Newly diagnosed with a NET?
13 Questions you may be wondering about

CNETS 2017
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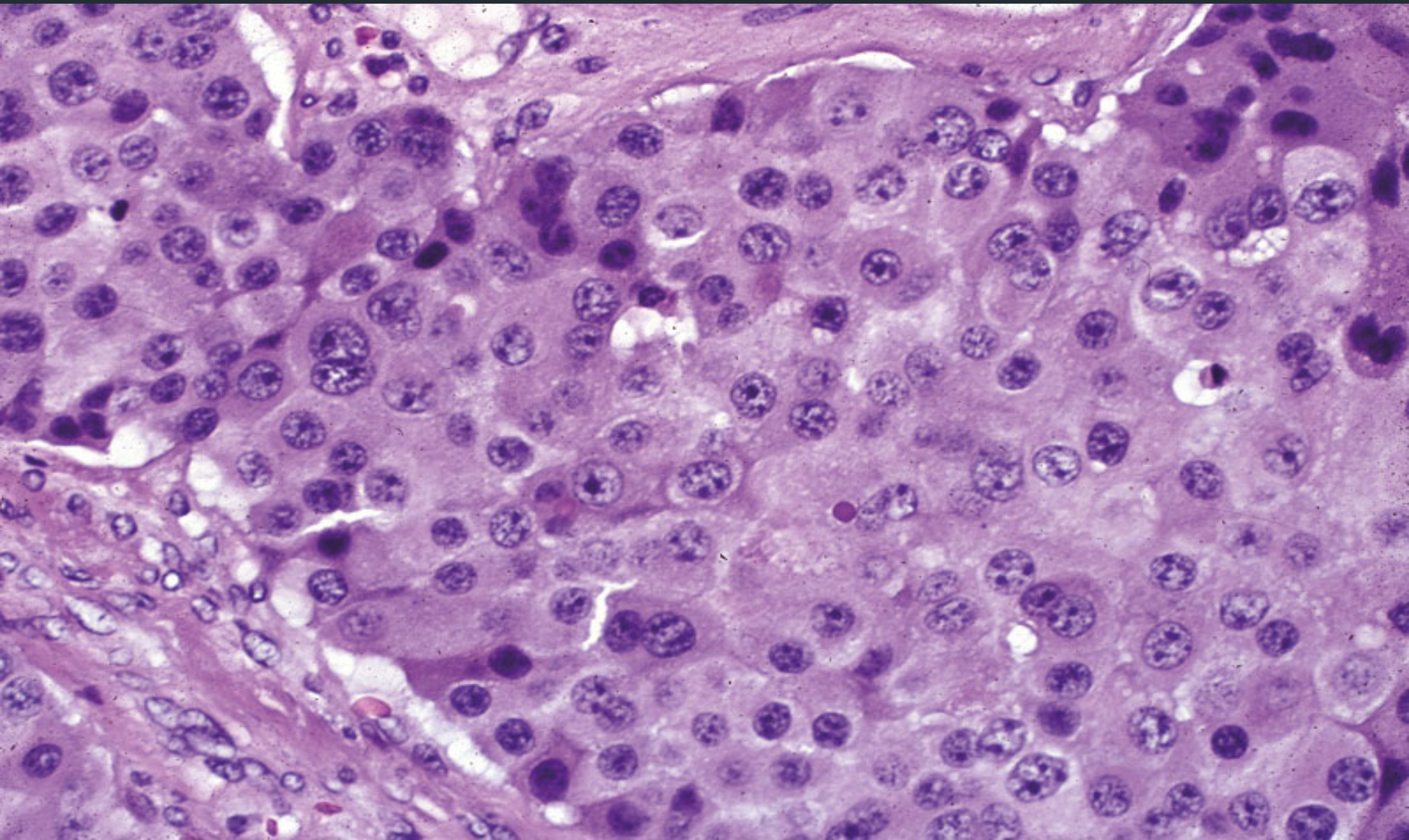
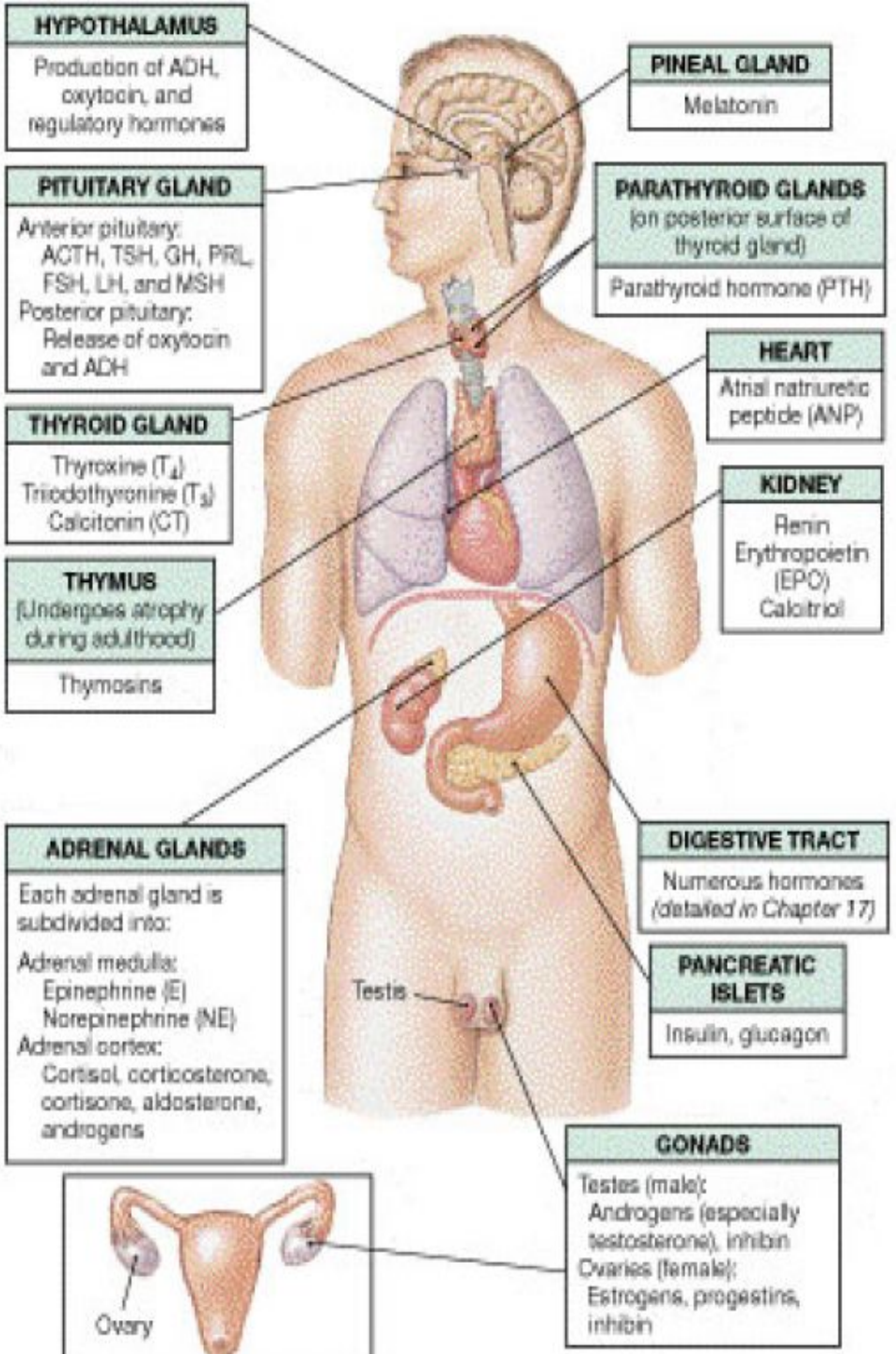
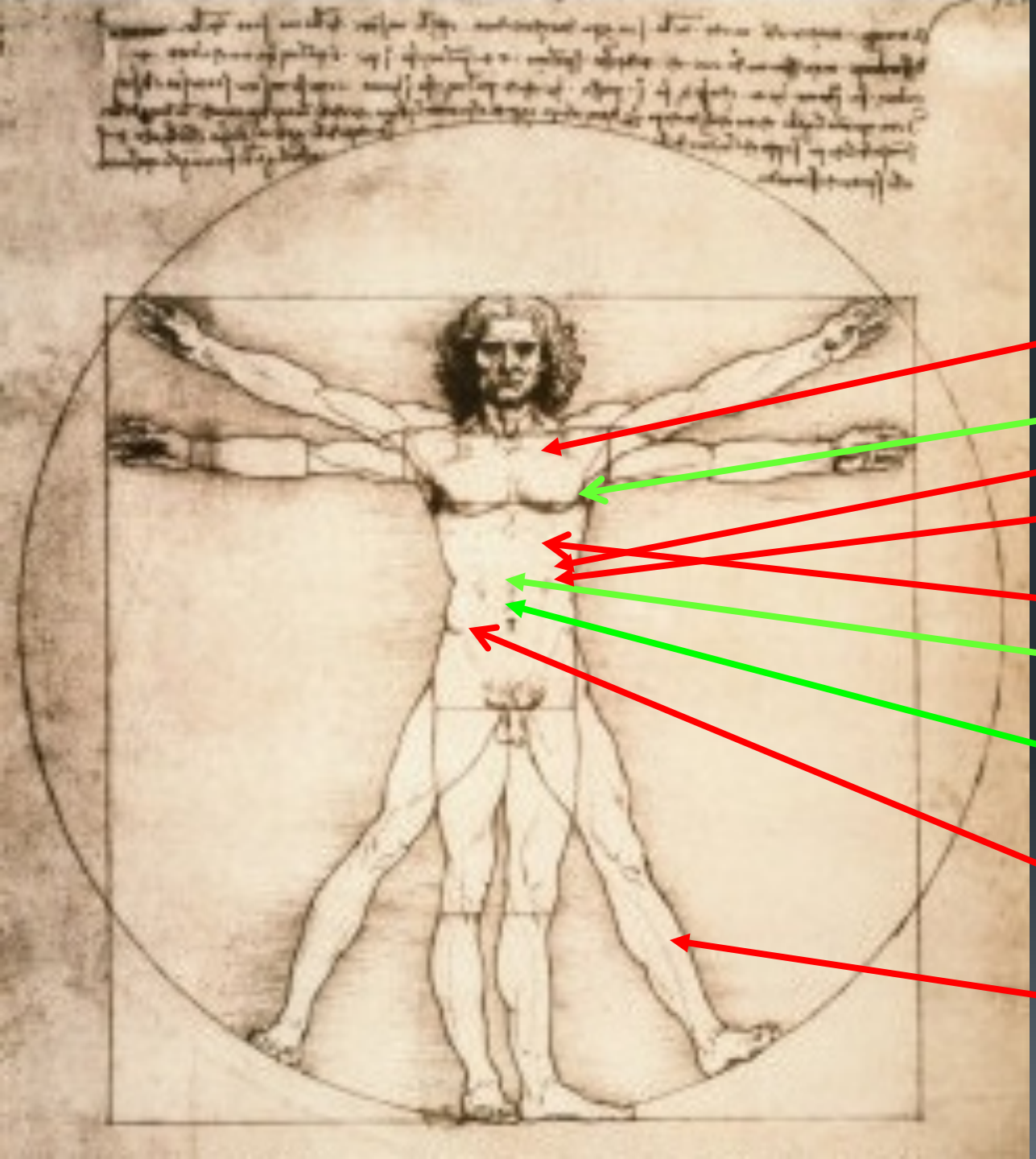
I have a what???




