

2021 ANNUAL REPORT

A Tribute to Margie & Robert E. Petersen and The Petersen Foundation



# An abundance of gratitude.



## Dear Friends,

I am proud to present NETRF's 2021 annual report. As you will see in these pages, NETRF has continued its leadership in NET research funding and patient education, at a time when our work in both areas is needed more than ever before.

As we look back on 2021, we want to thank all our donors who helped NETRF fund the largest group of grantees in our history, with a special thank you to the members of our Giving Societies, our most loyal supporters; Without all of you, we would not have been able to support the talented scientists whose careers are focused on finding better treatments and cures for NETs, nor would we have been able to serve the NET patient community through our educational activities.

This annual report is dedicated to the Margie and Robert E. Petersen Foundation, which has supported NETRF since 2015. This Foundation's generous gifts have fueled the growth of NETRF, enabling us to become a global force in funding NET research. Robert E. Petersen, automotive publishing giant and entrepreneur, overcame great challenges to achieve success, but died too soon from neuroendocrine cancer. We are happy to share his story and recognize the Margie and Robert E. Petersen's transformational partnership to advance the science of NETs.

It takes many people serving the same mission and working collectively to make great progress. Our Staff, Board of Directors, Board of Scientific Advisors, the scientists we fund, and the physicians with whom we collaborate—everyone shares the goal of better treatments and outcomes for people with neuroendocrine cancer.

With gratitude,

Elyse Gellerman Chief Executive Officer

### NETRF STAFF

(AS OF 12/31/2021)

Susan Payson, Chief Development Officer

John Kanki, PhD, Director of Research

Christine Coffey, Director of Communications

Eva May, Development Associate

Jennifer Long, Science Writer



# Growth and impact.

## Dear Friends of NETRF,

As NETRF's new Board President, and on behalf of the Board of Directors and professional staff, I am honored and pleased to report that NETRF had a very successful 2021.

In this year's annual report you'll read about the continued growth and success of our robust research program and the new NETRF grants totaling \$4.1 million awarded to 16 researchers from across the globe. You will learn about the continuing positive impact that our educational resources (patient conferences, NET Guide and our NETWise podcast) have on the lives of NET patients and caregivers. We also recognize the continued generosity of the Margie & Robert E. Petersen Foundation for its \$5 million gift which boosted NETRF's endowment to \$10 million.

NETRF's goals for 2022 are straightforward: expanding the breadth and diversity of our research program to advance our understanding of NETs and pursue more effective diagnostic tools, and treatments, while providing NET patients and caregivers the information they need to make informed decisions

around disease management and their overall wellbeing. We will work to expand our community of loyal donors to support this vital work.

I want to take this important opportunity to thank Dr. Joe Li for his steadfast leadership as our Board President for the past five years. It is equally important to thank Drs. George Fisher and Daniel Chung for their years of dedication and leadership as Co-Chairs on the NETRF Board of Scientific Advisors, which ensured that our research portfolio was well-balanced and funded innovative, unique and strong science.

On behalf of the Board of Directors and Staff, thank you for helping NETRF work toward achieving the vision set 17 years ago by our founder Nancy Lindholm - fund research to find cures and more effective treatments for neuroendocrine cancers.

