

15 Years Closer to a Cure



A Celebration of Progress Made Possible By You

Dear Friends,

When 2020 began, we had the highest hopes for the year. We had planned to travel to see so many of you at conferences, we looked forward to the continued progress of our funded researchers and our team was planning celebrations for [NETRF's 15th Anniversary](#). By March, it was clear the year would have challenges we could not have imagined. We left our office to work from home, put our suitcases back in the closet, and turned our attention to the ways in which we could meet the new needs of our researchers, patient community, and donors.

As we look back on 2020, we are proud to report progress despite the limitations imposed by the pandemic. NETRF's funded researchers around the world were out of their labs for several months, but they found ways to maintain their projects. We awarded grants to 11 new researchers in 2020 for promising approaches to NET biology and improved treatment.

NETRF surveyed our community about their COVID concerns and then used our existing educational channels to provide COVID information and resources. NETRF's patient conference and research symposium were virtual, and we are proud to report we attracted more attendees than ever before.

In the middle of all this, we began our 15th Anniversary celebration to pay tribute to those who helped to build the strong organization that is NETRF today.

NETRF is grateful for all the donors who gave more than 2,100 gifts totaling \$3.9 million in 2020. You have helped NETRF maintain research momentum despite the pandemic. We thank you for your loyalty and commitment.

On behalf of the NETRF Board of Directors, Scientific Advisors, and staff, please join us for this look at a unique 15th year.

With gratitude,



Elyse Gellerman
Chief Executive Officer



"If we looked at how much research into NETs was happening 15 years ago, there was spotty, occasional curiosity in the field. When I look now at how many different labs are involved, the sheer amount of global activity is ten-fold. A significant amount has been spawned by NETRF and we have a much higher level of work showing steady, consistent progress."

Steve Kaufer
NETRF Founding Board Member



BOARD OF DIRECTORS (AS OF 12/31/20)

Joe Li, MD, *Chair*
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James Panagis, MD
Carol Branaman (In Memoriam)

15 Years of Creating Hope



Dear Friends,

It is hard to believe that NETRF is 15 years old, founded by Nancy Lindholm

as Caring for Carcinoid, because no one else in the world was focused on supporting research in neuroendocrine cancer. NETRF recognized it had an incredibly important mission that was not and still is not being filled by any organization in this world.

I am very proud of what NETRF has done over the past 15 years. NETRF has been able to expand the number of researchers and the scope of research around the world. There have been numerous discoveries that would not have happened without NETRF support.

As we celebrate NETRF'S 15th anniversary, we recognize and thank those who had the initial vision for this organization and brought us to this point. We are truly grateful to everyone who has supported NETRF over the last 15 years. Your support enabled us to grow the scientific community, provide educational resources for patients and families, and be part of such an active and giving community.

Our mission has not changed since we began in 2005—to fund research to discover cures and more effective treatments for neuroendocrine cancers. Thanks to you, we are 15 years closer to a cure, and to extend, improve, and save lives of those affected by neuroendocrine cancer.

A handwritten signature in blue ink, appearing to read 'Joe Li'.

Joe Li, MD
Chair
NETRF Board of Directors

2005

Caring for Carcinoid was created by a patient, Nancy Lindholm when she was diagnosed with metastatic neuroendocrine cancer at 29 years old.

2005

NETRF funds more than \$1 million to three scientists in its first year to study gastrointestinal and pancreatic NETs.

2006

NETRF hosts first research symposium bringing together the leading experts in the field to discuss the latest developments and explore new collaborative efforts.

2009

NETRF hosts its first patient education conference to help patients better understand their diagnosis, learn about treatments and manage their symptoms.

2009

NETRF funds first international research project establishing a global presence.

2015

Caring for Carcinoid becomes the Neuroendocrine Tumor Research Foundation.

2019

NETRF launches the NETWise podcast and the Neuroendocrine Cancer Guide for Patients and Caregivers.

