

Neuroendocrine Tumor
Research Foundation

2018 ANNUAL REPORT

*Improving, extending
and saving lives*



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NETRF-funded researcher Hans Clevers, MD, PhD, Hubrecht Institute, Netherlands, grows NET stem cells into miniature organs, called organoids, to use for large-scale drug testing. (Photo: European Patent Office)

spark
hope.

NET
NEUROENDOCRINE TUMOR
RESEARCH FOUNDATION



spark ANSWERS

The mission of the Neuroendocrine Tumor Research Foundation (NETRF) is to fund research to discover cures and more effective treatments for neuroendocrine cancer. NETRF is committed to improving the lives of patients, families, and caregivers affected by neuroendocrine cancer by providing information and educational resources.



“Individuals and families facing NETs want answers that can only be uncovered with quality, meaningful scientific research.”

Joseph Li, MD
Chairman, NETRF Board of Directors

Dear Friends,

In 2018, we had many reasons to Spark Hope at the Neuroendocrine Tumor Research Foundation (NETRF). NETRF celebrated the largest number of grants awarded in a single year, received record support from the community, and provided educational outreach to more patients in more locations.

The biggest clinical advance of the year, [peptide receptor radionuclide therapy \(PRRT\)](#), was approved in the U.S., providing an effective treatment for many patients. NETRF invested in several projects to understand better why some patients, but not others, respond to PRRT to explore the development of better, more targeted radiopharmaceuticals.

[We welcomed 15 grantees to our collaborative community of researchers. NETRF also expanded our research to lung NETs](#), with our first grant to study bronchial NETs. This segment of the neuroendocrine tumor (NET) population has been underrepresented in research and we are committed to change that.

NETRF [launched the Spark Hope campaign](#), an ambitious \$10 million drive to accelerate the pace of NET research well into the future. We are grateful to the Margie and Robert E. Petersen Foundation for providing the match for the largest fundraising effort in NETRF history. We are honored by the more than 1,800 donors who responded to help us Spark Hope for NET patients and their families.

On behalf of the NETRF [Board of Directors](#), [Scientific Advisors](#), and [staff](#), thank you for supporting NETRF's mission so enthusiastically in 2018.

Sincerely,

Elyse Gellerman
NETRF Chief Executive Officer



15

New funded
projects



12

Researchers
new to NETRF



\$4.4M

Million in research funding

2018 BOARD OF DIRECTORS

Joseph Li, MD
Chair

Carol Branaman
Vice Chair

Josh Mailman
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James Panagis, MD
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Stephen Blackwood

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Brendan Foley, Jr.

Todd Gilman

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Jonathan Soroff

Nicholas Vantzelfde

NETRF 2018 Annual Report

A new era for NETs

It was a year that stood out among others in the history of NET research. In 2018, the viewpoint changed to reveal a vast landscape of possibility.

NETRF grantees explored approaches beyond the current therapeutic options: surgery, somatostatin analogs, chemotherapy, and interventional radiology. We funded innovative ideas with the potential to transform treatment as we know it. In 2018, we supported investigations or newly approved studies of:

- [PRRT enhancements](#)
- [CAR T-cell therapy](#)
- [Cancer vaccine](#)
- [Smart chemotherapy](#)
- [Organoids](#)

These targeted approaches seek out NET cells for destruction, while minimizing damage to healthy cells.

Cracking the NET code

To identify and investigate new therapies, one needs to first understand how a NET develops and grows in order to understand how to divert or stop it. That's why NETRF funded laboratory research to decipher the underlying molecular processes and pathways of NETs.

- For [pancreatic NETs](#) (pNETs), researchers explored the role of DAXX/ATRX mutations, first discovered through NETRF-funded research, which occur in 43% of pNETs.
- In [small intestinal NETs](#), comprehensive molecular profiling points to the possibility that a specific combination of molecular changes synergistically may work together to cause small intestinal NETs.

“These new PRRT radioisotopes can deposit a very high amount of energy capable of killing microscopic deposits of tumor. I think this technology someday, when combined with surgery to remove cancer, could potentially represent a cure.”

