

NEWS AND NOTES January 2024

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 **Virtual Support Group meeting the second Saturday of the month from 12:15-2:15, see their website for more information

**Blog posts by A G Dabbs on their website

From LACNETS ****Clinical Trials Guide:** [Clinical Trials \(lacnets.org\)](http://ClinicalTrials.org)

**Support Line [Support Line | LACNETS](http://SupportLine.org)

**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: <https://www.lacnets.org/lacnets-blog/netvitals>

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 CCF **Partnership with Clarified Precision Medicine to offer NET patients the opportunity to receive an expert review of their tumor sequencing. Please see: clarifiedprecisionmedicine.com/clarifiedselect
****Monthly** Lunch with the Experts features conversations the **second Thursday** at noon on CCF Facebook Live; they are always available in their Video file and are posted on the CCF YouTube channel the following Monday.

**NET Cancer Health Storylines is available from the CCF website; use it on your desktop or phone

https://www.healthstorylines.com/net-cancer-healthstorylines?fbclid=IwAR1lz8N_68HtYNAz09b64rTp4Mq0UlvMjEUtTBweiYf9Qb1yruHlRyb3vu4

** Ask the NET Experts – A Program from CCF:

https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2788218?fbclid=IwAR0rtLuLbYI75XpQEbVC878rMe-yFDKK9bvHGUap1zmqIhV_3t_BG6SqQMg

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*

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

From Lisa and Devin at TerSera Therapeutics: **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

**Find Food You Love: [Home | Food You Love Book](http://Home.FoodYouLove.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=IwAR2fsqItefgz0ZpYEraraT-j9MzZ1d9RzQfld_yX7OrBtMpcJZtAVH5Hfb0

RECURRING ARTICLES:

From Pat from the NANETS Nov 14th newsletter: Systemic Therapy for Tumor Control in Metastatic Well-Differentiated Gastroenteropancreatic NETs: ASCO Guideline:

[Systemic Therapy for Tumor Control in Metastatic Well-Differentiated Gastroenteropancreatic Neuroendocrine Tumors: ASCO Guideline | Journal of Clinical Oncology \(ascopubs.org\)](http://SystemicTherapyforTumorControlinMetastaticWell-DifferentiatedGastroenteropancreaticNeuroendocrineTumors:ASCOGuideline|JournalofClinicalOncology(ascopubs.org))

From Daiva and Chuck: Study Details for A Phase 1 / 2 Study to Evaluate CHM-2101, an Autologous Cadherin 17 Chimeric Antigen Receptor (CAR) T Cell Therapy: [Study Details | A Phase 1/2 Study to](http://StudyDetails|APhase1/2Studyto)

[Evaluate CHM-2101, an Autologous Cadherin 17 Chimeric Antigen Receptor \(CAR\) T Cell Therapy | ClinicalTrials.gov](#)

From Randy: “Sunitinib in pNETs: updated progression-free survival and final overall survival from a phase III randomized study: [Sunitinib in pancreatic neuroendocrine tumors: updated progression-free survival and final overall survival from a phase III randomized study - Annals of Oncology](#)

From LACNETS: Update on NETTER-2 Trial: [Novartis radioligand therapy Lutathera® demonstrated statistically significant and clinically meaningful progression-free survival in first line advanced gastroenteropancreatic neuroendocrine tumors \(GEP-NETs\) | Novartis](#)

From LACNETS: COMPOSE: PRRT with Lu-177 Edotreotide versus “Standard of Care” in Well-Differentiated Aggressive G2 & G# GEP-NETs: [COMPOSE: PRRT with Lu-177 EDOTREOTIDE versus “Standard of Care” in Well-Differentiated Aggressive G2 & G3 GEP-NETs \(lacnets.org\)](#)

From Janet T: Researchers at Dana-Farber Cancer Institute Facebook page: “Study provides new look at why rare cancer often evades treatments”: [Researchers at Dana-Farber Cancer... - Dana-Farber Cancer Institute | Facebook](#)

For those not on FB: [Study provides new look at why rare cancer often evades treatments - Dana-Farber Cancer Institute | Boston, MA](#)

From Randy: “Efficacy and safety of colesevelam for the treatment of bile acid diarrhoea: a double-blind, randomised, placebo-controlled, phase 4 clinical trial”: [Efficacy and safety of colesevelam for the treatment of bile acid diarrhoea: a double-blind, randomised, placebo-controlled, phase 4 clinical trial - ScienceDirect](#)

From Chuck: “She wrote to a scientist about her fatigue. It inspired a breakthrough.” [Fatigue patient’s case prompts discovery that may help with long covid - The Washington Post](#)

