Musician Terri Hendrix Gets Vocal About Her Challenges with Tremor

How Common is ET?

Join Us to Raise Awareness About Essential Tremor
The staff and board of the IETF hope you and your family had a happy and safe holiday season.

We shared a story in our October issue about revisions in our annual research grant program. Because of two generous donations from the Richard B. Peters and Lillian and David Courtheoux estates totaling over $2.1 million, we have increased the annual amount of the research grant to $150,000 the first year with the potential for $100,000 in funding for years two and three of the project based on results in annual progress reports. We are excited to announce we received 18 Letters of Intent (LOI) for the research grant. The LOI’s are being reviewed by members of our medical advisory board to determine which projects will be invited to submit full applications for the grant. We will keep you updated on this process as we move forward. (You can read more about each of these generous donors in this issue on pages 20-21).

We continue to add to our virtual events through our podcast series and virtual education webcasts on our YouTube page. To date we have shared six webinars, which have been viewed more than 43,000 times. We have posted 15 podcasts which have been downloaded more than 5,500 times. (To give you an idea how many people we reach with these virtual events, an average in-person ET Education Forum averages 100-125 people.) As soon as it is safe to do so we will start planning our in-person education events around the country so we can connect personally with all of you in the ET community. To access our 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, Insightec, Sage Therapeutics, Boston Scientific, Praxis Precision Medicines, Jazz Pharmaceuticals, and Cala Health for their support of these programs.

The IETF awarded four scholarships for the spring 2022 semester. Profiles of the four recipients are included in this issue of Tremor Talk and featured on our website. The deadline for the fall 2022 semester is May 1. If you know anyone with ET heading to technical school, community college, a four-year institution, or working on an advanced degree please encourage them to apply for our scholarship. November 30 was Giving Tuesday and for the past several years the donations received through this program help fund the Catherine Rice scholarship fund. This year we raised more than $5,600 thanks to your generous contributions.

Starting in the first quarter of 2022 you will be seeing a lot of information about upcoming clinical trials for ET specific medications from several of our pharma partners. If there is a clinical trial in your area you could be contacted via email or mail (depending on your contact preference) about potentially participating in one of these trials. We hope you will respond to these requests to help discover new ET specific treatment options.

We also want to thank all our support group leaders who are continuing to meet virtually during these crazy times. If you have a support group in your area, we encourage you to join. If you don’t, we also have our online support group through Facebook. Just look up Essential Tremor Awareness Group and ask to join.

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 (by emailing info@essentialtremor or calling 888-387-3667) so we can update our records and stay in touch.

Sincerely,

Patrick McCartney
Executive Director, IETF
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On the Cover: Musician Terri Hendrix believes it’s important to be your own advocate when dealing with a medical condition like vocal 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.

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.

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.”
How Common is Essential Tremor?

1,000 New Cases Arise in Americans Age 65 and Older Each Day

Elan D. Louis, MD, MS,
Department of Neurology, University of Texas Southwestern Medical Center, Dallas, Texas

One question my patients with essential tremor (ET) often ask me is “how common is essential tremor?” Knowing the answer to this question is important because it helps patients place what they are experiencing into some sort of larger context.

To answer this question, I go to the scientific literature for the answer. In a paper by Louis and McCreary published in 2021 in Tremor and Other Hyperkinetic Movements, the authors reviewed data from each of the 42 published population-based epidemiological studies of ET. These 42 studies were published over a 60-year period, from 1960 to 2020, and provided data from 23 countries in six continents on the “prevalence” of ET (i.e., the percentage of people in a given population who have ET).

The paper used two methods to analyze data from these 42 studies. Using one method, they calculated that 1.33% of all people of all ages have ET; using the second method, the values they obtained ranged from 0.4% to 0.67%. To simplify, if one combines these values from each method, then a “take-home” message is that approximately 1% of people, including people of all ages, have ET.

This information is of value; however, we all know that the chances of developing ET increase with age, and the same epidemiological studies tell us that the bulk of patients who have ET are age 65 and older. In the same paper, Louis and McCreary again used two methods to analyze data from the 42 epidemiological studies, and found that 5.79% to 8% of individuals age 65 and older had ET; and that in older age groups (e.g., individuals in their 90s), several epidemiological studies had reported that 20% or more had ET. The paper also noted men and women were equally likely to develop ET. This value, 5.79% – 8% of individuals age 65 and older, should be placed in a broader context. This value is similar to and even somewhat greater than the percentage of people in a similar age group who have Alzheimer’s disease (4.8%), indicating the high prevalence of ET.

Above, we have been discussing the percentage of people who have ET; however, we have not been discussing the actual number of people who have ET. What is that number? In an earlier study, published in 2014 in Tremor and Other Hyperkinetic Movements, Louis and Ottman used data from all available epidemiological studies to estimate the number of individuals in the United States who had ET. Their estimate ranged from 6.38 million to 7.63 million (average = 7.01 million), meaning that approximately 2.2% of the entire US population has ET. These are remarkably high numbers and percentages.

