

NEWS AND NOTES May 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 NCAN \*\*NET Patient Conference Charlotte NC May 14, 2022** see their website for more information
- From LACNETS \*\*Webinar Friday May 6<sup>th</sup> noon PT with Dr. Mark Lewis**  
**\*\*Virtual conference Saturday June 18<sup>th</sup> 8AM-5PM**  
**\*\* Weekly support group meetings each Wednesday, noon PT (3 PM ET)**
- From NETRF \*\*conference July 24<sup>th</sup> details to be announced**
- 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](https://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-yFDKK9bvHGUap1zmqlhV\\_3t\\_BG6SqQMg](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 \*\*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.**
- 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=IwAR2fsqItefegz0ZpYErarAT-j9MzZ1d9RzQfld\\_yX7OrBtMpcJZtAVH5Hfb0](https://www.carcinoidsyndrome.org/2017/12/19/nutrition-recipe-guide-people-gastrointestinal-neuroendocrine-tumors-carcinoid-syndrome/?fbclid=IwAR2fsqItefegz0ZpYErarAT-j9MzZ1d9RzQfld_yX7OrBtMpcJZtAVH5Hfb0)**

**NEW ARTICLES:**

- From Chuck, from MedPage: HUTCHMED Receives Complete Response Letter from the US FDA for Surufatinib for the Treatment of Advances 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 Mike and Chuck: Montclair Hospital Launches New Radiologic Therapy to Treat Tumors: <https://patch.com/new-jersey/montclair/montclair-hospital-launches-new-radiologic-therapy-treat-tumors>

From the April 28, 2022 CCF Luncheon with the Experts Dr. James Howe:

[https://uihc.org/james-howe?fbclid=IwAR0bMu8q6Uf5JggwA8UaCHGSoXngldfJL1gBHOff-BBX\\_oq7PRcdUrGtCQQ](https://uihc.org/james-howe?fbclid=IwAR0bMu8q6Uf5JggwA8UaCHGSoXngldfJL1gBHOff-BBX_oq7PRcdUrGtCQQ)

From the April 28, 2022 CCF Luncheon with Dr. Howe: University of Iowa Health Care Department of Internal Medicine, NET Center of Excellence:

[https://medicine.uiowa.edu/internalmedicine/divisions/endocrinology-and-metabolism/neuroendocrine-tumor-center-excellence?fbclid=IwAR2\\_fESdWEXPxg1bf0q6yFQJ6gQfXP\\_OP-YNLad1F7nPrtGCwxZNB-0TNcg](https://medicine.uiowa.edu/internalmedicine/divisions/endocrinology-and-metabolism/neuroendocrine-tumor-center-excellence?fbclid=IwAR2_fESdWEXPxg1bf0q6yFQJ6gQfXP_OP-YNLad1F7nPrtGCwxZNB-0TNcg)

and the link for NET Cancer Health Storylines: <https://www.healthstorylines.com/net-cancer-healthstorylines?fbclid=IwAR11JyInBox4px3qHt6m0cnW0oOWfMqBqI-QYHLUINvt0eAZEAv9QPivmhw>

and the link for MYCAPSSA (octreotide): [https://mycapssa.com/?fbclid=IwAR3V-MAXZIWqu7jyOhYsWtIKMQvCa1TOrzTe6id90PfadW1eJu1IXZV7\\_3E](https://mycapssa.com/?fbclid=IwAR3V-MAXZIWqu7jyOhYsWtIKMQvCa1TOrzTe6id90PfadW1eJu1IXZV7_3E)

From Pat, from NANETS: Unlocking the Code to Management of NENs: A Clinician's Perspective:

<https://ascopubs.org/doi/full/10.1200/OP.21.00628?bid=159665590&cid=DM10174>

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>

From Pat, from NANETS: Long-term survival and toxicity in patients with NETs treated with Lu177-

octroate peptide radionuclide therapy (PRRT): <https://pubmed.ncbi.nlm.nih.gov/35363879/>

From the April 21, 2022 CCF Luncheon with the Experts Dr. Julie Hallet:

[https://sunnybrook.ca/team/member.asp?t=49&m=552&page=neuroendocrine-tumour-cancer&fbclid=IwAR1o4XC9hHRkUg\\_2hwQ7AvfGibIKzLF478IYPW\\_nVo56EDVMuMIMGEBkmRg](https://sunnybrook.ca/team/member.asp?t=49&m=552&page=neuroendocrine-tumour-cancer&fbclid=IwAR1o4XC9hHRkUg_2hwQ7AvfGibIKzLF478IYPW_nVo56EDVMuMIMGEBkmRg)

and the link for Sunnybrook Health Sciences Centre:

<https://sunnybrook.ca/content/?page=neuroendocrine-tumour-cancer&fbclid=IwAR1CGJGYUwqZqzSmqnfNoJ-s1uMwux9PYqc6be2i7T9fDUN-taYIZqfOLGU>

and the link for NET Cancer Health Storylines:

<https://www.healthstorylines.com/net-cancer-healthstorylines?fbclid=IwAR11oai8yy3b63Lcl1egczlWY8UQo5T-51wkm4OQIYi0285ZiyoNGxjvGFM>

and the link for CNETS, Canadian Neuroendocrine Tumour Society:

[https://cnets.ca/?fbclid=IwAR1wPLO6\\_QLCq7goUD\\_Xia4v5eP77mBP-pTbMBo\\_GfV1UNry5rMlnBEzTVI](https://cnets.ca/?fbclid=IwAR1wPLO6_QLCq7goUD_Xia4v5eP77mBP-pTbMBo_GfV1UNry5rMlnBEzTVI)

From Mike and Chuck: Bioavailability Study for Mycapssa Announced by Amryt:

<https://patientworthy.com/2022/04/19/bioavailability-study-for-mycapssa-announced-by-amryt/>

From the April 14, 2022 CCF Luncheon with the Experts Dr. Boris Naraev:

<https://www.jupitermed.com/find-a-doctor/n/boris-naraev-md-phd-facp/?fbclid=IwAR1ra3Z55USlpYjM0vvn3o3yu9IQY4ZQreJ1Z-flsGgm7QsWTG6mlzcOEjQ>

From the April 14, 2022 CCF Luncheon: publications by Dr. Naraev:

<https://pubmed.ncbi.nlm.nih.gov/?term=Boris%20Naraev&fbclid=IwAR0jgP9VK20RHgjLdQXtQibRi0hyB5hVveDXbyZID0-fcwVNw0WfK2iCC28>

From the April 14, 2022 CCF Luncheon: Carcinoid Crisis: A Misunderstood and Unrecognized Oncological

Emergency:

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8833591/?fbclid=IwAR0s7UpIbt54y3J7oSDSpKRuzLq9AcdhdT5PtGteOYymLhPBthKOLomjwka>

From the April 14, 2022 CCF Luncheon: Lutetium 177Lu-Edotreotide Versus Best Standard of Care in

Well-differentiated Aggressive Grade-2 and Grade-3 GastroEnteroPancreatic NeuroEndocrine Tumores

(GEP-NETs)-COMPOSE (COMPOSE): <https://clinicaltrials.gov/ct2/show/NCT04919226>

From Mike and Chuck: New Radiologic Therapy is Available at Hackensack Meridian Mountainside

Medical Center for Patients with NETs: <https://www.tapinto.net/towns/verona-slash-cedar-grove/articles/new-radiologic-therapy-is-available-at-hackensack-meridian-mountainside-medical-center-for-patients-with-neuroendocrine-tumors>

From the April 7, 2022 CCF Luncheon with the Experts Dr. Heidi Connolly:

<https://www.mayoclinic.org/biographies/connolly-heidi-m-m-d/bio-20053291?fbclid=IwAR2UN5tSVqhz-6eKlZtR-49atMHrvGwDxY-A2JWmca-Gr2Z3k14DUKWvUoA>

And, Diagnosing and Managing Carcinoid Heart Disease in Patients with NETs: An Expert Statement:

[https://www.sciencedirect.com/science/article/pii/S0735109717301900?via%3Dihub&fbclid=IwAR1HPQ8BJ4Q\\_Tg\\_JWDWvfcRz3LRQRmG0r8hFG41FxPWDcaLNkgn6ddQIAs](https://www.sciencedirect.com/science/article/pii/S0735109717301900?via%3Dihub&fbclid=IwAR1HPQ8BJ4Q_Tg_JWDWvfcRz3LRQRmG0r8hFG41FxPWDcaLNkgn6ddQIAs)

