

TREMOR TALK

For Donors of the International Essential Tremor Foundation

Issue 39 | January 2023

*Come Hear
the Music
Play with
Becca Kidwell*

**Mark
Honeyman's
DBS Journey**

**Therapies and
Assistive Devices
to Enhance
Quality of Life**



International
Essential Tremor
Foundation

Your Voice for Essential Tremor

Update from the Executive Director



Our first ever ET Virtual Education Conference was a huge success. More than 1,800 people registered for the event. Thank you to our corporate partners who stepped up to provide their support. A special thank you

to Sage Therapeutics, Biogen, and Praxis Precision Medicines who were the presenting sponsors, and to Jazz Pharmaceuticals who was a platinum sponsor. If you were not able to attend the event live, all the sessions were recorded and are currently available to watch on our YouTube channel, [YouTube.com/EssentialTremorIETF](https://www.youtube.com/EssentialTremorIETF).

We are continuing our podcasts and webinar series. We recorded our latest podcasts with Dr. Elan Louis, who shared an update about his recent publication on the prevalence of essential tremor, and with Dr. Claudia Testa, who talked about her new book on essential tremor. We also have recorded a new webinar with Boston Scientific discussing Deep Brain Stimulation (DBS) and their image-guided programming options. To access these virtual events, go to our website, www.essentialtremor.org, and click on What We Do/Educational Programs. The IETF would like to thank our corporate partners Medtronic, Abbott, Boston Scientific, Insightec, Sage Therapeutics, Jazz Pharmaceuticals, Cala Health, and Alleevion Therapeutics for their support of these programs. We will continue to schedule a variety of podcasts and webinars and promote them through our *Tremor Gram* e-newsletter and our social media channels.

National Essential Tremor Awareness Month (NETA) is in March, and we are gearing up to promote ET awareness and education with a new poster, social media posts and our NETA month donation gifts. The IETF's former executive director, Catherine Rice, worked with then congressman Dennis Moore to establish house resolution number 1264 in April of 2010 to designate March as National Essential Tremor Awareness Month. We encourage you to take part in this month by sharing

our information on your social media platforms, and by speaking out to educate others about ET and its impact.

In the area of research, several ET specific medication trials are currently running. If you live in an area where a trial site is located, you should have received an email from the IETF with information on how to sign up. If you don't have email, you can visit our website and click on the What We Do/Research button to find out more information.

We hope you enjoy this issue of *Tremor Talk* which includes stories on an overview of ET assistive devices/therapies, an update from Mark Honeyman, who was featured in one of our past issues, and information on two new medical advisory board members, plus more.

As always, there is a lot going on at the IETF, but none of this happens without your support. Your donations are appreciated and allow us to continue to build on our mission to provide hope to the ET community through awareness, education, support, and research. 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:
Becca Kidwell spent her life yearning to be on the stage and now she's part of the cabaret community.



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unless otherwise stated.

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.

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.

HAVE YOU MOVED? Email us your new contact information, info@essentialtremor.org. Use the subject line "Change of Address."

Living with Essential Tremor

Therapies and Assistive Devices to Enhance Quality of Life

While there is no cure for essential tremor (ET), there are a number of assistive devices and therapies to lessen the impact.

There has been significant growth in this area during the past several years. The IETF has compiled a list of devices and therapies currently available on the market, including their main features, effectiveness and cost (when available). The information was gathered from each device or therapy's website .

We hope this will be a good resource for those looking for support.

Name of Device: Cala Trio™ by Cala Health

How it Works

Cala Trio™ therapy is a treatment designed to temporarily and effectively reduce hand tremor. It is the first and only non-invasive therapy that directly targets the source of the tremor by gently stimulating the wrist nerves with electricity (neuromodulation) and targeting the root cause of essential tremor. The stimulation interrupts the tremor in the brain's ventral intermediate nucleus of the thalamus. Gentle stimulation is sent to the median and radial nerves traveling to the brain.



Features

Cala Trio™ is FDA-cleared, safe, effective and individually calibrated to each patient's unique brain signal pattern. Cala Trio™ therapy avoids common side-effects and risks associated with traditional ET treatment options.

