



NEUROENDOCRINE TUMOR
RESEARCH FOUNDATION

DEDICATED TO CURING NEUROENDOCRINE CANCER

Annual Report 2016

Accelerating the pace of progress



MISSION

The mission of the Neuroendocrine Tumor Research Foundation (NETRF) is to fund research to discover cures and more effective treatments for carcinoid, pancreatic, and related neuroendocrine cancers. To achieve rapid discovery of cures, NETRF directs its donations to fund breakthroughs in the scientific research of neuroendocrine cancers. NETRF is committed to improving the lives of patients, families, and caregivers affected by neuroendocrine cancer by providing information and educational resources.

CHAMPIONS IN THE SEARCH FOR A CURE

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Elyse Gellerman, Senior Administrative Officer

Effie Tzameli, PhD, Director of Research

Laran Hyder, Associate Director of Development and Outreach



I advocate for patients to make sure that others don't have the same challenges I had in finding treatment when I was diagnosed. My hope is that with my work others will have access to better treatments and information to help them manage their care.

Josh Mailman

President NorCAI CarciNET; Inaugural Chair, Society of Nuclear Medicine and Molecular Imaging, Patient Advocacy Advisory Board; Board Member, NETRF



I was delighted to be invited to the NETRF Board of Scientific Advisors. My colleagues on the Board are world leaders. What I hope to bring to the board is my experience of basic science, translational, and clinical research, from a European perspective.

Chrissie Thirlwell, BSc, MD, PhD, FRCP

University College London; Member, Board of Scientific Advisors, NETRF

Dear Friends,

2016 was a transformative year for the Neuroendocrine Tumor Research Foundation (NETRF). We embraced an expanded range of possibilities with a \$15 million gift from the Margie and Robert E. Petersen Foundation. This generous infusion of support fueled our call for breakthrough research proposals that were multi-year, multi-disciplinary, and multi-institutional through our new Accelerator Grants program. Our announcement of these \$1+ million grants generated an unprecedented global response to move us closer to a cure.

We partnered with recognized research and clinical groups like the American Association for Cancer Research (AACR), the North American Neuroendocrine Tumor Society (NANETS), and the Education Research Foundation (ERF) of the Society of Nuclear Medicine and Molecular Imaging to engage basic, translational, and clinical researchers with our organization. We also intensified our overseas outreach, working more closely with the European Neuroendocrine Tumor Society (ENETS), comprised of leading NET clinicians and researchers, and the International Neuroendocrine Cancer Alliance (INCA), a global voice for the NET patient community.

To rescale operations to manage and monitor research programs of this size, we welcomed Elyse Gellerman as Senior Administrative Officer. We continued to build strength and perspective in our Board of Directors as well as our Board of Scientific Advisors with key additions to deepen connections with the patient community and the international NET community.

During this pivotal year, we cultivated and convened new resources in our search for a cure for neuroendocrine cancer. Our influence and impact expanded. We are now stronger and more mobilized. NETRF emerged as the catalyst to ignite unprecedented inquiry into an overlooked and misunderstood cancer. We are committed to forever changing the experience of a NET diagnosis for patients and families.

Sincerely,



A handwritten signature in blue ink that reads "Ron".

Ron Hollander
Executive Director



A handwritten signature in black ink that reads "Joseph".

Joseph Li, MD, SFHM, FACP
Chair, Board of Directors



NET patients usually have little to cheer about, but I was witness to a lot of hope in 2016. I am indebted to the hard work and sense of commitment that NETRF brings to curing me, and in the meantime, finding ways for me to be able to live with this disease as fully and happily as I can.

Carol Branaman
2016 Chair and Current Vice Chair
Board of Directors, NETRF

• **From the onset** of symptoms, patients saw **six health care providers** in **12 visits** over a mean period of **52 months** before being **diagnosed** with NETs

• **29%** of patients went **5 years before** receiving a **NET diagnosis**

• **58%** of patients had **metastases at diagnosis**

Singh S, et al. **Patient-Reported Burden of a Neuroendocrine Tumor (NET) Diagnosis: Results From the First Global Survey of Patients With NETs.** *Journal of Global Oncology.* 2017;3:1, 43-53.



