

Know Your

NETS

2023

Virtual Education
Conference

Saturday, July 22, 2023
11am–4pm ET

Presented by:



NEUROENDOCRINE TUMOR
RESEARCH FOUNDATION

DEDICATED TO CURING NEUROENDOCRINE CANCER



AT THE FOREFRONT

UChicago Medicine

Comprehensive Cancer Center

TABLE OF CONTENTS

Scroll or click on text or logos below to navigate to sections of the booklet. To return to the Table of Contents, click the round red TOC button at the end of each section. For optimal interactive performance, view this document in Read Mode.



NOTE TO ATTENDEES

This patient and caregiver education conference is not intended as and shall not be relied upon as medical advice. The Neuroendocrine Tumor Research Foundation encourages all users to discuss any information found here with their oncologist, physician, and/or appropriate qualified health professional.

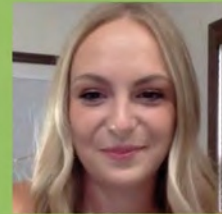
Attending this conference does not constitute a patient-physician relationship. The Neuroendocrine Tumor Research Foundation does not represent that any information provided here should supplant the reasoned, informed advice of a patient's oncologist, physician, or appropriate qualified health professional.

Thank you to our participants in the NET Thrivership Questions during today's conference. We are thankful for your voice and your perspective and sharing it with others.

Do you have a NET story to share? Please email us at info@netrf.org



Merlynn
Densley



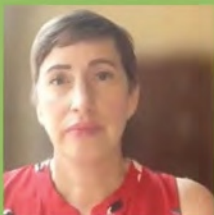
Hannah
Folkerts



Carrie
Camino



Arlesia
Taylor-Whitaker



Kelly
Baugham



Mario
Medina

WELCOME

Welcome to the 2023 KNOW YOUR NETs Virtual Patient and Caregiver Education Conference. It's our honor to be co-chairs for this event again this year. This is our fourth KNOW YOUR NETs Virtual Conference and we are proud of the series' popularity.

Thank you for helping us to shape the agenda for this year's KNOW YOUR NETs Conference. Based on what you told us you wanted to learn, we have assembled a group of outstanding speakers—all experts in their fields who have graciously given their time to participate in this program. You'll also hear from patients about their NET journeys and their advice about how to thrive.

You can submit your questions for our panel through SLIDO.com, using the event code NETRF. See the instructions for SLIDO in this booklet.

NETRF is grateful for all of our conference sponsors who have helped make this event possible. Please take a moment to review the educational content from our sponsors in this booklet. If you are looking for more information, check out NETRF's NET Knowledge Center.

Thank you for joining us today, supporting NETRF and most importantly, being an active and engaged participant to help us increase awareness of NETs. Your story matters and you are not alone. Together, we are committed to meeting the educational needs of those with neuroendocrine cancer and their families.



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



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

AGENDA

Watch for our Thrivership segments throughout today's program.

The Preconference Video, NETs 101 with Thor Halfdanarson, MD, Mayo Clinic is available to view at <https://www.youtube.com/c/NETRF>

Program times are Eastern Daylight Time.

START	TITLE	PRESENTER
11:00 AM	CONFERENCE WELCOME AND OPENING REMARKS	
11:06 AM	SURGICAL TREATMENT FOR PRIMARY TUMORS AND LIVER METASTASES	Xavier Keutgen, MD, FACS University of Chicago Medicine
11:24 AM	INTERVENTIONAL RADIOLOGY TREATMENTS FOR PRIMARY TUMORS AND LIVER METASTASES	Osmanuddin Ahmed, MD University of Chicago Medicine
11:40 AM	MEDICAL ONCOLOGY TREATMENTS FOR PRIMARY TUMORS AND LIVER METASTASES	Chih-Yi (Andy) Liao, MD University of Chicago Medicine
11:57 AM	WHAT'S NEW IN IMAGING: COPPER 64 DOTATATE VS. GA-DOTATOC PET/CT	Courtney Lawhn Heath, MD University of California, San Francisco
12:12 PM	WHAT'S NEW IN PRRT	Richard Baum, MD, THERANOSTICUM Frankfurt-Wiesbaden
12:28 PM	WHAT'S NEW IN CLINICAL TRIALS	Jaydira Del Rivero, MD National Cancer Institute
12:45 PM	WHAT'S NEW IN BASIC AND TRANSLATIONAL RESEARCH	Dawn Quelle, PhD University of Iowa and NETRF Co-Chair, Board of Scientific Advisors
1:07 PM	FINDING A NET SPECIALIST & MANAGING SECOND OPINIONS	Heloisa Soares, MD University of Utah
1:28 PM	TALKING WITH YOUR DOCTOR	Josh Mailman, MBA President, NorCal CarciNET and Member of the NETRF Board of Directors
1:42 PM	TREATMENT SEQUENCING TUMOR BOARD	Xavier Keutgen, MD University of Chicago Medicine Thor Halfdanarson, MD Mayo Clinic Courtney Lawhn Heath, MD University of California, San Francisco Heloisa Soares, MD University of Utah Osmanuddin Ahmed, MD University of Chicago Medicine Chih-Yi (Andy) Liao, MD University of Chicago Medicine
2:33 PM	MANAGING STRESS, FATIGUE MANAGEMENT AND EMOTIONAL WELLNESS	Jessica S. Thomas, LCSW NETRF
2:45 PM	SYMPTOM MANAGEMENT	David Metz, MD Retired, The University of Pennsylvania
3:08 PM	NUTRITION AND COOKING DEMO	Mark Allison, MBA Corporate Executive Chef at Forever Oceans, Former NET Caregiver
3:30 PM	LIVE QUESTION AND ANSWER SESSION	Introduced and Moderated by Dr. Keutgen & Dr. Halfdanarson



BECOME INFORMED, ENGAGED AND CONNECTED IN YOUR NET JOURNEY

Current and accurate patient education and information is vital to helping you live well with NETs, and we know that finding credible information and education can be challenging and difficult to navigate.

