SECOND ANNUAL Know Your

Virtual Patient and Caregiver Conference Sunday, November 7, 2021 10am-4pm EST





Comprehensive Cancer Center

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WELCOME

Greetings to all and thank you for joining us on this first Sunday in November for our second annual "Know Your NETs Virtual Patient and Caregiver Conference."

While we prefer to see you all in person and meeting virtually for a consecutive second year is not ideal, we are so grateful and appreciative to the more than 500 registrants attending today and the outstanding group of speakers who graciously gave of their time to support NETRF and our patient and caregiver community.

Today's presentations represent what YOU told us YOU wanted to learn about living with NETs. Questions can be submitted at any time via SLIDO.COM (see page 11) and there are two live Q & A sessions planned (see Agenda for details).

NETRF is grateful for our conference sponsors who have helped make this meeting possible. Please take a moment to review the educational content from our sponsors in this booklet.

Thank you for joining us today, supporting NETRF and most importantly, being an active and engaged participant to help us raise critical awareness of NETs as we Build a Better Future for NETs Patients.

Sincerely,



Elyse Gellerman, MHS, Conference Co-Chair CEO NET Research Foundation



Xavier Keutgen, MD, Conference Co-Chair Assistant Professor of Surgery University of Chicago Medicine

Program begins at 10AM Eastern.

TITLE	PRESENTER			
Pre-conference Welcome and Introduction	Elyse Gellerman, NETRF			
NETS 101	Andy Liao, MD, University of Chicago Medicine			
Conference Kickoff from Our Co-Chairs	Elyse Gellerman Xavier Keutgen, MD, University of Chicago Medicine			
What's New in NETs: Medical	Thor Halfdanarson, MD, Mayo Clinic			
What's New in NETs: Surgery and Interventional Radiology	Xavier Keutgen, MD Osmanuddin Ahmed, MD, University of Chicago Medicine			
Tailoring Treatments to Your Tumor Genetics	Andy Liao, MD			
Future Advancements in PRRT	Erik Mittra, MD, Oregon Health and Science University			
Treatment Sequencing for NETs: Panel Discussion	Drs. Keutgen, Liao, Halfdanarson, Ahmed, Mittra			
	BREAK			
Meet the Rese	archer: Michelle Kang Kim, MD			
More Than an Upset Stomach: Managing GI Symptoms	Carol Semrad, MD, University of Chicago Medicine			
Lung Neuroendocrine Tumors	Suki Padda, MD, Cedars-Sinai Cancer Institute			
Live Question and Answer Session	Moderated by Dr. Keutgen			
Keeping Your Liver Healthy	Helen Te, MD, University of Chicago Medicine			
Multidisciplinary Management of Bone Metastases	Tessa Balach, MD, University of Chicago Medicine Sean Pitroda, MD, University of Chicago Medicine			
	BREAK			
Meet the Re	searcher: Patricia Dahia, PhD			
Integrative Oncology for Neuroendocrine Tumors	Kathleen Cavanaugh, NP, MSN, University of California San Francisco			
NET Nutrition and Supplements	Leigh Anne Burns, MD, RD, LDN			
Trends in NET Research: Basic and Translational	Eric Nakakura, MD, University of California San Francisco			
Trends in NET Research: Clinical Trials	Jaydira Del Rivero, MD, National Cancer Institute/National Institutes of Health			
Live Question and Answer Session	Moderated by Dr. Keutgen			
Conference Close and Final Comments	Elyse Gellerman			

Agenda subject to change





A Podcast About Neuroendocrine Cancer

Being diagnosed with an uncommon cancer like a neuroendocrine tumor (NET) can feel isolating or overwhelming. NETWise, a podcast about neuroendocrine cancer, is here to help patients and caregivers navigate the world of NETs.

Listen in as the NET Research Foundation (NETRF) speaks with experts and patients who will help us to understand NET diagnosis, treatment, and everything in between. NETWise is for everyone, from newly diagnosed patients to longtime survivors, as well as caregivers and family members.

This is your guide to learning, listening, knowing, and being NETWise.

How to find NETWise, a New Way to Learn about NETs





DEDICATED TO CURING NEUROENDOCRINE CANCER

The Neuroendocrine Tumor Research Foundation (NETRF) is the largest private funder of neuroendocrine tumor (NET) research. We are dedicated to funding research to discover cures and more effective treatments for neuroendocrine cancers. NETRF also works to improve the lives of patients, caregivers, and families living with neuroendocrine tumors by providing them with resources to educate and empower them in their journey.

AN UNCOMMON AND UNDERFUNDED CANCER

NETs are a rare cancer that can form in many different organs of the body.

NET research receives only **one-tenth** of one percent of government-funded grants, and is **underfunded over** five-fold based on its prevalence in the U.S. NETRF helps bridge this gap by funding nearly 30% of all NET research. By supporting 2.5 times more NET investigators than any other funder, NETRF has established a vibrant scientific community dedicated to understanding NETs and its treatment. 175K Americans affected. **12K** New diagnoses in the U.S. each year.

50% Misdiagnosed first with another condition.

Average number of years from onset of symptoms to diagnosis.

SUPPORT IN 2020 THAT MADE A DIFFERENCE





RESEARCH IMPACT BY THE NUMBERS

15 YEARS OF NETRF SUCCESS, 2005-2020



NETRF GRANTS

15	15	11
53%	67%	67%
4.5M \$4	4,77M \$	2.8M
	15 53% 4.5M \$4	15 15 53% 67% 4.5M \$4,77M \$



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SPEAKER BIOGRAPHIES



Osmanuddin Ahmed, MD

Assistant Professor of Radiology, University of Chicago

Dr. Ahmed is an associate professor of Radiology at University of Chicago Medicine and is board certified in Diagnostic and Interventional Radiology. He received his medical degree from University of Illinois at Chicago and completed a vascular and interventional radiology fellowship at Stanford Hospital.



Tessa Balach, MD

University of Chicago Medicine

Tessa Balach, MD, is an associate professor, the Vice Chair of Education, and Orthopaedic Residency Program Director in the Department of Orthopaedic Surgery and Rehabilitation Medicine at The University of Chicago. Dr. Balach received her undergraduate education at The University of Chicago before medical school at New York Medical College. She returned to The University of Chicago for both her Orthopaedic Surgery residency and Musculoskeletal Oncology fellowship. Her clinical practice focuses on the care of bone and soft tissue tumors in adult and pediatric patients. She has focused interests in sarcomas and oligometastatic disease, medical education, and healthcare quality.



Leigh Anne Burns, MS, RD, LDN

Private Consultant

Leigh Anne Burns has practiced nutrition and dietetics for 30 years and currently works as a private consultant. Her work with the LSU Medcal School Oncology team included a specialty in neuroendocrine tumor treatment and launched Leigh Anne's career working with patients diagnosed with NET tumors. In 2005, the team joined efforts with a group of LSUHSC Medical School surgeons, nurses, and patient care members to develop a NET clinic in New Orleans. Now as a consultant, Leigh Anne is providing education and cancer care and serves as a mentor for registered dieticians interested in focusing on patients who have NETs.



