Your voice for essential tremor
What a great and exciting year! Perseverance in using many different ways to communicate has paid off for people within the ET community and extending far beyond.

When it comes to increased awareness, support, the distribution of free educational information and the funding of cutting-edge research, there were many programs that enabled us to reach thousands internationally. We are very proud of the accomplishments, and we continue to strive to make you aware of all the IETF can offer to you and your family.

Each year we publish an annual report to summarize all that was accomplished in a given year, and it is compiled just for you. So please take some time to read about the various activities so you will understand how we spent your hard-earned donations and how hard the IETF worked for you with only four staff employed.

The summary of benefit to you is outlined in the segments that review the scholarship program, mass communications, support group leader volunteers, patient education events, healthcare provider education, the website, Facebook, Twitter, Tremor Gram, Tremor Talk magazine, the funding of research and the advocacy efforts done in Washington, DC.

I want to give thanks to so many for such a successful year. A special thanks first and foremost to the IETF staff - Carol, Rebecca and Tara. Without their commitment, skills and talents, the goals could not have been reached. They always go the extra step to ensure that ET patients are provided the best educational information, support and programs that the IETF can provide. The next time you call/e-mail or write, please give them your thanks for all they do for everyone with ET.

And as always, my thoughts and profound thanks go to the donors and volunteers for their support and generosity. You mean the world to us and your commitment of time and financial support is the reason the IETF continues to thrive and grow ever larger each year. The IETF wouldn’t be where it is today without your support.

We also want to give special recognition to Tom Bruderle, IETF Washington, DC Liaison, who reaches out each and every week to increase awareness among federal legislators so ET remains at the forefront of our lawmakers’ minds. Without Tom’s advocacy efforts, ET would not be as well-known as it is in Congress. Thanks to his advocacy efforts, the IETF remains included in many activities and committees involving critical research and awareness.

A very special thanks to all of you who are IETF Facebook friends, Twitter followers, YouTube and Google Plus members who help spread the word about ET. Your outreach enabled the IETF to reach a staggering number of new people this year who would not otherwise have known where to turn. You made a big difference in so many lives.

So in closing, please don’t forget that the IETF belongs to you – you are the fuel that drives the engine of every activity, program and research endeavor and we are very proud to serve you.

As we look forward to next fiscal year, we again promise to work tirelessly on your behalf. Thank you for your support, commitment and loyalty. Though great strides have been made, we can do more and there is still so much more to do. Please join us in 2015-2016. We need your support more than ever.

Sincerely,

Catherine Rice
Executive Director
A single voice is seldom heard, but a thousand voices can shake the world.

Right: Alyssa Mendelsohn was one of five IETF scholarship recipients and a future leader for all people living with the challenges of ET.

Cover: Brett Wiscon’s, musician affected by ET featured in the December issue of Tremor Talk
Programs

Scholarships
Living with the daily challenges of essential tremor can be tough enough on its own. Living with ET while balancing a heavy course load and managing the financial burden of a higher education, can seem unbearable. The IETF’s scholarship program is dedicated to making sure ET does not stand in the way of an education. Each semester, the IETF awards $500 scholarships to qualified post-high school students of all ages, to lessen the burden of tuition.

The IETF was pleased to award four students who are affected by essential tremor with $500 scholarships for the 2014-2015 academic year: Alyssa Mendelsohn from Baltimore, MD.; Kaleigh Knapp from Concord, NC; Paul Schoolman from Sykesville, MD.; and Sarah Kunz from Waverly, MN.

In addition to the four primary scholarship awards, the IETF teamed with The Goulden Touch Foundation to award a $500 scholarship to Jared Beeson of Oconee, IL. Founded by All Pro Kicker Robbie Gould, the mission of The Goulden Touch Foundation is to simply help those in need in the areas of: health & wellness, medical research, social service and education. The mission of this scholarship was to help students in Illinois affected by ET.

“These five students exhibit impressive qualifications based on academic and extracurricular activities in their communities and will become outstanding, future leaders in helping create more awareness about essential tremor,” said Catherine Rice, Executive Director of the IETF. Read more about their stories on our website at www.essentialtremor.org/scholarships.

Scholarships can be used for supplies, books or tuition at licensed, accredited institutions of higher education (including trade schools) and are paid directly to the educational institution. The IETF needs additional generous donors to continue the IETF scholarship program. With donor support, we can help the many qualified and deserving applicants to finance some of their educational expenses. For more information about the scholarship program, please visit www.essentialtremor.org/scholarships.

