

NEWS AND NOTES MAY 2026

A Zoom Meeting

From National Cancer Institute: A multidisciplinary tumor board review of medical records; to find out how to submit your medical records contact Dr. Jaydira Del Rivero, MD, Director of the Center for Cancer Research Neuroendocrine Tumor Program: jaydira.delrivero@nih.gov

From NCAN **Support Group meeting Tuesday, May 26, 2026 7:30-9:00 EDT [Neuroendocrine Cancer Support Group Hosted by NCAN - Neuroendocrine Cancer Awareness Network](#)

**Patient conference NOLA (New Orleans, LA) on Saturday, June 6, 2026

**Virtual Support Group meeting, usually the last Tuesday of each month

**Blog posts by Anne Dabbs on their website

**Latest episode of NETs Get Real on their YouTube channel [NCANonYouTube.com](https://www.ncanonyoutube.com)

**The March 2026 patient conference is available on their YouTube channel

From NCF **NCF patient conference Atlanta GA May 16, 2026, 9:30-3 PM, see [NCF.net/Events/Atlanta](https://www.ncf.net/Events/Atlanta)

**Luncheon with the Experts Dr. Jason S Starr, May 28th Noon-1 PM EDT at [NCF.net/LWTE/May 28](https://www.ncf.net/LWTE/May%2026)

**NCF A Virtual Patient Conference June 20, 2026, see [NCF.net/events/2026conference](https://www.ncf.net/events/2026conference)

**Recorded presentation “The Latest in Neuroendocrine Cancer Clinical Trials” Dr. Soares

<https://www.ncf.net/high-grade-nen-resources>

**Recorded presentation “Novel Targeted Therapies in Neuroendocrine Cancers” Dr.

Thummalapalli <https://www.ncf.net/high-grade-nen-resources>.

** Neuroendocrine Cancer Foundation. Website: [NCF.net](https://www.ncf.net)

**Clinical Trials Guide: [Clinical Trials](#)

**Support Line [Support Line | NeuroendocrineCancer](#)

**Blog Post on a variety of topics on their website

** Weekly support group meetings each Wednesday, noon PT (3 pm ET)

**NET Vitals: worksheet to record your medical history: [NET VITALS | NeuroendocrineCancer](#)

**Luncheon with the Experts features conversations on NCF Facebook Live and on YouTube; they are available in their Video file.

**NET Cancer Health Storylines is available from the NCF website: [NET Cancer Health Storylines Mobile App — Health Storylines™](#) use it on your desktop or phone

From NETRF **An Updated Patient’s Guide to NETs is available info@netrf.org

**NETWise podcasts; you can sign up at www.netrf.org/podcast

From The Healing NET Foundation:

**Patient Care booklet *Navigating the NET Patient Journey* is available online from their website as well as their *Neuroendocrine Tumors: A Primer for Healthcare Professionals*

**Online gathering for Adolescents & Young Adults every third Sunday of the month 4 PM Pacific/7 PM Eastern [Conversations for Teens and Young Adults — The Healing NET Foundation](#)

**New Guide on High-Grade NECs: <https://www.carcinoid.org/2021/11/09/new-guide-on-high-grade-neuroendocrine-cancers/>

From TerSera Therapeutics for Xermelo:

**Our Clinical Nurse Educator is Heather Sabadasz, BSN, RN, OCN.

**For support with CS, please go to www.enrollxermelo.com and opt in. Once completed, a nurse educator will contact you within 48 hours. For the nursing support program, please go to: www.thenetnurse.com

From Lexicon **A Nutrition Guide: sign up via link: <https://community.aboutcarcinoid.com/>
**Also available from through CCF: https://www.carcinoidsyndrome.org/2017/12/19/nutrition-recipe-guide-people-gastrointestinal-neuroendocrine-tumors-carcinoid-syndrome/?fbclid=IwAR2fsqItfegz0ZpYEraraT-j9MzZ1d9RzQfId_yX7OrBtMpcJZtAVH5Hfb0