Todd Gilman
NETRF Board President

# BOARD OF DIRECTORS (AS OF 12/31/2021)

Joe Li, MD, Chair

Todd Gilman, Vice Chair

Josh Mailman, Treasurer

Brendan P. Foley, Jr., Clerk

Stephen Blackwood

Tony Detre

Stephen Kaufer

Mark Lewis, MD

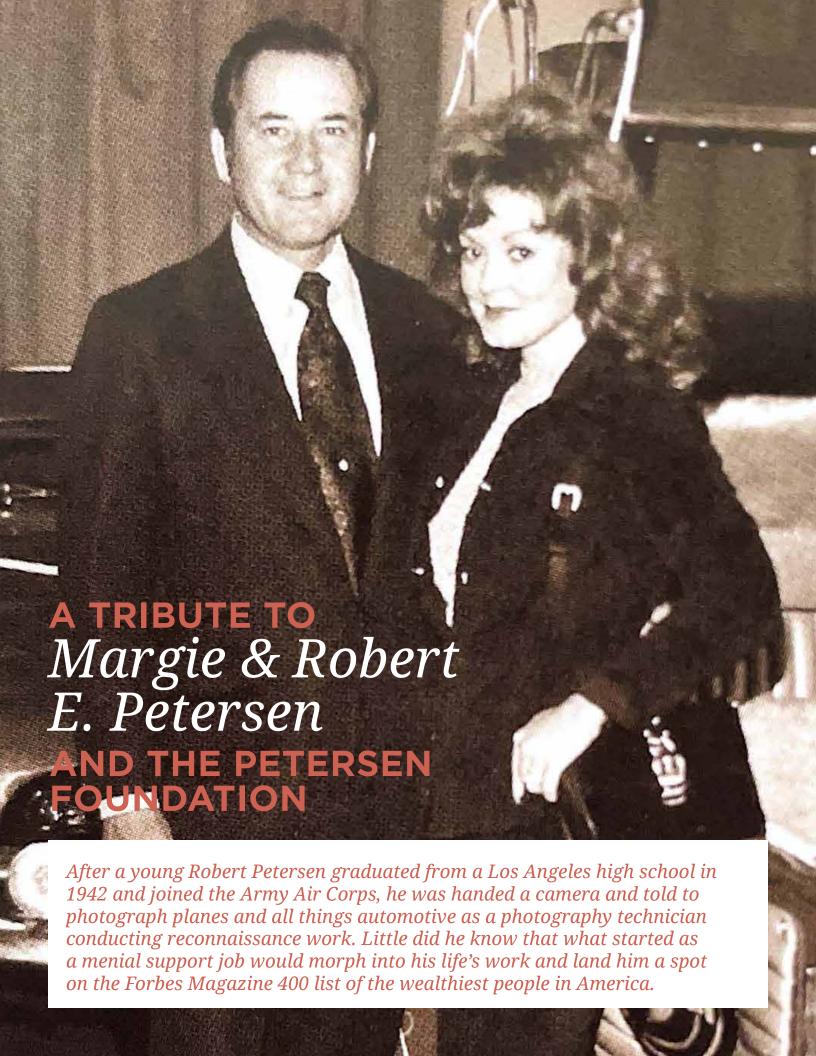
Julie Mebane

Laurie Rains

Jonathan Soroff

#### **Emeritus members**

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





NETRF's 2021 Annual Report is dedicated to Margie and Robert E. Petersen and their eponymous foundation that transformed the mission, scope, and breadth of NETRF and, subsequently, the lives and journeys of NET patients, caregivers and researchers.

If, some fifteen years ago in 2007 when Robert Petersen died of neuroendocrine cancer, a newly-diagnosed patient Googled neuroendocrine cancer or NETs, the search results would reveal very little in the way of patient education, and certainly not a significant amount

of scientific research.

Fast forward to 2015,
when NETRF received \$15
million from the Petersen Foundation.
This transformational gift allowed
NETRF to launch the most aggressive
research effort ever to understand
and treat NETs. NETRF designed
new research grant opportunities,
including the prestigious Petersen
Accelerator Award and an endowment
fund to perpetuate NET research.

In 2018 the Petersen Foundation announced a \$5 million matching gift and NETRF launched the \$10 million "Spark Hope" campaign, to bolster NETRF's success but more importantly, to help NETRF grow its donor community and raise NETRF's

profile as the largest private funder of researchers working to find therapies and treatments for neuroendocrine cancer.

Since 2015, the unparalleled support of the Petersen Foundation has allowed NETRF to tremendously increase its grant funding and expand its scope to fund nearly 40 researchers on four continents who are focused on identifying causes,

2022
Margie & Robert E. Petersen
NEUROENDOCRINE TUMOR
RESEARCH SYMPOSIUM

treatments and cures for NETs. The Foundation's financial support is indeed the bedrock of NETRF's tremendous growth and success.