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/ipсен-announces-investment-in-new-state-of-the-art-electronic-autoinjector-for-somatuline-autogel-somatuline-depot-lanreotide-designed-to-improve-patient-experience/>

From Daiva about CAR T therapy and upcoming trial in Q2 of 2022:

<https://www.pennmedicine.org/news/news-releases/2022/march/penn-developed-car-t-cells-suppress-gi-solid-tumor-cells-without-toxicity-to-healthy-tissue>

And the PDF of Dr. Xianxin Hua's paper "Potent suppression of NETs and gastrointestinal cancers by CD17 CAR T cells without toxicity to normal tissues": [https://www.nature.com/articles/s43018-022-00344-7.epdf?sharing\\_token=YLPzxf3dxlqmLsib5Uy2NRgN0jAjWel9jnR3ZoTv0MttuRjyH3rIRa\\_CVuvzFGSOtTFg\\_K-QdN9cbYaXHPbtU1GxKO7TOES8Z5muoV0aZXpzJC0xNZlydXsSXODmW58CJ42tXCDpmk1edafgyJRZsZKcYX2QxLeam7gwQJUiQ%3D](https://www.nature.com/articles/s43018-022-00344-7.epdf?sharing_token=YLPzxf3dxlqmLsib5Uy2NRgN0jAjWel9jnR3ZoTv0MttuRjyH3rIRa_CVuvzFGSOtTFg_K-QdN9cbYaXHPbtU1GxKO7TOES8Z5muoV0aZXpzJC0xNZlydXsSXODmW58CJ42tXCDpmk1edafgyJRZsZKcYX2QxLeam7gwQJUiQ%3D)

[https://www.nature.com/articles/s43018-022-00344-7.epdf?sharing\\_token=YLPzxf3dxlqmLsib5Uy2NRgN0jAjWel9jnR3ZoTv0MttuRjyH3rIRa\\_CVuvzFGSOtTFg\\_K-QdN9cbYaXHPbtU1GxKO7TOES8Z5muoV0aZXpzJC0xNZlydXsSXODmW58CJ42tXCDpmk1edafgyJRZsZKcYX2QxLeam7gwQJUiQ%3D](https://www.nature.com/articles/s43018-022-00344-7.epdf?sharing_token=YLPzxf3dxlqmLsib5Uy2NRgN0jAjWel9jnR3ZoTv0MttuRjyH3rIRa_CVuvzFGSOtTFg_K-QdN9cbYaXHPbtU1GxKO7TOES8Z5muoV0aZXpzJC0xNZlydXsSXODmW58CJ42tXCDpmk1edafgyJRZsZKcYX2QxLeam7gwQJUiQ%3D)

#### **RECURRING ARTICLES:**

From the March 31, 2022 CCF Luncheon with the Experts Dr. Rondell Graham:

[https://www.mayoclinic.org/biographies/graham-rondell-p-m-b-b-s/bio-20514323?\\_ga=2.13007991.1188589856.1648670128-879661719.1644609026&fbclid=IwAR2wDYuBQAU8naLi3JdKfzaleiDUKyxAZMphgCfZwfaxd2zFtmKR9GzKEc](https://www.mayoclinic.org/biographies/graham-rondell-p-m-b-b-s/bio-20514323?_ga=2.13007991.1188589856.1648670128-879661719.1644609026&fbclid=IwAR2wDYuBQAU8naLi3JdKfzaleiDUKyxAZMphgCfZwfaxd2zFtmKR9GzKEc)

From the March 31, 2022 CCF Luncheon: Mayo Clinic NETs: <https://www.mayoclinic.org/diseases-conditions/neuroendocrine-tumors/care-at-mayo-clinic/mac-20354135?fbclid=IwAR1WJG9KfYMz7ZEIH6CbEfc5M1x2FP0FLqg4D9bm2vPn2L8ZmEU3cc7pnrY>

From the March 24, 2022 CCF Luncheon with the Experts Dr. Nadine Mallak:

<https://www.ohsu.edu/people/nadine-mallak-md?fbclid=IwAR3QRIZw96D1Sot6KXwR7FmVlq7TOKOCmgdhavoAtL2wRwWAKglzpF1Eslg>