15 Years of Supporting the Most Promising Science

Groundbreaking Research Illuminates How Intestinal NETs Develop

In 2017, NETRF awarded one of its largest grants – the Petersen Accelerator Award – to Qiao Zhou, PhD from Cornell University and Ramesh Shivdasani, MD, PhD, at the Dana-Farber Cancer Institute. Their project, “[Epigenetic Regulators of Intestinal Endocrine Cells and Carcinoid Tumors](#),” focuses on how neuroendocrine tumors develop and grow in the intestines.

Zhou and Shivdasani set out to understand how neuroendocrine stem cells can go awry and give rise to tumors, and how the resulting NETs are different, in growth and function. Unlike most cancers, NETs are not primarily driven by the accumulation of DNA mutations, but likely by abnormal organization of DNA in the material that makes up a chromosome and defective gene regulation.

Proving this has been difficult for NET researchers because of the difficulties in gathering data from healthy neuroendocrine cells to compare with NETs. To solve this problem, Zhou and Shivdasani recently devised a novel method to generate large numbers of normal neuroendocrine cells from cultured human intestinal stem cells. Their efforts have enabled studies of DNA organization and cell-specific gene regulation at an unprecedented scale and have resulted

in the creation of detailed reference maps to compare with NETs.

Their latest findings uncovered defects that prevent NET cells from fully maturing, leaving them trapped in a state of unrestrained cell expansion. The insight into the aberrant development of intestinal NET cells sets the stage for researchers to propose and evaluate new therapeutic interventions. This ground-breaking work by Zhou and Shivdasani validates the importance of basic NET research, which has been a priority for NETRF funding since 2005.



Qiao Zhou
PhD, Cornell
University



\$30 MILLION
in NETRF-funded research in 15 years



94
funded studies in 10 countries



146
published scientific papers



5,064
citations of NETRF-funded research in scientific literature



>25%
NETRF has funded more than a quarter of all GEPNET research

BOARD OF SCIENTIFIC ADVISORS (AS OF 12/31/20)

Daniel Chung, MD, *Co-Chair*
George Fisher, MD, PhD, *Co-Chair*
Bradley E. Bernstein, MD, PhD
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Dawn E. Quelle, PhD
Anil Rustgi, MD
Ramesh Shivdasani, MD, PhD
Dung Thi Le, MD
Chrissie Thirlwell, MD, PhD

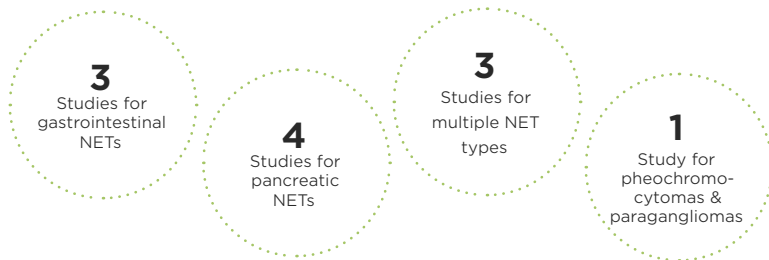
Emeritus members

Todd Golub, MD
Arnold Levine, PhD
Thomas J. Lynch Jr., MD
William Sellers, MD
Evan Vosburgh, MD

A Closer Look at the Science NETRF Made Possible in 2020

IN 2020, NETRF FUNDED 11 RESEARCH PROJECTS FOR \$2.82 MILLION

NETRF seeks research that may potentially transform what we know about neuroendocrine cancer, rather than achieve small incremental improvements. In 2020, [funded studies](#) are focusing on new approaches to control tumor growth, machine-learning assisted prognostic tools, and novel targets for PRRT.



