

TREMOR TALK

For Donors of the International Essential Tremor Foundation

Issue 33 | January 2021

**ADVANCING
INVESTIGATIONAL
DRUGS FOR ET**

**SCHOLARSHIP
RECIPIENT TAKES
ON CHALLENGES
WITH ACCEPTANCE
AND POSITIVITY**

**ET OF THE VOICE vs
SPASMODIC DYSPHONIA**



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Your Voice for Essential Tremor

Update from the Executive Director



The staff and board of the IETF hope you and your family had a happy and safe holiday season.

Educational Programs

As we shared in our October issue, the IETF has developed a variety of virtual

ET education opportunities. We launched this initiative in September and to date we have shared five webinars, which have been viewed over 10,800 times. Our podcast series also started in the fall. We have posted five podcasts that have been downloaded over 1,100 times. To access these virtual events you can go to our website and click on “What We Do/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 start planning 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.

Scholarships Awarded

The IETF awarded four scholarships for the spring 2021 semester. Profiles of the four recipients will be included in the June issue of *Tremor Talk* and featured on our website. The deadline for applications for the fall 2021 semester is May 1. If you know anyone with ET heading to technical school, community college, a four-year institution, or working on an advanced degree please encourage them to apply for a scholarship. December 1 was GivingTuesday and for the past several years the donations received through this program went directly to the Catherine Rice Scholarship Fund. This year we raised over \$5,400 thanks to your generous contributions.

National Essential Tremor Awareness Month

March is National Essential Tremor Awareness (NETA) Month and we are hard at work putting together plans to help raise awareness for ET. We will have awareness posters available along with IETF water bottles


and tote bags for donors to our NETA Month appeal. You can find out more information on our plans in this issue.

Thank You Support Group Leaders

We want to thank all our support group leaders who are continuing to meet virtually during these crazy times. 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 one of our past scholarship award winners, results from our *Tremor Talk* survey, and a story on Praxis and their upcoming clinical trial, just to name a few.

Keep in Touch with Us

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:

Scholarship recipient *Brandon Staple* is studying to be a neuropsychologist. His long-term goal is to be a physician who treats the body and the mind.



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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.

He's Called 'The Photo Painter'

Shaky Hands Don't Keep Max Nass from Doing What He Loves

At age 71 Max Nass is all about having fun. And he wants to make others smile. He thinks it's especially important during the COVID-19 pandemic.

So every day he shares a joke with his online community of about 10,000 people who live in his area of Boynton Beach, FL. He receives a lot of positive feedback so he decided to expand on his posts by illustrating the jokes with a photo.

Like the one shown here (*at right*) of the man who brought his own food to the movie theater.

Max creates the photos on his computer, crafting just the right ones through photo manipulation. He cuts out heads, objects, backgrounds – whatever he needs – and pastes them in place. It takes precision and patience. It also takes a steady hand, which he doesn't always have, because Max has essential tremor (ET).

His ET Diagnosis

His journey with ET began at age 21. At first he was thought to be suffering from depression. But when his hands began to shake it was apparent what he had, especially since both of his parents had ET. His father was a textile technician and managed to carryout the intricate detail it required. Max says to this day he doesn't know how his father did it. This might be said of the precision it takes for Max to create his artsy photos.

"It's what I do. My hands shake a little bit, but they're pretty good," he said.



"BARBECUE"

When I went to the movies, they wanted to throw me out for bringing my own food. My argument: the concession stand prices are outrageous. Besides, I haven't had a barbecue in a long time.

An Interest in Photography

He's not a photographer by trade, but he has dabbled in it throughout his life. At the age of 10, he started experimenting with taking photos and even set up his own dark room. When he was 16, he got a job as a camp photographer. He took group photos and processed and printed the photos on site. The job didn't pay, but it allowed Max to go to camp free during the summer. Eventually he began experimenting with manipulating photos.

In 2020, Max joined an online meetup group called The Art of Photography, where individuals submit photos each week to be critiqued. The group hosted a photo competition and Max won for his trampoline photo (*at right*).

"I hadn't won something in a long time. It felt very nice," he said.

Keeping Things Steady

So how does he manage such delicate work with shaky hands? He uses several tools and software that make it easy for him. He creates the photos using Corel PaintShop Pro 2021 Ultimate. It's not cheap (around \$100), but not as expensive as some photo programs, he said. He uses a keyboard with larger keys and instead of a regular mouse, he uses The RollerMouse Red plus (which cost him around \$269).

He's also experimented with different cameras and found that using a mobile phone camera with image stabilization works best for him.

"I'm not afraid of technology," he said. "When you love something, you're not afraid."

(Continued on page 6)



"WHAT'S SO FUNNY?"

My wife was away and I bought a trampoline to replace our bed. When she came home...she hit the ceiling.



"BAYSIDE PIER"

An example of Max's "photo painting."




***“JUNGLE
SUNRISE”***

*Another “photo
painting” by
Max.*

(Continued from page 5)

He doesn't just swap out heads, objects and backgrounds to manipulate photos, he also embosses, so it looks as if he's painting on top of photos. It's earned him the nickname “the photo painter” by his The Art of Photography group. He said God gave him a creative mind.

Max had been volunteering two days a week at an elementary school near him before COVID hit. He loved being in the classroom as he spent his career in the field of education as a counselor. He retired about eight years ago so now he has more time to enjoy his photo editing.