NEW ARTICLES:

From Maureen, from the UK: Neuroendocrine Cancer: A Growing Crisis: [Neuroendocrine Cancer: A Growing Crisis | Parliament Politics Magazine](#)

From Pat, from the INCA Monthly Newsletter: Quality of Life survey for pNETs patients: [Online Survey Software | Qualtrics Survey Solutions](#)

From Pat, from The Healing NET Foundation: Healing NET conversations for Teens and Young Adults, Sunday May 17, 2026, 4 PM Pacific/7 PM Eastern [Conversations for Teens and Young Adults — The Healing NET Foundation](#)

RECURRING ARTICLES:

From Pat, from the INCA Monthly Newsletter: Neuroendocrine Cancer UK podcast on Lung NETs: [BTOG Podcasts | BTOG | British Thoracic Oncology Group](#)

Also: Quality of life and care experiences in a US multi-institutional NET cohort: [Quality of life and care experiences in a US multi-institutional neuroendocrine tumor cohort | JNCI: Journal of the National Cancer Institute | Oxford Academic](#)

From Janet L: recordings of the Penn Medicine conference will be available at med.upenn.edu/nets2026 starting Thursday April 16, 2026 through 2027

From Justin: NET – Vitamin B12 (Cobalamin): [Neuroendocrine Tumours \(NET\) - Vitamin B12 \(Cobalamin\) - Ronny Allan - Living with Neuroendocrine Cancer](#)

From Pat via the INCA Monthly Newsletter: Nutrition in NENs Resources: [Nutrition in NENs Resources From INCA Members - INCA](#)

Also: From Neuroendocrine Cancer UK: The Invisible Cancer, a new report: [Invisible Cancer - Neuroendocrine Cancer UK](#)

Also: Outcomes of PRRT with Lu-Dotatate in patients with metastatic Pheo & Para: [Outcomes of Peptide Receptor Radionuclide Therapy with 177Lu-DOTATATE in Patients with Metastatic Pheochromocytoma and Paraganglioma | Journal of Nuclear Medicine](#)

Also: Somatostatin analogs in NETs with Ki-67 index of greater than or equal to 10%: [Somatostatin analogs in neuroendocrine tumors with Ki-67 index of ≥10% - Braegelman - 2026 - Journal of Neuroendocrinology - Wiley Online Library](#)

Also: Neuroendocrine neoplasms of the stomach. Update on diagnostic criteria, classification, and prognostic markers: [Neuroendocrine neoplasms of the stomach. Update on diagnostic criteria, classification, and prognostic markers | Virchows Archiv | Springer Nature Link](#)

From Daiva: [Home | 15th Focus on Neuroendocrine Tumors | Perelman School of Medicine at the University of Pennsylvania](#) Friday, April 10th at The Rittenhouse Hotel in Philadelphia; this is an in-person and virtual conference

From Pat, as mentioned at the December 7th Zoom meeting: [The ripeness level of your banana actually matters for your health — here's how](#)

From Mayo Clinic via Donna: What is Carbon Ion Therapy: [Carbon Ion Therapy: A Look Inside the Cancer Treatment](#)

From INCA via Pat: Educational webinar from the ENETS & INCA NET Cancer Day 2025: [The Recording of the ENETS & INCA NET Cancer Day 2025 Educational Webinar Is Available to Watch - INCA](#)

From INCA via Pat: Information packs for NETs cancers: [Free Access to NET Info Packs in 12 languages - INCA](#)

From NCF via Pat: Latest Immunotherapy for NETs webinar Dec 11, 2025: [Dec2025 | NeuroendocrineCancer](#)

From NETRF via Chuck: AlphaMedix Shows Promising Phase 2 Results in Advanced NETs: [AlphaMedix™ Shows Promising Phase 2 Results in Advanced Neuroendocrine Tumors - NETRF](#)

From NETRF via Chuck: Progress Seen in CDH17 CAR T Trial: [Progress Seen in CDH17 CAR T Trial - NETRF](#)

