

# NET

# IMPACT

## Thrivership & Research Education Program

**Saturday, November 4, 2023  
3pm-7pm (MST)**

**The Grand America Hotel  
555 South Main Street, Salt Lake City, UT**



**NEUROENDOCRINE TUMOR  
RESEARCH FOUNDATION**

DEDICATED TO CURING NEUROENDOCRINE CANCER

# WELCOME

Welcome to NET Impact, NETRF's Thrivership and Research Patient Education Program. We are excited to be with you in Salt Lake City.

Our focus today is two-fold—what's new in neuroendocrine cancer research and treatment, plus how to thrive and live well with NETs. Thank you to our physician co-chairs, Drs. Heloisa Soares and Mark Lewis, for their participation and guidance. We are grateful to all our speakers for sharing their expertise with you today.

We hope you will increase your knowledge about neuroendocrine cancer today and take home some strategies to manage the challenges that accompany a NET diagnosis. The conference is an opportunity to meet fellow patients and caregivers, and to give and receive support along the way.

NETRF would like to thank our sponsors, Novartis and Crinetics, who have helped to make this conference possible. We want to thank NANETS for its collaboration. We also want to recognize Merlynn Densley, leader of the Utah NET Support Group, for his assistance and input into this conference.

Above all, know that you are not alone if you have neuroendocrine cancer. NETRF is here as a resource, not just for today, but every day. We welcome your feedback about this conference, and how we can best meet your NET educational needs. Thank you for your time and interest!



**Elyse Gellerman, MHS**  
CEO  
NET Research Foundation

## 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.

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**Salt Lake City, Utah**  
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**3:00PM-7:00PM (MST)**

**CONFERENCE CO-CHAIR**  
**Heloisa Soares, MD**  
University of Utah

**CONFERENCE CO-CHAIR**  
**Mark Lewis, MD**  
Intermountain Healthcare

- 3:00-4:10PM**    **NET THRIVERSHIP MEET AND GREET** (Light snacks and refreshments will be served)
- 4:15PM**        **WELCOME & PROGRAM INTRODUCTION**  
Elyse Gellerman, MHS, CEO, NET Research Foundation
- 4:25PM**        **NETS—WHAT DO WE KNOW NOW?**  
Mark Lewis, MD, Intermountain Healthcare
- 4:45PM**        **SURGERY FOR NETS**  
Alex Gangi, MD, Cedars Sinai
- 5:05PM**        **NUCLEAR MEDICINE AND PRRT—WHAT IS NEW?**  
Jonathan Strosberg, MD, Moffitt Cancer Center
- 5:25PM**        **NET IMPACT THROUGH: SYMPTOM MANAGEMENT**  
Heloisa Soares, MD, University of Utah
- 5:45PM**        **NET IMPACT THROUGH: BASIC AND TRANSLATIONAL RESEARCH/CLINICAL TRIALS**  
Jaydira del Rivero, MD, National Cancer Institute
- 6:05PM**        **NET THRIVERSHIP: PRACTICAL TOOLS FOR MANAGING STRESS & FATIGUE**  
Jessica S. Thomas, LCSW, NETRF Director of Patient Education
- 6:25PM**        **NET IMPACT PROGRAM Q&A PANEL**  
Mark Lewis, MD, Intermountain Healthcare; Heloisa Soares, MD, University of Utah; Jaydira del Rivero, MD, National Cancer Institute; Alex Gangi, MD, Cedars Sinai; Jonathan Strosberg, MD, Moffitt Cancer Center
- 6:55PM**        **PROGRAM CLOSURE & EVALUATION**  
Elyse Gellerman, MHS, CEO, NET Research Foundation

*Program subject to change.*

**Register at: <https://netrf.org/for-patients>**

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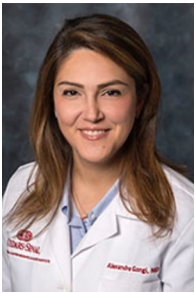


# GET TO KNOW OUR SPEAKERS



**Jaydira del Rivero, MD**  
**National Cancer Institute**

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 of NANETS and is a member of the NCI NET Task Force.



