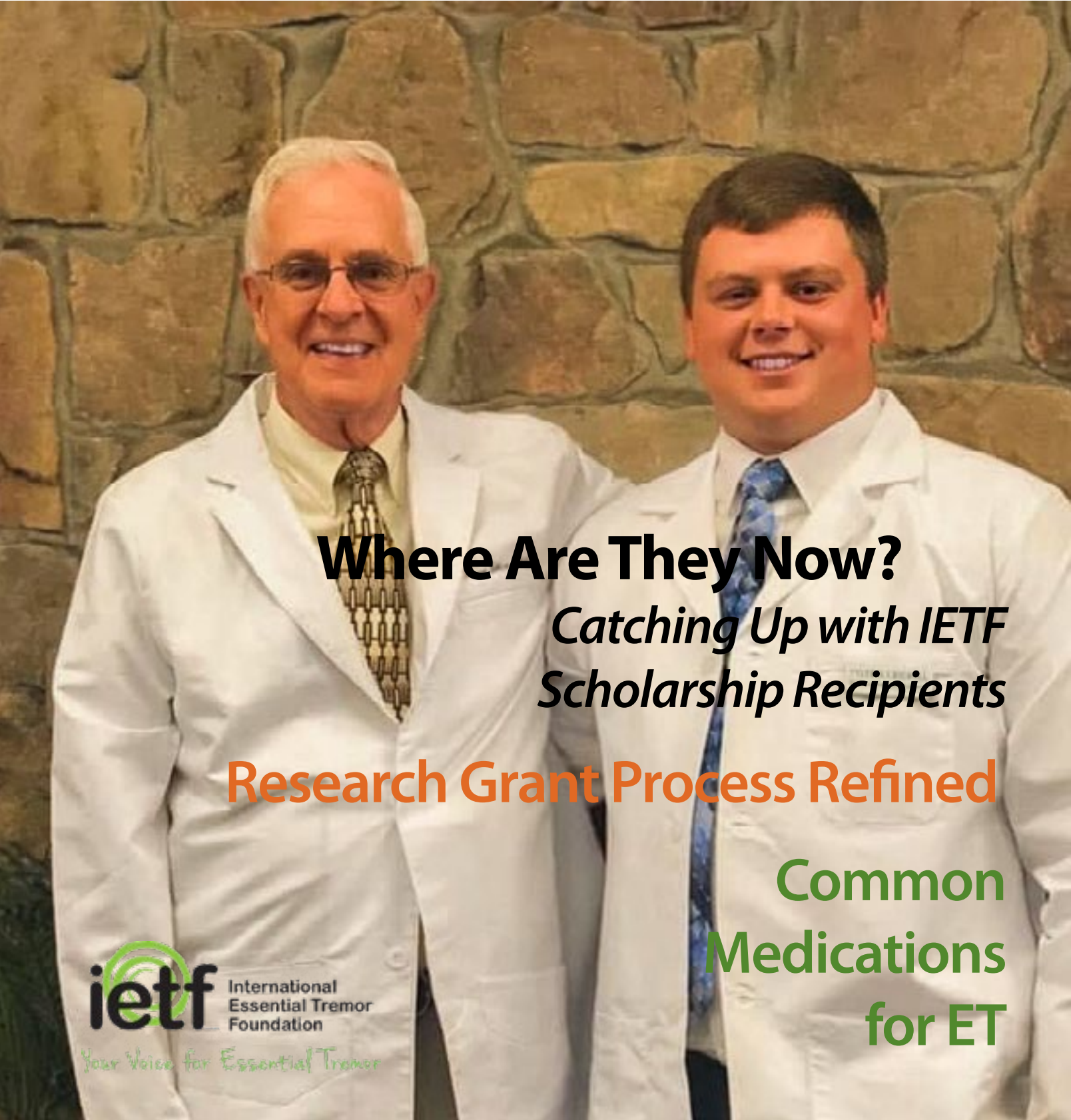


TREMOR TALK

For Donors of the International Essential Tremor Foundation

Issue 35 | October 2021



Where Are They Now?