Until you understand a problem, you can't solve it. You can't cure a disease until you understand it.

Ramesh Shivdasani, MD, PhD
Dana-Farber Cancer Institute;
Harvard Medical School;
2016 Co-Chair and continuing
Member, Board of Scientific
Board of Advisors, NETRF

THE URGENT NEED FOR A CURE

NETRF works with patients in the U.S. and beyond. We see universal needs for better treatment and cures for neuroendocrine cancer.

NETRF participated in critical efforts to assess the impact of NETs on patients' daily lives. We worked with the International Neuroendocrine Cancer Alliance (INCA) on the first global NET patient survey and the Carcinoid Cancer Foundation (CCF) on a Carcinoid Syndrome Impact Survey. These surveys captured the voice of the patient, documented the burden of this disease, and conveyed the urgent need for fundamental improvements in care.

In 2016, NETRF Executive Director Ron Hollander was elected President of INCA, an alliance of 20 patient advocacy groups from around the world, which works to increase awareness and improve the NET patient experience. On November 10, INCA launched its first "Let's Talk About NETs" campaign for World NET Cancer Day.

ACCELERATING IMPROVEMENTS IN TREATMENT

Discovering the molecular underpinnings of NETs

We don't understand NETs the way we understand other cancer types. We know very little about mutations that drive different NETs, and we do not have good experimental tools (cell lines, model systems, etc.) to study NETs in the laboratory. With that in mind, NETRF has pursued a multipronged strategy to tackle the problem. Grant-funded renowned laboratory scientists are trying to "crack the code" of these tumors by asking and seeking answers to the right questions.

- What changes turn a normal cell into a cancer cell?
- What are the driving mutations in the relevant genes, and how do they affect cell function?
- What are the key cellular changes, and how early do these changes occur in pre-cancerous cells?

SPARKING INNOVATION AND EXPLORATION

Leveraging advancements in other cancers for NETs

We funded research to explore the use of immunotherapy in NETs, given its success in other cancer types. NETRF-funded researchers are investigating fundamental questions.

- What immune cells are in NETs and how can we take advantage of that?
- Can we train our immune system to attack cancer cells?
- Can we create new technologies to trick and activate our immune system?

Moving research from the bench to the bedside

NETRF funded translational research to help improve patient care. We collaborated with the North American Neuroendocrine Tumor Society (NANETS) and the Society of Nuclear Medicine and Molecular Imaging on new studies of targeted therapy and peptide receptor radionuclide therapy (PRRT). Patient enrollment opened for an ongoing clinical trial of a potentially safer and more effective approach to PRRT.

2016 Awards for Basic and Translational Research

MULTIDIMENSIONAL IMMUNE PROFILING OF ADVANCED PANCREATIC NEUROENDOCRINE TUMORS

Daniel M. Halperin, MD — MD Anderson Cancer Center

Objective: To examine the immune milieu in annotated specimens of patients with advanced panNETs, correlating with clinical outcome.

PROFILING OF SECRETED IMMUNE MEDIATORS IN NEUROENDOCRINE TUMORS

Matthew Kulke, MD — Dana-Farber Cancer Institute, Harvard Medical School

Objective: To characterize responses to PD-1 inhibition in tissue models of small intestine neuroendocrine tumors, and to characterize immune markers that may be associated with survival.

SYSTEMATIC EVALUATION OF THE IMMUNE ENVIRONMENT OF NETS

Tim Meyer, MD, PhD — UCL Cancer Institute, University College London

Objective: To characterize the immune landscape in NETs and the effect of therapy on immune cell tumor infiltration, and to identify relevant immune-modulatory pathways.

DEVELOPMENT OF A MOUSE MODEL OF PANCREATIC NEUROENDOCRINE CANCER

Eric Nakakura, MD, PhD — University of California, San Francisco

Objective: To characterize a xenograft mouse model of panNET cancer for use in the development and testing of potential new therapies.

