RAISING THE CURTAIN ON ET

INTERNATIONAL ESSENTIAL TREMOR FOUNDATION
2019-2020 ANNUAL REPORT
From the Executive Director

Essential tremor (ET) is the most common movement disorder in the world with an estimated 10 million people in the United States affected by ET in some varying degree.

The International Essential Tremor Foundation (IETF) was founded in 1988 by Drs. Harold Klawans and Bill Koller. The IETF was originally located and incorporated in Chicago, IL and moved to Kansas City in 1997 when Dr. Koller joined the staff at the University of Kansas Medical Center.

We are a 501(c)3 non-profit organization guided by an executive board of directors, a medical advisory board, and an executive director with a staff of two. The organization consists of patients, physicians, educators, health care workers, parents, relatives, friends, and volunteers.

Our mission is to provide hope to the essential tremor (ET) community worldwide through awareness, education, support, and research. We provide a variety of resources for the ET community including ET education events (both in person and virtual), 70 + support groups (including an online support group on Facebook), scholarships to students with ET, and funding ET specific research grants to help find better treatments and hopefully someday a cure for ET to name a few.

We are able to focus on our mission because of the generous support of our donors and corporate partners. Our President’s Club and Legacy Society members are listed in this annual report and on our website.

We love to hear from you so please feel free to contact us with any questions, concerns, or ideas.

Patrick McCartney
Executive Director

IETF Board of Directors
RESEARCH GRANTS

To encourage research in the area of essential tremor and increase understanding of the condition, each year the IETF awards up to two $50,000 research grants to scientists. The grants fund promising studies addressing the nosology, etiology, pathogenesis and treatment of ET.

One research grant was awarded during the 2019-20 budget year. The recipient was Shyamal Mehta, Ph.D, assistant professor of neurology, Mayo Clinic, Arizona, for the study, “Assessing the Relationship Between ET and Dementia.”

SCHOLARSHIPS

The IETF awards up to eight higher education scholarships each year to students with essential tremor. The $1,000 scholarships help ease the financial burden for students, and connect students to a caring community so they know they are not alone. During the 2019-20 budget year, scholarships were awarded to:

- Elizabeth Carroll–University of Massachusetts, Amherst
- Anna Easley–William Carey University, Hattiesburg, Miss.
- Robert Holder–Georgia Southern University, Statesboro
- Alyssa Jones–Trinity University, San Antonio
- Colin Pool–University of California Berkeley
- Madison Young–Arkansas Tech University, Russellville, Ark

SUPPORT GROUPS

Essential Tremor Support Groups connect people from around the globe together to learn and share their experiences in an understanding and accepting environment. The IETF oversees more than 70 support groups around the world, including an online closed group on Facebook, the Essential Tremor Awareness Group.

CLINICAL TRIALS PROMOTION

Research can’t move forward without testing the safety and effectiveness of medications and therapy devices. That’s why the IETF promotes ET clinical trials looking for participants.
NATIONAL ET AWARENESS MONTH

Each March, the IETF hosts a special National Essential Tremor Awareness Month campaign. During the 2020 campaign, the IETF encouraged everyone to “raise the curtain” on essential tremor with NETA Month posters, individual fundraisers, awareness events and social media posts. Special NETA Month t-shirts and tote bags were sent to donors to keep awareness going all year long.

EDUCATION FORUMS

To provide support and education to ET patients and caregivers, the IETF hosts several ET Education Forums each year. Each forum brings together 125-150 individuals who want to learn more about ET, experts who want to share their knowledge, and vendors who share devices, support systems and research about the work they do in the area of movement disorders.

HEALTHCARE PROVIDER EDUCATION AND SUPPORT

Our goal is to connect the essential tremor community with qualified treatment specialists. The IETF produces and offers educational materials to all physicians, at no cost, as a resource for patients. These include reference guides about essential tremor, ET fact sheets, surgical options brochures, information materials on tremor disorders in children and more.

To maintain connections with neurologists, family physicians and the medical community at large, the IETF attends healthcare provider conferences each year.
The IETF connects with the ET community through several social media platforms:

- Facebook.com/InternationalEssentialTremorFoundation
- Twitter.com/EssentialTremor
- Instagram.com/EssentialTremorFoundation
- YouTube.com/EssentialTremorIETF
- linkedin.com/company/the-international-essential-tremor-foundation

**WEBSITE**

www.essentialtremor.org

The IETF website serves as an up-to-date source of information on all things essential tremor. From current research studies on ET, to coping tips, support group meetings, awareness initiatives and educational programs, the site is packed with content.

**TREMOR TALK**

Annual donors to the IETF receive a one-year subscription to Tremor Talk magazine. The 32-page magazine is published three times a year. It includes in-depth personal stories of ingenuity and perseverance, coping skills, research updates, education, and awareness information.

**TREMOR GRAM**

This is the IETF’s free monthly e-newsletter. In 2019-20, it kept more than 23,000 subscribers in the ET community up-to-date on current ET news and IETF activities taking place.
PRESIDENT’S CLUB

The IETF values contributions in all amounts. Donations of $1,000 or more annually go a long way to further the IETF’s mission. These individuals are celebrated as President’s Club donors. The IETF is grateful for the many individuals who remain loyal President’s Club members year after year.

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LEGACY SOCIETY

The IETF Legacy Society enables individuals to allocate funds so their support for the IETF’s mission can continue after their death. And equally important, their name and memory will be tied to the IETF forever. Planned giving also contributes to the stability and long-term growth of the IETF.

The IETF is thankful for these Legacy Society members:

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Jacqueline Sydow
Janet Whittlesey
Leon Wilhelm

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.