

TREMOR TALK

Issue 30 | January 2020



**STAYING
TRUE TO
HIMSELF**
*Singer/Songwriter
Encourages Others
to Look Past
Differences and
'Look at the Heart'*

**GENETIC
CONCEPTS
AND ET**

**DIFFERENTIATING
ET FROM PD**

ietf International
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Your Voice for Essential Tremor

Update from the Executive Director



The staff and board of the IETF hope you and your family had a very happy holiday season and have a great new year. As we kick off 2020 here are some of the projects we have been working on since the September issue of *Tremor Talk* magazine.

We hosted two Essential Tremor Education Forums in the fall. The first forum was in September in St. Louis and the second in November in Kansas City. Both forums had over 165 reservations. We would like to thank Medtronic for their educational grant which funds these forums along with our other corporate partners who sponsor these events. Our next ET Education Forum is scheduled for March 28 in Chicago at the Naperville Marriott. We will let you know the rest of our 2020 dates as we get them scheduled.

In December, our partner Sage Therapeutics invited me to Boston. Sage is focusing on disorders where there is a high unmet need for additional treatment options. They are working to understand the underlying mechanisms for numerous disorders of the brain and central nervous system (CNS) to help develop therapies that may address current treatment gaps for patients. I had the opportunity to meet with their staff working on an upcoming phase II clinical trial and present to their full staff at a lunch and learn about the IETF and the resources we have available for patients, family members, and caregivers. I will be meeting with one of our newest partners, Jazz Pharmaceuticals, in February to make a similar presentation. These are great avenues to educate and raise awareness for ET and the IETF.

We had another opportunity to raise awareness at the American Academy of Family Physicians Family Medicine Experience conference in September in

Philadelphia. This was the fourth year we have exhibited at this conference. These family doctors are very knowledgeable about essential tremor but most are not aware of the IETF. We distribute our patient handbooks, medical alert cards and other materials to share with their patients.

I also serve on the board of directors for the American Brain Coalition and in October, I traveled to Chicago for their annual board meeting. It was another great opportunity to network and raise awareness for the IETF.

The deadline for our 2020 research grants is February 28. We are excited to announce the IETF Board of Directors approved raising the limit for the grants from \$25,000 to \$50,000. We hope this increase in funding will encourage more grant applications to help find new treatments and hopefully someday a cure for ET. If you would like to review some of the past grants we have funded visit our website, essentialtremor.org and click on the research tab.

We hope you enjoy this issue of *Tremor Talk* which includes information on our plans for NETA month, our spring scholarship award winners, and a profile of our newest board member, just to name a few of the topics.

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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Contents

- 4 **Education** Differentiating Essential Tremor from Parkinson Disease
- 6 **Research** Genetic Concepts and ET
- 7 **Awareness** March is National Essential Tremor Awareness Month
- 10 **Support** Can Occupational Therapy Help Someone with ET?
- 12 **Support** A Legacy of Support and Hope
- 18 **Foundation** IETF to Launch New Mobile-Responsive Website
- 20 **Research** Jazz Pharmaceuticals Expands into Movement Disorders
- 21 **Foundation** IETF Welcomes New Board Member
- 23 **Support** Spring 2020 Catherine Rice Scholarship Recipients
- 26 **Support** Psychosocial Aspects of Tremor
- 27 **Memorials & Honorariums**
- 28 **President's Club**
- 30 **ET Support Groups**

Features

- 14 **Feature** Young Singer/Songwriter Encourages Others to Look Past Differences and 'Look at the Heart'



On the Cover:
16-Year-Old Matthew Peterson aspires to be a composer and he's well on his way. He is one of four in his immediate family diagnosed with essential tremor.



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.

Differentiating Essential Tremor from Parkinson Disease

By Kelvin L. Chou, MD and Kara Wyant, MD

You sit down at a table, ready to address envelopes so that you can send out holiday cards, when you notice your hand shaking while writing. The shaking fluctuates over the next few months, but instead of going away, appears to be worsening. You start doing searches on the internet to see if you can figure out what is going on and read about two common tremor disorders, essential tremor (ET) and Parkinson disease (PD). You wonder which of these conditions you might have. This article discusses the differences between ET and PD and describes general patterns that help doctors distinguish ET from PD.

