

MORE *Research.*  
MORE *Education.*  
MORE *Impact.*



**spark**  
*hope.*

**NET**  
NEUROENDOCRINE TUMOR  
RESEARCH FOUNDATION

ANNUAL REPORT  
2019



*The mission of the Neuroendocrine Tumor Research Foundation is to fund research to discover cures and more effective treatments for neuroendocrine cancers.*

## Dear Friends,

By all measures, 2019 was an extraordinary year for the Neuroendocrine Tumor Research Foundation (NETRF). Our impact on the community of neuroendocrine tumor (NET) patients and researchers expanded significantly, as did our community of donors who have enthusiastically supported our mission.

It was a year when NETRF-funded scientists announced new discoveries in understanding NETs and overcame a long-standing barrier to NET research. We funded more projects in a single year than ever before in our history to expand our scientific portfolio. These projects represent a broader perspective on neuroendocrine tumor biology and new approaches to improve treatment.

NETRF launched new educational activities to provide more options for patients and families seeking NET information. We are proud of our NETWise podcast and Patient Guide and the response from thousands of patients who are finding value in these materials. These programs would not have been possible without the support of sponsors, the willingness of physicians to share their expertise, and the dedication

of patients who share their stories to inform others. We loved working with so many of you throughout the year.

NETRF is grateful for the more than 2,300 supporters who helped us raise \$4.7 million in 2019. We celebrated great success in our Spark Hope campaign to raise \$10 million for NET research, with the generous support of the Margie and Robert E. Petersen Foundation. Families throughout the country found spirited ways to gather to support NETRF.

The year had its challenges, including the loss of members of our NET community who we deeply miss. We remember them and honor all those with neuroendocrine cancer. NETRF remains true to our mission.

On behalf of the NETRF Board of Directors, Scientific Advisors, and staff, we hope you enjoy this look back at a tremendous year.

With gratitude,

  
[Elyse Gellerman](#)  
Chief Executive Officer

### **BOARD OF DIRECTORS** (AS OF 5/1/20)

Joe Li, MD, *Chair*  
Todd Gilman, *Vice Chair*  
Josh Mailman, *Treasurer*  
Brendan Foley, Jr., *Clerk*  
Stephen Blackwood  
Tony Detre  
Stephen Kaufer  
Mark Lewis, MD  
Julie Mebane  
Laurie Rains  
Jonathan Soroff

### **Emeritus members**

James Panagis, MD  
Nicholas Vantzelfde

### **IN MEMORIAM**

NETRF lost [Carol Branaman](#), a longtime member of our Board of Directors, to neuroendocrine cancer in 2019. After joining the NETRF Board in 2011, Carol served as Board Chair and Vice Chair. Her impact on the organization was profound and will continue for years to come.

**Ramesh Shivdasani, MD, PhD,** Dana-Farber Cancer Institute, Harvard Medical School, and other NETRF-funded researchers discovered molecular information that may help predict the recurrence of non-functional pancreatic NETs. The finding, published in *Nature Medicine*, could lead to new testing. Results could inform treatment planning decisions, such as more aggressive treatment or frequent monitoring.



**BOARD OF SCIENTIFIC ADVISORS**

(AS OF 5/1/20)

Daniel Chung, MD, *Co-Chair*

George Fisher, MD, PhD, *Co-Chair*

Bradley Bernstein, MD, PhD

James Bibb, PhD

Lisa Bodei, MD, PhD

Guillermina (Gigi) Lozano, PhD

John Minna, MD

Dawn Quelle, PhD

Anil Rustgi, MD

Ramesh Shivdasani, MD, PhD

Dung Thi Le, MD

Chrissie Thirlwell, MD, PhD

Evan Vosburgh, MD

**Emeritus members**

Todd Golub, MD

Arnold Levine, PhD

Thomas Lynch Jr., MD

William Sellers, MD

**ACCELERATING RESEARCH, ADVANCING EDUCATION**

2019 BY THE NUMBERS

*Awarded*



**\$4.7 MILLION**

in new grant funding for 16 research studies

*Supported*



**30**

active research studies in 8 countries

*Invested*



**92%**

of revenue into research and education

*Educated*



**25,700**

people with NET information

# Milestone achievement: NET cell lines established

A valid cell line is a fundamental building block for cancer research. When NETRF was established in 2005, the lack of NET cell lines was one of the primary obstacles limiting NET research. Since then, NETRF has funded and initiated multiple projects to generate NET cell lines. Currently, [three projects have produced validated NET cell lines](#). The Margie and Robert E. Petersen Foundation and the Sharon Levine Foundation have helped to support these critical efforts.