In 2021, The Petersen Foundation bestowed its final \$5 million gift to increase NETRF's endowment.

"I know the Petersens would be very happy with the exceptional and impressive research they are funding," said Kevin Strauch, Trustee of the Petersen Foundation. "We also know that expanding and engaging the potential and existing donor base of NETRF is critical to the organization's continued growth, both in terms of research outcomes and essential patient education." he added.

As a lasting recognition for their transformational support, NETRF's annual research symposium has been renamed 'The Margie and Robert E. Petersen Neuroendocrine Tumor Research Symposium' beginning in 2022.

"I can think of no greater tribute to Mr. and Mrs. Petersen than naming this successful research symposium in honor of their commitment to neuroendocrine cancer research that will lead to a cure," Strauch added.

If 2021 indicates what the future holds for NETRF and its community, that future is blindingly bright. 2021 was an exceptionally successful year for NETRF, with the largest class of funded researchers and \$4.3 million awarded to combat NETs.

We think Margie and Robert would be incredibly proud of what their support has allowed NETRF to accomplish, and we can't wait to see what our exceptional scientists discover.

# **RESEARCH SNAPSHOT:** THREE PETERSEN FUNDED RESEARCHERS SHARE UPDATES ON THEIR PROJECTS

## MULTIPRONGED APPROACHES TO DEVELOP IMMUNOTHERAPY TARGETING NETS

#### Xianxin Hua, MD, PhD University of Pennsylvania

- YEAR(S): 2018
- GRANT TYPE: Accelerator
- RESEARCH TYPE: Translational
- PRIMARY TUMOR SITE: Pancreas
- AREA OF INQUIRY: Immune environment

# How has your research progressed since you received the NETRF Petersen Foundation funding?

"Receiving the NETRF accelerator grant was an enormous boost to our research, and we have made great progress developing and investigating the efficacy of the CDH17CARTs. In fact, just earlier this year we published in Nature Cancer our initial results from preclinical models confirming that the CDH17CARTs work very effectively to eradicate NETs, and do not cause toxicity in healthy tissues."



### DEVELOPMENT OF IN VITRO AND IN VIVO PRECLINICAL MODELS FOR SMALL BOWEL NET

#### Po Hien Ear, PhD University of Iowa

- YEAR(S): 2019
- GRANT TYPE:
   NETRF/NANETS Grant
- RESEARCH TYPE: Translational
- PRIMARY TUMOR SITE: Small intestine
- AREA OF INQUIRY: Models

# How has your research progressed since you received the funding?

"Receiving the funding was a career changer for me. With the NETRF grant, I was able to transition from a staff scientist position to faculty at the University of Iowa. Without this grant, I don't think the university could hire me as faculty. My advice to all new researchers is that the NET community is incredibly supportive and there are so many opportunities ahead. Transitioning to NET research was the best career move that I've made. Much is still unknown in this field so there are ample opportunities for career growth."

# COMPREHENSIVE MOLECULAR CHARACTERIZATION OF LUNG SUPRACARCINOIDS

#### Lynette Fernandez-Cuesta, PhD International Agency for Research on Cancer (IACR-WHO)

- YEAR(S): 2019
- GRANT TYPE: Investigator
- RESEARCH TYPE: Translational
- PRIMARY TUMOR SITE: Lung
- · AREA OF INQUIRY: Models

# What is the status of your project now, almost three years in?

"We have identified a good number of supracarcinoids and their molecular characterization has revealed important knowledge in the biology and progression of lung NETs and NENs. We are finalizing the interpretation of the results and we will soon draft the manuscript. These findings have inspired us to move towards two new axes of research: exploring how Artificial Intelligence can help in identifying supra-carcinoids and also performing single-cell sequencing and spatial transcriptomics to better understand the evolutionary processes and the role the microenvironment may play on them. Future work will be complemented by work using organoid models through our collaboration with Dr. Talya Dayton, who we have met and started working with thanks to NETRF!

Also, as a NETRF-funded researcher we've been invited to join the ENETs lung NET task force."