Effectiveness

The largest therapeutic clinical trial in ET, PROSPECT, was conducted using the Cala Trio™ device. Studies have shown that commonly prescribed medications benefit about half of patients with essential hand tremor which is similar to results from Cala Trio™ therapy. The electrical stimulation uses the same pathways as brain implants.

Insurance Coverage

Your health plan provider is more likely to approve your Cala TAPS (transcutaneous afferent patterned stimulation) therapy when accompanied by medical necessity documentation from your medical records.

Cala Customer Care supports every patient by ensuring that each claim submitted has the appropriate medical necessity documentation to support a prior authorization. Cala obtains the information from each prescribing healthcare professional's medical records. Currently, each prior authorization request is reviewed case-by-case by the patient's healthcare plan administrator. Cala will provide the patient with an estimated copay based on the insurance plan.

Cost

If you and your prescriber decide that Cala Trio therapy is not right for you, you may return the device before the end of the first 60-days, and you will not be held responsible for any costs. (Patient agreement is required; patients using Medicare benefits are not eligible.)

Availability

Cala Trio is available by prescription from your doctor. Currently, it is only available in the U.S.

Website: www.calatrio.com

Name of Device: Read-Steady®

How it Works

Read-Steady is a fully customizable, anti-tremor orthotic glove system. Invented by an occupational therapist and made in the USA, it serves as a single tool to reduce both action and resting tremor patterns.



Features

Unlike commercial weighted gloves, which are designed for strength training, each Read-Steady system weighs less than one pound total and works by applying sensory cues based on unique, individual tremor patterns.

Effectiveness

Since its introduction in 2015, Read-Steady has helped thousands of people regain their confidence and life again. On average, it reduces hand and arm tremors by 50% with no known side effects.

Insurance Coverage

The Read-Steady® glove is custom fabricated in the USA and the company is contracted with most major insurance companies. Individual benefits vary and results are communicated prior to commitment and/or custom fabrication.

Cost

The cost of Read-Steady varies depending on your method of payment and your need, ranging from \$300 to \$1,300. Components are custom-fitted pieces and the total cost is based on your specific needs. The first cover for each component is included in the initial cost. Additional covers are available for purchase online. Due to the custom nature of each device, orthoses glove components are non-refundable.

Availability

A physician's prescription is required. Read-Steady is available in the U.S. and internationally. Customers living outside the U.S. will be self-pay and can turn in the receipt to their insurance company for reimbursement.

Website: www.readi-steady.com

Name of Device: Steadi-Two by Steadiwear

How it Works

Steady-Two is a self-calibrating glove designed to reduce tremors in the wrist using battery-free technology inspired by earthquake design and magnetic technology.

Features

There are no side effects or risks associated with the Steadi-Two. The device is an FDA-registered Class I medical device that can be used on either hand with minimal adjustments. Please contact us before placing your order if you have any medical device implants.



Effectiveness

The Steadi-Two has shown tremor reduction of up to 80% in 2/3 of users. Over 600 early bird testers were very satisfied with the outcomes while completing tasks related to eating, drinking, and writing.

Insurance Coverage

The Steadi-Two device is fully covered for all Veterans in the USA via Pisces Healthcare and has coverage from a significant number of insurers on a case-by-case basis.

Cost

Regularly \$649 but reduced to \$449 USD when applying the exclusive code IETF200 at the checkout. The Steadi-Two includes a one-year warranty, free shipping and a 30-day money-back guarantee.

Availability

The Steadi-Two can be shipped to locations within Canada and the US in seven business days. If you are located outside those geographic regions or have other questions, please reach out to Steadiwear at info@steadwear.com or by phone at 888-505-0992.

Website: www.steadwear.com

Name of Device: Tremelo by Five Microns

How it Works

Tremelo is a non-invasive hand tremor reduction device designed to help you enjoy life, independence and daily activities.

Features

It's an FDA Class I approved device that has been tested in clinics across the United States. It is non-invasive, requiring no electricity. It uses the technology of pure mechanics to counteract essential tremor in your arm or hands. It doesn't include chemicals, or nerve or brain stimulation and there are no side effects.