From NETRF via Chuck: Another CAR T-Cell Clinical Trial Open to NEC patients: [Another CAR T-Cell Clinical Trial Open to Neuroendocrine Cancer Patients - NETRF](#)

From NETRF via Chuck : Early Clinical Trial of 61Cu-TraceNET Shows Promise in Improving NET Imaging: [Early Clinical Trial of 61Cu-TraceNET™ Shows Promise in Improving NET Imaging - NETRF](#)

From NETRF via Chuck: New Lab Models Reveal Hidden Weaknesses in Pheochromocytoma and Paraganglioma Tumors: [New Lab Models Reveal Hidden Weaknesses in Pheochromocytoma and Paraganglioma Tumors - NETRF](#)

From NETRF via Chuck: Your Sample Can Change the Future of Neuroendocrine Cancer Care: [Your Sample Can Change the Future of Neuroendocrine Cancer Care - NETRF](#)

****Please see our website (njcarcinoidnetwork.org) for additional articles****

Other items of interest:

From Randy at the September 2022 Zoom meeting: **Topical Coolant Spray “Medi-First Cold Spray” available on Amazon: https://www.amazon.com/gp/product/B008SI1VDG/ref=ppx_yo_dt_b_asin_title_o09_s02?ie=UTF8&psc=1

From Randy at the February 2022 Zoom meeting: **List of Apps for compiling your medical records: <https://tinyurl.com/2pd5y9w3>

From a patient on ACOR: **Eovist contrast has “more distribution and excretion pathways...which allows for an additional contrast phase in the scan and more information to aid in diagnosis.” Ask for it specifically, even with the technician or radiologist who is performing the scan.

Patient Access Network: **from Jim and Janet: Member services 1-800-806-7501, Benefits information: 1-800-316-7263.

“Medical information has to be completed by the provider’s office; PAN has been able to assist in handling out of pocket expenses, deductible for specific chemo drugs; all other insurances are used first.”

Patient resources suggested by Lynn in Monmouth County: **the Livestrong Program at the Red Bank YMCA; the Monmouth Medical Center Cancer Support Group; and

**Mary's Place by the Sea in Ocean Grove - a respite home for women receiving treatment for cancer <https://www.marysplacebythesea.org>

**Maureen holds writers’ workshops at Mary’s Place by the Sea in Ocean Grove on Tuesdays and Thursdays.

ISI InterScience Institute: to request a copy of their biomarker testing code book go to interscienceinstitute.com, or download a PDF version

Organizations and websites:

Neuroendocrine Cancer Foundation: NCF
Neuroendocrine Carcinoid Awareness: NCAN
Neuroendocrine Tumor Research Foundation: NETRF
The Healing NET Foundation
Clinical Trials information
Ronny Allan blog
Carcinoid Syndrome from CCF
NET Patient Foundation

Find them at

ncf.net
netcancerawareness.org
netrf.org; newsletter available
thehealingnet.org; newsletter available
clinicaltrials.gov
ronnyallan.com
carcionoidsyndrome.org
netpatientfoundation.org (located in London)

Discussion boards:

ACOR.org (find the carcinoid group)
Smartpatients.com (find the carcinoid group)
Inspire.com (Lung NET group, others)

Facebook groups:

Carcinoid Coffee Café
Lovable Lungnoids

Dr Liu's Zebras: A Neuroendocrine Cancer
Community
NET Patients Sharing Knowledge & Experience

Carcinoid Neuroendocrine Cancer Awareness

Carcinoid Connection (also: carcinoid.com)
Carcinoid Awareness (also: aboutcarcinoid.com)
Zebra Caregivers Talk NETS (no patients)
My Dazzle (sponsored by Lexicon)

NETs get COOKING
Green Zebras (cannabis for NET cancer)
Young Zebras: A Support Group for Young NET
Cancer patients and their caregivers
ZEBRA awareness Global NETS
Zebra Zone: NET cancer Support Group (linked to
Neuroendocrine Cancer Connection)