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 local and national 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.

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.

Fun Facts

- Incidence of Neuroendocrine Tumors

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- NETs Prevalence compared to other GI Tumors

- Sites of Primary NETs
**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.

**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
- 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
- Fibrous deposits constrict valves
- Pulmonary valve - stenosis
- Tricuspid valve - fixed open → regurgitation

Prevention - control serotonin levels


**Biologic Agents and Cellular pathways**

These agents help to regulate by inhibiting

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

**Things to know about Biologic Therapies**
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

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://endocrinodiseases.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...