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



BOARD OF
SCIENTIFIC ADVISORS

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Massachusetts General Hospital

George Fisher, MD, PhD
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Kettering Cancer Center

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Anil Rustgi, MD
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Ramesh Shivdasani, MD, PhD
Dana-Farber Cancer Institute,
Harvard Medical School

Chrissie Thirlwell, MD, PhD
University College London
Cancer Institute

Evan Vosburgh, MD
Yale University

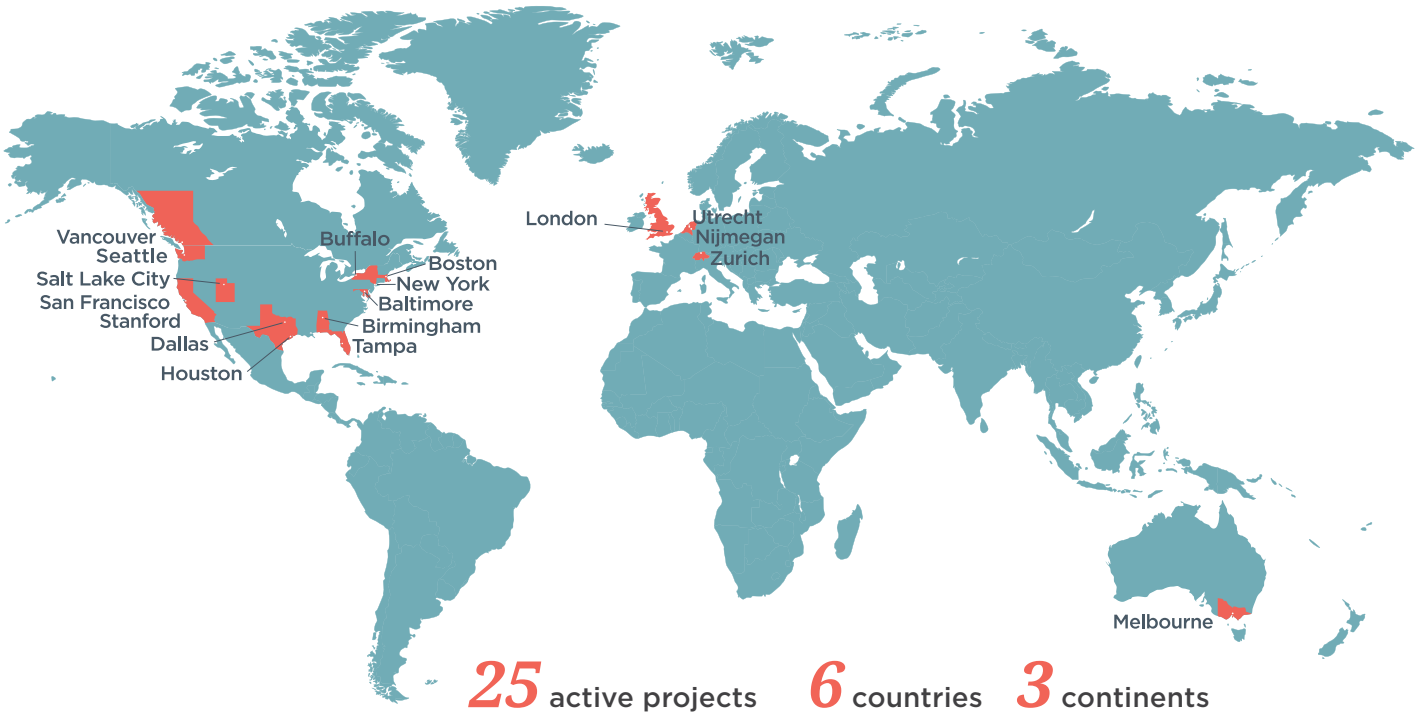
Funding the future of PRRT

In 2018, U.S. patients, families, and oncologists welcomed the [FDA approval](#) of a new radiopharmaceutical (Lutetium Lu-177 dotatate), which is delivered via PRRT. This new treatment option offers those with somatostatin receptor-expressing gastrointestinal and pancreatic NETs a chance for a longer life.

To increase the precision, safety, and role of PRRT, NETRF funded \$1.7 million in translational research to work toward:

- [Expanding PRRT to NETs without somatostatin receptors](#)
- [Developing novel radionuclides \(Tb-161, Ac-225\) with increased precision](#)
- [Investigating alpha-particle PRRT in lung NETs](#)
- [Binding radiopharmaceuticals more tightly to cancer cells to increase radiation accumulation](#)

Research locations 2018



Engaging the best and brightest

To accelerate our progress in achieving breakthrough discoveries in NETs, NETRF funds research by the best scientific minds in the world. [Five of the scientists helping NETRF advance our knowledge of NETs were ranked in the top 1% of scientists worldwide](#) in terms of influence by Clarivate Analytics.