NETRF's NET Knowledge Center is a comprehensive resource organized to direct you to the information you need to be engaged in your NET journey while connecting you to a community of resources.

INFORMATION

Learn more about NETs

A NET diagnosis often comes with lots of questions and concerns. These resources explain the different kinds of NETs, diagnostic testing, and risks so you and your family can better understand your condition.

ENGAGEMENT

Take the next step regarding your NET diagnosis

With many different kinds of NETs, it's important to find to the best possible care and treatment. These resources explore finding specialists, NET treatments, and how to best care for yourself.

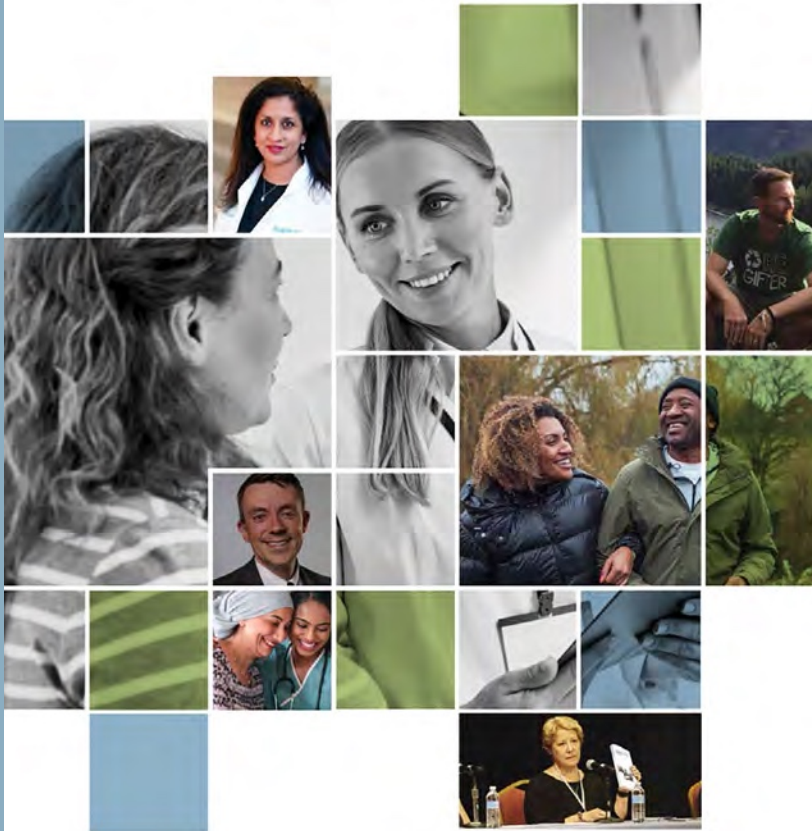
COMMUNITY

Connect with more people and resources about NETs

When it comes to NETs, it takes a community. Explore the many ways you can find out the latest about NET care and research and what's happening in the NET community.



Visit the Knowledge Center, netrf.org/for-patients or scan the QR Code.



NEUROENDOCRINE CANCER

A guide for patients and families

NETRF's free
Neuroendocrine
Cancer Guide for
Patients and Families
is available as a PDF
(via email) or mailed
(US & Canada only).

Our updated 2022
edition includes 16
additional pages
of information and
graphics to help
patients and families
understand
neuroendocrine
cancer.

To order your copy visit,
netrf.org/for-patients/ or
scan the QR code here:



Ask Questions Online through Slido!

OPTION 1

1. 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.

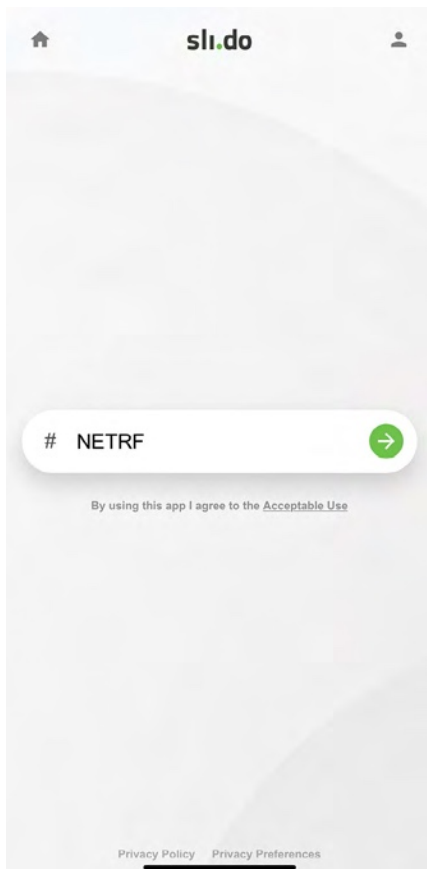
OPTION 2

1. Click [this link](#) to automatically go to the Questions page.

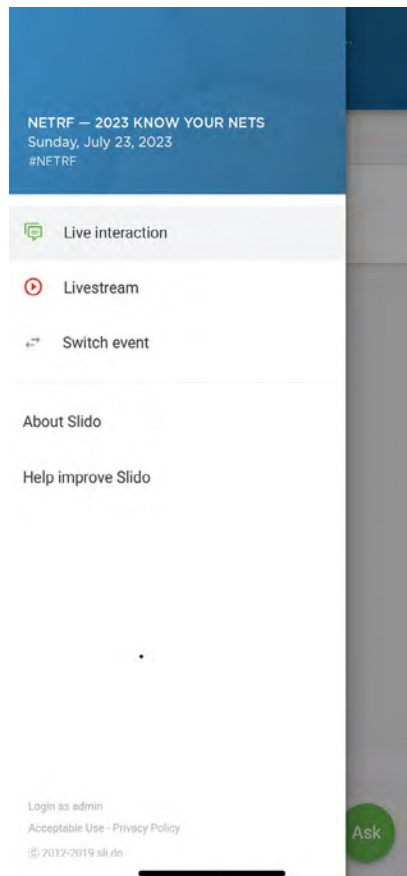
DO NOT use your name. Please ask anonymously or use your initials.

