

NEWS AND NOTES September 2025
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 Miami FL **NET Cancer Patient Conferences: September 21, 2025 New Brunswick NJ, December 2025

 **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

From NCF **formerly LACNETS now known as Neuroendocrine Cancer Foundation. Website: 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](#)

From CCF **In partnership with NCF: Luncheon with the Experts features conversations on alternate Thursdays at noon (eastern time) on CCF Facebook Live and on YouTube; they are always available in their Video file.

 **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

 **NET Cancer Health Storylines is available from the CCF 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:

****Our new 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

****Find Food You Love: [Home | Food You Love Book](#)**

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=IwAR2fsqIftfegz0ZpYEraraT-j9MzZ1d9RzQfld_yX7OrBtMpcJZtAVH5Hfb0**

NEW ARTICLES:

 From Chuck, "A single exercise session may slow cancer cell growth, new study shows" [Can exercise slow cancer cells? A new study suggests it can. - The Washington Post](#)

RECURRING ARTICLES:

From Chuck, based on our discussion at the July 20, 2025 Zoom meeting: 9 Medications That Cause Joint and Muscle Pain: [9 Medications That Can Cause Joint and Muscle Pain - GoodRx](#) From Chuck: The surprisingly simple treatment that could transform cancer care: [Opinion | A simple treatment can improve cancer survival - The Washington Post](#)

From Chuck: Structured Exercise after Adjuvant Chemotherapy for Colon Cancer: [Structured Exercise after Adjuvant Chemotherapy for Colon Cancer | New England Journal of Medicine](#) From Amy and Anthony, his story: <https://medicalstories.tv/title/nets/>

From Chuck, a Slideshow for Carcinoid Syndrome: [Carcinoid Syndrome Causes, Symptoms, & Treatments](#)

From the July 10, 2025 CCF/NCF Luncheon with the Experts Dr. Diane Reidy-Lagunes: [Diane Reidy-Lagunes, MD | Medical Oncologist | Duke Health](#)

From the July 10, 2025 Luncheon: [Clinical Trials](#)

From Maureen: A Forgotten Cancer is Surging in Young People, and Experts are Puzzled: [A Forgotten Cancer Is Surging in Young People, And Experts Are Puzzled : ScienceAlert](#)

From Chuck: Epidemiology of NETs of the Appendix in the USA: a population-based national study (2014-2019): [Epidemiology of neuroendocrine tumors of the appendix in the USA: a population-based national study \(2014-2019\) - PMC](#)

From Pat, Daiva, and Janet L: CAR-T Cell Therapy for NET Cancer, Now in Clinical Trial, Receives FDA FAST TRACK Designation: [CAR T-Cell Therapy for Neuroendocrine Cancer, Now in Clinical Trial, Receives FDA FAST TRACK Designation - NETRF](#)

See also the NETRF announcement on Instagram and Facebook featuring Dr. Eads from UPenn Medicine

From Chuck: Cancers Can Be Detected in Bloodstream Three Years Prior to Diagnosis: [Cancers can be detected in bloodstream three years prior to diagnosis | Hub](#)

From Chuck, regarding Capecitabine: Two Women Faced Chemo. The One Who Survived Demanded a Test to See if It Was Safe. [Two Women Faced Chemo. The One Who Survived Demanded a Test to See if It Was Safe. | MedPage Today](#)

From the May 1, 2025 Luncheon with the Experts Dr. Mintallah (Menna) Haider: [Mintallah Haider | Moffitt](#)

From the May 1, 2025 Luncheon: Lung NET Resources: [Lung NET Resources | NeuroendocrineCancer](#)

From the May 1, 2025 Luncheon: Positive Results of the CABINET Trial Show Cabozantinib as New, Effective Treatment in Advances NETs: [Positive Results of the CABINET Trial Show Cabozantinib as a New, Effective Treatment in Advanced Neuroendocrine Tumors](#)

From the April 17, 2025 Luncheon with the Experts, “Episode 38: NEN Treatments Focus on Liver-directed Therapies: [Episode 38: NEN Treatments: Focus on Liver-Directed Therapies \(Part 1: Overview and Ablative Techniques Including Histotripsy\) | NeuroendocrineCancer](#)

From the April 17, 2025 Luncheon with the Experts, “New Progress in Treatment Options...” [New Progress in Treatment Options...](#)

From the April 17, 2025 Luncheon with the Experts, Dr. James Howe: [James Howe | University of Iowa Health Care](#)