Kathleen Cavanaugh, NP, MSN

University of California San Francisco Health

Kathleen Cavanaugh is a Nurse Practitioner with over 20 years of experience caring for people with cancer. Her career started as an RN working on an in-patient oncology unit and has taken her through many roles in infusion centers and outpatient cancer centers. She completed a fellowship in Integrative Medicine through the Andrew Weil Center for Integrative Medicine at the University of Arizona. She currently works at the UCSF Osher Center for Integrative Medicine where she sees patients affected by cancer, helping them to safely and effectively incorporate complementary and integrative modalities alongside conventional cancer treatments.



Jaydira Del Rivero, MD

National Cancer Institute/National Institutes of Health

Dr. Del Rivero is the endocrine oncologist at the Developmental Therapeutics Branch, NCI/NIH. She serves as the principal investigator of the Natural History Study for Neuroendocrine Tumor and Adrenocortical Cancer, which aims to provide the basis for developing therapeutic interventions, prevention/screening guidelines, endpoints for future clinical trials, and patient-reported outcome measures. Her efforts focus on developing novel treatment approaches and targeted therapies for endocrine malignancies like advanced gastroenteropancreatic neuroendocrine tumors, adrenal cancer, and pheochromocytoma/ paraganglioma, and she leads treatment trials at the NCI. Dr. Del Rivero currently serves on the Board of Directors and Guidelines Committee NANETS and is a member of the NCI NET Task Force.



Elyse Gellerman, MHS, Conference Co-Chair

CEO, NET Research Foundation

Elyse was appointed Chief Executive Officer of the NET Research Foundation in November 2017. Since joining NETRF in 2016, she has managed operations and worked to develop and implement the Foundation's strategic, business, marketing and financial plans. Elyse was previously a Regional Vice President for Sarah Cannon, the oncology service line for Hospital Corporation of America (HCA), leading the development of cancer programs for a seven-hospital division across Colorado and Kansas. She has served in key roles for Susan G. Komen as the Denver Affiliate Board President and a National Board member, and for the Leukemia and Lymphoma Society, as Executive Leadership Council chairperson in 2015. In 2011, Elyse was recognized by the White House as a Champion for Change in the fight against Breast Cancer. She has a bachelor's degree from Cornell University and a master's degree in Healthcare Systems from the University of Denver.



Thor Halfdanarson, MD

Professor of Oncology, Mayo Clinic

Dr. Halfdanarson is a professor of Oncology at the Mayo Clinic College of Medicine and Science and a consultant in Medical Oncology at the Mayo Clinic. He specializes in GI oncology with a focus on NETs, staffs the Unknown Primary Clinic, serves as the chair of the GI Tumor Group and is the co-chair of the Pancreatic/Neuroendocrine Tumor Board. Dr. Halfdanarson is a member of the NCCN guidelines panel for NETs, the past chair of the Guidelines and Publications Committee of NANETS, is the current secretary and on the Board of Directors of NANETS, and is a faculty member for the European Society of Medical Oncology for neuroendocrine and endocrine neoplasms and cancers of unknown primary.



Xavier Keutgen, MD, Conference Co-Chair

Assistant Professor of Surgery, University of Chicago

Dr. Keutgen is a surgical oncologist with particular expertise in treating neuroendocrine, thyroid, parathyroid and adrenal tumors. He is the director of the University of Chicago Neuroendocrine Tumor Center and works closely with multidisciplinary team that specializes in NETs. Dr. Keutgen, a Belgian native, received his medical degree from the University of Heidelberg (Germany), and completed his residency at New York Presbyterian Hospital-Weill Cornell Medical Center and fellowships at the University of Zurich (Switzerland) and the National Cancer Institute (NIH).



Chih-Yi "Andy" Liao, MD

Assistant Professor of Medicine, University of Chicago

Dr. Liao is an assistant professor of Medicine at University of Chicago Medicine. He is a medical oncologist and clinical investigator who specializes in treating gastrointestinal neuroendocrine tumors and hepatobiliary cancers. He serves as the principal investigator of many clinical trials for these cancers and is the medical oncology lead for the University of Chicago's Neuroendocrine Tumor Program.



Erik Mittra, MD, PhD

Oregon Health & Science University

Dr. Mittra is a professor of Diagnostic Radiology and Chief of Nuclear Medicine & Molecular Imaging at Oregon Health & Science University. He received his medical and graduate degrees through the joint MD/PhD program at Stony Brook University followed by residency and fellowship in Nuclear Medicine at Stanford University. Dr. Mittra is interested in all aspects of molecular imaging and therapy. Targeted radionuclide therapies (TRT) are of particular interest and he is nationally recognized in this area. He is active with the Society of Nuclear Medicine and Molecular Imaging, the North American Neuroendocrine Tumor Society, and the Healing NET Foundation.



Eric Nakakura, MD, PhD

University of California San Francisco

Dr. Eric Nakakura is a cancer surgeon who specializes in tumors of the liver, pancreas, bile ducts and gastrointestinal tract and a Professor in the Department of Surgery at UCSF. He helps manage complex gastrointestinal tract cancers, soft tissue sarcomas and gastrointestinal neuroendocrine tumors, including carcinoid and islet cell tumors. Dr. Eric Nakakura received his medical degree at Stanford Medical School then went to Johns Hopkins to complete a residency in general surgery and a fellowship in surgical oncology. He was a specialist registrar in surgery at the John Radcliffe Hospital in Oxford, England. At Johns Hopkins, he received a doctoral degree in cellular and molecular medicine. At UCSF, Dr. Nakakura's research activity and surgical practice is focused on neuroendocrine tumors.



Sukhmani Padda, MD

Cedars-Sinai Cancer Institute

Dr. Padda is the director of Thoracic Medical Oncology at Cedars-Sinai Medical Center. She completed an internal medicine residency and hematology/oncology fellowship at Stanford University in 2014. After serving as faculty at Stanford University, she joined Cedars-Sinai Medical Center Division of Oncology, Department of Medicine in 2021. In collaboration with multidisciplinary clinical experts and scientists, Dr. Padda's goals are focused in expanding clinical trials and translational research in thoracic oncology. Dr. Padda's research focus includes examining novel targeted therapeutics in genomic subsets of non-small cell lung cancer (e.g., EGFR, KRAS) and conducting clinical research in lung neuroendocrine tumors and thymic malignancies.



Sean Pitroda, MD

University of Chicago Medicine

Dr. Sean Pitroda is an assistant professor of Radiation and Cellular Oncology at the University of Chicago. He has clinical expertise in treating primary central nervous system and genitourinary cancers, as well as metastatic cancers to various organs. As a scientist, Dr. Pitroda discovered the first biological basis for curable oligometastatic disease. He anticipates his findings will have important implications in the selection of local therapy for those patients with curable metastatic disease from those whose few metastases are a part of a large cascade of widespread disease, thereby changing the paradigm for the treatment of metastatic cancers.



Carol Semrad, MD

University of Chicago Medicine

Dr. Semrad received her gastroenterology training at Columbia University in New York City and postdoctoral training in intestinal ion transport and subsequent training in nutrition at Memorial Sloan-Kettering Cancer Center. For the past 30 years, she has cared for patients and contributed to translational research, scholarship, and education in small bowel disease and endoscopy. She is involved in translational research in the study of immune mechanism in the pathogenesis of celiac disease that has advanced the understanding of how celiac disease is triggered.