These numbers are significant, but they are not the only numbers that underscore the high disease burden ET carries. Above, we discussed “prevalence”, which is the percentage of people in the population who have ET. Another epidemiological term is “incidence”. This is the number of people who develop ET each year. It is a measure of the rate at which new ET cases are arising on a yearly basis rather than the number of patients who currently have ET. A population-based study of the incidence of ET was conducted in Spain on 2005 among persons age 65 and
older. In that study, the authors reported that among persons age 65 and older, 616 per 100,000 developed ET each year. Stated in another way, one would expect 616 new ET cases arising each year among each 100,000 individuals in the population age 65 and older. There are approximately 55 million Americans age 65 and older. If 616 new cases are expected each year for every 100,000 of these, then approximately 333,000 new ET cases would be expected to arise each year among the approximately 55 million Americans age 65 and older. This is equivalent to 27,750 new ET cases per month or 925 new ET cases per day. Another “take home” message is that we can estimate that approximately 1,000 new ET cases arise in Americans age 65 and older each day.

Now we return to the initial question. How common is ET? It is very common. Data on the prevalence and incidence of ET are important. They serve to underscore how common ET is and how many people it affects in the population – indeed, ET is a medical issue with significant human and public health impact. An ET patient is not alone. Armed with this knowledge of the high prevalence of ET, physicians and scientists are better positioned to convince funding bodies of the value of ET research. Such research is needed in order to better understand the causes of ET and to eventually devise more effective treatments.

References


Louis ED, Ottman R. How many people in the United States have essential tremor? Deriving a population estimate based on epidemiological data. Tremor Other Hyperkinet Mov 2014; 14; 4:259 doi: 10.7916/D8TT4P4B.


Correspondence: Elan D. Louis, MD, MS, Department of Neurology, University of Texas Southwestern, 5323 Harry Hines Blvd, Dallas, TX, 75390-8813 USA. Email: elan.louis@UTSouthwestern.edu
By Katie Sale,
Executive Director,
American Brain Coalition

The Brain Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative was established in April of 2013. The BRAIN Initiative ultimately aims to help researchers find new ways to treat, cure, and prevent diseases of the brain. The BRAIN Initiative is a collaborative effort among many government agencies and private sector partners.

The goal of the Initiative is to develop and apply new tools for understanding how neural circuits underlie complex behaviors in health and disease. To do so, the BRAIN Initiative leverages emerging technologies, uses these discoveries as the foundation for therapeutic strategies, and disseminates and democratizes these technologies for discovery and clinical applications.

The 2019 BRAIN 2.0 strategic report encouraged the National Institutes of Health (NIH) to stay on its current trajectory but also urged the balancing of individual-investigator research with team science, enhancing integration of neuroscience with neuroethics that considers broader societal implications, and devoting ample resources to transformative projects. One transformative project funded by the BRAIN Initiative is the development of a “parts list” and “wiring diagram” for the “marvelously complex computer,” the human brain. The “parts list” project is the brain cell census focusing on the human brain with a targeted launch in FY22 and the “wiring diagram” is to create a connectivity map for an entire mammalian brain with an intended launch in FY23. To help leverage these resources, the BRAIN Initiative is developing tools for cell access in rodent and non-human primate brains and in human brain tissue with a long-term goal of new therapeutic strategies for human brain disorders.

A BRAIN Initiative movement disorder example is the development of a prosthetic device that allows a paralyzed patient to communicate with the outside world by thinking of letters and turning that into written text – typing at a rate of 90 characters per minute with 95% accuracy. Another movement disorder example is adaptive deep brain stimulation devices for Parkinson’s disease patients with fully implanted devices, wireless streaming of information, and identification of biomarkers that can instruct the stimulator to intervene but only when there is improper movement, potentially reducing side effects of deep brain stimulators that are always “on.”

The International Essential Tremor Foundation is a member of the American Brain Coalition, a community of patient advocates and professionals engaged in advocating for BRAIN Initiative federal funding. The American Brain Coalition is proud to have recently become the newest member of the BRAIN Initiative Alliance. Comprised of federal and non-federal members and affiliates, the BRAIN Alliance mission is to coordinate and facilitate communications from its members related to the BRAIN Initiative.

IETF will continue to keep our members updated on the advances of the BRAIN Initiative, and will reach out on advocating opportunities as they arise. 🌟
The IETF records educational programs you can watch and listen to from home.

**Diagnosis & Treatment Options for ET, Parts I & II**  
This two-part program focuses on the pathogenesis of essential tremor, genetic factors, diagnostic techniques, plus surgical and non-surgical options.

**Coping with the Physical and Emotional Effects of Essential Tremor**  
Learn about coping strategies, useful techniques and devices to help manage essential tremor.

**Essential Tremor: Pediatric Onset**  
Dr. Keith Coffman, director of the movement disorders clinic at Children’s Mercy Hospital, talks about the presentation of ET in children.

**The Development of CAD-1883 through Proof-of-Concept in Essential Tremor**  
Tim Piser, with Novartis, talks about the company’s development of CAD-1883 for the treatment of ET.

**Tremors, Quakes and Shakes of the Voice**  
Gain an understanding of vocal tremor and spasmodic dysphonia through this presentation by Dr. Michael Johns, director of the voice center at the University of Southern California.

**Exploring New Therapies for Essential Tremor**  
Gabi Belfort, M.D., Ph.D., VP, clinical development sciences at Praxis Precision Medicines, talks about a new investigational medication for essential tremor, PRAX-944.

Find all our virtual education events online at: https://bit.ly/ETEducationVideos
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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