*Catching Up with IETF
Scholarship Recipients*

Research Grant Process Refined

Common
Medications
for ET

Update from the Executive Director



The month of July began with the IETF moving in to our new office. As with any move, we had some transition issues especially with our phone and internet set up, but everything seems to be working well now. The new

office is great and includes some features we didn't have in our old space including a conference room and a full kitchen. We've shared some photos on the back cover of this issue. Our new physical address is:

IETF
13628 W. 95th Street
Lenexa, KS 66215

We still have our P.O. Box where we receive most of our mail (PO Box 14005, Lenexa, KS 66285). Our phone numbers have remained the same. Another positive of the new space is we will save approximately \$5,000 a year in rent and utilities.

2021 Research Appeal Results

The 2021 research appeal dropped the first week of July. As a reminder, 100% of all donations made for research go to fund our grant program. To date we have received over \$46,000 in donations from more than 500 donors. We thank you for your support in our efforts to find more and better treatment options for ET. There is an article in this issue explaining our new research grant program beginning in 2022.

Become an ET Trailblazer


The IETF is now offering a new donation option to support our mission. The ET Trailblazers program

allows donors to make an automatic monthly recurring donation. This helps donors spread their donation out and eliminate the need to remember to do it on an annual basis. This is a great option for someone on a fixed income who cannot afford one large donation each year. Please share this new program with anyone you know who might be considering a donation to the IETF.

New Podcasts Available

Since the last issue of *Tremor Talk* we have added some new podcasts to our library including an interview with Lord Julian Fellowes, the creator of *Downton Abbey*, and Dr. Binith Cheeran, medical director for neurological therapies at Abbott Labs, discussing the newest innovations in DBS surgery. Check them out on our website.

We hope you enjoy this issue of *Tremor Talk*, which includes stories on a new clinical trial by Praxis, a comprehensive list of ET medications, and some outgoing and incoming IETF board members. We also caught up with some of our former IETF scholarship recipients to see what they're doing now and asked them about the impact of receiving an IETF scholarship.

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:
IETF scholarship recipient Tyler Criswell with his grandfather at Tyler's white coat ceremony at the University of Alabama.



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.



Commonly Prescribed Medications for Essential Tremor

While a cure for essential tremor (ET) has not yet been found, medications may help improve your quality of life. If your ET is mild, you may not need treatment. However, if your ET interferes with your ability to work, perform daily activities or interact socially, you may want to consider medication. Maybe you are taking one of the following and have found success, or if not, perhaps you can check with your doctor about another medication listed below.

MEDICATIONS LIST

Propranolol (Inderal®)

Propranolol is the only medication approved by the Food and Drug Administration (FDA) for the treatment of ET and is available in immediate and long-acting formulations. Propranolol is a beta-blocker that is a drug used primarily for treating high blood pressure. Side effects of propranolol are usually mild and are more frequent at higher doses. The main side effects are decreased heart rate and blood pressure. Tell your doctor if you have heart failure, diabetes, or asthma. Patients who respond usually require a total daily dosage of 240 mg or less. Other beta-blockers such as atenolol, metoprolol, and nadolol can also be beneficial for treating ET.

Primidone (Mysoline®)

Primidone is an anti-seizure medicine that can be effective in treating ET. Although it might have initial side effects such as nausea, poor balance, dizziness, fatigue, drowsiness, and flu-like symptoms, these side effects often resolve over time. To reduce the possibility of side effects, start with a small dose at bedtime (12.5 mg or one-quarter of one tablet) and gradually increase the dosage according to your doctor's instructions.

Clonazepam (Klonopin®), diazepam (Valium®), lorazepam (Ativan®), and alprazolam (Xanax®)

These anti-anxiety medications may be useful in patients who do not respond to other medications or who have associated anxiety. Side effects include sleepiness, dizziness, depression, fatigue, loss of coordination, memory loss, and confusion. These drugs are usually less effective than propranolol and primidone, and they can be addictive. There is also risk of withdrawal symptoms if the drugs are stopped suddenly.