INVITING COLLABORATION AND PARTICIPATION

Increasing momentum with new, promising talent and techniques

NETRF expanded the collaborative NET research community by recruiting renowned investigators to the field with the Petersen Investigator Award. These researchers' laboratories bring the latest advancements in genomic sequencing and engineering to this under-resourced, uncommon cancer. We also partner with leading physician and researcher associations on collaborative grants to recruit new investigators from their membership.

Building a researcher network

NETRF again gathered the top NET researchers and physicians together for its Annual Research Symposium, so attendees can build connections across disciplines, across institutions, and across oceans. To recognize NETRF's first executive director and research director upon her departure after more than ten years of leadership, we designated the Lauren T. Erb Lecture as an enduring component of the symposium.



I got involved because I realized it was an unmet need. Thanks to NETRF, we got a grant to do a 20-patient pilot study to test the safety of second generation PRRT. So far we have treated 19 people. The results were presented and are very promising with a remarkable response rate.

Diane Reidy-Lagunes, MD
Memorial Sloan Kettering
Cancer Center



The Accelerator Grants are large enough to attract the best laboratory and clinical scientists from different disciplines around the world. Creating a network of leading researchers focused on neuroendocrine tumors is our strategy to control and eventually cure this rare and diverse set of diseases.

George Fisher, MD, PhD
Stanford University;
Co-Chair, Board of Scientific
Advisors, NETRF



One of the big needs in the field of neuroendocrine tumors has been bringing new investigators into the field. That is one of the things that is going to be vital if we are going to continue to make progress.

Matt Kulke, MD, PhD
Dana-Farber Cancer Institute,
Harvard Medical School



To me entering this field was an opportunity to delve into a new area of research that I was very intrigued by. We are just at the beginning of studies that will basically identify the cooperating elements in neuroendocrine tumors.

Gigi Lozano, PhD
MD Anderson Cancer Center;
2016 Petersen Investigator

2016 Petersen Investigator Awards

TREATING NEUROENDOCRINE TUMORS VIA SYNTHETIC LETHALITY

Michael German, MD — University of California San Francisco

Objective: To analyze how the UPR-MEN1-MAPK pathways interact to control neuroendocrine cell survival and death, and to evaluate synthetic lethal interactions in a tumor model of panNETs.

THE MECHANISTIC UNDERPINNINGS OF PANNETS

Guillermina (Gigi) Lozano, PhD — MD Anderson Cancer Center

Objective: To generate and characterize mouse models to better understand panNETs and the events that contribute to tumor development.

2016 Collaborative Research Grants

TARGETING THE ALTERNATIVE LENGTHENING OF TELOMERE (ALT) PATHWAY IN PANCREATIC NEUROENDOCRINE TUMORS

Christopher Heaphy, PhD — The Johns Hopkins University School of Medicine

This grant was issued in partnership with the North American Neuroendocrine Tumor Society (NANETS), and made possible by a gift from the Margie and Robert E. Petersen Foundation.

Objective: To determine whether the underlying molecular mechanisms unique to the ALT pathway can be exploited therapeutically.

NUCLEAR MEDICINE PILOT FOR DIAGNOSIS AND TREATMENT OF NETS INTRA-ARTERIAL PEPTIDE RECEPTOR RADIONUCLIDE THERAPY (IA-PRRT) USING 90Y-DOTA-TOC

Thomas Hope, MD — University of California San Francisco

This grant was issued in partnership with the Education and Research Foundation (ERF), and made possible by a gift from the Margie and Robert E. Petersen Foundation.

Objective: To evaluate possible 90Y-DOTA-TOC hepatic, marrow, and renal toxicity, and imaging of tumor response to hepatic arterial injection, three months post-therapy.

TARGETING NEUROENDOCRINE TUMORS BY SUPPRESSING A CELL-SURFACE PROTEASE

Xianxin Hua, MD, PhD — Abramson Cancer Center, University of Pennsylvania

This grant was made in collaboration with the American Association for Cancer Research (AACR).

Objective: To elucidate the novel mechanisms accounting for the development of NETs and then develop new mechanism/target-based therapy to improve the treatment of NETs.