HYPOTHALAMUS
Production of ADH, oxytocin, and regulatory hormones
PINEAL GLAND
Melatonin
PITUITARY GLAND
Anterior pituitary: ACTH, TSH, GH, PRL, FSH, LH, and MSH
Posterior pituitary: Release of oxytocin and ADH
PARATHYROID GLANDS (on posterior surface of thyroid gland)
Parathyroid hormone (PTH)
HEART
Atrial natriuretic peptide (ANP)
THYROID GLAND
Thyroxine (T_4)
Triiodothyronine (T_3)
Calcitonin (CT)
KIDNEY
Renin
Erythropoietin (EPO)
Calcitriol
THYMUS (Undergoes atrophy during adulthood)
Thymosins
ADRENAL GLANDS
Each adrenal gland is subdivided into:
Adrenal medulla: Epinephrine (E) Norepinephrine (NE)
Adrenal cortex: Cortisol, corticosterone, cortisone, aldosterone, androgens
DIGESTIVE TRACT
Numerous hormones (detailed in Chapter 17)
PANCREATIC ISLETS
Insulin, glucagon
Testis
GONADS
Testes (male): Androgens (especially testosterone), inhibin
Ovaries (female): Estrogens, progestins, inhibin
Ovary

The anatomic spectrum Of NETs



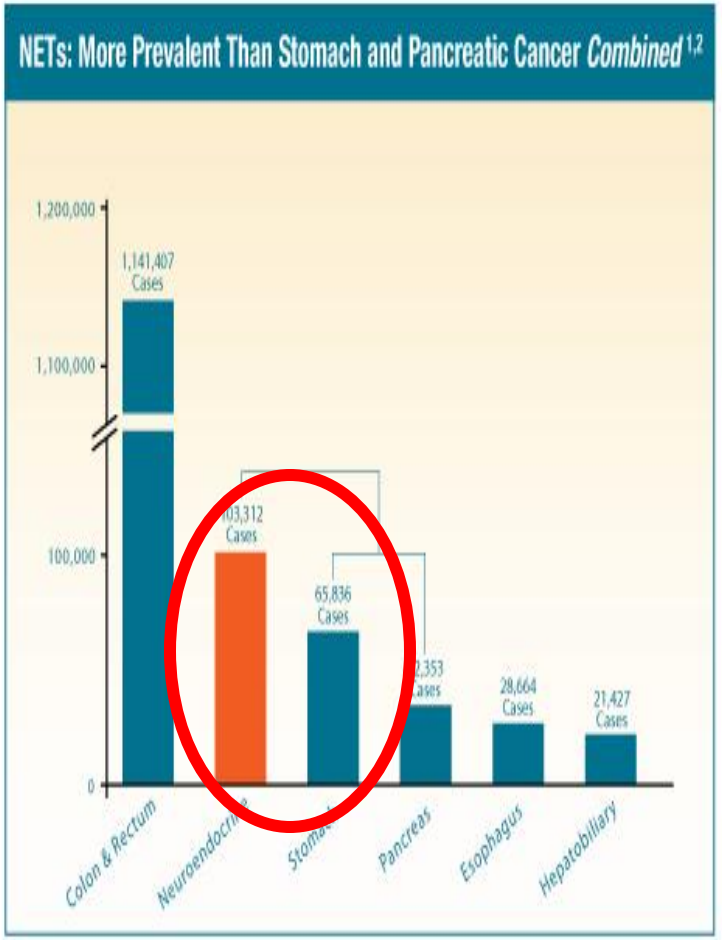
Why was it/is it so confusing when I was diagnosed?

- Diagnosis often poorly communicated
- Often comes out of the blue
- Poorly understood by general medical community
- Information often incomplete
- The indiscriminate terror of a cancer diagnosis
- Catastrophization vs minimization

How common is this?