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.

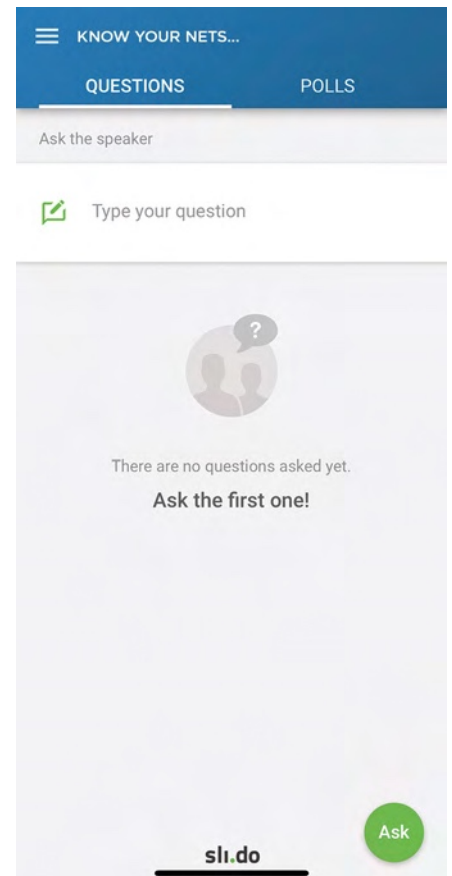
Screen 1

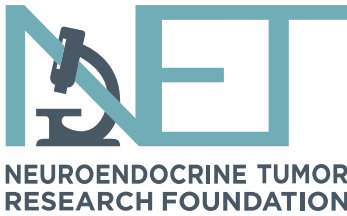


Screen 2



Screen 3





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.

5
Average number of
years from onset of
symptoms to diagnosis.



Funded
research in
15 countries +
17 U.S. states



\$36
million in
funded
research



129
grants awarded
137
investigators
funded



150+
published
research
manuscripts



\$0.82
of each \$1.00
supported
research and
education in 2022

SPEAKER BIOGRAPHIES



Osmanuddin Ahmed, MD
University of Chicago Medicine

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.



Mark Allison, MBA
Corporate Executive Chef, Forever Oceans

Chef Mark William Allison is a native of England who has worked around the world in culinary arts for over 40 years. From authoring multiple books like “150 Projects to Get You into Culinary Arts” to appearing on TV Cooking Channels’ “Cooking School Confidential”, and PBS’s “Overdraft”, Mark is an influential leader in the cooking industry. In 2008 Mark’s wife was diagnosed with NET cancer and passed away March 19, 2015, nearly eight years after being diagnosed with neuroendocrine cancer. Mark is a loving father of three boys.



Richard Baum, MD, PhD
THERANOSTICUM

Dr. Baum is Chairman and Clinical Director of THERANOSTICS Center for Molecular Radiotherapy and Precision Oncology, ENETS Center of Excellence and Professor of Nuclear Medicine, Johann Wolfgang Goethe University of Frankfurt/Main, Germany. A trailblazer in the modern era of paired diagnostic and therapeutic radionuclides, Dr. Baum embodies the full spectrum of theranostics, having led highly impactful projects in diagnostic imaging, quantitative dosimetry, image-guided treatment planning, adaptive therapy and of course novel therapeutics. In his leadership role in the World Association of Radionuclide and Molecular Therapy, he has made major intellectual contributions-most recently advocating for and demonstrating the utility of personalized dosimetry to guide RPT. In addition, Dr. Baum is also responsible for a number of important firsts, including the first radioimmunotherapy performed in Germany (1985), the first peptide receptor therapy in Germany (1997) and the first ¹⁷⁷Lu-based PSMA radioligand therapy in the world (2013).



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.



Thor Halfdanarson, MD

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 and cancers of unknown primary, serves as the Associate Medical Director of the Cancer Clinical Trials Office at the Mayo Clinic Comprehensive Cancer Center and is the co-chair of the Pancreatic/Neuroendocrine Tumor Board. Dr. Halfdanarson is a member of the NCCN guidelines panel for NETs, the Co-Chair of the NET Group at Alliance for Clinical Trials in Oncology and the current Vice President of NANETS.



Xavier Keutgen, MD, FACS

University of Chicago Medicine

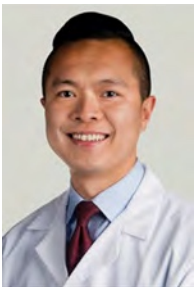
Dr. Keutgen is an Associate Professor of Surgery and a surgical oncologist with particular expertise in treating neuroendocrine, thyroid, parathyroid and adrenal tumors. He is the director of the University of Chicago Neuroendocrine Tumor Center and works closely with a multidisciplinary team that specializes 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).



