



DRIVING
DISCOVERY



AN ABUNDANCE OF GRATITUDE

Dear Friends,

I am continually inspired and humbled by the dedication of our community of scientists and the gratitude of the patients and families we serve. As I look back on 2022, I'm proud that our NETRF staff, Board of Directors, Scientific Advisors, grantees, and volunteers collectively made a tremendous impact on NET research and patient education.

Impact drives all of us at NETRF—from funding an early-career scientist who, without our funding, would not be able to pursue a new NET discovery, to talking to an overwhelmed, newly-diagnosed person with NETs who finds information and reassurance in our NET Guide and NETWise podcast. It's in our DNA and we remain true to our mission since we began in 2005 and every day since.

Our 2022 research funding brings NETRF's lifetime investment to \$36 million, sparking discoveries

that are advancing science and unlocking some of the mysteries of NETs that continue to elude us. As an organization, we created a new strategic plan for the future and recruited new talented staff members to chart our course to new discoveries and new ways to serve our patient community.

First and foremost, thank you to our donors who make our work, and the work of so many scientists around the world, possible. NETRF could not achieve this impact without you. You are valued

partners in our progress. Please enjoy our 2022 Annual Report and accept our sincere gratitude.


Elyse Gellerman
Chief Executive Officer



IMPRESSIVE PROGRESS

Dear Friends,

I want to thank you and our entire NETRF community for your support in 2022. What we collectively achieved was impressive. NETRF funded fourteen researchers determined to find new treatments and cures for neuroendocrine cancer, gathered our global grantees at the first in-person Margie & Robert E. Petersen Research Symposium since 2019, and provided education to thousands of NET patients and their families.

As the leading private global funder of NET research, NETRF plays a pivotal role in attracting and energizing talented scientists to advance NET discoveries. NETRF is often the only source of financial support for researchers eager to study NETs. We are proud of our leadership in supporting these NET trailblazers, building a vibrant, collaborative scientific community, and ensuring the promise of future discoveries.

Yes, we are proud of our accomplishments in 2022. Thank you for your generosity. But we cannot rest until everyone with NETs has more treatment options and a cure. We have much more work to do, and we need your help.

As you review NETRF's 2022 Annual Report, we hope you will be inspired to continue to support NETRF, so we can pursue our vital and life-changing

work to provide brighter futures for people living with NETs.


Todd Gilman
President, NETRF
Board of Directors

The Neuroendocrine Tumor Research Foundation is the largest private global funder of NET research and the leading resource for expert patient education and support.

NETRF STAFF

(AS OF 12/31/2022)

Elyse Gellerman | *Chief Executive Officer*
John Kanki, PhD | *Director of Research*
Susan Harrington | *Chief Development Officer*
Christine Coffey | *Director of Communications*
Jessica Thomas | *Director of Patient Education*
Laken Baird | *Development Coordinator*
Jennifer Long | *Science Writer*

BOARD OF DIRECTORS

(AS OF 12/31/2022)

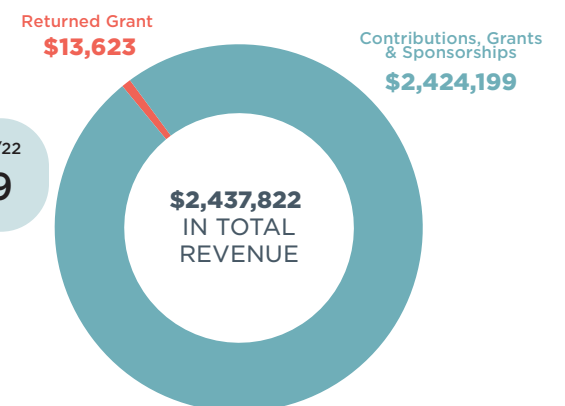
Todd Gilman | *President*
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Stephen Blackwood
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Steve Kaufer
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Jonathan Soroff

EMERITUS MEMBERS:

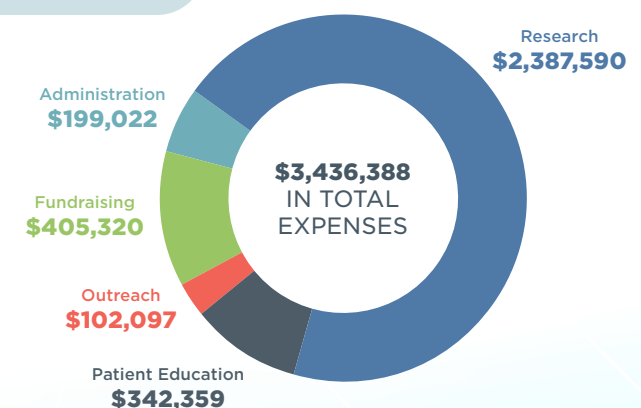
Nicholas Vantzelfde
James Panagis, MD
Carol Branaman (In Memorium)

2022 REVENUES AND EXPENSES

Total Net Assets as of 12/31/22
\$14,008,789



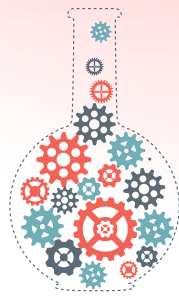
82 cents of every dollar raised by NETRF is invested in research and education.



FROM NETRF AUDITED FINANCIALS

*“The quality of the scientific presentations
has been absolutely superb.”*

*~ Chrissie Thirlwell, MD, PhD,
Co-chair, NETRF Board of Scientific Advisors*



2022

Margie & Robert E. Petersen

**NEUROENDOCRINE TUMOR
RESEARCH SYMPOSIUM**

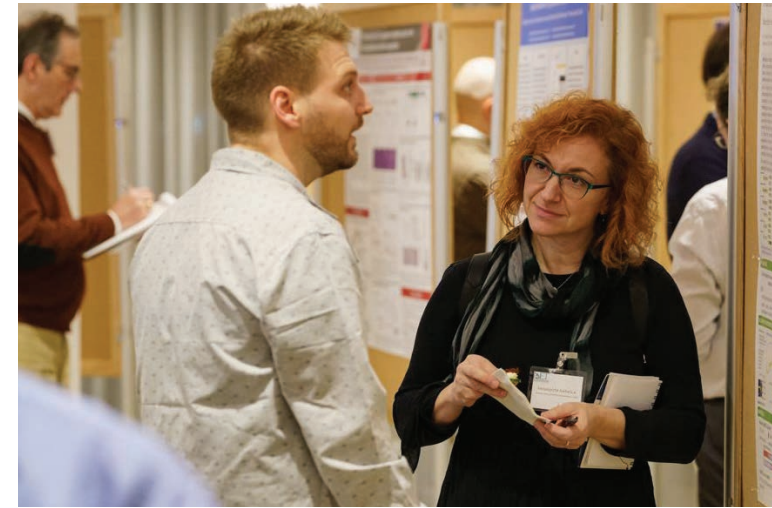
One of the hallmarks of NETRF’s annual Research Symposium is collaboration between scientists. In November 2022, we were proud to return to an in-person Margie & Robert E. Petersen Neuroendocrine Tumor Research Symposium. More than 100 researchers attended in Boston, with more than 100 tuned in from around the world. There was tremendous energy and enthusiasm as these leaders in the field shared their discoveries.

The impressive work presented illustrated NETRF’s strategic funding of basic and translational research to better understand NET tumor biology, which is crucial to developing new treatments.

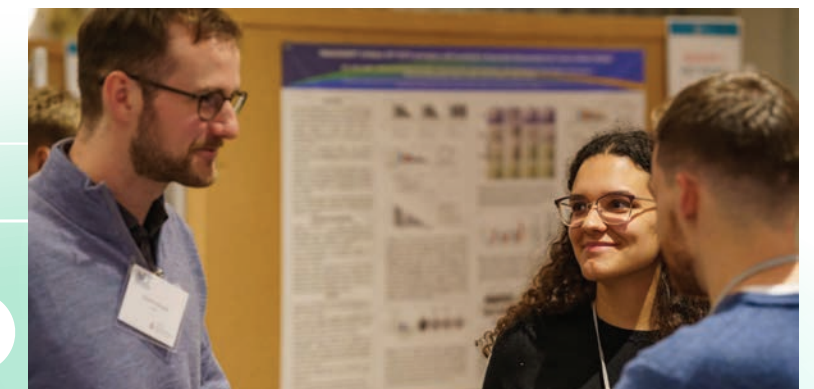
NETRF scientific leaders also introduced the new NET Models Consortium, an international group of investigators focusing on growing and distributing NET tumor models. A lack of models is a significant obstacle to the advancement of NET research. NETRF has invested millions of dollars to fund scientists who