From Chuck: Metformin and Statins articles: [The potential role of metformin in the treatment of patients with pancreatic neuroendocrine tumors: a review of preclinical to clinical evidence - PMC \(nih.gov\)](#)

And [Role of metformin and other metabolic drugs in the prevention and therapy of endocrine-related cancers - ScienceDirect](#)

From Pat, from NANETS: [ASCO Reading Room | Pamela Kunz, MD, on Capecitabine-Temozolomide for Advanced Pancreatic NETs | MedPage Today](#)

From Pat, from NANETS: [Understanding the increasing incidence of neuroendocrine tumors - PubMed \(nih.gov\)](#)

From Chuck and Mike: [Ipsen announces investment in new state-of-the-art electronic autoinjector for Somatuline® Autogel® / Somatuline® Depot \(lanreotide\) designed to improve patient experience \(yahoo.com\)](#)

From Chuck and Mike: [Interim Analysis of a Prospective Validation of 2 Blood-Based Genomic Assessments \(PPQ and NETest\) to Determine the Clinical Efficacy of 177Lu-DOTATATE in Neuroendocrine Tumors - PubMed \(nih.gov\)](#)

From Maureen: US Rep. Joaquin Castro had surgery to remove cancerous tumors: [Texas Congressman Joaquin Castro had cancer surgery | The Texas Tribune](#)

From Pat from NANETS: [BioMark Presents Novel Liquid Biopsy Data in Pulmonary Neuroendocrine Tumors \(yahoo.com\)](#)

From Pat: [Drugs to activate STING could help prevent cancer metastasis \(news-medical.net\)](#)

From Chuck: [Necrolytic migratory erythema as the first manifestation of pancreatic neuroendocrine tumor - PMC \(nih.gov\)](#)

From Randy, and discussed by Randy and Murf at the March meeting: [Learn More | Join All of Us](#)
Through the NIH, they are looking for 1 million volunteers to share health information; the more NETs patients who enroll, the more they can learn something about us.

From Janet L: [Making Sense of a Complex Disease: A Practical Approach to Managing Neuroendocrine Tumors. | Semantic Scholar](#)

From Murf: [Hemicolectomy versus appendectomy for patients with appendiceal neuroendocrine tumours 1–2 cm in size: a retrospective, Europe-wide, pooled cohort study - The Lancet Oncology](#)

From Randy via the Chat at the February meeting: [CIO 2021-20 Efficacy of Transarterial Bland Embolization with Everolimus \(EveroEmbo\) for Hepatic Metastatic Neuroendocrine Tumors \(hmpgloballearningnetwork.com\)](#)

From Randy via the Chat at the February meeting: [Paltusotine, a novel oral once-daily nonpeptide SST2 receptor agonist, suppresses GH and IGF-1 in healthy volunteers - PubMed \(nih.gov\)](#)

From Chuck, as discussed at the February meeting: [Serum lipid levels correlate to the progression of gastric cancer with neuroendocrine immunophenotypes: A multicenter retrospective study - PubMed \(nih.gov\)](#)

From Chuck, based on our discussion at the February meeting about tyramines: [MAOIs and diet: Is it necessary to restrict tyramine? - Mayo Clinic](#)

From Pat, from NANETS: [Early-Stage Primary Lung Neuroendocrine Tumors Treated with Stereotactic Body Radiotherapy: A Multi-Institution Experience - PubMed \(nih.gov\)](#)

From Effie: [A multidisciplinary approach to the work up and management of pulmonary carcinoid tumors and DIPNECH: a narrative review - Ramirez- Translational Lung Cancer Research \(amegroups.com\)](#)

From Mike and Chuck: [Volume Doubling Time of Pulmonary Carcinoid Tumors Measured by Computed Tomography - ScienceDirect](#)

From Mike and Chuck: Her crippling digestive problems were caused by a ‘zebra’ malady: [Years of pain, digestive problems preceded a diagnosis - The Washington Post](#)

From Pat: [At-home saliva test diagnoses cancer with over 90% accuracy \(thebrighterside.news\)](#)

From Pat and Chuck: [Groundbreaking blood test can identify over 50 types of cancer \(thebrighterside.news\)](#)

From Mike and Chuck: [The Patient's Point of View: COVID-19 and Neuroendocrine Tumor Disease - PubMed \(nih.gov\)](#)

From Mike and Chuck: [Novel preclinical gastroenteropancreatic neuroendocrine neoplasia models demonstrate the feasibility of mutation-based targeted therapy - PubMed \(nih.gov\)](#)

