MEDICARE COVERAGE OF ESSENTIAL TREMOR

TAKING ON A 100-MILE ULTRAMARATHON TO BENEFIT THE IETF

GYROGLOVE STABILIZES HAND TREMORS

SPRING SCHOLARSHIP RECIPIENTS RECOGNIZED

A COOL APPROACH TO TREMOR REDUCTION

For Donors of the International Essential Tremor Foundation

Issue 28 | June 2019
As summer kicks in, we hope you and your family get a chance to enjoy the warm weather after a rough winter. Since our last issue in January, the IETF staff and board have been hard at work raising awareness for essential tremor (ET) and educating people on the disorder.

I recently returned from the American Academy of Neurology (AAN) Conference in Philadelphia. The IETF attends the AAN conference each year to connect with neurologists and our corporate partners to raise awareness for the IETF and educate them on the resources we have available for their patients and customers. I’ll be back in Philadelphia in September to exhibit at the American Academy of Family Physicians (AAFP) conference. The AAFP conference provides the opportunity to network with family physicians who are often the first doctors to diagnose ET patients. During the previous three years at AAFP, I’ve spoken with hundreds of doctors. Most of them are currently treating ET patients, but did not know about the IETF.

The Villages Campaign
To kick off National Essential Tremor Awareness (NETA) Month we connected with The Villages in Florida, which is the largest retirement community in the United States with over 150,000 residents. During March and April we ran several newspaper ads along with two inserts to raise awareness for ET and the IETF. This campaign added more than 350 new contacts to our database through requests for ET information packets and sign-ups for our email list. We plan to run similar awareness campaigns in a variety of retirement communities around the country in the future.

ET Education Forums
We held our first ET Education Forum of the year in March in San Diego. We had a great turnout and a presentation by one of our medical advisory board members, Dr. Fatta Nahab, and Dr. David Barba from UC San Diego. By the time you receive this issue we will have also held our ET Education Forum in Hartford, CT. We will host the next forum in St. Louis, MO on September 14.

On April 18 we partnered with the National Spasmodic Dysphonia Association on a teleconference on voice tremor. Our speaker was Dr. Michael Johns who is the director of the USC Voice Center. If you didn’t get a chance to join us you can find the recording of this teleconference and all our past ones on our website essentialtremor.org

Million Dollar Mark
We are also excited to announce that at the end of our fiscal year on March 31, 2019, the IETF received over $1 million in income marking our second consecutive year to achieve this level of support. These funds help us continue to promote our mission to provide hope to the essential tremor (ET) community worldwide through awareness, education, support, and research.

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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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.
A Cool Approach to Tremor Reduction
By Lisa Warren, MHS, OTR/L

With essential tremor (ET) being one of the most common types of tremors, it is unfortunate better non-invasive therapies are not available to alleviate the impairment caused by this diagnosis. A survey of 223 patients in a clinical database revealed that 70.9% had taken Primidone or propranolol, and 56.3% had discontinued one or both medications. Thus, these first-line medications for ET clearly fail to meet the needs of many patients.

In 2005, a study by Feyes, et.al., found the use of a cooling mat on the forearm of persons with action tremors, reduced tremors. It is thought that the reduction is probably caused by a combination of decreased nerve conduction velocity, changed muscle properties, and reduced muscle spindle activity. These findings are clinically important because applying peripheral cooling might enable persons with essential tremor to perform functional activities more efficiently. In 2017, Wagle, et.al., trialed cooling with standard cold packs to reduce tremor in persons with essential tremor and Parkinson’s tremor. Studies have reported a beneficial effect of forearm cooling on upper limb tremor for those with a diagnosis of essential tremor or multiple sclerosis tremor.

In our clinic at the University of Florida Health Rehab at the Fixel Institute for Neurological Diseases, the occupational therapists teach many of our essential tremor patients the limb cooling strategy for home use. Limb cooling can provide a temporary tremor reduction benefit. I will describe in this article the simple technique we use at the University of Florida Health to provide a temporary reduction in hand tremor to allow those with essential tremor to participate in meaningful tasks with greater accuracy and satisfaction. Our technique uses common items found in most homes. We use gel cold packs that can be obtained at most drug stores.