have generated new tumor models. The Consortium is designed to ensure that these models are shared with any researchers who need them.



The symposium kicked off with a welcome reception that showcased more than 20 researchers presenting posters of their work.





In 2022, NETRF-funded research yielded discoveries and advanced our understanding of NETs and how they can be treated. Several of these discoveries have the potential to improve NET treatment. Sixteen of our grantees published scientific papers in respected journals.

Dr. Andreas Kjaer, in a 2022 paper published in the *Journal of Nuclear Medicine*, reported the results of a NETRF-funded prospective clinical trial at Copenhagen University Hospital. The trial confirmed that a biomarker called “uPAR” is expressed in both low-grade and high-grade neuroendocrine tumors. Moreover, high uPAR expression was associated with poor prognosis. Dr. Kjaer’s findings could have a significant impact on the diagnosis, prognosis, and treatment of NETs. The presence and high or low expression of uPAR could help physicians better assess a patient’s risk of progression and metastasis. The findings also suggest uPAR could be a receptor for radionuclide therapy, with the possibility of targeting tumors that have high uPAR expression and poor prognosis. Dr. Kjaer is the recipient of a 2020 NETRF Investigator Award.

“Researchers entering the NET field can apply expertise that they have in other types of cancer to drive innovation in NET research. It’s supporting careers and sparking collaboration because funding for these scientists builds the community.”

- Dawn Quelle, PhD, Co-chair, NETRF Board of Scientific Advisors



In a 2022 cover article in *Cell Reports*, Dr. James Bibb, Dr. Priyanka Gupta, PhD, and their team reported on their discovery of a chain of errors in cell metabolism that give rise to pheochromocytoma tumors.

This is a major advance in our understanding of how alterations in cell metabolism provoke neuroendocrine cancer cells, and trigger those cells to divide uncontrollably. The discovery of this new cascade of chain reactions has revealed several new potential anti-cancer drug targets. The study also has yielded a new animal model for this form of neuroendocrine cancer, which can be used to test new anti-cancer treatments. Dr. Bibb is the recipient of a NETRF 2021 Accelerator Award for similar work in PNET Modeling, Mechanisms, and Experimental Treatment. According to Dr. Bibb, this work “advances our understanding of how alterations in metabolism drive cancer and hopefully will allow us to bring forward more effective treatments.”

2022 GRANTS

mTORC1 Signaling Drives Amino Acid Biosynthesis to Promote PanNET Growth
Scott André Oakes, MD | The University of Chicago

Radiosensitizing NETs: A Two-Pronged Approach Using ERA and Pin1 Inhibition
Xavier Keutgen, MD | The University of Chicago

Reconciling Lung Carcinoids Histopathological and Molecular Classifications
Matthieu Foll, PhD | International Agency for Research on Cancer

COPPER PET with 61Cu-NODAGA-LM3 for the Detection of Neuroendocrine Tumors
Melpomeni Fani, PhD | University Hospital Basel

Increasing the Therapeutic Window in PRRT with Long-Acting SSAs
Daphne de Vries-Huizing, PhD | Netherlands Cancer Institute
Generously funded by ITM

Biopsy Specimen Molecular Stratification of Metastatic Pulmonary Carcinoid
Jules Derks, MD, PhD | Maastricht University

Characterizing Drug-Tolerant Persister Cells in Relapsed High Grade Neuroendocrine Carcinomas
Carl Gay, MD, PhD | The University of Texas MD Anderson Cancer Center
Generously Funded by The Martha O'Donnell Pagel Fund for Research of Rare Cancers

