

# TREMOR TALK

For Donors of the International Essential Tremor Foundation

Issue 34 June 2021



## Shakey Nan Becomes a Voice for the ET Community

## ET the Most Common Cause of Head Tremor

## Exercise in ET

**ietf** International  
Essential Tremor  
Foundation  
*Your Voice for Essential Tremor*

# Update from the Executive Director



As we shared in our January issue, the IETF has created a variety of virtual essential tremor (ET) education opportunities since September 2020. To date we have shared five ET Virtual Education Events, which have been viewed nearly 30,000 times. By the

time this issue is printed, our next education event, “Essential Tremor: Pediatric Onset” presented by Dr. Keith Coffman from Children’s Mercy Hospital in Kansas City, will be posted. Our podcast series, “Talking Essential Tremor” also started in the fall of 2020. We have produced eight podcasts which have been downloaded over 2,600 times. Some upcoming podcasts include interviews with Katie Sale, the executive director of the American Brain Coalition and Lord Julian Fellowes, creator of the British TV drama series “Downton Abbey.”

To access these virtual events you can go to our website and click on “What We Do” and then “Educational Programs.” The IETF would like to thank our corporate partners Medtronic, Abbott, Insightec, Sage Therapeutics, Jazz Pharmaceuticals, and Cala Health for their support of these programs. As soon as it is safe to do so, we will restart our in-person education events around the country so we can connect personally with the ET community. When we have new events scheduled, we will share them on our website, social media, *Tremor Talk* and through mailings.

Our 2020-21 fiscal year ended on March 31, 2021 and we are proud to announce the IETF had the highest income total in our history of over \$3 million. We also received the largest one-time donation since the IETF was formed in 1988 of over \$2 million (restricted for ET research). Thank you to the Richard B. Peters estate for this very generous donation and for including the IETF in his estate.

March was National Essential Tremor Awareness month and we had another successful fundraising appeal generating over \$48,000 along with raising awareness for essential tremor

worldwide. It’s not too late to donate and receive your IETF water bottle and/or tote bag. Several of our corporate partners shared NETA month information on their social media channels in March. I also spoke at a virtual event organized by the National Tremor Foundation in the United Kingdom sharing information about the IETF and answering questions from the attendees.

In June the IETF will be awarding our fall scholarships and our 2021-22 fiscal year research grants. The medical advisory board is currently reviewing and scoring the research grant applications. These grants are partially funded by a gift of funds from the estates of Lillian and David Courtheoux. We will announce the research grant recipient(s) as soon as a decision is made along with our scholarship award winners.

We also want to thank all our support group leaders who are continuing to meet virtually during the pandemic. I met via Zoom with the Horsham, PA and the Elkridge, MD groups in April. I enjoyed the opportunity to share with the group the resources the IETF provides and answer their questions. If you have a support group in your area, we encourage you to join. If you don’t, we also have our online support group through Facebook. Just look up Essential Tremor Awareness Group and ask to join.

We hope you enjoy this issue of *Tremor Talk* which includes stories on exercise and ET, a profile of our newest medical advisory board member, and our spring 2021 scholarship award recipients, just to name a few.

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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*Tremor Talk* is published three times a  
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**On the Cover:**  
*Shakey Nan shows a map which marks areas around the world where her listeners and readers live.*



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](mailto: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.



# Essential Tremor is the Most Common Cause of Head Tremor

*By Dr. Albert Fenoy,  
Director, Deep Brain Stimulation Program  
Associate Professor, Department of Neurosurgery  
McGovern Medical School  
The University of Texas at Houston*

Patients with essential tremor (ET) usually present with hand tremor, an involuntary shaking of the hands dependent on position. However, head tremor can also develop in the course of ET or present as a singular symptom. ET is the most common cause of head tremor. Cervical dystonia, or spasmodic torticollis, is another less common cause. Patients with Parkinson's disease can also develop head tremor.