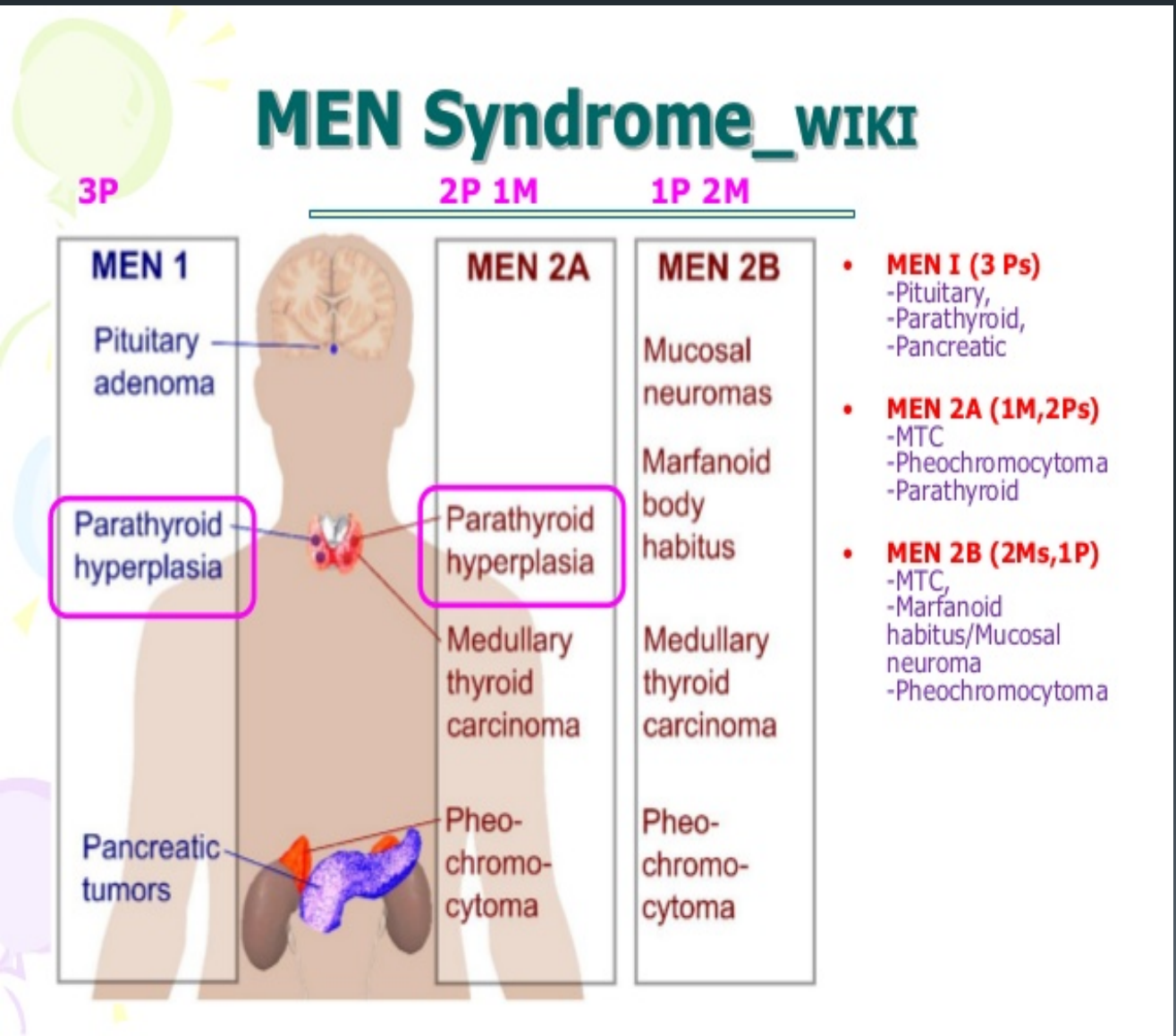
	Rate Per 100,000	% Δ Since 1994	Absolute* New Cases 2009
All Cancers	611.42	13%	62,174
All NETS	5.86	138%	596
Small Intestine NETS	1.01	140%	103

*Hallet J et al. Cancer 2014.



1. Yao JC, Hassan M, Phan A, et al. One hundred years after "carcinoid": epidemiology of and prognostic factors for neuroendocrine tumors in 35,825 cases in the United States. *J Clin Oncol*. 2008;26(18):3063-3072.
2. National Cancer Institute. Surveillance, Epidemiology, and End Results (SEER) Stat Fact Sheets. http://seer.cancer.gov/csr/1975_2004/results_merged/topic_prevalence.pdf. Accessed September 30, 2009.

How did this happen and is it hereditary?