Defining the Multicellular Ecosystem of Nonmetastatic & Metastatic PanNETs
Aatur D. Singhi, MD, PhD | University of Pittsburgh
Generously Funded by the Karpus Family Foundation

Establishment of Novel PDXovo Models for Neuroendocrine Neoplasms
Iacovos Michael, PhD | Sunnybrook Research Institute

Personalized Immunotherapy for Atypical Pulmonary Carcinoids
Kevin McHugh, PhD | Rice University

Spatial Transcriptomic Profiling of the PanNET Tumor Microenvironment
Christopher Heaphy, PhD | Boston Medical Center

Targeting Serotonin Metabolism in SBNETs
Po Hien Ear, PhD | The University of Iowa

Development of a Novel Anti-SSTR Bispecific T-cell Engager (BiTE)-like Molecule for the Treatment of Neuroendocrine Tumors (NETs)
Eleonora Pelle, MD | Moffitt Cancer Center
This grant was issued in collaboration with NANETS

Improving Imaging and Radiotherapy of NETs by Endocytic Modulation of Somatostatin Receptors
Patricia Ribeiro Pereira, PhD | Washington University
This grant was issued in collaboration with the Education and Research Foundation for Nuclear Medicine and Molecular Imaging (ERF).

TRANSFORMATIONAL FUNDING FOR BURGEONING SCIENTISTS:



KEVIN McHUGH, PhD

“NETRF funding has had an enormous effect on my career as a young scientist by providing me with support to pursue a potentially transformative treatment for NETs using cutting-edge engineering tools.”



DAPHNE De VRIES-HUIZING, PhD

“The NETRF funding enabled us to investigate the effect of long-acting somatostatin analogues on the uptake of peptide receptor radionuclide therapy (PRRT). Thanks to NETRF we can study methods to advance the PRRT treatment and improve the quality of life of patients with neuroendocrine tumors, now and continuously in the future.”



MATTHIEU FOLL, PhD

“Receiving NETRF funding has played a significant role in my research career, especially considering the challenges in securing financial support within the rare cancers field. NETRF’s backing has provided stability for my work in this area, while also connecting me with an incredible network of fellow researchers. These connections have opened up various collaborative opportunities, enhancing the scope and influence of our research. Furthermore, being associated with past NETRF awardees, who are known for their exceptional contributions to the field, has also been a tremendous honor and recognition by my peers.”

Patient Education matters. NETRF is committed to providing credible, current and meaningful patient education to the NET community.



The 2022 Know Your NETs conference was a success. We welcomed 816 unique viewers for the conference representing a 63.8% increase of new viewers compared to 2021's conference. The conference generated another 6,320 post event views on NETRF's YouTube channel.

Conference Attendee Feedback:

- “ Topics were exactly what I wanted to know more about.”
- NET patient from Holland, Michigan
- “ Wonderful, comprehensive and useful content in every presentation. Seamless transitions from one presentation to the next.” - NET patient from Falmouth, MA
- “ Relevant, balanced, promising.”
- NET patient from Toronto, Canada
- “ Hearing about up to date treatments. These conferences are invaluable. You always learn new things.”
- NET patient from Ridley Park, PA

The NET patient's voice matters. Annually, NETRF uses a crowd sourcing survey to learn what NET patients and caregivers want to know more about and what is important to them.



NET Patient Guide distribution through the years:

- 2022- 1891
- 2021- 1659
- 2020- 1785

In June of 2022, NETRF released an expanded and updated version of our NET Patient Guide. Guides have been sent to NET patients & caregivers, cancer clinics, providers and support groups.