Before outlining the clinical features of ET and PD and differences between them, it is important to realize that there are two types of tremor: rest and action. A rest tremor occurs in a body part where there is no muscle contraction or activity. If the rest tremor occurs in a hand, it would thus be noticeable when the hand is relaxed in the lap and go away when the hand is in use. In contrast, an action tremor occurs in a body part where there is muscle activity, such as with maintenance of posture (i.e. tremor in hands/arms when holding the hands straight out in front of the

body or in a plank position) or with movement (i.e. tremor in hands/arms when eating or drinking).

What is ET?

ET is the most common tremor condition in the world, and is characterized by an action tremor affecting both hands and sometimes the head and/or voice. This tremor progresses slowly, and may be present for many years, even decades, before it is ever bothersome. The level of disability from ET varies from person to person. Some may have mild tremors that are more of an annoyance and do not cause problems. Others may have severe tremors that interfere with daily tasks such as writing, typing, using a mouse, applying makeup, eating (especially soup or cereal), or drinking from a glass of water. Communication may also be impaired because of voice tremor. In many cases, the symptoms of ET cause social embarrassment.

What is PD?

PD is a slowly progressive degenerative disorder. While it is common, affecting about 1 in 1000 people in the general population or 1 in 100 people over the age of 65, it does not occur as frequently as ET. There are three main motor symptoms of PD: tremor, bradykinesia (or slowness of movement) and rigidity (or stiffness). The typical tremor of PD is a rest

tremor, opposite of the tremor seen in ET, and will improve or go away with action. However, the defining symptom of PD is actually not tremor, but bradykinesia, which can cause slowed and/or decreased movement. Bradykinesia contributes to many of the clinical features of PD, such as a decrease in facial expression or a shuffling character to the gait.

Differences between ET and PD

Based on the above descriptions, it seems like it should be fairly easy to tell the difference between ET and PD, but this is not always the case. ET patients may have rest tremor in the hands in addition to action tremor, while PD patients may have action tremor in the hands in addition to rest tremor. This tends to occur more often when the tremors are severe. Therefore, doctors use other features on examination to help differentiate the two disorders.

First, the tremor in PD typically starts on one side and spreads to the other side after a few years. The side that is initially affected usually remains the most affected side throughout the course of the disease. In contrast, tremor in ET usually affects both hands more equally at onset. ET may also cause a tremor of the head and voice. In PD, head tremor is rarely seen and the voice may be softer/

raspier, but not tremulous. Tremors in the legs/feet are uncommon in ET and more likely to occur in patients with PD.

Earlier in this article, bradykinesia (slowness of movement) and rigidity were highlighted as the main features of PD in addition to tremor. The bradykinesia of PD is often expressed as incoordination or weakness and affects fine motor tasks such as buttoning clothes, zipping up jackets, tying shoelaces, or typing. When affecting the legs, bradykinesia may cause difficulty standing up from a chair, shorter steps, dragging of the legs, or even “freezing”, where a person stops suddenly and is unable to move. Bradykinesia is not traditionally associated with ET, where the tremor itself causes difficulty with fine motor tasks.

There are several exam techniques that your doctor might do to help differentiate ET from PD. One of them is watching you write. Handwriting in PD typically becomes smaller and more cramped the more one writes, while the handwriting in ET is typically large and shaky (or sloppy). Drawing spirals or drawing a straight line can also bring out a tremor in patients with ET but not necessarily in PD. Since activity causes the tremors in ET, your doctor may have you perform specific actions, such as pouring water or



bringing a cup to your mouth. Your doctor may also suggest other tasks, such as saying the months of the year backwards, doing mental arithmetic, or walking down the hall, in order to bring out rest tremors.

MRIs are usually unrevealing in both ET and PD. However, an imaging test called “DaTscan” may help to separate PD from ET in difficult cases. For this imaging study, a radiolabeled dye is injected into a vein which binds to dopamine nerve cells in the brain. PD is characterized by loss of dopamine nerve cells, so a scan showing less dopamine cells would be more suggestive of PD, while a normal scan would be more supportive of an ET diagnosis.