Helen S. Te, MD FAST, FAASLD, AGAF

University of Chicago Medicine

Dr. Helen S. Te is a professor of Medicine in the Section of Gastroenterology at the University of Chicago Medicine as well as the medical director of the Adult Liver Transplant Program. Her clinical practice consists of general and transplant hepatology patients. She uses a personalized approach and nimble innovations as the basic elements of her clinical management. This strategy has earned her peer recognition with the America's Top Doctor and Chicago Magazine Top Doctor awards for the past 10 years. This year, she received the Physician of Distinction award from the American Society of Transplantation.

Ask Questions Online through Slido!

- On your phone, tablet or computer, open your web browser and go to www.slido.com, then enter our event code: NETRF (screen 1)
- 2. Click on Live Interaction (screen 2). That's it! You are ready to ask questions or vote a question up (screen 3). There's no need to duplicate a question.

DO NOT use your name. Please ask anonymously or use your initials.

While we cannot guarantee your question will be addressed, questions with the highest numbers of votes stand a better chance of getting answered by the speaker.



SPEED UP THE SEARCH FOR CURES with your tumor tissue donation

Researchers rely on fresh samples of neuroendocrine tumor (NET) tissue to understand the causes of NETs and to explore new treatments. From donated tumor tissue, researchers isolate and grow NET cells in dishes (called cell lines) for laboratory study.

Unfortunately there are not enough NET cell lines for researchers to use.

Some NET cells grow very slowly or not at all in the lab. The lack of NET cell lines slows important NET research. Neuroendocrine Tumor Research Foundation (NETRF) has teamed up with Pattern.org to solve this decades-old problem. And we need your help.

- 1. Visit Pattern.org to learn about NET tissue (or fluid) donation.
- 2. Register and provide your consent.
- 3. Pattern.org will work with your doctor to collect excess tissue (or fluid) from surgery not needed for your care.
- 4. Your tumor tissue (or fluid) from surgery will be sent to the laboratory to be grown into cell lines and, if successful, shared with scientists throughout the world.

Your tumor tissue donation can fuel more research

Explore tumor tissue donation in advance of an upcoming surgery. It's free, easy, confidential, and has no effect on your clinical care.

How tumor tissue helps us discover new treatments





Following surgery, excess tumor tissue is sent to a research laboratory

Tumor tissue is grown and made available to researchers throughout the world.



Researchers study

the NET cell line's

DNA and RNA

Data patterns will reveal possible drug targets



Potential treatments are tested on the NET cell line



Promising treatments undergo further testing



7 Validation and clinical trials may lead to new, more effective treatments for patients

Take the first step today.

For more information on NET tissue donation, visit netrf.org/tumor-tissue-donation or pattern.org.





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The NET Research Foundation is grateful to partner with Ipsen Pharmaceuticals to make this printed glossary available to our attendees.

KNOW YOUR NETS GLOSSARY



1	А	В	С	D	Е	F	G	Н	I	J	K	L	Μ
N	0	Ρ	Q	R	S	Т	ι	J	V	W	Х	Υ	Z

1

5

5-hydroxyindoleacetic acid (5-HIAA) test A test that measures the amount of 5-HIAA in the urine. 5-HIAA is a substance that is broken down, or metabolized, from serotonin. It's often done to detect certain tumors in the digestive tract (like carcinoid tumors) and to track a person's condition.

1

18F-dihydroxy-phenylalanine

A radioactive substance or tracer. It's used in PET scans to detect the location of NETs. It can also be called fluorodopa or 18F-DOPA.

A

Abdomen

The abdomen is the belly area between the chest and pelvis. It contains the pancreas, stomach, intestine, liver, gallbladder, and other organs.

Ablation

In medicine, ablation is the removal of a body part, tissue, or its function. The procedure may be done by surgery, hormones, drugs, radiofrequency, heat, or other methods.

ACE Inhibitor

An ACE inhibitor is a drug that's used to lower blood pressure. The full name is angiotensin-converting enzyme inhibitor.

Acute

Acute symptoms are symptoms or signs that begin and worsen quickly.

Adenocarcinoma

An adenocarcinoma is a cancer that begins in glandular (or secretory) cells. Glandular cells can be found in a tissue that lines certain internal organs. They make and release substances in the body, such as mucus, digestive juices, or other fluids. Most cancers of the breast, pancreas, lung, prostate, and colon are adenocarcinomas.

Adenoma

A tumor that is not cancer. It starts in gland-like cells of the epithelial tissue (a thin layer of tissue that covers organs, glands, and other structures in the body).

Adjunctive therapy

A supporting treatment used together with the primary treatment. Also called adjunct therapy.

Adjuvant therapy

Cancer treatment that is given after the primary treatment to lower the risk of cancer coming back. Adjuvant therapy may include chemotherapy, radiation therapy, hormone therapy, targeted therapy, or biological therapy.

Adrenal glands

Two small organs near the kidneys that release hormones. These hormones help control heart rate, blood pressure, and other important body functions. Also called suprarenal gland.

Adrenaline

A hormone and neurotransmitter. Also called epinephrine.

Adverse events

An unexpected medical problem that happens during treatment with a drug or other therapy. Adverse events may be mild, moderate, or severe, and may be caused by something other than the drug or therapy being given. Also called a side effect or adverse effect.

Analgesic

A drug that reduces pain, like aspirin, acetaminophen, or ibuprofen.

Analog

In chemistry, a substance that is similar, but not identical, to another.

APUDoma

An APUDoma is an endocrine tumor that rises from an APUD cell (amine precursor uptake and decarboxylation).

Atrophic Gastritis

Atrophic gastritis develops when the lining of the stomach has been inflamed for several years. The inflammation is most often the result of a bacterial infection caused by the *H. pylori* bacterium. The bacteria disrupt the barrier of mucus that protects the stomach lining from acidic juices that help with digestion. If it's not treated, the infection can gradually destroy the cells in the stomach lining.



Benign (tumor)

A benign tumor is a noncancerous tumor. They may grow larger but they do not usually spread to other parts of the body. Also called nonmalignant tumors.

Biomarker

A biological molecule found in blood, other body fluids, or tissues that is a sign of a normal or abnormal process, or of a condition or disease. A biomarker may be used to see how well the body responds to a treatment for a disease or condition. Also called molecular marker and signature molecule.

Bone scan (Bone scintigraphy)

A procedure to check for abnormal areas or damage in the bones. A bone scan may be used to diagnose bone tumors, or cancer, that has spread to the bone. It may also be used to help diagnose fractures, bone infections, or other bone problems. Also called bone scintigraphy.

Bronchial NETs

Bronchial NETs are neuroendocrine tumors that develop in the lungs. There are two types depending on where they occur. The first is central bronchial. They are tumors located in the trachea (windpipe) and around the main central area of the lungs. The second is peripheral bronchial, located in the outer areas of the lungs.

Bronchoscope

A thin, tube-like instrument that is used to examine the inside of the trachea and bronchi (air passages that lead to the lungs), and lungs. A bronchoscope has a light and a lens for viewing, and may also have a tool to remove tissue.

Bronchoscopy

A nonsurgical procedure that looks inside the airways of the lungs by using a bronchoscope.

С

Caregiver

A family member or paid helper who regularly looks after a child or a sick, elderly, or disabled person.

Carcinogenesis

The process by which normal cells transform into cancer cells.

