

# NET

# IMPACT

## Thrivership & Research Education Program

**Saturday, May 4, 2024  
2:30-7:30pm**

**Renaissance Providence Downtown  
5 Avenue of the Arts, Providence, RI**



**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 Providence.

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. Jennifer Chan and Pamela Kunz, for their participation and guidance. We thank 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 sincerely thanks our sponsors, Crinetics, Curium, TerSera and Wren Laboratories, who helped make this conference possible, and we extend tremendous gratitude to NANETS for their collaboration.

Above all, know that you are not alone if you have neuroendocrine cancer. NETRF is here as a resource for today and 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, NETRF

## 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, 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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**CONFERENCE CO-CHAIR**  
Jennifer Chan, MD, MPH  
Dana-Farber Cancer Institute

**CONFERENCE CO-CHAIR**  
Pamela Kunz, MD  
Yale School of Medicine

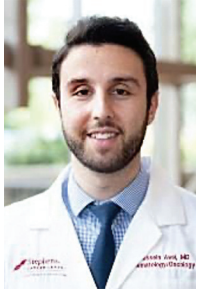
- 2:30-3:45PM**    **NET THRIVERSHIP MEET AND GREET**
- 4:00PM**        **WELCOME & PROGRAM INTRODUCTION**  
Elyse Gellerman, MHS, CEO, NETRF
- 4:10PM**        **NET IMPACT- WHAT DO WE KNOW NOW?**  
Thor Halfdanarson, MD, Mayo Clinic
- 4:30PM**        **NET IMPACT THROUGH SURGERY AND INTERVENTIONAL RADIATION TREATMENTS FOR NETS**  
Thomas Clancy, MD, Dana-Farber Cancer Institute
- 4:50PM**        **NET IMPACT THROUGH NUCLEAR MEDICINE AND PRRT- WHAT IS NEW**  
Heather Jacene, MD, Dana-Farber Cancer Institute
- 5:10PM**        **NET IMPACT THROUGH SYMPTOM MANAGEMENT**  
Kim Perez, MD, Dana-Farber Cancer Institute
- 5:30PM**        **BREAK**
- 5:40PM**        **NET IMPACT THROUGH BASIC AND TRANSLATIONAL RESEARCH**  
Chris Heaphy, PHD, Boston University School of Medicine
- 6:00PM**        **NET IMPACT THROUGH CLINICAL TRIALS**  
Hussein Assi, MD, Boston University School of Medicine
- 6:20PM**        **NET THRIVERSHIP THROUGH RESILIENCE IN MOTION: FOSTERING EMOTIONAL WELLNESS**  
Jessica S. Thomas, LCSW, NETRF Director of Patient Education
- 6:40PM**        **NET IMPACT PROGRAM TUMOR BOARD**  
Hussein Assi, MD, Boston University School of Medicine; Jennifer Chan, MD, MPH, Dana-Farber Cancer Institute  
Thomas Clancy, MD, Dana-Farber Cancer Institute; Thor Halfdanarson, MD, Mayo Clinic  
Chris Heaphy, PHD, Boston University School of Medicine; Pamela Kunz, MD, Yale School of Medicine  
Kim Perez, MD, Dana-Farber Cancer Institute
- 7:05PM**        **Q&A PANEL FACILITATED BY:**  
Jennifer Chan, MD, MPH, Dana-Farber Cancer Institute; Pamela Kunz, MD, Yale School of Medicine
- 7:25PM**        **CLOSING THOUGHTS**  
Elyse Gellerman, MHS, CEO, NETRF

*Program subject to change.*

Sponsored by



# GET TO KNOW OUR SPEAKERS



**Hussein Assi, MD**  
**Boston University School of Medicine**

Dr. Assi is an assistant professor of medicine at Boston University Chobanian and Avedisian School of Medicine and a medical oncologist in the Hematology/Oncology section at Boston Medical Center. His work focuses on gastrointestinal malignancies, specifically on neuroendocrine tumors and novel therapeutics in NETs. His current research focuses on studying prognostic biomarkers in pancreatic NETs. He earned his medical degree from the American University of Beirut in Lebanon and completed his residency in internal medicine at Albany Medical Center in Albany, NY. He completed his fellowship training in hematology/oncology at the University of Oklahoma Health Sciences Center while earning a master's degree in clinical and translational sciences.