**Alexandra Gangi, MD**  
**Cedars Sinai Medical Center**

Dr. Gangi joined the faculty at Cedars Sinai in 2017 after completing her surgical oncology training at the H. Lee Moffitt Cancer Center in Tampa, Florida. She is double board certified by the American Board of Surgery in general surgery and complex general surgical oncology and serves as the director of the Gastrointestinal Tumor Program and Cancer Regional Therapies Program at Cedars Sinai Medical Center. She specializes in the surgical management of hepato-pancreatico-biliary malignancies, metastatic colorectal cancers, and sarcoma. Her research focuses on understanding the role of the tumor microenvironment for metastatic NETs and the use of S-adenosylmethionine (SAMe) to attenuate chemotherapy-induced liver toxicity while improving tumor-specific responses. Additionally, she is involved in numerous translational and clinical research projects examining comparative effectiveness of various surgical and medical treatments in gastroesophageal and HPB malignancies.



**Mark Lewis, MD**  
**Intermountain Healthcare**

Dr. Lewis is the director of gastrointestinal oncology at Intermountain Healthcare. He received his medical degree, completed his internal medicine residency, and served as chief resident at Baylor College of Medicine in Houston, Texas. After completing a hematology/oncology fellowship at the Mayo Clinic in Rochester, Minnesota, where he served as chief fellow, he returned to Houston where he worked at The University of Texas MD Anderson Cancer Center with a dual appointment in general & gastrointestinal medical oncology before assuming his current position in 2016. Dr. Lewis is a member of the NETRF Board of Directors. He is a frequent speaker and author on topics related to neuroendocrine tumors, medical oncology, and the impact of a cancer diagnosis.



**Heloisa Soares, MD**  
**University of Utah Health**

Dr. Heloisa Soares is a medical oncologist with a focus in GI and neuroendocrine cancers. She is an associate professor at the Huntsman Cancer Institute (HCI) at University of Utah. Dr. Soares received her medical degree at Faculdade de Medicina do ABC in Brazil, where she was born. She completed her residency training at the Mount Sinai Medical Center of Florida and her hematology-oncology fellowship training and PhD in molecular biology at UCLA. She serves as the Medical Director for the Clinical Trials Office as well as the co-physician leader in the GI Clinical Trials Research Group at HCI. In 2019, she was elected as a member of the board of directors for The North American Neuroendocrine Tumor Society (NANETS). Additionally, she is a member of the NCI NET taskforce and member of SWOG and NRG cooperative groups. She is also a panel member for the Neuroendocrine and Adrenal Tumors NCCN Clinical Practice Guidelines in Oncology.



**Jonathan Strosberg, MD**  
**Moffitt Cancer Center**

Dr. Jonathan Strosberg is a professor at Moffitt Cancer Center specializing in the management of neuroendocrine malignancies. He is a graduate of Harvard University and Cornell University Medical College and completed his residency and fellowship training programs at Georgetown University Hospital and Moffitt Cancer Center. He leads Moffitt's Neuroendocrine Tumor Division and Department of Gastrointestinal Oncology Research Program. Dr. Strosberg has published over 150 articles on the diagnosis and management of neuroendocrine malignancies, with first-author publications in *The New England Journal of Medicine*, *The Journal of Clinical Oncology*, *Annals of Oncology*, *Clinical Cancer Research* and other major journals. He is a recipient of the National Cancer Institute's Clinical Investigator Team Leadership Award. He also serves on the board of directors of the North American Neuroendocrine Tumor Society, the Neuroendocrine Guidelines Committee of the National Comprehensive Cancer Network and the Neuroendocrine Task Force of the National Cancer Institute.



**Jessica S. Thomas, LCSW**  
**NETRF Director of Patient Education**

Jessica Thomas, LCSW, brings nearly two decades 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. Jessica's professional passion has been to empower patients and their 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.

