

# STIFLE

## NET CANCERS FOUNDATION, INC.



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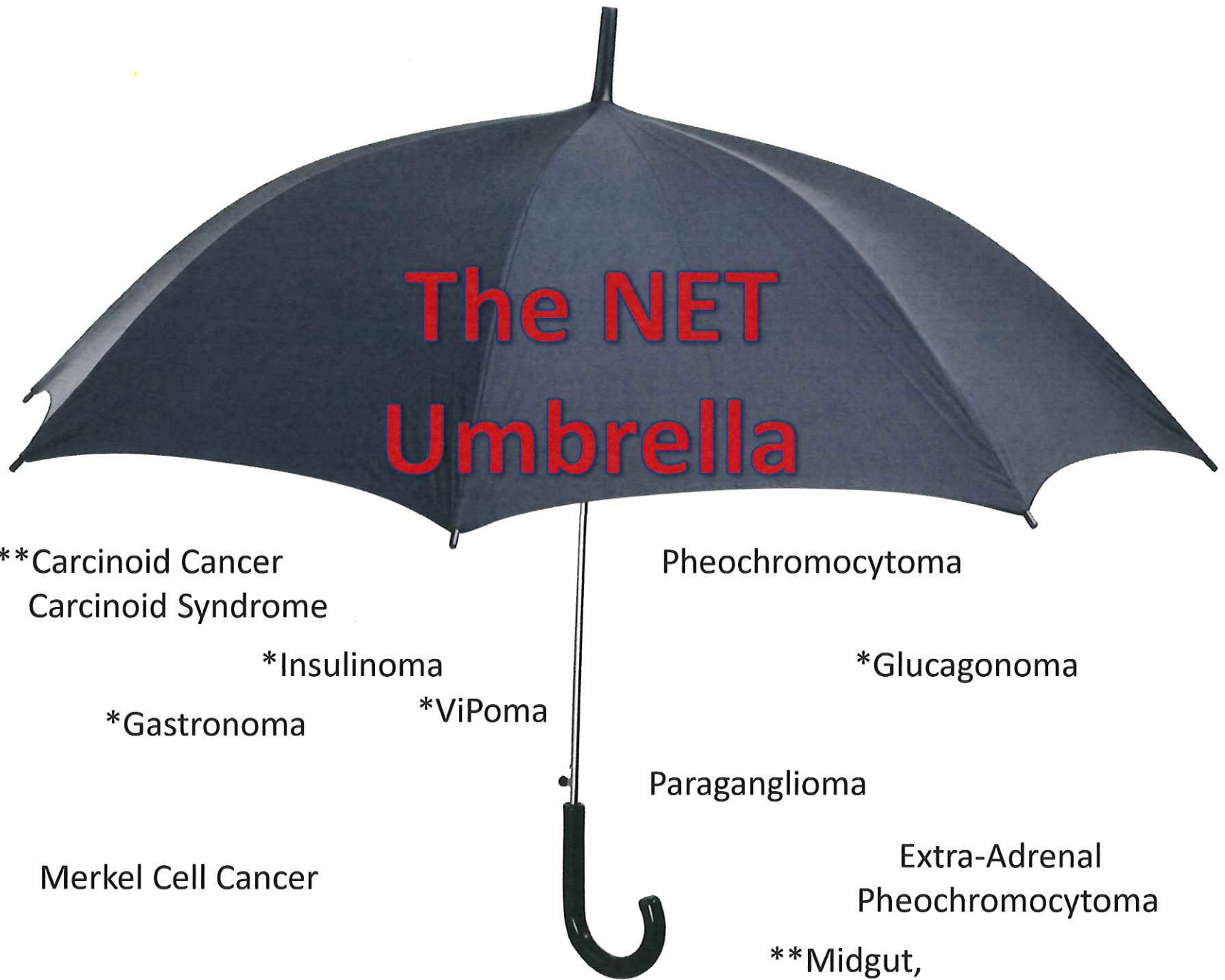
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# Our Mission

- To provide patients, caregivers, non-patients, general public, state/local government, the entire medical community at large, including but not limited to their affiliates, organizations, educational institutions, medical students and healthcare professionals, the tools and resources to facilitate awareness and education with the ultimate goal of evoking change at core levels to promote wellness and ultimately to improve quality of life, extend mortalities and ultimately save lives.