**SUPPLIES NEEDED**

1 cold pack from the freezer (that is large enough to wrap around the forearm) or 2 small cold packs

1 pillow case

1 towel

**TECHNIQUE**

1. Place the cold pack(s) in the pillow case. The pillowcase will help protect the skin
2. Place the cold packs around the muscular portion of the forearm insuring the top and bottom of the forearm are wrapped. The cold pack should be between the elbow and wrist, but not cover either the elbow or the wrist.

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3. Place the towel over the top of the cold packs, on top of the forearm
4. Leave the forearm wrapped in the cold packs for 10-15 minutes.

This limb cooling technique can lead to decreased tremor for 1.5-2 hours. This may be enough time to allow the person with tremor to complete a task in which tremors are interfering. Many utilize this strategy prior to tool use, crafting, handwriting/paying bills, before going out to eat, etc … We have found in our clinic that this technique is most beneficial for those with a grade 1.5 to a grade 3 on the Tremor Rating Scale. Your neurologist or occupational therapist can assess your tremor to determine if it is in the range in which limb cooling can be successful.

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**After Treatment**

In the examples below, a patient with essential tremor performed a handwriting assessment before and after limb cooling.

Sample (A) is a line draw test in which the person with essential tremor draws lines from left to right. Following the line draw, limb cooling was applied for 12 minutes for this particular patient.

Sample (B) is the line draw assessment completed by the same patient, after cooling. In these samples, it is easy to see the impact cooling has on decreasing tremor intensity.

**SAMPLE A  (Before Cooling)**

**SAMPLE B  (After Cooling)**
Advancing the Understanding of Brain Functions/Disorders Through Education and Public Advocacy

By Katie Sale, Executive Director
American Brain Coalition

The American Brain Coalition (ABC) is proud to call the International Essential Tremor Foundation (IETF) one of its members, and especially thrilled to have IETF’s Executive Director, Patrick McCartney, participate as a member of ABC’s Board of Directors.

The ABC is a non-profit organization comprised of over 100 of the leading patient advocacy and voluntary health organizations, as well as professional neurological, psychological, and psychiatric associations. We also have the support of a number of publicly-traded corporations that actively engage in brain-related research and development. Together, we seek to advance the understanding of brain functions and reduce the burden of brain disorders through education and public advocacy.

The ABC has most recently been concerned with multiple reports over the past few years showing a considerable decrease in industry investment in treatments for ailments of the central nervous system (CNS) including movement disorders such as essential tremor. The ABC leadership has focused our policy priorities on this issue. As a first step, the ABC designed a message from the neuroscience community to be circulated to Congress, the Administration, and the public to raise awareness of the opportunities created by federal investment in science and the challenges that still exist to bringing treatments to patients.

This statement provides an expression of broad concern in the nonprofit brain community regarding divestment from neuroscience development at a time where federal government investments are creating opportunities for new treatments. It represents a commitment, as individual organizations and as a community, to devote more time to taking a holistic look at neuroscience R&D to identify ways we can facilitate the development of new therapies for patients. The ABC believes it is important to create an environment that fosters the translation of basic research discoveries – made possible by the over $7 billion in annual funding for neuroscience research at the National Institutes of Health and efforts like the BRAIN Initiative – into the development of treatments for patients and their physicians. The Brain Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative is aimed at creating tools that will accelerate discovery and build the foundation we need to revolutionize our understanding of the human brain.

We are thrilled the IETF has signed on to our Statement of Challenge and Opportunity, expressing our joint commitment to better understanding, and more effectively resolving, the barriers we continue to face in translating neuroscience discoveries to the development of life-changing therapies for patients with brain-related conditions. Please visit the ABC’s website to view the Statement, and learn more about our Coalition.

Go to www.americanbraincoalition.org to learn more and to read the “Statement of Challenge and Opportunity.”
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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