

TREMOR TALK

For Donors of the International Essential Tremor Foundation

Issue 32 | October 2020

THE RELATIONSHIP BETWEEN ET AND PARKINSON'S

**ACTRESS
DEE WALLACE**
*Talks About ET and
Stepping into Her Own
Power*

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Essential Tremor
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**DR. KUO HONORED
FOR ESSENTIAL TREMOR
RESEARCH**

Update from the Executive Director



The staff and board of the IETF hope you and your family are still staying safe and healthy during these crazy times. Since the pandemic started, most of the staff has been working from home with periodic visits to the office to

get some work done we can't do from home. This has not stopped us from continuing to promote ET awareness and provide educational materials and programs to the ET community.

Virtual Education Events

Since we have postponed all our ET Education Forums we have been working on some virtual education events. We shared two virtual ET education videos on diagnosis and treatment options for ET. Thank you to Dr. Avram Frait from Northwestern Medicine and Dr. Leo Verhagen from Rush University Medical Center in Chicago for presenting. These two videos have had over 1,500 views. We typically average 100-150 people at our ET Education Forums so these virtual events allow us to reach a lot more people. If you haven't had a chance to see the videos you can find them on the IETF website at www.essentialtremor.org under Educational Programs.

New Podcast Series

We just launched a new podcast series called, "Talking Essential Tremor." The series will explore a variety of topics on essential tremor including symptoms, diagnosis, treatment options, support, new research, and much more. Our first episode, "Talking DBS Therapy with Medtronic" is an interview with Lisa Johaneck, senior principal medical affairs scientist and technical fellow at Medtronic. The podcasts are posted on our website and will soon be available on a variety of platforms including Spotify. The IETF would like to thank our corporate partners Medtronic, Abbott, Insightec, Sage Therapeutics and Cala Health for their support of both the podcast series and the Virtual Education Events.

Applications Open for Spring Scholarships

The deadline for the IETF spring 2021 scholarships is October 31. If you know any students with essential tremor who would be interested in this scholarship opportunity (for undergraduate, graduate, or technical schools) please have them contact the IETF office and we will send the guidelines and an application. We award four \$1,000 scholarships each semester. Since 2013 we have awarded over \$47,000 in scholarships.

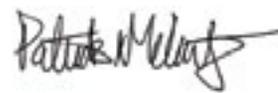
IETF Website

Our new website was unveiled this spring (www.essentialtremor.org). The new site is much cleaner and easier to navigate. One great feature of the site is it is mobile friendly so you can access any of the information on ET awareness, education, support, and research anywhere you go on your phone or tablet. If you get a chance, check out the new site and share your feedback with us. We hope you find the site helpful and share it with anyone you know affected by essential tremor, including family members and caregivers.

We hope you enjoy this issue of *Tremor Talk* which includes stories on actress Dee Wallace, information on our fall scholarship recipients, and Medtronic's new Percept™ PC Neurostimulator, just to name a few.

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:
Dee Wallace is an actress, author, speaker and healer. Diagnosed with ET, she practices healing techniques which give her relief.



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.

The Relationship Between Essential Tremor and Parkinson's Disease

**By Steven Bellows, MD¹ and Joseph Jankovic, MD,¹
Parkinson's Disease Center and Movement Disorders
Clinic, Department of Neurology,
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(www.jankovic.org)**

When people come to their doctor for evaluation of a tremor, two common possible diagnoses are essential tremor and Parkinson's disease. Essential tremor is a common condition that may start at any age and often runs in families, even though no genetic cause has yet been found. Parkinson's disease is a neurodegenerative disease associated with loss of dopamine neurons in the brain, characterized by not only tremor but also a slowly progressive slowness of movement, stiffness of muscles, gait and balance problems and other, non-motor symptoms including cognitive decline. Patients with essential tremor usually have a predominant "action tremor", meaning their tremor is most noticeable when they are doing something with their hands, like reaching for an object, holding a plate, drinking from a glass of water, or writing. Tremor in Parkinson's disease is usually a "rest tremor", meaning it happens when an arm or leg is not doing anything or when a patient walks, and typically improves when performing an action. "Positional tremor", or a tremor that occurs when holding a limb in the air, often starts immediately after raising an arm in patients with essential tremor. In contrast, in patients with Parkinson's disease this postural tremor may only emerge after waiting several seconds, the so-called "re-emergent tremor." Patients with essential tremor may have head tremor or tremulous voice, which is almost never present in patients with Parkinson's disease. Essential tremor patients often have other family members with tremor, and frequently note improvement in their tremor with alcohol. Despite these characteristic differences in clinical presentation, the distinction between the two diseases can be difficult in some cases, particularly

when there are overlapping features. Thus, people with essential tremor can sometimes have mild parkinsonian features such as slight slowness, stiffness, and even a rest tremor, but these symptoms are not enough to make a diagnosis of Parkinson's disease. A person with essential tremor is also not immune to Parkinson's disease, and can develop the condition later in life much like anyone else.