## Why a cell line is needed

Cells extracted from human tumor tissue can be grown in the lab to be used in experiments. Known as a “cell line,” these “models” of cancer allow researchers to:

- Understand how cancer grows
- Find targets for treatment
- Test treatments

## NET CELL LINES PRODUCED FROM NETRF-FUNDED RESEARCH IN 2019

NET Site	Institution	Country
Pancreas, small intestine, lung	Hubrecht Institute	Netherlands
Small intestine	Broad Institute of MIT and Harvard	United States
Pancreas	Ulm University Hospital	Germany

## ON THE FRONT LINES OF DISCOVERY

### NEXT-GENERATION SCIENTIST PRESENTS NOVEL FINDINGS

As part of a [Petersen Accelerator Grant team](#), Talya Dayton, PhD, grows 3-D replicas (called organoids) of lung, intestine, and pancreas tumors in laboratory dishes to study the causes and treatments of NETs at Dr. Hans Clevers' lab, Hubrecht Institute, Netherlands.

No one was sure whether the project would be a success. In early 2018, Dr. Dayton said the organoids were proliferating slowly, as the team worked to figure out the requirements needed to grow each tumor subtype. “To realize our success, we needed four years of research funding, which we were pleased to receive from

NETRF,” said Dr. Dayton. “No other organization would have made that commitment. Now NETRF’s investment is paying off.”

With promising results now being generated, this early-career, postdoctoral fellow finds herself at the forefront of groundbreaking NET research. For the last two years, Dr. Dayton’s presentations on the project have earned top recognition at the international meeting of the European Neuroendocrine Tumor Society (ENETS).



In addition to the Clevers Lab’s ongoing analyses of the organoids to understand the molecular underpinnings of NETs, the project is also supplying organoid cell

