

# TREMOR TALK

For Donors of the International Essential Tremor Foundation

Issue 29 | October 2019

**TREMELO  
SAFELY  
STABILIZES  
HAND  
TREMORS**

**CALA TRIO:  
PERSONALIZED  
THERAPY FOR ET**

**HAVE YOU  
JOINED OUR  
ONLINE  
SUPPORT  
GROUP?**

**NEW SEASONS OF  
BRAVERY:  
HER ET HELPED HER BREAK  
THROUGH A GLASS CEILING  
SHE NEVER KNEW EXISTED**

**WIN A  
HAND-CRAFTED  
DULCIMER**



International  
Essential Tremor  
Foundation

Your Voice for Essential Tremor

# Update from the Executive Director



Summer has wrapped up and we hope you enjoyed some vacation time with your family and friends. When September rolls around the schedule really picks up here at the International Essential Tremor Foundation (IETF). Here are some of the things

we have been working on and some upcoming projects.

## Research Funding

Our annual research appeal was mailed on August 1. The IETF has awarded over \$800,000 in research grants over the years from the support of our loyal donors. One hundred percent of the donations received for this appeal are designated for essential tremor (ET) research. To date we have raised over \$30,000 with a goal of \$35,000 for this appeal.

## ET Education Forums

On June 1 we held an ET Education Forum in Hartford, CT and had one of the largest crowds ever for one of our events. More than 225 people joined us and heard from Dr. Duarte Machado on diagnostic and treatment options for ET, and Amy Pace, an occupational therapist, who spoke on daily coping techniques for ET. A special thank you to Dr. Machado and his staff along with our support group leader Helen Moser for promoting the event. By the time you receive this magazine we will have held our next ET Forum in St. Louis and we have another event scheduled on November 2 in Kansas City. We hope you get the opportunity to join us at one of these events or one in the future.

## Exhibit at The Villages

On December 5 the staff will be traveling to The Villages in Florida to exhibit at the Lake Sumter Landing Tree

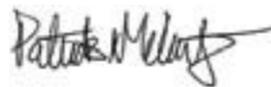
Lighting Festival. During National Essential Tremor Awareness Month in March, we conducted a targeted awareness campaign in The Villages, which is the largest senior living community in the country. We generated over 400 new contacts for our database from this two-month campaign. This event will provide another opportunity to reach out to this community to promote ET awareness and education along with the resources the IETF has available to patients, doctors, family members, and caregivers.

## Website Update

We are excited to announce we have begun work on an update of the IETF website. The current website was created in 2013 and a lot has changed in the world of technology since then. Our plan is to make the website easier to navigate and more responsive and viewable on mobile devices. We will be engaging our board, staff, and support group leaders as we work on this project to make sure the website is as user friendly as possible for the ET community. We will keep you updated as we get closer to launching the new version of the website.

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:**  
Musician Emily Ann Peterson has added the titles "author" and "speaker" to her repertoire since her ET diagnosis.

Photo by Laura Schneider



**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.

# Could an Existing Drug Used to Treat Other Movement Disorders Be Targeted for Essential Tremor?

For people experiencing hand tremors, simple tasks such as writing can become a frustrating endeavor. Several therapies exist for tremors – from oral pharmacological options to surgical interventions – however, for many individuals, the side effects and invasive nature of these operations offer minimal benefit.

The research team at the London Movement Disorders Centre produced a useful and less invasive tremor treatment tool called TremorTek. Using motion sensors, TremorTek is an experimental medical device that can provide personalized diagnostic information about the patient's tremor location in their arm, the specific muscle groups producing the tremors and tremor severity. Doctors then use this information to guide injections of botulinum toxin (Brand name: Botox, Dysport, Xeomin) to reduce tremor intensity. Some physicians have attempted to use this injectable drug to treat tremor in the past; however, the benefits and side-effects have always been mixed. Physicians who tried to inject their tremor patients still have to rely entirely on their eyes for visual assessment and decide which muscles in the arm to treat. The human eye can only see so much. Dr. Mandar Jog is the movement disorders neurologist leading the research.

“Using technology to measure tremor will make treatment easier,” Dr. Jog said. “Imagine going into your doctor's office for a quick check-up. The sensors tell the doctor your tremor levels and location, and then you get drug injections in your arms, like a flu shot. After a few days, your tremor goes away all thanks to a doctor who used smart technology to improve the drug effect. This will become a reality in a few years.”

