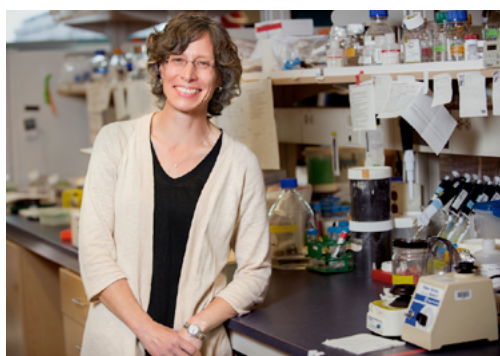
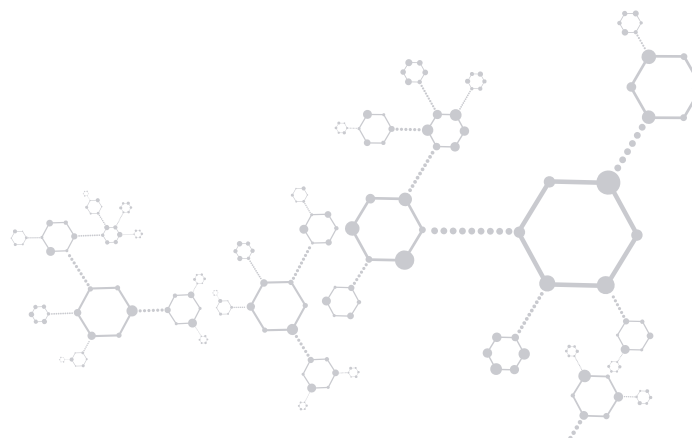
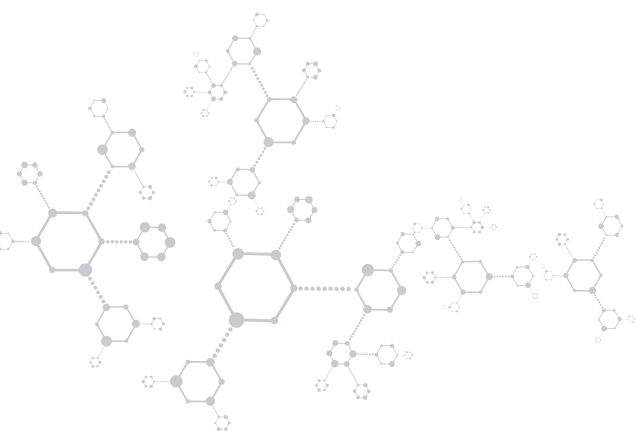


**NEUROENDOCRINE TUMOR
RESEARCH FOUNDATION**

DEDICATED TO CURING NEUROENDOCRINE CANCER



FOSTERING INNOVATION » FUELING DISCOVERY »



**2017
Annual
Report**

Champions in the search for a cure

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

Dear Friends,

The NET Research Foundation's Board of Directors is made up of people who have a personal connection to neuroendocrine tumors (NETs). We have board members who live with NETs, as well as those whose closest loved ones face it.

We have front row seats to the NET patient experience. That is why we give time and money to this Foundation. We know research in NETs is desperately under-resourced. And we understand the impact of that. Not enough is known about NETs. Not enough government or commercial entities conduct research to understand NETs. As a result, patients don't have enough treatment options.

As patients and caregivers, we don't accept the status quo. NETs deserve more attention, more resources, and more solutions. Through NETRF we work to change that.

Alone we can't fight NETs. But together as a community who understands the toll of this illness, we can make a difference. We can deploy the greatest minds and the most sophisticated technology to move us forward.

I hope you share our pride as you read about all that we have accomplished. I hope you too will join us to create a new, brighter future for patients and families living with NETs.