### 2021 RESEARCH GRANT AWARDS

#### James Bibb, PhD

University of Alabama at Birmingham PANNET MODELING, MECHANISMS, AND EXPERIMENTAL TREATMENT

#### Carl Gay, MD, PhD

The University of Texas MD Anderson
Cancer Center
DEFINING DISTINCT SUBTYPES OF NECS TO
PREDICT THERAPEUTIC VULNERABILITIES

#### Chang Chan, PhD

Rutgers University
INVESTIGATING PANNET TUMORIGENESIS
WITH SINGLE CELL GENOMICS

#### Justin Annes, MD, PhD

Stanford University School of Medicine NET-SMART THERAPY: A TARGETED PRODRUG STRATEGY (II)

#### Lisa Bodei, MD, PhD

Sloan Kettering Institute for Cancer Research PRESCIENT - PET RESPONSE CRITERIA FOR NEUROENDOCRINE TUMORS

#### Jerome Cros, PhD

University of Paris

MOLECULAR HETEROGENEITY IN PANCREATIC NEUROENDOCRINE TUMOR (MOYPAN)

#### Minah Kim, PhD

Columbia University Medical Center TARGETING ANGIOPOIETIN-2 TO IMPROVE ICI THERAPY EFFICACY IN PNET METASTASIS

#### Dan Merrick, MD

University of Colorado Anschutz
Medical Campus
MOLECULAR EVENTS
UNDERLYING DEVELOPMENT AND
PROGRESSION OF DIPNECH

#### Michael Roehrl, MD, PhD

Memorial Sloan Kettering Cancer Center SINGLE-CELL PROTEOMICS OF PANCREATIC NEUROENDOCRINE TUMORS

#### Huanhuan Chen, PhD

The University of Chicago
A HUMAN PLURIPOTENT STEM CELLBASED MODEL FOR LUNG CARCINOID

#### Mauro Cives, MD

University of Bari NEOANTIGEN-REACTIVE T CELLS FOR PERSONALIZED TREATMENT OF PANNETS

#### William Hwang, MD, PhD

Massachusetts General Hospital DEVELOPMENTAL LINEAGES AND MICROENVIRONMENTAL HETEROGENEITY IN PNETS

#### Panagiota Kafasla, PhD

Alexander Fleming Biomedical Sciences Research Center ALTERNATIVE SPLICING IN PNET: AN UNEXPLORED SOURCE OF THERAPEUTIC TARGETS

#### Pedro Marques, MD, PhD

Hospital de Santa Maria, Centro Hospitalar Universitário Lisboa Norte EPE ROLE OF CCL2 AND IL-8 IN PITUITARY NEUROENDOCRINE TUMOR MICROENVIRONMENT

#### Amit Tirosh, MD

The Sheba Fund for Health Service and Research HYPOXIA ONCO-METABOLIC DRIVERS IN PANCREATIC AND SMALL INTESTINE NET

#### Paul Schaffer, PhD

University of British Columbia
PRECLINICAL TOXICITY AND THERAPY
STUDY OF 225AC-CROWN-TATE

NETRF GRANTEE INSTITUTIONS US & GLOBALLY



Boston

Seattle

# Joe Castrovinci

"It matters to us that we support the scientific research that has enabled me to live with NETs this long."

-JOE CASTROVINCI, FOUNDING MEMBER. NETRF LEGACY SOCIETY

A New York City native who dreamed of being a college professor, Joe Castrovinci was a newly minted Ph.D. in 1979 when he moved to California and took a job in corporate communications. "There wasn't much opportunity in academia in the late 70s, and I needed to work, so I took a job in corporate communications, writing articles and speeches, and editing publications. I spent most of my working life at AT&T, which turned out to be a great gig," he said.

Retired in 2010, it was that same year that Joe's primary care physician didn't like some of the blood results she reviewed after a routine exam.

"I had zero symptoms," he said. "I was feeling completely normal."