Topiramate (Topamax®)

Topiramate is an anticonvulsant that has been shown to be effective in controlling tremor in some patients. Side effects include numbness or tingling, memory loss, and weight loss.

Gabapentin (Neurontin®)

Gabapentin is a generally well tolerated anticonvulsant, but controlled studies have produced conflicting results regarding its efficacy in ET. At best, this drug has a very modest benefit. It is tried by patients whose tremor is unmanageable by other medications. Side effects include fatigue, slurred speech, drowsiness, impaired balance, and nausea especially when beginning drug therapy.

MISCELLANEOUS AGENTS

Mirtazapine (Remeron®)

Mirtazapine is an antidepressant. Due to its lack of effectiveness for the majority of patients and its significant side effects, mirtazapine is not recommended for the routine treatment of ET. Adverse effects include sleepiness,



confusion, dry mouth, weight gain, frequent urination, balance and gait difficulty, nausea, and blurred vision.

Botulinum Toxin Injections (BOTOX®, Myobloc®)

If medications fail, you may consider injections of botulinum toxin into the affected muscles. Botulinum toxin injections have been useful in the treatment of some patients with head and voice tremor and sometimes hand tremor. The toxin must be placed into target muscles by a trained specialist and repeat injections will be needed approximately every three months. Transient weakness of the injected muscle is a potential side effect. This treatment can be expensive, and

since no botulinum toxin has been approved for ET, be sure to check with your insurance provider about coverage

Alcohol

Adults with ET often notice that responsible drinking of alcohol - having one or two drinks before dinner or at social events - reduces tremor for one to two hours. However, a more severe rebound tremor can occur after the effects of alcohol have worn off. The addicting and intoxicating effects of alcohol limit its use. 🍷

Considerations When Taking Any Medication

- Always follow your physician's directions when taking any medication.
- All medications have potential side effects. Become aware of the potential side effects of the medications you take. Ask questions of your physician and/or pharmacist.
- Contact your physician if you experience any side effects.
- Inform your physician and pharmacist of all medications you are taking, including over-the-counter medications, vitamins and herbal remedies.
- Although not always possible, try to use one pharmacy for all of your prescriptions.



Learn more about treatment options for essential tremor at www.essentialtremor.org/resources/living-with-et/treatments/

The Evolving Role of Focused Ultrasound for Essential Tremor

By Arif Dalvi, MD, MBA

Director,

Comprehensive Movement Disorders Program

Palm Beach Neuroscience Institute

West Palm Beach, Florida

Many patients with essential tremor suffer decades of increasingly debilitating tremor before considering surgical options. Deep brain stimulation (DBS) surgery has been FDA-approved and available since 1997 for control of intractable ET. However, the procedure is complex. It involves placing an electrode in the brain through a burr hole in the skull. Following this, a pacemaker-like device is implanted below the collar bone to provide electrical current through the electrode for high-frequency deep brain stimulation. Due to the complexity of the procedure, many patients chose to forgo DBS, which could have been a viable surgical option.

Magnetic Resonance Imaging Guided Focused Ultrasound (MRIGFUS) is a new surgical modality that avoids the need for electrode or pacemaker implantation. The procedure is performed in an MRI suite rather than an operating room and avoids the need for any surgical incision or burr hole. It occupies a middle ground between medications, which may have proven ineffective, and DBS, which has a robust improvement profile and a long-term track record of efficacy but is more invasive.