Gratefully,

Joe Li, MD
Chair, Board of Directors



Elyse Gellerman
NETRF Chief Executive Officer

Dear Families and Friends,

2017 was a year of unprecedented growth and achievement by NETRF. NETRF funded a record \$5.3 million in research grants, including our first four-year Accelerator Grants. The 2017 grants represent new scientific collaborations, made possible by our ability to support larger, international projects with potential for breakthroughs in understanding NETs. We recruited more new researchers to NETRF to join us in the pursuit of advanced treatments and cures.

NETRF also stepped up work to empower NET patients worldwide through education and resources to improve quality of life. As more patients are diagnosed with NETs and those diagnosed are living longer, both trends confirmed by research published in 2017, we know the speed of diagnosis and access to specialized care are still barriers. To address this need, NETRF expanded our educational programs into the Midwest, improved patient-focused newsletter content and increased on-demand video resources for patients.

NETRF had some internal transformational changes to support our growth. Dr. Effie Tzameli joined the team as Director of Research, and Donna Dubuc was named our Director of Communications. These additional team members have brought their passion and expertise to support our expanded programs. We also said farewell to Ron Hollander, who helped create the vision for what NETRF is today.

Thank you to the more than 1,500 donors who supported us in 2017. Your gifts enabled us to move the field forward, closer to the goal of cures for neuroendocrine tumors. As our partners in this progress, we look forward to even greater impact in 2018.

Many Thanks,

Elyse Gellerman
Chief Executive Officer



"The insights that we've gained have really provided advances in terms of how we understand the disease, and where we go from here. The belief is, that until we really fundamentally understand these unique molecular processes that are happening in this unique tumor type, we're not going to make significant headway in terms of new therapies."

Dan Chung, MD, Co-Chair,
NETRF Board of Scientific Advisors

2017— Breaking Records, Fueling Discovery

New grants totaling
\$5.3 million

16 active projects

30 funded researchers

First ever four-year
Accelerator Grants
awarded



“Thanks to funding from NETRF we have begun to look at the immune environment of NETs. We didn’t find high rates of the classic immune response target PD-L1. What we did find is a robust infiltration of an immune cell that is part of the innate immune system, which has not been part of the conversation before about the use of immunotherapy in NETs.”

Daniel M Halperin, MD,
MD Anderson Cancer Center



2017: A Groundbreaking Year

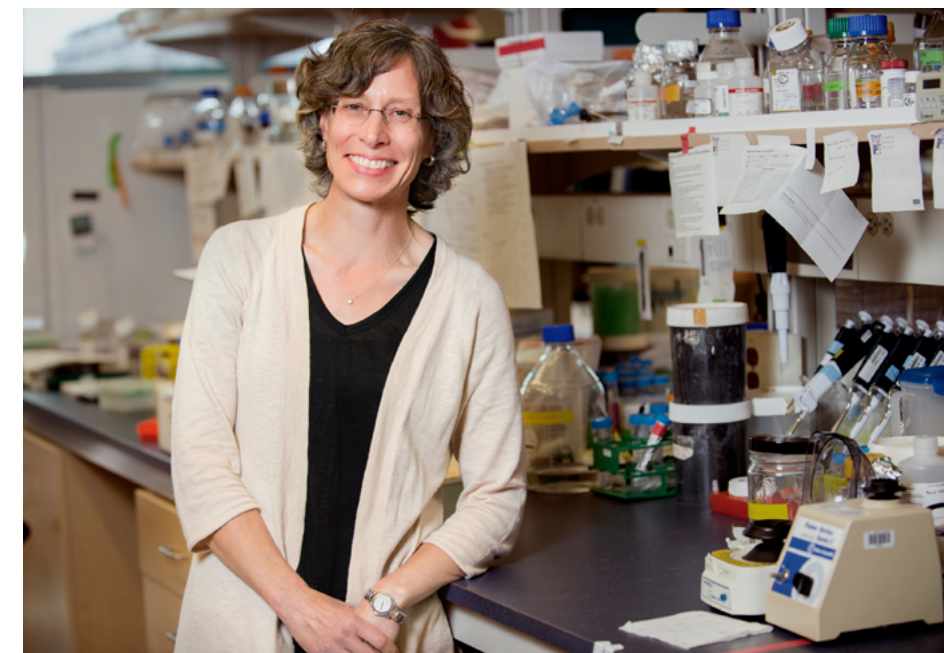
The NET Research Foundation expanded its research portfolio to include new areas of investigation to model, study, and understand how and why neuroendocrine cells become cancerous. Researchers used cutting-edge approaches to look for specific changes in DNA, RNA, proteins, and cells to find and exploit key vulnerabilities. NETRF also invested in new approaches to deliver radionuclide therapy to patients, and to test the efficacy of different drugs in the preclinical setting.