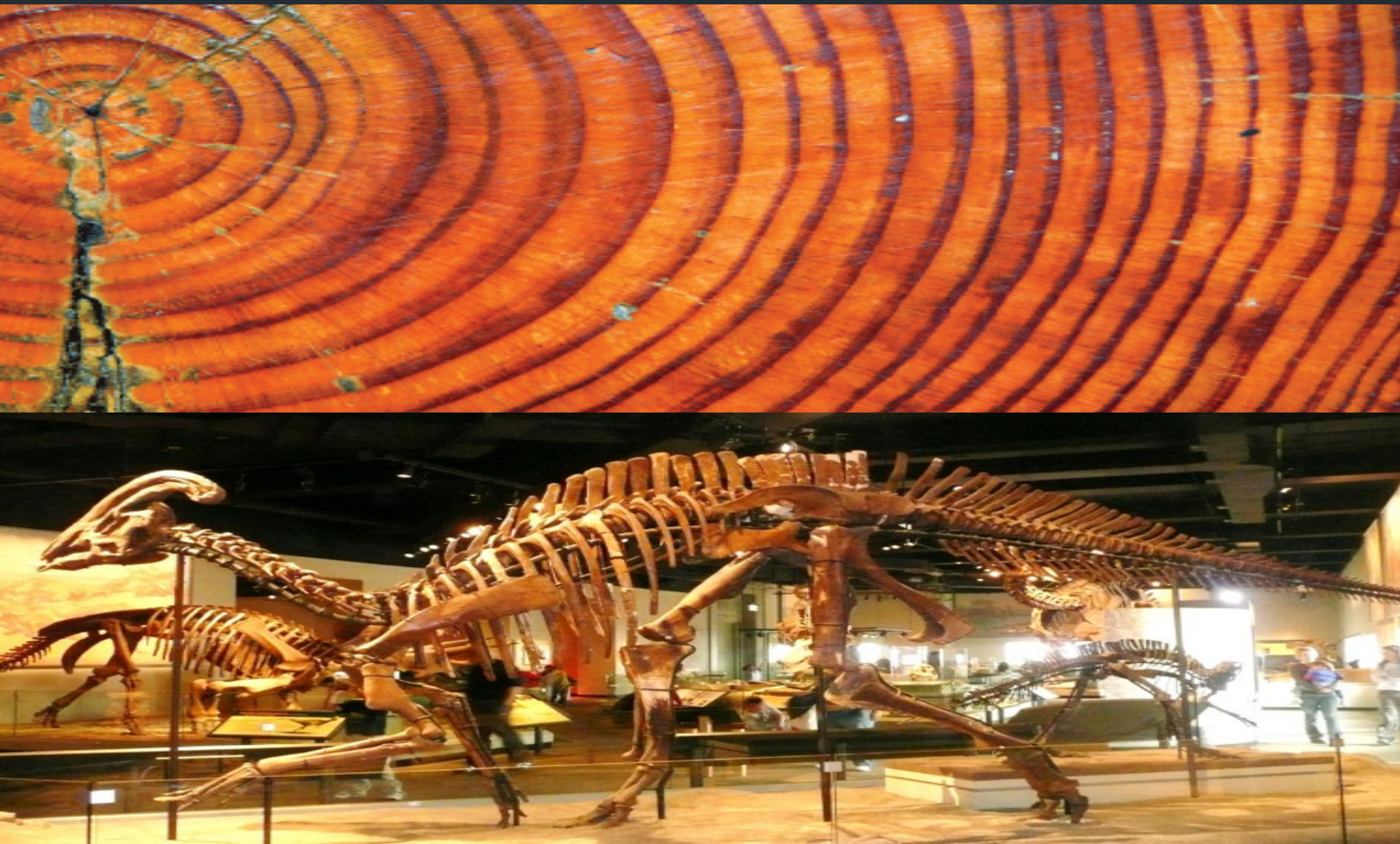


For the vast majority of cases; we simply don't know

Incidence of Genetic testing In NETS: ???

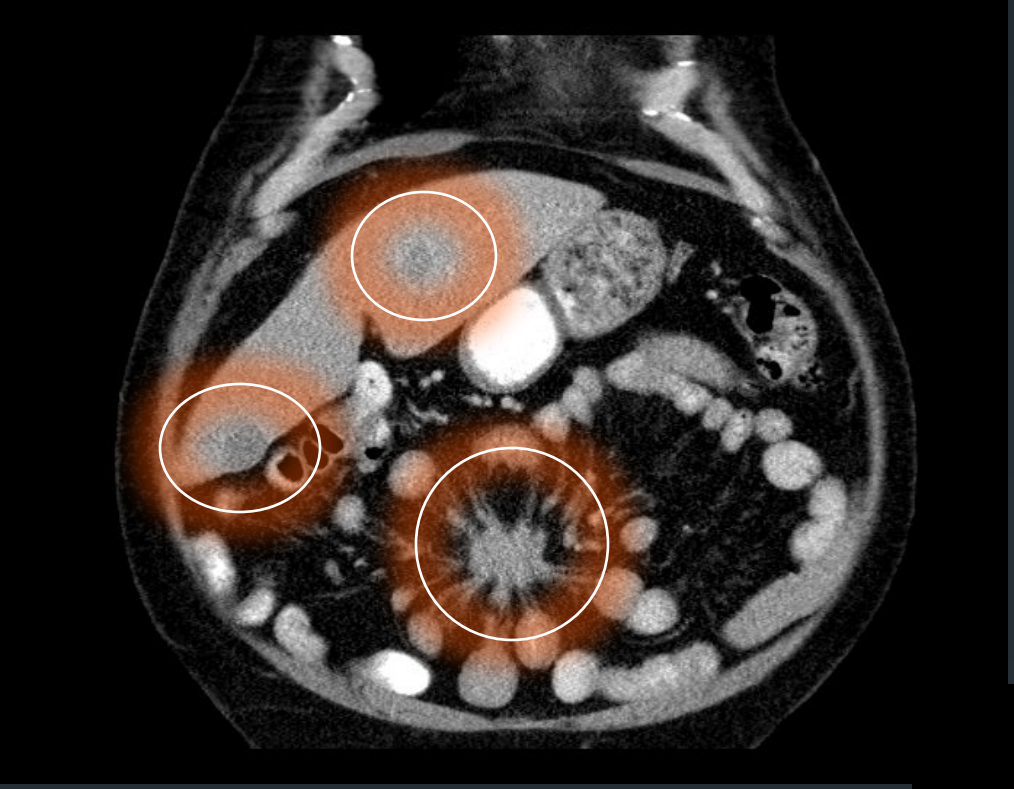
When did it start?

We never really know…….