And: OHSU School of Medicine: <https://www.ohsu.edu/school-of-medicine/diagnostic-radiology/nuclear-medicine-and-molecular-imaging?fbclid=IwAR2NSKTPI77F4YRE-9yhZYb5138rUr01wbAdbzTAQSuQ63EPpE3h9EVj36Q>

And: Wren Laboratories:

<https://www.wrenlaboratories.com/?fbclid=IwAR1BGMrWlVnXvM6spGGrNL4TAvNECSOSgGsyavpudBNqTWOHRAo5I0HRVUq>

And: CCF YouTube channel: <https://www.youtube.com/user/CarcinoidNETs>

And: Dr. Das's article on External Validation of a Clinical Score for Patients with NETs Under Consideration for PRRT:

<https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2788218?fbclid=IwAR2z96CDL6jfxTfpN-RZuJRmemLDyGoeJJRCpns9ZFDzfWgVh7qgt15Sjas>

From Chuck and Pat: Genomic characterization of metastatic patterns from prospective clinical sequencing of 25, 000 patients: [https://www.cell.com/cell/fulltext/S0092-8674\(22\)00003-4](https://www.cell.com/cell/fulltext/S0092-8674(22)00003-4)

From Chuck and Pat, the MSKCC Newsletter: a video from MSKCC: Metastasis: How Cancer Spreads: [https://www.mskcc.org/videos/metastasis-how-cancer-spreads?utm\\_source=newsletter&utm\\_medium=email&utm\\_campaign=dev\\_march](https://www.mskcc.org/videos/metastasis-how-cancer-spreads?utm_source=newsletter&utm_medium=email&utm_campaign=dev_march)

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

From the March 3, 2022 CCF Luncheon with the Experts Dr. Pamela Kunz:

[https://medicine.yale.edu/profile/pamela\\_kunz/?fbclid=IwAR3JamfCa4SjZvauGdYEj3xfa997ba45ol6XjOtAi1dAsES66BdDtya3kFU](https://medicine.yale.edu/profile/pamela_kunz/?fbclid=IwAR3JamfCa4SjZvauGdYEj3xfa997ba45ol6XjOtAi1dAsES66BdDtya3kFU)

And Clinical Trials of Telotristat Ethyl for the Treatment of Carcinoid Heart Disease in Patients with Metastatic NET:

<https://clinicaltrials.gov/ct2/show/NCT04810091?term=Xermelo&cond=neuroendocrine+cancer&cntry=US&state=US%3ATX&draw=2&rank=1>

From Pat and MSKCC Newsletter: Theranostics: A Smart Bomb for Cancer: [https://www.mskcc.org/msk-news/winter-2021-22/theranostics-smart-](https://www.mskcc.org/msk-news/winter-2021-22/theranostics-smart-bomb#:~:text=Like%20other%20forms%20of%20targeted,and%20kill%20the%20cancer%20cells.)

[bomb#:~:text=Like%20other%20forms%20of%20targeted,and%20kill%20the%20cancer%20cells.](https://www.mskcc.org/msk-news/winter-2021-22/theranostics-smart-bomb#:~:text=Like%20other%20forms%20of%20targeted,and%20kill%20the%20cancer%20cells.)

From Chuck and Kate: Atypical Lung Carcinoid with EML4/ALK Fusion Detected with Circulating Tumor DNA: <https://www.cureus.com/articles/86307-atypical-lung-carcinoid-with-eml4alk-fusion-detected-with-circulating-tumor-dna>

From Chuck and Grace: Management of bronchopulmonary NETS:

<https://journal.binayfoundation.org/article/32244-management-of-bronchopulmonary-neuroendocrine-tumors>

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 and Chuck: NexImmune Announces Research Collaboration with Rutgers, The State University of New Jersey, Related to Neuroendocrine Tumor Targets: <https://ir.neximmune.com/news-releases/news-release-details/neximmune-announces-research-collaboration-rutgers-state>

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: 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](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 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 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 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](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-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](http://smile.amazon.com)

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

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

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

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

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

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

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

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

### **Discussion boards:**

[ACOR.org](http://ACOR.org) (find the carcinoid group)

[Smartpatients.com](http://Smartpatients.com) (find the carcinoid group)

[Inspire.com](http://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](http://carcinoid.com))  
Carcinoid Awareness (also: [aboutcarcinoid.com](http://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)