After a series of scopes and scans, Joe's care team decided that exploratory surgery was necessary, and it provided the elusive answer: Joe had a neuroendocrine tumor in his mid-gut with mets to his liver. After surgery to remove most of the tumors, he was essentially back to normal health.

"Living where we do, we are incredibly fortunate to have access to outstanding healthcare, and I ended up in the exceptional care of Dr. Emily Bergsland at the University of California at San Francisco, and she is still my NET provider. You'd

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be very hard-pressed to find a more conscientious or knowledgeable doctor, or one more committed to the well-being of her patients."

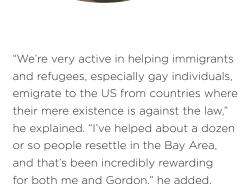
"As soon as we had a solid diagnosis, I also went online and found the NorCal CarciNET support group, which proved to be a huge lifeline. Once his diagnosis was solidified, Joe had surgery at the Stanford University Medical Center and started sandostatin shots to manage his tumor, which he still receives today. "I was really stable, very healthy for eight or nine years post-diagnosis," he added.

"Find your community and know that you are NOT alone in this journey.

And now, with the pandemic, our communities are easily accessible thanks to social media and Zoom," he said.

"Believe me, I know how incredibly lucky and fortunate I am to live with and manage this disease successfully, and thanks to ongoing research funded by NETRF and others, I hope and expect to continue to be able to control it." he said.

Joe and his husband Gordon, a retired MIT and Stanford-trained theoretical physicist spend their time supporting non-profit organizations important to them. Joe uses his love of the written word to write and edit content for non-profits and works to settle refugees from Iran and Uganda.



As Legacy Society members, Joe and Gordon have included NETRF in their estate planning.

"We know that I have lived this long and this well strictly due to the hard work and sacrifice of researchers and patients who navigated NETs for years before my diagnosis; they laid the groundwork for the successful treatments and therapies that allowed me to live relatively unscathed with this disease for many years. It is important to us that we give back and support NETRF until the time comes when neuroendocrine cancer ceases to be an elusive and insidious disease and is finally cured."

LEARN MORE ABOUT THE NETRF LEGACY SOCIETY HERE:



netrf.org | 617.946.1780

# A CHAMPION FOR NETRF Erica Roberts

"Anything that I have done, and any impact I have made in support of NETRF is because of the lessons he taught me."



Champion Society member Erica Roberts remembers her father telling her and her brother from a very early age how important it was to surround themselves with positive influences.

William Preston Roberts, Jr. (known as Tipps to family and friends) was that positive influence on Erica, brother Preston, and a community that loved him. William died from neuroendocrine cancer in 2016, after an eight-year struggle with the disease.

"He never looked really sick, so no one knew he was battling cancer, but my dad fought every day to stay alive," said Erica.

"My dad had a HUGE heart - and he loved his work as a mentor at a local correctional facility. My parents instilled in us very early on the value of giving back, so I've always been as generous as I can be with charitable pursuits; once my dad was diagnosed, I decided to channel my charitable budget to a monthly gift to NETRF."

Her family also holds an annual walk each Thanksgiving in honor of her dad. "We raise money for NETRF and hope to continue to increase awareness, participation and giving over time. I donate to NETRF each month to remember him and in hopes that a cure will be found so that another

daughter doesn't have to lose her dad in the same way I lost mine."

"I'm so pleased to learn that some of NETRF's research monies were awarded to Dr. Bibb at The University of Alabama, Birmingham - that is where my dad received the most compassionate and comprehensive care during his NET journey."

"Anything that I have done, and any impact I have made, in support of NETRF is because of the lessons he taught me," Erica says. "I am evidence that my dad was here and that his life mattered."

Since losing her dad and then living through the isolation and challenges of the pandemic, Erica took the time to refocus her professional life and pursue her creative side.

"I think the pandemic taught us so many lessons about life/work/family balance and flexibility and it helped me realize I also have a strong creative side that I needed to nurture, so I started my own custom stationary business. I think expressing myself through design and working in a dynamic space, where law can be very static, has really helped me in my grieving process and I know my dad is smiling down on me."