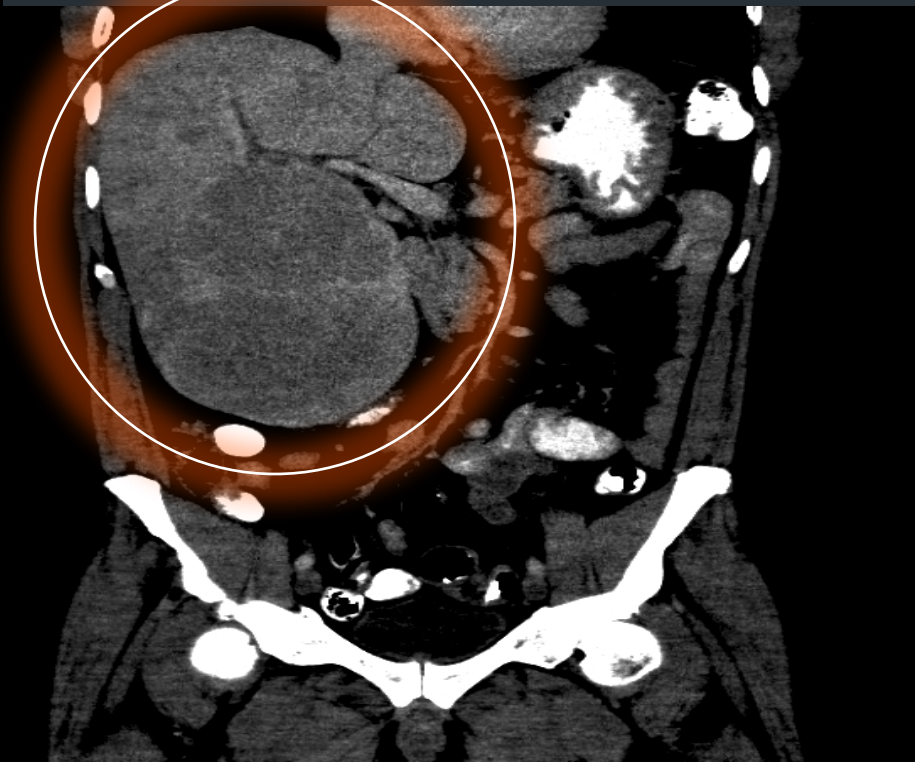
Why wasn't it diagnosed sooner?

- Many cases grow very slowly without any symptoms, or hormonal syndrome, over years
- Those with symptoms are often diagnosed and treated for other benign conditions before anyone thinks of NET
- The most sensitive tests for NETs are not readily available across Canada
- Historically, medical hoofbeats means horses, not zebras



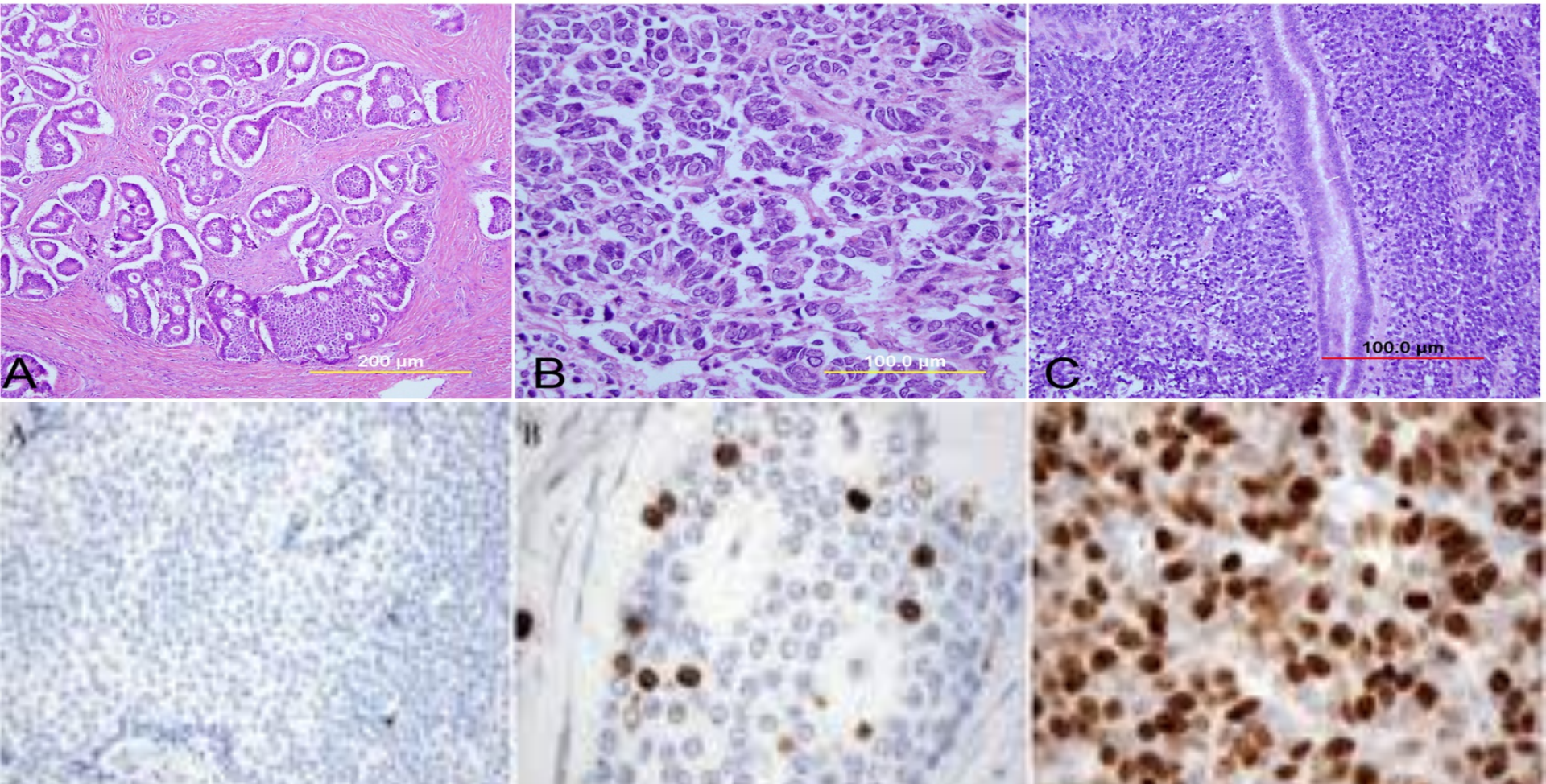
Can it be cured?