Published this year in the *Toxins* medical journal, the latest clinical trial demonstrated Dr. Jog and his tremor research team were effective in treating more than 30 tremor patients in both arms at the same time, resulting in individuals

*“Using technology to measure tremor will make treatment easier. Imagine going into your doctor's office for a quick check-up. The sensors tell the doctor your tremor levels and location, and then you get drug injections in your arms, like a flu shot.”*

■ Dr. Mandar Jog,  
London Movement  
Disorder Centre

regaining arm functioning and improving quality of life after a single dose. The journal article is online at [www.mdpi.com/2072-6651/11/2/125/htm](http://www.mdpi.com/2072-6651/11/2/125/htm). Likewise, in a phase 2 placebo-controlled drug clinical study in the US and Canada, sponsored by Merz Pharma, TremorTek was used with botulinum toxin to treat participants with essential tremor, and the data showed significantly improved motor performance after four weeks. (The study is available online at <https://parkinsonsnewstoday.com/2018/08/28/xomin-effective-essential-tremor-patients-phase-2-trial/>.)

The researchers from LondonMDC have thus far published more than seven clinical papers and have treated



over 100 tremor patients in their study. Dr. Jog plans to release his team's newest clinical trial data later this year, where another 50 tremor patients were treated.

“With more publications, we hope other researchers and government agencies put a spotlight on funding new tremor treatments,” Dr. Jog said. “We made an existing drug better and it enables doctors to personalize the drug treatment per patient. If we all use reading glasses to see better, why can't we use diagnostic technology to treat tremor patients better?”

**Watch this patient video to see the before and after results from Dr. Jog's research study, [www.youtube.com/watch?v=YY2d1JQ36AI](http://www.youtube.com/watch?v=YY2d1JQ36AI). For more information visit [www.londonmdc.ca](http://www.londonmdc.ca).**

*This article was written by Jack Lee, clinical research associate, and Dr. Mandar Jog, movement disorders neurologist, professor of neurology, and director of the London Movement Disorder Centre. Both researchers are affiliated with Western University and the Lawson Health Research Institute.*

*For information on general treatment options for ET, visit [www.essentialtremor.org/treatments/](http://www.essentialtremor.org/treatments/)*

# Year in Review

April 1, 2018 through March 31, 2019



Each year, the International Essential Tremor Foundation (IETF) likes to update the essential tremor (ET) community about the progress made in the past year and share highlights of our accomplishments.

The mission of the IETF is to provide hope to the essential tremor community, worldwide, through awareness, education, support and research. We host educational programs, advocate for and support ET research and provide support systems to help people struggling with ET. For the second consecutive year, the IETF raised more than \$1 million thanks to loyal donors. This support enables us to carryout our mission, with the ultimate goal of finding a cause and cure for ET.

The IETF's fiscal year is not the traditional calendar year; it spans from April 1 through March 31. 🌱

## REVENUE

Contributions	\$	434,541
Investment income	\$	114,295
Grants	\$	50,000
Memorials/Bequests	\$	276,962
Exempt function revenues	\$	7,046
Research	\$	97,175
Special events <sup>1</sup>	\$	112,789

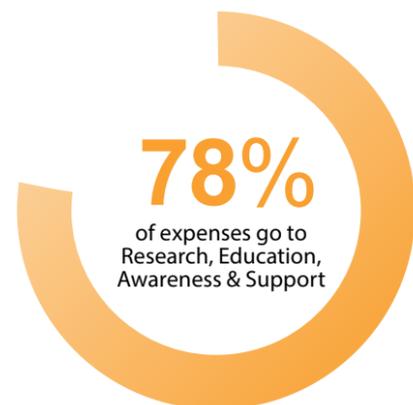
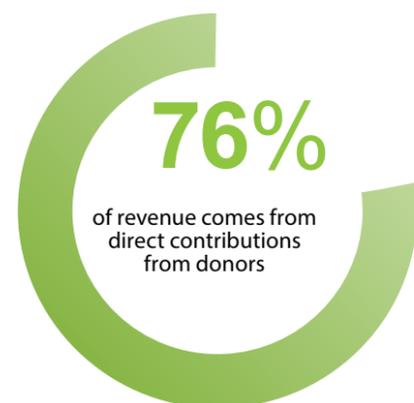
**TOTAL REVENUE \$1,121,746**

## EXPENSES

Program <sup>2</sup>	\$	496,474
Management/General <sup>3</sup>	\$	92,062
Fundraising <sup>4</sup>	\$	42,364

**TOTAL EXPENSES \$ 630,900**

**NET ASSETS \$3,496,561**



<sup>1</sup> Includes revenue received from National Essential Tremor Awareness Month.

<sup>2</sup> Includes awareness, education, support and research activities and initiatives.

<sup>3</sup> Includes expenses related to office overhead such as supplies, computers, copier, salaries, and rent.

<sup>4</sup> Includes National Essential Tremor Awareness Month activities, annual appeal, and annual donations.

## Tremor Gram eNewsletter



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

## IETF Website

[www.essentialtremor.org](http://www.essentialtremor.org)

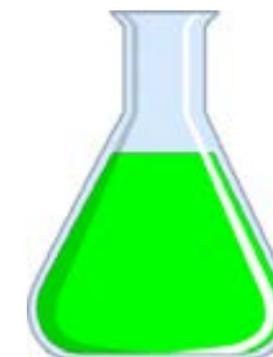
We had **221,223** users to our website during the 2018-19 budget year (a four-fold increase over the previous year). There were **514,439** pageviews.