Other differences between ET and PD include the observation that at least 50% of people with ET also

have family members who are affected. This percentage is much lower in people with PD (<10%). The symptoms of PD also tend to start when one is older, with an average onset between 65-70 years of age. ET can affect anyone at any age.

Summary

People are naturally concerned when they begin to have a tremor. While there are many conditions that can cause tremor, this article describes differences between two of the most common tremor conditions: ET and PD. It is important to remember that this article is for informational purposes and is not a substitute for a diagnosis from a doctor. In order to obtain a formal diagnosis, please consult with a neurologist, preferably one who specializes in movement disorders. 🌱



Download the flyer “ET vs Parkinson’s disease” from the IETF website at www.essentialtremor.org/free-downloads/

Genetic Concepts and ET

Who Gets Essential Tremor?

By Mitchell F. Brin, M.D.

ET occurs in all parts of the world. The highest prevalence rates reported are in Sweden and Finland. In the United States (U.S.), the estimated prevalence is 300 to 415 per 100,000 population. There is considerable variation in age of onset, and incidence rates increase with age, with onset most common after age 40.

A study in the U.S. by Dr. A.F. Haerer and colleagues found ET to be more prevalent in women than in men and more prevalent in whites than in blacks. Dr. A.H. Rajput, though, found incidence rates to be no different for men and women.

The hereditary nature of ET has been recognized for 100 years. Dr. M. Critchley noted in 1949 that sporadic cases occur, but there is a strong genetic determinant, with an autosomal dominant mode of transmission being most common. It is generally accepted that 35% to 50% of the cases of ET are familial. For the purposes of this article, ET refers to the category of tremor that has no known cause and can be inherited.

There are various ways that a disorder can be inherited or passed on within a family (pattern or mode of inheritance), including autosomal recessive, autosomal dominant, x-linked recessive or multifactorial inheritance.

Autosomal Recessive

In a recessive pattern of inheritance, an individual with the disorder has received two genes for the disorder, one from each parent. The parents are referred to as “gene carriers” and do not exhibit the disorder themselves. Recessive disorders tend to be more common among specific ethnic groups; classic examples are Tay-Sachs disease among Ashkenazi (eastern European) Jews and sickle-cell anemia among blacks.

Autosomal Dominant

In a dominant pattern of inheritance, an individual has

inherited the gene for the disorder from one of the parents, and this is sufficient to cause symptoms. If a disorder is dominant, many or few family members can be affected since each has a 50/50 chance of inheriting the gene. The disorder may be passed on from parent to child to grandchild, and thus continue for many generations. It is also possible for a dominant gene to be expressed in different ways so that some family members can be more severely affected than others.

When a dominant gene “skips a generation” or is passed on by an individual who shows no symptoms of the disorder, this is referred to as non-penetrance. The unaffected individual can have affected children. Some well-known examples of dominant disorders are Huntington’s disease (Woody Guthrie died with this) and neurofibromatosis (the so-called Elephant Man’s disease).

X-linked Recessive

An unusual pattern, with x-linked or sex-linked inheritance, males are typically affected by the disorder and unaffected females are carriers of the gene that is on the X (sex-determination) chromosome (females carry two X chromosomes, males have one X and one Y chromosome). Examples of x-linked disorders are hemophilia and muscular dystrophy.

Multifactorial Inheritance

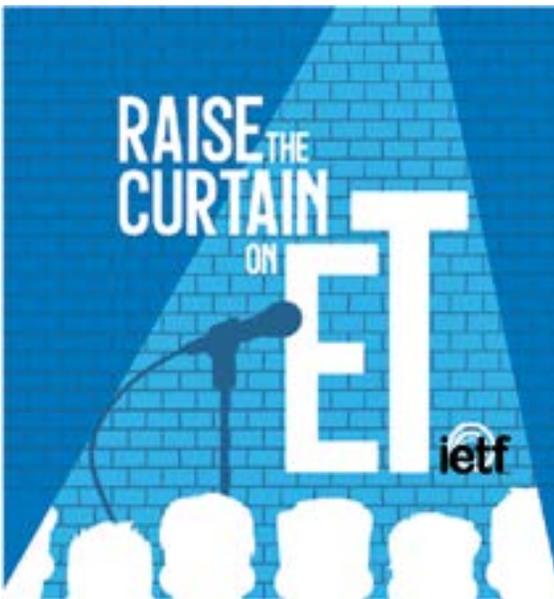
One other pattern of inheritance is multifactorial inheritance, which means that many factors, both genetic and environmental, can combine together to cause a disorder.