# The Need

- As a group, rare cancers are the leading cause of cancer deaths in the USA, **and specific to Neuroendocrine Tumors, incidence of cases has risen 6.5 fold in last 5 years and is rising dramatically due to advances in detection, awareness and education of the disease. MORE WORK NEEDS TO BE DONE, especially within the medical community at large.**
- In USA, 2016 nearly 600,000 rare cancer patients were diagnosed and 472,853 patients died; this is more than 7x the number of Americans who die in car accidents every year and a mortality rate higher than other common cancers.
- **Nets currently has no cure, no possibility of remission, has limiting treatment options/availability to patients but is treatable.** Compared to other more common cancers, Net Cancers receives virtually no media attention, has major gaps in public awareness/education, has miniscule funding from NIH and other resource outlets and research is insufficient.
- **Research, Awareness, Resources, Education (RARE)** =s the equation for improving quality of life, increasing longevity, and hopefully to save lives



# The NET Umbrella

\*\*Carcinoid Cancer  
Carcinoid Syndrome

\*Insulinoma

\*Gastrinoma

\*VIPoma

Pheochromocytoma

\*Glucagonoma

Paraganglioma

Merkel Cell Cancer

Extra-Adrenal  
Pheochromocytoma

\*\*Midgut,  
\*\*\*Foregut,  
\*\*Hindgut

\*P-Nets

\*\*G-Nets

\*\*\*L-Nets



# What are Nets?

- Umbrella term for a group of unusual, often slow-growing cancers, which develop from cells in the diffuse endocrine system. Can take several years to manifest/present; typically misdiagnosed as more commonplace diagnoses. By the time a Net is found it is usually metastatic and has gone to other organs. **Nets can move aggressively also. Unique to each individual as is treatment.**
- **NET CANCERS are difficult to diagnose. Misdiagnosis occurs in over 75% of cases; average span of time to correctly diagnose 3-7 years; if discovered earlier, surgical removal is first line of treatment. If spread to other organs, becomes problematic.**
- Most commonly found in the gastrointestinal system but can manifest in the lung, pancreas, ovaries, testes, among many other sites. (it can be found in the eyes, ears, nasal cavity, bones, organs, brain, reproductive system; sneaky and stealth)
- **Carcinoid tumors** are the most common type of Net, which is a cancer that arises from cells that make and release a variety of hormones that regulate body functions.

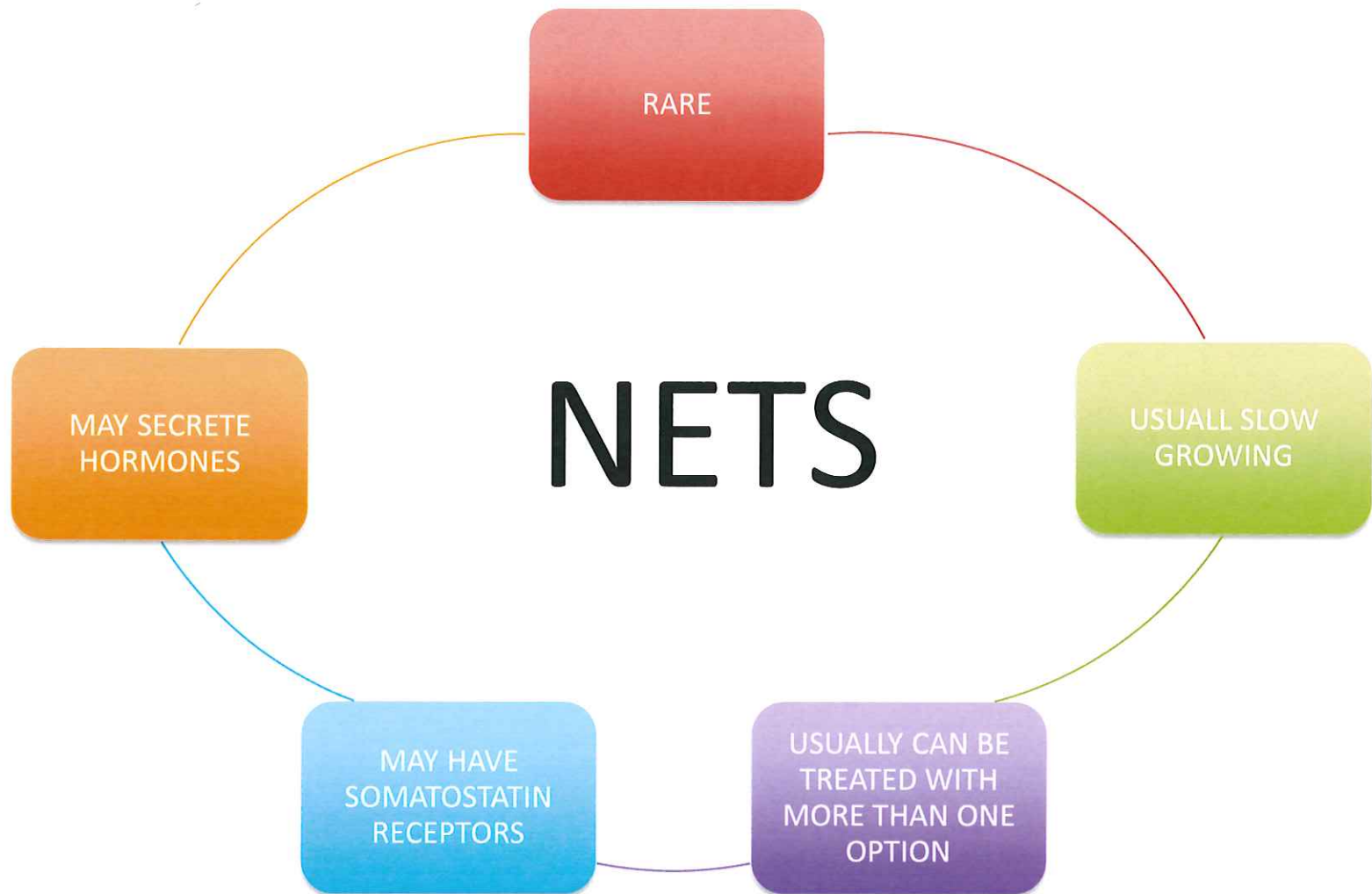
# How are Net Cancers formed?

