The theme for this year’s annual report is Leading, Learning, Connecting, Discovering. The International Essential Tremor Foundation (IETF) is the leading essential tremor (ET) organization in the world, working to advocate for people with ET and leading through education and awareness of the condition. We promote learning through educational programs and activities. We connect people together through support groups and connect ourselves to organizations to help advocate for our cause. Through research, we are working to discover new methods of treatment and providing hope to people with ET. This would not be possible without the help of many people.

First, I would like to thank our loyal donors, support group leaders, and corporate partners for their support and generosity.

This fiscal year, the IETF raised more than $1.2 million, our most successful year ever.

As the number of patients diagnosed with ET continues to increase, your support becomes even more important. We cannot do what we do, including raising awareness, providing educational materials and events, awarding scholarships to students affected by ET, and dedicating more than $750,000 in research grants without your donations of time, talent, and treasure. I also want to thank our staff, Dawanna Fangohr and Tammy Dodderidge. They do a great job on a variety of projects involving our finances, support groups, database management, and our marketing and communications. Their hard work and dedication allow us to further our mission to provide hope to the ET community worldwide through awareness, education, support, and research. The next time you call, email, or write please thank them for all they do for the IETF and the ET community.

And, of course I want to thank our Board of Directors and Medical Advisory Board who are committed to the mission of the IETF and guarantee we meet our financial and research commitments along with the ethical and moral responsibilities for everyone with essential tremor.

The IETF continues to try to improve the way we deliver our messages. This year, we hosted three teleconferences on a variety of topics with more than 500 reservations for each call. If you missed one of the teleconferences, we have posted recordings of each call on our website on the “Education Programs” page. We also continue to host regional ET Education Forums. During the 2017-18 budget year we visited Cleveland, OH; Sacramento, CA; and Philadelphia, PA. Our plans for the 2018-19 budget year include ET forums in Minneapolis, MN; Dallas, TX; and Tampa, FL. We hope you can attend one of our events when we come to your town.

In an effort to improve our marketing and communications efforts, we have contracted with Merrigan & Co. Merrigan produces innovative and productive marketing tools to perfect the art and science of direct marketing to serve the unique needs of nonprofit organizations. They work with us to figure out the best course of action for the IETF’s specific messaging and strategic challenges. Merrigan’s work on our NETA month appeal helped increase donations $17,000 more than the previous year’s appeal.

We have also increased our social media efforts focusing on Twitter and Facebook along with reviving our Tremor Talk blog. If you are on social media, please follow the IETF and share our posts. This is an easy way to increase awareness and educate people about ET and the resources the IETF provides to patients, doctors, family members, and caregivers.

We continue to strengthen our current partnerships and build new ones with a variety of companies, associations, and other nonprofits who focus their efforts on promoting ET education, awareness, and treatments. Working together we can combine our efforts for a unified voice for the ET community.

So, as we start the new fiscal year we continue our commitment to work for you on raising ET awareness, providing the most up-to-date information, and funding research to find the cause and, hopefully, someday a cure for ET.

Thank you, again, for your support of the IETF. Feel free to contact our office if you need materials or information to share. You are our best advocates and we hope you continue to spread the word about essential tremor and the IETF.

Sincerely,

Patrick McCartney,
Executive Director
OUR MISSION

To provide hope to the essential tremor (ET) community worldwide through awareness, education, support, and research.

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Leading and Learning through

EDUCATION & AWARENESS PROGRAMS

Throughout its history, the IETF has led the charge in educational programming and resources for people with essential tremor. From community forums and teleconferences to brochures and materials for physicians, the IETF has increased awareness of ET and created a learning environment for those affected by it.

ET EDUCATION FORUMS

The IETF conducted several education forums during the year to reach out to the ET community in different regions of the U.S. The IETF partnered with local medical centers, neurologists, occupational therapists, and pharmaceutical/technology companies to host these events. The forums were free to those with ET and their caregivers.

- August 26, 2017 – Cleveland, OH
- November 4, 2017 – Sacramento, CA
- March 10, 2018 – Philadelphia, PA

"We thank you for the excellent seminar you presented in Philadelphia. We definitely benefitted by attending."

"My husband and I attended the IETF Essential Tremor Forum on Saturday, March 10 in Philadelphia and found it to have been a Saturday morning very well spent."

