

NEWS AND NOTES June 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**
- From LACNETS **Virtual conference Saturday June 18th 8AM-5PM: see email or website to register**
** Weekly support group meetings each Wednesday, noon PT (3 PM ET)
- From NCAN **Michigan conference June 25th: see email or website to register**
- From NETRF **conference July 24th: see email or website to register**
- 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_68HtYNAz09b64rTp4Mq0UlvMjEUtTBweiYf9Qb1yruHIRyb3vu4
** Ask the NET Experts – A New CCF Program:
https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2788218?fbclid=IwAR0rtLuLbYI75XpQEbVC878rMe-yFDKK9bvHGUap1zmqIhV_3t_BG6SgQMg
- 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 and opt in. Once completed, a nurse educator will contact you within 48 hours. For the nursing support program: 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=IwAR2fsgltfegz0ZpYErarAT-j9MzZ1d9RzQfld_yX7OrBtMpcJZtAVH5Hfb0

NEW ARTICLES:

- From Mike and Chuck: Drug combination shows promise for treating pNETs: [Drug combination shows promise for treating pNETs | EurekAlert!](#)**
- From Mike and Chuck: Novartis' surprise radiotherapy production halt nearing an end as FDA docs shed light on plant woes: [Novartis' surprise radiotherapy production halt nearing an end as FDA docs shed light on plant woes | Fierce Pharma](#)**
- 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 the May 12, 2022 CCF Luncheon with the Experts Dr. Jason Starr:

https://www.mayoclinic.org/biographies/starr-jason-s-d-o/bio-20439448?fbclid=IwAR2nzSjr496xK6-UPXS7W2ZUkQoL1zTqQBabsNfg67eAo_EKICTG0Ljh4-8

From the May 12, 2022 CCF Luncheon: NETs care at Mayo Clinic: https://www.mayoclinic.org/diseases-conditions/neuroendocrine-tumors/care-at-mayo-clinic/mac-20354135?fbclid=IwAR0HfAim5cSP8R1QagV3UltXpoj_DP3h3pY3zTpS_gAr1P9eeW_Hv-uk4t0

From the May 12, 2022 CCF Luncheon: Diagnosed with a NET? 6 Questions to Ask Your Doctor:

https://www.carcinoid.org/wp-content/uploads/2015/07/6-Questions-to-Ask-Dr.-Info-Final-No-Crop-Marks-2017-10-17.pdf?fbclid=IwAR3cji0-Jih_WOnTrB7EshlWI-YyiOUxVeHxhz0J5R-qp5oO_RAMEptxKy8

From Pat, NANETS newsletter: Real-world efficacy of lutetium PRRT in patients with NETS:

<https://pubmed.ncbi.nlm.nih.gov/35485450/>

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/>

RECURRING 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

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=IwAR0bMu8q6Uf5JgqWA8UaCHGSoXngldfJL1gBHOff-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

and the link for NET Cancer Health Storylines: <https://www.healthstorylines.com/net-cancer-healthstorylines?fbclid=IwAR1IjyInBox4px3qHt6m0cnW0oOWfMqBqI-QYHLUINvt0eAZEAv9QPIVmhw>

and the link for MYCAPSSA (octreotide): 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-octrotate 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

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

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

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.ipsen.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 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 CDJ17 CAR T cells without toxicity to normal tissues": <https://www.nature.com/articles/s43018-022->

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[7.epdf?sharing_token=YLPzxfF3dxlqmLsib5Uy2NRgN0jAjWel9jnR3ZoTv0MttuRjyH3rIRa_CVuvzFGSOtFg_K-QdN9cbYaXHPbtU1GxKO7TOES8Z5muoV0aZXpzJC0xNZlydXsSXODmW58CJ42tXCDpmk1edafqyJRZsZKczYX2QxLeam7gwQJUiQ%3D](https://www.cell.com/cell/fulltext/S0092-8674(22)00003-4)

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

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

From Pat and MSKCC Newsletter: Theranostics: A Smart Bomb for Cancer: <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

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

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

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-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 February 6th 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

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)