EDUCATING PATIENTS, FAMILY MEMBERS, AND CAREGIVERS

Knowledge is power. Being part of a community is curative

NETRF brought hundreds of people together in day-long educational conferences to support patients' involvement in their care and engagement in the NET community.

- Bay Area NET Conference, January 24, 2016
- Penn Medicine Patient Education Conference, April 15, 2016
- Los Angeles Patient Education Conference, June 25, 2016
- NYC Regional NET Patient Conference, November 10, 2016

The presentations from these conferences are streamed live and then archived on our website, providing valuable information for patients and families who are unable to attend.

GIVING AND CARING

The transformational gift of \$15 million by the Margie and Robert E. Petersen Foundation at the end of 2015, elevated the organization's strength, leadership, and reach. In 2016, we worked to build and sustain this new level of intensity, which raised the caliber of NET research on behalf of patients worldwide. Sustaining meaningful research of this magnitude requires widespread participation from the NET community.

We deeply appreciate every dollar donated for propelling our search for a cure into the fast lane. Many donations were made as tributes in honor or memory of a loved one. Several patients supported NETRF with gifts from their estates. These heartfelt gifts played a vital role in our ability to fund lifesaving research. Charity events, held on our behalf, also enhanced our ability to educate and provide resources to the NET community and allowed us to apply funds in innovative research programs. We thank all our generous donors for recognizing that we must accelerate and sustain the pace of progress.



I financially support NETRF because as an orphan disease there isn't enough government funding and visibility from major foundations. So it is going to take a lot of smaller donors in addition to the big grant from the Margie and Robert E. Petersen Foundation to make research move forward.

Todd Gillman
Board Member, NETRF

FINANCIAL REPORT

Balance Sheet 2016

ASSETS

Current Assets

Cash & equivalents	\$ 8,645,754
Contributions receivable	\$ 568,087
Pre-paid expenses	\$ 6,429
Total current assets	\$ 9,220,270
Investments	\$ 5,006,855
Contributions receivable, endowment	\$ 5,000,000
Total assets	\$ 19,227,125

LIABILITIES AND NET ASSETS

Current liabilities

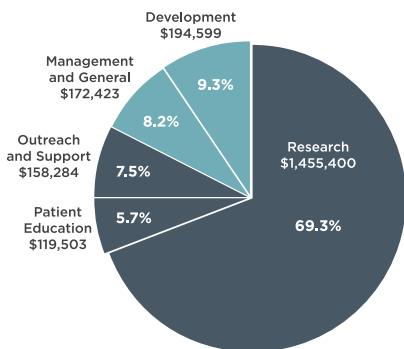
Accounts payable and accrued expenses	\$ 92,572
Grants payable	\$ 1,113,500
Total current liabilities	\$ 1,206,072
Grants payable long term	\$ 275,000

Net assets

Unrestricted	\$ 7,246,053
Temporarily restricted	\$ 5,500,000
Permanently restricted	\$ 5,000,000
Total net assets	\$ 17,746,053
Total liabilities and net assets	\$ 19,227,125

Revenues and Expenses 2016

DETAIL OF EXPENSES



■ Program Services
■ Supporting Services

PUBLIC SUPPORT AND REVENUE

Contributions, grants, and sponsorships	\$ 2,173,052
Interest income	\$ 3,735
Realized/unrealized gains	\$ 5,883
Total support and revenues	\$ 2,182,688

EXPENSES

Program services	\$ 1,733,187
Supporting services	\$ 367,022
Total expenses	\$ 2,100,209

Change in net assets \$ 82,479



We steadfastly steward every donation. I am proud to say that \$.83 of every dollar funds NET research and patient education programs.

Elyse Gellerman
Sr. Administrative Officer, NETRF



Download financial statement



NETRF was recognized for its strong financial position, transparency, and accountability for the second year in a row by Charity Navigator. This 4-star rating indicates the utmost in fiscal responsibility, ethical practices, and governance.



NETRF achieved the Gold GuideStar Nonprofit Profile level for its deep commitment to nonprofit transparency and accountability.



**NEUROENDOCRINE TUMOR
RESEARCH FOUNDATION**

DEDICATED TO CURING NEUROENDOCRINE CANCER

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