

NEWS AND NOTES January 2022
A Zoom Meeting cancelled 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. Del Jaydira Del Rivero, MD, Director of the Center for Cancer Research Neuroendocrine Tumor Program: jaydira.delrivero@nih.gov**
- From NETRF **A Patient's Guide to NETs is available through their website
**A Research Study that looks at connection between NETs and COVID-19 infection outcomes
**An eNET Study to learn about symptoms and quality of life for NET patients
**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
**weekly Lunch with the Experts features conversations each Thursday at noon on CCF Facebook Live, always available in their Video file, and 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
- 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 **NET Vitals: worksheet to record your medical history: <https://www.lacnets.org/lacnets-blog/netvitals>
- From Lisa 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.
- 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

NEW ARTICLES:

- From the January 6, 2022 CCF Luncheon with the Experts Dr. Erik Mittra: https://www.ohsu.edu/people/erik-s-mittra-md-phd?fbclid=IwAR3MU62bHjWO4RluE2kBTz5aNFd0OUBx_oRiy3w4CsjUVtFgCVU10p8aK4I
- From the January 6, 2022 CCF Luncheon with the Experts Dr. Erik Mittra: Landscape Analysis of Phase 2 and 3 Clinical Trials for Targeted Radionuclide Therapy: https://jnm.snmjournals.org/content/62/8/1031.long?fbclid=IwAR2zxTBmwNjPnhFF-xviZUM3uDX_tbX1uawCzoWVaoTDKBzvutmYyVbWlc
- From the January 6, 2022 CCF Luncheon with the Experts Dr. Erik Mittra: Acronyms Used in the Carcinoid and NET community: https://www.carcinoid.org/2017/04/19/acronyms-used-carcinoid-neuroendocrine-tumor-community/?fbclid=IwAR38vhvFLDI8uSavkDnKUU6TUqyUwEjOuj1fldTG0CIDmJT_wgVsyIp5lao
- From Pat: Coronavirus disease 2019 in patients with neuroendocrine neoplasms: Preliminary results of the INTENSIVE study: <https://www.sciencedirect.com/science/article/pii/S0959804921004044>
- From Pat: Radiomedix and Orano Med Announce the Initiation of the Phase II Multi-Center Clinical Trial of Alphamedix™ for Targeted Alpha-Emitter Therapy of Neuroendocrine Cancers: <https://www.globenewswire.com/news-release/2022/01/03/2360157/0/en/Radiomedix-and-Orano-Med-Announce-the-Initiation-of-the-Phase-II-Multi-Center-Clinical-Trial-of-Alphamedix-for-Targeted-Alpha-Emitter-Therapy-of-Neuroendocrine-Cancers.html>

From CCF: Management of Large Cell Neuroendocrine Carcinoma:

https://www.frontiersin.org/articles/10.3389/fonc.2021.653162/full?fbclid=IwAR3ZAFccVMeoSHWjPiHeX5m-KJombhcU1atIfrxL2piSICVd9rsL7_d8U54

From the December 17, 2021 CCF Luncheon with the Experts Dr. Alia Thawer: NET Cancer Health Storylines: https://www.healthstorylines.com/net-cancer-healthstorylines?fbclid=IwAR25Q3AVgg0K6zEzVU-MLJixYSF08iJvj2TI8yr6Q6ysv-Bn47JZVz_dC4E

From the December 17, 2021 CCF Luncheon with the Experts Dr. Alia Thawer: Emla 2.5%--2.5% Topical Cream – Uses, Side Effects, and More: <https://www.webmd.com/drugs/2/drug-2358-8170/emla-topical/lidocaine-prilocaine-cream-topical/details?fbclid=IwAR2X5xHUREKGJLREDcDEoIbuu5lVba-arTU2X5hXBC8xyQCmJUzi-VjBPc>

From the December 9, 2021 CCF Luncheon with the Experts Dr. Arvind Dasari:

https://faculty.mdanderson.org/profiles/nageshwara_dasari.html?fbclid=IwAR10oA3pAVefX1CVMTVpzAOi5cW6CcY1xhl3Xi-jrC62D4BH-jS1XC8bmJI

From the December 9, 2021 CCF Luncheon with the Experts Dr. Arvind Dasari:

<https://www.mdanderson.org/cancer-types/neuroendocrine-tumors.html?fbclid=IwAR2v1tM5Cqu0Cz07bJRo8x0vMOYxwUqSkZS7x4a2j5zcFSiqqpnYFE5XFyo>

RECURRING ARTICLES:

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

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

From Pat and Chuck: Cancers are in an evolutionary battle with treatments-evolutionary game theory could tip the advantage to medicine: <https://theconversation.com/cancers-are-in-an-evolutionary-battle-with-treatments-evolutionary-game-theory-could-tip-the-advantage-to-medicine-170175>

From Pat and Chuck: Stanford researchers develop synthetic molecule that seeks out and destroys cancer tumors: <https://www.thebrighterside.news/post/stanford-researchers-develop-synthetic-molecule-that-seeks-out-and-destroys-cancer-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 Chuck: Multiple tumors without kinship occur simultaneously in the small intestine in NEC: <https://medicalxpress.com/news/2021-11-multiple-tumors-kinship-simultaneously-small.html>

From the November 4, 2021 CCF Luncheon with the Experts Dr. Sean Cleary: INCA International Neuroendocrine Cancer Alliance Global NET Patient Information Pack: https://incalliance.org/net-info-packs/?fbclid=IwAR3At8cFnOLV3Wfownsedr41PLOHGjadWSubtLhrMnVVLF_OrB6YCq5_n3l