Carcinoid crisis

Carcinoid crisis is when all of the symptoms of carcinoid

syndrome occur at the same time. It is generally found in people with carcinoid tumors. The crisis may occur suddenly, or it may be associated with stress, chemotherapy, or anesthesia. It's characterized by an abrupt flushing of the face, and sometimes upper body. Severe falls in blood pressure and bronchospasm with wheezing can (infrequently) occur.

Carcinoid syndrome

Carcinoid syndrome is a group of symptoms associated with functional carcinoid tumors, like diarrhea or flushing.

Carcinoid tumors

Slow-growing tumors usually found in the gastrointestinal system (most often in the small intestine and rectum), and sometimes in the lungs or other sites. Carcinoid tumors may spread to the liver or other sites in the body, and they may secrete substances such as serotonin or prostaglandins that cause carcinoid syndrome.

Carcinomas

A type of cancer that begins in the skin or in the tissues that line or cover internal organs.

Catecholamines

A type of neurohormone (a chemical made by nerve cells and used to send signals to other cells). Catecholamines are also a collective term for the hormones epinephrine, norepinephrine, and dopamine.

Chemotherapy

Anti-cancer drugs given either by mouth or by injection into a vein or muscle to kill cancer cells.

Cholelithiasis

Cholelithiasis is the medical term for gallstones; hard, crystal-like lumps that form out of a fluid called bile.

Chromogranin A (CgA)

A protein found inside neuroendocrine cells that can be released, along with other hormones, into the blood. It can be found in higher than normal amounts in patients with certain neuroendocrine tumors, small cell lung cancer, and prostate cancer. Measuring the amount of chromogranin A in the blood can help diagnose cancer or other conditions.

Colon

The longest part of the large intestine, a tube-like organ connected to the small intestine at one end, and

the anus at the other. The colon removes water, some nutrients, and electrolytes from partially digested food. The remaining material (solid waste called stool) moves through the colon to the rectum, and leaves the body through the anus.

Colonoscopy

A test that examines of the inside of the colon (gut). During this test, a colonoscope is inserted into the anus and passed up inside the colon. The colonoscope, a thin, tube-like instrument, has a very small light and video camera at the end for viewing.

Computed tomography (CT) scan

A CT scan is an imaging method that uses X-rays to create pictures of cross-sections of the body.

Crohn's disease

Crohn's disease is one of a group of diseases called inflammatory bowel disease. It causes inflammation of the digestive system. It can affect any area from the mouth to the anus. Crohn's disease can increase the risk of colorectal cancer and small intestinal cancer. Symptoms include fever, diarrhea, stomach cramps, vomiting, and weight loss.

Cryoablation

A procedure that involves freezing cancer cells to kill them. A thin surgical instrument called a cryoprobe is inserted through the skin and directly into the tumors to freeze them. Also known as cryotherapy or cryosurgery.

Cryoprobe

A surgical instrument used to apply extreme cold to tissues.

Cryosurgery

Also known as cryoablation, a procedure that involves freezing cancer cells to kill them. A thin surgical instrument called a cryoprobe is inserted through the skin and directly into the tumors to freeze them. Also known as cryotherapy or cryosurgery.

Cytotoxic agent

Any substance that kills cells, including cancer cells. These substances can help stop cancer cells from dividing and growing, and may even cause tumors to shrink in size.

Deep subcutaneous injection (subcutaneous injection)

A deep subcutaneous injection is a method of administering medication. Subcutaneous means under the skin. In this type of injection, a short needle is used to inject a drug into the tissue layer between the skin and the muscle. Also known as subcutaneous injection.

Debulking

A type of surgery used to remove as much of the cancer as possible to help make chemotherapy or radiation possible or more effective.

Dietitian

A healthcare professional who is an expert in diet and nutrition. A dietician can advise patients on how to eat healthily.

Differentiation

In cancer, refers to how mature (developed) the cancer cells are in a tumor. Tumor cells that are differentiated can resemble normal cells. They tend to grow and spread at a slower rate than undifferentiated or poorly differentiated tumor cells which grow uncontrollably.

DNA

Molecules inside cells that carry genetic information and pass it from one generation to the next. The full name is deoxyribonucleic acid.

Dopamine

A hormone and neurotransmitter (messenger) released by the nervous system.

Duodenum

The first part of the small intestine, attached to the stomach. This is the part food enters immediately after it leaves the stomach. It helps digest food further and absorb nutrients and water for the body.

Dysplasia

Cells that may look abnormal under a microscope but are not cancer.

An imaging test that uses ultrasound to produce moving images of the heart and blood flow through the heart's valves and structures. Also called a cardiac echo or simply an echo.

Efficacy

F

How well a treatment works. The measurements that determine efficacy are decided in advance of a clinical trial and are constantly monitored as the trial progresses.

Endocrine cancer

Cancer that occurs in endocrine tissue; the tissue in the body that secretes hormones.

Endocrine system

The endocrine system consists of hormone-producing cells. Hormones are chemical substances that are carried through the bloodstream. They have a specific regulatory effect on the activity of other organs and cells in the body. The neuroendocrine system is part of the endocrine system. The endocrine system controls growth, sexual development, sleep, hunger, and the way the body uses food.

Endocrinologist

A doctor that specializes in diagnosing and treating conditions caused by hormonal or endocrine imbalances in the body.

Endoscope

A long, thin, flexible tube that has a light and a video camera at the end and is inserted into the body via the mouth. They can also be used to collect a sample of tissue (biopsy) for further examination.

Endoscopy

A nonsurgical procedure that is used to look inside a person's digestive tract using an endoscope.

Epinephrine

Epinephrine, also called adrenaline, is a naturally occurring hormone. It's one of two chemicals released by the adrenal gland (the other is norepinephrine). Epinephrine increases the speed and force of heartbeats and thereby the work that can be done by the heart. Epinephrine has been produced synthetically as a drug since 1900. It remains the drug of choice for treatment of anaphylaxis, life-threatening allergic reactions.

F

Fine-needle aspiration

A procedure that removes tissue samples with a very thin needle.

First-line therapy

The first drug, or set of drugs, given to treat cancer.

Fluorodeoxyglucose

A radioactive substance or tracer that is used in a PET scan to help identify the presence of certain tumor types within the body. It measures how much energy (glucose) the tumors are using. Usually abbreviated to FDG.

Flushing (carcinoid flushing)

A reddening of the skin. Episodes of severe flushing can be triggered by exercise, alcohol, stress, and certain foods in 75% of patients with carcinoid syndrome. Carcinoid syndrome occurs in about 10% of patients with carcinoid tumors. With time, flushing may appear without provocation. The character of the flush differs depending upon the site of origin of the tumor.

Functioning tumors

Neuroendocrine tumors (NETs) that make an excess of hormones and cause signs and symptoms. Also known as functional tumors.

Fusion scan (MIBG, OctreoScan or other scans)

The fusion scan electronically fuses, or combines images from an OctreoScan, MIBG scan (or any other PET scan) with those of a CT scan. Together, they render a final image that may be superior to those of the individual scans.

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Gallbladder

The pear-shaped organ found below the liver. Bile is concentrated and stored in the gallbladder.

Gallium-68

A radioactive substance or tracer that can be combined with a protein that targets somatostatin receptors. When injected into the body, it can be used to identify specific neuroendocrine cancer cells during a PET scan.