Courtney Lawhn Heath, MD

University of California, San Francisco

Dr. Courtney Lawhn Heath is an Assistant Professor of Molecular Imaging and Therapeutics in the Department of Radiology and Biomedical Imaging at the University of California San Francisco (UCSF), where she leads their peptide receptor radionuclide therapy (PRRT) program. She also serves as a member of the Scientific Review Board for the North American Neuroendocrine Tumor Society (NANETS), and is an elected Board member of the PET Center of Excellence in the Society of Nuclear Medicine and Molecular Imaging (SNMMI). Her research interests include somatostatin receptor targeted PET and targeted radiopharmaceutical therapy.



Chih-Yi (Andy) Liao, MD

University of Chicago Medicine

Dr. Liao is an Assistant Professor of Medicine at University of Chicago. 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 Associate Director of University of Chicago's Gastrointestinal Oncology Program and the Co-Director of the Neuroendocrine Tumor Program.



Josh Mailman, MBA
Patient Advocate and President, NorCal CarciNET Community

Diagnosed with a pancreatic NET in 2007, Josh is an internationally recognized advocate for NET patients and integrative oncology, nuclear medicine, and molecular imaging. He is the inaugural chair of the Society of Nuclear Medicine and Molecular Imaging's Patient Advocacy Advisory Board, Board Member and Treasurer of the Neuroendocrine Tumor Research Foundation, a member of The Education and Research Foundation for Nuclear Medicine and Molecular Imaging Board, and president of NorCal CarciNET Community, one of the largest NET patient communities in the United States. He is currently the sole patient rights advocate for the Nuclear Regulatory Commission's Advisory Committee for the Medical Use of Isotopes, is a member of the National Cancer Institute's GI Steering Committee, and serves as co-chair of the Patient Advocate Steering Committee. In 2015, Josh was honored with the Warner Advocacy Award, given annually by Novartis Oncology Patient Advocacy and The NET Alliance, as well as the SNMMI's President's Award for his work on behalf of patients in the nuclear medicine field.



David C. Metz, MD

Dr. Metz is a retired Professor of Medicine and past Associate Chief for Clinical Affairs in the Division of Gastroenterology at the University of Pennsylvania in Philadelphia, where he previously directed the Acid-Peptic Disease Program and codirected the GI Physiology Laboratory, the Swallowing Disorders Program and the multidisciplinary Neuroendocrine Tumor Program. He was actively involved in clinical research, serving as a principal investigator on a number of trials evaluating upper gastrointestinal disease states. He remains active in national gastroenterology societies and is a past president of the North American Neuroendocrine Tumor Society (NANETS), from which he received a lifetime achievement award in 2021.



Dawn Quelle, PhD
University of Iowa

Dr. Quelle is a Professor of Neuroscience & Pharmacology and Pathology at the University of Iowa Carver College of Medicine. She joined the faculty at the University of Iowa in 1997 and has led the Cancer Genes and Pathways Program in the Holden Comprehensive Cancer Center since 2009. Her laboratory studies druggable mechanisms of tumor pathogenesis with a focus on neuroendocrine tumors (NETs) and malignant peripheral nerve sheath tumors (MPNSTs). Her investigations are highly collaborative and benefit from the input of both basic and clinical scientists. Her research is funded by several multi-PI grants from the NIH to explore the role of an oncogenic GTPase, named RABL6A, in NETs and MPNSTs. Her findings have identified novel combination therapies that effectively suppress both cancer types in preclinical tumor models, and excitingly, sensitize tumors to immunotherapy. Dr. Quelle's team is working with clinical colleagues to translate those discoveries into new treatment options for MPNST and NET patients.



Jessica Thomas, LCSW
NETRF Director of Patient Education

Jessica brings more than 19 years of experience as a clinical social worker specializing in helping patients and caregivers within the areas of neurology, oncology and chronic illness. Most of her professional experience is as a mental health provider in the chronic illness field helping patients navigate the emotional aspects of physical disease. Jessica was diagnosed with a chronic disease in her mid twenties. This influenced her professional passion to empower patients and caregivers to explore, find and embrace their definition of "what matters most" while living with a chronic, progressive or terminal illness. She cares greatly about community, patient-centered care, research, patient experience and outcomes. In 2022, Jessica joined the NETRF team as the Director of Patient Education.



NETwise

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.

If you're interested in participating in one of our upcoming NETwise podcasts as a patient, caregiver or clinician, please email

info@netrf.org.

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



netrf.org/podcast



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

KNOW YOUR NETS GLOSSARY



I A B C D E F G H I J K L M
N O P Q R S T U V W X Y 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.

B

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.

C

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.

D

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 dietitian 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.

E

Echocardiogram

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

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.

G

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.

H

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.

Ileum

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).

K

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).

L

Linear accelerator

A machine that uses electricity to form a stream of fast-moving 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.

M

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).

N

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.

O

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 long-term 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.

S

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.

T

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.

V

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.

X

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.

Z

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.

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FOREVER OCEANS HEALTHY RECIPES

Forever Oceans™ Kanpachi, Jicama, Thai Red Chili, Lime, & Mint Salad.

Serves 4

Ingredients:

- 4 6oz. portions of Forever Oceans™ Kanpachi fillet (or your favorite piece of fish)
- Sea salt
- Freshly ground black pepper
- 2 tablespoons olive oil

Salad

- 1 large ripe mango, peeled, pitted, and cut in thin matchsticks
- 1 small to medium jicama, peeled and cut into quarter inch thick rounds then into matchsticks
- ¼ red onion, peeled and thinly sliced
- 1 lime, juice of
- Pinch sea salt
- 1 tablespoon extra-virgin olive oil
- 1 tablespoon local honey
- 1 pear, cored and cut into matchsticks
- 1 tablespoon fresh mint, chopped
- 1 tablespoon fresh cilantro, chopped
- 1 small to medium Thai red chili, deseeded and flesh minced. (optional)

For the Salad: Take a large bowl and add the first 7 ingredients. Lightly toss together, and cover with plastic. Place in the refrigerator to infuse the flavor for 1 hour.