What has been more controversial is whether people with essential tremor are at higher risk of developing Parkinson's disease.¹ Some studies have shown a higher proportion of patients with essential tremor developed Parkinson's disease than would be expected, ranging from 3.1 to 20.8% of those included in these studies.²⁻⁵ In one study, which followed patients with and without essential tremor for several years, patients with essential tremor were four times as likely to develop Parkinson's disease (3.0% of essential tremor patients versus 0.7% of patients without essential tremor).² Several families have been noted to have members with both essential tremor and Parkinson's disease.⁶ In one study, patients with Parkinson's disease were more likely to have a family history of essential tremor.⁷ Another study compared patients with and without Parkinson's disease, and those with Parkinson's disease were over 7 times as likely to have a tremor 10 years before their diagnosis,⁸ although it's unclear if this tremor was essential tremor or an early isolated tremor. Both conditions can have similar "non-motor" features, such as thinking and memory changes, mood issues, and dream-enactment behavior.¹

The evidence is more complicated when researchers have looked at the brains of patients with essential tremor and Parkinson's disease. "Lewy bodies", a typical pathological finding noted in the brains of patients with Parkinson's disease when examined at autopsy, have been also noted in the brains of patients of essential tremor,⁹ but this has



not been a consistent finding.¹⁰ Some studies have used an imaging technique called a “DaTscan” to look for similarities between essential tremor and Parkinson’s disease.¹¹ In a DaTscan, a radioactive tracer that attaches to dopamine-producing neurons is given to the patient. The DaTscan is able to see how much tracer is present in a person’s brain, and thus measure if there is any loss of dopamine-producing neurons (such as would be expected in Parkinson’s disease). One study found normal DaTscan results in healthy patients, abnormally low uptake of tracer in patients with Parkinson’s disease, and results in-between for patients with essential tremor.¹² Another study showed lower tracer uptake in people with essential tremor versus people without essential tremor when using computer-aided analysis, suggesting some degree of dopamine-producing neuron loss.¹³

Clarifying the relationship between essential tremor and Parkinson’s disease is challenging as there is no specific diagnostic test or biomarker that reliably differentiates these two conditions. Many studies looking at the rates of Parkinson’s disease in patients with essential tremor are “retrospective”, meaning that they gather data from looking in the past through patients’ charts. Data that is more reliable comes from “prospective” studies that follow groups over time, but these studies are often difficult to undertake. Complicating matters further, as noted earlier, essential tremor patients can sometimes have parkinsonian symptoms such as rest tremor, slowness of movement and loss of balance.¹⁴ If someone develops a rest tremor, it can sometimes be difficult to say whether their essential tremor is getting worse or whether they are beginning to show signs of Parkinson’s disease. In a detailed review of 300 patients followed at the Parkinson’s Disease Center and Movement Disorders Clinic, Baylor College of Medicine in Houston, Texas, 26% had evidence of associated Parkinson’s disease.

(Continued on page 6)

Key Points

- Essential tremor and Parkinson’s disease are two common causes of tremor, particularly in elderly patients.
- Essential tremor typically is an action tremor while Parkinson’s disease usually has a rest tremor.
- Patients with essential tremor can develop some signs and symptoms of Parkinson’s disease, such as rest tremor, but patients with Parkinson’s disease rarely have head or voice tremor.
- There is some epidemiologic evidence to suggest that essential tremor patients have a higher chance of developing Parkinson’s disease.
- A movement disorders neurologist is best equipped to distinguish between the two most disorders, but additional studies such as a DaTscan may be helpful.
- Making a proper diagnosis is important for future prognosis and treatment.



News articles pertaining to essential tremor are posted on the IETF website at www.essentialtremor.org/news/et-in-the-news/

(Continued from page 5)

If there is any concern for symptoms of Parkinson's disease, the first step is to seek out evaluation from an experienced neurologist, and preferably one with additional training in movement disorders. The diagnosis of Parkinson's disease can typically be made by listening to a patient's history and performing a physical examination, where the neurologist will look closely at your type of tremor and see if you have any slowness, stiffness, changes in your walking, or other signs of Parkinson's disease. However, if there is any uncertainty about the diagnosis, the neurologist may order a DaTscan to look for evidence of decreased dopamine neurons, which would be suggestive of Parkinson's disease.

Patients with essential tremor and Parkinson's disease do often need different treatment strategies. Medications for essential tremor, such as propranolol or primidone, are often aimed at improving action tremor and not rest tremor or other parkinsonian symptoms. These other symptoms require Parkinson's disease medications, such as carbidopa/levodopa, dopamine agonists, or anticholinergic medications such as trihexyphenidyl or amantadine. Botulinum toxin injections can potentially be used for treatment of tremor in both conditions.¹⁵ Deep brain stimulation and focused ultrasound have been used for patients with disabling tremor due to either condition.¹⁶ 

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**TOGETHER, WE CAN
FIND ANSWERS.** 



Thank You for Supporting Essential Tremor Research!