TELECONFERENCES

June 13, 2017 – Mindfulness: Coping with Anxiety, Depression, and the Social Stigma of ET
October 10, 2017 – Children and Essential Tremor
INFORMED SERIES

The IETF participated in the TV production "Informed Series" to educate the public about ET and to raise awareness for the IETF in a public television format. Inform produced a five-minute corporate profile, a five-minute educational segment for public television stations nationwide, and a one-minute educational commercial segment.

WEBINAR

The IETF hosted an educational webinar in 2017 to reach out to the ET community. Titled, “Diagnosis & Treatment Options for ET,” it added a visual element to the standard audio teleconference programming traditionally offered by the IETF.

NATIONAL ESSENTIAL TREMOR AWARENESS MONTH

Since 2010, the IETF has used the nationally designated National Essential Tremor Awareness Month in March as an educational platform for ET. The theme for 2018 was “ET Has No Familiar Face” which communicated the message ET can impact people of any age or race. The goal was to dispel some of the myths of the condition and to raise awareness of how widespread it is.

During National Essential Tremor Awareness Month, donors who gave $30 received a themed t-shirt. For a $50 donation, donors received a t-shirt and IETF tote bag. These items help raise awareness to essential tremor all year long.
Discovering through RESEARCH

Each year, the IETF contributes thousands of dollars toward research to find better treatments and a cure for essential tremor. The IETF Research Grant Program to date has not only supported research, but also encouraged the development of more studies focused on essential tremor. Each year, the IETF manages a research appeal to raise money for this grant program. In 2017, the IETF raised more than $61,000 for ET research.

TO DATE, THE IETF HAS CONTRIBUTED MORE THAN $750,000 TOWARD RESEARCH.

2017-18 FUNDED RESEARCH

DOUBLE-BLIND, PLACEBO-CONTROL, CROSS-OVER TRIAL OF CANNABIDIOL FOR ESSENTIAL TREMOR

The focus of this study is to collect the necessary data needed to determine whether further research is warranted to develop cannabidiol (CBD) as a viable tremor suppressant for essential tremor. Results obtained will provide the critical knowledge needed to request National Institutes of Health (NIH) funding for a drug development program to pursue the shorter-term development of CBD for essential tremor and the longer-term development of similar, yet more targeted, novel agents.
GENOME-WIDE COPY NUMBER VARIATIONS AND ET

Like many other common human diseases and traits, ET is known to cluster in families and it is believed to be influenced by several genetic and environmental factors. Overall genetic variants that are associated with, or are the cause of, ET have been sought for over a decade but the involvement of an emerging class of genetic variant that is collectively referred to as “Copy Number Variants” (CNVs) has not yet been properly examined in familial ET.

ELUCIDATING THE ROLES OF THE CA2+-ACTIVATED ION CHANNELS IN ESSENTIAL TREMOR

Essential tremor is a complex and progressive neurological disorder that affects more than 1% of the general population and 5% of the population over 65 years. After many years’ efforts, we are only beginning to develop some limited understandings of the pathogenesis. Based on extensive animal and human patient studies, we now know that abnormal oscillatory activity of an interconnected brain network, called the cortico-olivo-cerebello-thalamic circuit, is a common feature of ET.

RECRUITMENT FOR CLINICAL TRIALS

Research could not happen without clinical trials, and clinical trials could not happen without participants. So, the IETF continues to promote research opportunities through partners like Cala Health, Sage Therapeutics, Yale University, and more.

BRAIN BANK

The IETF continued its Brain Bank during the 2017-18 budget year, communicating the need for legacy donations of brain tissue for research and discovery. Through the Essential Tremor Centralized Brain Repository at Yale University, doctors can actively study what happens to the brains of people with ET.

The 2017 Research Appeal raised awareness to the fact that there is no medication specifically designed for essential tremor.

essentialtremor.org
Connecting through SUPPORT

A network of support offers a myriad of benefits for people with essential tremor. These include new coping techniques, information sharing and supportive relationships, which can lead to a better quality of life and enhanced mental well-being.

The IETF continues to connect people together through support groups. During the 2017-18 budget year, 64 support groups were helping people with ET bond with others like themselves through the sharing of personal experiences.

College scholarships also continued as a means of support for students with essential tremor. College scholarships help ease the financial burden for students during a transitional time in their lives.

THE IMPACT OF STUDENT SCHOLARSHIPS WAS ENHANCED DURING THE 2017-18 SCHOOL YEAR WHEN THE IETF BOARD OF DIRECTORS APPROVED INCREASING SCHOLARSHIP AWARDS FROM $500 TO $1,000.

