

TREMOR TALK

For Donors of the International Essential Tremor Foundation

Issue 27 | January 2019

**WHAT'S NEW
AND OLD IN
VOCAL TREMOR?**

**TOOLS TO TACKLE
THE TASK**

**SHINE A LIGHT
ON ET DURING
NETA MONTH**

**CAN CBD
CALM YOUR
TREMOR?**

**FASHION
CAREER CUT
SHORT DUE
TO ET**



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Your Voice for Essential Tremor

Update from the Executive Director



As we wrap up a very successful 2018 at the International Essential Tremor Foundation (IETF) we are already working on several 2019 initiatives, many which will include support from partnering companies.

Education Programs

We had the opportunity to meet more than 500 of our supporters at our ET Education Forums in 2018. We hosted events in Philadelphia, Minneapolis, Dallas, and Tampa. Along with the ET Education Forums we also held two teleconferences with more than 200 participants for each. Thank you to our partner Medtronic for providing an annual grant to help fund these events. Also, thank you to our other corporate partners Cala Health, Abbott, and Insightec who sponsored these events. For 2019, we have several ET Education Forums already planned. Mark your calendars if you live in one of these areas:

- March 2 in San Diego, CA
- June 1 in Hartford, CT
- September 14 in St. Louis, MO

Tremor Talk Blog

We also revived our Tremor Talk blog in 2018, posting several articles on a variety of topics including relieving stress during the holidays, understanding the new tax laws and how they affect your giving options, and how the best caregivers practice self-care, just to name a few. To read these articles and more visit tremortalk.org.

Social Media Efforts

So much communication is done these days through social media and the IETF made a real effort to increase our presence on Twitter and Facebook in 2018, and we also created Instagram and LinkedIn accounts. These provide additional ways for us to raise

awareness and educate more people about ET and the resources the IETF has available for patients, doctors, and caregivers. These efforts have also increased the traffic to our website essentialetremor.org. We look forward to continuing to use these tools in 2019 to advocate for the ET community. Feel free to share our social media outlets with all your friends and family.

New Year, New Initiatives

The new year will bring several exciting opportunities for new potential treatment options and research opportunities for ET patients. This issue of *Tremor Talk* includes stories from several of our partners who are working on medical devices or ET specific medications. They include CALA Health, Steadiwear, Cavion, and Cadent Therapeutics. The IETF is also excited to provide funding for a groundbreaking study on CBD as a treatment option for ET at UC-San Diego led by our medical advisory board member Dr. Fatta Nahab.

And don't forget March is National Essential Tremor Awareness Month. In this issue of *Tremor Talk* you will find information on how you can get involved by hosting a DIY fundraiser, ordering NETA month posters to share in your community and the new NETA month t-shirts and tote bags.

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

Contents

- 4 Education** What's Old and New in Vocal Tremor?
- 10 Support** Tools to Tackle the Task
- 13 Education** ET Teleconferences: Listen In!
- 17 Research** Cala Health Conducting Landmark Clinical Study on ET
- 18 Research** Steadiwear Creates Tremor Stabilizing Glove
- 19 Foundation** Little Fundraisers = Big Support
- 20 Foundation** Shine a Light on Essential Tremor During NETA Month
- 22 Research** Cavion's ET Drug Making Clinical Progress
- 25 Research** Cadent Therapy Regulates Neuron Firing to Help Manage Tremor
- 26 Research** Can CBD Help Calm Your Tremors?
- 27 President's Club**
- 28 Honorariums & Memorials**
- 29 Fundraising** Chipotle Fundraiser in KC March 4
- 30 ET Support Groups**

Features

- 8 Feature** 91-Year-Old Shares Her Journey with ET
- 14 Feature** Fashion Career Cut Short Due to ET



On the Cover:
Charlene Johnson,
former NY fashion
designer

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What's Old and New in Vocal Tremor?