62,300 views of educational videos through our NETRF YouTube channel

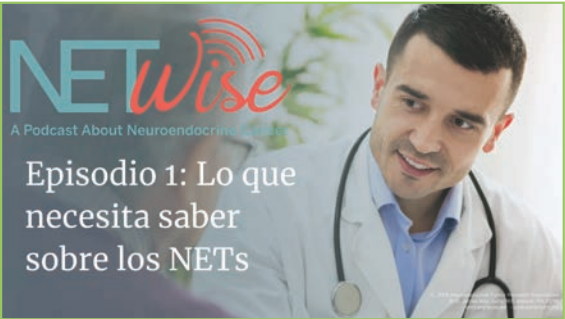


NETWise is a podcast for NET patients and caregivers that features NET specialists and NET patients. In 2022 the podcast saw a unique monthly audience reach of over 10k. NETWise has a global reach of over 93 countries.

In 2022 we added new episodes to NETWise including two episodes about NET research which help educate our listeners about basic and translational research. We will continue to produce new episodes related to living with and thriving with NETs.

Your NET Story Matters.

Thank you to our NET patients and caregivers who have shared their story on NETWise.



Representation matters:

In November, NETRF released our first NETWise episode and infographic for the Spanish-speaking community. We have also launched a Spanish resources page on our website.



Our Director of Patient Education, Jessica Thomas, LCSW, served as an expert panelist at the 2022 NORD Breakthrough Summit discussing mental health and rare cancer.



FACES OF PHILANTHROPY

CARRIE CAMINO

When Carrie Camino felt a “little twinge” in her abdomen - almost like a muscle pull - she was fortunate that her doctor took her concerns seriously. Within hours, Carrie was sent for a CT scan and the next day her doctor notified her that she had a mass on her pancreas. While her initial surgery was deemed successful and the tumor was removed, a year later neuroendocrine tumors were found on her liver.

As Carrie began a new course of treatment, she wanted to better understand her options so that she could live her fullest life. She reached out to NETRF for resources.

“I was so grateful to speak with NETRF. They understood my journey and my wish to lead a healthy, active life, not only for myself, but for my husband and daughter. They connected me to a local support group where I met a woman, very similar to me, who graciously spent hours talking with me and sharing her experience with NETs. If I hadn’t found her and NETRF, I don’t know where I’d be. And I hope that

someday I can be that comforting resource for someone who is newly diagnosed.”

Carrie’s 13 year-old daughter and her friends rallied around her. Together they hosted a lemonade stand and then a bake sale, raising nearly \$4,000 for NETRF. Carrie also made a personal gift in support of NETRF’s Giving Tuesday campaign.

“There have been some beautiful and meaningful aspects of this journey so far, and we choose to focus on the positive elements. We will continue to donate to NETRF because we know that NETRF-funded researchers are passionate about finding better treatments and a cure - they are thinking about this 24/7 and they are going after it. The promise and hope inspired by ongoing research and the latest treatments is exciting!”



JIM JUNGSTEN

Jim Jungsten met Sheryl Sorem, his soulmate, on what was supposed to be just another average workday. “Sheryl brought joy to my life every single day. We packed a lot of life into our seven years together.”

Sheryl was diagnosed with Stage 3 colon cancer in October of 2020. After many months of radiation and chemotherapy to shrink her tumors, she underwent successful surgery in July 2021 to remove the cancer.

“The doctor was very happy with the surgery. We thought we were past the bad times, but about a month after her surgery we got a call from the surgeon; he sent a portion of Sheryl’s tumor to the Mayo Clinic for analysis, and it came back indicating Sheryl had metastatic neuroendocrine cancer. She was gone within a month.”

Sheryl was an athlete and an avid golfer, so Jim organized and hosted a golf tournament in Sheryl’s honor last summer and donated proceeds to NETRF.

“My friends, family and golf community were witness to our experience and continue to support me and my devotion to making a difference for people navigating this disease. My mission now in life since Sheryl passed is to fund research to find a cure for this terrible disease. I will raise money for NETRF as long as I draw breath. People need to know about this insidious disease, where to find help and what questions to ask. I know Sheryl would expect nothing less from me, so that’s how I honor her life and keep her memory alive.”

“I want to fund a grant in her name - I want her name to be synonymous with hope and discovery and progress.”



BRITTANY HOLZHAUER

Brittany dealt with persistent and unexplained gastrointestinal issues for most of her adult life. But between the arrival of her daughter, Lorelei, in 2019 and her son, Dean, in 2021, Brittany’s symptoms worsened; she began experiencing chest pain, night sweats, and flushing.