Dysfunction of circuits in the brain are thought to be the mechanism for essential tremor. It is proposed that the ventrointermediate nucleus (Vim) of the thalamus, deep in the brain, plays a key pacemaker role in this disease. If an abnormal rhythmic output develops in deeper structures that connect to the Vim, such as in the cerebellar dentate nucleus or inferior olivary nucleus, an abnormal signal travels downstream through the red nucleus to the Vim and motor cortex via the dentato-rubro-thalamic tract (DRTt), manifesting as tremor.

The vast majority of patients with ET present with hand tremor. However, about a third of ET patients have head tremor by itself or with hand tremor. Head tremor can also develop in ET patients over the length of their disease, as severity of other tremor increases. Voice tremor can also develop over time. In ET, hand tremor is postural, occurring with action resisting gravity such as holding

objects away from the body. Stress can intensify tremor. Parkinson's disease tremor, conversely, is found in the hand usually at rest, and can also occur in the lip or jaw. Patients with Parkinson's disease have slowness of movement, muscle rigidity, and gait difficulties that are not seen in ET.

Cervical dystonia is another less common cause of head tremor. Dystonia is another disease due to an abnormally functioning circuit in the brain. Here though, this circuit causes abnormal muscle tone which in turn causes muscle spasm and abnormal posturing. In the case of cervical dystonia, the sternocleidomastoid muscle is usually affected more on one side, becoming much larger with spasm, leading to an abnormally sustained neck posture or torticollis. The neck muscular spasms can cause head tremor. Cervical dystonia can occur in isolation or over time become generalized over the body. It is usually associated with neck pain due to muscular spasm, which is unlike ET.

Sensory tricks such as touching the cheek or chin (geste antagoniste) is a common remedy used by patients with cervical dystonia to lessen the severity of the tremor. Also, as there is asymmetry to the neck, there typically is a preferential direction for a patient to look or a specific position to adopt to reduce the tremor and the pain associated with it.

It is important to properly diagnose the tremor so a proper treatment plan can be prescribed. This is performed clinically, however, imaging of the brain is performed to rule out structural lesions such as stroke,

multiple sclerosis or tumor. A DaTscan can be ordered when it is unclear if the tremor is due to ET or parkinsonism; as a DaTscan targets the dopamine transporter which is deficient in parkinsonism, a normal level is found in ET. Blood tests can be performed to rule out hyperthyroidism or Wilson's disease.

Treatment of head tremor in essential tremor usually starts with medication such as propranolol and primidone, and can also include gabapentin and topiramate. It is more difficult to control than hand tremor. In cervical dystonia, treatment usually starts with benzodiazepines and baclofen. Botulinum toxin can also be used to reduce head tremor when applied to spastic head muscles, such as the sternocleidomastoid, in cervical dystonia. As these toxins block the release of neurotransmitters, the muscles stop contracting, thereby reducing spasms and tremor. However, it usually is not fully effective and must be repeated every three months.

Deep brain stimulation (DBS) surgery is a more invasive option to treat tremor and is promoted when conservative measures fail. Introduced in 1987, it became FDA approved in 1997 for the treatment of tremor and 2003 for treatment of dystonia. It has thus been used for over 30 years with a very high success rate, decreasing tremor in individuals by 80-90%. As it is an invasive procedure,

the procedure does carry a risk of bleeding or infection, at about 1-2%. Electrodes are placed in the brain at a node in an abnormally functioning circuit to normalize its firing. In the case of ET, the electrode typically targets the Vim or the DRTt. In dystonia, the target is typically the globus pallidus internus. Unlike hand tremor, head tremor can be difficult to control with medications alone and so sometimes DBS is the best treatment option.