Surgery is the only curative treatment currently available



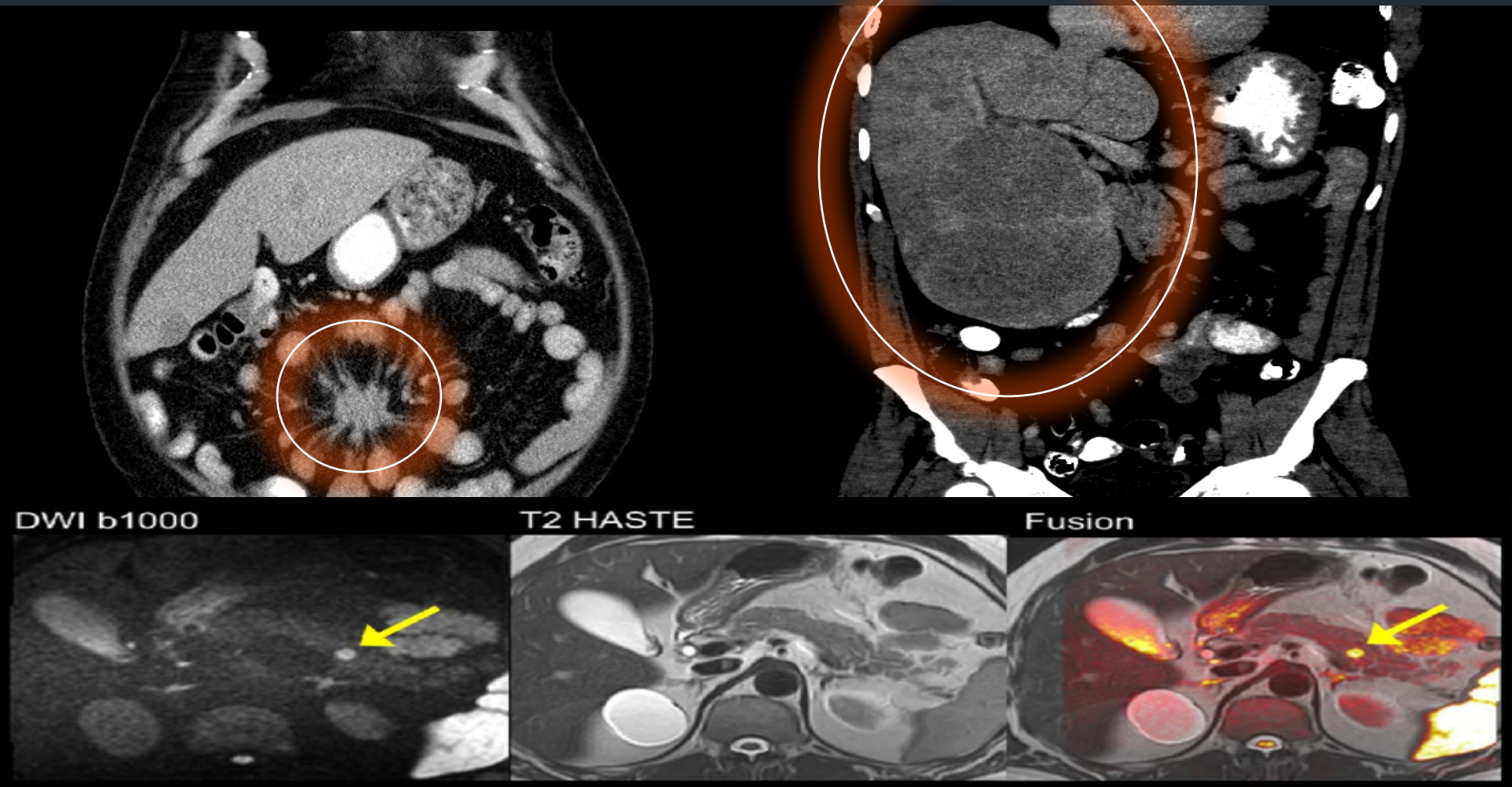
What is this Ki-67 I keep hearing about?

A test done in the pathology lab to ‘grade’ your tumor and to see how ‘active’ it is



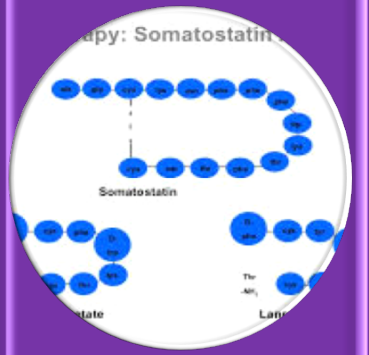
Is this why I have been feeling poorly?