From our April 6th Zoom meeting, 2 articles about the Octreotide protocol: [ENETS Consensus Guidelines for the Standards of Care in Neuroendocrine Tumors: Pre- and Perioperative Therapy in Patients with Neuroendocrine Tumors - PMC](#) and [Elimination of Perioperative Octreotide Does Not Increase Rate or Duration of Carcinoid Crisis in NETs](#)

From the April 3, 2025 Luncheon with the Experts Dr. Julie Hallet: [Julie Hallet MD, M.Sc., FRCSC - Sunnybrook Hospital](#)

From the April 3rd Luncheon with the Experts: National Cancer Institute: Surveillance, Epidemiology, and End Results Program (SEER): [Surveillance, Epidemiology, and End Results Program](#)

From the April 3rd Luncheon with the Experts: PRRT [Peptide Receptor Radionuclide Therapy \(PRRT\) | NeuroendocrineCancer](#)

From the March 20, 2025 Luncheon with the Experts Dr. Delphine Chen: [dlchen7 | UW Radiology](#)

From the March 20th Luncheon with the Experts NCF Support Line: [Support Line | NeuroendocrineCancer](#)

From the March 6, 2025 Luncheon with the Experts Dr. Nitya Raj: [Nitya Raj, MD - MSK Gastrointestinal Medical Oncologist](#)

From March 6th Luncheon with the Experts: NEN Treatments: Focus on Liver-directed therapies: [Episode 38: NEN Treatments: Focus on Liver-Directed Therapies \(Part 1: Overview and Ablative Techniques Including Histotripsy\) | NeuroendocrineCancer](#)

From March 6th Luncheon with the Experts: Focus on Liver-directed therapies: [Episode 39: NEN Treatments: Focus on Liver-Directed Therapies \(Part 2: Intra-Arterial Techniques and Sequencing\) | NeuroendocrineCancer](#)

From March 6th Luncheon with the Experts: Clinical Trials Guide: [Clinical Trials](#)

From March 6th Luncheon with the Experts: PRRT trials: [Peptide Receptor Radionuclide Therapy \(PRRT\) | NeuroendocrineCancer](#)

From March 6th Luncheon with the Experts: Positive Results of the CABINET Trial Show Cabozantinib as a New, Effective Treatment in Advanced NETs: [Positive Results of the CABINET Trial Show Cabozantinib as a New, Effective Treatment in Advanced Neuroendocrine Tumors](#)

From Pat, based on discussion at the March 2, 2025 meeting, two articles about adults and measles vaccinations: [Do adults need a measles vaccine booster? : Shots - Health News : NPR](#) and [Do You Need A Measles Booster? Your Birth Year Will Reveal The Answer](#)

From Daiva: The 14th Annual Penn NET patient & caregiver conference Friday March 28th: [14th Annual Focus on Neuroendocrine Tumors | Perelman School of Medicine at the University of Pennsylvania](#)

From Daiva: Chimeric Therapeutics CAR-T Therapy: [Chimeric Therapeutics CEO discusses progress with promising cancer treatment trials | ASX:CHM, OTC:CHMME](#)

From the February 20, 2025 Luncheon with the Experts: NEN Treatments: Focus on Liver-directed Therapies: [Episode 38: NEN Treatments: Focus on Liver-Directed Therapies \(Part 1: Overview and Ablative Techniques Including Histotripsy\)](#)

From the February 20, 2025 Luncheon with the Experts: Dr. Charles Nutting, Interventional Radiologist: [LIVE with Dr. Charles Nutting! - YouTube](#)

From Ronny Allan via Maureen: NETest 2.0-A decade of innovation in NET diagnostics: [NETest® 2.0—A decade of innovation in neuroendocrine tumor diagnostics - Kidd - Journal of Neuroendocrinology - Wiley Online Library](#)

From Randy: Histotripsy at NYU: [Histotripsy: A New Ablation Therapy for Liver Tumors | NYU Langone Health Physician Focus](#)

From Randy: Advances in tumor Management: Harnessing the Potential of Histotripsy: [Advances in Tumor Management: Harnessing the Potential of Histotripsy - PMC](#)

From Randy: Histotripsy-A Novel and Intriguing Technique of Liver Ablation: [Histotripsy—A Novel and Intriguing Technique of Liver Ablation | Gastroenterology | JAMA Surgery | JAMA Network](#)

From the January 30, 2025 CCF Luncheon with the Experts: Dr. Namrata Vijayvergia, MD: [Namrata Vijayvergia | Fox Chase Cancer Center - Philadelphia PA](#)

