

TREMOR TALK

For Donors of the International Essential Tremor Foundation

Issue 26 | September 2018

**NONMOTOR
SYMPTOMS
OF ESSENTIAL
TREMOR**

**INTERNATIONAL
TREMOR CONGRESS
RECAP**

**PREPARING
FOR YOUR
VISIT TO THE
DOCTOR**

***MEMOIR FOCUSES
ON RUSSIAN STUDIES,
AMERICAN POLITICS
AND ESSENTIAL
TREMOR***

**HOW CAREGIVERS
CAN REPLENISH
THEMSELVES**

ietf International
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Foundation

Your Voice for Essential Tremor



Update from the Executive Director



Summer is winding down and we hope you and your family had the opportunity to get away and enjoy some vacation time. Here's a recap of some of the things that have happened since our last issue of *Tremor Talk*.

Our 2018 research appeal took place in July with 100% of your donations going to support the IETF's research efforts. For the first six weeks of the appeal, we raised over \$33,000, an increase of more than \$7,400 from the same time period last year. The recipients of our 2018 IETF research grants are featured in this issue of *Tremor Talk*.

Since 2005 your donations have allowed the IETF to award close to \$800,000 in research grants to help find better treatments for essential tremor (ET), and hopefully someday, a cure. There are brilliant doctors and researchers all over the world focusing on ET specific research. Our hope is the seed money the IETF provides will continue to inspire and encourage more research in this area. If you would like to read more about the research grants the IETF has funded in the past, check out the recap of the studies on our website at essentialtremor.org.

The IETF held an ET Education Forum in Minneapolis in June. We had a great turnout with 130 reservations. The attendees heard from Dr. Lauren Schrock from the University of Minnesota Neurology Department. Two more ET Education Forums are scheduled this year. We will be in Dallas on Saturday, September 15 and Tampa on Saturday, October 27. If you live in those areas we hope you can join us for these free events.

We also hosted our second teleconference of the year on September 12. Dr. Gordon Baltuch, the director for the Center for Functional and Restorative Neurosurgery at Penn Medicine in Philadelphia, spoke on surgical

options for ET. If you weren't able to join us on the call a recording of the teleconference, along with past ones, is posted on our website. You have the option to listen on your computer or call a toll-free number and listen to them on your phone. The calls last about an hour.

A part of the IETF's mission is to increase awareness and education for ET and we are always working on these goals. In August, the staff attended a local Parkinson's Symposium hosted by the University of Kansas Medical Center's Parkinson's Disease and Movement Disorder Center to share information on the resources the IETF has available. I will also be attending the American Academy of Family Physicians Family Medicine Experience conference in New Orleans in October. This is a great opportunity for us to educate family physicians (who are often the first to diagnose ET patients) on ET and the IETF. This will be our third year attending this conference.

This issue of *Tremor Talk* includes a lot of great stories including a review of the past fiscal year, a 30th anniversary piece, information on the first Tremor Congress and the announcement of our 2018 research grant recipients. We hope you enjoy the information. Feel free to share your copy with anyone who wants to learn more about ET and the IETF.

As always, there is a lot going on at the IETF. But, none of this happens without your support. Your donations are greatly appreciated and allow us to continue to build on the work we do. We love to hear from you, so please feel free to contact us with any questions, concerns, or ideas you might have. If you have moved recently or your email address has changed please let us know so we can update our records and stay in touch.

Sincerely,

Patrick McCartney
Executive Director, IETF



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On the Cover:
Cover photo from Louis Menashe's new memoir.



Confidentiality Statement: The IETF does not sell or share any member or non-member personal information, including physical addresses, email addresses and phone numbers.

Please send comments, questions, and story ideas to: IETF *Tremor Talk* Editor, PO Box 14005, Lenexa, Kansas 66285-4005 USA or call toll free 888-387-3667 or email tammy@essentialtremor.org.

This publication is not intended to provide medical advice or be a substitute for qualified medical care. Appropriate treatment for your condition should be obtained from your physician. The content of this publication offers information to those with essential tremor. The IETF does not endorse any product advertised in this publication unless otherwise stated.

YEAR IN REVIEW

IETF Raises More Than \$1.2 Million During 2017-18 Fiscal Year

At the end of each fiscal year, we update our donors/supporters on the progress we are making as a foundation and demonstrate how their support has enabled us to continue the work we do. Our 2017-18 fiscal year was our most successful to date in fund raising, with more than \$1.2 million raised. Here's an overview of some of our 2017-18 activities. ☺

Education and Awareness

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, we have increased awareness of ET and created a learning environment for those affected by it.

ET Education Forums

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

Teleconferences

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

National Essential Tremor Awareness Month

The IETF continued National Essential Tremor Awareness Month in March as an educational platform for ET. The theme was “ET Has No Familiar Face” which communicated the message that ET can impact people of any age or race.



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 nearly \$800,000 toward research.



Support

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. During the 2017-18 school year, the IETF Board of Directors approved increasing scholarship awards from \$500 to \$1,000.

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, including *Tremor Talk* magazine.



Website

Top 10 Pages

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

Advocacy

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 challenges of the condition.