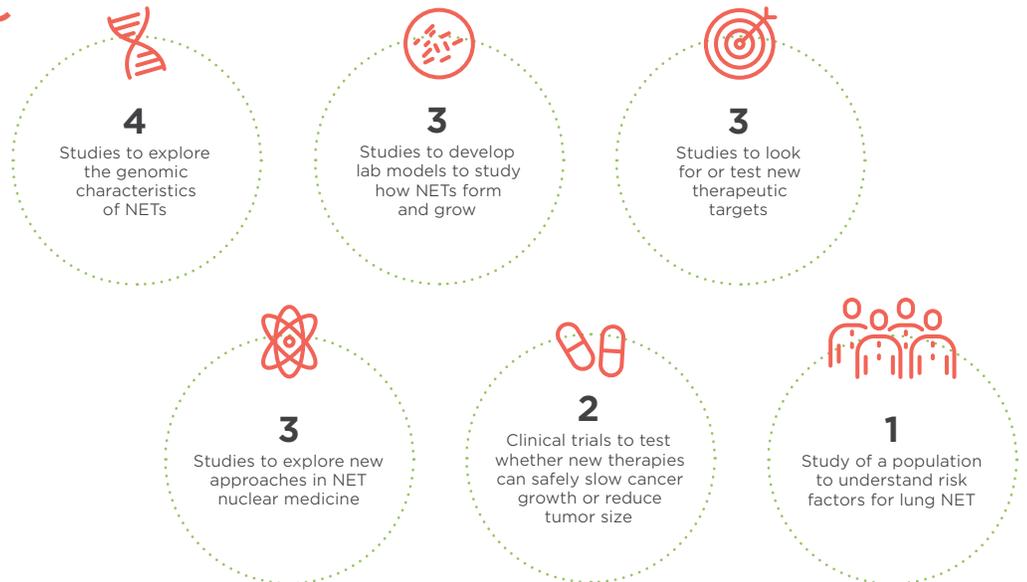
# More research awards around the globe

*In 2019, NETRF funded 16 research projects for \$4.7 million.*

This is a new record for the number of grants awarded in a single year. Awards were distributed across a range of research types as part of a multi-pronged effort to understand and cure NETs. NETRF also expanded its geographic reach and areas of inquiry. Four studies explored lung NETs. For the first time, NETRF funded two studies of NETs that occur in the adrenal system (i.e., pheochromocytoma, paraganglioma). Seventy-five percent of the grants awarded in 2019 were to institutions that are new to NETRF.

## A WIDER CONTINUUM OF SCIENTIFIC DISCOVERY

NETRF 2019 grantees are conducting basic, translational, clinical, and epidemiological research of NETs in the lung, adrenals, small intestine, and pancreas.



## AMERICAN INSTITUTIONS:

- [Columbia University Medical Center, New York, NY](#)
- [Dana-Farber Cancer Institute, Boston, MA](#)
- [Rutgers Cancer Institute of New Jersey, New Brunswick, NJ](#)
- [Tufts Medical Center, Boston, MA](#)
- [University of California, San Francisco, CA](#)
- [University of Iowa, Iowa City, IA](#)
- [University of Utah, Salt Lake City, UT](#)
- [University of Texas Health Science Center, Houston, TX](#)
- [University of Michigan, Ann Arbor, MI](#)
- [Vanderbilt University Medical Center, Nashville, TN](#)

## INTERNATIONAL INSTITUTIONS:

- [Erasmus MC, University Medical Center, Rotterdam, Netherlands](#)
- [Hebrew University of Jerusalem, Jerusalem, Israel](#)
- [International Agency for Research on Cancer \(IARC-WHO\), Lyon, France](#)
- [Istituto Auxologico Italiano - Istituto di Ricovero e Cura a Carattere Scientifico, Milan, Italy](#)
- [Radboud University, Nijmegen, Netherlands](#)
- [Weizmann Institute of Science, Rehovot, Israel](#)

# Education — more options, more enlightenment

**3,100**

podcast and  
booklet users

**28  
expert  
speakers**

from 16 different institutions  
at NETRF patient conferences  
in Chicago, Boston,  
and Denver

**100% of  
attendees  
surveyed**

rated NETRF  
conferences as  
outstanding or  
very good



## EXPANDED LEARNING OPPORTUNITIES

Being diagnosed with an uncommon cancer, like NET, can feel isolating or overwhelming. There are a lot of new, confusing terms. Reliable information can be hard to find. NETRF introduced two new NET educational tools to give patients and their caregivers more ways to learn in 2019.

- **NETWise:** [A podcast about neuroendocrine cancer](#) is available through all the major streaming services. Regular episodes of NETWise address the symptoms, stages, grades, types, and treatments with NET expert and patient interviews.
- **Neuroendocrine Cancer:** [A guide for patients and families](#), a 64-page booklet packed with illustrations, definitions, and fast facts, was introduced on World NET Cancer Day 2019. It is a handy reference to help people play an active role in their care.

The podcast is made possible with support from the Vincent E. Taylor Patient Education Fund, Lexicon, Advanced Accelerator Applications, a Novartis Company, and Ipsen Pharmaceuticals.

Both the podcast and the patient guide are available on [netrf.org](http://netrf.org), re-designed in 2019, to offer more information about living with neuroendocrine cancer.

These new resources complement NETRF's [regional patient and caregiver conferences](#), live stream events, and [extensive video library](#).

"NETRF's new NETWise podcasts and the new booklet, Neuroendocrine Cancer: A guide for patients and families, are incredible additions to the valuable educational resources they provide for the NET Community."

**JAN RATTAZZI**  
Patient Advocate

# A MISSION TO HONOR THE MEMORY OF A GREAT MAN

## SUZANNE LUDLOW TURNS EXPERIENCE INTO ACTION

As a caregiver, Suzanne Ludlow learned about NETs the hard way — by going to appointment after appointment with her now late husband, Vincent Taylor. Through Vincent's six-year-journey, Suzanne learned to trust her feelings, educate herself continually, and advocate with and for her husband.

