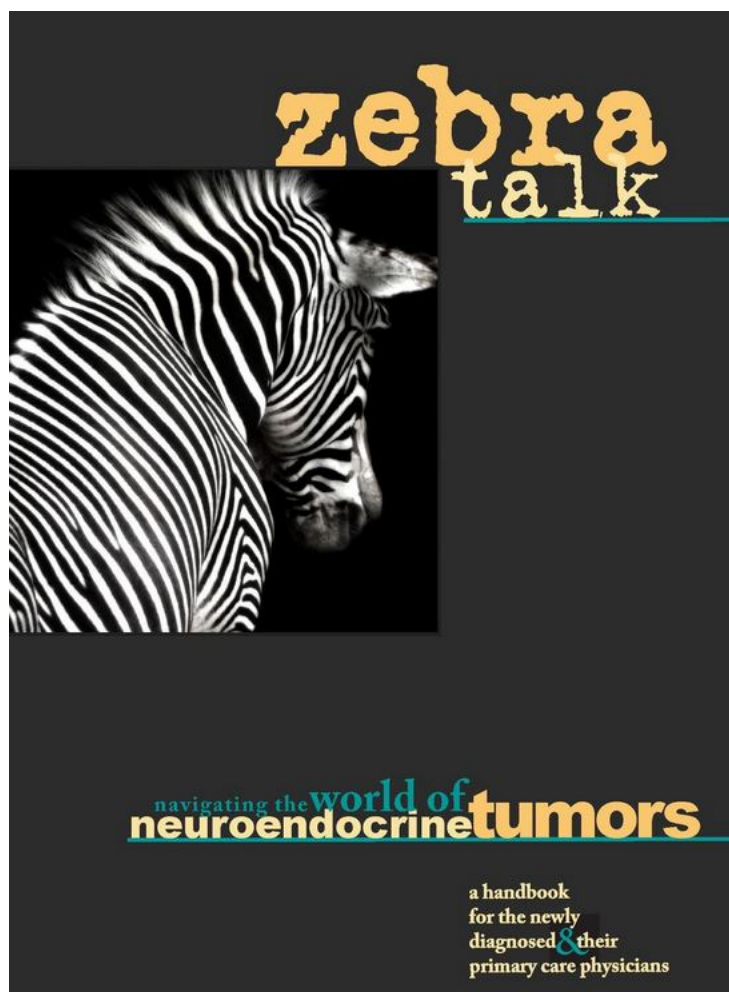


## **Zebra Talk -- A Handbook for Newly Diagnosed Carcinoid & Neuroendocrine Tumor Patients and Their Primary Care Physicians**

There's a terrific new resource for carcinoid and neuroendocrine tumor patients and their primary care physicians entitled [Zebra Talk](#). According to **Suzi Garber** of Bucks County, Pennsylvania, **editor**, the handbook "is intended as a reference for those newly diagnosed with NETs (neuroendocrine tumors), in the process, or hoping to explore this bewildering world. It is also a guide to resources that can empower patients through knowledge and the mentorship of others to make informed decisions for medical care." Suzi describes the handbook as a "virtual bridge that will allow patients to grow a relationship and inspire worthwhile communications between a patient and their primary care medical professional, their support team, and close friends."



What do you do first after receiving a diagnosis of a NET? **Zebra Talk** walks you through the steps.

The handbook **outlines the different types of NETs** including:

- gastrointestinal carcinoids,
- bronchial (lung) carcinoids,
- pancreatic neuroendocrine tumors (pNETs),


- paragangliomas and pheochromocytomas,
- and Merkel cell carcinoma (skin).

Information about the blood tests for NETs, tumor classifications, scans and other imaging such as MRI (magnetic resonance imaging) and capsule endoscopy is also included in the handbook.

## What are Neuroendocrine Tumors? (NETs)

NETs can be indolent (slow growing), non-aggressive, low-grade tumors that are well-differentiated. These low grade tumors such as carcinoid & islet cell (5% of all pancreatic tumors) are the most common types of NETs. They can metastasize to anywhere in the body (the liver being the most frequent site). The other end of the spectrum, fast-growing, i.e., high grade tumors, are poorly differentiated and highly aggressive.

NETs are a group of solid tumors (*tissues growing or dividing abnormally*) that arise from cells that release hormones in response to a signal from the central nervous system. These tumors can secrete large amounts of hormones which in turn can cause a range of symptoms. The most common site of origin is in the gastrointestinal tract, but they can occur in the lungs, reproductive organs, kidneys, and thymus (*actually anywhere*). There are many types of NETs and each requires a different approach in terms of diagnosis and subsequent treatment. NETs can be **functional or nonfunctional** depending on if they produce hormones (*functional*). Each *functional syndrome* (see p.4) has a predilection for certain sites. At the early stages of the disease there may be no symptoms. Some people remain asymptomatic indefinitely; nonfunctional NETs may produce symptoms due to increased tumor size over time.



**What are the various therapies for NET patients?** Different types of surgery and liver-directed therapies are categorized. The guide includes descriptions of somatostatin analogs, chemotherapy, investigative agents, targeted therapies and anti-tumor and anti-angiogenic agents.

**Carcinoid heart disease, bowel obstruction, and carcinoid crisis** are all possible complications of **carcinoid syndrome**. **Zebra Talk** describes each of these and shares important information about the use of octreotide during surgery to reduce the risk of carcinoid crisis.

A section of **Helpful Hints** is an excellent guide for patients who are new to the journey of living with carcinoid or other NETs. Every medical vocabulary word within any paragraph in the handbook includes a definition in parentheses for a quick understanding of what is being said.

**Internet Resource Links** enable patients to easily access information about locating carcinoid/NET specialists, learning about clinical trials, nutrition, watching videos on carcinoid/NETs, attending conferences and events for the NET community, molecular profiling, clinical/medical papers, and much more.

The handbook also features a **NET Glossary, Useful Facts to Know about Testing**, and a chart of **Gallium-68 Dotatate PET/CT U.S. clinical trial sites**.



**Suzi Garber** has been living with a NET diagnosis since 2006, having had surgery to remove her primary mid-gut carcinoid tumor 7 years ago. She is the founder/support group leader of [The Philly NETs](#), a hospital to community liaison, and patient advocate. She was the only patient on the team that created the neuroendocrine clinic at the **University of Pennsylvania's Abramson Cancer Center**, received the **Advocate of the Year Award** in 2011 from the University of Pennsylvania, and remains as liaison to the community at large for the NET program. Suzi says she "has been misdiagnosed, tardily diagnosed, treated for the wrong disease, and turned down for surgery five times until she heard a yes." **She recently participated in the National Institutes of Health (NIH) Gallium-68 clinical trial.** To read more about her experience at the NIH, [click here](#).

To download a copy of **Zebra Talk**, [click here](#). (After downloading the handbook, it can be opened with Adobe Acrobat so that copies can be printed).

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