ET SUPPORT GROUPS

During 2017-2018, the IETF managed support group programs in the following states and countries:

- Alabama
- Arizona
- Arkansas
- California
- Colorado
- Connecticut
- Florida
- Georgia
- Illinois
- Kansas
- Kentucky
- Massachusetts
- Michigan
- Minnesota
- Mississippi
- Missouri
- New Hampshire
- New Mexico
- New York
- North Carolina
- Ohio
- Oregon
- Pennsylvania
- Rhode Island
- South Carolina
- Tennessee
- Texas
- Utah
- Virginia
- Washington
- Wisconsin
- Australia
- Canada
- Denmark
- Germany
- Ghana
- India
- Spain
- Trinidad & Tobago

A new ET support group was established in Monument, Colorado this past year by co-leaders (from left) Jean Nichols and Margaret Fiandaco.

WHAT PEOPLE ARE SAYING ABOUT SUPPORT GROUPS

“At every meeting I learn something new. Also, it feels so good to be in the company of other people who share the same problems.”

“My experience with the support group has made me more willing to be public about my tremors, to educate people about ET.”
FALL 2017 SCHOLARSHIP RECIPIENTS

Allison Dyke - Kuyper College
Robert Holder - Georgia Southern University
Brogan Speraw - Ohio University
Madison Young - Arkansas Tech University

SPRING 2018 SCHOLARSHIP RECIPIENTS

Kelley Cordeiro - Molloy College
Ezra Thomas - Merrimack College
Brogan Speraw - Ohio University
Madison Young - Arkansas Tech University

“IETF encouraged me to reach out to my community by organizing awareness walks and starting a support group. And, they provided me with a college scholarship. With their support, I have met wonderful people who understand what having tremors is all about, and I know I am not alone.”

— Allison Dyke

“During college, I will continue to refuse to allow my disability to hold me back. It may be a challenge, but it is a challenge I intend to take on wholeheartedly, doing my best to make sure I succeed in all my academic endeavors.”

— Brogan Speraw

“I want to thank the IETF for the opportunity to be considered for a scholarship, which can help me achieve my educational goals. I would like to say that ET has not affected my life, but the IETF has!”

— Kelley Cordeiro
MARKETING & COMMUNICATIONS

Through targeted marketing and communications initiatives, the IETF crafted and delivered a variety of messages during the 2017-18 budget year designed to promote, educate, and draw awareness to the IETF’s mission, achievements, and brand. Mediums used to deliver these messages included email, social media, press releases, the IETF website, and online and printed publications.

SOCIAL MEDIA

- YouTube Subscribers: 966
- Twitter Followers: 1,359
- Facebook Essential Tremor Awareness Group Members: 6,356
- Facebook Likes: 10,724

WEBSITE

Unique pageviews: 354,743

TOP 10 PAGES

1. /home
2. /about-et/
3. /mobile-home/
4. /treatments/assistive-devices/
5. /treatments/
6. /treatments/medication/
7. /coping/
8. /about-the-ietf/
9. /find-a-physician/
10. /find-a-support-group/
TREMOR TALK BLOG

The Tremor Talk blog was revived to share information and stories to inspire, inform, and connect people together. Several guest bloggers contributed their experiences and messages of hope to the ET community.

TREMOR GRAM E-NEWSLETTER

This free electronic newsletter was emailed once a month to all those connected with the IETF. It is a way to keep the ET community up-to-date on all things ET, including upcoming educational programs, clinical trials, resources, and foundation news.

TREMOR GRAM WAS EMAILED TO MORE THAN 20,000 PEOPLE AND HAD AN OPEN RATE OF 25%, WHICH IS HIGHER THAN THE INDUSTRY STANDARD.

TREMOR TALK MAGAZINE

Published three times a year, Tremor Talk magazine continued to serve as the showcase publication of the IETF. It featured articles about the daily struggles experienced by people with essential tremor, provided updates on ongoing research, and included medical articles written by neurologists and movement disorder specialists.
Leading through

ADVOCACY

The IETF continued to collaborate with many organizations to advocate at the federal level for increased essential tremor research, access to quality care, long-term services, and general public awareness. The organization maintained its role as a leader in working to make life better for millions of Americans with ET.

Through attendance at national conferences, conventions, and meetings, and membership and/or collaborations with national organizations and coalitions, IETF staff worked to advance policies and programs that support people with ET and to foster understanding of the consequences of the condition.