**“It took us several years to understand that we needed to see a NET specialist rather than relying on our otherwise excellent oncologists,” said Suzanne.**

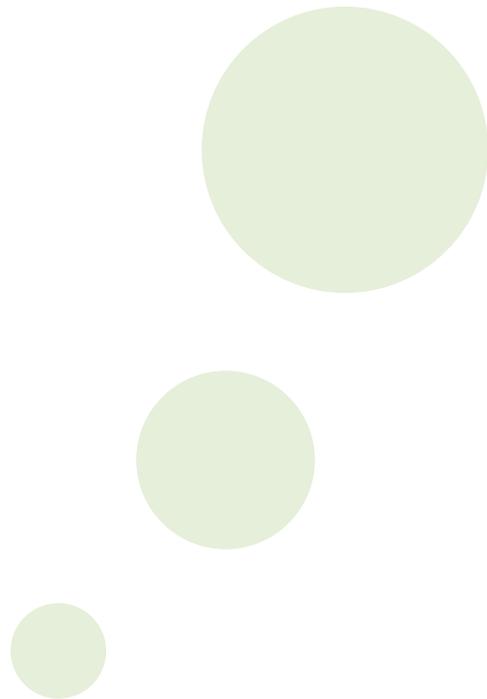
After Vincent passed, Suzanne acted to improve the experience for those that followed in their footsteps. Suzanne created the Vincent E. Taylor Patient Education Fund with her husband's life insurance policy to help fund NETRF's new podcast and patient guide.

“I want others to understand the complexities of this uncommon disease faster than we did,” said Suzanne.

Suzanne's commitment to education helped them align treatment with Vincent's values and beliefs. Vincent worked until three months before his death, saw his son graduate from college, and enjoyed the things he valued most—family, friends, music, cooking, and road trips—without letting his cancer define him.

**“Although Vincent was living with cancer,” said Suzanne, “he focused on the ‘living’ part.”**

**Vincent's legacy now lives on through NETRF's enduring educational resources.**



# Fundraising — more generosity, more impact



**\$4.7  
million in  
fundraising**



**2,300+  
gifts**



**Donors  
from 45 out  
of 50 states**



**\$8.2 million  
raised**  
towards Spark Hope campaign  
goal of \$10 million

## *Volunteers champion the need for more research*

We are grateful to all of our passionate supporters who organized volunteer-run events. These inspiring communities raised much-needed funds for NETRF. We are pleased to recognize 15 successful events on our behalf, spanning the country, raising over \$125,000. Please take special notice of those events that have become long-standing, annual efforts. We encourage you to connect with our development team to set up your next event.

## **VOLUNTEER-RUN EVENTS IN 2019**

- **Benefit Breakfast for NETRF and NET Cancer Awareness, 3rd Annual**, North Yarmouth, ME
- **Biking for Debbie, 6th Annual**, Ashland, MD, to York County, PA
- **Blackwood Family Annual Polar Plunge**, Corolla, NC
- **Carl Schaad Retrospective Art Sale**, Sherborn, MA
- **Dean Paras Foundation Annual Run/Walk**, Westlake, OH
- **Fight NET Cancer with Katherine**, Severna Park, MD (see to the right)
- **Friday Night Football**, TX
- **Maros Felsen 5K Run/Walk**, Wilmington, DE
- **“Nothing But NET” relay team**, Detroit Free Press - TCF Bank Marathon, Detroit, MI
- **Palo Alto Moonlight Walk, 8th Annual tribute to Julie Seltzer Firsty**, Palo Alto, CA
- **Women’s Informal Network gala honoring Aretha Franklin**, Detroit, MI
- **World NET Cancer Day event honoring Michele van Dewerker**, Cherry Valley, NY
- **“Queen Next Door” book launch and signing**, Detroit MI
- **Slamdunkin’ for NETs**, Roxboro, NC
- **Veracode Employee Hackathon & Food Sale**, Burlington, MA

# FIGHTING BACK FOR A BETTER FUTURE

## KATHERINE'S RALLYING CALL TO HER COMMUNITY

Only eight months into her neuroendocrine cancer journey, 30-year-old Katherine Mueller of Maryland decided to fight back. "I am strong. I have a voice," she wrote. "I have the opportunity to inspire, motivate, and make a difference."