Gallstone

Solid material that forms in the gallbladder or common bile duct. Gallstones are made of cholesterol or other substances found in the gallbladder. They may occur as one large stone or as many small ones, and vary from the size of a grain of sand to a golf ball.

Gastrin

A hormone released after eating from special cells in the lining of the stomach. Gastrin causes the stomach to release an acid that helps digest food.

Gastritis

Gastritis is an inflammation, irritation, or erosion of the lining of the stomach. Common symptoms may include appetite loss, indigestion, black stools, nausea, and vomiting. Some people may not experience symptoms.

Gastroenterologist

A doctor that specializes in diagnosing and treating disorders of the gastrointestinal tract (digestive system). This can include the food pipe (esophagus), stomach, liver, and gut (intestines).

Gastroenteropancreatic neuroendocrine tumors (GEP-NETs)

A rare type of tumor that can form in the pancreas or in other parts of the gastrointestinal tract, including the stomach, small intestine, colon, rectum, and appendix. GEP-NETs usually form in cells that secrete hormones. Some of these tumors make extra amounts of hormones (and other substances) that can cause signs and symptoms of disease, including a condition called carcinoid syndrome. GEP-NETs may be a benign (noncancerous) or malignant (cancer).

Gastrointestinal NETs (GI-NETs)

Previously called carcinoid tumors, GI-NETs are the most common type of neuroendocrine tumors (NETs). They are found in the gastrointestinal (GI) tract, and include tumors that develop in the bowel, stomach, or food pipe (esophagus). Also called gastric NETs or GI-NETs.

Gastrointestinal tract

The organ system responsible for consuming, digesting, absorbing nutrients, and getting rid of food (waste). The gastrointestinal tract includes the mouth, throat, esophagus, stomach, small and large intestine, rectum, and anus.

Gastroscopy

An examination of the inside of the stomach by using a flexible fiberoptic tube (a gastroscope). The gastroscope is passed through the mouth and esophagus and into the stomach.

Glucagon

A hormone produced by the pancreas that helps to increase blood sugar (glucose).

Grade

A description of how cancer cells and surrounding tissues look under a microscope, and how quickly they are likely to grow and spread. Grades are used to help plan treatment and determine prognosis. Also called histologic grade and tumor grade.



Hematology

The science that studies the blood.

Hepatic

Having to do with the liver. For example, the right and left hepatic ducts.

Hepatic chemoembolisation

A therapeutic method used to treat primary liver tumors and cancer tumors that have spread to the liver (metastatic liver tumors).

Histamine

A type of neurotransmitter that has many effects in the body. It's a part of the body's immune response and is released during an allergic reaction. It causes small blood vessel to widen and become leaky, which can cause tissues to swell. Histamine can also cause smooth muscles to contract (tighten), gastric acid to be made, and the heart rate to increase.

Hormone

Chemical substances that are carried through the bloodstream and have specific regulatory effect on the activity of other organs or cells in the body.

Inflammatory bowel disease (IBD)

A disorder in the intestine. Signs and symptoms can include abdominal pain, bloating, and changes in bowel habits, like constipation, diarrhea, or both. Also called irritable bowel syndrome.

Irritable bowel syndrome (IBS)

A disorder in the intestine. Signs and symptoms can include abdominal pain, bloating, and changes in bowel habits, like constipation, diarrhea, or both. Also called irritable bowel syndrome.

lleum

The last section of the small intestine that attaches to the large intestine.

Immunotherapy

An artificial stimulation, or imitation, of the body's immune system to treat or fight disease.

Injection

Pushing medication into the body through the use of a syringe or needle. There are different types of injections. Intramuscular (IM) injections: Into the muscle. Intravenous (IV) injections: Into the vein. Subcutaneous (SC) injections: Into the fatty tissue under the skin.

Insulin

A hormone made by the pancreas that helps maintain normal blood sugar levels.

Interferon

A substance that can improve the body's natural response to infections and other diseases. Interferons help stop cancer cells from forming new cancer cells and can slow down the growth of tumors. The body normally produces interferon. It can also be made in the laboratory to treat cancer and other diseases.

Intervention

The treatment, procedure, or other action taken to prevent or treat disease, or help improve health.

Interventional study

A clinical trial in which researchers assign one or more interventions to a group of suitable participants. The results of this study can help provide researchers with information about cause and effect.

Intramuscular injection

An injection that is delivered directly into the muscle.

Intraoperative radiation therapy (IORT)

Radiation therapy that is given during surgery.

Irradiation

A treatment method that delivers radiotherapy to the whole body. It uses high-energy radiation to destroy cancer cells and shrink tumors. Also called radiation therapy.

J

Jejunum

The middle section of the small intestine (between the duodenum and ileum).



Ki-67 index

The Ki-67 index measures how much Ki-67 protein is present in cancer cells. Ki-67 is a protein used to diagnose and assess the prognosis of tumors, including neuroendocrine tumors (NETs).

_	

Linear accelerator

A machine that uses electricity to form a stream of fastmoving subatomic particles. This creates a high-energy radiation that may be used to treat cancer.

Localized

A tumor contained in one area of the body.

Lung function tests

Tests that look at how well the lungs work by measuring how much air a person can exhale after taking in a deep breath. Also called pulmonary function tests.

Lutetium-177

A radioactive substance that can be combined with a protein to target somatostatin receptors. It releases radiation and kills the tumor cells.



Magnetic resonance imaging (MRI) scan

An MRI uses a large magnet and radio waves to look at organs and structures inside your body.

Malignant tumors

Malignant tumors are made up of cells that grow out of control. Cells in these tumors can invade nearby tissues and spread to other parts of the body.

Metastasis

A process that describes how cancer cells spread from one part of the body to another.

Metastasize

To spread from one part of the body to another.

MIBG scan

An imaging test that uses radiopharmaceutical metaiodobenzylguanidine (MIBG) to help locate and diagnose certain types of cancer in the body.

Multidisciplinary team

Healthcare professionals from various clinical areas who help advise patients about the different aspects of NETs care.

Multiple endocrine neoplasia (MEN)

A rare, genetic condition that causes tumors to develop in endocrine glands, most common in the parathyroid glands, pituitary gland, and the pancreas. Also known as MEN (acronym).



Neuroendocrine cells

Cells that release hormones into the blood in response to a signal from the nervous system.

Neuroendocrine tumors (NETs)

A tumor derived from neuroendocrine cells. Neuroendocrine cells release a hormone in response to a signal from the nervous system. Neuroendocrine tumors can secrete an excess of hormones and cause a variety of symptoms. Examples of neuroendocrine tumors are carcinoid tumors, islet cell tumors, medullary thyroid carcinoma, and pheochromocytoma.

Neuroendocrine system

Having to do with interactions between the nervous system and endocrine system. The neuroendocrine system is comprised of cells that are a cross between traditional hormone-producing cells and nerve cells.



Oncology

The study and treatment of cancer. Doctors who specialize in oncology are called oncologists.

Oncologist

A doctor who specializes in oncology.

P

Palliative Care Team

A team of specialized doctors, nurses, and other healthcare professionals who are trained to provide supportive care, such as pain relief to people with longterm terminal illnesses, particularly during the last days of life.