# FAST FACTS ABOUT NETs



- 175,000+ people in the U.S. are living with a NET.
- More than 12,000 people in the U.S. are diagnosed with a NET each year.
- NET incidence has increased 6.4x from 1973 to 2012.<sup>1</sup>
- The average length of time from first symptoms to diagnosis is 4.3 years.<sup>2</sup>
- The average number of health care visits made before a NET diagnosis is 11.8 visits.<sup>2</sup>
- Up to 58% of patients had metastases at diagnosis.
- The increase in the number of people diagnosed with NETs is attributed in part to improvements in diagnostic techniques and greater awareness of NETs.

## ABOUT THE NEUROENDOCRINE TUMOR FOUNDATION (NETRF)

The Neuroendocrine Tumor Research Foundation is the largest private global funder of NET research, investing \$36 million in landmark research since 2005. NETRF's mission is to drive transformational discoveries in the study of neuroendocrine tumors. We are leading the fight to bring life-changing treatments to families and to find a cure.

### NETRF:

- Invests boldly in the most promising scientific projects worldwide
- Funds and nurtures the most brilliant NET scientists who bring their original thinking and determined spirit to their work
- Offers hope to patients and families
- Shapes the future of neuroendocrine cancer care to save lives

More often than not, NETRF is the only funding source available for scientists working to understand this complicated and uncommon cancer. Through 2020, NETRF funded two and a half times more NET investigators than the National Institutes of Health (NIH). If not for NETRF funding, these investigators would likely pursue other areas of cancer research.

NETRF's impact on the field of NET research has been profound. Thanks to NETRF-funded discoveries and the efforts of the NET medical community, the therapeutic landscape of NET management looks entirely different now than it did in 2005, when NETRF began. Such advances are not random. They are the fruit of many years of NETRF-funded research.

## EDUCATING AND EMPOWERING PATIENTS

NETRF is dedicated to the thousands of patients, families, and caregivers affected by neuroendocrine tumors (NETs). We provide expert educational resources to help you understand your diagnosis, make informed health care decisions, and to help you thrive.

### Our resources include:

- NET Knowledge Center, a comprehensive digital resource for information, engagement, and community resources
- Neuroendocrine Cancer Guide, a hands-on reference for the tests, treatments, and management of NETs
- NETWise Podcast series
- Extensive YouTube library with videos about diagnosis, treatment, research, and living with NETs
- Patient and caregiver education conferences
- Searchable databases of NET doctors, multidisciplinary treatment programs, and support groups

<sup>1</sup> Dasari A, Shen C, Halperin D, et al. *Trends in the incidence, prevalence, and survival outcomes in patients with neuroendocrine tumors in the United States. JAMA Oncol. 2017;3(10):1335-1342.*

<sup>2</sup> Singh S, Granberg D, Wolin E, et al. *Patient-reported burden of a neuroendocrine tumor (NET) diagnosis: results from the first global survey of patients with NETs. J Glob Oncol. 2016;3(1):43-53.*





## 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**

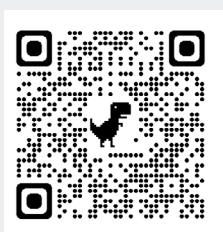
#### **Take the next step regarding your NET diagnosis**

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 NET Knowledge Center, [netrf.org/for-patients](https://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/](https://netrf.org/for-patients/) or  
scan the QR code here:







# 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](mailto:info@netrf.org).

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



[netrf.org/podcast](https://netrf.org/podcast)