For the Forever Oceans™ Kanpachi: Season the Forever Oceans™ Kanpachi (or your favorite piece of fish) lightly with salt and pepper, place a medium size frying pan on the stove over a medium to high heat, and add the oil. Carefully place each piece of fish skin side down into the hot pan. Cook for 2 to 3 minutes, then turn over, allow to cook a further 2 to 3 minutes or until cooked to your liking.

To Serve: Remove the bowl from the fridge, take off the plastic, and add the remaining ingredients. Lightly toss again to coat and serve with the pan fried Kanpachi. Enjoy!

Easy Peasy Carrot Soup

Serves 4

Ingredients:

- 1 ½ to 2lb pound carrots, washed, roughly chopped (depends on how thick you like your soup)
- 1 yellow onion, peeled and roughly chopped
- 2 cloves of garlic, peeled and crushed
- Sea salt and freshly ground black pepper
- 4 cups low-sodium vegetable stock
- 1 can unsweetened lite coconut milk (full fat if you prefer)
- 2 tablespoons Thai-style chili sauce (optional)

Place the carrots, onion and garlic into a medium size saucepan, season with salt and pepper, then pour in the stock. Place on the stove over a medium heat, bring to a boil then turn down to a simmer, cook for 15 minutes, stirring occasionally, until the vegetables are tender, and then carefully pour into a blender along with the coconut milk and chili sauce. Blend until smooth, pour back into the pan and reheat, taste and season (if needed), serve. Serve hot or cold.

These recipes are shared in honor of Chef Mark Allison's wife, Alison Davies, who passed away from neuroendocrine cancer in 2015.

Please visit links for more recipes:

www.chefmarkallison.com www.foreveroceans.com



Neuroendocrine Tumor Program



AT THE FOREFRONT

UChicago Medicine

Comprehensive Cancer Center

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.

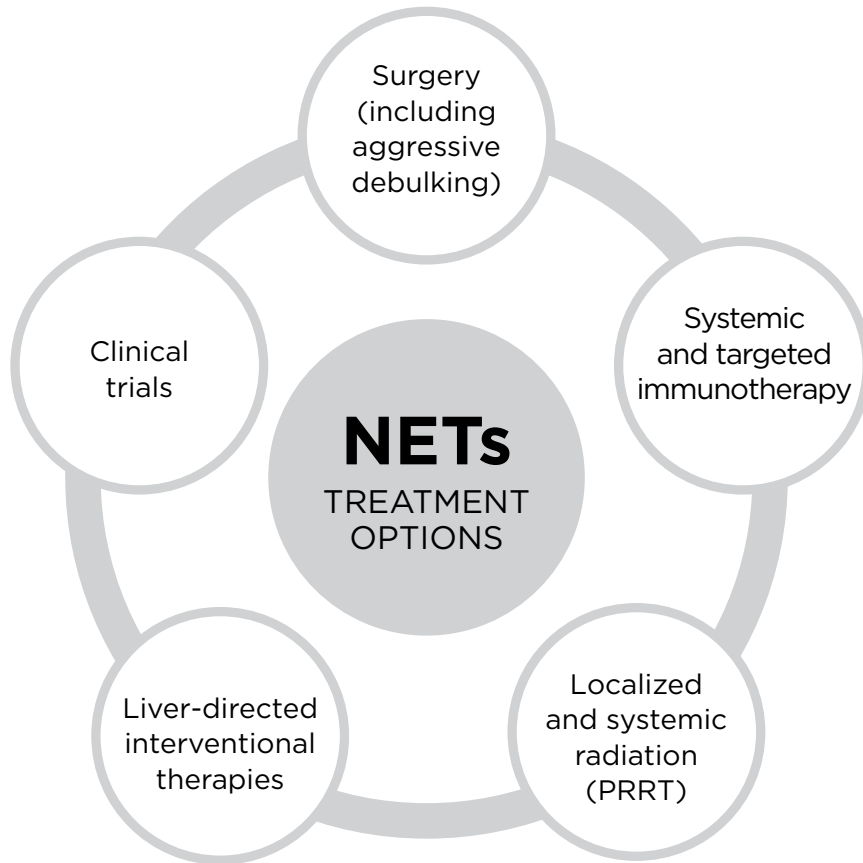
- The most advanced surgical techniques, including minimally invasive/robotic procedures and complex approaches to remove and destroy NETs that have spread to the liver.



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

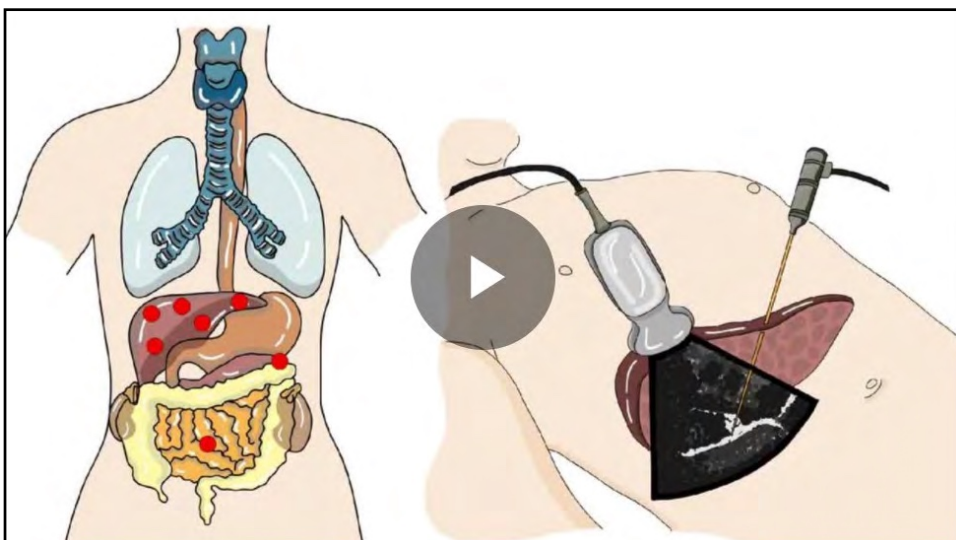
- Leading-edge technologies like precision-enhancing navigation-controlled ablation of liver tumors and Peptide Receptor Radionuclide Therapy (PRRT), a systemic, targeted approach that delivers radiation to NET cells without damaging other organs.
- The only medical cyclotron in the region for creating 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.