Volunteers
Part of the IETF mission is to provide support to those affected by essential tremor. The IETF was very proud of the 70 volunteer Support Group Leaders who gave of their time and talents for the betterment of their communities. In FY2015, volunteers representing 32 states and 6 countries, donated nearly 10,000 hours of service by holding support group meetings for those affected, educating healthcare providers about the resources the IETF has available, and representing the foundation at local events and health fairs. The estimated value of their combined efforts was $217,330.
Patient Education
One of the key factors to the IETF mission begins with education. By facilitating free, educational seminars for essential tremor patients, families, healthcare providers and the general public, the IETF can provide well-rounded information and bring greater awareness to this life-altering condition throughout the nation.

This past fiscal year, the IETF hosted 16 seminars in the following cities:

- Kennewick, WA
- Greenville, SC
- La Jolla, CA
- Atlanta, GA
- Commack, NY
- Oakbrook, IL
- Fort Wayne, IN
- Raleigh, NC
- Concord, NH
- Phoenix, AZ
- Chesterfield, MO
- Emeryville, CA
- Williamsport, PA

These seminars cover topics including the diagnostic process, treatment options, current research, support groups and occupational therapy options. The IETF teams with world-renowned movement disorders specialists to provide ET patients an incredible educational experience through presentations and Q&A panel discussions.

To build on the current successful educational seminar series, the IETF wanted to expand on these events to include a more comprehensive approach to education, to meet the needs of patients during all aspects of ET in a new, dynamic setting. This year, the IETF hosted its first ever ET Expo in Phoenix, AZ. This interactive Expo spent a full day covering the entire gamut of topics on ET. The best movement disorder neurologists and neurosurgeons in the area presented on the many different aspects of ET, giving attendees a well-rounded view of their condition. Along with the presenters, event sponsors from Barrow Neurological Institute, Banner Sun Health Research Institute, Active Forever, Banner Good Samaritan Medical Center, Medtronic Corporation, and GE Healthcare joined other exhibitors to educate attendees about local ET resources and to demonstrate a hands-on experience on the newest assistive technologies.

The 291 Expo attendees left the day feeling more informed and uplifted by meeting others going through the same daily challenges. “I sat around five new friends from Prescott at the Expo,” Steve A. said after the event. “With all
those people there, it’s the first time I did not feel alone by having ET.” The IETF has yet to confirm whether this expo format will be continued in the future, but we will continue to find new and innovative ways to bring the latest information to our supporters for years to come.

For those who could not attend our Expo or events in person, webcast recordings are saved online at www.essentialtremor.org/about-et/webcasts. Here, anyone in the world can view presentations from past events and have access to further education within the ET community.

For more information about IETF patient education events, including dates and locations of future seminars and webcasts, visit our website at www.essentialtremor.org/seminars.

Healthcare Provider Education
To increase awareness of the needs of ET patients and to provide greater access to resources for healthcare professionals, the IETF attends several healthcare provider conferences around the nation.

Physicians, nurses, and students from all over the world attend these conferences giving the IETF a unique opportunity to expand its educational reach to a global audience.

At the following conferences, the IETF distributed educational materials to nearly 50,000 healthcare providers to further global understanding of essential tremor:

- American Academy of Neurology
  Philadelphia, PA
- American Academy of Family Physicians
  Washington, DC
- American Academy of Family Physicians
  Residents and Students
  Kansas City, MO
- American Academy of Neuroscience Nurses
  Anaheim, CA
- American Association of Nurse Practitioners
  Nashville, TN
- American Academy of Physician Assistants
  Boston, MA
- American College of Physicians
  Orlando, FL
- American Occupational Therapy Association
  Baltimore, MD
- Gerontological Advance Practice Nurses
  Association
  Orlando, FL

Healthcare providers attending these conferences were also mailed educational materials, to update their colleagues and office staff about essential tremor and enable them to provide high quality printed information to their ET patients. Free patient materials are always available on the website at www.essentialtremor.org/for-healthcare-providers or by telephone.
Communications

Electronic Communications
The IETF touches many people worldwide thanks to the advancements in technology and communications. Through an interactive and user-friendly website, informative and frequent e-mails, and a strong social media presence, the IETF reaches thousands across the globe.

Electronic communications not only allow us to reach more people than ever before, they allow us to make meaningful connections at a fraction of the cost of postal mailings. The IETF connects people together on several social media sites to help raise awareness among the general public and to provide additional communication avenues and support for those affected.

Follow the IETF’s latest information at the following places:

- Website: www.EssentialTremor.org
- Twitter.com/EssentialTremor
- Blog: TremorTalk.org
- Facebook.com/InternationalEssentialTremorFoundation
- Search for International Essential Tremor Foundation on Google+
- YouTube.com/essentialtremorIETF
The IETF website, www.essentialtremor.org, is often a starting point for many people living with ET. It’s a place where we deliver the most up to date information on the full gamut of topics regarding ET. Last year, the IETF website had a total of 184,971 visits averaging more than 500 visits per day, most of which (approximately 78%) were new visitors to the site.