Effectiveness

Tremelo is designed to reduce mild to severe essential tremor in your arms and hands by 85-90%. It was created

specifically for ET and does not help with Parkinson's disease or other movement disorders.

Insurance Coverage

At this time, Five Microns is not set up to work with Medicare, Medicaid or any insurance.

Cost

Tremelo costs \$749 and comes with a 30-day money-back guarantee. Payment plans are available.

Availability

At this time, Tremelo is only being distributed in the U.S. However, the intention is to grow to reach outside this territory. Please contact Five Microns at info@fivemicrons.com or at 559.770.2002 for more information.

Website: www.fivemicrons.com

Name of Device: VILIM Ball by Vilimed

How it Works

VILIM Ball is a handheld therapeutic device for hand tremor reduction. It gives essential tremor patients relief from tremor symptoms for the time they need to perform ordinary life tasks such as eating, drinking, writing, using electronic devices, etc. To use, take the loaded device in the palm of your hand, squeeze it slightly with your fingers to prevent it from falling out, and press the power button. The therapy lasts about 5-10 minutes, after which the device switches itself off.



Features

VILIM ball's working principles are based on mechanical vibration. Mechanical vibrations affect the nervous and muscular tissues in the hand that exchange nerve signals with the cerebral cortex. The cerebral cortex controls the movement of the human body. Mechanical vibrations of VILIM ball change the nerve signals transmitted between the cerebral cortex and the arm and suppresses hand tremors. The effect is felt immediately after treatment and lasts for up to four hours. It's lightweight and is the size of a tennis ball so it can easily travel with you. A wrist strap helps ensure it does not fall out of your hands during therapy.

Effectiveness

90% of patients who have used it have felt positive therapeutic results and improvement. Studies have shown that, on average, it reduces hand-shake by about 20-50%.

Insurance Coverage

(No information available about insurance)

Cost

VILIM ball device costs 349 € (euros) or about \$371 US dollars. The package also includes a wrist strap to protect the ball from being ejected, a magnetic charger and an adapter * (depending on equipment). VILIM ball comes with a 14-day money-back guarantee. It also comes with a two-year warranty.

Availability

It is available in the US, EU and UK.

Website: www.vilim.lt/en/vilim-ball/



Look for ET assistive devices online at www.essentialtremor.org/resource/assistive-devices/ or scan the QR code with your smartphone camera.



How the VA is Adopting Innovative New Technology for Patients with Essential Tremor

By Dr. Kalea Colletta, Neurologist at Edward Hines Jr. VA Hospital, and Ben Duncan, US Air Force Veteran

Dr. Kalea Colletta's Experience Working at the VA Treating ET

My interest in movement disorders started at a young age, after seeing my grandmother's battle with Parkinson's disease. We were very close, and I would attend her medical appointments with her. This proved to be the first step on my path to my current career as a neurologist at Edward Hines Jr. VA Hospital. While at the VA, I've had the privilege of working with inspiring and determined patients who have had their lives upended by essential tremor (ET).



At first, ET is often mistaken for Parkinson's disease, a similar, more widely-known movement disorder. However, ET is much more widespread, impacting 10 times more Americans than Parkinson's does. Treatment options for ET have historically been limited to medications with many potential side effects and, as a last resort, brain surgery. But fortunately, the VA has made significant progress in expanding treatment options for Veterans experiencing ET in recent years.

One of the most memorable patients I've treated was a Veteran with debilitating tremors. At the time, Edward Hines Jr. VA Hospital recently agreed to provide Cala TAPS therapy – an FDA-cleared, non-invasive treat-

ment option for ET – to Veterans through the prosthetics department. This Veteran was one of the first patients to whom I prescribed the therapy, and the results spoke for themselves. After wearing the Cala Trio device, this patient could complete daily tasks that they had lost the ability to perform. Before this treatment, the patient had difficulties managing to eat even a simple meal, but today, they're engaging in many activities that they had long given up.