Propelling Scientific Advances for NETs

NETRF quickly engages the best scientists and labs—anywhere in the world—to advance NET research. Specifically, the Foundation has leveraged findings from other cancer types and applied them to NETs.

In 2017, NETRF invested to see if some of the most promising developments in cancer can be applied to NETs.

- **CAR T-cell therapy.** NETRF funded the same institution credited with bringing CAR T-cell therapy out of the lab and into the clinic for blood cancer to study this new precision therapy in NETs.
- **Immunotherapy.** NETRF’s ongoing series of studies looked into why and how the immune system of NET patients does not recognize cancer as foreign and does not attack the cancer.
- **Liquid biopsy.** NETRF funded a study to learn how using blood—instead of tissue—biopsies could improve care in NETs.



Recruiting More Researchers to NETs

NETRF had significant success in “building the bench” to get more scientists looking for a cure by:

- Engaging best-in-class established researchers to begin work on NETs.
- Attracting up-and-coming talent to the field.
- In 2017, NETRF added many new talented investigators.
 - [Babak Behnam Azad, PhD](#), Johns Hopkins Medical Center
 - [Laura Banaszynski, PhD](#), UT Southwestern Medical Center
 - [Hans Clevers, MD, PhD](#), Hubrecht Institute, Netherlands
 - [Sharon Gorski, PhD](#), Genome Sciences Centre, Canada
 - [Nitya Raj, MD](#), Memorial Sloan Kettering Cancer Center
 - [Brian Untch, PhD](#), Memorial Sloan Kettering Cancer Center
 - [Qiao Zhou, PhD](#), Harvard University

In 2017, the number of researchers applying for funding from NETRF doubled. Thirty percent of the requests for funding came from researchers new to NETs.



“One of the best returns on investment NETRF can make is to recruit young creative talent to the field. Through our Pilot Research Grants program, we have achieved tremendous success in bringing truly dedicated, passionate people to help us improve outcomes and cures for NETs through research.”

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



“NETRF has invested \$20 million in cutting-edge research around the globe. With this funding and research, we are clearly advancing our understanding of this disease and bringing better clinical treatments to patients in need. My philanthropy includes NETRF each year because dollars equals research and research gets us closer to a cure.”

Steve Kaufer, CEO, TripAdvisor
and NETRF Board Member

This 2017 Accelerator Grant team met at a NETRF research symposium and learned—despite being on opposite sides of the U.S and the Atlantic Ocean—together they had the expertise and technology to try to find the cause of small intestinal NETs



Chrissie Thirlwell, MD, PhD; Matthew Meyerson, MD, PhD; Eric Nakakura, MD, PhD.

“I want to identify new treatments for my patients and understand what treatments to use when. To do that we are working to understand where these tumors come from and what makes them tick. Funding to do this is really rare, and I would say in my working lifetime this is the first time that such funds have been put towards studying neuroendocrine tumors, so it’s a fantastic opportunity.”

Chrissie Thirlwell, MD, PhD,
University College London
Cancer Institute



Together in the Search for a Cure

NETRF believes by working together we can move more quickly towards finding new treatments for NETs. Through its Annual Research Symposium, NETRF creates and maintains a unique atmosphere of collegiality, collaboration, and trust between researchers, providing a platform for scientists to openly share unpublished data. This has helped initiate many crucial collaborations resulting in much needed translational research with therapeutic potential.