From Mike and Chuck: [FDA Grants Fast Track Designation to ITM-11 for Gastroenteropancreatic Neuroendocrine Tumors \(onclive.com\)](#)

From Mike and Chuck: [18F-AIF-NOTA-octreotide outperforms 68Ga-DOTA-TATE/-NOC PET in neuroendocrine tumor patients: results from a prospective, multicenter study - PubMed \(nih.gov\)](#)

From Mike and Chuck: [Incidence of psychiatric illness in patients with neuroendocrine tumors: a comparative population-based analysis | SpringerLink](#)

From the September 11, 2022 NJCCN zoom meeting: [Appropriate Use Criteria for Somatostatin Receptor PET Imaging in Neuroendocrine Tumors - PMC \(nih.gov\)](#)

From Mike and Chuck: [Cancers | Free Full-Text | Neuroendocrine Tumors: A Comprehensive Review on Nutritional Approaches | HTML \(mdpi.com\)](#)

From Kate and Chuck: [Lung neuroendocrine neoplasms: recent progress and persistent challenges | Modern Pathology \(nature.com\)](#)

From Kate and Chuck: [Incidence and Survival Outcomes in Patients with Lung Neuroendocrine Neoplasms in the United States - PMC \(nih.gov\)](#)

From Mike and Chuck: [MSK Researchers Discover How Cancer Cells Change Identity To Escape Therapies | Memorial Sloan Kettering Cancer Center \(mskcc.org\)](#)

From Mike and Chuck: [Amryt Receives Orphan Drug Designation from the FDA for \(globenewswire.com\)](#)

From Mike and Chuck: [The Evolving Role of Radioembolization in the Treatment of Neuroendocrine Liver Metastases - PubMed \(nih.gov\)](#)

From Mike and Chuck: [Sequencing of Therapies in Progressive Neuroendocrine Tumors | SpringerLink](#)

From Pat, via MSKCC newsletter: [Rectal Cancer Disappears After Experimental Use of Immunotherapy | Memorial Sloan Kettering Cancer Center \(mskcc.org\)](#)

From Randy: Cancer Trial's Unexpected Result: Remission in Every Patient
[Small Study on Rectal Cancer Results in Remission in Every Patient - The New York Times \(nytimes.com\)](#)

From Mike and Chuck: [Drug combination shows promise for treating pNETs | EurekAlert!](#)

From Mike and Chuck: [Cancers | Free Full-Text | New Therapy Options for Neuroendocrine Carcinoma of the Pancreas—The Emergent Substance GP-2250 and Gemcitabine Prove to Be Highly Effective without the Development of Secondary Resistances In Vitro and In Vivo \(mdpi.com\)](#)

From Mike and Chuck: https://journals.lww.com/oncology-times/Fulltext/2022/05050/Good_Response_With_ONC201_for_Rare_Neuroendocrine.5.aspx?context=FeaturedArticles&collectionId=2

From Mike and Chuck: In patients with well-differentiated NETs, there is no apparent benefit of SSAs after disease control by PRRT: <https://pubmed.ncbi.nlm.nih.gov/35503379/>

Link for Sunnybrook Health Sciences Centre: <https://sunnybrook.ca/content/?page=neuroendocrine-tumour-cancer&fbclid=IwAR1CGJGUWqZqzSmqnFNoJ-s1uMwux9PYqc6be2i7T9fDUN-taYlZqfOLGU>

From Mike and Chuck: Prognostic significance of laterality in lung NETs:
<https://pubmed.ncbi.nlm.nih.gov/35301675/>

From Mike and Chuck: INCA Global NET Patient Information Pack: <https://incalliance.org/net-info-packs/>

From Mike, referenced during our zoom meetings: Gebauer's Pain Ease:
<https://www.gebauer.com/pain-ease-procedural-video-wf>

From Mike and Chuck: Circulating Progastrin, a Novel Blood-Based Biomarker for Detection of Poorly Differentiated NEC and Well Differentiated NETs: https://www.mdpi.com/2072-6694/14/4/863/review_report

From Mike: Diagnostic value of Ga68 Ga-DOTA-labeled-somatostatin analogue PET/MRI for detecting liver metastasis in patients with NETs: a systematic review and meta-analysis:
<https://link.springer.com/article/10.1007/s00330-021-08527-z>

From CCF: Management of Large Cell Neuroendocrine Carcinoma:
https://www.frontiersin.org/articles/10.3389/fonc.2021.653162/full?fbclid=IwAR3ZAFccVMeoSHWjPiHeX5m-KJombhcU1atIfrxL2piSICVd9rsL7_d8U54