- Still not fully understood
- Similar to all forms of cancer, Nets arise when cells multiply rapidly. Normal cells divide in a controlled manner but in cancer the control signals go awry.
- Abnormal cells divide quickly resulting in tumor growth; Net cancer tumors are usually malignant (cancer).
- Grading and analysis of primary tumor – critical in management of treatment

# Classification of NETS

## Who Classification

- 1) well-differentiated Grade 1 K167 <2%
  - 2) well-differentiated Grade 2 K167 2-20%
  - 3) poorly differentiated Grade 3 K167 >20%
- 
- Survival rates for Grade 3 are dismal; 33 months median
  - Grade 1 and 2 prospects are much better
  - K167-staining – tumor analysis mitotic rate of how fast cells are multiplying





# TESTING, TESTING, TESTING SCANS, SCANS AND MORE SCANS

- There are a number of different tests and scans which may be used to detect a Net cancer. Some of these tests work by looking for hormonal changes triggered by the cancerous cells, while others look for the tumor itself.
- Bioscopy – proliferation index is called K-167 (MIB1); how fast are cells dividing out;
- Blood test- “net markers”; Chromogranin A/B, pancreatic polypeptides, insulin, gastrin, neurotensin, VIP (baso-intestinal peptide), full blood count, kidney function, liver function, thyroid function, pituitary hormone screen (ACTH), prolactin, growth hormones and cortisol, serum calcium, parathyroid hormone levels
- HIAA-5 (hydroxyindolacetic acid) urine
- Endoscopy, Endoscopic Ultrasound, Wireless Capsule, Colonoscopy
- Depending upon the stage of the disease or changes occurring with the patient; OctreoScan, CT Scan, MRI Scan, Pet Scan, MIGB, Bone Scan, Echocardiogram; possible transesophageal echo and cardiac catheterization

