

Your Voice For Essential Tremor



Inspiration *and* Action

The past fiscal year was certainly inspiring for many reasons. The push for greater ET awareness through the **National ET Awareness Month** and **Tulips for Tremor** campaigns for ET research set incredible records in giving. Further, we discovered passionate individuals working to make their voice heard in their community. As part of the IETF's mission, we shared their stories with the world.



Joy Schaaf

We were inspired by **Joy Schaaf**, the 8-year-old in Ohio that raised awareness through her fundraising. Impressive engineering students at **Bishop Kelly High School InvenTeam** in Idaho developed and tested assistive devices to help people with ET.

Doctors Adrian Handforth, Fatta Nahab, Holly Shill and other researchers are working tirelessly to find the cause of essential tremor that will one day lead to better treatments. Selfless individuals like **Marlene Exner** and **Natalie Kusiek** demonstrated the power of one person to raise major funds for research and awareness. And many volunteers spent time to lead support groups, raise funds, or educate their communities about ET.

Such inspiration backed by action has fueled the IETF's mission to be "your voice for essential tremor." We listen

to your concerns and ideas, we share your stories and accomplishments, and we represent your voice in research, legislation, and public awareness.

The IETF represents 10 million people in the U.S. and those overseas with ET. With your support, we speak with one powerful voice.

We are a 501(c)3 non-profit organization dedicated to your cause. We reach thousands of people each year through our programs and services supported by your donations and inspiration.

The financial section of this annual report summarizes how the IETF has allocated donations and funds to effectively operate and carry out our mission. This report presents highlights of our work over the past fiscal year—accomplishments only feasible with your support.

Thank you for your partnership as we strive to serve you. While there is much work to be done, it doesn't seem as insurmountable with devoted people like you!

Sincerely,

A handwritten signature in black ink that reads "Catherine S. Rice".

Catherine S. Rice
Executive Director
International Essential Tremor Foundation

Spirit of Hope Award

Each year, the **Shari Finsilver Spirit of Hope Award** is presented annually to the person that embodies Shari's spirit and commitment to combating ET, supporting the IETF, and spreading hope to those with ET and their loved ones. Shari was the first recipient of this prestigious award.



This year's Shari Finsilver Spirit of Hope Award recipient **Dr. Paul Donohue** writes a daily column titled *To Your Health* that is syndicated to more than 175

newspapers. The question-and answer series is one of the oldest health columns in North America, having first appeared in the 1950s.

Dr. Donohue, who has ET, took over the series thirty years ago. Dr. Donohue is board-certified in his primary specialty, internal medicine, that emphasizes diagnosis and non-surgical treatment of illnesses. He also is board-certified in the subspecialty of infectious diseases. Through his column he has provided hope to millions of people seeking help for ET.

President's Club

Donations *April 1, 2011 - March 31, 2012*

Mr. & Mrs. Joseph Atkinson
Patricia Bassett
Mr. & Mrs. David Berryhill, Jr.
Paul Broyhill - Broyhill
Family Foundation
Barbara Byrnside
John & Dolores Cakebread
Lillian A. Courtheoux
Mary E. Couzens
Mr. & Mrs. Al Davis
Marjorie H. M. Downey
Patricia Dupree
Carmen A. Eanni
Shari & Stan Finsilver
Mr. & Mrs. Richard Frinier
Juanita Froelich
Margaret Gorman
Glen Greeley
Carol Gruen
Benjamin Hampton
Gertrude Hankin
Frank J. Hanna, Jr.
Mr. & Mrs. Martin Holford
Susan Kahn
John C. Kerasotes
Jeanette S. Koppelman

Michele Leber
Stephen Lescher
Sarah Lozier
Dr. Kelly Lyons
John G. Mancino
Stephanie Mendel
Herbert J. & Beverly Myers
Rosemary Nothwanger
Robert M. Oster
Mr. & Mrs. Randal Peterson
Mr. & Mrs. Roland Pohlman
Christine Pudvan
Mr. & Mrs. Joseph G.
Robinson
Vivien Augusta Rock
Mr. & Mrs. Lee Smith
Mr. Frank Soroka
Mr. & Mrs. Alan Spoon
Mr. & Mrs. Walter Stearns
Mr. & Mrs. Gerald Swanson
Mr. James A. Thomas
Mr. & Mrs. Michael Traggio
Nancy Uppal
Mr. John S. Watterson III
Mr. & Mrs. Leo Wilz
Mr. Fred M. Young, Jr.

The IETF receives little or no federal, state, regional or local funding. Member donations remain the key to providing funding for research, awareness, education and support for people diagnosed with ET. In Fiscal Year 2012, the IETF received 6,908 donations that came from different sources including memorials given in memory to a loved one, honorariums given to honor an individual, general donations, membership dues, research donations, IETF Legacy Society donations through bequests, real estate, and life insurance, and donations given through various fundraising campaigns.