AMERICAN INSTITUTIONS:

- Beckman Research Institute of the City of Hope, Duarte, CA
- Icahn School of Medicine at Mount Sinai, New York, NY
- University of California, Los Angeles, CA
- The University of Chicago
- The University of Texas Health Science Center at Houston
- The University of Texas Health Science Center at San Antonio
- UT Southwestern Medical Center, Dallas, TX

INTERNATIONAL INSTITUTIONS:

- Copenhagen University Hospital
- Princess Margaret Cancer Centre, part of University Health Network, Toronto, and the Ontario Institute for Cancer Research
- University College London
- University Hospital Klinikum rechts der Isar at Technical University Munich

Advancing our Understanding of Metastatic NETs

[A NETRF-Pilot Project led by Justin Annes, MD, PhD](#), from Stanford University identified a potential clinical biomarker that could help identify NET patients



whose disease is likely to advance rapidly and would benefit from more aggressive treatments. Dr. Annes found that when an enzyme called peptidylglycine α -amidating monooxygenase (PAM) is lacking or produced by NET cells at a reduced rate, the incidence of metastatic disease increased. If confirmed by additional laboratory and clinical studies, PAM could emerge as a new NET prognostic biomarker that may help predict the likelihood of disease spread, recurrence, and patient treatment response.

Advancing a New Generation of Researchers

Parijat Senapati, PhD, of the Beckman Research Institute of the City of Hope is part of the next generation of NET investigators that NETRF is committed to nurturing. NETRF presented Senapati with the [2020 Mentored Award](#) to research whether defects in the ATRX



and DAXX genes activate certain sequences in DNA that cause pancreatic NETs to form. Senapati's findings could be used to develop diagnostic biomarkers and immunotherapeutic strategies to target pancreatic NETs.

15 Years of Scientific Discoveries

2009

NETRF grantee discovers key predictor gene of NET response to chemotherapy.

2010

NETRF funds a project that discovers mutations on DAXX and ATRX genes that had never before been implicated in cancer.

2011

NETRF partners with the American Association for Cancer Research to fund first collaborative grants.

2017

NET organoid tumor models are created at Hubrecht Institute, Netherlands.

2018

NETRF funds first LungNET research project.

2019

NETRF-funded researchers discover new subtypes of non-functional pNETs that may help predict recurrence.

2019

NETRF expands research funding opportunities to include pheochromocytomas and paragangliomas.

2020

NET cell line created at the Broad Institute to be shared with researchers around the world.

“Watching NETRF’s impact on patients and on scientific progress is thrilling. The foundation has empowered patients and researchers alike to understand, and eventually conquer, a mysterious group of cancers.”

Ramesh Shivdasani, MD, PhD
Dana-Farber Cancer
Institute

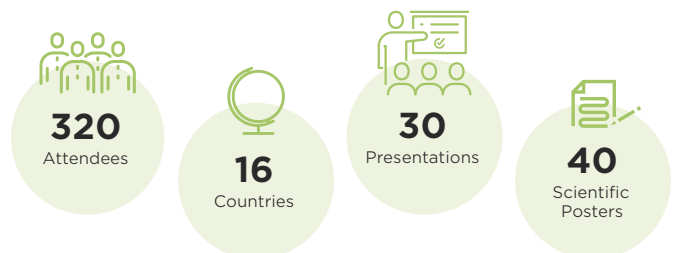


COVID-19 IMPACT

When labs shut down in the spring of 2020, NETRF offered all active grantees a no-cost, six-month extension to their projects and reaffirmed our funding commitment. All NETRF-funded researchers were able to resume their projects by the fall.

RESEARCH SYMPOSIUM GOES VIRTUAL

In response to the pandemic, the Research Symposium became a virtual meeting, attracting more than 320 attendees from throughout the world. This is almost three times the annual in-person attendance over the past several years. A scientific poster session was added for the first time, allowing more researchers to present their work. A total of 70 researchers presented their work from 16 countries.



15 Years of Meeting Patient Needs – No Matter the Challenge

Patient education was never as important than in 2020. When the COVID-19 pandemic began, the neuroendocrine cancer community had so many questions about their risk, their often-delayed treatments, and how to manage the medical and social impacts of lockdowns. NETRF stepped up to meet the challenge of providing educational resources by strengthening our existing programs to offer “anytime, anywhere” educational resources during this extraordinary period.