Breaking Down the Latest Research



*By Neel K. Bhatt, MD¹
and Michael M. Johns, MD²*

Vocal tremor can occur secondary to certain neurologic disorders and can have significant impact on a patient's ability to communicate.¹⁻³

In general, vocal tremor produces rhythmic instability in voice intensity and pitch, often characterized by a tremulous voice quality.⁴⁻⁶ Patients with essential tremor (ET) can experience various body tremors, and sometimes the disease can affect the voice – which is termed essential vocal tremor (EVT).⁷ While EVT is usually associated with concurrent tremors in the head, limb, tongue, and trunk,^{8,9} EVT can also occur as an isolated finding within the voice box.⁷ Patients with vocal tremor can have generalized movement disorders, trouble communicating, and difficulty eating/drinking, and each of these issues may necessitate specialized management. For this reason, patients with vocal tremor are often best evaluated and treated using a team based approach with specialists from neurology, otolaryngology (ear, nose and throat doctors), and speech-language pathology (voice therapists).

EVT alone can significantly affect an individual's quality of life. Louis and colleagues¹⁰ compared patients with EVT and Parkinson's disease using the Voice Handicap Index (VHI) – a scale developed to measure the psychosocial impacts of voice disorders. Patients with severe vocal tremor reported similar levels of functional, emotional, and physical vocal disability compared to those with Parkinson's disease.

Symptoms and Diagnosis

EVT tends to occur more frequently in women. The symptoms usually begin in the seventh decade of life and its onset is typically gradual.¹¹ The acoustic modulation (i.e. change in pitch and intensity) is roughly between 4 and 8 oscillations per second.¹² To aid in diagnosis, clinicians may ask the patient to read vowel-filled passages, since the vocal tremor is more perceptible with the prolonged voicing of vowel sounds. Vocal tremor can be seen during flexible laryngoscopy – a painless procedure to view the larynx and throat while one is speaking. If the tremor is sufficiently severe, EVT can cause complete

breaks in the voice. Voice breaks are a common feature of another voice condition, a focal dystonia called spasmodic dysphonia. This can sometimes make differentiating the two disorders challenging. Furthermore nearly one in three patients with spasmodic dysphonia also have vocal tremor.¹³ A skilled team of laryngologists (ENT doctors specializing in voice), neurologists with movement disorders expertise, and speech pathologists with voice experience can work together with you to ensure a precise diagnosis.

Vocal tremor produces a rhythmic instability in voice intensity and pitch, often characterized by a tremulous voice quality.

Boxtox Treatment

Botulinum toxin A (BoNTA), commercially known as Botox[®], can be injected in or around the voice box and is considered the gold standard treatment for EVT.¹⁴⁻¹⁶ The injections provide a temporary improvement in the severity of tremor, lasting for several months before another injection is needed. The treatment is typically administered by otolaryngologists (ENT doctors) who specialize in voice conditions. For most patients, injections can be performed in the office while awake. The patient's neck is first anesthetized, and a small caliber needle is advanced through the patient's neck into the vocal fold muscle. Once the needle is confirmed to be correctly positioned, a small amount of BoNTA is injected. See this link for a video example: <https://www.csurgeries.com/video/emg-guided-botulinum-toxin-injection-adductor-spasmodic-dysphonia>. After a few days, the toxin begins to take effect by weakening the vocal fold muscles and allowing the patient to speak with less tremor.

Treating vocal tremor with BoNTA, however, can be challenging. The reason for this is many patients have a combination of tremors inside and outside the voice
(Continued on next page)



The IETF website has information on botox injections and other essential tremor treatment options, www.essentialtremor.org/treatments/

(Continued from previous page)

box.¹⁷ Sulica and Louis studied a group of patients with EVT and found that most patients have additional tremors within the upper airway including the tongue, palate, and throat. Even if BoNTA is successfully injected into the vocal muscles, it may not address these other tremors that affect the voice. Injecting BoNTA into the other sites of tremor (tongue, palate, and throat) is not recommended since this can cause severe swallowing problems. Another treatment challenge is that each injection can produce an initial period of over-effectiveness, marked by a soft and breathy voice. Occasionally, injecting the voice box can cause temporary impairment with swallowing. Some patients are too bothered by the temporary deterioration in voice/swallowing and decline subsequent treatments. Usually, however, with artful treatment and careful dosing, BoNTA helps the majority of people with vocal tremor.