We offer a large spectrum of treatment options for our Neuroendocrine Tumors patients.



Understanding Neuroendocrine Tumors

Visit UChicagoMedicine.org/NETs to watch video



Research areas of focus and impact



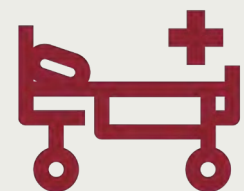
Population research



Translational research



Cancer genetics and immunotherapy



New treatments, early phase clinical trials

 **AT THE FOREFRONT**
UChicago Medicine
Comprehensive Cancer Center

Recognized as an NCI Designated Comprehensive Cancer Center



An official cancer center designation by the [National Cancer Institute \(NCI\)](#) 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. UChicago Medicine has had this prestigious designation for nearly 50 years.

In addition to this NCI 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



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



Blase Polite, MD
*Hematology and
Oncology (Cancer)*



Daniel Appelbaum, MD
Nuclear Medicine



Osmanuddin Ahmed, MD
*Vascular and
Interventional
Radiology*



Namrata Setia, MD
Pathology

Get a Second Opinion

Seeking the opinion of an expert can ease your mind and help you feel more secure in the decisions you are making. At UChicago Medicine, we offer both on-site and remote second opinions. In addition to recommending standard therapies, our physicians may also offer innovative treatment options not widely available at most hospitals, including clinical trials that may be right for you.

**To learn more, call
1-855-702-8222
or visit
UChicagoMedicine.org/cancer-appointment.**



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

**To make an appointment, call 800-824-0200
or email NETS@uchospitals.edu**

NOW ENROLLING

CRN00808-11

Phase 2 Investigational Once-Daily Oral Study Drug for Patients with Carcinoid Syndrome associated with Neuroendocrine Tumors (NETs)

About the study

Study centers are enrolling participants for a Phase 2 clinical study evaluating the safety and potential effects of paltusotine, an investigational once-daily oral drug for patients with carcinoid syndrome associated with NETs. Paltusotine is an investigational drug which means that it has not been approved by any regulatory authority.

What will **The Study** involve?

- ✓ This study includes a Screening Period and a Treatment Period. The Screening Period is from 2 to 12 weeks.
- ✓ There is an 8-week Treatment Period with an optional 50-week extension.
- ✓ You will take the study drug once a day, by mouth, each morning. All participants will receive paltusotine in place of their current treatment.
- ✓ You will be asked to complete a daily electronic symptom diary (eDiary) provided by your study doctor.
- ✓ Qualified participants may receive the study drug and study-related care at no cost.

Who may qualify?

18+ years old

Confirmed NETs and carcinoid syndrome

Currently treated with octreotide or lanreotide **OR** not treated with octreotide or lanreotide and with active symptoms

Other eligibility criteria will apply.

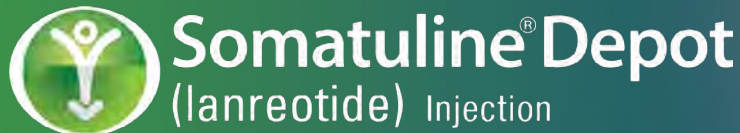


IPSENCARES®

Coverage, Access, Reimbursement & Education Support

Medication Support Nurse Program

A resource for patients prescribed Somatuline Depot and enrolled in IPSEN CARES



Individualized Support Services Provided by an IPSEN CARES Nurse Include:

- Disease state and therapy education, consistent with the US Prescribing Information
- Injection Experience
- Coordination of Nurse Home Health Administration services and HCP injection training, if appropriate
- Identification of potential gaps in care

The **Medication Support Nurses** are available from **M-F, 8 am - 8 pm ET.**

Medication Support Nurses are provided by Ipsen and do not work under the direction of the patient's healthcare provider or give medical advice. They are trained to direct patients to their provider for treatment-related advice, including further referrals.

What is SOMATULINE® DEPOT (lanreotide) Injection?

SOMATULINE DEPOT is a prescription medicine used in adults for:

- the long-term treatment of patients with acromegaly who have had an inadequate response to surgery and/or radiation, or for whom surgery and/or radiotherapy is not an option; the goal to treatment in acromegaly is to reduce growth hormone (GH) and insulin growth factor-1 (IGF-1) levels to normal;
- the treatment of a type of cancer known as neuroendocrine tumors, from the gastrointestinal tract or the pancreas (GEP-NETs) that has spread or cannot be removed by surgery; and
- the treatment of carcinoid syndrome to reduce the need for the use of short-acting somatostatin medicine.

It is not known if SOMATULINE DEPOT is safe and effective in children.

IMPORTANT SAFETY INFORMATION

Do not take SOMATULINE DEPOT if you are allergic to lanreotide.