The top three pages visited (excluding the homepage) were Assistive Devices, About ET and Treatments. Other popular pages included Liftware, Coping, Medications, About the IETF and Free Downloads - where visitors can download and print reference documents reviewed by the IETF Medical Advisory Board members.

One-hundred eighty-eight countries/territories across the globe accessed the IETF site last fiscal year. Apart from the United States and Canada, users from the United Kingdom, Australia, Brazil, India and Germany topped the list, showing us once again our extensive global reach.

Although the majority of the users still access the IETF website using a desktop computer, 25% of the traffic on the website was conducted on a mobile device. That’s an 11% increase over last year. Based on the increased traffic from mobile devices, the IETF launched a new mobile friendly site to be easily accessed on smartphones, tablets and other mobile devices. The mobile site now allows users to navigate with ease through all the same components of the IETF’s standard website but through a more user-friendly application.

Social Media
The IETF has created a widely successful social community where people living with ET and their family members can join together to share common feelings, challenges, and support for one another in a safe and private environment. Through Facebook, Twitter, Google+, YouTube and our Tremor Talk blog, visitors can interact with one another as we help raise awareness among the general public and provide additional communication avenues.

- The IETF’s official Facebook page increased 23% with 1,393 new likes, which brought the total to 7,415 connections made through Facebook.
- The IETF also facilitates a Facebook support group called the “Essential Tremor Awareness Group”. With more than 3,300 members, this “closed” group serves as an active support system offering privacy and interaction for users to share with one another.
- Twitter grew to over 900 followers, which is a 29% increase over last year, making more than 71,152 total impressions.
- 362 people have subscribed to the IETF’s YouTube channel with more than 125,062 views.
Tremor Gram
Each month the IETF sends out Tremor Gram, our free, electronic newsletter, to nearly 18,000 people. Sending short and informative e-mails on a regular basis helps increase participation in IETF educational events, assists in recruiting people to take part in ET-related research studies, drives additional traffic to the website, and builds loyalty and support among the donors.

The IETF e-mails have an average open rate of 28%, which is higher than the industry standard. Click-through rates are determined by the number of people who actually click on a link within an e-mail. The average click-through rate for non-profits is 12.46%. IETF click-through rates are consistently nearly 20%.

Press Release Distribution
To reach beyond our circle of constituents and contacts, the IETF sends press releases through a wire service to not only inform the general public about IETF activities, but to create greater awareness throughout the nation.

To publicize scholarships, research updates, education events, awareness walks and activities, and other important organization updates, the IETF sent out 43 press releases to news outlets.

While just sending out 43 press releases through our PR networks, we extended the reach to a greater extent.

- E-mail Count - 5,597
- Media Contact Count - 5,890
- Media Deliveries - 90,662
- Total Pickups - 10,243

The press releases are distributed to media contacts where they are then delivered to several other media sources through their networks. The total pickups refer to the amount of sources that post the release through their networks, extending our audience for maximum exposure. In the years to come, we hope to continue to create even greater awareness for ET than ever before.
Tremor Talk Magazine

Published three times a year, Tremor Talk is the IETF’s 32-page, full-color, professional publication all about essential tremor. The magazine features articles written by both healthcare professionals and IETF staff on a variety of ET-related topics: personal stories about people who have ET illustrate the challenges of living with essential tremor and the unique ways real people are able to conquer those challenges and prevail; medical articles are authored by some of the top minds in the movement disorders field and are written in common place language so that anyone can understand; and research articles offer a glimpse of what scientists are working on today and what might be obtainable in the future.

Tremor Talk is a member publication and is mailed only to IETF annual donors.

April 2014
Jean Davidson graced the cover of the April magazine. Granddaughter of one of the original founders of Harley-Davidson, Jean shared her very personal story of love, loss and living with essential tremor. Other topics included were: therapy options for those with vocal tremor, a listing of research studies that were recruiting ET patients, and a timely article about the potential medical use of marijuana for ET. We were also saddened to report the loss of Dr. Roy Bakay, a long-standing member of the IETF Medical Advisory Board and talented movement disorders neurologist, who passed away after a long battle with cancer.

August 2014
In this issue, Brett Wiscons, author and musician, talked about his own struggles coming to terms with his diagnosis of essential tremor. He shared how he used to hide his shaky hands, and how he was working to make them become his “new normal”. Articles on Primary Writing Tremor (PWT), IETF funded research, IETF scholarship winners, and general health and wellness tips for those with ET where also included.

January 2015
Allison Dyke was a shy and quiet little girl who had been bullied relentlessly because of her tremor. It wasn’t until she was introduced to the world of beauty pageants that she realized the strength and confidence she had within her. You can find Allison on the cover of the January issue. In this same issue, Dr. Leon Dure, pediatric movement disorders neurologist, explained the physical, social and emotional impact of ET on children, teens and young adults. Other articles covered how the U.S. social security disability system works (or doesn’t) for those with ET, the importance of Arizona’s IETF funded brain bank for ET research, and a full guide on how to get involved with Essential Tremor Awareness Month.