Medical therapy is not considered as effective as BoNTA for vocal tremor. However, Propranolol, which is a mainstay treatment for ET, may have utility in some patients with EVT.¹⁴ Justicz and colleagues studied patients with EVT treated with propranolol and assessed the medication's efficacy using the Voice-Related Quality-of-Life (VRQOL) questionnaire. The authors found that propranolol produced a significant improvement in the patient-reported VRQOL score, but objective voice assessments were unable to show a dramatic improvement. That said, a trial of medical therapy is usually worthwhile as it may offer some additional benefit to BoNTA alone.

Voice Therapy to Improve Communication

Voice therapy does not have a well-established role as a sole treatment for EVT, but there is good evidence that speech-language pathologists can equip people with strategies to improve the effectiveness of their communication.^{18,19} Voice therapy is helpful for some patients with vocal tremor, particularly after BoNTA. The success of voice therapy, however, is highly dependent on the speech-language pathologist's experience treating

patients with EVT.

Surgical Options for Vocal Tremor

Deep brain stimulation (DBS) has been introduced as a surgical option for treating EVT. Sataloff and colleagues²⁰ were the first to report using DBS to treat EVT. They implanted bilateral DBS into the ventral intermediate nucleus of the thalamus in two patients and showed improvement in voice quality following the surgery. Since then, the technique has continued to progress. Ho and colleagues²¹ reported using a multidisciplinary approach to DBS in order to optimize voice outcomes. They used intraoperative acoustic data and visual inspection of the voice box in the awake patient to improve pitch and intensity modulation. With continued technical refinement, DBS has promise as a durable treatment option for EVT.

Magnetic resonance guided focused ultrasound (MRgFUS) is a non-surgical therapy to treat essential tremors.^{22,23} This technique uses a cranial ultrasound to generate heat ablation to target thalamic nuclei. Magnetic resonance image-guidance provides a high degree of anatomic detail and can ablate with great precision.²⁴ Studies have shown that MRgFUS improves the clinical assessment of essential tremor and patient-reported quality of life for the majority of patients.²⁵ For select patients with vocal tremor, MRgFUS may be an attractive option for those seeking a long-term solution and wishing to avoid surgery. However, there is little published research supporting the use of MRgFUS in specifically treating vocal tremor.

In Summary

Vocal tremor can significantly affect an individual's ability to communicate. While medical and procedural treatment options can improve EVT for most people, each therapy modality has limitations in effectiveness and carry some risk. People with EVT are best cared for by a communicating team of movement disorders specialists, laryngologists, and voice-specialized speech language pathologists. Recognizing that no one

See this link for a video example of a botox injection:

www.csurgeries.com/video/emg-guided-botulinum-toxin-injection-adductor-spasmodic-dysphonia.

treatment can alleviate symptoms of EVT completely, there is a need to continue refining and expanding therapy options. The IETF is helping this with research grants and by connecting the community of researchers and people with EVT. ☺

* * * * *

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91-Year-Old Shares Her Journey with Essential Tremor

The incident happened more than 80 years ago, but Shirley Silver carried it with her all of her life.

She was nine years old in her elementary classroom, learning penmanship with the rest of her classmates. But, due to her essential tremor (ET), she could not form her “O’s” correctly. Instead of looking at what might be wrong, her teacher chastised her and made her feel embarrassed and ashamed.

“That was the beginning of a very self-conscious personality that I developed,” said the 91-year-old Cinnaminson, NJ resident. “I tried to hide it. Even my own mother never talked to me about it. I think it was a cultural thing. People thought if you didn’t talk about it, it would go away.”

She was labeled a “nervous child.” Her handwriting worsened as she grew older. As a teenager she could barely sign her name. Even as an adult, signing her name was a traumatic experience for her.

“I tried to hide it. Even my own mother never talked to me about it. I think it was a cultural thing. People thought if you didn’t talk about it, it would go away.”

“The self-consciousness hit me very badly, because I know other people today who have essential tremor and they have not let it get the best of them. But I started out on a bad foot with that teacher. She made me feel ashamed and I never was able to drop it,” she said.