KNOW YOUR NETS

NETRF pivoted its Chicago patient education conference to a virtual event, crowdsourcing the topics the NET community wanted to see included in our program. More than 300 attended the virtual conference and there were more than 8,339 views of conference videos on our YouTube channel.



Dr. Mark Lewis,
an oncologist with Intermountain Healthcare and NETRF Board member, provided guidance and answers for NET patients in a special series of NETRF-produced COVID-19 videos.

“I am new to the NET community, so this was my first conference. I loved that it was virtual as I might not have been able to travel to a meeting. I learned a lot about NETs. I was very impressed with the big group of caring doctors and health care professionals. I really appreciate them sharing their knowledge and time. Thank you to NETRF for putting this all together for us.”

— 2020 Know Your NETs Attendee



14,800
*Downloads of
NETWise Podcast
Episodes*



2,149
*Patient Education
Guide Requests*



4,814
*Downloads of NETRF
videos and special
podcast episodes
on COVID-19*

15 Years of Commitment

Ed & Jan Peine

15 YEARS OF PHILANTHROPY

There are people who sincerely believe in making a difference in this world. Jan Peine was one of those people. She had a gentle heart and kind touch that made this world a better place for NET patients.

In 2005, Jan Peine was diagnosed with a neuroendocrine tumor. That marked the beginning of her nine-year journey with cancer. Throughout every step of the journey, Ed Peine, her husband of 32 years, walked alongside her.

Not long after Jan's diagnosis, Ed and Jan traveled to Pennsylvania for a patient education conference. That's where they met Nancy Lindholm and accepted her invitation to attend a small post-conference gathering where she told them about her idea to raise money for neuroendocrine cancer research. Ed recalls her saying "We need to have some research that focuses on our cancer."

From that day, Ed and Jan became loyal supporters of NETRF. "The fact that NETRF reaches out and makes sure that anyone who has a good research idea gets funding, with an impressive scientific panel to evaluate those ideas and decide who gets funding," says Ed. "That is impressive to me."

Jan gave back to the NET community in other ways as well. Jan formed a patient support group in Houston in 2006 and served as its leader until 2013. Regardless of whether she felt well or if she was struggling with the physical challenges of her own treatment, Jan was always there for other NET patients. Ed says she kept notes on every patient who reached out to her for education and support. She had tremendous energy to help fellow patients and guide them to the educational resources they sought.

Although Jan passed in 2014, Ed continues to support NETRF through a gift every year in the hope that research will continue to advance our ability to prolong the lives of those with neuroendocrine cancer. "I would consider research to be a success if it adds to the quantity and quality of life," says Ed.

In recognition of 15 years of consecutive giving, NETRF has named Ed Peine a member of our Founders Giving Society.



2020 FUNDRAISING BY THE NUMBERS



**\$3.9
million in
fundraising**



**2,100
gifts**



**1,300
family
members
& friends**
*gave in tribute to
loved ones*



**Donors from
47 states &
10 countries**



**87%
87 cents of
every dollar**
*spent in 2020 supported
research and education*

15 Years of Unparalleled Generosity

Every gift to NETRF makes an impact on the patients and families of today and tomorrow. In 2020, we created the [NETRF Giving Societies](#) to honor our most dedicated, longstanding donors. We thank you for believing in our mission and for standing by us through the years. Your generosity makes it possible for us to fund critical research in neuroendocrine cancers.

FOUNDERS

Founders' Society members have given gifts to NETRF every year since we began as Caring for Carcinoid. Thank you for 15 years of philanthropy.

ED PEINE | STEVE AND LISA KAUFER | ANNE DOYLE

CHAMPIONS

Our Champions have supported NETRF for more than a decade. They are part of the cornerstone of NETRF's next 15 years of advancement.