2017-18 CONFERENCES/CONVENTIONS

• American Academy of Neurology – April 2017
• Movement Disorder Society – June 2017
• University of Kansas Parkinson’s Conference – August 2017
• American Academy of Family Physicians – September 2017

AFFILIATIONS

The IETF is proud to be a member, participant, or partner of the following organizations:

Alliance for Patient Access | American Brain Coalition | CIBR | Coalition for Clinical Trials Awareness | Coalition for Health Funding | Community Health Charities | Cures Acceleration Network (CAN) | Genetic Alliance | Midwest Neurological Coalition | Global Genes RARE Foundation Alliance | National Institute of Neurological Disorders and Stroke | National Council of Nonprofits | One Mind | Tremor Action Network

essentialtremor.org
FINANCIALS

REVENUE

Contributions                                $340,637
Investment income                           $71,316
Grants                                     $50,000
Memorials/Bequests                          $539,188
Exempt function revenues                    $16,443
Research                                   $61,435
Special events\(^1\)                        $83,147

TOTAL REVENUE                              $1,259,432

EXPENSES

Program\(^2\)                                $449,265
Management/General\(^3\)                    $94,871
Fundraising\(^4\)                          $36,681

TOTAL EXPENSES                              $580,817

NET ASSETS                                  $3,005,715

\(^1\) Includes revenue received from National ET Awareness Month.
\(^2\) Includes awareness, education, support, and research activities and initiatives.
\(^3\) Includes expenses related to office overhead such as supplies, computers, copier, salaries, and rent.
\(^4\) Includes National Awareness Month activities, annual appeal, and annual donations.
LEGACY SOCIETY

Members of the IETF’s Legacy Society are those who have named the IETF as the ultimate beneficiary of a planned gift. Such gifts might include a bequest and/or gifts of life insurance. These gifts contribute to the stability and long-term growth of the organization. It is the ideal way for their support for the foundation to live on for years to come.

The following individuals and families are Legacy Society members:

<table>
<thead>
<tr>
<th>DECEASED DONORS</th>
<th>LIVING DONORS</th>
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<tr>
<td>Warren Conklin Apgar Bequest</td>
<td>Judy Adams</td>
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<td>Robert Barfoot</td>
<td>Patricia Anesi</td>
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<td>Thelma Beatty Trust</td>
<td>Leslie Balas</td>
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<td>Berner Charitable and Scholarship Foundation</td>
<td>Karen Christenson</td>
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<td>Marietta Budak</td>
<td>Lillian Courtheoux</td>
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<td>Butler Family Trust</td>
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<td>Shirley A. Cavanagh Bequest</td>
<td>Marilyn Foreman</td>
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<td>Willima B. Cole Trust</td>
<td>Goodenough Family Trust</td>
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<td>Nancy M. Craig Trust</td>
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<td>Lorraine Hellstern</td>
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<td>Beryl G. Deming Trust</td>
<td>Sam Hodges</td>
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<td>Margaret Edwards Estate</td>
<td>Joseph L. Hores</td>
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<td>Irene Feimer Anger Bequest</td>
<td>Raymond &amp; Sarah Lamont</td>
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<td>Howard Fisher Trust</td>
<td>Richard Marcus</td>
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<td>Albert Gendron Living Trust</td>
<td>Carol Post</td>
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<td>Byron Scott</td>
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<td>Frans Jahger</td>
<td>Jacqueline Sydow</td>
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<td>Edmond Jamieson</td>
<td>Janet Whittlesey</td>
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<td>Laurita Hall Johnson Trust</td>
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<td>Dorothy Helen King Bequest</td>
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For information on becoming a Legacy Society member, contact the IETF Executive Director toll free at 888.387.3667.
## PRESIDENT’S CLUB

Donors who contribute $1,000 or more to the IETF annually are recognized as “President’s Club” members. Many thanks to the individuals who made this commitment during our 2017-18 budget year.

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INTERNATIONAL ESSENTIAL TREMOR FOUNDATION
Providing HOPE to the essential tremor community world-wide through...

EDUCATION & AWARENESS
- Free educational materials for physicians and people with essential tremor
- Free ET forums and teleconferences
- Annual National Essential Tremor Awareness Month campaign

RESEARCH
- Annual grants for ET research studies
- ET research study recruitment
- Brain Bank with Yale University

SUPPORT GROUPS
- ET support groups around the world
- Essential Tremor Awareness Group on Facebook

SCHOLARSHIPS
- College Scholarships for students with ET
- $31,500 awarded to date

ADVOCACY
- Partnerships with health organizations worldwide

essentialtremor.org