The IETF Legacy Society

enables individuals to allocate funds for specific activities after their death so that good work can continue and their memory can live on. We honor its members and recognize them for their contribution to the IETF mission, vision and goals.

Bequests

are an important part of ensuring that the IETF mission thrives and continues. Bequest funds are instrumental in funding valuable research and programs now and in the future. We are truly grateful to the many generous benefactors who left a legacy that has enabled us to carry on our work. These individuals reached beyond themselves to ensure that those with essential tremor would receive benefit now and in the future.

We are forever indebted to them. To learn more about leaving a legacy, please consult your financial advisor and visit www.essentialtremor.org/plannedgiving for more information.

Presidents Club (Donors who give \$1,000 or more)

We value contributions in all amounts and are very appreciative for the donations received. We also thank our many generous donors that contributed \$1,000 or more. These individuals are every donor's superheroes because their sizeable contributions make a significant impact to research, awareness campaigns and more. While other organizations have Michael J. Fox, and other notable individuals, we have loyal Presidents Club members that contribute more than their share to help others and enable the IETF to do more.

Corporate Support

Corporate donations in support of awareness and education activities were received from the Medtronic Corporation, \$46,256; Medtronic Foundation, \$35,000; and St. Jude Medical, \$4,850. The IETF greatly appreciates the support of its mission and, as a result, program outreach is provided to more individuals with ET than would have been possible without the support.

IETF Legacy Society Bequests in FY12

Margaret S. Edwards Estate	\$176,661
Irene Feimer Anger Trust	3,467
Fisher Bequest	47,077
Laurita Johnson	225,620
Mary Schmier Rev. Trust	969
Martin Stinar Trust	39,839

Total Bequest Funds \$493,633

Programs

Scholarships

The IETF provides support to persons with essential tremor (ET) such as helping selected students lessen the financial burden of attaining higher education. The scholarships are \$500 each and can be used for tuition or books at licensed, accredited institutions of higher education and are paid directly to the educational institution. In Fiscal Year 2012, \$2,000 was distributed to eight deserving students. Awards have been provided to Lauren Gray of Gainesville, Florida; Brandon Affeldt of Westfield, Massachusetts; Bethany Shipley of Edmond, Oklahoma; Carolina Conway of Tustin, California; Kyle Garnick of Hudson, New Hampshire; Melissa Masimore of Hubbard, Ohio; Sydney Strahm of Rockwall, Texas; and Bethany Shipley of Edmond, Oklahoma.



Patient education

In Fiscal Year 2012, the IETF held 22 educational seminars in Ann Arbor, Santa Barbara, Atlanta, Augusta, Bethesda, Edison, Foster City, Greensboro, Greenville, Jacksonville, Las Vegas, Madison, Minneapolis, Morgantown, Philadelphia, Pittsburgh, Reno, Spokane, Tucson, Winston-Salem, Kansas City and Boca Raton.

Nearly 1,700 people at the seminars listened to a local neurologist, who specializes in movement disorders, and a neurosurgeon as they spoke about the diagnosis process and treatments available for people with ET. Attendees participated in a question and answer session after the presentation. Additional seminars are planned for Fiscal Year 2013. Visit the IETF website to register. Partial funding for these events is provided by the Medtronic Corporation.

Health care provider education

In continuing educational outreach, the IETF attended seven annual health care provider conferences to bring greater awareness about essential tremor and the IETF among 21,500 health care professionals in attendance. The IETF distributed information cards that outlined the diagnosis process and treatment options for people with ET. In addition, our staff distributed handouts and ET information that explained the difference between ET and Parkinson's disease (PD).

All IETF material is available to healthcare providers free. It can be ordered at www.essentialtremor.org, by calling 888.387.3667, or through email at info@essentialtremor.org.

Communications

Discover (formerly *The Scoop*), the IETF's research newsletter published three times/year, shares current research findings and studies, ET awareness and education articles. *Tremor Talk*, the IETF magazine published twice/year, is our premier publication that covers stories of people with ET, health care, support, research, and much more.

Our communication extends to Facebook, Twitter, and website essentialtremor.org, where we interact with the ET community. We also send our monthly e-newsletter *Tremor Gram* as a quick means of keeping in touch and delivering news of note.



We launched a **new blog, TremorTalk.org** to better communicate with the public and people with ET. The blog addresses questions, lists posts on important ET-specific topics, and will feature articles by health-care professionals. Visit the site, comment, and get involved!

Awareness

DC Connection

Tom Bruderle, Washington, D.C. Liaison for the IETF, continues to educate and bring greater awareness to congressional lawmakers. Tom, who also has ET, has a long list of accomplishments while working in DC.

