

General Information

Today's date

Patient name

last, first

Gender

Female

1. My neuroendocrine tumor (NET) was found:
check all that apply

Date of birth

mm/dd/yy

Year of diagnosis

mm/dd/yy

Male

Incidentally (routine exam, unrelated procedure)

Due to obstruction

Phone number

Email

NET symptoms/carcinoid syndrome

Other

Part 1 | Diagnosis

2. I am a neuroendocrine tumor (NET) patient and my primary (origin) tumor is:

Thymus

Small intestine
(ileum)

Rectum

Stomach

Proximal colon

Lung

Appendix

Pheo/para

Pancreas

Distal colon

Unknown

*Other*3. My NET has spread (metastasized) to (*check all that apply*):

Not metastatic at this time

LOCATION

AT DIAGNOSIS

PROGRESSION/NEW IMAGING

DATE *mm/dd/yy*

Liver

Bones

Mesentery

Peritoneum

Other

Part 2 | Pathology - Function - Symptoms

4. My Ki-67 index is % found on Pathology Report dated .

Changed from previous biopsy?

I brought my Pathology Report

Yes

No

N/A

5. My neuroendocrine tumor is (*select an answer in each row*):

ROW 1

Well-differentiated

Poorly differentiated

Don't know

ROW 2

Grade 1

Mitotic index <2, Ki-67 0-2

Grade 2

Mitotic index 2-10, Ki-67 3-20

Grade 3

Mitotic index >10, Ki-67 >20

Don't know





Part 2 | Pathology - Function - Symptoms - cont'd

6. My neuroendocrine tumor is (*indicate most current*):

Functional (hormone-producing)

Non-functional

Don't know

7. I have symptoms (*check all that apply*):

Diarrhea

Weight loss

Fatigue

Abdominal
cramping

Palpitations/fast
heartbeat

Wheezing

Flushing

Pain

Shortness of
breath

Hypertension/high
blood pressure

Bloating/gas

Other

8. I have had symptoms for _____ years (*if applicable*).

Part 3 | Imaging & Diagnostics

9. I have had the following types of imaging, and possess the disk and/or report (*if applicable*):

TYPE OF IMAGING	DATE(S) / DATE RANGE	DISK	REPORT
MRI (3 most recent)	—		
CT (3 most recent)	—		
Octreotide scan	—		
DOTATATE PET (i.e. Ga68 PET/CT or Cu64 PET/CT)	—		
FDG-PET	—		
PET	—		
Echocardiogram	—		
Colonoscopy	—		
Upper Endoscopy	—		
MIBG	—		
Capsule Endoscopy	—		
<i>Other</i>	—		
<i>Other</i>	—		





Part 4 | Labs

10. I have had the following labs and possess the report (*if applicable*). Indicate if abnormal.

TYPE OF LAB	DATE(S) / DATE RANGE	REPORT
Complete Blood Count (CBC)	—	
Basic Metabolic Panel (BMP) or Complete Metabolic Panel (CMP)	—	
Chromogranin A (CgA)	—	
Serotonin	—	
5-HIAA urine plasma	—	
Plasma (blood) Metanephrine and/or 24-Hour Urine	—	
Pancreastatin	—	
Neurokinin A	—	
A1C	—	
Other	—	
Other	—	
Other	—	

Part 5 | Surgery & Treatments

TYPE	DATE(S)	LOCATION	PHYSICIAN	REPORT
11. Surgery to remove primary tumor(s) (<i>Indicate all that apply</i>)				
Small bowel				
Pancreas				
Lung				
Adrenal				
Other				
12. Surgery to remove metastatic tumor(s) (<i>Indicate all that apply</i>)				
Liver				
Spleen				
Lung				
Other				





TYPE	DATE(S)	LOCATION	PHYSICIAN	REPORT
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13. Other surgery

Gallbladder removal (Cholecystectomy)				
Other				
Other				

14. Liver-directed treatment (indicate all that apply)

Radiofrequency ablation				
Chemoembolization (TACE)				
Bland embolization				
Radioembolization (Thera-Sphere®, SIR-Spheres®, TARE)				
Other				

15. Somatostatin Analogs (SSA) & others (indicate all that apply)

TYPE	DOSE	FREQUENCY	START DATE	LAST DOSE (DATE)
Sandostatin LAR (octreotide, long-acting)				
Sandostatin (octreotide, short-acting)				
Somatuline Depot (lanreotide)				
Xermelo (telotristat etiprate)				

16. Chemotherapy / Biologically-Targeted / Immunotherapy, including Clinical Trials/ PRRT (Peptide Receptor Radionuclide Therapy, i.e. Lutathera®) (indicate all that apply)

TYPE	DOSE/FREQUENCY	START DATE	END DATE	PHYSICIAN
Xeloda (capecitabine)			—	
Temodar (temozolomide)			—	
CAPTEM (capecitabine & temozolomide)			—	
Afinitor (everolimus)			—	
Sutent (sunitinib)			—	
Cisplatin/etoposide			—	
PRRT			—	
Other			—	
Other			—	





Part 6 | Additional information

17. I am diabetic:

Type I

Pre-diabetic

Type II

I am not diabetic

Notes on diabetes (including diet-controlled, taking meds, taking insulin, physician managing diabetes):

18. Allergies (*medications/food*):

19. Family history (*specify cancer and/or rare diseases*):

20. I have had Genetic Testing:

Yes

No

Don't know

Mutation(s) found

21. Medications/supplements (*including vitamins, digestive enzymes*):

22. Current physician(s) & medical team (*Including names, institution, phone numbers*)

Primary care provider:

Other providers (*i.e. endocrinologist, cardiologist, navigator*):

Medical oncologist:

Surgeon:

Nuclear medicine physician:

23. Social support

Number in household:

Employment Status:

Full-time

Part-time

Retired

On disability

Has employment been affected by diagnosis?





Notes to ask my physician:

Resources (available at www.LACNETS.org/resources)

More resources at www.LACNETS.org/resources

LACNETS - Learn Advocate Connect Neuroendocrine Tumor Society | www.LACNETS.org

Canadian NET patient resource guide, definitions, reference guide | bit.ly/CNETS_Resource

Cancer Legal Resources Center: legal, disability, insurance, financial | www.cancerlegalresources.org

Carcinoid Cancer Foundation - Checklist for the newly diagnosed | www.carcinoid.org

Healing NET Foundation (see NET PRIMER PDF) | www.thehealingnet.org

International Neuroendocrine Cancer Alliance | <http://incalliance.org>

NET glossary | www.knowyournets.com/materials

Neuroendocrine Tumor Research Foundation | www.netrf.org

North American Neuroendocrine Tumor Society | <https://nanets.net/resources/patient-resources>

Northern California CarciNET Community | www.NorCalCarciNET.org

PRRT Info (by patient advocates Josh Mailman & Gary Murfin) | www.PRRTinfo.org

Triage Cancer - Resource for legal, insurance, financial | www.triagecancer.org