- The 2017 NET Research Symposium brought together more than 100 NET investigators from around the world to create new partnerships.
- Three research grants totaling \$425,000 were awarded in collaboration with leading professional associations:
 - North American Neuroendocrine Tumor Society (NANETS)
 - American Association for Cancer Research (AACR)
 - Education and Research Foundation for Nuclear Medicine and Molecular Imaging (ERF)



Educating and Empowering Patients

NETRF champions the empowerment of neuroendocrine cancer patients with education about this uncommon disease and resources to improve quality of life.

- In 2017, NETRF supported four patient and caregiver conferences, including its first Midwest Conference. More than 600 patients attended all the conferences. Many more watched livestream feeds from home.
- NETRF increased its online resources offering practical information about symptom management and wellness, including online tools to find treatment teams, physicians, and support groups.
- For World NET Cancer Day in November, NETRF set new records in social media reach by collaborating with the International Neuroendocrine Cancer Alliance (INCA) in a global push to increase awareness of this rare cancer.



“You learn from the doctors, things you wouldn’t have time to talk to them about in the office visit and you have an opportunity to network with other patients about what they have been through and what you might expect if you are going to have a procedure.”

Gerri McDowell,
Attendee, NETRF Patient and
Family Conference



“There are not many lay accessible friendly sources of information for patients. I usually refer them to NETRF to watch the [NET101](#) video just to get the basics if they want information on emerging therapies. It is a really great resource for patients.”

Pam Kunz, MD
Stanford Cancer Center

A Beacon of Joy, Meg's Story

by her parents, Gaye and David Reynolds-Gooch

Soon after hearing Meg had an advanced stage of neuroendocrine carcinoma, Meg surprised us by commenting, "It could be so much worse." As a nurse on the medical unit at Seattle Children's Hospital, Meg was accustomed to working with kids with very serious chronic conditions.

Very early on we learned the power of connection and strength that comes from extended family and friends uniting to offer support and grounding amidst an incredible health challenge. #TeamMeg socks, designed by a friend, became a tangible symbol of support. Over 150 family and friends bought socks and tickets to an event that raised money to defer costs so Meg could live boldly at a time when she couldn't keep up her full-time schedule.

Team Meg socks were also fitting as Meg, a long-distance runner, did not allow cancer to define her or the way she lived her life. Cancer was an uninvited obstacle presenting hurdles that she literally ran right through and flew over with infinite grace, speed and strength. Meg never dipped in her zest for life overflowing with adventure, laughter, love. Meg's medical colleagues call Meg the "baby whisperer" with a special gift for nursing sick children that left permanent imprints on innumerable lives—patients, families, co-workers. Meg and her sister, Kate, always took a long run while waiting for results of her most recent scan. Meg continued long runs until two months before she died.

Meg's neuroendocrine oncologist called Meg's diagnosis a most complex case. Meg quickly learned how to research, interview and select the best oncologists and specialists and became a full partner in navigating evolving treatment options such as PRRT, which Meg underwent July through December 2016 in Basel, Switzerland. It was Meg who requested memorial gifts be given to the Neuroendocrine Tumor Research Foundation.

At Meg's Celebration of Life last September on the shores of Puget Sound, we again experienced the amazing power of connection. Over 450 family and friends from all walks of our lives gathered, intimately woven together by profound loss and desire to honor a life well-lived. Nurse Meg took care of us all and is forever in our hearts—running alongside, encouraging us to dream bigger, live stronger—finding purpose, laughter and joy each day.

Meg possessed infectious exuberance, which touched people throughout her life.

Once again Meg's community came together to honor Meg's request to support NETRF: nearly 150 friends and family gave donations to NETRF to honor our *Beacon of Joy*.