**Jennifer Chan, MD, MPH**  
**Dana-Farber Cancer Institute**

Dr. Chan is an associate professor of Medicine at Harvard Medical School and senior physician in the Division of Medical Oncology at Dana-Farber Cancer Institute in Boston, MA. Her clinical practice focuses on caring for patients with neuroendocrine tumors and gastrointestinal cancers. She is the director of the Neuroendocrine and Carcinoid Tumors program and the clinical director of the Gastrointestinal Cancer Center at the Dana-Farber/Brigham and Women's Cancer Center. She has been the principal investigator for multiple clinical trials investigating novel therapies for neuroendocrine tumors and studies examining factors associated with clinical outcomes in NET patients. Dr. Chan is the Vice President of NANETS.



**Thomas Clancy, MD, FACS**  
**Dana-Farber Cancer Institute**

Dr. Clancy is co-director of the Pancreas and Biliary Tumor Center at Dana-Farber Cancer Institute and director of the Program in Pancreatic Cancer in the Division of Surgical Oncology at Brigham and Women's Hospital. He also serves as an assistant professor of Surgery at Harvard Medical School. Dr. Clancy earned his medical degree from Harvard Medical School and completed his residency and fellowship at Brigham and Women's Hospital.



**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, focusing on NETs and cancers of unknown primary. He is the Associate Medical Director of the Cancer Clinical Trials Office at the Mayo Clinic Comprehensive Cancer Center and 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 President of NANETS.



**Christopher Heaphy, PhD**  
**Boston University School of Medicine**

Dr. Heaphy is a cancer biologist who uses a combination of tissue-based, cell-based, and molecular approaches to conduct basic and translational research studies focused on elucidating the role of telomere alterations in the initiation and progression of human diseases, particularly cancer, including neuroendocrine tumors. He received his doctorate from the University of New Mexico School of Medicine and did postdoctoral training at the Johns Hopkins University School of Medicine. Dr. Heaphy is a recipient of a 2022 NETRF Pilot Research Award for his work to profile the tumor microenvironment of PNETs.



**Heather Jacene, MD**  
**Dana-Farber Cancer Institute**

Dr. Jacene is the clinical director of Nuclear Medicine/PET-CT at Dana-Farber Cancer Institute and associate program director of the Brigham and Women's Joint Program in Nuclear Medicine. She also serves as an associate professor of Radiology at Harvard Medical School. She received her medical degree from the University of Medicine and Dentistry of New Jersey-Robert Wood Johnson Medical School and completed her residency and fellowship training in nuclear medicine at Johns Hopkins University.



**Pamela Kunz, MD**  
**Smilow Cancer Hospital at Yale-New Haven and Yale Cancer Center**

Dr. Kunz is a medical oncologist and international expert in neuroendocrine tumors. She serves as the director of the Center for Gastrointestinal Cancers at Smilow Cancer Hospital and Yale Cancer Center and the division chief of GI medical oncology. She received her medical degree from the Geisel School of Medicine at Dartmouth and completed her residency and fellowship at Stanford University. Dr. Kunz is an associate professor of internal medicine (medical oncology) at Yale School of Medicine. She is the past President of NANETS and has been named a 2024 Fellow of the American Society of Clinical Oncology (FASCO).



**Kimberly Perez, MD**  
**Dana-Farber Cancer Institute**

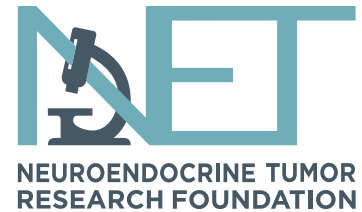
Dr. Perez is a senior physician at Dana-Farber Cancer Institute and an assistant professor at Harvard Medical School with clinical interests in gastrointestinal cancers and neuroendocrine tumors. She received her medical degree from the George Washington University School of Medicine and completed her residency in internal medicine and fellowship training in hematology/oncology at the Warren Alpert Medical School of Brown University.



**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 in 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 \$37.6 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

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

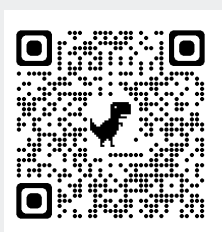
#### Take the next step regarding your NET diagnosis

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.



