

NEWS AND NOTES Mid-summer 2022  
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. Del Jaydira Del Rivero, MD, Director of the Center for Cancer Research Neuroendocrine Tumor Program: [jaydira.delrivero@nih.gov](mailto:jaydira.delrivero@nih.gov)**
- From LACNETS \*\* Weekly support group meetings each Wednesday, noon PT (3 PM ET)  
\*\***Health & Wellness Virtual Retreat Saturday August 13<sup>th</sup>, registration at their website**  
\*\***Live Webinar: Update on Lung NETs with Dr. Sukhmani Padda, Thursday August 25<sup>th</sup> (12 PM PT) registration on their website**
- From NETRF \*\*conference July 24<sup>th</sup>: [KNOW YOUR NETs 2022 Virtual Conference - NETRF](#)**
- From Pheo Para Alliance: \*\*Patient Conference August 21-25: [Pheo Para Patient Conference - Pheo Para Alliance](#)**
- 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](http://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](https://www.healthstorylines.com/net-cancer-healthstorylines?fbclid=IwAR1lz8N_68HtYNAz09b64rTp4Mq0UlvMjEUtTBweiYf9Qb1yruHlRyb3vu4)  
\*\* Ask the NET Experts – A New CCF Program:  
[https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2788218?fbclid=IwAR0rtLuLbYI75XpQEbVC878rMe-yFDKK9bvHGUp1zmqIhV\\_3t\\_BG6SqQMg](https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2788218?fbclid=IwAR0rtLuLbYI75XpQEbVC878rMe-yFDKK9bvHGUp1zmqIhV_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 \*\*NET Vitals: worksheet to record your medical history: <https://www.lacnets.org/lacnets-blog/netvitals>  
\*\*What's New with NETS webinar by Dr. Pamela Kunz:  
<https://www.youtube.com/watch?v=fdQvnIR3bRQ>
- From Lisa at TerSera Therapeutics: \*\*For support with CS, please go to [www.enrollxermelo.com](http://www.enrollxermelo.com) and opt in. Once completed, a nurse educator will contact you within 48 hours. For the nursing support program:  
[www.thenetnurse.com](http://www.thenetnurse.com)  
\*\*Find Food You Love:
- 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](https://www.carcinoidsyndrome.org/2017/12/19/nutrition-recipe-guide-people-gastrointestinal-neuroendocrine-tumors-carcinoid-syndrome/?fbclid=IwAR2fsqItefgz0ZpYEraraT-j9MzZ1d9RzQfld_yX7OrBtMpcJZtAVH5Hfb0)

**NEW ARTICLES:**

- From Mike and Chuck: Amryt Receives Orphan Drug Designation from the FDA for Mycapssa<sup>®</sup> (oral octreotide) for the Treatment of Carcinoid Syndrome: [Amryt Receives Orphan Drug Designation from the FDA for \(globenewswire.com\)](#)
- From Mike and Chuck: Mycapssa: [MYCAPSSA<sup>®</sup> \(octreotide\) delayed-release oral capsules](#)
- From Mike and Chuck: The Evolving Role of Radioembolization in the Treatment of Neuroendocrine Liver Metastases: [cancers-14-03415.pdf](#)

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

From the July 7, 2022 CCF Luncheon with the Experts Dr. Diane Reidy-Lagunes: [Diane Reidy-Lagunes | Memorial Sloan Kettering Cancer Center \(mskcc.org\)](#)

From the July 7, 2022 CCF Luncheon with Dr. Reidy: What is Dostarlimab, the Drug Used in the 'Unprecedented' Cancer Trial? [Dostarlimab: What Is the Drug With Unprecedented Cancer Trial Results? – NBC New York](#)

From the CCF Luncheon with Dr. Reidy: Lung NETs and DIPNECH: [\(1\) Lung Neuroendocrine Tumors and DIPNECH - YouTube](#)

From the CCF Luncheon with Dr. Reidy: Cancer Straight Talk Podcast from MSK: [Cancer Straight Talk Podcast from MSK | Memorial Sloan Kettering Cancer Center | Memorial Sloan Kettering Cancer Center \(mskcc.org\)](#)

From the CCF Luncheon with the Experts Dr. Jaydira Del Rivero: [Jaydira Del Rivero, M.D. | Center for Cancer Research](#)

From the CCF Luncheon with Dr. Del Rivero: Unique Opportunity for NET patients: [email : Webview : Unique Opportunity for Neuroendocrine Tumor Patients \(e2ma.net\)](#)