Collaboration and cooperation

We believe we are better together than apart. NETRF encourages team science including a range of disciplines and often more than one institution. We also require that findings be shared widely and openly to bolster the field of NET research. Annually, we convene a [research symposium](#) where NET researchers and clinicians share progress, ideas, and perspectives on active, unpublished research.

Funded Institutions*

>> United States

Cold Spring Harbor Laboratory
Columbia University
Dana-Farber Cancer Institute
Fred Hutchinson Cancer Research Center
Harvard University
Johns Hopkins School of Medicine
MD Anderson Cancer Center
Massachusetts General Hospital
Memorial Sloan Kettering Cancer Center
Moffitt Cancer Center
Roswell Park Comprehensive Cancer Center
Stanford University Cancer Center
Tufts University School of Medicine
University of Alabama at Birmingham
University of California, San Francisco
University of Massachusetts
University of Pennsylvania
University of Wisconsin-Madison
UT Southwestern Medical Center

>> International

BC Cancer, Canada
Cancer Research UK
Genome Sciences Centre, Canada
Hubrecht Institute, Netherlands
Kings College London, UK
Paul Scherrer Institut, Switzerland
UCL Cancer Center, UK
University of Melbourne, Australia

*Since 2005



“I realized this is going to be a marathon and if I am going to persevere through it, I am going to need to have joy through it.”

David Van Bibber

Finding joy

David Van Bibber is the leader of the San Diego Neuroendocrine Tumor Support Group. A NET patient for many years, David provides comfort and information to other people facing a NET diagnosis.

Since his 2010 diagnosis at the age of 32, David's priorities and perspectives have changed. As a result, he has invested more deeply in his health, family, and community. Now, he is reaping the rewards of that investment and finding daily joy in his life. He has good days and bad days. But he always focuses on making the most of every day God has given him.

David has learned to focus his thoughts, energy, and actions on living for what matters most. It is a holistic approach involving his soul, mind, and body.

He turns to NETRF's newsletter and website for updates about the disease, which he shares with his fellow support group members. We thank David for sharing his story with our NETRF community.

spark AWARENESS

“There is so much to learn. You cannot get it on your own. You hear about the new things. I am on board with and have benefited from some of the new medications and tests. It's your life, what is more important?”

Shelley Walchle, RN
Attendee NETRF patient
and family NET conference



Empowering more patients in more places

Cancer is a physically, emotionally, spiritually, and socially challenging disease. For an uncommon cancer, those challenges are magnified. Local physicians may have never treated NETs. It can be hard to find a NET specialist and when you do, you may have to travel hundreds of miles for appointments. Treatments go beyond radiation and chemotherapy.

Suddenly, you need to understand terms like peptide receptor radionuclide therapy, interventional radiology, and Gallium-68 dotatate PET/CT.

All of this occurs at a time when you are weakened and worried, making it harder to know what to do next.

For these reasons, [NETRF expanded its patient and caregiver resources](#) to include more conference live stream broadcasts, support group presentations, increased social media content, and more online information about living with NETs.



1,300

Patients and caregivers in 10 cities attended conferences and support group presentations



21,000

Website searches for NET physicians or support groups



29,300

YouTube views of NETRF videos



Spark Hope campaign

NETRF launched Spark Hope, a \$10 million fundraising campaign, in 2018.

The Spark Hope campaign is fueled by a challenge grant generously given by the Margie and Robert E. Petersen Foundation. When gifts are made to the campaign, the Petersen Foundation matches them dollar-for-dollar up to \$5 million to raise \$10 million for NET research. In 2018, NETRF raised \$2.8 million towards the \$10 million goal. The Petersen Foundation has provided NETRF the opportunity to launch the most ambitious research effort we have ever undertaken to control and cure neuroendocrine cancers.



\$10M

Million Spark Hope goal



Healing through action

Sanjiv Jain partnered with NETRF to raise \$40,000 with a two-mile fundraising walk to honor his late wife, Sonya Jain, on World NET Cancer Awareness Day. Sonya Jain, founder, and former CEO, eGlobalTech, passed from neuroendocrine cancer in December 2017. “Despite her 15-year fight with cancer, Sonya lived life to the fullest—she founded eGlobalTech, raised two beautiful daughters, played sports, enjoyed yoga, and traveled worldwide during her short life,” said Sanjiv Jain.

Power of participation

Last year, more than 1,800 donors chose to give to NETRF. Charitable giving is personal, powerful, and truly an extension of people’s values.