## 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 fund raisers, 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 Month Posters
- Gained **446** new page followers on Facebook
- Accepted **238** new people into the ET Awareness Group on Facebook (a closed online support group)



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

# ACCEPTANCE

## is Her Coping Mechanism for Essential Tremor

Essential tremor (ET) is not just a condition of the elderly. Rachel Roth is proof of that. The 28-year-old Agoura Hills, CA resident has had ET since she was five. What has helped her cope the most is accepting her condition.

“If you don’t accept yourself as a person with a disability and you just are negative about it and say, ‘this is it. I can’t do anything,’ then you are letting life and time pass you by,” Rachel said. “But if you actually accept it and have that confidence and use it to your ability as a way of empowerment, then it’s something that makes life and time a lot easier. There are so many skills you can gain if you have confidence and acceptance.”

Raising awareness about ET has been a priority for Rachel. As a communication major at the University of California San Diego, she did not let having ET impede her ability to go to a top rate school. She used ET as her platform when she gave speeches and produced videos. She captured ET through photography and worked on individual and group projects. She saw it as an opportunity to let people know that ET exists and explained the impact it has on people of all ages. She even agreed to be the subject of a documentary film her friend and classmate produced titled, “ShakeItUp!” It can still be viewed online today through YouTube. (Watch it at <https://shkeitup.wordpress.com/>.)

But, Rachel didn’t stop there. She went on to reach out to people all over the world through Facebook support groups, and maintains a presence in more than 30 groups today. She started a blog to write about living with ET, and her social media posts on Instagram and Twitter frequently mention her successes despite her challenges. She has connected with people as far away as Israel and Pakistan. She focuses on helping people understand what ET is.

“People know what Parkinson’s disease is so I use that as a point of reference to say, if you know what a resting tremor is with Parkinson’s, then think about the reverse

of that. ET is the action tremor,” she explained.

Her employer, CoverHound Insurance Solutions Inc., a digital insurance agency, recently presented her with a Net Promoter Score (NPS) Advocate Award for the 6th consecutive quarter for excellence in customer satisfaction. Upon accepting the award, true to form, Rachel took the opportunity to share her story about ET to educate and inform.



*“If you don’t accept yourself as a person with a disability and you just are negative about it and say, ‘this is it. I can’t do anything,’ then you are letting life and time pass you by.”*

■ Rachel Roth

“Whether I am at work or at home, I take any opportunity I can to raise awareness, educate and advocate for the essential tremor community,” Rachel said. “I try in any way I can to touch the customers I can with my story and show them it is okay to share their story. Vulnerability has allowed me to be where I am today with speaking on the phones and in public.”

Rachel estimates she has reached more than 1,000 people through her awareness efforts.

## Have You Joined Our Online Support Group?



ESSENTIAL TREMOR AWARENESS GROUP

“Jane” has noticed her essential tremor seems to be progressing with age. “Tom’s” doctor just prescribed gabapentin and he’s not sure how his body will react. “Lisa” is trying to set up a 504 Plan for her son at school and doesn’t know what questions to ask.

These people live in different parts of the world and are experiencing different challenges, but they are part of a community of people with essential tremor on whom they can rely to support them. **It’s called the Essential Tremor Awareness Group.**

Connecting people with others who have similar symptoms and challenges is the premise behind this private Facebook Support Group. It’s open to anyone who has essential tremor, but it is a closed group to maintain members’ privacy. Those who want to join must request membership. The page is monitored and managed daily by the International Essential Tremor Foundation (IETF).

It has been in existence for more than 10 years and has 8,500 members. Approximately 72 percent are women and more than 27 percent men.

Members represent the United States, the United Kingdom, Australia, Canada, India, Brazil, New Zealand, South Africa, the Philippines and Pakistan. Approximately 95 percent of members are age 25+. The largest age groups represented are 45-54 and

65+ each representing about 23 percent of the members. Conversations are taking

place 24/7 all over the world. And if you can’t keep up with the conversations, you can always “search” a particular topic using the “search this group” feature to find all conversations about that topic.

Want to join in the conversation? Request permission to be a part of this group at [www.facebook.com/groups/5884699022/](http://www.facebook.com/groups/5884699022/)

Has anyone used botox for tremors?

I was just diagnosed, wondering if there are any other artists dealing with this. . .

You are worthy. You are worthwhile. And most importantly, the world needs your voice, even if and when it shakes. Please reach out if you feel you need help.

My four-year-old was just diagnosed and I’m feeling lost as to what causes this condition and what else I can do to help her.

Thank you for your encouragement and stories. They are really helpful when there is so little information available.



To join the IETF’s Facebook Support Group go to [www.Facebook.com/groups/5884699022/](http://www.Facebook.com/groups/5884699022/)

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](http://www.essentialtremor.org/donate).



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