OUR STORY

In 1988, a neurologist and pioneer in the field of movement disorders zeroed in on tremor conditions. Dr. William Koller, at the University of Kansas Medical Center in Kansas City, Kansas, ran clinical trials and took a particular interest in essential tremor (ET), but also other types of tremor including orthostatic tremor, tremor from multiple sclerosis, tremor resulting from brain trauma, etc. His devotion to the field led to the establishment of the International Tremor Foundation (ITF) in 1988. Based in Chicago, the organization focused on all types of tremor and shared an office with the United Parkinson Foundation. Formal documents of incorporation for the foundation were filed in 1992. In 1997, the merger of the United Parkinson Foundation with the Parkinson Disease Foundation (in New York) prompted the ITF to relocate. Executive Director Catherine Rice moved the foundation to the Overland Park, KS region of Kansas City. This new location positioned them closer to their founder, Dr. Koller.

As the organization grew, so did its need to focus in on one area of tremor. Over a 10-year period, other organizations had been formed to focus on tremors associated with other diseases and conditions. This, combined with Dr. Koller’s investment in essential tremor, led to a more refined focus and a name change for the organization in 2001 – the International Essential Tremor Foundation (IETF).

Throughout its history, the IETF has continued to expand its reach and raise awareness and support for essential tremor across the globe. It is estimated that essential tremor affects more than 10 million people in the U.S. alone, and that number continues to increase. The need for an organization that raises awareness to and advocates for people with ET has never been more critical.

Today, the IETF is the leading organization in the world dedicated to those affected by ET.

MISSION

The International Essential Tremor Foundation provides hope to the essential tremor (ET) community worldwide through awareness, education, support and research.

Awareness. We promote greater ET awareness and educate at every level—from healthcare providers to caregivers to the general public.

Education. We empower individuals to regain control of their lives, by providing educational information, treatment options and coping skills.

Support. Our network of support groups across the globe provides inspiration and fellowship among those living with ET.

Research. We fund scientific research to identify more effective treatments and to discover a cure for ET.

Essential tremor is a neurological condition that causes a rhythmic shaking of the hands, head, voice and/or torso, making everyday activities such as drinking, eating and writing difficult, if not impossible. There is no known cure.

“Essential,” in medical terms, refers to “a symptom that is isolated and does not have a specific underlying cause.”

The Archimedes spiral in our logo is a diagnostic tool for essential tremor. Asking a patient to draw an Archimedes spiral is one of the ways physicians diagnose ET.
The IETF is the leading essential tremor (ET) organization in the world, working to advocate for people with ET 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 over $1 million dollars for the second year in a row.

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, scholarships to students affected by ET, and awarding more than $800,000 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, e-mail, 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 two teleconferences on a variety of topics (see page 8). If you missed one of the teleconferences recordings of each call are posted on our website on the “Education Programs” page. We also continue to host regional ET Education Forums. During our 2018-19 budget year, we visited Minneapolis, MN; Dallas, TX; Tampa, FL; and San Diego, CA. We have future events scheduled in St. Louis, MO, and Kansas City, MO. We hope you can attend one of these events when we come to your town.

To improve our marketing and communications efforts, the IETF has increased its social media efforts focusing on Twitter, Facebook and Instagram. We also share stories on our Tremor Talk blog. If you are on social media please follow the IETF and share our posts. This is an easy way for you to help us increase awareness and educate people on ET and the resources the IETF provides to patients, doctors, and anyone interested in learning more about ET.

We continue to strengthen our current partnerships and build new ones with a variety of companies, associations, and other non-profits who focus their efforts on promoting ET education and awareness. Several of our partners are continuing their efforts to explore new treatment options or improving existing 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 through Tremor Q&A, Tremor Talk, and our social media channels, 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 to share via personal meetings, phone calls, or social media. 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

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Tammy Dodderidge,
Marketing & Communications Manager

Dawanna Fangohr,
Finance, Database & Volunteer Manager
Raising awareness to essential tremor and connecting with the essential tremor community are part of the daily work of the International Essential Tremor Foundation. We’ve highlighted some of our top awareness initiatives for 2018-19.