The VA has a deep commitment to our nation's Veterans, and some extremely impactful improvements were recently

What is Cala Trio?

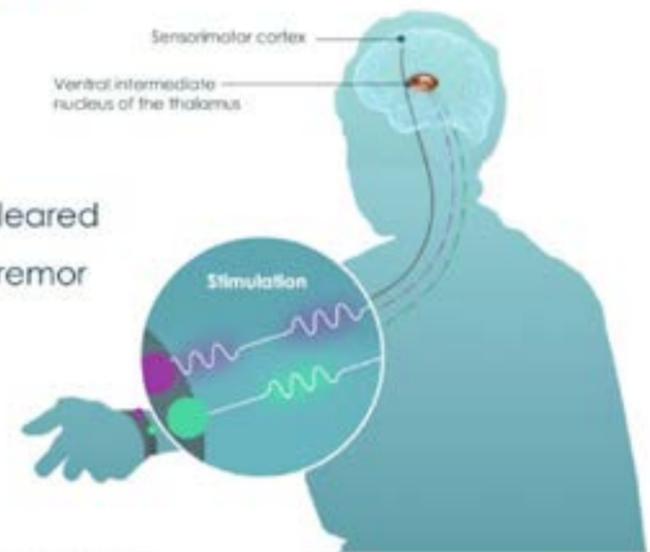
Cala Trio is the only FDA-cleared bioelectronic medicine that is clinically validated to temporarily reduce hand tremors. The device uses TAPS, or Transcutaneous Afferent Patterned Stimulation, which is an innovative, non-invasive, wearable, on-demand therapy that helps patients feel in control and get back to their daily activities, improving their quality of life.

Unlike prescription drugs, Cala Trio will not cause systemic side effects or drug-to-drug interactions and is preferred by patients over pharmaceutical and surgical options. After an initial calibration process, Cala Trio is individualized to a patient's tremor. Then, whenever a patient wants tremor reduction, they can run their own therapy sessions on the wearable device. For more information on Cala TAPS therapy, visit www.calatrio.com.



How Cala Trio™ works

Cala Trio is the only therapy cleared by the FDA to treat essential tremor without surgery or drugs

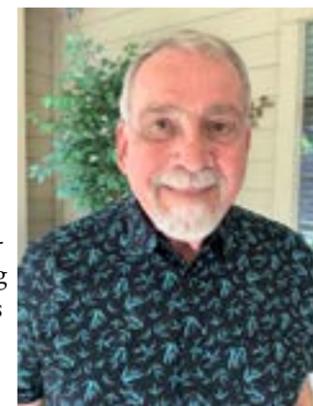


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made through the passage of the PACT, Blue Water Navy Vietnam Veterans and The Mission Acts. These pieces of legislation have greatly enhanced VA healthcare and benefits for Veterans from every era, and they have also been key to expanding the breadth of services offered by the VA. Because of these acts, I'm able to access cutting-edge treatments at no cost to my patients, and transform their experience with ET – making my work more rewarding and significantly improving my patients' lives.

Ben Duncan's Personal Experience With ET

About 14 years ago, I was diagnosed with ET. I woke up and held my glasses in the morning to determine if I would have a good, medium or bad day depending on how intense my tremors were. They increased to the point where my wife of 43



years needed to spoon-feed my meals and help me with everyday tasks that I normally wouldn't think twice about, like buttoning up my shirt or tying my shoes.

Previously, I was a successful executive in three career fields. I'm also a military Veteran; I served 21 years in the US Air Force. I was a determined person who had achieved success and happiness in life until I was diagnosed with ET. This condition thoroughly altered my physical and mental health, leading me to the point where I contemplated taking my own life. My shakes completely stripped me of my independence and will to live.

After my primary care physician diagnosed me with ET and prescribed medications to treat my symptoms, I also met with a VA neurologist to continue my treatment. For four years, I worked with my VA doctors to adjust my medications until I was finally at the maximum dosage of three strong medications. However, these medications provided me with side effects that were almost as bad as my tremors (balance issues, dizziness, drowsiness, etc.), and they only brought me back to 60% of my past





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.

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