Each July, the IETF invites the essential tremor (ET) community to get involved in supporting ET research by making a donation to our research grant fund. We are pleased to announce, this year your contributions totaled more than \$49,000 to date. We are so grateful for your support!

These contributions go directly to support research grants awarded to scientists to support new studies which will help us “raise the curtain” on essential tremor. If we understand the cause of ET, then new, tailored treatments can be developed. The ultimate goal: a cure.

Last year, the IETF Board of Directors approved increasing the amount of research grants from \$25,000 to \$50,000 to encourage more research in the area of essential tremor. The IETF awards up to two grants per year to proposals addressing the nosology, etiology, pathogenesis, treatment and other topics relevant to ET.

**\$49,000
Raised**

Thanks to your generosity, the IETF has contributed \$900,000 toward essential tremor research since 2001.

If you haven't made a research donation, you can still make one online, www.essentialtremor.org/donate/giving-options/. 100% of research donations are dedicated to research grants. 

Keep up with IETF supported research on our website,
www.essentialtremor.org/what-we-do/research/.



Medtronic

Deep Brain Stimulation (DBS) for Patients with Essential Tremor **Medtronic's New Percept™ Captures and Records Brain Signals While Delivering Therapy to Patients**

For people with essential tremor (ET), tasks such as tying one's shoelaces, brushing teeth or holding a utensil are much more difficult than they are for the average person. For the 10 million Americans suffering with essential tremor, these everyday activities are everyday obstacles. While the condition may not be life threatening, symptoms worsen with age and may become severe.

Though the cause of essential tremor in patients is largely unknown, breakthrough research in science and medicine is underway and options to help manage ET symptoms are available. These options vary from medications, surgery, lifestyle changes such as avoiding caffeine and alcohol along with managing stress levels, and more recently, personalized deep brain stimulation.

Deep brain stimulation, or DBS, was introduced more than two decades ago to help patients manage symptoms of neurological movement disorders. Most commonly associated as a treatment for Parkinson's disease, neurostimulation is a proven way to deliver controlled, electrical pulses to the area in the brain that causes the tremor. It can also be successful for patients with ET.

In the last 20 years, DBS technology has evolved neurostimulation to a very precise and effective science. With the recent approval by the FDA of the Percept™ PC device with BrainSense™ technology*, neurologists are now able to personalize stimulation based on the patient's brain signals*.

What Exactly is DBS?

DBS is an individualized therapy delivered from a small pacemaker-like device, placed under the skin of the chest or abdomen, to send electrical signals through very thin wires (leads) to a targeted area in the brain related to the symptoms of a neurological disorder.

A New Treatment is the Next Level in Brain Sensing

Amid the coronavirus pandemic, the FDA approved a new DBS device from Medtronic – known as the Percept™ PC device with BrainSense™ technology*. The Percept™ PC device has a new unique technology unlike any other device currently available in the DBS space. It is the first and only DBS neurostimulation system with the ability to chronically capture and record brain signals while delivering therapy to patients with neurologic disorders associated with essential tremor, Parkinson's disease, dystonia**, epilepsy or obsessive-compulsive disorder (OCD**).

How Does the Percept™ PC Device Work?

A pacemaker-like device is placed under the skin of the chest, with small electrical leads connected to different regions of the brain.

The Percept™ PC device allows for a more personalized* treatment program for patients with essential tremor, Parkinson's disease, epilepsy, dystonia** or OCD** by correlating readings with patient-recorded actions and symptoms, as well as medication intake, allowing their physicians to tailor their neurostimulation accordingly. A

customized Samsung mobile device also allows patients to manage their own therapy within physician prescribed limitations.

For the first time, this technology gives clinicians feedback directly from the DBS patient's brain. With such data-driven, patient-specific insights, we believe it can change the standard of care for essential tremor patients. 

Medtronic DBS Therapy for Parkinson's is not for everyone. Not everyone will receive the same results. Patients should always discuss the potential risks and benefits of the therapy with a physician. A prescription is required. DBS Therapy requires brain surgery. Risks of brain surgery may include serious complications such as coma,

bleeding inside the brain, stroke, seizures, and infection. DBS Therapy may cause worsening of some symptoms. See Important Safety Information www.medtronic.com/PDSafety or call Medtronic at 800-328-0810.

**Signal may not be present or measurable in all patients. Clinical benefits of brain sensing have not been established.*

*** Humanitarian Device: Medtronic DBS Therapy has been authorized by Federal Law for the use as an aid in the management of chronic, intractable (drug refractory) primary dystonia and for people with chronic, severe, treatment-resistant obsessive-compulsive disorder. The effectiveness of this device for these uses has not been demonstrated.*





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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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