- Sometimes……..



Do I need Chemotherapy or Radiation?

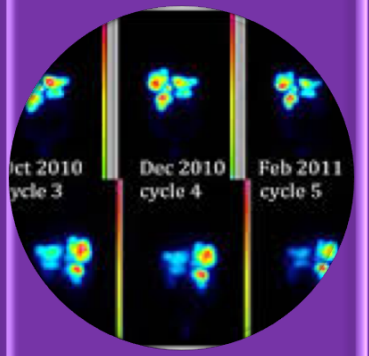
In general not……
if you do, it is completely different than 'typical' chemo/radiation….



SSA Analogues

Liver-directed surgery

Liver-directed ablation/RFA/TACE/TAE/Y90



PRRT: Leu-177 I123-MIBG

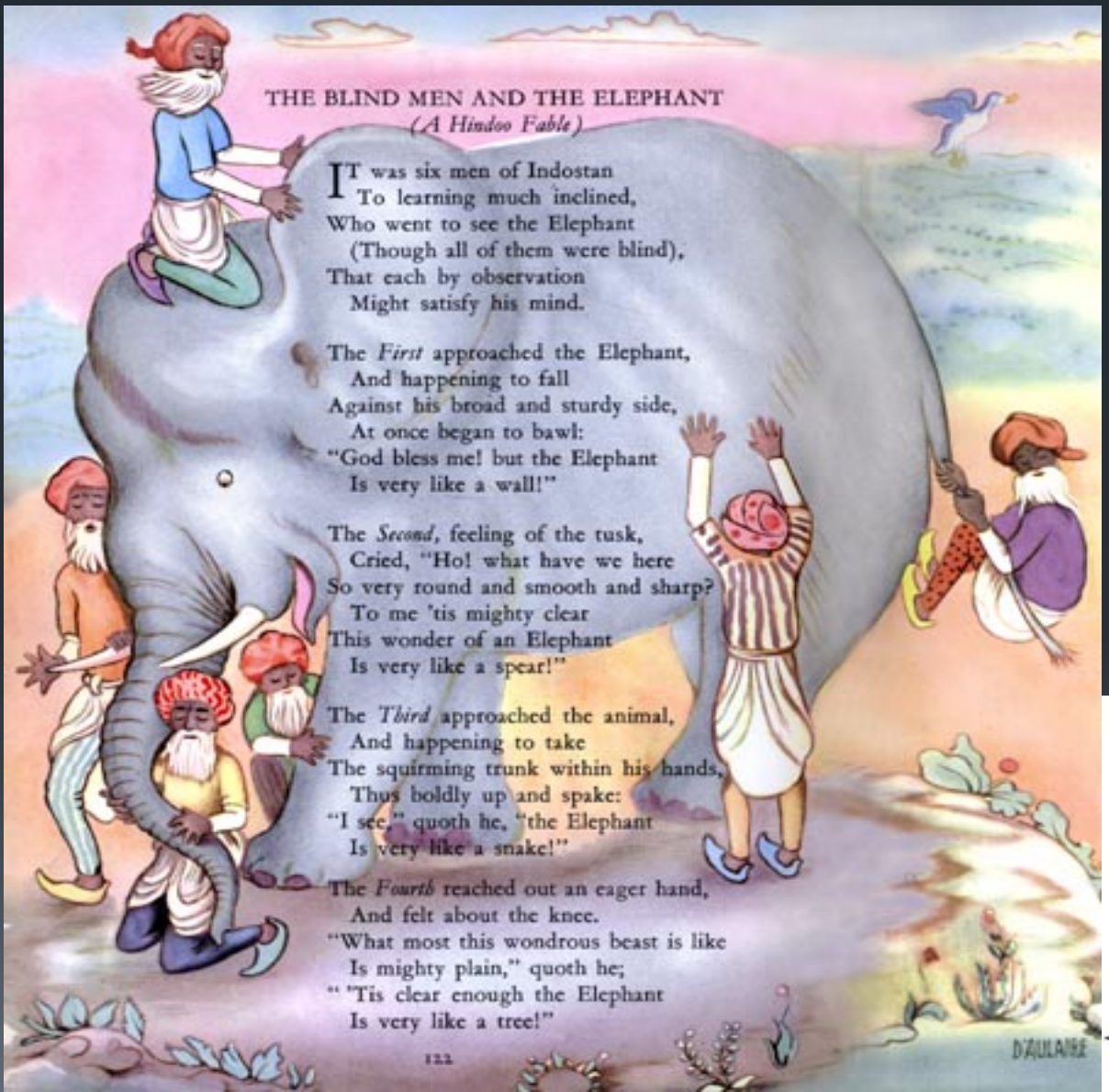
Everolimus Sunitinib CapTem

Clinical Trials

What is my prognosis?

- Highly variable depending on your particular situation:
  - Extent of disease/surgical resection potential
  - Site of primary origin
  - Symptom burden
  - Rate of growth/proliferation
  - Whether or not there is an associated hormonal syndrome and whether it can be controlled
  - Availability of multiple new treatment options
  - Sensitivity of your tumor to different treatments
  - Other competing risks to your health

Who is going to help take care of me?



Surgeon
Medical Oncologist
Nuclear Medicine Team
Multiple Nurses
Pathologist
Radiologist
Endocrinologist
Gastroenterologist
Geneticist

Question 14

- What is a group of Zebras called?

A Dazzle !