

NEWS AND NOTES March 2023
A Zoom Meeting due to coronavirus COVID 19

- 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 **Blog posts by A G Dabbs on their website
**Patient Conferences: March 11, 2023 Silver Springs MD; April 15, 2023 Omaha NE; June 3, 2023 San Diego CA; September 9, 2023 Cleveland OH; October 21, 2023 Miami FL
- From NETRF **A Patient's Guide to NETs is available through their website
**NETWise podcasts
- 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_68HtYNAz09b64rTp4Mq0UlvMjEUtTBweiYf9Qb1yruHIRyb3vu4
** Ask the NET Experts – A Program from CCF: https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2788218?fbclid=IwAR0rtLuLbYI75XpQEbVC878rMe-yFDKK9bvHGUap1zmqlhV_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 LACNETS ** "Update on NET Clinical Trials" with Dr. Heloise Soares Friday March 10 at 12 PM Pacific time: register at LACNETS.org/Mar2023
**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 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](#)
- 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-j9MzZ1d9RzQfld_yX7OrBtMpcJZtAVH5Hfb0

NEW ARTICLES:

- 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 NETs: [Making Sense of a Complex Disease: A Practical Approach to Managing Neuroendocrine Tumors. | Semantic Scholar](#)
- From Murf: Hemicolectomy versus appendectomy for patients with appendiceal NETs 1-2 cm in size: a retrospective, Europe-wide, pooled cohort study: [Hemicolectomy versus appendectomy for patients](#)

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

RECURRING ARTICLES:

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: [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: [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: [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 tyramines: [MAOIs and diet: Is it necessary to restrict tyramine? - Mayo Clinic](#)

From Pat, from NANETS: Early-Stage Primary Lung NETs Treated with Stereotactic Body Radiotherapy: A Multi-Institution Experience: [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: [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 Computer Tomography: [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 other 90% accuracy: [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: [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: [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: [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 NETS: [FDA Grants Fast Track Designation to ITM-11 for Gastroenteropancreatic Neuroendocrine Tumors \(onclive.com\)](#)

From Mike and Chuck: F18-AIF-NOTA-octreotide outperforms Ga68-DOTA-TATE/-NOC PET in NET patients: results form a prospective, multicenter study: [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 NETs: a comparative population-based analysis: [Incidence of psychiatric illness in patients with neuroendocrine tumors: a comparative population-based analysis | SpringerLink](#)

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

From Randy at the September 11, 2022 NJCCN zoom meeting: CIO 2021-20 Efficacy of Transarterial Bland Embolization with Everolimus (EveroEmbo) for NETs:

[CIO 2021-20 Efficacy of Transarterial Bland Embolization with Everolimus \(EveroEmbo\) for Hepatic Metastatic Neuroendocrine Tumors \(hmpgloballearningnetwork.com\)](#)

From Mike and Chuck: NETs: A Comprehensive Review on Nutritional Approaches:

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

From Kate and Chuck: Neuroendocrine neoplasms: recent progress and persistent challenges: [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: [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: [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 Mycapssa® (oral octreotide) for the Treatment of Carcinoid Syndrome: [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: [The Evolving Role of Radioembolization in the Treatment of Neuroendocrine Liver Metastases - PubMed \(nih.gov\)](#)

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

From Pat, via MSKCC newsletter: Rectal Cancer Disappears After Experimental Use of Immunotherapy: [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:

[Drug combination shows promise for treating pNETs | EurekAlert!](#)

From Mike and Chuck: New Therapy Options for NECs 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: [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: Good Response With ONC201 for Rare NETs: 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-taYIZqfOLGU>

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: Tidotamab Induces Best Overall Response of Stable Disease in Advanced NETs:

<https://www.oncnursingnews.com/view/tidotamab-induces-best-overall-response-of-stable-disease-in-advanced-neuroendocrine-tumors>

From Mike and Chuck: Lanreotide Demonstrates Confirmed Efficacy in Advanced Bronchopulmonary NETs: <https://www.onclive.com/view/lanreotide-demonstrates-confirmed-efficacy-in-advanced-bronchopulmonary-nets>

From Mike and Effie: Liquid Biopsy Blood Biomarker Possible Predictor of Tumor Recurrence, Cost Savings: <https://www.ajmc.com/view/liquid-biopsy-blood-biomarker-possible-predictor-of-tumor-recurrence-cost-savings>

From Chuck: NETs require individualized treatment approach:

<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-](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=IwAR1O8YIMR7mPSyDi88jUjrVZrR5I3UoAy9JnBvbZ2pVk9gWnQjggednSMXY>

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.

NOTE: As of February 20, 2023, Amazon will no longer be donating \$.005 for every dollar spent on eligible purchases. See the article above from Mike.

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)