Through his efforts he is responsible for 87 cosponsors of the National Neurological Diseases Surveillance System Act of 2011 (HR 2595) a bill to amend the Public Health Service Act to provide for the establishment of permanent national surveillance systems for multiple sclerosis, Parkinson's disease, and other neurological diseases and disorders (including essential tremor).

The system would enhance and expand infrastructure and activities to track the epidemiology of neurological diseases which is information that would be extremely valuable to identify the prevalence of ET.

Tom has also attended valuable meetings of the American Society for the Experimental Neurotherapeutics (ASENT), American Brain Coalition and One Mind for Research founded by Patrick Kennedy, a 10-year program launched to research brain disorders. Tom helped get the congressional resolution for National ET Awareness Month passed in 2010.

National ET Awareness Month (NETA)

The IETF proudly recognized the second anniversary of House Resolution (H.RES.) 1264, sponsored by former Congressman Dennis Moore (Third District - Kansas), officially designating the month of March as "National Essential Tremor Awareness Month."

The IETF hosted ongoing community awareness events across the country to build a better understanding of ET and provided those affected with the basic knowledge necessary to become their own advocate when seeking treatment. The Foundation also distributed literature and brochure holders to over 550 physician offices, provided free posters, organized radio and newspaper announcements, posted announcements on Twitter, Facebook, through e-mail on TremorGram and website www.essentialtremor.org. A national press release was sent out to the media. Bracelets, bookmarks, caps, and shirts were sold to generate revenue and donations were requested to help support the awareness activities. The IETF received \$17,250 in public and member donations.

The Arizona House of Representatives issued a state proclamation in Arizona designating March as ET Awareness Month. Another similar proclamation was issued by the mayor of Katy, Texas.

Financials

Revenues

Contributions¹ - \$88,648
Investment Income - \$3,725
Membership Dues - \$318,763
Memorials/Bequests - \$459,589
Function revenues - \$20,387
Program Service Fees - \$2,270
Research - \$42,881
Special Events² - \$38,844

Total Revenue \$1,025,672

Expenses

Program³ - \$487,328
Management/General⁴ - \$89,477
Fundraising expenses⁵ - \$49,358

Total Expenses \$626,163

A copy of the 990 Tax Return for Tax Year 2011 is available by contacting Catherine Rice at 888-387-3667.

¹ Corporate contributions totaled \$86,106 and \$2,542 donated by the public for general support.

² Revenue received from the Tulips for Tremor Campaign and 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 Tulips for Tremor Campaign, the annual appeal, National ET Awareness Month activities and membership initiatives.

Research

Tulips for Tremor Campaign

The Tulips for Tremor Campaign is a symbol of hope, a fundraiser for research and a mission to raise awareness for those with essential tremor. In Fiscal Year 2012 the IETF placed special emphasis on funding research to find better treatments and a cure. The campaign raised \$20,100.



To view a map that shows where this year's Tulips for Tremor donations came from across the U.S. and around the world, visit <http://goo.gl/maps/JC2wG>.

Research Grants

Dr. Adrian Handforth of the Veterans Administration Greater Los Angeles Healthcare System of Los Angeles was awarded a **\$20,000 grant** in support of the project, **“Finding a New Target for Essential Tremor Therapy.”**

Dr. Holly Shill, Director of the Christopher Center for Parkinson's Research at Banner Sun Health Research Institute, was awarded a **\$22,080 grant** in support of the project, **“Neuropathological and Biochemical Substrates of Essential Tremor.”**



Bishop Kelly High School's Engineering Design team, based in Boise, Idaho, participated in the 2011-2012 Lemelson-MIT InvenTeam program at the EurekaFest held at MIT in Boston and to support their work, the IETF awarded a grant of **\$2,500** to help underwrite travel expenses. The student team is developing two tools that may one day assist people with essential tremor.

VOLUNTEERISM

Art in the Garden

Watercolor artist **Fred Ekman** (right) donated a significant portion of his original artwork for a spring 2012 fundraiser titled **Art in the Garden**. The event raised over \$3,000 for essential tremor research and education.



IETF ambassadors **Joe Bremhorst** and **Sharon Alexander** donated many hours of their time to help organize the event.

Support Groups

The IETF relies on the grassroots effort of support groups to organize, meet, distribute information, and support individuals on a local basis. Volunteer leaders stepped forward to expand the initiative to 74 support groups in 30 states and 7 support groups overseas. Volunteers served 5,206 hours equivalent to a total value of \$112,661. These groups are vital in providing support for people in ways that the IETF cannot possibly achieve with a full-time staff of four. Our thanks goes out to each and every volunteer.

Visit essentialtremor.org to learn more about the IETF's programs, services, and activities.