More than two hundred families chose to honor their loved ones by establishing tribute funds to benefit NETRF.

Every gift is important so we can grant the needed funds it takes to fund the top research initiatives around the globe.

“I lean towards hope.”

Brendan and Deb Foley, from Dublin, Ohio, are major supporters of the Spark Hope campaign. They support NETRF on behalf of their teenaged son who has neuroendocrine cancer.

Brendan and Deb first became involved in NETRF as they searched for information about their son’s diagnosis and learned about the Foundation’s research. Since that time, they have pledged a major gift and challenged new donors to support NETRF research.

Brendan also joined the Board of Directors in the fall of 2018.

“Research and science have helped and cured other cancers,” says Brendan. “Why shouldn’t the same be true for neuroendocrine cancer?”



\$4.2M

Million raised in 2018



1,800+

Generous donors



44

States and 6 countries represented in donor community



Honoring Beth Ripston and her gift for future NET research

Beth Ripston was a successful investment consultant, a volunteer at her church, a loving family member, and a warm, funny person who enjoyed life. She was also a NET patient, a loyal donor, volunteer at NETRF, and a founder of the Big Apple NET Support Group. Beth passed away in October 2018. NETRF honors Beth's life and recognizes her bequest to ensure research momentum to help future NET patients.

"Beth had a true-oriented compass when it came to living her life. She lived each day to its fullest and never wasted time," said her brother, Neil. In 2016, Beth joined the NETRF Investment Committee, sharing her finance experience and helping to guide the Foundation's investment strategy. Beyond her professional expertise, Beth was a go-to person for newly diagnosed NET patients and participated in NETRF's NYC-area educational programs.

In recognition of her commitment, Beth included NETRF in her estate plans. Her generous estate gift helps ensure NET research will continue and her involvement with the Foundation will continue. We remember Beth fondly for her spirit and her contribution to NETRF.

Learn how to advance NET research in your [estate plans](#). Contact Susan Payson, NETRF Chief Development Officer at: susan.payson@netrf.org or 617.946.1782.

Financial stewardship and accountability

NETRF is recognized for its [financial stability, transparency, and accountability](#). We strategically invest our resources and thoughtfully steward every gift we receive.

Balance Sheet 2018

| | | | |
|-------------------------------------|----|----------------------|--|
| Current assets: | | | |
| Cash & equivalents | \$ | 2,395,071 | |
| Contributions receivable | | 1,784,485 | |
| Other receivable | | 33,291 | |
| Prepaid expenses | | 25,786 | |
| Total current assets | | 4,238,633 | |
| Investments | | | |
| Contributions receivable, long-term | | 14,453,554 | |
| | | 366,849 | |
| Total assets | | \$ 19,059,036 | |

Liabilities and Net Assets

| | | | |
|---|----|----------------------|--|
| Current liabilities: | | | |
| Accounts payable and accrued expenses | \$ | 187,462 | |
| Grants payable | | 3,476,680 | |
| Total current liabilities | | 3,664,142 | |
| Grants payable long term | | 3,045,765 | |
| Net assets: | | | |
| Without donor restrictions | | 6,650,615 | |
| With donor restrictions | | 5,698,514 | |
| Total net assets | | 12,349,129 | |
| Total liabilities & net assets | | \$ 19,059,036 | |

Staff
(as of June 2019)

Elyse Gellerman
Chief Executive Officer

Susan Payson
Chief Development Officer

John Kanki, PhD
Director of Research

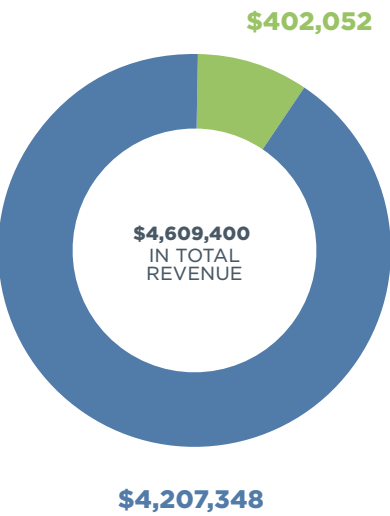
Laran Hyder
Director of Education and Outreach

Donna Dubuc
Director of Communications

93%

OF REVENUE DEVOTED TO RESEARCH AND EDUCATION PROGRAMS

Revenue and expenses 2018



- Contributions, Grants, and Sponsorships
- Investment Income



- Research
- Patient Education and Outreach
- Administration and Development




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