Pancreas

A pear-shaped gland located in the abdomen between the stomach and the spine. It is about six inches long and releases enzymes that help the body digest food. The pancreas also produces insulin, which helps control the amount of sugar in the blood.

Pancreatic neuroendocrine tumor (pNETs)

Pancreatic neuroendocrine tumors (pNETs) are tumors that form in hormone-making cells (islet cells) of the pancreas. These include functioning and non-functioning tumors.

Pancreatic polypeptide

A hormone produced by the pancreas. Levels of pancreatic polypeptides are high in the blood of people with pancreatic NETs (pNETS). Blood levels can therefore be used to help in the diagnosis of, and monitor, pNETs.

Pathologist

A physician who identifies diseases and conditions by studying the structure and characteristics of cells and tissues.

Peptic ulcer disease

Peptic ulcer disease involves sores that develop in the lining of the stomach, lower esophagus, or small intestine. Also known as stomach ulcers.

Peptide receptor radionuclide therapy (PRRT)

A form of molecular targeted therapy which is performed by using a small peptide that is coupled with a radionuclide emitting beta radiation. PRRT is an innovative nuclear medicine therapy for the systemic treatment of tumors, including metastasized neuroendocrine tumors.

Percutaneous alcohol injection

A therapy involving the injection of pure alcohol through the skin, directly into cancerous tumors in the liver to kill cancer cells. A CT scan or an ultrasound guides needle into the tumor. Used to treat liver cancer. Also known as a percutaneous ethanol injection (PEI).

Placebo

A placebo is a substance that has no effect on the disease, but is used as a control to compare the effects of an actual treatment. It could be a pill, a shot, or some other type of "fake" treatment. What all placebos have in common is that they do not contain an active substance meant to affect health.

Positron emission tomography (PET)

A PET scan is an imaging technique that can show how body tissues are working, as well as what they look like. It can help diagnose and assess the severity of a cancer. For this scan, a radioactive tracer is injected into a vein.

Primary Care Physician (PCP)

A primary care physician (PCP) or general practitioner (GP) is a medical doctor who diagnoses and treats all types of medical conditions. GPs are often the first healthcare professional a patient will see before they are referred for specialist care. A practice nurse works alongside the GP to assess, screen, treat, and educate patients on health, and help monitor those with long-term conditions.

Primary site

The place in the body where a tumor starts.

Primary treatment

The main, or first, treatment used by the healthcare provider to treat cancer in the body.

Primary tumor

The original, or first, tumor in the body. Cancer cells can spread from a primary tumor to other parts of the body and form secondary tumors. This process is called metastasis.

Probiotic supplements

Probiotic supplements are live bacteria and yeasts that are good or helpful for your gastrointestinal (digestive) system.

Prognosis

A medical prediction about the probable cause and outcome of a disease.

Proliferative index

A measure of the number of cells in a tumor that are dividing (proliferating).

Prophylaxis

Preventative treatment or action

R

Radiation

The use of high-energy X-rays to kill cancer cells.

Radiation therapy

A procedure involving the use of high-energy radio waves, such as X-rays, gamma rays, electron beams, or protons, to destroy or damage cancer cells. Also called radiotherapy, irradiation, or X-ray therapy.

Radioembolization

Radioembolization uses radiation to treat neuroendocrine tumors (NETs) that have developed in the liver. It uses a thin tube to inject radioactive substance into the blood vessel that goes to the liver. The radioactive substance destroys the blood vessels where the tumor grows killing the cancer cells. Also called intra-arterial brachytherapy.

Radiofrequency ablation (RFA)

Radiofrequency ablation (RFA) uses heat made by radio waves to kill cancer cells. RFA is given using a probe (electrode) that is injected through the skin and into the tumor. The electrical current from the probe heats the cancer cells to high temperatures and can destroy them.

Radiologist

A medical doctor who specializes in diagnosing and treating disease and injury through the use of medical imaging techniques, like X-rays, and ultrasound.

Radionuclide

A radionuclide (sometimes called a radioisotope or isotope) is an unstable form of a chemical element that releases radiation as it breaks down and becomes more stable.

Radiotherapy

A procedure involving the use of high-energy radio waves, like X-rays, gamma rays, electron beams, or protons, to destroy or damage cancer cells.. Also called irradiation or X-ray therapy.

Resection

The surgical removal of an organ or structure, such as a tumor.



Safety

A measure of a participant's health and well-being during and after a clinical trial. Safety is the top priority in the clinical trials. That's why members of the research team closely monitor changes in participants' health throughout the trial.

Scintigraphy

An imaging test that produces two-dimensional images of the distribution of radioactivity in tissues after the internal administration of a radiopharmaceutical imaging agent.

Secondary cancer

A tumor formed from cancer cells that spread from a primary tumor to other parts of the body. The secondary tumor is the same type of cancer as the primary tumor. Also known as a secondary tumor or metastasis.

Serotonin

A hormone and neurotransmitter that is found in many tissues of the body.

Small bowel capsule endoscopy

A way to record images of the gastrointestinal (digestive) system. It involves swallowing a small capsule about the size and shape of a pill. The capsule contains a very small video camera that takes pictures of the inside of the gut.

Somatostatin

Somatostatin is a polypeptide type of hormone usually found in the hypothalamus and inhibits the secretion of other hormones including growth hormone, insulin, and gastrin.

Somatostatin analog (SSA)

Medication that copies or mimics the action of the hormone somatostatin. Somatostatin analogs may reduce the symptoms of neuroendocrine tumors (NETs) by stopping the body from making too many hormones. They may help slow tumor growth. Given by injection.

Somatostatin receptor scintigraphy (SRS)

A type of radionuclide scan used to find carcinoid and other types of tumors. Radioactive compound that targets somatostatin receptors is injected into a vein and travels through the bloodstream. The radioactive compound attaches to tumor cells that have receptors for somatostatin. A radiation-measuring device makes pictures showing where the tumor cells are in the body. This procedure is also called somatostatin receptor scintigraphy (SRS).

Sonography

A procedure that uses high-energy sound waves (ultrasound) to look at tissues and organs inside the body. Ultrasound is also known as sonography.

Subcutaneous injection (deep subcutaneous injection)

A subcutaneous injection is a method of administering medication. Subcutaneous means under the skin. In this type of injection, a short needle is used to inject a drug into the tissue layer between the skin and the muscle. Also known as deep subcutaneous injection

Surgeon

A highly skilled doctor who performs operations, such as the removal of neuroendocrine tumors (NETs).

Surgery

Surgery for neuroendocrine tumors (NETs) involving the physical removal of tumors.

Targeted cancer therapies

Drugs or other substances that block the growth, development, and spread of cancer cells. These treatments are also known as molecularly targeted therapies.

Thyroid

A gland that is part of the endocrine system and regulates hormones in the body. The thyroid absorbs iodine from the bloodstream to produce thyroid hormones. The thyroid hormones regulate metabolism in the body.

Transarterial chemoembolization (TACE)

A procedure that blocks (embolizes) the blood supply to a tumor and administers chemotherapy directly into the tumor. TACE is used to treat liver cancer. It's also called chemoembolization or hepatic artery embolization (HAE).

U

Ultrasound scan

An ultrasound scan is a procedure that uses high-energy sound waves (ultrasound) to look at tissues and organs inside the body. Ultrasound is also known as sonography.