Past issues of Tremor Talk are available at www.essentialtremor.org/about-et/publications-library.
Awareness

National Essential Tremor Awareness Month

2014 marked the fourth anniversary of the passing of House Resolution 1263 - the official designation of March as National ET Awareness Month, which was initiated by the IETF and sponsored by former Congressman Dennis Moore (3rd District - KS). In order to help raise awareness of essential tremor around the world this year, the Foundation asked its members, donors, and volunteers to put on their walking shoes and start moving for ET awareness!

Registrations to walk poured in from all over the country. People were really excited to gather their friends and family, put on their awareness month t-shirts, and take to the streets on March 22 to help raise essential tremor awareness. This year’s walk was very informal, with no set city or pre-determined routes. We simply asked people to get out in their communities and walk and talk about ET. We were not sure how people would react to the idea. However, any concerns we had quickly dissipated as the registrations started arriving. The walk was a simple and easy way for people of all ages to get involved with raising awareness and show their support for those affected.

Several IETF donors and support group members participated in the walk, from Indianapolis, IN to Madison, AL. Even IETF Canadian support group crossed the border to come and walk with their American friends in Michigan! Some walked inside their local malls and fitness centers, while others welcomed spring with a stroll through their public parks and walking trails. We are grateful to everyone who hit the streets to help raise awareness.

Walking was not the only way to get involved in raising awareness. IETF members like Lillian Courtheoux wrote letters to her local newspaper editors in Rochester, NY and sent out press releases to her local media. Others handed out literature and educational information at local farmers markets, like the San Francisco Bay Area support group.

“That is my platform now: overcoming personal adversity and essential tremor.”

Right: Allison Dyke has had essential tremor since she was a small child. Now she’s raising awareness as Miss Michigan Jr. Teen.
Members gave out spiral buttons to friends and family, handed out ET bookmarks, and bought awareness bracelets from the IETF’s online store. Some even requested proclamations from their governors and mayors, asking them to recognize March as Essential Tremor Awareness Month. Several of these proclamations were passed. The governors of both California and Connecticut passed proclamations, as well as the mayors of Palm Desert, CA and the little town of Cherryvale, KS. Whether it’s a huge state or a small town, supporting awareness is vital to helping the public better understand this condition.

March is such an important month. It is our opportunity to get the story of what ET is and how it effects the lives of millions, out in the public eye. It allows us all the opportunity to speak about ET nationally. Many of our members have remarked that although essential tremor is estimated to affect more than 10 million Americans, no one seems to know what it is or they assume it is related in some way to Parkinson’s disease. That is precisely why March is so vital.

Having a nationally recognized awareness month gives us all something to rally behind, to be part of, and to help grow into a larger movement. Every time a letter to the editor is published or someone reads the facts about ET on the back of one of the bookmarks, they become aware. Awareness fosters understanding. And that understanding then leads to compassion. But it takes all of us working together; it takes all of us spreading the word and speaking out about ET. March is the ideal time to do it and help those around us become aware of ET, better educated about ET and compassionate to those affected by ET.
Raising awareness, from small town USA all the way to D.C.
The Washington Report
Tom Bruderle is the Washington, DC liaison for the IETF, who works tirelessly to represent the interests of the IETF and its donors. Each month he offers updates on his congressional contacts and current legislation that impacts those affected by essential tremor. As someone who has spent his career working the halls in Washington, DC and as someone who has essential tremor himself, Tom is well-versed on the impact of ET on daily living and he knows how to educate legislators on the needs of those affected.

Committee Work
With help from the IETF Executive Director, Catherine Rice, Tom was appointed to the Advocacy (legislative affairs) Committee of the American Brain Coalition (ABC) and participated in several teleconferences. The ABC brings together afflicted patients and their families, caregivers, and the professionals that conduct research and treat diseases of the brain to leverage their combined resources to improve the quality of life for all people affected by brain and nervous system diseases. The Committee’s goal is to be a united voice for the people affected by these conditions, and to work with Congress to alleviate the burden of brain disease.

Each year the National Institutes of Health (NIH) working with the National Institute of Neurological Disorders and Stroke (NINDS) invites a select few members of key nonprofit organizations to attend the Institute’s Nonprofit Forum. The Forum provides an opportunity for nonprofit leaders to network with colleagues and to engage in discussions with NINDS staff. Tom represented the IETF at the 2014 Forum entitled “Progress through Partnership”. He met with several members of related nonprofits, encouraging them to join the IETF on future visits to members of the Senate Committee on Aging.