Anania Family

Paul Anderson

James Beatty

Mark and Cindy Blotner

Gail Borgen

Tim and Carol Branaman

John Caruso

Harvey and Mary Beth Cody

Lesley and Ronnie Compton

Jeanette Concilio

Nicole Feeley

Wayne Firsty

Jennifer Flaniken

Robert and Kristina Frick

Paul Godlewski

Samuel Greenfield and

Patricia Jackson

Blair and Dori Haas

John Harris

Lois Hirt

Petra Kernahan

Joseph Li, MD

Ted and Susan McCullough

Karen Bopp and Elliott McEntee

Bill and Marisa Panagis

James Panagis, MD and

Terese Panagis

Don and Susan Pine

Victor Rhodes

Jason and Helen Seltzer

Melissa Suman

Nick Vantzelfde and Lauren Erb

Philip Wolf

ADVOCATES

The Advocates represents our largest society and includes more than 150 donors. Each member of this society has been with us for more than five years. Their support has fueled the acceleration in NET research and better treatments for patients.



For a listing of all the members of the [NETRF Advocates Society](#), please visit our website. We've created a special page to honor their philanthropy. To visit, scan the camera of your smart phone over the QR code and tap the link.

A PARTNER IN FUNDING CRITICAL RESEARCH

NETRF is grateful for the tremendous support and dedication of the **Goldhirsh-Yellin Foundation**. Since 2013, they have been an invaluable partner in funding research for cures and treatments for NET patients.

15 Years of Extraordinary Support

"I remember with enormous fondness and admiration, Nancy Lindholm, who founded the Caring for Carcinoid Foundation 15 years ago. In the beginning, we were a scrappy and small organization, but Nancy's vision and fierce intelligence inspired an extraordinary standard that continues to be a hallmark of NETRF, for superlative research, collaboration, and results."

Anne Doyle
Former NETRF Board Chair



"When my daughter was diagnosed and I was learning about the disease, there was no debate in my mind that NETRF was way ahead. The reason I give annually is that it is remarkable to see how many grants have been given to scientists. That gives us hope. My most obvious and ambitious wish for the future is a cure. It is important to my family as well as thousands of patients."

Dale Conklin
NETRF Donor



"I was brought into the NETRF community because of a unique scientific expertise. It has been amazing to interact with other outstanding scientists and clinicians who have made major contributions to our understanding of neuroendocrine tumor biology and have expanded treatment options for patients."

Guillermina Lozano, PhD
NETRF Board of Scientific Advisors



Since our founding in 2005, NETRF has received more than 25,000 gifts. That's an extraordinary commitment to finding a cure for neuroendocrine cancer. This generosity has enabled NETRF to become the largest private funder of NET research. We are grateful for every donor and every gift. Thank you.

A GIFT THAT TRANSFORMED NETRF

In 2015, the Margie and Robert E. Petersen Foundation made a truly transformational \$15 million gift to NETRF. Robert E. Petersen was a giant in publishing and died



from neuroendocrine cancer in 2007. The three-year gift fueled NETRF's ability to launch the most aggressive research effort ever undertaken to understand and treat neuroendocrine cancer. NETRF developed new research grant opportunities including the Petersen Accelerator Award, significantly increased the dollars awarded for research each year, and vastly expanded our global reach. The gift also established an endowment fund to support NET research in perpetuity.