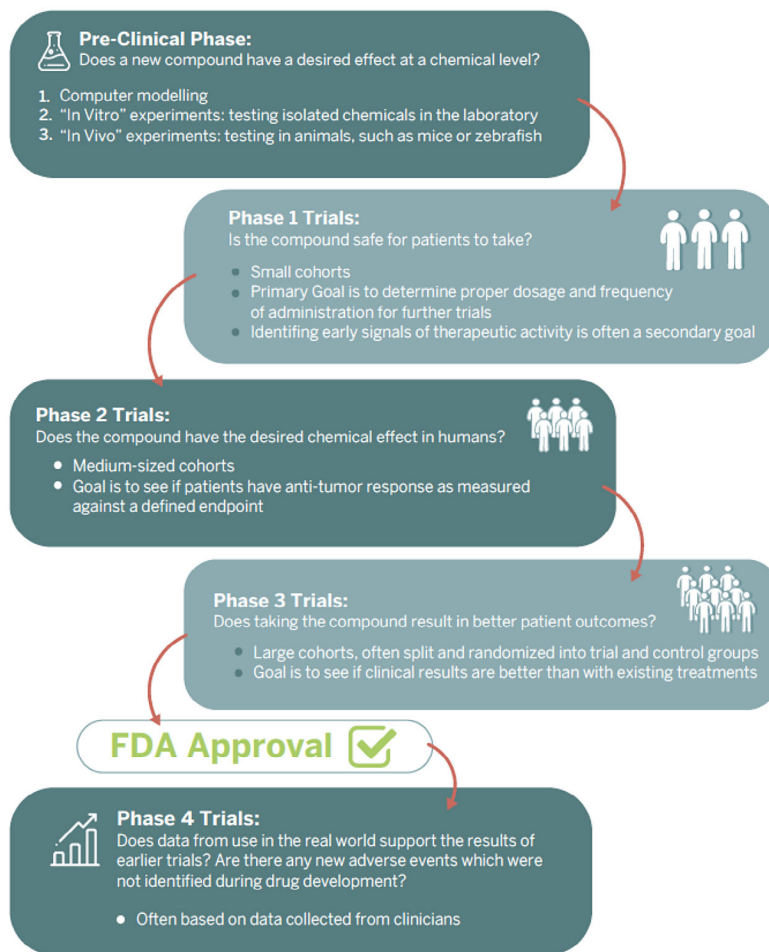
# CLINICAL TRIALS



Clinical trials can provide patients with innovative treatments and are the final step in a long process that begins with research in a lab. Before any new treatment is used in people in clinical trials, researchers work for many years in the lab to understand its effects by testing it first on cells or in animals. They then work to determine the best dose for treatment, the side effects the drug may cause, and how the effectiveness of the drug compares to current treatments. It can take 10-15 years to develop a new drug to the point of a first clinical trial.

## Phases of Clinical Trials

Clinical trials occur in phases. Once a new treatment is successful in one phase, it may proceed to the next phase.



### FIND A CLINICAL TRIAL



There are many clinical trials for neuroendocrine cancer. Scan this QR code to access the NET Trial Finder, or visit [netrf.org/for-patients/trial-finder/](https://netrf.org/for-patients/trial-finder/)



To learn what kinds of questions to ask your care team about clinical trials, scan this code, or visit [netrf.org/for-patients/treatment-of-nets/how-to-find-a-clinical-trial/](https://netrf.org/for-patients/treatment-of-nets/how-to-find-a-clinical-trial/)

# THANK YOU FOR DRIVING BREAKTHROUGH NET DISCOVERIES FOR TREATMENTS AND CURES.

NETRF invests boldly in the most promising NET research worldwide. More often than not, NETRF is the **first or only funding source for NET scientists. We have funded two and half times more NET investigators than the NIH.** Thanks to your support, NETRF is empowering scientists with the resources to push the boundaries of discovery.

## *Join Us!*

- Renew your Annual Gift
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To make your gift today,  
please visit [netrf.org/give-now](https://netrf.org/give-now)  
Every gift matters. Thank you!



## A Word of Thanks!

Thank you for joining us at our NET Impact: Thrivership & Research Education Program. We hope you found the sessions informative and valuable.

If you have any questions about NETRF, our research and resources, and how we can best support you on your NET journey, please contact us at [info@netrf.org](mailto:info@netrf.org).

We are grateful to our generous partners and friends like you. Thanks to your support, NETRF can host educational conferences and advance research, opening new doors to NET discoveries.

If you would like to make a gift to NETRF, please visit [netrf.org/donate](https://netrf.org/donate). Your support is vital to help us save and improve the lives of more people—today and in the future.

NETRF greatly appreciates the generosity of the following sponsors who made this educational program possible. Thank you!



Visit our YOUTUBE channel for patient education videos.



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

