

NET

IMPACT

Thrivership & Research Education Program

**Saturday, September 23, 2023
9:15am-4pm (CST)**

**The Frank Fickett Scout Training & Service Center
12500 North IH 35, Austin, Texas 78753**



**NEUROENDOCRINE TUMOR
RESEARCH FOUNDATION**

DEDICATED TO CURING NEUROENDOCRINE CANCER

WELCOME

Welcome to NET Impact, NETRF's Thrivership and Research Patient Education Program. This is our first in-person patient conference since 2019 and we are excited to be with you in Austin.

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. Daniel Halperin and Scott Paulson, for their participation and guidance. We are grateful to all our speakers for sharing their expertise with us.

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 also an opportunity to meet fellow patients and caregivers, to give and receive support along the way.

We would also like to recognize and thank our sponsors who have helped to make this conference possible. Please visit them in our exhibit area.

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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9:15-10:00AM	EXHIBIT HALL & NET RESOURCE CENTER
10:00-10:15AM	WELCOME & PROGRAM INTRODUCTION Elyse Gellerman, MHS, CEO, NET Research Foundation
10:15-10:45AM	NETS—WHAT DO WE KNOW NOW? Scott Paulson, MD, Texas Oncology
10:45-11:15AM	SURGERY FOR NETS Jessica Maxwell, MD, MBA, MD Anderson Cancer Center
11:15-12:00PM	NUCLEAR MEDICINE AND PRRT—WHAT IS NEW & WHAT IS HAPPENING IN YOUR COMMUNITY Beth Chasen, MD, MD Anderson Cancer Center Mike Herman, MD, Texas Oncology
12:00-12:30PM	KEYNOTE SPEAKER: US CONGRESSMAN JOAQUIN CASTRO
12:30-1:15PM	LUNCH
1:15-1:45PM	NET IMPACT: BASIC AND TRANSLATIONAL RESEARCH Patricia Dahia, MD, PhD, University of Texas Health Science Center at San Antonio
1:45-2:35PM	NET IMPACT: NET CLINICAL TRIALS: TRIALS AND TRIBULATIONS Dan Halperin, MD, MD Anderson Cancer Center Scott Paulson, MD, Texas Oncology
2:35-2:45PM	BREAK
2:45-3:20PM	NET THRIVERSHIP: FINDING BALANCE: MANAGING STRESS, FATIGUE MANAGEMENT AND NAVIGATING EMOTIONAL WELLNESS Jessica S. Thomas, LCSW, NETRF Director of Patient Education
3:20-3:55PM	NET IMPACT PROGRAM Q&A PANEL Beth Chasen, MD, MD Anderson Cancer Center; Patricia Dahia, MD, PhD, University of Texas Health Science Center at San Antonio; Dan Halperin, MD, MD Anderson Cancer Center; Mike Herman, MD, Texas Oncology; Jessica Maxwell, MD, MBA, MD Anderson Cancer Center; Scott Paulson, MD, Texas Oncology
3:55-4:00PM	PROGRAM CLOSURE & EVALUATION Elyse Gellerman, MHS, CEO, NET Research Foundation

Program subject to change.

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

Sponsored by



GET TO KNOW OUR SPEAKERS



U.S. Congressman Joaquin Castro

Congressman Joaquin Castro has been proud to represent his hometown of San Antonio (TX) in the U.S. House of Representatives since 2013. In Congress, his work focuses on building out what he calls the “Infrastructure of Opportunity” - the great public schools and universities, sound health care system, and good-paying jobs that allow Americans to pursue their dreams. He was diagnosed with neuroendocrine cancer last year and takes monthly Lanreotide injections to slow and freeze the growth of his neuroendocrine tumors. He lives in San Antonio with his wife and three young children.



Beth Chasen, MD **MD Anderson Cancer Center**

Dr. Chasen is a Professor in the Department of Nuclear Medicine, Division of Diagnostic Imaging at The University of Texas MD Anderson Cancer Center, Houston, TX. She is board certified by the American Board of Nuclear Medicine and the American Board of Radiology.



Patricia Dahia, MD, PhD **University of Texas Health Science Center at San Antonio**

Dr. Dahia is a tenured Professor of Medicine at the University of Texas Health Science Center at San Antonio and the Mays Cancer Center at UTHSCSA and the holder of the Robert Tucker Hayes Distinguished Chair in Oncology. Her career has focused on research in cancer genetics, with emphasis on pheochromocytomas and paragangliomas. Because treatment options are currently limited for patients who have metastatic pheochromocytomas and paragangliomas, Dr. Dahia’s funded NETRF project aims to develop new three-dimensional, organ-like systems (called organoids) to reproduce pheochromocytomas and paragangliomas in the laboratory. In this research, Dr. Dahia is collaborating with Dr. Alice Soragni (UCLA) to study organoids properties and to explore whether they may also be amenable to drug testing. If successful, this model will generate a unique resource that represents the genetic and clinical variability of these tumors, enabling researchers to better understand the biology of these tumors. The models may also illuminate how the tumors may respond to drug testing that may lead to future clinical trials.