# 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)



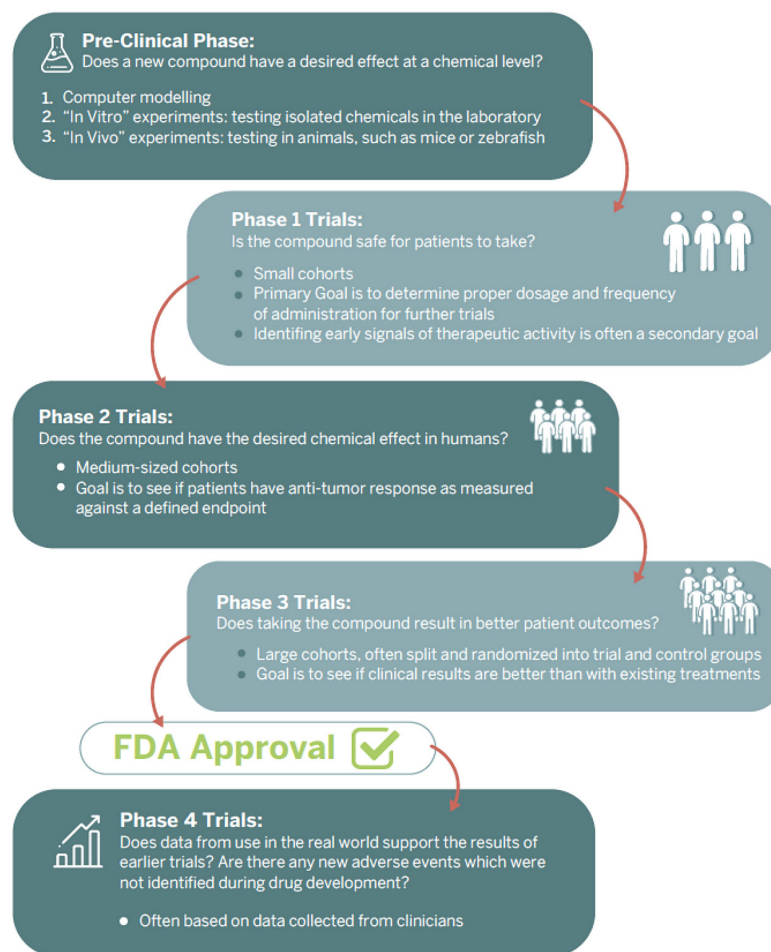


# CLINICAL TRIALS

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



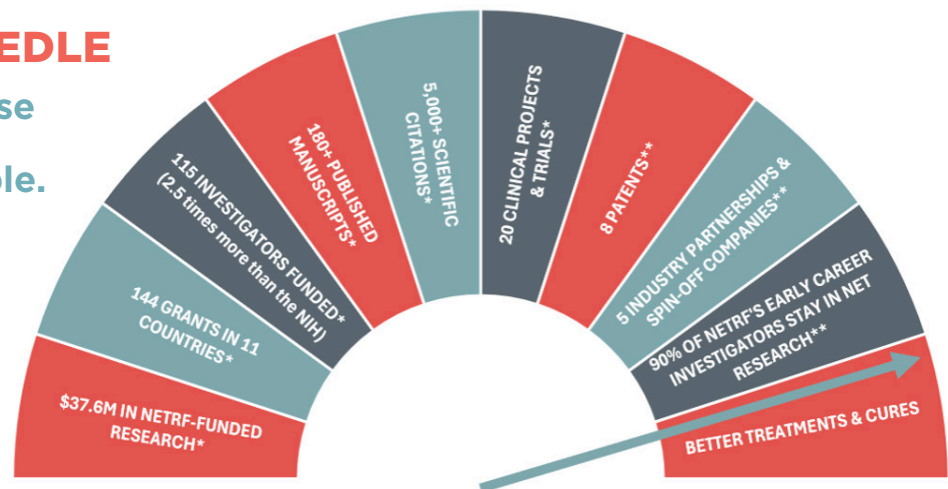
There are many clinical trials for neuroendocrine cancer. Scan this QR code to access the NET Trial Finder, or visit [netrf.org/for-patients/trial-finder/](https://netrf.org/for-patients/trial-finder/)

# 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.

## MOVING THE NEEDLE

Without NETRF, these NET breakthroughs would not be possible.



## Join Us!

- Renew your Annual Gift
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- Establish a Bequest or Planned Gift
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- Double Your Impact with a Corporate Match
- Make a Gift via a Donor Advised Fund
- Donate Stock and Bonds
- Make a Gift from an IRA Account
- Become a Corporate Sponsor

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.

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:



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