National Essential Tremor Awareness Month

In March, we asked people around the world to help us “Shine a Light on Essential Tremor” during National Essential Tremor Awareness (NETA) Month. From sharing posts on social media to hosting individual fundraisers, the essential tremor community once again stepped up to take part in this annual awareness effort. Here are some of our results:

- Reached 83,576 people through Facebook
- Earned more than 48,000 impressions on Twitter
- Achieved 59,078 pageviews on the IETF website
- Raised $43,583 in donations
- Distributed 268 NETA Posters
- Gained 446 new page followers on Facebook
- Accepted 238 new people into the ET Awareness Group on Facebook (a closed online support group)

“Fue un poco de mi vida esto ha sido que he tenido que enfrentar por mí mismo. Y esto entero experiencia me ha hecho sentir que no estoy solo.”

ET Awareness Campaign with The Villages, Florida

The IETF partnered with The Villages, Florida, one of the largest retirement communities in the United States, to raise awareness about essential tremor. Through a series of advertisements in The Villages Newspaper, the IETF defined essential tremor, provided information about the mission of the IETF and offered free ET information packets. More than 350 residents responded.

Welcome Series Connects Individuals to the IETF

Connecting more people with essential tremor to the IETF was the goal of this Welcome Series campaign. It encouraged people to connect with the IETF by signing up for the email and/or mailing list, and provided them with information about the services provided by the IETF.

Networking with Healthcare Providers

To increase awareness of the needs of ET patients and to provide greater resources for healthcare providers, the IETF attended several healthcare provider conferences in 2018-19.

- American Academy of Neurology, Los Angeles, CA
- Parkinson’s Symposium, Overland Park, KS
- American Academy of Family Physicians, New Orleans, LA
- Movement Disorder Symposium, Overland Park, KS
All year long, the IETF works to educate people with essential tremor about the latest diagnostic tools, management techniques, treatment options and current research. Through education forums, teleconferences, publications, the Tremor Talk blog and other educational resources, we strive to keep everyone informed and connected.

**2018-19 Essential Tremor Education Forums**

- June 23, 2018 in Minneapolis, MN at the Minneapolis Airport Marriott
- September 15, 2018 in Dallas, Texas at the Sheraton Dallas Hotel by the Galleria
- October 27, 2018 in Tampa, FL at The Westshore Grand Hotel
- March 2, 2019 in San Diego, CA at the University of California, San Diego

**Essential Tremor Teleconferences***

- April 18, 2018 -- Surgical Options for ET
- Sept. 12, 2018 -- ET vs. Parkinson’s: How Do They Differ?

*Recordings of the teleconferences are available online at www.essentialtremor.org/teleconferences/

**Brochures and Other Printed Materials**

Each year the IETF provides thousands of copies of informational materials about essential tremor to physicians, medical institutions and the ET community.

**Tremor Talk Magazine**

Published three times a year, this 32-page magazine is provided to all donors to the IETF. It features research and support articles, support group listings, stories from the ET community and more.

**Tremor Talk Blog**

The Tremor Talk Blog shares stories of hope for people with ET. We have guest bloggers from the ET community, the medical community, the scientific community and student scholarship recipients. More than 183,000 people visited the Tremor Talk Blog site during the 2018-19 budget year.

**Tremor Gram E-Newsletter**

We had a 15% increase in subscribers to our Tremor Gram newsletter during the 2018-19 budget year. A total of 22,900+ people receive it each month.

**IETF Website**

www.essentialtremor.org

We had 221,223 users to our website during the 2018-19 budget year (a four-fold increase over the previous year). There were 514,439 pageviews.

**Scholarship Program**

The IETF supports college students with essential tremor by awarding eight scholarships each year.
OUR DEDICATION TO RESEARCH

“New and ongoing research for ET gives hope to us young people. Even though our conditions may worsen over time, there are also so many ways modern medicine can help us live our lives normally and we all need to work toward that goal together.”

