

Understanding Neuroendocrine Tumors: Key Things You Should Know About NETs Ⓜ

(NAPSA)—Worldwide NET Cancer Awareness Day (WNCAD) was established in 2010 by patient advocacy groups from around the world to increase understanding of neuroendocrine tumors (NETs), an uncommon and frequently misdiagnosed type of cancer, to honor those affected by the disease and to recognize advancements made in the management of NETs.

To help raise awareness and increase understanding of this cancer, Grace Goldstein, patient advocate and Chief Operating Officer of the Carcinoid Cancer Foundation, and Al Benson, M.D., a Professor of Medicine in the Division of Hematology/Oncology at the Feinberg School of Medicine and Associate Director for Clinical Investigations at the Robert H. Lurie Comprehensive Cancer Center of Northwestern University, discuss key things to know about NETs.

Q: What are Neuroendocrine tumors (NETs)?

Dr. Benson: Neuroendocrine tumors (NETs) are an uncommon type of cancer that can develop throughout the body, most commonly in the gastrointestinal tract, pancreas and lungs. Signs and symptoms of NETs can vary depending on the type, size and location of the tumor. Unfortunately, many types of NETs will not cause any symptoms or may cause nonspecific symptoms which are often confused with other conditions. For example, some symptoms of NETs include abdominal pain, flushing, and diarrhea, which can be misdiagnosed as ulcers, irritable bowel syndrome or other gastrointestinal conditions.

Because of the absence of symptoms or vague symptoms

associated with NETs, the cancer is difficult to detect and the estimated time to diagnosis is five to seven years, during which a patient may have seen several doctors before arriving at the appropriate specialist. For this reason, NET patients are often diagnosed at an advanced stage when the cancer has already spread to other parts of the body.

Q: Who is affected by NET?

Grace: According to the latest statistics, there are somewhat more than five cases of NETs reported each year per 100,000 people. However, the incidence of NETs is increasing dramatically, having more than quadrupled in the past 30 years. People with a family history of cancer, women and those with diabetes are at an increased risk of developing a NET.

Q: How can people with NETs manage their condition?

Dr. Benson: The first step in managing NETs is receiving an accurate diagnosis from a physician as early as possible. Thanks to advances in research, doctors now have a deeper understanding of NETs and more resources are available to help people with NETs better manage the disease after they've been diagnosed. Currently, there are numerous therapeutic options available for patients with NETs including surgery, radiation therapy, chemotherapy and medical therapies.

It is also important that people with NETs see a multidisciplinary team, including oncology specialists, endocrinologists, gastroenterologists, pathologists, interventional radiologists, surgeons and nurses, to help manage all aspects of their condition.

Q: Are there resources available for people living with NETs? How can I provide support to the NET community?

Grace: Having access to support services is vital to families affected by NETs, as living with an uncommon type of cancer can take an emotional toll on both patients and their caregivers. Also important is ensuring patients have access to educational information so they are well-informed and can advocate for their care. Organizations, such as the Carcinoid Cancer Foundation, www.carcinoid.org, and programs like the NET Alliance, provide patients and caregivers with resources, including access to full-time advocates available by telephone and email and comprehensive websites which provide free publications and videos designed to educate and provide patients with support.

Supporting initiatives, such as Worldwide NET Cancer Awareness Day on November 10th, is a great way to become involved with the NET community, showing both patients and their caregivers they are not alone.

Posting online resources, such as www.thenetalliance.com and www.netcancerday.org, on Worldwide NET Cancer Awareness Day via Twitter and Facebook, can help to raise critical awareness of the disease.

For more information on NET, visit www.thenetalliance.com. Initiated by Novartis Oncology, the NET Alliance is a program that strives to increase disease awareness and understanding, improve NET diagnosis and monitoring, support the development of new NET management techniques and foster patient-focused activities.