Reaching out to other organizations is a key factor in bringing neurological conditions to the forefront of conversation. Tom contacted Mr. Ted Thompson, the new president of the Parkinson’s Action Network (PAN). PAN has a unique structure as the one organization in Washington, DC advocating on behalf of the entire Parkinson’s community. Tom met with Thompson to learn more about the direction PAN will be moving under his new leadership, to update PAN on IETF activities, and to explore opportunities for cooperation and collaboration.

Tom visited the health staff of Sens. Orrin Hatch (R-UT), Jeff Flake (R-AZ) and Dean Heller (R-NV), Richard Blumenthal (D-CT) and Susan Collins (R-ME), members of the Special Committee on Aging, to educate them about essential tremor and request that they place essential tremor and increased funding for the (NIH/NINDS) on their policy agendas. While special committees have no actual legislative authority, they can study issues, conduct oversight of programs, and investigate reports of fraud and waste. Throughout its existence, the Special Committee on Aging has served as a focal point in the Senate for discussion and debate on matters relating to older Americans. The staff was receptive to the information Tom provided them. They were very grateful to have such up-to-date information and offered to be of assistance in the future.

Legislation
Tom, along with IETF Executive Director Catherine Rice, are always working to move research for ET forward. To that end, Tom and Catherine actively supported several bills that would increase funding and the understanding of neurological disorders. With the 21st Century Cures proposal, Congress looked at all the steps involved in bringing a new medication or assistive device to market in the United States. They looked for ways to streamline the process; close the gaps between advances in scientific knowledge and regulatory policies created to save lives. Over several months, members of Congress examined the whole process, from the discovery to development to delivery, to determine what steps can be taken to keep scientific innovation moving forward at full speed; opening the door to faster FDA approvals for potentially groundbreaking research. In July 2015, U.S. House of Representatives passed the 21st Century Cures Act (H.R. 6) by a resounding vote of 344 to 77.

The Advancing Research for Neurological Diseases Act (H.R. 292), introduced by Reps. Michael Burgess (R-TX) and Chris Van Hollen (D-MD), will guide the Centers for Disease Control and Prevention (CDC) in tracking the occurrence and frequency of neurological diseases, including essential tremor. The goal of H.R. 292 is to find ways to better understand future health care needs, note overall changes in health practices, assess disease burden, promote education and support neurological research. More than half of the initial co-sponsors for this bill were recruited by Tom working on behalf of the IETF. In January 2015, this bill was referred to the Subcommittee on Health for review.
Research

Each year researchers with an interest in studying the various aspects of essential tremor are encouraged to submit scientific proposals for grant funding from the IETF. To date, your research donations provided more than $750,000 to fund 30 promising studies.

Below you will find information about the three studies that were selected to receive 2014 IETF research grants.

The Role of Excitotoxicity in Essential Tremor Cerebellum

The cause and development of ET remains poorly understood. Functional imaging studies show cerebellar abnormalities in patients living with ET. The goal of this research is to investigate the role of excitotoxicity in the postmortem essential tremor cerebellum. Excitotoxicity is the pathological process by which nerve cells are damaged and killed by excessive stimulation by neurotransmitters. It has been a suggested approach for ET, however there has yet to be any direct evidence that excitotoxicity plays a role in ET patients.

Researchers propose to test this hypothesis by examining the number of excitatory synapses (structures that permit a neuron to pass an electrical or chemical signal to another cell) and the levels of excitotoxicity markers in the ET cerebellum. This will be the key step to understanding the process of the cerebellar degenerative process in ET. The study will be conducted by Dr. Sheng-Han Kuo at the Essential Tremor Centralized Brain Repository at the New York Brain Bank at Columbia University in New York.

Cerebello-Thalamo-Cortical Coupling in ET

Tremor is often associated with abnormal activity within different brain regions, particularly the thalamus and cerebellum. Deep brain stimulation (DBS) reverses symptoms of tremor but is an invasive procedure. Transcranial stimulation of the cerebellum may represent a non-invasive therapeutic option for ET patients. Transcranial stimulation (tACS) is a new technique allowing manipulation of rhythmic patterns in the brain’s cortex with externally applied electrical frequencies.

Researchers propose to test the effectiveness of cerebellar stimulation in ET patients previously operated on for DBS. To further understand how this treatment provokes tremor reduction, they will analyze the brain neuronal activity in other ET patients who are candidates for DBS by using electric current recordings of the thalamus, cerebellum and cortex.

The study will be conducted by Dr. Marie-Laure Welter at Groupe Hospitalier Pitié-Salpêtrière in Paris, France.