Meg's family. Left to Right: Ryan, Meg, Christopher, Kate, David, and Gaye



Garrett and Joan Born



The family, friends, and neighbors of Jacob Carwile, who died from NET at 35 years old in 2010, gather every year for a memorial golf tournament in Livingston, TN.

Power of Participation

Tribute gifts recognize and celebrate life events. Last year, NETRF received over 1,000 tribute gifts that honored:

- Friends and family members living with NETs
- The loss of a loved one
- Special occasions for a friend or family member
- Physicians who had an impact on families

The power of these gifts guarantees that our mission continues. When you make a tribute donation, you will receive an acknowledgment of your gift. NETRF also notifies the individual or family that you have chosen to honor, informing them of your thoughtfulness.

For more information on how to make a tribute gift, please visit netrf.org/donate.



Vicki Dailey organized an 82-mile bike trip from MD to PA as a tribute to her sister Debbie's seven-year journey with NETs.



The town of North Yarmouth, ME, gathered for a hunter's breakfast at the local fire station in tribute to three community members lost to NETs.



“As a patient, I support NETRF because I believe in their mission and realize how important research is. NETRF funds aggressive research strategies, and since my diagnosis, funding and progress have only increased. This helps me and other patients have hope for better treatments.”

Carol Branaman, Vice Chair,
NETRF Board of Directors



A Culture of Philanthropy

For more than a decade, NETRF has experienced rapid growth in research funding because of the generous gifts given from individuals, families, and private foundations who believe in our work. Whether a donor makes a gift of appreciated stock to avoid a capital gains tax, allocates a distribution from their Donor Advised Fund or includes NETRF in their estate plans, all types of contributions are welcomed and appreciated and have helped us accelerate progress in answering challenging questions about neuroendocrine cancer. We look forward to collaborating with new and longstanding donors on their future gifts.

The Foresight of the Petersen Foundation

In 2015, the Margie and Robert E. Petersen Foundation gave NETRF a significant gift of \$15 million, \$5 million of which was earmarked to establish an endowment fund. Due to their investment in our long-term sustainability, our endowment is now an opportunity for future funding. We are profoundly grateful to the Petersen Foundation and to all our donors who allow us to continue to do important work on behalf of the research community and NET patients.

For more information on ways of giving, please contact Susan Payson, Chief Development Officer, at susan.payson@netrf.org or (617) 946-1780.

“I was so impressed by the passion displayed by these brilliant men and women when discussing their NET research. And when you add to that their clear interest in collaborating with each other—in some cases across continents—I have to think new treatments and even cures for NETs will result. This is why I will continue to support NETRF.”

Tim Stanny, NETRF supporter

94% of NETRF Revenue in 2017 went to funding programs.



“In 2017, we were excited to fund powerhouse proposals that marry ground-breaking ideas with state-of-the-art technologies. These projects bring together some of the brightest minds in the field, to help transform the landscape of NET research.”

Effie Tzamelis, PhD,
NETRF Director of Research

Financial Report [→ Download financial report](#)

Balance Sheet 2017

Current Assets:

Cash and Equivalents	\$ 6,693,121
Contributions Receivable	\$ 749,154
Other Receivable	\$ 30,000
Prepaid Expenses	\$ 26,624

Total Current Assets	\$ 7,498,899
Investments	\$ 10,826,061
Contributions Receivable, long-term	\$ 489,131
Total Assets	\$ 18,814,091

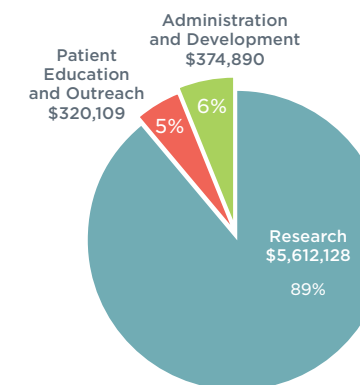
Current Liabilities:

Accounts Payable/Accrued Expenses	\$ 131,311
Grants Payable	\$ 1,830,772
Total Current Liabilities	\$ 1,944,083
Grants Payable-Long-term	\$ 2,547,828

Net Assets:	
Unrestricted	\$ 8,164,199
Temporarily Restricted	\$ 1,157,981
Permanently Restricted	\$ 5,000,000
Total Net Assets	\$ 14,322,180
Total Liabilities and Net Assets	\$ 18,814,091

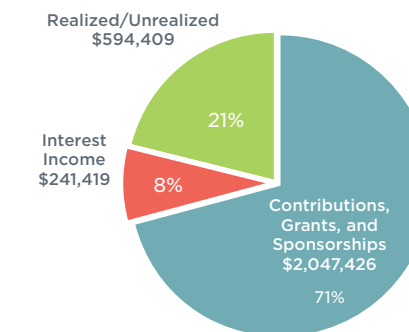
Revenues and Expenses 2017

Detail of Expenses



■ Patient Education and Outreach
■ Admin & Development
■ Research

Detail of Revenues



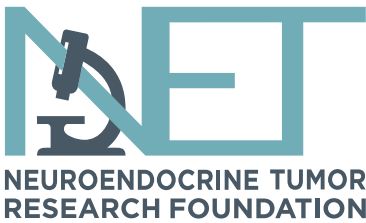
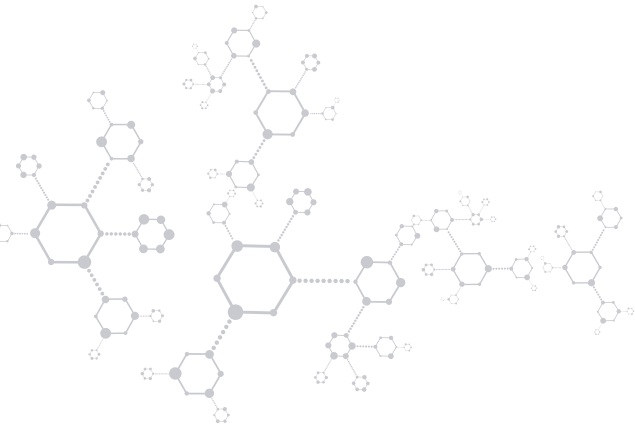
■ Interest Income
■ Realized/Unrealized
■ Contributions, Grants, and Sponsorships

2005–2017 Grantee Organizations

- Abramson Cancer Center, University of Pennsylvania
- Cambridge Research Institute
- Cancer Research UK
- Cold Spring Harbor Laboratory
- Columbia University
- Dana-Farber Cancer Institute
- Fred Hutchinson Cancer Research Center
- Genome Sciences Centre, Canada
- Harvard University
- Hubrecht Institute, Netherlands
- Johns Hopkins School of Medicine
- Sidney Kimmel Comprehensive Cancer Center, Johns Hopkins University
- Kings College London, UK
- Massachusetts General Hospital
- MD Anderson Cancer Center
- Memorial Sloan Kettering Cancer Center
- Paul Scherrer Institut, Switzerland
- Stanford University Cancer Center
- Tufts University School of Medicine
- University of California, San Francisco
- UCL Cancer Center, UK
- University of Massachusetts Medical Center
- University of Melbourne, Australia
- UT Southwestern Medical

Mission


The mission of the Neuroendocrine Tumor Research Foundation (NETRF) is to fund research to discover cures and more effective treatments for 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.



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(617) 946-1780
netrf.org

[Donate online at netrf.org/donate](https://netrf.org/donate)

 [@CureNETs](https://twitter.com/CureNETs)

 [@NETResearchFoundation](https://facebook.com/NETResearchFoundation)

 [@Neuroendocrine Tumor Research Foundation](https://youtube.com/NeuroendocrineTumorResearchFoundation)



NETRF was recognized for its strong financial position, transparency, and accountability for the third 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.