Undifferentiated (poorly differentiated)

A term used to describe tumor cells that grow uncontrollably and lack the structures and function of normal cells. Alternatively, well-differentiated tumor cells resemble normal cells, and tend to grow and spread at a slower rate than the undifferentiated (poorly differentiated) tumor cells.



Vaso-intestinal peptide (VIP)

A hormone found in the pancreas, intestine, and central nervous system. It stimulates the release of electrolytes and water by the intestinal mucosa.

Von Hippel-Lindau syndrome (VHL)

A rare genetic condition that causes tumors and cysts to grow in certain parts of the body like the brain, spinal cord, eyes, inner ear, adrenal glands, pancreas, kidney, and reproductive tract. These tumors are usually noncancerous but some can be. People with VHL syndrome have an increased risk of developing certain types of cancer, especially kidney cancer and pancreatic cancer.

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X-ray therapy

A type of radiation therapy that uses high-energy radiation from X-rays to kill cancer cells and shrink tumors.

Y

Yttrium-90 (Y-90)

A radioactive substance that can be combined with a protein to target somatostatin receptors. It releases radiation and kills the tumor cells.

Ζ

Zollinger-Ellison syndrome

A disorder in which tumors produce large amounts of gastrin. It can lead stomach ulcers, esophageal reflux (when acid or bile flows into the food pipe and irritates the lining), and diarrhea. It results from the overproduction of stomach acid caused by rare neuroendocrine tumors.

Neuroendocrine Tumor Program

UChicago Medicine Comprehensive Cancer Center

AT THE FOREFRONT

One of the highest volume centers in the country, the **University of Chicago Medicine Neuroendocrine Tumor (NET) Program** offers unique therapy options for even the most advanced cancers. We offer:

- A multidisciplinary program consisting of nationally recognized experts who specialize in diagnosing and treating all forms of NETs.
- A multidisciplinary in-person and virtual clinic that allows you to be seen by our oncologists and surgeons at the same time.
- A dedicated NET nurse navigator to guide you through the program and facilitate your treatment plan in collaboration between specialists.
- The most advanced surgical techniques, including minimally invasive/robotic procedures and complex approaches to remove and destroy NETs that have spread to the liver.
- Leading-edge technologies like precision-enhancing navigation-controlled ablation of liver tumors and Peptide Receptor



Our Multidisciplinary Neuroendocrine Tumor Board meets regularly to discuss complex cases.

Radionuclide Therapy (PRRT), a systemic, targeted approach that delivers radiation to NET cells without damaging other organs.

- The only medical cyclotron in the region for creating novel radiotracers for NETs, which helps create next-generation PRRT treatments, in-house.
- Molecular profiling of NETs allowing for a personalized approach using therapies that work best on your tumor.
- One of the most experienced genetic counseling programs in the country to treat patients with NETs linked to hereditary conditions.
- Researchers conducting the latest studies on NETs, both in the laboratory and the clinic.



Understanding Neuroendocrine Tumors

Visit UChicagoMedicine.org/NETs to watch video



Recognized as An NCI Designated Comprehensive Cancer Center



An official cancer center designation by the <u>National Cancer Institute (NCI)</u> is the highest federal rating a cancer center can achieve. It's the gold standard for cancer programs and is bestowed upon the nation's top cancer centers in recognition of their innovative research and

leading-edge treatments. The University of Chicago Medicine has been home to such a designated center since 1973.

In addition to this National Cancer Institute designation, UChicago Medicine is also recognized for the comprehensive nature of our research, care, education and community outreach programs. We are one of only two institutions in the state of Illinois — and 51 in the United States — to be recognized as a comprehensive cancer center.

Meet the Neuroendocrine Tumors Team



Xavier Keutgen, MD Endocrine Surgery



Daniel Appelbaum, MD Nuclear Medicine



Chih-Yi Liao, MD Hematology and Oncology (Cancer)



Osmanuddin Ahmed, MD Vascular and Interventional Radiology



Blase Polite, MD Hematology and Oncology (Cancer)



Namrata Setia, MD Pathology

Research areas of focus and impact



Population research



Basic, translational research



Cancer genetics and immunotherapy



New treatments, early phase clinical trials

Our dedicated nurse navigator will guide you through the program and facilitate your treatment plan in collaboration with our multidisciplinary team.

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Hi, I'm Sandy, your RealSupport[™] sidekick!

I'm here to show you all the resources RealSupport[™] has to offer.

If you have severe diarrhea and flushing associated with carcinoid syndrome, you are not alone. RealSupport[™] is here with information and tools to help you manage your symptoms.

Sandostatin[®] LAR Depot (octreotide acetate) has been helping patients for over 30 years.*

Download helpful materials like an informational brochure, symptom trigger guide, and more.

<u>Ч</u>

Visit us.sandostatin.com/ downloads or scan the QR code >



Watch the Sandy Video Series where we talk about diet and lifestyle tips, co-pay support, and lots more.

Visit us.sandostatin.com/ RealSupport or scan the QR code >



This program does not replace the information provided by your doctor. *Includes Sandostatin Immediate-Release Injection and Sandostatin LAR Depot for all approved indications.

INDICATION AND USAGE FOR SANDOSTATIN LAR DEPOT

Sandostatin[®] LAR Depot (octreotide acetate) for injectable suspension is indicated for patients in whom initial treatment with immediate-release Sandostatin[®] (octreotide acetate) Injection has been shown to be effective and tolerated for

- Long-term treatment of the severe diarrhea and flushing episodes associated with metastatic carcinoid tumors
- Long-term treatment of the profuse watery diarrhea associated with VIP-secreting tumors

In patients with carcinoid syndrome and VIPomas, the effect of Sandostatin Injection and Sandostatin LAR Depot on tumor size, rate of growth, and development of metastases has not been determined.

IMPORTANT SAFETY INFORMATION

Warnings and Precautions: Treatment with Sandostatin LAR Depot may affect gallbladder function, with postmarketing reports of gallstones resulting in complications (inflammation of the gallbladder, bile duct, and pancreas, and requiring surgical removal of the gallbladder); sugar metabolism; thyroid and heart function; and nutritional absorption, which may require monitoring by your doctor. Call your doctor if you experience signs or symptoms of gallstones or any of their complications.

Please see additional Important Safety Information for Sandostatin LAR Depot on the next page.





IMPORTANT SAFETY INFORMATION Sandostatin[®] LAR Depot (octreotide acetate) for injectable suspension

Warnings and Precautions: Treatment with Sandostatin[®] LAR Depot (octreotide acetate) for injectable suspension may affect gallbladder function, with postmarketing reports of gallstones resulting in complications (inflammation of the gallbladder, bile duct, and pancreas, and requiring surgical removal of the gallbladder); sugar metabolism; thyroid and heart function; and nutritional absorption, which may require monitoring by your doctor. Call your doctor if you experience signs or symptoms of gallstones or any of their complications.

Before Taking Sandostatin LAR Depot: Tell your doctor if you have a history of heart disease or are taking other medications, including cyclosporine, insulin, oral hypoglycemic agents, beta-blockers, and bromocriptine.

Common Side Effects: Most patients experience side effects at some time. Some common side effects you may experience include back pain, fatigue, headache, abdominal pain, nausea, and dizziness.