“It's what I love to do,” he said. “I feel great. And mostly, I love to make people laugh.” 

(If you want to reach out to Max, email the editor, tammy@essentialtremor.org, for his contact information.)

Max's Photo Tips for People with ET

- Use a tripod if possible.
- For photo editing, keyboards with large keys are helpful.
- Instead of a regular mouse, Max uses Roller-Mouse Red Plus (listed on our website) when editing his photos (it's a bit of an investment, but worth the money according to Max). It provides extra palm support to help steady hands.
- Invest in a camera lens with “image stabilization” for keeping images in focus. Mobile phones can include this as well. Max likes to use a cell phone because it's lighter weight and more portable. He uses a Samsung Galaxy S10, which includes image stabilization.



Watch & Learn

ESSENTIAL TREMOR VIRTUAL EDUCATION EVENTS

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ET VIRTUAL EDUCATION EVENTS

Tune into the IETF's online education programs. Watch and listen right from your own home.

Diagnosis & Treatment Options for Essential Tremor, 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.

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



INSIGHTEC



Essential Tremor of the Voice vs Spasmodic Dysphonia

By *Madeleine Pethan, M.S., C.C.C.-S.L.P.,*
and *Michael M. Johns, M.D.*

Introduction

Certain neurologic conditions can cause people to have problems with their voice. These voice problems can often lead to more difficulty communicating throughout daily life. It is important that patients with neurological voice disorders are evaluated by an otolaryngologist, or ENT doctor, in addition to their neurologist to determine the diagnosis and discuss treatment options. Many patients with essential tremor also experience essential tremor of the voice. Essential tremor of the voice can often be confused with another neurologic voice disorder known as spasmodic dysphonia.

What is Essential Tremor?

Essential tremor is a disorder of the central nervous system that may result in tremulousness of the head, limbs, tongue, palate, and/or larynx. The tremor may occur while a structure is at rest or in action. For example, someone's hand may be tremulous while resting in their lap or it may not become tremulous until they reach for a cup of coffee on the table. Action tremor can occur while someone is purposefully moving the affected structure, or while postural muscles are contracting to hold the structure in the appropriate position. Essential tremor is characterized by rhythmic, involuntary movements of muscles during purposeful movements. Typically, essential tremor is absent at rest and maximal during the maintenance or termination of a movement. This is similar to essential tremor of the voice in that the voice box or larynx will only become tremulous when activated for voicing during speech.

What is Essential Tremor of the Voice?

Essential tremor may present as a generalized neurologi-

Both diseases, in certain speech contexts, will cause voice breaks, or stoppages during speech. Spasmodic dysphonia and essential tremor of the voice are also known to occur at the same time.

cal disorder, affecting many structures of the body, or as an isolated symptom of the voice. Patients with essential tremor of the voice may not necessarily have generalized tremor in the limbs, trunk, or other major postural muscles. In other words, the voice tremor may be the only primary characteristic. The larynx, or voice box, is not the only structure which can cause essential tremor of the voice. Tremor of the voice can be caused when any of the structures in the speech system are affected. Essential tremor of the voice may be caused by tremor in the soft palate, tongue, pharynx, or even muscles of respiration. Extralaryngeal tremor (i.e., outside the voice box) has been reported in up to as many as 93% of patients with diagnosed essential tremor of the voice. Similarly, most patients with essential tremor of the voice also have tremor affecting their hands, leg, chin, or trunk.

Essential tremor seems to be associated with aging, although the reasons are still inconclusive. Most studies report average age of onset from the late 40s to early 50s. The highest prevalence of essential tremor of the voice is in the seventh decade of life. Heredity may affect the likelihood of developing tremor. The frequency (speed) of tremor is typically between three and seven times per



second. Medications that often reduce generalized or extremity tremor, typically are not as effective for the voice symptoms.

The most prominent voice symptom and diagnostic indicator for essential tremor of the voice is a periodic or rhythmic modulation of either frequency (i.e., pitch) or intensity (i.e., loudness) in the voice. This modulation is most noticeable during prolongation of a vowel. For this reason, tremor will be most apparent when someone is speaking vowel laden sentences (i.e., you were away all year). Tremor may become so severe that a stoppage of voice occurs. This is one of the reasons that essential tremor of the voice is often confused with spasmodic dysphonia. Both diseases, in certain speech contexts, will cause voice breaks, or stoppages during speech. Spasmodic dysphonia and essential tremor of the voice are also known to occur at the same time.

What is Spasmodic Dysphonia?

Spasmodic dysphonia (SD) is classified within a family of neurological conditions called focal dys-

tonia is a condition in which movement is abnormal in an isolated part of the body. SD causes abnormal movement of the vocal folds similar to the way a condition called blepharospasm causes abnormal contraction of the eyelid. SD is different from blepharospasm, however, in that its effects are only noticed during meaningful tasks (i.e., speech). Interestingly, vegetative functions of the larynx, such as coughing, laughing, whispering, and even singing, may be normal.

Two types of SD are well described in the medical literature: abductor and adductor type. The two are clinically distinguishable by the way the voice sounds.

In the case of adductor type SD, adductor muscles—or “closing” muscles of the vocal folds—can spasm during connected speech. The voice sounds strained or strangled with intermittent stoppages of the voice. The severity can range from mild, or barely noticeable, to so severe that any attempt at producing a word brings great effort to

(Continued on page 10)

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.

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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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