ET Brain Bank at the Arizona Study of Aging and Neurodegenerative Disorders

Now in its third IETF-funded year, researchers will continue to examine the brain tissue of those with ET and other neurological disorders after death, searching for a greater understanding of how ET changes the features of the brain, and hopefully leading to more effective diagnostic tools. They will also compare the clinical findings of early onset ET and ET beginning after age 65. They will then clinically categorize action tremor in the elderly and serially assess tremor and non-motor signs. Researchers will examine all brain areas using previous standardized assessments with the goal to explore whether there are any brain regions that may have been overlooked in smaller surveys in the past. This study will be conducted by Dr. Holly Shill and Dr. Charles Adler at Banner Sun Health Research Institute in Tucson, AZ.

Right now the IETF is working to raise enough money to fund next year’s research grants. Your research donation could make the difference between critical research being funded or being turned away. Every donation, no matter the size, counts. Please help keep research moving forward by making a research donation today. Call (toll free) 888.387.3667 to donate over the phone, mail a check to the IETF (PO Box 14005, Lenexa, KS 66214) or save a stamp and make your research donation online at the IETF website, www.essentialtremor.org/ways-to-give.
Brain Biochemistry Proves Little Risk Between ET & Parkinson’s Clinical Characteristics of ET & Enhanced Physiological Tremor in Childhood

Moving Forward
RESEARCH & HOPE FOR ESSENTIAL TREMOR

The road to discovery can be a long and difficult one. But we are at a pivotal moment in ET research where significant scientific progress is being made. Your donation could make the difference between critical research being funded, or being turned away.

Every donation, no matter the size, counts. Help us keep research moving forward. Please donate.

ET Brain Bank - Study of Aging & Neurodegenerative Disorders
High School Engineering Students Develop ET Tools through Lemelson-MIT program
Quality of Life with Essential Tremor (QUEST) survey

Researchers Identify Potential Cause of ET in Loss of GABA Receptors
Study Shrugs Light on Drugs’ Potential for Tremor Suppression

Postmortem Neurochemical Alterations in ET Patients: A Clinicopathologic Study of ET
Worldwide Consensus Conference on ET to Identify Research Goals

Scientists Identify LINGO1 Protein Linked to Essential Tremor
An Innovative Damping Exoskeleton Approach to ET Treatment
Analysis of Candidate Genes for Familial Essential Tremor

Identification of the Neural Generators in ET using Functional Magnetic Resonance Imaging
Essential Tremor Centralized Brain Repository

2014 IETF-FUNDED RESEARCH
Cerebello-Thalamo-Cortical Coupling in ET: Effects of High-Frequency Stimulation on Brain Activity & Tremor
The Role of Excitotoxicity in ET Cerebellum
A Feasibility Study for an ET Brain Bank at the Arizona Study of Aging and Neurodegenerative Disorders

Learn more about these studies and all other IETF-funded research at www.essentialtremor.org/research.
Contributions

The IETF receives little or no federal, state or local government funding. Contributions from those affected by ET, mostly in the form of annual donations, sustain the IETF. This fiscal year, the IETF received 6,465 donations totaling $621,972. That equates to just .0008% of the estimated 10 million Americans affected by essential tremor actually donating in support of the organization whose sole purpose is to help those with ET. These donations were used to fund ET research grants, provide free education and materials, offer vital support services, and fund programs that raise awareness in communities around the world.

Financials

Revenue

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<tr>
<th>Source</th>
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<td>Investment income</td>
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<td>Memorials/Bequests</td>
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<td>Program service fees</td>
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<td>Research</td>
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<td>Special events²</td>
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Expenses

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<td>Fundraising⁵</td>
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<td><strong>Total Expenses</strong></td>
<td><strong>$724,337</strong></td>
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</tbody>
</table>

¹ Corporate contributions totaled $6,600. $604,127 was donated by the public for general support.

² Revenue received from National ET Awareness Month.

³ Includes awareness, education, support and research activities and initiatives.

⁴ Includes expenses related to office overhead such as supplies, computers, copier, salaries, and rent.

⁵ Includes National Awareness Month activities, annual appeal, and annual donations.
The President’s Club

The President’s Club honors individuals that contribute $1,000 or more annually to the IETF. President’s Club members are everyone’s heroes. Members are recognized in several IETF publications, such as Tremor Talk magazine, on the IETF website and in the IETF annual report. Every dollar received by the IETF is greatly appreciated, but these large donations make a significant impact on the Foundation’s ability to fulfill its mission each year. Please join us in recognizing these generous donors:

**Platinum ($10,000+)**
Shari & Stan Finsilver
Mr. & Mrs. Walter Stearns

**Gold ($5,000+)**
Mr. & Mrs. Martin Holford
Bonita Lowry
Loren Parks
Mr. & Mrs. Randal Peterson

**Silver ($2,500+)**
Lyudmila Broder
John Marth
Rosemary Nothwanger
Mr. & Mrs. Larry Roberts
Byron Scott
Marsha Morgan Sitterley
Florence A. Slater
Nancy Uppal