If you'd like to join Erica and become a monthly donor to NETRF, just scan the QR code for more details.

"I can't give a lot, but I give what I can and I'll continue to use this donation to remember my dad's incredible life."



BECOME A MONTHLY DONOR LIKE ERICA!



## **GIVING SOCIETIES**

Every gift to NETRF makes an impact on the patients and families of today and tomorrow. 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.

JAMES BEATTY | JEANETTE CONCILIO | ANNE DOYLE AND JAMES STOCK | STEVE AND LISA KAUFER | ED PEINE | VICTOR RHODES

#### **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.

Michael and Sheryl Anania Mark and Cindy Blotner

Karen Bopp and Elliott McEntee

Gail Borgen Tim Branaman John Caruso

John and Nancy Celick Harvey and Mary Beth Cody Lesley and Ronnie Compton

John and Anne Farrell

Nicole Feeley Michelle Ferritto

Wayne and Susan Firsty Carla Flaim and Vicki Dailey

Jennifer Flaniken

Robert and Kristina Frick Todd and Terry Gilman

Paul Godlewski

Loretta and Thomas Gordon Samuel Greenfield and

Patricia Jackson Blair and Dori Haas

John Harris Lois Hirt

Susan Holzman

Lou and Monica Kaplan

Petra Kernahan Vera and Mel Levine Joseph Li, M.D.

Ted and Susan McCullough

James Panagis, M.D. and

Therese Panagis

Bill and Marisa Panagis

Scott Passet

Don and Susan Pine

Erica Roberts

Jason and Helen Seltzer

Melissa Suman

Nick Vantzelfde and Lauren Erb

Philip and Judith Wolf

Michelle and David Wolf-Bloom

Zeldin Family Foundation

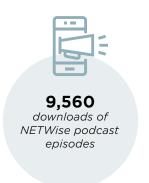
Deborah and Wayne Zuckerman



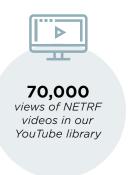
For a listing of all the members of the NETRF giving societies, please visit our website. We've created a special page to honor their philanthropy. To visit, scan the camera of your smart phone over the QR code and tap the link.

# PATIENT EDUCATION AND ADVOCACY ARE CORNERSTONES OF NETRF





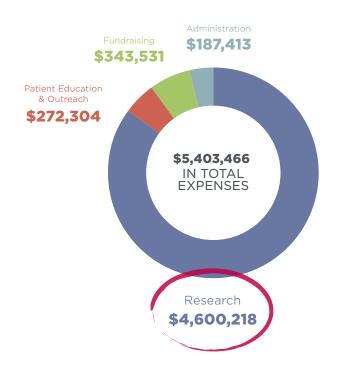


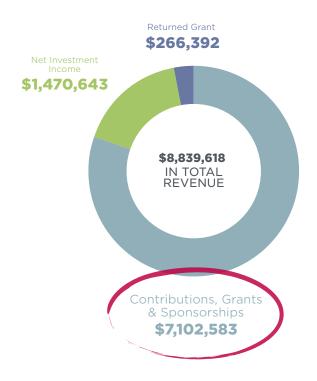


# **REVENUES & EXPENSES**

SOURCE: NETRF AUDITED FINANCIALS 2021



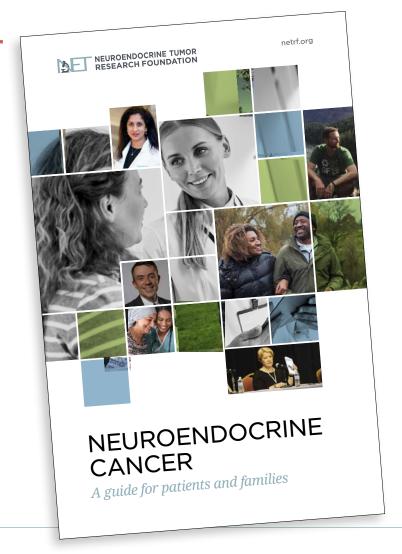




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