From the 1/30/25 Luncheon: LACNETS Support Line: [Support Line | LACNETS](#)

From the 1/30/25 Luncheon: Carcinoid Heart Disease "[Carcinoid Heart Disease](#)" • 2024 LACNETS Event • Feb 14, 2024

From the 1/30/25 Luncheon: Understanding GI NETs Found on Endoscopy: [Jan2025 | LACNETS](#)

From the 1/30/25 Luncheon: Peptide Receptor Radionuclide Therapy (PRRT): [Peptide Receptor Radionuclide Therapy \(PRRT\) | LACNETS](#)

From the 1/30/25 Luncheon: Beyond the Basics: The Pathology of NET [Episode 19: Beyond the Basics: The Pathology of NET](#)

From Ilene: Duke Medicine announces Dr. Diane Reidy-Lagunes appointed Chief of Medical Oncology: <https://medicine.duke.edu/news/dr-diane-reidy-lagunes-appointed-chief-medical-oncology>

From Effie: Dr. Reidy Chief Medical Oncology Duke Department Medicine: [Dr. Diane Reidy-Lagunes Appointed Chief of Medical Oncology | Duke Department of Medicine](#)

From Shantelle: Patient Histotripsy story https://www.hoag.org/patient-stories/hoag-patient-receives-newly-fda-approved-cancer-treatment-histotripsy/?utm_source=sfmc&utm_medium=email&utm_campaign=46823544_20250129

From Randy: Status of the Alpha PRRT Trial: [1198P-RYZ101-301-ESMO-2023-poster-UPLOAD.pdf](#)

From Jo: "Atypical Small Cell Carcinoma, a Rare Type Lung Cancer, Identified by MSK Research Team": [New, rare type of small cell lung cancer identified | ScienceDaily](#)

From Randy the 2024 Run for the Stripes Video: <https://youtu.be/oR3l6qPndGg>

From Carol: [Exploring new ground with a clinical trial of a NET cancer vaccine - NETRF](#)

From November 7th NANETS Connect: In Major Win for Patients, CMS Adjusts Nuclear Medicine Reimbursement Policy, Expanding Access to Life-Saving Scans: [CMS Adjusts Nuclear Medicine Reimbursement Policy, Expanding Access to Life-Saving Scans - SNMMI](#)

From October 31st NANETS Connect: Circulating Chromogranin A as Surveillance Biomarker in Patients with Carcinoids – The CASPAR Study: [Circulating Chromogranin A as Surveillance Biomarker in Patients with Carcinoids – The CASPAR Study | Clinical Cancer Research | American Association for Cancer Research \(aacrjournals.org\)](#)

From October 24th NANETS Connect: The prognostic and therapeutic value of the tumor microenvironment and immune checkpoints in pancreatic neuroendocrine neoplasms: [The prognostic and therapeutic value of the tumor microenvironment and immune checkpoints in pancreatic neuroendocrine neoplasms | Scientific Reports \(nature.com\)](#)

From October 24th NANETS Connect: Resolution of VIPoma-related Symptoms with Peptide Receptor Radionuclide Therapy: [Frontiers | Resolution of VIPoma-related Symptoms with Peptide Receptor Radionuclide Therapy \(frontiersin.org\)](#)

From the October 3, 2024 CCF Luncheon with the Experts: Dr. David Zhen: [David Zhen, MD | Fred Hutchinson Cancer Center](#)

From the October 3, 2024 CCF Luncheon with the Experts: Paltusotine in CS: [Paltusotine in Carcinoid Syndrome \(lacnets.org\)](#)

From the October 3, 2024 CCF Luncheon with the Experts: Positive Results of the CABINET Trial Show Cabozantinib as a New, Effective Treatment in Advances NETs: [Positive Results of the CABINET Trial Show Cabozantinib as a New, Effective Treatment in Advanced Neuroendocrine Tumors \(lacnets.org\)](#)

From NETRF: [Historic CAR T trial opens at University of Pennsylvania - NETRF](#)

From NETRF: [Phase II Trial Shows Potential for Second-Line Therapies for Neuroendocrine Carcinomas - NETRF](#)

From NETRF: [Taking a Look at Proteins: Pioneering NETRF-Funded Research in Pancreatic Neuroendocrine Tumors - NETRF](#)

From NETRF: [Dr. Santoro Fernandes Receives 2024 NANETS/NETRF BTSI Grant - NETRF](#) this research is to develop a predictive model for which NET patient will benefit most from PRRT