“I attributed my symptoms to being post-partum and breastfeeding, but still I went to see my primary care provider. After several scans and tests, we got my diagnosis: Stage IV Pancreatic Neuroendocrine Tumors (pNET). The diagnosis was overwhelming. I went from being proud of my career and new family - everything that I worked so hard for - to feeling like I was losing it all in seconds. My heart broke thinking about my children and what this diagnosis would mean for them.”

What’s more, when Brittany went back and reviewed her scans from 10 years prior, the tumors were visible on her pancreas and liver even at that time. Because they were not identified, she continued to be misdiagnosed for a full decade.

“But, I come from a family of do-ers. Once I had a definitive diagnosis, my family and I started The CureNET Project to raise money to fund

NETRF research, and also to support other NET patients facing financial challenges while they seek treatment. I’m a pharmacist, so I know and appreciate the importance of science, research, and discovery. Partnering with NETRF, together we can help advance NET research and find better treatments and a cure.”

Since launching The CureNET Project, Brittany, her family, and her community have raised and donated more than \$70,000 to NETRF with no plans of stopping.

“I know how lucky I am to have a huge support system and resources to ease my burden, but many others don’t have the same support to get the care they need. We will always help whenever we can.”



TERESA RYSSEMUS

Originally from Bogotá, Colombia, Teresa was just 20 when she met Henk, a Dutchman, and together they moved to California to raise their five children and launch an electronic manufacturing business. When Henk was first diagnosed with liver NETs more than 20 years ago, Teresa and Henk thought that a cancer diagnosis meant that his time would be short-lived.

“We dove into Henk’s illness, trying to learn as much as we could about this rare cancer and the treatment options available, crisscrossing the country to attend patient conferences and speak with the experts.”

Teresa and Henk were inspired to help raise awareness and advance NET research and became enduring donors to NETRF as members of our Advocates Giving Society. After decades of thriving, Henk passed away. Teresa remains grateful, though, for the time they had together.

“Thanks to NETRF and their research, Henk had such a good quality of life for a long time.” She continues to support NETRF to help future generations of her family and others affected by NETs, including those who may not have the financial resources to travel for treatment.

“I contribute to NETRF because I want to ensure that each person - no matter their income or language - can access the best treatment options. Not everyone can do that. I want to help change that with NETRF.”



WE ARE GRATEFUL TO OUR GENEROUS PARTNERS LIKE **YOU** WHO **PLAY A VITAL ROLE** IN HELPING US ACHIEVE **BREAKTHROUGH** **NET DISCOVERIES.**

Your support has a multiplier effect on the NET research landscape, unlocking NET mysteries and propelling better treatments. Your gifts also help provide the most credible patient education worldwide. Through your partnership, we are working to save and improve lives—today and in the future.

There are many ways your generosity can make an impact:

- Renew your Annual Gift
- Become a Monthly Donor
- Make a Tribute Gift
- Establish a Bequest or Planned Gift
- Host an Event or Online Fundraiser
- Double Your Impact with a Corporate Match
- Make a Gift via a Donor Advised Fund
- Donate Stock and Bonds
- Make a Gift from an IRA Account
- Become a Corporate Sponsor

To make your gift today, please visit netrf.org/give-now
Every gift matters. Thank you!



WE PAY SPECIAL TRIBUTE TO MEMBERS OF OUR GIVING SOCIETIES,

enduring partners who have made ongoing investments in NET research. We celebrate your integral partnership and are thankful for your very generous philanthropy.

Founders:

Donors since our inception in 2005

Champions:

Donors of 10-16 years

Advocates:

Donors of 5-9 years



A SPECIAL THANKS TO OUR DONORS, BOARD MEMBERS, AND GRANTEES

who joined NETRF to celebrate the transformational impact of the Margie and Robert E. Petersen Foundation last fall at the Petersen Automotive Museum in Los Angeles. We are grateful to the Petersen Foundation Trustees for their partnership!