SOMATULINE DEPOT may cause serious side effects, including:

- Gallstones
- Changes to your blood sugar (high or low blood sugar),
- Slow heart rate, and
- High blood pressure

Please see additional Important Safety Information throughout and accompanying full Prescribing Information and Patient Information.

IMPORTANT SAFETY INFORMATION (Continued)

Tell your healthcare provider (HCP) if you have any of the following symptoms:

- **Symptoms of gallstones** may include sudden pain in your upper right stomach area (abdomen), sudden pain in your right shoulder or between your shoulder blades, yellowing of your skin and whites of your eyes, fever with chills, and nausea.
- **Symptoms of high blood sugar** may include increased thirst, increased appetite, nausea, weakness or tiredness, urinating more than normal, and fruity smelling breath.
- **Symptoms of low blood sugar** may include dizziness or lightheadedness, sweating, confusion, headache, blurred vision, slurred speech, shakiness, fast heartbeat, irritability or mood changes, and hunger.
- **Symptoms of slow heart rate** may include dizziness or lightheadedness, fainting or near-fainting, chest pain, shortness of breath, confusion or memory problems, and weakness or extreme tiredness.

The most common side effects of SOMATULINE DEPOT in people with:

- **Acromegaly:** diarrhea, cholelithiasis, abdominal pain, nausea, injection-site reactions, constipation, flatulence, vomiting, arthralgia, headache, and loose stools
- **GEP-NETs:** stomach area (abdominal) pain; muscle and joint aches; vomiting; headache; pain, itching or a lump at the injection site
- **Carcinoid syndrome:** headache, dizziness, muscle spasm; side effects were generally similar to those commonly seen with GEP-NETs

SOMATULINE DEPOT may cause dizziness. If this happens, do not drive a car or operate machinery.

Tell your HCP right away if you have signs of an allergic reaction after receiving SOMATULINE DEPOT, including swelling of your face, lips or tongue; breathing problems; fainting, dizziness or feeling lightheaded (low blood pressure); itching; skin flushing or redness; rash; or hives.

Before taking SOMATULINE DEPOT, tell your HCP about all your medical conditions including if you:

have diabetes; have gallbladder, heart, thyroid, kidney or liver problems; are pregnant or plan to become pregnant; or are breastfeeding or plan to breastfeed. It is not known if SOMATULINE DEPOT will harm your unborn baby or pass into breast milk. You should not breastfeed if you receive SOMATULINE DEPOT and for 6 months after your last dose. SOMATULINE DEPOT may affect your ability to become pregnant.

Tell your HCP about all the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements. SOMATULINE DEPOT and other medicines may affect each other, causing side effects. SOMATULINE DEPOT may affect the way other medicines work, and other medicines may affect how SOMATULINE DEPOT works. Your dose of SOMATULINE DEPOT or your other medications may need to be changed. If you have diabetes, your HCP may change your dose of diabetes medication when you first start receiving SOMATULINE DEPOT or if your dose of SOMATULINE DEPOT is changed.

Especially tell your HCP if you take:

- Insulin or other diabetes medicines,
- A cyclosporine (Gengraf, Neoral, or Sandimmune), or
- Medicines that lower your heart rate, such as beta blockers.

Know the medicines you take. Keep a list of them to show your HCP when you get a new medicine.

Tell your HCP if you have any side effect that bothers you or that does not go away. These are not all the possible side effects of SOMATULINE DEPOT. For more information, ask your HCP.

To report SUSPECTED ADVERSE REACTIONS, contact Ipsen Biopharmaceuticals, Inc. at 1-855-463-5127 or FDA at 1-800-FDA-1088 or www.fda.gov/medwatch.

SCAN HERE >
to visit www.ipsencares.com
to learn more about the **IPSEN CARES**
Program and enrollment options



Please see additional Important Safety Information throughout and accompanying full Prescribing Information and Patient Information.

THE ACTION-1 STUDY

A clinical research study for adults with well-differentiated gastroenteropancreatic neuroendocrine tumors (GEP-NETs) that have progressed following treatment with ^{177}Lu -SSA therapy

NOW ENROLLING PARTICIPANTS

What is the ACTION-1 Study?

The **ACTION-1** Study is a 2-part, Phase 1b/3 clinical research study for adults with inoperable, advanced, somatostatin receptor expressing (SSTR+), well-differentiated GEP-NETs that have progressed following prior ^{177}Lu -labelled somatostatin analogue (^{177}Lu -SSA) therapy.

Part 2 (Phase 3) will evaluate the safety and efficacy of the investigational drug, RYZ101, compared with investigator-selected standard of care (SoC) therapy.

“Investigational” means the study drug has not been approved by regulatory authorities like the US Food and Drug Administration (FDA) and can only be used for research purposes.

Initially, 18 participants across 8 study centers in the USA joined Part 1 of the ACTION-1 Study. Part 1 enrollment is now complete. Approximately 80 study centers worldwide will join Part 2 of **ACTION-1**.



How long will the ACTION-1 Study last?

The estimated duration of the entire study including follow-up will be approximately 7 years.

After a 4-week screening period, the study treatment period is expected to last for 32 weeks for the RYZ101 arm or 25 weeks for the Standard of Care (SoC) arm. Follow-up visits will be scheduled every month for 3 months after the final infusion of RYZ101 or week 25 for participants randomized to SoC, then every 3 months for 12 months, and switching to every 6 months thereafter for approximately five years.

Travel and accommodation expenses for study visits may be reimbursed for participants.



For participating locations, please visit [ClinicalTrials.gov](https://clinicaltrials.gov) (NCT05477576) or email RayzeBio at clinicaltrials@rayzebio.com.

Who can participate?