From Chuck: Phase 3 Trial of Cabozantinib to Treat Advances NETs: [Phase 3 Trial of Cabozantinib to Treat Advanced Neuroendocrine Tumors | New England Journal of Medicine \(nejm.org\)](#)

From the July 25, 2024 CCF Luncheon with the Experts Dr Gagandeep Singh: [Gagandeep Singh, Surgical Oncologist | City of Hope](#)

From the July 25, 2024 CCF Luncheon LACNETS Episode 3 podcast: Surgery for NETs: [Episode 3: Surgery for NETs \(lacnets.org\)](#)

From the July 25, 2024 CCF Luncheon NENETS Consensus Paper on the Surgical Management of pNETs: [The North American Neuroendocrine Tumor Society Consensus Paper on the Surgical Management of Pancreatic Neuroendocrine Tumors - PubMed \(nih.gov\)](#)

From the July 11, 2024 CCF Luncheon with the Experts Dr. Jennifer Chan: [Jennifer Chan, MD, MPH - Dana-Farber Cancer Institute | Boston, MA](#)

From the July 11th CCF Luncheon LACNETS Support Line: [Support Line | LACNETS](#)

From Chuck: Appropriate Use Criteria for Somatostatin Receptor PET Imaging in NETs: [Appropriate Use Criteria for Somatostatin Receptor PET Imaging in Neuroendocrine Tumors | Journal of Nuclear Medicine \(snmjournals.org\)](#)

From Chuck: "I'm an oncologist. Here's what I advised my mom after her cancer diagnosis." [What should I do after a cancer diagnosis? - The Washington Post](#)

From the May 16, 2024 CCF Luncheon with the Experts,

From NANETS Connect May 16, 2024: Cabozantinib in patients with unresectable and progressive metastatic pheochromocytoma or paraganglioma (the Natalie Trial): a single-arm, phase 2 trial: [Cabozantinib in patients with unresectable and progressive metastatic pheochromocytoma or paraganglioma \(the Natalie Trial\): a single-arm, phase 2 trial - ScienceDirect](#)

From NANETS Connect May 16, 2024: Staging and Management Updates for NET: [Staging and Management Updates for Neuroendocrine Tumors \(NET\) - InventUM \(miami.edu\)](#)

From the May 2, 2024 CCF Luncheon with the Experts, Dr. Sandy M Kotiah, MD: [Dr. Sandy Kotiah, Medical Oncologist in Baltimore - Mercy \(mdmercy.com\)](#)

May 2, 2024 CCF Luncheon: Histotripsy Treating Liver Tumors with Sound Waves: [Histotripsy - UChicago Medicine](#)

May 2, 2024 CCF Luncheon: ACTION-1: Alpha PRRT with Ac-225 in GEP-NETs: [ACTION-1: Alpha PRRT with Ac-225 in GEP-NETs \(lacnets.org\)](#)

May 2, 2024 CCF Luncheon: CABINET: Cabozantinib in Advances pNET and Carcinoid Tumors [CABINET: Cabozantinib in Advanced pNET and Carcinoid Tumors \(lacnets.org\)](#)

From Chuck: Overdosing on chemo: A common gene test could save hundreds of lives each year: [Overdosing on chemo: A common gene test could save hundreds of lives each year – The Times Herald](#)

From Pat via NANETS: Effectiveness and Safety of Retreatment with 177Lu-DOTATATE in Patients with Progressive NETs: A Retrospective Real-World Study in the US: [Effectiveness and Safety of Retreatment with 177Lu-DOTATATE in Patients with Progressive Neuroendocrine Tumors: A Retrospective Real-World Study in the United States | Journal of Nuclear Medicine \(snmjournals.org\)](#)

From Pat via NANETS: Primary Resistance to RET Inhibition in a RET Fusion-Positive Pancreatic Neuroendocrine Carcinoma: [Primary Resistance to RET Inhibition in a RET Fusion-Positive Pancreatic Neuroendocrine Carcinoma | The Oncologist | Oxford Academic \(oup.com\)](#)

From Pat via NANETS: PITX2 as a Sensitive and Specific Marker of Midgut NETs: Results from a Cohort of 1157 Primary Neuroendocrine Neoplasms: [PITX2 as a Sensitive and Specific Marker of Midgut Neuroendocrine Tumors: Results from a Cohort of 1157 Primary Neuroendocrine Neoplasms - ScienceDirect](#)

From Pat via NANETS: Patient derived tumoroids of high-grade neuroendocrine neoplasms for more personalized therapies: [Patient derived tumoroids of high grade neuroendocrine neoplasms for more personalized therapies | npj Precision Oncology \(nature.com\)](#)

From Pat: Dr. Jaydira Del Rivero is currently recruiting for three clinical trials:

Tissue Procurement and Natural History Study of Neuroendocrine Neoplasms (NENs) Including Adrenocortical Carcinoma (ACC).