2017-18 Conferences/Conventions

- American Academy of Neurology – April 2017
- Movement Disorder Society – June 2017
- University of Kansas Parkinson's Symposium – August 2017
- American Academy of Family Physicians – September 2017

Financial Statement

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



32% of revenue comes from direct contributions from donors

EXPENSES

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

Total Expenses	\$ 580,817
Net Assets	\$ 3,005,715



77% of expenses go to Research, Education, Awareness & Support

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.



Get a full overview of our 2017-2018 fiscal year by reviewing our annual report online at www.essentialtremor.org/about-the-ietf/

International Tremor Congress

A comprehensive meeting on advances in the diagnosis and management of tremor, and the science of tremor disorders.

*By Sheng-Han Kuo, M.D.
Columbia University Medical Center*

The Idea

Tremor is the most common movement disorder and many patients with tremor continue to live with tremor-related disability. Current technology has created an opportunity for new diagnostic approaches, surgical procedures, and pharmacologic innovations, which hold promise for treatment of tremor, but the development of new therapy for tremor is still slow.

One of the major obstacles for new therapy development is the lack of a platform for academic researchers, pharmaceutical industries, and funders to unify the research efforts specifically for tremor. Different from other research fields, such as Alzheimer's disease or Lou Gehrig's disease, tremor does not have its own medical conference, which would facilitate the dialogues between the researchers and would greatly advance the speed of research discovery.

To overcome this problem, Drs. Elan D. Louis at Yale University, Ming-Kai Pan at National Taiwan University and I came up with the idea to have the 1st International Tremor Congress to promote the collaboration between tremor researchers and between academia and industry. In

addition, we also wanted to inspire the next generation of neurologists and neuroscientists to go into the field of tremor research.

The Planning

After we developed the idea for this conference, we started to plan for it. Thanks to the organizing committee and also Laura Yasso at Columbia University Continuing Medical Education, we quickly came up with a draft for the conference.

Surprisingly, we soon had tremor investigators from all over the world agreeing to come to this meeting to give talks, to exchange research ideas, and to present their research findings. Additionally, we also had tremendous financial support from industries, including Merz, Cadent Therapeutics, Biohaven Pharmaceuticals, Cala Health and Neurocrine Biosciences, among others. We also had support from foundations, such as the American Parkinson's Disease Foundation, the Parkinson's Foundation, and the International Essential Tremor Foundation. With this important support, we were able to host this conference at the newly developed Roy and Diana Vagelos Education Center at Columbia University in New York City.

Because of the overwhelming positive responses from the research

communities, we had over 200 registrations, which included academic researchers, investigators from industry, neurology residents and fellows, and graduate students and postdocs who are interested in tremor.

“This conference brought a sense of community among people who aim to develop new ways to treat tremor.”

The Congress

On May 11, the morning of the first day of the 1st International Tremor Congress, the lobby of the new education center was filled with researchers interested in tremor who were there to discuss new ideas for developing tremor therapy! The day started out with Drs. Stanley Fahn from Columbia University and Mark Hallett from the National Institutes of Health, two research giants who pioneered tremor research, discussing the history and the current understanding of tremor research. And then many experts in the field continued to discuss the advancement of the tremor field from different angles,

such as human pathology, animal models, novel devices, imaging, and physiology measurements. Program officers from the National Institutes of Health, Drs. Codrin Lungu and Daofen Chen, also discussed funding opportunities for tremor research, which is crucial for the progress of the field. The second day of the conference focused more on educating the trainees regarding the clinical pipeline development for tremor and the diagnostic and treatment challenges for patients living with tremor.

Feedback/Goals Achieved

After the two-day meeting, we had plenty of positive feedback and we realized it is important to have this conference on a regular basis moving forward. Particularly important feedback came from those who really benefitted from the exchange of knowledge and research ideas. In addition, the trainees were excited to become the next-generation of tremor researchers.



More than 200 academic researchers, neurology residents, graduate students and investigators from various industries were in attendance at the 1st International Tremor Congress held on May 11. Plans are under way to host this event every other year.

Perhaps most importantly, this conference brought a sense of community among people who aim to develop new ways to treat tremor and also want to know how the dysfunctional motor control in the brain can generate tremor. One of the major shortcomings for the conference was the lack of participation of patient advocate groups and/or people who live with tremor, and we plan to address this in future conferences.

Conclusion

We have learned a great deal and know there is a need for a platform for tremor researchers to exchange research ideas and discoveries. Our 1st International Tremor Congress was the first step towards this. Moving forward, we will have this conference every other year, so the next conference will be in 2020. It will certainly be something to look forward to. More people and more research will push toward better treatment for tremor. ☺

Thank you for your interest in *Tremor Talk*. We hope you enjoyed this free preview. If you would like to get this magazine in its entirety in your mailbox three times a year, just become an IETF donor.

To become a donor, call the IETF (toll free) at 888.387.3667 or donate online at www.essentialtremor.org/donate.



The mission of the International Essential Tremor Foundation (IETF) is to provide hope to the essential tremor community worldwide through awareness, education, support and research.