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 the October 28, 2021 CCF Luncheon with the Experts Dr. Mohid Khan: TerSera Announces Publication of Real-World Study on Xermelo in Patients with CS Diarrhea:

https://www.prnewswire.com/news-releases/tersera-announces-publication-of-real-world-study-on-xermelo-telotristat-ethyl-in-patients-with-carcinoid-syndrome-diarrhea-301409241.html?fbclid=IwAR1zGaFu650cCc5Uu-G3EAWQoKq5nCN6qNKx4saOe_e7GQatjzGdRo_s2rQ

From Chuck: NETs require individualized treatment approach:

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

From the October 21, 2021 CCF Luncheon with the Experts Dr. Karel Pacak:

Pheochromocytoma/paraganglioma: recent updates in genetics, biochemistry, immunohistochemistry, metabolomics imaging and therapeutic options:

https://gs.amegroups.com/article/view/34807/27999?fbclid=IwAR12uGJsXj6lxK8pS3rn4w7uSK7vznC5828pCplNtlg92gs5R4_6wllBhk

From the October 21, 2021 CCF Luncheon with the Experts Dr. Karel Pacak: Pheochromocytoma and Paraganglioma: An Endocrine Society Clinical Practice Guideline:

https://academic.oup.com/jcem/article/99/6/1915/2537399?fbclid=IwAR16aZwXhjs1UXIEVu1q2byZrUp_ZtmZK-zlThpO51fMewMp-8KF3kZzv4

From Mike and Chuck: video interview with Dr. Matthew Kulke on NETs: Options for Initial Therapy:

<https://www.onclive.com/view/neuroendocrine-tumors-options-for-initial-therapy>

From the October 14, 2021 CCF Luncheon with the Experts Dr. Emil Lou: The 5 E's (of Carcinoid Syndrome): <https://ronnyallan.net/2016/05/25/the-5-es/?fbclid=IwAR3CxdTnph3C5bD3ntFWL-wJoy0qPstwOz5Oll3hNH67JR5vDkdsDYAS4cU>

From the October 14, 2021 CCF Luncheon with the Experts Dr. Emil Lou: NANETS' Position Statement COVID-19 Vaccination for NEN patients: https://nanets.net/images/resources/covid-19/NANETS_COVID_vaccine_position_statement_2-1-2021.pdf?fbclid=IwAR1Lut6prCCWWZfht5c4CWWMczcqa3h3vc41H-STEFrcz4drjOYvpO4xGmE

https://nanets.net/images/resources/covid-19/NANETS_COVID_vaccine_position_statement_2-1-2021.pdf?fbclid=IwAR1Lut6prCCWWZfht5c4CWWMczcqa3h3vc41H-STEFrcz4drjOYvpO4xGmE

https://nanets.net/images/resources/covid-19/NANETS_COVID_vaccine_position_statement_2-1-2021.pdf?fbclid=IwAR1Lut6prCCWWZfht5c4CWWMczcqa3h3vc41H-STEFrcz4drjOYvpO4xGmE

From Mike and Chuck: Prediction of recurrence after surgery based on preoperative MRI features in patients with pNETs: <https://link.springer.com/article/10.1007/s00330-021-08316-8>

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

From Chuck: Testing Lutetium Lu 177 Dotatate in Patients with Somatostatin Receptor Positive Advanced Bronchial NETs: <https://clinicaltrials.gov/ct2/show/NCT04665739#contacts>

From Mike and Chuck: Interview with Dr. Diane Reidy-Lagunes on Testing:

<https://www.onclive.com/view/neuroendocrine-tumor-pathogenesis-and-molecular-testing>

From Mike and Chuck: It May not be Too Little or Too Late: Resecting Primary Small Bowel NETs when there is Metastatic Disease: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7337966/>

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

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

From Mike and Chuck: FDA approves First Drug for Von Hippel-Lindau-Associated Tumors:

<https://www.medpagetoday.com/hematologyoncology/renalcellcarcinoma/94034>

From Mike and Chuck: Survival Benefit of Primary Tumor Resection Among Elderly Patients with pNETs: <https://pubmed.ncbi.nlm.nih.gov/34379172/>

From Mike and Chuck: Novel Approaches Optimize PRRT for NETs:

<https://www.targetedonc.com/view/novel-approaches-optimize-peptide-receptor-radionuclide-therapy-for-neuroendocrine-tumors>

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=IwAR1O8YIMR7mPSyDi88jUjrVZrR5I3UoAy9JnBvbZ2pVvk9qWnQjggednSMXY>

FAQs NET Tissue Donation: https://netrf.org/2019/06/12/faqs-tumor-tissue-donation/?fbclid=IwAR1_q5Pvl_6eKWvwtmaMSBEaDCBw-wMbPHKnXxTdcfEg0KFpq6Aawc-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 a Facebook group: **Ga68 and PRRT are available at Hackensack Medical Center: Dr. Martin Gutierrez, oncologist, Dr. Brett Lewis, radiologist

From Marilyn: **PRRT with Lutathera is available to St Barnabas in Livingston; the head of department is Dr Scoppetuolo who was Ralph's doctor

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>

Amazon Smile Foundation: we receive **\$.005** for every dollar spent on eligible purchases. Go to: smile.amazon.com

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

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)

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)