**Bronze ($1,000+)**
Foundation Dorothy Jurs & Janice Mader
Jewels of Katy Mrs. Betty Schwarz
Mr. & Mrs. Norman L. Johnson
Andrew Jones
Susan Kahn
Margaret Klein
Mr. & Mrs. Thomas C. Koehler
Michele Leber
Terry Lee
Stephen Lescher
Michael Libman
Jane Limbaugh
Liwerant Family Fund of the Jewish Community Foundation
Kelly Lyons
Michael Mahoney
Laura McCool
Paul McGrady
Stephanie Mendel
Kevin Nulty
Louis Orloff

Robert M. Oster
Anupam Pathak
Charles E. Paules Jr.
Mary Pohlman
Dr. & Mrs. David Rabinowitz
Robert L. Richmond
Jack Robinson
Mr. & Mrs. Joseph G. Robinson
Mr. & Mrs. Jerry Slater
Ms. Neena Slater
John W. Smith Jr.
Mr. & Mrs. Lee Smith
Frank Soroka
Mr. & Mrs. Gerald Swanson
Rick Taylor
The Alvin and Fern Davis Foundation
Elmer Werner
Mr. & Mrs. Williams
Mr. & Mrs. Leo Wilz
Fred M. Young Jr.
Memorials

Giving a memorial donation is a meaningful way to pay tribute and show how those close to you continue to live on in your heart. Below you will find a list of friends and family members who have donated in memory of their loved one. Memorials are listed in ALL CAPS, and donors are listed below.

DICK BERGGREN’S WIFE
North Shore ET Support Group

MOTHER AND SISTER
Ms. Joyce Hearn

PAT AND RON
Cowan’s Brother
Shari & Stan Finsilver

JACK ALLEN
Dr. & Mrs. Howard McQuillen

JIM ALTHAUS
Mr. Charles Damsel

ETTA BRIDGEMAN
BECHTEL
Mr. Charles Damsel

MADELINE BEENY
Ms. Sharon Berger

JOHN BERNARD
Mr. Gilbert Herman

DR. THOMAS BOWLUS
Ms. Ruth Shelley

DOROTHY BUDZEK
Washing Systems, LLC

BETTY JEANNE CARPER
Mr. Terry Massey

BERNICE COHEN
Mrs. Joan Zapin

REV. ORVILLE CRUEA
Mrs. Beth Davenport
Mr. & Mrs. Michael Ginaven
Mr. Arthur Hall
Mr. Randy Hart
Ms. Sallie Johnson
Mr. & Mrs. Keith Justus
Ms. Suzana Mueller
Ms. Donna Shiltz
Mr. & Mrs. Michael Slominski
Trudy Clark & Ruth Dean
Ms. Mary Vulin
Ms. Diane Walker
Ms. Jennifer Walton
Mr. & Mrs. Fred Williams
Ms. Kathryn Wine
Mr. & Mrs. Bill Zielensbach
Ms. Amy Pickenpaugh

ANNE CUSTANCE FAHRNER
Huachuca Mountain Stamp Club

CURTIS CUTTING
Mrs. Mary Smith

AUDREY DAHLGREN
Mr. Gordon E Dahlgren
Mr. & Mrs. Philip Dyer

EVELYN DIAMOND
Mr. & Mrs. Mark Benjamin
Mr. & Mrs. Alan R Berns
Ms. Katherine Gaines
Ms. Ellen Greenberger
Mr. Jerry Leaness

JOSEPH DIMONTI
Mr. & Mrs. Richard Boffi
Mr. & Mrs. Robert Crapulli
Mr. & Mrs. Bob Diorio
Ms. Anne Dimonti
Ms. Judith Doherty
Ms. Jill Gosantos
Mr. & Mrs. Paul Henry
Mr. & Mrs. Anthony Lupino
Mrs. Evelyn Palombo
Mr. & Mrs. Arthur Schattle
Ms. Nancy Tyboroski
Mr. & Mrs. Phillip Wildenhain

ANNE DISTEFANO
Mr. Anthony Alimenti
ECH Medical Staff
Mr. & Mrs. David Neuhaus

FRANK LEVI EATON
Mr. Charles Damsel

MARIANNE ERICKSON
Mr. Leroy Erickson

SHARON EVANS
Mr. Joan Zapin

ROBERT FENDELL
Mr. & Mrs. Steven Andelman
Ms. Susan Fendell
Ms. Lauren Roy

ROBERT GILBERT
Ms. Carol Jerome

GLORIA GOLDEN
Ms. Estelle Bloom
Ms. Janet Fernandez
Mr. & Mrs. Terry Leaness
Mrs. Alice Luftig
Mr. & Mrs. Francis Nordone
Ms. Bertha Person
Ms. Maxanne Resnick