Other Information: Patients with carcinoid tumors and VIPomas should adhere closely to their scheduled return visits for reinjection in order to minimize exacerbation of symptoms.

Indications and Usage

Sandostatin[®] LAR Depot (octreotide acetate) for injectable suspension is indicated for patients in whom initial treatment with immediate-release Sandostatin[®] (octreotide acetate) Injection has been shown to be effective and tolerated for

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You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

Please click here for full Prescribing Information for Sandostatin LAR Depot.





Important Safety Information and Indication

- XERMELO may cause constipation which can be serious. You should stop taking XERMELO if severe constipation or severe, persistent, or worsening abdominal pain develops. Talk to your doctor if you have these symptoms.
- The most common side effects of XERMELO include nausea, headache, increase in liver enzymes, depression, ٠ flatulence, decreased appetite, swelling of your hands and feet fever, abdominal pain, and constipation
- Talk to your doctor about all medications you are taking as some may interact with XERMELO ٠
- XERMELO is not recommended if you have moderate or severe liver impairment

Indication

XERMELO is a prescription pill, used along with somatostatin analog (SSA) therapy, for Carcinoid Syndrome diarrhea in adults who are not adequately controlled by SSA therapy.

We're Here to Help



Did you know TerSera Therapeutics has a personalized nursing support Program?

Do you have questions about Carcinoid Syndrome Diarrhea?

TerSera's Nursing Support Program connects patients who have carcinoid syndrome diarrhea (CSD) to a dedicated, consistent Clinical Nurse Educator (CNE) who specializes in Neuroendocrine tumors and CSD.

Your CNE will provide you disease and nutrition education. Learn about the relationship between your diet and CSD, understand the role of hormones, including serotonin, and receive guidance for finding CSD friendly foods (you'll receive a FREE book on Nutrition).

In addition, your CNE will provide you help to ensure your nurses, physicians and specialty pharmacists are kept up to date on your progress while on treatment.

Get the most out of your treatment with TerSera's personalized nurse support program. Sign up now for ongoing nursing support.

Call, visit or scan to get started.

www.theNETnurse.com

844-344-4035



Please see the Xermelo Full Prescribing Information

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Understanding Pheochromocytoma and Paraganglioma

Pheochromocytoma (pheo) and paraganglioma (para) are rare neuroendocrine tumors that can dramatically impact survival in people of all ages.¹



Every year in the US,
fewer than 9 out of a
million people are diagnosed
with pheo or para.²

However, the disease is likely **underdiagnosed**.¹

As many as **130,000 people** are living with the disease in the US.^{1,3}

There are over **100 different signs and symptoms**

associated with pheo and para.4

Common symptoms^{5,6}:

- High blood pressure
- 2 Palpitations
- 3 Headaches
- 4 Excessive sweating
- 5 Pain in the chest and abdomen

- 6 Uncontrollable shaking
- 7 Anxiety and panic attacks
- 8 Weakness and fatigue
- 9 Nausea and vomiting
- 10 Paleness



Pheo and para tumors produce "fight or flight"

"fight or flight" hormones, which can overwhelm the nervous system and cause the spontaneous onset of multiple symptoms.⁵ These

"pheo attacks" can be sudden, intense, and debilitating.¹

If pheo and para tumors are not diagnosed and appropriately treated, **the disease will likely be fatal.**⁷

For people with advanced* disease:

Survival beyond 5 years can be **as low as**



*Advanced refers to unresectable, locally advanced, or metastatic disease.



Up to 30% of deaths are the result of symptoms caused by tumor-produced hormones.⁹



Progenics Pharmaceuticals, Inc., a Lantheus company, is committed to advancing the fight against pheochromocytoma and paraganglioma.

To learn more about Lantheus, visit Lantheus.com.

To learn more about pheo and para, talk to your doctor or visit KnowPheoPara.health.

References: 1. Martucci VL, Pacak K. Curr Probl Cancer. 2014;38(1):7-41. 2. Almeida MQ, et al. Clinics. 2018;73:e756s. 3. US Census Bureau. US and World Population Clock. https://www.census.gov/popclock/. Accessed October 1, 2017. 4. Phan A. Case-Based Discussion-Systemic Therapies for Advanced PHED and PGL. In: European Society for Medical Oncology (ESMO) Congress 2014; September 26-30, 2014; Madrid, Spain. 5. Gunawardane PTK, Grossman A. Adv Exp Med Biol. 2017;956:239-259. 6. Pacak K. J Clin Endocrinol Metab. 2007;92(11):4069-4079. 7. Kantorovich V, Eisenhofer G, Pacak K. Ann N Y Acad Sci. 2009;1148:462-468. 8. Park J, et al. Korean J Urol. 2011;52:241-246. 9. Baudin E, et al. Eur J Endocrinol. 2014;171(3):R111-R1122.

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NEUROENDOCRINE TUMORS

ABOUT CRINETICS

Crinetics is a pharmaceutical company that develops much-needed therapies for people with rare endocrine diseases, which impact thousands of patients' lives, and those of their families. We have an opportunity to improve things for these people. Our seasoned team has extensive experience in drug discovery and development in endocrine targets, and we've built a highly productive drug discovery organization.

To learn more about our team and our mission, visit our website at www.crinetics.com

OUR PALTUSOTINE PIPELINE

Neuroendocrine tumors, or **NETs**, originate from the neuroendocrine cells commonly found in the gut, lung, or pancreas. NETs all share similar characteristics but may behave differently, comprising a spectrum of insidious, growing tumors to aggressive, quick-growing tumors. NETs are the **second most common GI cancer** after colon cancer. 171,000 adults have NETs.

Paltusotine, our leading drug candidate for the treatment of acromegaly, is also being developed for the treatment of NETs with associated carcinoid syndrome.

Paltusotine (oral SST2 agonist)	DISCOVERY	PRE-CLINICAL	PHASE 1	PHASE 2	PHASE 3
ACROMEGALY					
NETs, CARCINOID SYND	ROME				

If you have been diagnosed with NETs with carcinoid syndrome, we would like to speak with you. Your insights will help up further develop our paltusotine program to better serve patients just like you. Compensation is provided for your time to complete surveys and interviews. If you would like to learn more or participate, please scan the provided QR code or email us at patientinsights@crinetics.com.



SCAN THE QR CODE TO LEARN MORE

HUTCHMED Clinical Trials in Neuroendocrine Tumors (NET)



HUTCHMED MISSION:

HUTCHMED is an innovative, commercial-stage biopharmaceutical company committed to the discovery and global development of targeted therapies and immunotherapies for the treatment of cancer and immunological diseases.

HUTCHMED has clinical trials open and enrolling for people with neuroendocrine tumors in the US, Europe, Japan and China.



5 Global Clinical Trials Currently Enrolling for people with NET

If you would like more information on HUTCHMED-sponsored clinical trials in NET, please discuss with your healthcare team. Thank you for attending the 2021 KNOW YOUR NETs Virtual Patient and Caregiver Conference. We would like to gratefully acknowledge all of our speakers for their presentations, all panelists for their insight, and all volunteers for their knowledge and help to make this conference a reality.

Educational Support

Thank you to the following sponsors for their generous support:





Find videos of this patient and caregiver education conference and others like it at:



Connect with us and other patients, caregivers, and family members online:



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