Understanding the role research plays in improving treatments, Katherine set out to raise \$25,000 for NETRF. She called her fundraiser, "Fight NET Cancer with Katherine."

**"Katherine is truly a warrior," said Matt Mueller, Katherine's husband. "She is determined to use her journey to help fundraise for a cure."**

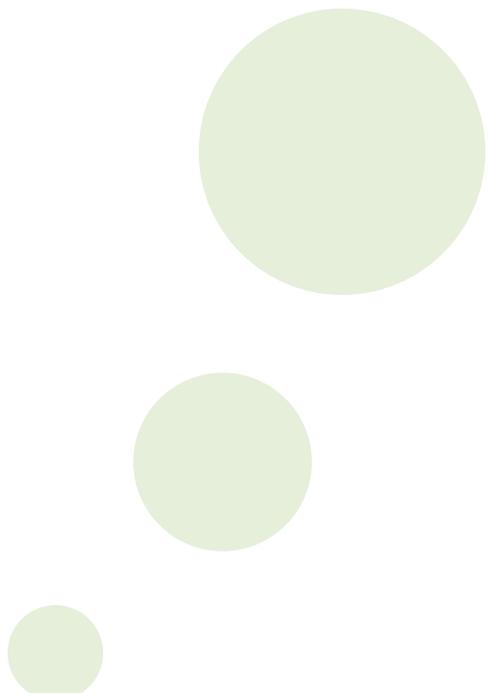
With a can-do attitude and faithful community contacts, Katherine, Matt, and her parents, Robin and Larry Sells, went into event-planning mode. The Sells, Muellers, and many others organized a triumphant, daylong music festival with 13 bands, headlined by Nashville recording star Chad Bearden. More than 550 people purchased tickets. Fifteen local businesses sponsored the event, including the host location — Severna Park Taphouse, where owners Jessica and Mark Tinordi recruited their entire staff to donate time and to host event guests.

Under sunny August skies, there were silent auctions, raffles, photo booths, spirits, and food. Above the music and laughter, hope circulated through the crowd: hope that a young woman, whose adult life was just beginning, could help fund a breakthrough in an uncommon, overlooked cancer.

Together, with her support system of family and friends, Katherine raised nearly \$74,000, three times what she set out to do.

**"The energy and love at this event were palpable," said Katherine. "I am so grateful for everyone that showed up to support us."**

**Her rallying call had indeed been answered. An army responded.**



## A LEGACY OF CARING FOR OTHERS

### MARILYN'S GIFTS WILL BENEFIT MANY

Marilyn Kline had a spirit and a love of adventure that she shared with everyone around her. Not content to just hike the trails near her home in San Francisco, she went to Spain to hike the 500-mile El Camino. Her volunteer work took her far beyond the Bay Area to Poland to build homes for the elderly. Marilyn was passionate about her work as an eldercare manager and was an advocate for vulnerable populations.

When Marilyn was diagnosed with a neuroendocrine tumor in 2017, she showed this same perseverance by learning all she could about treatments and research for NETs. This quest for information led her to NETRF. Marilyn made the cross-country trip to attend the NETRF Research Symposium in 2018. While she managed her disease, Marilyn began to volunteer for NETRF, providing feedback on patient education materials and being interviewed for an episode of NETWise, NETRF's podcast. She and her mother, Donna Kline, supported NETRF through annual gifts and a fundraiser for her 50th birthday.

**“Marilyn was a true spirit, a wonderful daughter who was never content to ‘run faster on well-worn tracks.’ She was her own person. I miss her more than words can describe,” shared Donna Kline.**

Marilyn died in October 2019 from neuroendocrine cancer, just eleven days before her 51st birthday. Before her death, she named NETRF as a beneficiary of her estate, which included her IRAs. It was important to her to ensure that research to improve treatment and find a cure would continue.