—Deirdre, IETF College Scholarship Recipient

Research is the key to finding the cause of essential tremor. Advancing knowledge about its cause can lead to promising new treatments, therapeutic interventions and even a cure someday.

Supporting research is part of the mission of the IETF. Here are some of our research initiatives:

Research Grants. Each year, the IETF requests grant proposals from the scientific community to further our understanding of essential tremor. We seek proposals that address the nosology, etiology, pathogenesis or treatment of essential tremor or other topics relevant to essential tremor.

Research Advocacy. Advocacy is the empowering arm of research. Planting seeds with scientists/researchers, technology groups and others who have the expertise and connections needed to conduct essential tremor research is key.

Clinical Trials Recruitment. Testing the safety and effectiveness of medications and devices is critical to their approval. That’s why clinical trials are important. The IETF regularly promotes the essential tremor research studies looking for participants.

Brain Bank. The IETF continues its recruitment for brain tissue for several Brain Banks throughout the United States. These research banks study the post-mortem brains of people with essential tremor.

Since 2001, the IETF has contributed more than $800,000 to essential tremor research.

Learn more about ET research and IETF-funded research at www.essentialtremor.org/research/.

OUR FINANCIALS

REVENUE

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<th>Description</th>
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<td>Contributions</td>
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TOTAL REVENUE $1,121,746

EXPENSES

- Program: $496,474
- Management/General: $92,062
- Fundraising: $42,364

TOTAL EXPENSES $630,900

NET ASSETS $3,496,561

76% of revenue comes from direct contributions from donors

78% of expenses goes to Research, Education, Awareness, & Support

1 Includes revenue received from National Essential Tremor 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 Essential Tremor Awareness Month activities, annual appeal, and annual donations.
Support in Your Area

Essential Tremor (ET) Support Groups are informal self-help groups run by and for people with ET, under the umbrella of the IETF. They are places to talk openly about the challenges of living with ET, share ideas and feel connected.

Support Online Group

For individuals who don’t have an ET Support Group in their area, or can’t get out to a support group, there is support available online through the Essential Tremor Awareness Group on Facebook. Everyday, thousands of people connect to share stories and ideas, and provide support for each other.

www.facebook.com/groups/5884699022/

OUR SUPPORT GROUPS

A Life-Changing Experience

Shirley Silver was nine years old when she began to shake, but she wasn’t formally diagnosed with essential tremor until she was an adult. She felt self-conscious, nervous and even ashamed of her shaking.

As an adult, she got involved in an International Essential Tremor Foundation (IETF) Support Group and it changed her life.

“My knowledge, my confidence – everything was boosted by the support group and it changed her life,” she recalled.

Shirley shared her story with the IETF in 2018 at the age of 91. She passed away a short time later. We applaud her bravery and share her life lessons to help others.
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.

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 2018-19 budget year.

Deceased Donors

- Warren Conklin Apgar Bequest
- Robert Barfoot
- Thelma Beatty Trust
- Berner Charitable and Scholarship Foundation
- James Breene
- Marietta Budak
- Butler Family Trust
- Shirley A. Cavanagh Bequest
- William B. Cole Trust
- Nancy M. Craig Trust
- E. Ruth Crum Trust
- Albert Gendron Living Trust
- Beryl G. Deming Trust
- Margaret Edwards Estate
- Irene Feimer Anger Bequest
- Howard Fisher Trust
- Albert Gendron Living Trust
- Howard Fisher Charitable Trust
- William & Mary Shelley Trust
- Dorothy Johnson
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- Carol Post
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- Leon Wilhelm

For information on becoming a Legacy Society member, contact IETF Executive Director Patrick McCartney toll free at 888.387.3667.
Connect With Us

Join our email list – www.EssentialTremor.org

Read our blog – TremorTalk.org


Follow us on Twitter – www.Twitter.com/EssentialTremor

Follow us on Instagram – www.Instagram.com/essentialtremorfoundation/


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