From Jacq: Belzutifan/MK-6482 for the Treatment of Advanced Pheochromocytoma/Paraganglioma (PPGL) or Pancreatic NET (pNET) (MK-6482-015): <https://clinicaltrials.gov/ct2/show/NCT04924075>

From Mike and Chuck: Molecular Genomic Assessment Using a Blood-based mRNA Signature (NETest) is Cost-effective and Predicts NET Recurrence with 94% Accuracy:
<https://pubmed.ncbi.nlm.nih.gov/34183517/>

From Mike and Chuck: <https://www.oncnursingnews.com/view/tidutamab-induces-best-overall-response-of-stable-disease-in-advanced-neuroendocrine-tumors>

From Mike and Chuck: <https://www.onclive.com/view/lanreotide-demonstrates-confirmed-efficacy-in-advanced-bronchopulmonary-nets>

From Mike and Effie: <https://www.ajmc.com/view/liquid-biopsy-blood-biomarker-possible-predictor-of-tumor-recurrence-cost-savings>

From Chuck: <https://www.healio.com/news/hematology-oncology/20211021/neuroendocrine-tumors-require-individualized-treatment-approach>

From Chuck: A Novel Liquid Biopsy (NETest) identifies Paragangliomas and Pheochromocytomas with High Accuracy: <https://pubmed.ncbi.nlm.nih.gov/34515661/>

From Chuck: A Multigenomic Liquid Biopsy Biomarker for NET Disease outperforms CgA and has Surgical and Clinical Utility: https://www.semanticscholar.org/paper/A-Multigenomic-Liquid-Biopsy-Biomarker-for-Tumor-Modlin-Kidd/4b9b1458b64083a8cf83336ed0c6e500708186e9?utm_source=alert_email&utm_content=AuthorP

[aper&utm_campaign=AlertEmails_WEEKLY&utm_term=AuthorPaper&email_index=0-0-0&utm_medium=2488505](https://www.nccn.org/patients/guidelines/content/PDF/neuroendocrine-patient.pdf)

NCCN (National Comprehensive Cancer Network) Guidelines for Patients:

<https://www.nccn.org/patients/guidelines/content/PDF/neuroendocrine-patient.pdf>

European Neuroendocrine Tumor Society (ENETS): https://www.enets.org/current_guidelines.html

Canadian Neuroendocrine Tumour Society (CNETS): <https://cnets.ca/patients-caregivers/resources/438-2/>

Wren Laboratories:

<https://www.wrenlaboratories.com/?fbclid=IwAR1O8YIMR7mPSyDi88jUjrVZrR5I3UoAy9JnBvbZ2pVk9qWnQjggednSMXY>

FAQs NET Tissue Donation: [https://netrf.org/2019/06/12/faqs-tumor-tissue-](https://netrf.org/2019/06/12/faqs-tumor-tissue-donation/?fbclid=IwAR1_q5Pvl_6eKWvwtmaMSBEaDCBw-wMbPHKnXxTdcfEg0KFpq6Awc-RQa4)

[donation/?fbclid=IwAR1_q5Pvl_6eKWvwtmaMSBEaDCBw-wMbPHKnXxTdcfEg0KFpq6Awc-RQa4](https://netrf.org/2019/06/12/faqs-tumor-tissue-donation/?fbclid=IwAR1_q5Pvl_6eKWvwtmaMSBEaDCBw-wMbPHKnXxTdcfEg0KFpq6Awc-RQa4)

Your Surgery or Fluid Drain can Advance Cancer Research:

<https://pattern.org/?fbclid=IwAR16DOxL6VScbv5QI5DTG99T3SpRiZuU0gCbID5WiyEXxA4PYEbhbgZU9nl>

From Chuck: 'I'm a Cardiologist, and Here's What It Really Means When You're Out of Breath From Walking Up the Stairs' <https://www.msn.com/en-us/health/fitness/i-m-a-cardiologist-and-here-s-what-it-really-means-when-you-re-out-of-breath-from-walking-up-the-stairs/ar-BB1f5ZJC?ocid=msedgdhp>

****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:

Carcinoid Cancer Foundation: CCF

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

LACNETS: Los Angeles Carcinoid NET Society

Find them at

carcinoid.org

netcancerawareness.org

netrf.org; newsletter available

thehealingnet.org; newsletter available

clinicaltrials.gov

ronnyallan.com

carcionoidsyndrome.org

netpatientfoundation.org (located in London)

lacnets.org

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)