal treatment, support and care.

INCA represents 26 patient advocacy organizations from 22 countries around the globe.

What is NET Cancer Day?

NET Cancer Day is an annual event held on the 10th of November, created to increase awareness of neuroendocrine tumors.

NET Cancer Day is about drawing attention to a group of less common cancers with increasing numbers being diagnosed and starting a global conversation amongst communities, medical professionals and governments.

#LetsTalkAboutNETs

Why NET Cancer Day matters?

Neuroendocrine tumors are frequently misdiagnosed and early detection is key. In a survey conducted by INCA at the end of 2019, it was found that 46% of patients have advanced stage neuroendocrine cancer by the time they are correctly diagnosed. For many of these patients a cure is not possible.

Frequently misdiagnosed with conditions such as: anxiety, menopause, Irritable Bowel Syndrome (IBS), asthma or diabetes, a greater awareness of NETs amongst the community and medical profession is needed.



SUPPORT

How can you support NET Cancer Day this year?

Help INCA,

the home of NET Cancer Day, spread the word further than ever before on November 10 by making #LetsTalkAboutNETs a global conversation - both online and throughout all communities.

The focus of this year's campaign is to highlight the challenges patients and clinicians face around Early Diagnosis. This toolkit will provide you with all of the information you need to help spread the word on

November 10



#LetsTalkAboutNETs

THE AIM OF NET CANCER DAY IS TO:



Raise awareness of NETs among key decision makers, health professionals and the general public, to improve quality of life and prognosis for NET patients and decrease misdiagnosis.



Help the voice of NET patients be heard by more people.



Focus on NETs for a day to bring hope and information to people living with NETs, their caregivers and families.



Ensure equity in access to care and treatment for NET patients around the world.



Encourage more funds for research, treatments, patient support and resources for NET.