Effectiveness of FUS

In 2016 the FDA approved ExAblate Neuro for control of ET not responding to medical treatment. The approval was based on a clinical trial of 76 ET patients, 2/3 of whom got the actual procedure, and 1/3 had a sham surgery followed by the actual procedure. The target in the brain was the thalamus, and surgery was performed on only one side of the brain. Initial improvement in tremor was 47% at the



3-month mark compared with 0.1% in the control group. At the 12-month mark, the treated group continued to show improvement in tremor at 40% compared to baseline. The procedure was well tolerated but did include side effects, including numbness in the fingers, headache, imbalance, and unsteady gait. Objective ataxia occurred in 20% of patients and subjective imbalance in 16% with persistent difficulties in 5% of patients. Side effects during the procedure included a feeling of heat or pressure in the head, vertigo, and nausea that resolved shortly after the procedure. One patient had symptoms suggestive of a transient ischemic attack following

the procedure. The question remained whether this beneficial effect would be maintained for longer than one year. We now have follow-up results out to three years indicating that the initial improvement was maintained with minimal degradation in tremor control. No long-term side effects were seen. At the three-year mark, tremor improvement was reported in the 38-50% range, while the improvement in disability was observed to be 43-56%. Previously noted side effects remained mild or moderate and showed resolution in some patients.

Medicare Coverage in All 50 States

In April 2018 Medicare began covering MRIgFUS for essential tremor in some states. Since July 2020 the Medicare coverage has been expanded nationwide to all 50 states. CMS guidelines approved MRIgFUS unilateral thalamotomy for patients with medication refractory and disabling ET or Tremor-Dominant Parkinson's disease. Bilateral thalamotomy (on both sides of the brain) is not covered, and some limitations have also been outlined. Many private carriers in some states have also started covering this treatment option. Patients are best advised to discuss insurance issues with their treating physicians to determine insurance coverage specific to their situation.

Who is Not a Good Candidate

There are a number of general and specific contraindications. Patients who are unable to go through MRI procedures as they have MRI-incompatible heart pacemakers, aneurysm clips, neurostimulators, or other MRI-incompatible implanted medical devices cannot go through the MRIgFUS procedure. Medical contraindications include brain tumors, kidney disease on dialysis, high risk of deep vein thrombosis and unstable cardiac disease. The patient should discuss specific contraindications with their treating team in detail before the procedure. A CT scan of the head is also ordered prior to the procedure to calculate the thickness of the skull; a measure called the skull density ratio (SDR). Low SDRs require a higher energy requirement and different centers have different cut-off points for the SDR recommended to minimize adverse outcomes.

MRIgFUS has been shown through clinical trials to be a safe procedure. However, early side effects are not uncommon. Paresthesias in the face or hands have been reported but tend to resolve in most cases within a year. Gait disturbances, including an unsteady gait, are also reported, with this issue persisting in about 4% of patients at the one-year mark. Extension of the lesion to the internal capsule can result in motor weakness, but this side effect was rarely observed. Some patients may also have side effects during the procedure, including a sensation of heat or pressure, vertigo immediately after the procedure, and occasionally nausea or vomiting around the time of the procedure. Some patients may also have difficulty adjusting to the placement of a stereotactic frame on the head required for the procedure. While MRIgFUS has been described as a noninvasive procedure, it is important to note that it does involve creating a lesion in the thalamus and, therefore, can create irreversible side effects.

Ongoing Research

Further work is ongoing, including clinical trials of MRIgFUS in Parkinson's disease. Insights from the outcomes of these trials can further guide patients with essential tremor, especially regarding the long-term safety of the procedure. In addition, alternative targets to the thalamus such as the zona incerta are being explored, which can potentially improve outcomes. Newer imaging techniques, including diffusion-weighted MRI with tractography, can further define the ideal target for lesioning. While MRIgFUS is a new technology, it is an important addition as an option for patients with moderate to severe ET, especially in those with comorbidities that make DBS surgery less than ideal. 🌱

Reference:

Elias WJ, Lipsman N, Ondo WG, et al. A Randomized Trial of Focused Ultrasound Thalamotomy for Essential Tremor. *N Engl J Med.* 2016;375(8):730-739. doi:10.1056/NEJMoa1600159



Learn more about DBS and other surgical options for ET at www.essentialtremor.org/resources/living-with-et/treatments/

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.