- Aged 18 years or older
- Histologically-proven low grade (Grade 1-2), well-differentiated, inoperable, advanced GEP-NETs
- Progressive GEP-NET (gastrointestinal or pancreas) following 2–4 cycles of ^{177}Lu -DOTATATE, ^{177}Lu -DOTATOC or ^{177}Lu -HA-DOTATATE (premature treatment discontinuation should not have been due to progressive disease)
- No prior radioembolization



For participating locations, please visit ClinicalTrials.gov (NCT05477576) or email RayzeBio at clinicaltrials@rayzebio.com.

LEARN MORE ABOUT US AND RYZ101

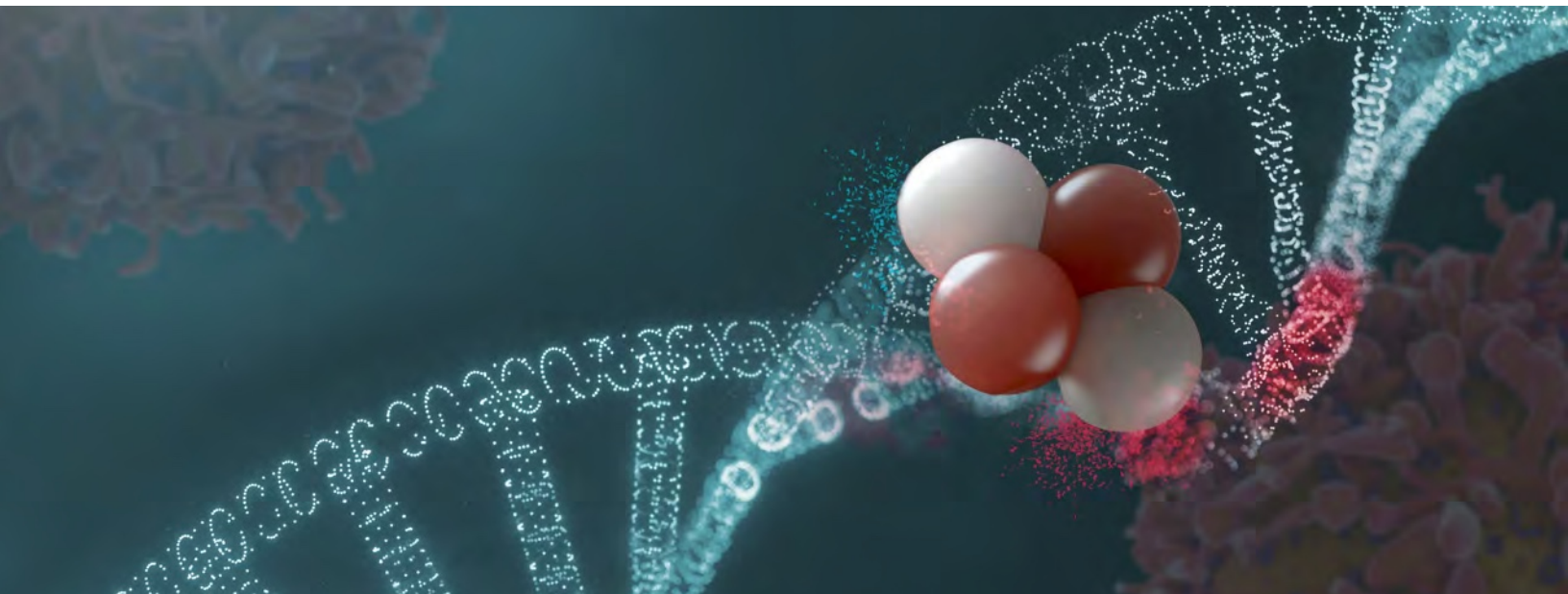
What is RYZ101?

RYZ101 is an investigational, targeted, alpha particle-emitting radiolabeled somatostatin analog, designed to deliver **Actinium-225 (Ac-225)** to tumors overexpressing SSTR. **Ac-225** is a highly potent alpha particle-emitting radioisotope. Alpha particles deliver more energy but stop after a distance of a few microns making them more cytotoxic to tumor cells and less damaging than beta particle emitters to healthy cells.

About RayzeBio



RayzeBio is a biotechnology company focused on improving outcomes for people with cancer by harnessing the power of targeted radioisotopes. With a focus on clinically validated solid tumor targets, RayzeBio is developing novel drug conjugates to deliver potent therapeutic radioisotopes such as **Actinium-225**, an alpha-emitter.





If your carcinoid syndrome diarrhea relief stalls,

**IT'S TIME
FOR XERMELO**

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.

Please click for [Full Prescribing Information](#).

Get support as you start XERMELO

TerSera NurseSupport is here to support you and provide recommendations to help you live your best life with CSD. Your nurse can serve as a resource for:



Starting XERMELO



Nutrition education



Advocacy connections



CSD education

Once you register, your nurse will **connect with you via phone**. In addition, TerSera NurseSupport participants can receive a nutrition and recipe guide designed to offer carcinoid syndrome-friendly food options.



Enroll in TerSera NurseSupport today!

Scan the **QR code** or visit [TheNetNurse.com](https://www.thenetnurse.com).

Important Safety Information

- Do not take XERMELO if you have a history of hypersensitivity to telotristat or any of the ingredients in XERMELO.
- 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, 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.
- XERMELO is not recommended if you have moderate or severe liver impairment.

You are encouraged to report negative side effects of prescription drugs to the FDA. To report suspected adverse reactions, contact the FDA at 1-800-FDA-1088 or www.fda.gov/medwatch. You may also contact TerSera Therapeutics at 1-844-334-4035 or medicalinformation@tersera.com.

Please click for [Full Prescribing Information](#).

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XER-P-0439 (07/2023)



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