Not every person with ET may have head tremor, or vice versa. If you do have head tremor, it is important to talk to your physician – not only for the correct diagnosis, but also to find the best treatment option available. 🌱



Learn more about treatment options for essential tremor at [www.essentialtremor.org/resources/living-with-et/treatments/](http://www.essentialtremor.org/resources/living-with-et/treatments/)

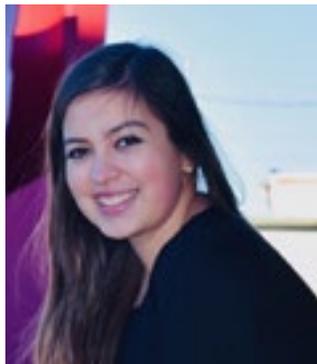
## *IETF Surpasses \$51,000 in Education Awards*

# Meet Our Newest Scholarship Recipients

Congratulations to our spring 2021 Catherine Rice Scholarship recipients! Each of these students will receive a \$1,000 scholarship to support them at their college/trade school. To date, the IETF has awarded more than \$51,000 in scholarships to students with essential tremor, thanks to the generosity of our donors.

### **Maria Hermosillo Arrieta, Mount Mercy University, Cedar Rapids, Iowa**

Essential tremor impacted Maria's life from an early age, but she wasn't formally diagnosed until she was 18. She steered clear of situations where others would notice it, and on especially hard days with her tremors she would stay home from school.



"Although I tried to brush off my condition and make it seem like nothing was happening, it was pretty obvious to everyone around me, as I got bombarded with questions all the time, wondering if I had some mental illness such as social anxiety or if I was just a particularly nervous person," she said.

Maria grew up in a small town in Mexico where healthcare services were lacking. She and her family moved to the U.S. four years ago and she was able to finally get a proper diagnosis and the support she needs. She is taking medication which helps.

"Although ET stole moments from my past, I won't let it steal my future," she said.

### **Robert Holder, Georgia Southern University, Statesboro**

Robert's parents noticed he had a "minor tremble" in his hands around the age of two. As he grew older, it worsened.

He has learned over time the "triggers" that make it more profound such as caffeine, being in new situations or being anxious. But he has chosen to not let essential tremor (ET) define who he is.



"I will continue to accomplish my goals. It may be a little more difficult, but I can do it," he said.

He enjoys helping others and during the past several years, he has built and maintained a food pantry in his community. Despite the frustrations he felt during the pantry's construction, he felt an overwhelming sense of accomplishment when it was completed.

Robert will complete his bachelor's degree in exercise science in the fall of 2021 and plans to then pursue a degree in occupational therapy.

"I want to be able to help others, like myself, who have obstacles to overcome," he said.



## *Applications for Spring 2022 Scholarships*

*It's not too early to apply for a spring 2022 scholarship. The application form and criteria are posted on our website, [www.essentialtremor.org/resources/scholarships/](http://www.essentialtremor.org/resources/scholarships/). The deadline for applications is October 31, 2021.*

### **Colin Pool, University of California – Berkeley**

Essential tremor brings daily challenges to Colin's life, like spilling spaghetti sauce on his jacket during a first day or breaking merchandise during his job of scanning items as a grocery clerk. Like many, he has experienced his ET worsening as he has grown older. He has learned that spikes in his tremors indicate he is not paying attention to his overall wellness. So he tries to do things that he enjoys to relieve his stress.



His ET has made him empathetic to others' needs. He volunteers at a school for underprivileged kids.

"I was blessed to mentor children who suffered various social and learning disabilities much greater than my own," he said.

Colin is in his second year at UC Berkeley and said he has seen ambitious research with devices that can cancel out tremor. His goal is to start a business to provide medical equipment for people with ET.

### **Emily Williams, University of Oklahoma, Norman**

Emily was 10 years old when she was diagnosed with essential tremor (ET). She had been taking piano lessons for five years and had just started percussion in her school band. She was determined not to let her ET define her.



Having ET meant practicing was more exhausting for her. But she learned to work around breaks and would work during her lunch hours or before and after school.

At the University of Oklahoma she made The Pride of Oklahoma Marching Band. And she is proud that she has also excelled in her studies – achieving a 4.0 her first semester.

"With the help of my parents, the disabilities council and my neurologist, my goal for college is to graduate with honors," she said.

She never brings up her ET, but when others notice her shaking she educates them. She tells them she can do everything they do, but it just may take her a little longer. 



