

Navigating the course of your care



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WHAT WOULD YOU TELL A NEW MEMBER OF YOUR GROUP?

Improving your care through

- Participation
- Knowledge
- Relationships



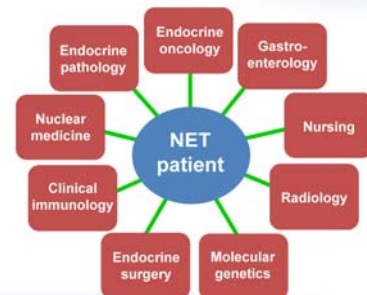
Participating

- ▶ Establishes your ACTIVE role in the partnership
- ▶ Creates DYNAMIC relationships.
- ▶ STRATEGICALLY selecting options and recognizing opportunity
- ▶ EMPOWERS you to control your care and have some control over your disease

What you can do.....

- ▶ Increase your knowledge
 - Disease
 - Understand your particular "version" of the disease
 - Investigate treatments and procedure options
 - Keep a diary of your symptoms and responses to treatment
 - changes both physically and psychologically
- ▶ Speak Up
 - Question what you do not understand
 - Take notes and keep records
 - Participate in the decision making aspect of your care
- ▶ Get Active
 - Join patient support groups meetings or on list serves
 - Get information on your health care resources and potential options

You are the Captain of your care



Why a Multidisciplinary Approach?

- Due to relative rarity of your disease, you want relevant experience and expertise!
- Diagnostic information should be critically reviewed for consensus of evidence based care

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Consult with a Center of Excellence

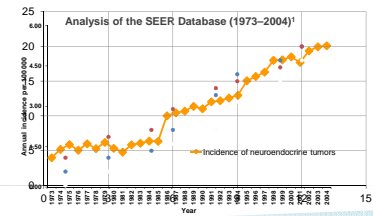
- Access to Multidisciplinary Care in a single setting
- Confident of the right diagnosis - Tissue is always the issue!
- Knowledge of diagnosis and patient education opportunity
- Access to new treatment and symptom management strategy
- These centers work with your Oncologist over time to help guide your care

You maybe a Zebra but you are part a larger herd than you think.

Fun Facts

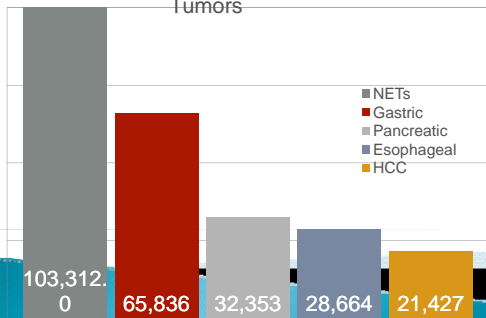
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Incidence of Neuroendocrine Tumors



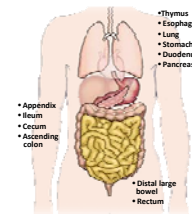
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NETs Prevalence compared to other GI Tumors



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Sites of Primary NETs



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Myths

Carcinoid patients never get depressed cause they produce serotonin

Carcinoid is not a real cancer

If you can control your diarrhea with Imodium then there is no benefit of expensive therapies such as somatostatin analogs.

Carcinoid does not run in families

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Things you may not know about carcinoid syndrome

Carcinoid Crises

Signs and Symptoms:

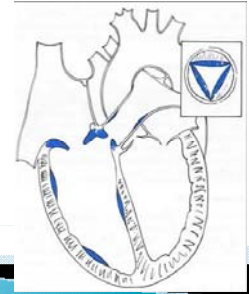
- Lightheadedness
- Elevations or reductions in blood pressure
- Changes in pulse rates and respiratory rates
- Confusion or disorientation
- Muscle twitching similar in description to clonic jerking
- Profound weakness or momentary inability to move extremities
- vary in severity and can be life threatening.
- can occur or reoccur up to 12 hours after a surgical procedure.

Carcinoid Heart Disease

Irreversible cardiac involvement

- Fibrosis of the endocardium, mainly affecting the tricuspid and pulmonic valves^{1,2}
- Fibrous deposits constrict valves^{1,2}
- Pulmonary valve – stenosis
- Tricuspid valve – fixed open → regurgitation

Prevention– control serotonin levels

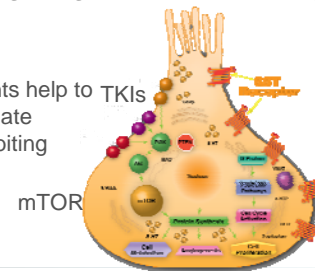


1. Jensen RT, Doherty GM. In: *Cancer: Principles & Practice of Oncology*, 6th ed. Baltimore, Md: Lippincott Williams & Wilkins; 2001:1813–1833.
 2. Kaplan LM. In: *Harrison's Principles of Internal Medicine*, 12th ed. New York, NY: McGraw-Hill; 1991:1386–1393.
 3. Data on file. Velez CS, Stucky-Marshall L. *Managing Patients with Carcinoid Disease*. East Hanover, NJ: Novartis Pharmaceuticals Corporation; 2003.
 4. Zusterhorst JM, et al. *Br J Cancer*; 2004;90:2073–2079.

Things to know about Biologic Therapies

Biologic Agents and Cellular pathways

These agents help to regulate by inhibiting



- Secretion of hormones and peptides
- Cell metabolism and growth
- Cell reproduction
- Development of blood vessels to the cancer cell
- Cancer cell ability to spread

Somatostatin analogs

No contraindications but.....
Things to be evaluated periodically

Blood Glucose
Thyroid Function
Vitamin B12 levels
Signs and symptoms for fat malabsorption
Cardiac Rhythm
Signs and symptoms of gallbladder sludge or stones

RESOURCES

- NJCCN – www.NJCarcinoidNETwork.org
- <http://netcancerawareness.org>
- <http://caringforcarcinoid.org/newly-diagnosed>
- <http://www.netpatientfoundation.org>
- www.thenetalliance.com
- <http://www.carcinoid.com>
- www.novartisoncology.com/for-patients-and.../neuroendocrine-tumors.jsp
- www.carcinoid.org/support/resources/financial-assistance
- <http://endocrinediseases.org>



To name just a few!!!

WHAT WOULD YOU TELL THIS PERSON?

- Your new member is 55 year old female with history of symptoms of diarrhea. She was diagnosed with IBS 3 years ago. She has flushing but she has never really thought about it much - she was having menopausal hot flashes.
- One day her pain in her abdomen was severe. She thought she was having an appendicitis attack. She went to the emergency room. A CT of the abdomen showed a tumor in her liver. A biopsy was consistent with a neuroendocrine tumor. She was referred to local oncologist who rounded on her. Her friends knew other patients who were under his care and the opinion was he was very nice.
- When she went to see him, he didn't tell her much about her disease. He said she had a neuroendocrine cancer and that was a good one to have. He ordered additional tests and said he would see her back with results.
- Meanwhile, she went on the internet and reached out to your group.



Thank You