Daniel Halperin, MD **MD Anderson Cancer Center**

Dr. Halperin is a medical oncologist and clinical investigator primarily focused on the development of novel treatments for patients with neuroendocrine tumors (NETs). He serves as chair of the NET Multidisciplinary Conference (Tumor Board) at MD Anderson, and represents the institution on the the Neuroendocrine and Adrenal Tumor guideline committee of the National Comprehensive Cancer Network (NCCN). As a clinical investigator, he leads clinical trials of new drugs for patients with NETs at MD Anderson, and works together with a team of laboratory and population scientists to understand more fully the molecular underpinnings and clinical manifestations of neuroendocrine tumors. He serves on the Board of Scientific Advisors of the NET Research Foundation and the Scientific Advisory Committee of the Healing NET Foundation, as well as chairing the North American Neuroendocrine Tumor Society Scientific and Research Committee in 2021.



Mike Herman, MD
Texas Oncology

Dr. Herman is board certified in radiation oncology and practices at Texas Oncology. He has published and presented at national conferences on several clinical research topics, including head and neck cancers, metastatic cancer treated with radiosurgery, rectal cancer, and lymphoma. He is the recipient of the 2009 American College of Medical Quality Scholar Award and the University of Florida Society of Teaching Scholars - Resident Teaching Award. Dr. Herman was also inducted into the Gold Humanism Honor Society recognizing excellence in clinical care, leadership, compassion, and dedication to service.



Jessica Maxwell, MD, MBA
MD Anderson Cancer Center

Dr. Maxwell is a surgical oncologist at MD Anderson Cancer Center. She completed her General Surgery residency at the University of Iowa, and spent two years as an NIH T32 Research Fellow in the lab of Dr. James Howe. Their published research focused on the genetic underpinnings of gastrointestinal NETs and surgical outcomes of NET cytoreduction. She completed a fellowship in Complex General Surgical Oncology at MD Anderson and stayed on as the clinical lead of the surgical NET team. She won the NANETS Young Investigator award in 2021 and is studying the neuroendocrine tumor microenvironment, with a goal of translating the work at the bench into clinical trials and novel therapies to improve the lives of NET patients.



Scott Paulson, MD
Texas Oncology

Dr. Paulson currently works at Texas Oncology-Baylor Charles A. Sammons Cancer Center, where he has directed the Neuroendocrine Research and Treatment Center for nearly a decade. He is the current medical director for clinical research for Texas Oncology, a private practice oncology group comprising over 500 physicians, and co-chairs the GI research committee for Sarah Cannon Research Institute. He has been actively involved in treating patients with NET for over 10 years.



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 2012.¹
- The average length of time from first symptoms to diagnosis is 4.3 years.²
- The average number of health care visits made before a NET diagnosis is 11.8 visits.²
- 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

¹ 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.

² 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 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:





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.

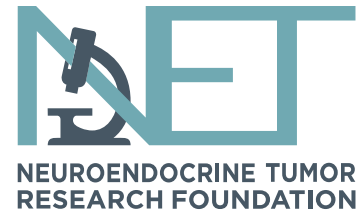
How to find NETWise, a New Way to Learn about NETs



netrf.org/podcast



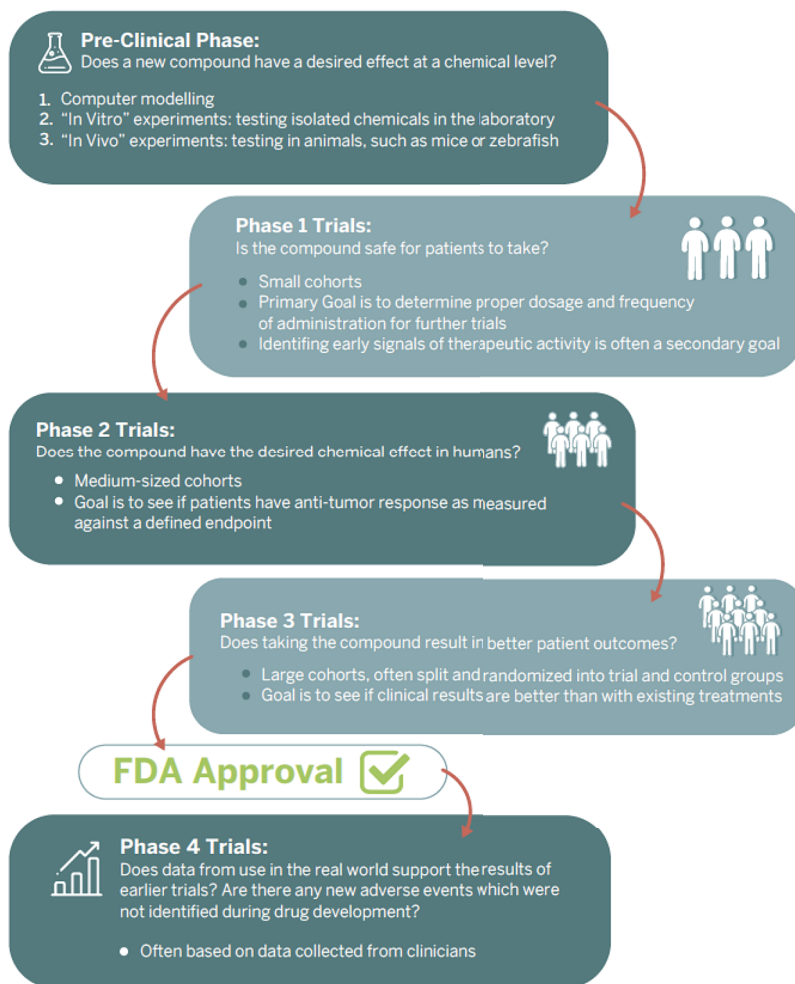
CLINICAL TRIALS



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/



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/

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.

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. 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!



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

 @NETRF

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

 @CureNETs  @NETRF