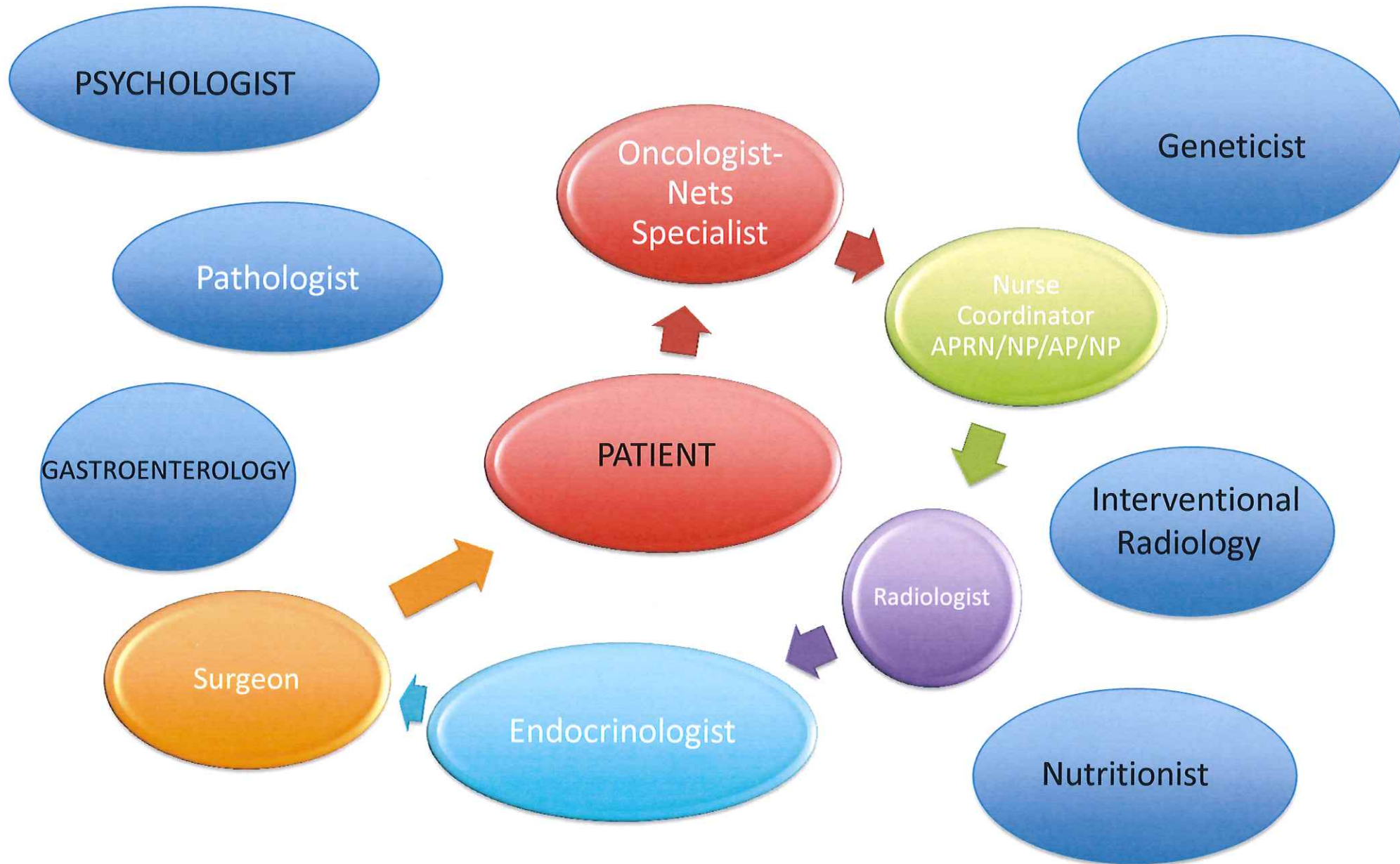
BE YOUR OWN ADVOCATE AND NET DETECTIVE

IF YOU DON'T SUSPECT IT, HOW CAN YOU DETECT IT!

# SYMPTOMS

- The symptoms of Net cancers can vary, depending upon the location and biological properties. Very often the symptoms mimic more common conditions. Early symptoms may include vague tiredness or digestive complaints, or there may be no symptoms at all!
- Intestinal Carcinoid –  
Bowel Obstruction, Flushing, Diarrhea,  
Abdominal pain, Wheezing
- Bronchial Carcinoid –  
Wheezing, Coughing, Bloody Sputum
- Pancreatic Net –  
Epigastric pain, Chronic ulcer disease, low blood sugar,  
Rash, Diabetes, Diarrhea

# Multidisciplinary Approach to care



# Website/data references

- [www.NIH.gov](http://www.NIH.gov)
- [www.cancercare.org](http://www.cancercare.org)
- [www.carcinoid.org](http://www.carcinoid.org)
- [www.asco.org](http://www.asco.org)
  
- [www.StifleCancerFoundation.org](http://www.StifleCancerFoundation.org)
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