We are grateful to Marilyn for her generosity and her confidence in NETRF's work. She leaves a legacy that will help other patients, another great measure of her caring and dedication to help others.

## DONATING AN IRA TO CHARITY

When you name a charity as a beneficiary to receive your IRA or other retirement assets upon your death, rather than donating retirement assets during your lifetime, there are many benefits for surviving family and chosen charities. For information on making a [planned or bequest gift](#) to NETRF, please contact [Susan Payson](#), Chief Development Officer, at [susan.payson@netrf.org](mailto:susan.payson@netrf.org)

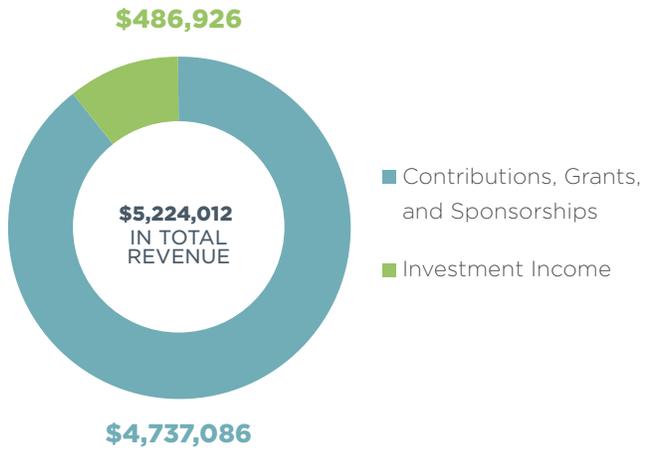


### *Remembering makes a difference*

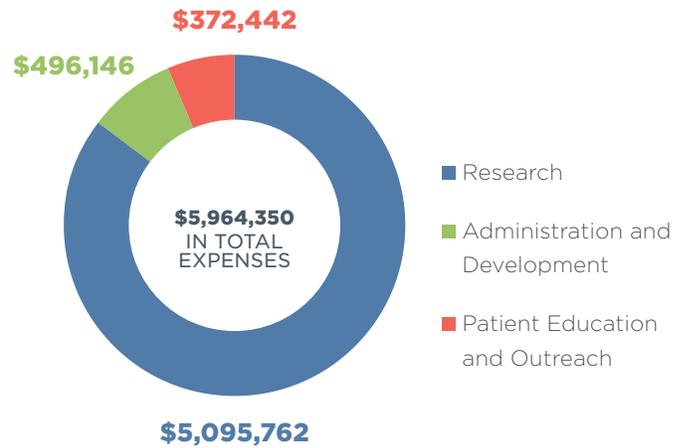
In 2019, 323 families and friends paid tribute to their loved ones through meaningful expressions of love and hope, raising close to a half million dollars for NETRF. (See a list of those who were honored at [netrf.org/tributes2019](https://netrf.org/tributes2019).) Each tribute serves as a reminder of why we work to eliminate neuroendocrine cancer.

NETRF launched the *Everlasting Impact Tribute* in 2019, a dynamic program that allows families to translate awareness into action for a larger, longer impact on NET research.

# REVENUE AND EXPENSES 2019



IRS Form 990, 2019



Audited Financial Statement, 2019

## AUDITED FINANCIALS FOR 2019

### Assets

#### Current assets:

Cash & equivalents	\$	3,971,039
Contributions receivable		1,459,273
Other receivable		16,410
Prepaid expenses		31,888
<b>Total current assets</b>		<b>5,478,610</b>

Investments 16,611,879

Contributions receivable, long-term 222,283

**Total assets** **\$ 22,312,772**

### Liabilities and Net Assets

#### Current liabilities:

Accounts payable and accrued expenses	\$	151,682
Grants payable		5,542,168
<b>Total current liabilities</b>		<b>5,693,850</b>

Grants payable long-term 3,335,946

#### Net assets:

Without donor restrictions	6,769,275
With donor restrictions	6,513,701
<b>Total net assets</b>	<b>13,282,976</b>

**Total liabilities & net assets** **\$ 22,312,772**

#### NETRF STAFF

**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

**Eva May**  
Development Assistant



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