*Learn more about the IETF's scholarship program at [www.essentialtremor.org/resources/scholarships/](http://www.essentialtremor.org/resources/scholarships/)*

# Albert Fenoy Joins Medical Advisory Board

The IETF recently welcomed Dr. Albert Fenoy to its Medical Advisory Board. Medical advisory board members are essential tremor experts from leading academic and medical institutions around the world. They provide insight and scientific direction to the IETF staff and board. (See an entire list of IETF Medical Advisory Board members on page three of this magazine.)



*Albert J. Fenoy, MD  
Director, Deep Brain Stimulation Program  
Associate Professor, Department of Neurology  
McGovern Medical School  
The University of Texas at Houston  
UTHealth Neurosciences*

Dr. Fenoy is a board-certified neurosurgeon with expertise in deep brain stimulation for movement disorders such as Parkinson's disease, tremor and dystonia, and psychiatric diseases such as obsessive-compulsive disorder and depression. He also specializes in neuromodulation procedures for chronic pain, as well as surgery for neck and back degenerative disease, including minimally invasive techniques.

Dr. Fenoy received his undergraduate degree from Princeton University and his medical degree at the State University of New York at Stony Brook. He completed his residency in neurosurgery at the University of Iowa and went on to complete a fellowship in functional neurosurgery at the Centre Hospitalier Universitaire de Grenoble, France, in December 2008.

Dr. Fenoy is a member of Alpha Omega Alpha, the Congress of Neurological Surgeons and the American Academy of Neurological Surgeons. Also holding a faculty appointment in the Department of Psychiatry and Behavioral Sciences, Dr. Fenoy has been critical in developing at McGovern Medical School at UTHealth an FDA-approved clinical trial on the use of deep brain stimulation in treatment-resistant depression. The UTHealth Neuroscience deep brain stimulation program is indeed robust: Dr. Fenoy has performed over 600 deep brain stimulation procedures since joining in 2009.

Dr. Fenoy has presented research at several national and international conferences that has subsequently been published in *Movement Disorders*, *Journal of Neurosurgery*, *Brain Research*, *Neuromodulation*, *Stereotactic and Functional Neurosurgery*, and *Translational Psychiatry*. His research has focused on the use of diffusion tensor imaging and optimization strategies for targeting in deep brain stimulation, on the electrophysiology of the basal ganglia and response to neuromodulation, and on biomarkers of response to neuromodulation therapy in treatment-resistant depression.

Dr. Fenoy has also recently been awarded a 5-year \$2.1 million National Institutes of Health R01 grant to study the temporality of structural and functional connectivity changes in essential tremor after deep brain stimulation. 

*Watch & Learn*  
**ESSENTIAL TREMOR  
VIRTUAL EDUCATION  
EVENTS**



**The IETF records educational programs you can watch and listen to from home.**

***Diagnosis & Treatment Options for ET, Parts I & II***

*This two-part program focuses on the pathogenesis of essential tremor, genetic factors, diagnostic techniques, plus surgical and non-surgical options.*

***Coping with the Physical and Emotional Effects of Essential Tremor***

*Learn about coping strategies, useful techniques and devices to help manage essential tremor.*

***IETF: Past, Present and Future***

*This video provides an overview of the work of the IETF, and the history of the foundation.*

***The Development of CAD-1883 through Proof-of-Concept in Essential Tremor***

*Tim Piser, chief scientific officer with Cadent Therapeutics, talks about the company's development of CAD-1883 for the treatment of essential tremor. One study has already been completed and now Cadent is positioned for further development of this medication.*

***Essential Tremor: Pediatric Onset***

*About five percent of patients with ET experience symptoms as children. Dr. Keith Coffman, director of the movement disorders clinic at Children's Mercy Hospital, talks about the presentation of ET in children and how the need for treatment differs from adults.*

**Find our virtual education events online at: <https://bit.ly/ETEducationVideos>**

**THANK YOU** to our corporate partners who help make these virtual education events and podcasts possible!





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).



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.

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