As Shirley grew up, she realized that her father also had essential tremor. However, he attributed his to exposure



to mustard gas during World War I. Shirley and her sisters got a kick out of watching their father at the dinner table as he tried to use the salt shaker.

“He would pick up the salt shaker to put salt on whatever we had for a main dish and salt would go every place but on that piece of meat or whatever it would be. My sisters and I thought it was the funniest thing in the world,” she recalled.

Over the years, Shirley came to realize that her parents were just trying to protect her by not talking about her essential tremor or sharing her condition with others.

As an adult, she got involved in an International Essential Tremor Foundation (IETF) support group and it changed her life.

“My knowledge, my confidence – everything – was boosted by this group. It was wonderful. It took me all that time to say ‘I’m not the only one,’” she recalled.

Shirley wanted to share her story so that people who might be experiencing the same shame and embarrassment would know they are not alone. She wants others with essential tremor, especially young people, to know “don’t

worry about what people think. Spend your time on more creative things.”

She is grateful to the IETF for raising awareness to essential tremor and providing support and hope to people with ET.

“If it hadn’t been for the IETF, I would still be back in kindergarten in my ability to cope with tremor,” Shirley said. ©



(Left) This is an early photo of Shirley Silver, which was one of her favorites from her childhood.

(Below) Shirley Silver with her three grandchildren and her great-grandson.



In Memoriam

Shirley Silver passed away in December 2018. She had the opportunity to read this story after it was written and was happy to have us share it. We publish it as a tribute to her life and memory. Our thoughts are with her family.

What is an ET Support Group?

- An ET Support Group is an informal, self-managed, self-help group. It is not a therapy group or a 12-step program. It is run by and for people who have ET or who have a family member or friend who has ET.
- An ET Support Group is a place to be you. The group is a place where people feel welcomed and accepted, can talk openly, and can exchange ideas about the challenges of living with ET. It is a place where privacy and confidentiality are accepted.
- An ET Support Group is a source of information and practical suggestions about ET and about the International Essential Tremor Foundation (IETF).

See our list of ET Support Groups on pages 30-31. Interested in starting a support group in your area? Contact Dawanna Fangohr, dawanna@essentialtremor.org or call toll-free 888-387-3667.

TOOLS

to Tackle the Task



*By Kelli Reiling, OTD, OTR/L, MSCS,
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As an occupational therapist, people ask what it is that I do. Simply stated, an occupational therapist focuses on what brings meaning and purpose to individuals who may be dealing with any number of conditions or situations. For individuals who have essential tremor, I hope to shed light on tools and considerations, which may ease completion of daily activities, such as eating, dressing, and handwriting.

While there are a number of options available, I highly recommend completing a trial of equipment prior to purchase. What

“Regardless of the equipment or strategies chosen to assist with daily life tasks, I truly encourage routine exercise, core strengthening, stretching exercises, and general wellness activities such as meditation be included in an individual’s home program.”

works for one individual may not always work for another. Often times, a referral to an occupational therapist in an outpatient setting who focuses on movement disorders may be your best option. The idea is the occupational therapist will have access to a variety of devices (tools) for potential trial. Another resource I like to provide to the individuals I work with is the following website: <https://www.performancehealth.com/products/home-care-daily-living>.

While I still encourage device trials, the provided link directs you to the home care and daily living page, which allows you to review equipment options and get an idea of what is available.

As stated earlier, I would like to focus on eating, dressing, and handwriting as these are the activities individuals I serve report the greatest difficulty managing. Granted, equipment options vary. I will highlight a few equipment options and suggest strategies. Often, individuals implement strategy suggestions first with equipment added only as needed.

Regardless of the equipment or strategies chosen to assist with daily life tasks, I truly encourage routine exercise, core strengthening, stretching exercises, and general wellness activities such as meditation be included in an individual’s home program. Individuals can incorporate these exercises into activities such as laundry, cleaning, and leisure. Additionally, stress management activities are beneficial to include, as stress will cause symptoms to worsen.



To learn more about ET assistive devices, visit
www.essentialtremor.org/treatments/assistive-devices/

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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.