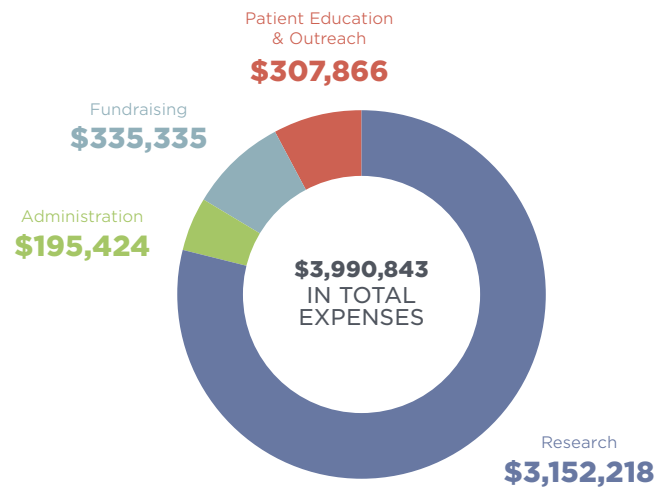
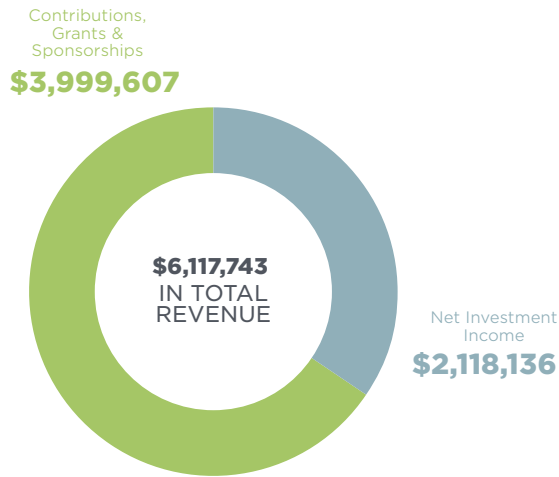
In 2018, the Petersen Foundation again stepped up to support NETRF, with a \$5 million matching grant to launch our \$10 million Spark Hope campaign. With this support, and gifts from 3,900 donors, NETRF celebrated the completion of the \$10 million campaign in 2020.

We are enormously grateful and honored by the Margie and Robert E. Petersen Foundation's commitment and investment in our mission.

spark
hope.

AUDITED FINANCIALS FOR 2020

15 Years of Careful Financial Stewardship



Assets

Current assets:

Cash & equivalents	\$	4,321,077
Contributions receivable		491,922
Other receivable		88,791
Prepaid expenses		18,701

Total current assets 4,920,491

Investments 18,729,001

Contributions receivable, long-term 130,000

Total assets \$ 23,779,492

Liabilities and Net Assets

Current liabilities:

Accounts payable and accrued expenses	\$	159,368
Grants payable		6,002,235

Total current liabilities 6,161,603

Grants payable long-term 2,208,013

Net assets:

Without donor restrictions		7,743,954
With donor restrictions		7,665,922

Total net assets 15,409,876

Total liabilities & net assets \$ 23,779,492

NETRF STAFF

(AS OF 6/1/21)

Elyse Gellerman
Chief Executive Officer

Susan Payson
Chief Development Officer

John Kanki, PhD
Director of Research

Melissa Phillips
Director of Communications

Eva May
Development Associate

Jennifer Long
Science Writer

15 Years Closer to a Cure

At NETRF, we are celebrating our 15th Anniversary and the people who made this milestone possible. You'll find more of these remarkable individuals featured throughout this special report. We are forever grateful for the commitment of our patients, physicians, researchers and donors and for those who shepherded this organization over the last decade and a half. Thank you for your dedication to finding a cure for neuroendocrine cancer.

"Congratulations to NETRF on 15 years of supporting patients and driving progress to defeat neuroendocrine cancer. I was honored to serve as NETRF's Executive Director for over five truly transformational years, working with our dedicated Board, Scientific Advisors, and "small but mighty" staff."

Ron Hollander
Former NETRF Executive
Director



"My wife and I became interested in NETRF as a way to move research forward for a disease that is underserved and underfunded. We hope that with increased funding and awareness we can ultimately cure this disease."

Dr. William Sellers
Board of Scientific Advisors
Emeritus



"I'm proudest of the community of researchers that NETRF assembled. We did not just attract them, but we nurtured them so they would stay intellectually curious about NETs."

Lauren Erb
Former NETRF Executive
Director



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@CureNETs @NETRF NETRF netresearch

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