From the CCF Luncheon with Dr. Del Rivero: Tissue Procurement and Natural History Study of NENs including Adrenocortical Carcinoma (ACC): [Tissue Procurement and Natural History Study of Neuroendocrine Neoplasms \(NENs\) Including Adrenocortical Carcinoma \(ACC\) - Full Text View - ClinicalTrials.gov](#)

From the CCF Luncheon with the Experts Dr. Philip A. Philip: [Philip Philip, MD | Henry Ford Health - Detroit, MI](#)

From the CCF Luncheon with the Experts Dr. Nitya Raj: [Nitya Raj | Memorial Sloan Kettering Cancer Center \(mskcc.org\)](#)

From the CCF Luncheon with Dr. Raj: 'Unprecedented' 100% of First 14 Untreated Patients with Rectal Cancer Respond to PD-1 Blocker Dostarlimab-gxly: ['Unprecedented' 100% of First 14 Untreated Patients With Rectal Cancer Respond to PD-1 Blocker Dostarlimab-gxly - The ASCO Post](#)

From the CCF Luncheon with Dr. Raj: Nutrition and Recipe Guide for People with Gastrointestinal NETs and Carcinoid Syndrome: [Nutrition and Recipe Guide for People with Gastrointestinal Neuroendocrine Tumors and Carcinoid Syndrome - Carcinoid Syndrome](#)

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 \(nytimes.com\)](#)

#### **RECURRING ARTICLES:**

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](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/>

From Chuck, from MedPage: HUTCHMED Receives Complete Response Letter from the US FDA for Surufatinib for the Treatment of Advanced NETs: [https://www.hutch-med.com/wp-content/uploads/2022/05/a220502\\_HKEX\\_E.pdf](https://www.hutch-med.com/wp-content/uploads/2022/05/a220502_HKEX_E.pdf)

From Chuck: Updated Guidance for COVID-19 Vaccination from NCCN Recommends Fifth mRNA Shot (Second Booster Dose) for Immunocompromised People: <https://www.nccn.org/home/news/newsdetails?NewsId=3252>

From Pat, from NANETS: Survival and Incidence Patterns of Pancreatic NETs over the Last 2 Decades: A SEER Database Analysis: <https://academic.oup.com/oncolo/advance-article/doi/10.1093/oncolo/oyac049/6555099?login=false>

Link for Sunnybrook Health Sciences Centre: <https://sunnybrook.ca/content/?page=neuroendocrine-tumour-cancer&fbclid=IwAR1CGJGYUwqZqzSmqnFNoJ-s1uMwux9PYqc6be2i7T9fDUN-taYIZqfOLGU>

Link for CNETS, Canadian Neuroendocrine Tumour Society: [https://cnets.ca/?fbclid=IwAR1wPLO6\\_QLCq7goUD\\_Xia4v5eP77mBP-pTbMBo\\_GfV1UNry5rMInBEzTVI](https://cnets.ca/?fbclid=IwAR1wPLO6_QLCq7goUD_Xia4v5eP77mBP-pTbMBo_GfV1UNry5rMInBEzTVI)

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 Chuck: Ipsen announces investment in new state-of-the-art electronic autoinjector for Somatuline Autogel/Somatuline Depot (Lanreotide) designed to improve patient experience: <https://www.ipсен.com/press-releases/ipsen-announces-investment-in-new-state-of-the-art-electronic-autoinjector-for-somatuline-autogel-somatuline-depot-lanreotide-designed-to-improve-patient-experience/>

From Mike, referenced during our March and April 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](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 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](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: 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 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-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](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-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](http://njcarcinoidnetwork.org)) for additional articles\*\***

#### **Other items of interest:**

From Randy at the February 6<sup>th</sup> Zoom meeting: **\*\*List of Apps for compiling your medical records:**

<https://tinyurl.com/2pd5y9w3>

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](https://smile.amazon.com)

ISI InterScience Institute: to request a copy of their biomarker testing code book go to [interscienceinstitute.com](https://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](https://carcinoid.org)

[netcancerawareness.org](https://netcancerawareness.org)

[netrf.org](https://netrf.org); newsletter available

[thehealingnet.org](https://thehealingnet.org); newsletter available

[clinicaltrials.gov](https://clinicaltrials.gov)

[ronnyallan.com](https://ronnyallan.com)

[carcionoidsyndrome.org](https://carcionoidsyndrome.org)

[netpatientfoundation.org](https://netpatientfoundation.org) (located in London)

[lacnets.org](https://lacnets.org)

**Discussion boards:**

[ACOR.org](https://www.acor.org) (find the carcinoid group)

[Smartpatients.com](https://www.smartpatients.com) (find the carcinoid group)

[Inspire.com](https://www.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](https://carcinoid.com))

Carcinoid Awareness (also: [aboutcarcinoid.com](https://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)