GUSTAVE GOLDMAN
Ms. Carolyn Rosof

ROSE GOODMAN
Mr. Mark Goodman

DR. KENNETH GOULD
Mr. & Mrs. Sheldon Kopel

MARY GRABOSKI
Mr. Byron Scott

MARY GRANDIA
Mr. & Mrs. Donald Grandia
Mr. & Mrs. Kenneth Grandia
Health Catalyst
Mr. & Mrs. Kyle Lieber
Mr. & Mrs. Thomas Maclean
Ms. Genevieve Smith
The Estate of Mary Grandia

VIRGINIA HOFFMAN
Barry & Susan Roberts

LOIS HOWARD
Mr. Charles Damsel

JAMES HICKMAN
HYLER
Abington High School Class of 1961

DALE ILNI
Mr. Harold Kort

MOLLIE & ERWIN ISAACSON
Ms. Sharon Ritt

ADOLF JACOBSEN
Mr. Christopher Jacobsen
Honorarium

Honorarium donations are great ways to recognize important achievements and successes like: getting a new job, celebrating a birthday or anniversary, graduation, Bar Mitzvah and Bat Mitzvah events, or just to say “I was thinking about you”. Below you will find a list of people who have donated in honor of a special occasion in a friend or family member’s life.

DANIELLE MALLORY
Ms. Laura Strauss

RICHARD COURTHEOUX
Ms. Lillian Courtheoux

ROBIN MALLORY
Ms. Laura Strauss

DR. DEBRA PLINER
Ms. Laura Strauss

RICHARD & PERRI COURTHEOUX
Ms. Lillian Courtheoux

ROBIN MALLORY
Ms. Laura Strauss

ROBIN MALLORY
Ms. Laura Strauss

JOE DRISCOLL
Col. & Mrs. Barry Pencek

Gayle Schendzielos
P.E.O. Chapter GI

SID & CELE AWERBUCK
Mr. Ryan Weiss

CATHY SLAVIK
Shari & Stan Finsilver

DEBBIE & CHARLES AVERBOOK
Shari & Stan Finsilver

CAROL ST. CHARLES
Mr. Jay Munro

Koby Ben-Ezra
Mr. & Mrs. Jerry Rubin

LYNDA ST. JAMES
Mr. & Mrs. Skip Fumia

KOBY BEN-EZRA
Mr. & Mrs. Jerry Rubin

Mr. & Mrs. Robert Hakim
Julie & Jason Levy

HELEN ZIMMERMAN
Mrs.. Michele Barker

CYNTHIA BORBY
Mr. & Mrs. Mark Lyman

MARY CATHERINE GIB-BONS
Mr. & Mrs. Thomas Coyne

AMY & KYLE GRIFFIN
Mr. & Mrs. J. Robert Booth

LILLIAN COURTHEOUX
Mr. & Mrs. Richard Courtheoux

LEWIS KAGAN
Mr. Eric Cosares

Right: Metro Detroit Support Group co-leader, Sabrina Pilarski, with support group members Elissa Kline and Barbara Placco
Legacy Society

Members of our Legacy Society have expressed their commitment to IETF through a very special and important form of financial support. These donors 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 a great way to have your support live on for years to come.

If you would like to learn more about the Legacy Society or how to leave a bequest or gift of insurance to the IETF, please visit www.legacy.vg/essentialtremor or call our IETF Executive Director, toll free at 888.387.3667.

The following individuals and families have generously named the IETF as beneficiaries in their wills or life insurance policies:

**Deceased Members**
- Warren Conklin Apgar Bequest
- Thelma Beatty Trust
- Shirley A. Cavanagh Bequest
- Nancy M. Craig Trust
- Beryl G. Deming Trust
- Irene Feimer Anger Bequest
- Howard Fisher Trust
- Albert Gendron Living Trust
- Laurita Hall Johnson Trust
- Dorothy Helen King Bequest
- Rose Kleiner Trust
- Barbara Kurtz Trust
- Lynn W. Martin Estate
- Paul T. Perney Trust
- Schmier Family Revocable Trust
- William & Mary Shelley Trust
- Martin Stinar Trust
- Delbert D. Utgaard Trust
- Melville VanBuskirk Bequest
- Kathleen Wambold Estate
- Lillian Courtheoux
- Shari & Stan Finsilver
- Marilyn Foreman
- Mary Gibbons
- Anne Gilstrap
- Sam Hodges
- Joseph L. Hores
- Raymond & Sarah Lamont
- Richard Marcus
- Carol Post
- Dorothy Stevenson
- Jacqueline Sydow

**Living Members**
- Judy Adams
- Patricia Anesi
- Leslie Balas
- Karen Christenson
OUR MISSION

The IETF funds research to find the cause of essential tremor (ET) that will lead to better treatments and a cure, increases awareness, and provides educational materials, tools, and support for healthcare providers, the public, and those affected by ET.