Many patients with ET have no family history of tremor. These are called sporadic occurrences, and may reflect either the first time in a family that the gene is being expressed or a mutation or change in the genetic material. Other possibilities are that relatives who may have carried the gene for tremor died too young to show signs, or perhaps tremor was very mild in ancestors, was never diagnosed, or simply never discussed. 🍷



March is National Essential Tremor Awareness Month

Shaking is a part of life for millions of Americans who have essential tremor (ET), and millions more around the world. But often times it's misunderstood, misjudged and even misdiagnosed.



Awareness and education are so important if we, as an ET community, want to move forward in the search of a cause and cure for ET. How? Join us in March to “Lift the Curtain on ET” during National Essential Tremor Awareness (NETA) Month. This is the theme for our 2020 awareness campaign. We want to put essential tremor center stage and shine a spotlight on it to emphasize the impact it has on daily life. We want the public to understand it. We want scientists to focus on it. We want to empower those who have it to step out onto the stage and educate others.
(Continued on next page)

MARCH
National Essential Tremor Awareness
MONTH
EssentialTremor.org

How Did NETA Month Begin?

In 2007, under the leadership of former Executive Director Catherine Rice, the IETF set out with a plan to bring greater awareness to this unknown and silent condition called essential tremor. We took our fight directly to Washington D.C. We knew if we could get official recognition of the condition on a national level, if essential tremor was viewed as a serious neurological condition affecting a significant portion of the population, then we could set a precedent for future advocacy efforts.

Rep. Dennis Moore (D-KS) met with Catherine directly at his office in Overland Park, KS (which is also the home of the IETF). He personally knew someone, a close friend, who was really struggling to cope with essential tremor. He was moved by the mission of the organization, the passion of the community, and his firsthand knowledge of how essential tremor can impact someone's life. In the spring of 2010, Rep. Moore introduced House Resolution 1264 to officially recognize March as National Essential Tremor Awareness (NETA) Month.

By December, 53 co-sponsors in the House signed on and the IETF had gained enough support to bring the bipartisan resolution to the full House for a vote. It had taken three years of meetings and conference calls and discussions to get the resolution to the House floor and it was an amazing accomplishment when it finally passed. It was then that March officially became National Essential Tremor Awareness Month.



National Essential Tremor Awareness Month resources are available at www.essentialtremor.org/awarenesstools/



(Continued from previous page)

MARCH is National Essential Tremor Awareness MONTH EssentialTremor.org

Get Involved in Raising Awareness about ET

- Post messages about NETA Month on Facebook and Twitter or share the posts from the IETF.
- Replace your Facebook and Twitter header and cover photos during March with the new NETA Month banners. You can download them from the IETF website, www.essentialtremor.org/awarenesstools/.
- Send a donation to the IETF in honor or memory of someone you know. Honorariums and memorials will be posted on the IETF website.
- If you or someone you know has ET, arrange to be a guest speaker at a local school or community meeting to increase ET awareness.
- Order a FREE Essential Tremor Awareness Poster. Offer it to your physician to display in his/her office or take it to your office, local library, community center or other public place. Orders can be placed online at www.essentialtremor.org/awarenesstools/.
- Make a \$30 donation to the IETF and receive an NETA Month t-shirt you can wear during March and all throughout the year to educate people about ET. Or make a \$50 donation and receive both the t-shirt and IETF tote bag.
- Host a Facebook fundraiser to raise both awareness of ET and funds for the IETF to support education and awareness activities all year long.
- Start a support group in your area.

Order a FREE Essential Tremor Awareness Poster (right) and offer it to your physician or display it at your office, local community center or other public location to raise awareness.

(Below) Donate \$30 to the IETF and receive this NETA Month t-shirt. For a \$50 donation, you will receive both the t-shirt and tote bag.



www.essentialtremor.org/awarenesstools

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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