NCT05237934. <https://clinicaltrials.gov/study/NCT05237934?term=del%20rivero,%20jaydira&rank=3>

Testing the Addition of an Anticancer Drug, Olaparib, to the Usual Chemotherapy (Temozolomide) for Advanced Neuroendocrine Cancer.

NCT04394858. <https://clinicaltrials.gov/study/NCT04394858?term=del%20rivero,%20jaydira&rank=1>

Antibody Drug Conjugate ADCT-701 in Neuroendocrine Tumors and Carcinomas

NCT06041516 <https://clinicaltrials.gov/study/NCT06041516?term=del%20rivero,%20jaydira&rank=2>

From Murf: Palliative Care Has a Branding Problem: [Palliative Care Has a Branding Problem | MedPage Today](#)

From NETRF February 2024 e-Update: Understanding Survival Factors in Lung NETs: Insights from the CA Cancer Registry: [Understanding Survival Factors in Lung Neuroendocrine Tumors: Insights from the California Cancer Registry - NETRF](#)

From NETRF February 2024 e-Update: Making progress against rare cancers: A case study on NETs: [Making progress against rare cancers: A case study on neuroendocrine tumors \(d31hzlkh6di2h5.cloudfront.net\)](#)

From NETRF February 2024 e-Update: FDA Paves Way for New Liver Tumor Treatment with Histotripsy: [FDA Paves Way for New Liver Tumor Treatment with Histotripsy - NETRF](#)

From Jennifer: What cancers does Galleri screen for? [Blood Test to Detect Cancer Signal Presence | Galleri®](#)

From the NANETS Jan 25th newsletter: New cancer therapy approach slows growth of advanced gastrointestinal tumours-Sunnybrook Research Institute: [New cancer therapy approach slows growth of advanced gastrointestinal tumours - Sunnybrook Research Institute](#)

From the NETRF Jan 19th newsletter: NETTER-2 Trial shows Lutathera as First-Line Treatment Significantly Reduces Disease Progression or Death: [NETTER-2 Trial Shows Lutathera® as First-Line Treatment Significantly Reduces Disease Progression or Death - NETRF](#)

From the NETRF Jan 19th newsletter: Growth-factor Dependence in Lung NETs: [Growth-factor Dependence in Lung Neuroendocrine Tumors - NETRF](#)

From the NETRF Jan 19th newsletter: Exploring Midgut NETs Through the Lens of the Microbiome: [Exploring Midgut NETs Through the Lens of the Microbiome - NETRF](#)

From the NCAN FB page: Making progress against rare cancers: A case study on NETs: <https://doi.org/10.1002/cncr.35184>

From the NANETS Jan 14th newsletter: The Phases of Cancer Resiliency: [The Phases of Cancer Resiliency \(curetoday.com\)](#)

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 \(ascopubs.org\)](#)

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 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 & G3 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=IwAR1CGJGYUwqZqzSmqnFNoJ-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-KJombhcU1atIfrxL2piSlCVd9rsL7_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=AuthorPaper&utm_campaign=AlertEmails_WEEKLY&utm_term=AuthorPaper&email_index=0-0-0&utm_medium=2488505

[Kidd/4b9b1458b64083a8cf83336ed0c6e500708186e9?utm_source=alert_email&utm_content=AuthorPaper&utm_campaign=AlertEmails_WEEKLY&utm_term=AuthorPaper&email_index=0-0-0&utm_medium=2488505](https://www.semanticscholar.org/paper/A-Multigenomic-Liquid-Biopsy-Biomarker-for-Tumor-Modlin-Kidd/4b9b1458b64083a8cf83336ed0c6e500708186e9?utm_source=alert_email&utm_content=AuthorPaper&utm_campaign=AlertEmails_WEEKLY&utm_term=AuthorPaper&email_index=0-0-0&utm_medium=2488505)

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=IwAR1O8YIMR7mPSyDi88jUjrVZrR5l3UoAy9JnBvbZ2pVk9qWnQjggednSMXY>

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=IwAR16DOxL6VScbv5Ql5DTG99T3SpRiZuU0gCbID5WiyEXxA4PYEbhbZU9nl>

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/B008S11VDG/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)