Adam McKay: A Storyteller’s Tale

Who was The Tremulous Hand of Worcester?

IETF Funds New Research

Essential Tremor & Alcohol
Thoughts from the Executive Director

This issue of Tremor Talk focuses on research, one of the most talked about topics from the ET community.

The IETF mailed our research appeal in July with a goal of raising $35,000 by the end of September. One hundred percent of every dollar donated to research goes to finding the cause of and hopefully someday a cure for ET. Since 2002, the IETF has funded more than $1 million dollars in research grants. To learn more about the grants we have funded visit www.essentialtremor.org/Research.

We have currently received a $28,500 in research donations. If you have donated, I thank you for your generosity and support. If not, I hope you will consider supporting research. Donations can be made online or if you did not receive your appeal, contact our office, and we will drop one in the mail to you.

Also in this issue, we are excited to feature Academy Award winner Adam McKay. Adam has struggled with ET since his early 20’s, but it hasn’t stopped him from becoming one of the most accomplished writers and directors in Hollywood. Adam has become a good friend of the IETF, and we are looking forward to building our relationship with him and benefiting from his capacity to educate and raise awareness.

The IETF is pleased to welcome a new addition to our staff. Dawanna Fangohr joined the IETF in July as our finance and database manager. Carol Rucker has retired after eight years with the IETF. Carol was a great help to me in my transition as the new executive director and will be missed. Dawanna brings a strong background in database management and accounts payable and receivable. Dawanna will probably be the first person you talk to when you call our office. Please welcome her to the IETF.

In a continuing effort to raise awareness and help educate you about your ET, I encourage you to save the date for the next ET teleconference at 4:00 p.m. CT on Thursday, October 13. Our topic will be coping techniques for ET, and our speaker will be Kelli Reiling, OT. Kelli received an undergraduate degree and post professional doctorate degree in occupational therapy from the University of Kansas. She has practiced for 23 years in a variety of settings which include acute hospitalization, inpatient rehabilitation, sub-acute hospitalization, outpatient rehabilitation, skilled nursing, and community-based practice.

As always, there is a lot going on at the IETF. But none of this happens without your support. We love to hear from you so please feel free to contact us with any questions, concerns, or ideas you might have.

Sincerely,

Patrick McCartney
Executive Director, IETF
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Adam McKay brings some serious star power to the ET community

Cover & above: Adam McKay. Photo credit: Miller Mobley. ©2015 PARAMOUNT PICTURES.

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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 info@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.
2015: The Year in Review

The mission of the IETF is to provide global educational information, services, and support to children and adults challenged by essential tremor, to their families and healthcare providers, as well as to promote and fund ET research. Each year the Foundation produces an annual report to inform donors, volunteers, stakeholders, and the general public about the Foundation’s accomplishments over the last 12 months and give an overview of the financial health of the organization. The IETF’s 2015 fiscal year (FY) spans from April 1, 2015 through March 31, 2016.

According to Charity Navigator, an independent charity watchdog group which evaluates charitable organizations in the United States, nonprofit organizations should spend no more than 25% of their total expenses on administrative overhead and fundraising costs combined. In FY2015, overall management and fundraising expenses for the IETF were just 20%, down slightly over last year. That means $.80 out of every dollar given as an annual donation goes directly into the programs and services provided by the IETF. Donations designated for a specific campaign, such as research, are considered “restricted”. One hundred percent of these restricted gifts go to the program designated by the donor.

In addition to a decrease in overall administrative expenses, expenses associated with IETF’s programs and services also decreased. FY2016 saw a change in the IETF’s educational methodology, placing greater emphasis on patient accessibility rather than total number of seminars hosted. In previous years the IETF had hosted up to 25 seminars around the U.S., costing tens of thousands of dollars per event. We now host three to four regional seminars annually, bringing in exhibit sponsors to help offset costs. It’s a win-win for everyone; sponsors can present their wares to a very targeted audience, attendees can learn about products and services which may enhance their quality of life, and the Foundation furthers its mission without increasing expenses.

But with the decrease in the number of seminars, it was feared too many people would miss out on the quality information only the IETF can provide. In order to allow more people access to the information they need to make good choices for their health, the IETF introduced an educational telephone conference series, much to the delight of our constituents. With no computer access or Internet needed, telephone conferences offer people the chance to take part in an educational seminar without ever leaving home. This is a great option for those who may have mobility problems, limited access to transportation, or who live in rural communities or communities outside of the United States. At just a fraction of the cost of an in person seminar, the
teleconference model allows the IETF to increase the number of people served, while substantially decreasing expenses. Program expenses dropped 20% over last fiscal year due in large part to this change.

One of the most interesting (and concerning) trends we see in the financial reports is the decline in the actual number of donations made. For reference, in FY2013 the IETF received 5,718 individual donations. In FY2014, that number dropped to 5,527. In FY2015, the total number of gifts dropped again to 4,772. This is a 17% decrease over three years. However, we also noted the average gift amount was increasing. So although the total number of donations is going down, the amounts of those donations are going up. This tells us we need to put greater emphasis on finding new people and donors to add to our community, while continuing to offer superior service and support to those who have been with us for years.

In order to find new people and new donors to help sustain us in the future, the IETF utilizes numerous tools and technology to reach people around the world. One of the best tools in our arsenal is the IETF website, essentialtremor.org. Website traffic was up 29% over last year and more than 77% of that traffic was from new visitors. New information is posted all the time, keeping pace with the ever changing world of ET research, news, and technology.

Social media is another way the Foundation reaches new audiences. Utilizing Facebook, Twitter, Google+, and YouTube, the IETF brings people together through a variety of communication avenues. People can choose how they prefer to interact with us; whether it’s a tweet, post, a phone call, or snail-mail letter, the IETF will be there to facilitate stimulating conversations and offer accurate and timely information. As each of our social networks grow, so does our reach. Today, we are in a very good position to reach the next generation of ET patients.

Please visit the Annual Report section of our website at www.essentialtremor.org/about-the-ietf, to read the full report and review past reports. You will learn exactly how the IETF brings hope to those affected by essential tremor; through programs and services which promote awareness, patient and healthcare provider education, the funding of critical research, and offering quality support to everyone who needs it. You will learn how the financial support of caring and compassionate people like you will help move the IETF forward into the future and beyond. ☺
Supporting the future - Fall 2016

Each semester, the IETF awards scholarships to qualified post-high school students of all ages, anywhere in the world, to lessen the burden of higher education. Scholarship can be used for supplies, books, or tuition at licensed, accredited institutions of higher education (including trade schools).

This is not our first time meeting Jack Peters. He is an old friend of the IETF, having been featured in the IETF’s Fall/Winter 2010 issue of Tremor Talk magazine at the ripe old age of 12. We’ve been privileged to watch Jack grow up, as his mom always kept the Foundation up-to-date on how Jack was doing up in Redgranite, WI.

Jack has always been open about his tremor with friends and family, and he looks for opportunities to raise awareness about the condition. “One of my teachers, who also has ET, suggested we put an informational presentation together for the class,” Jack said. “It was very well received.” His classmates and theater friends all know about his ET and are very accepting of both his abilities and his limitations.

And even though moving away in the fall to attend the University of Wisconsin-Stout (Wisconsin’s Polytechnic University) will mean starting over, Jack doesn’t see it as a problem. “I see my tremor as an opportunity,” he said, “an opportunity to inform other people about me and the millions of other people around the world who also have ET.”

Austin Siekkinen is a scholar-athlete who ranked in the top quarter of his high school class in Hobbing, MN. He participated in several varsity level sports throughout high school and was a member of a variety of academic clubs. He volunteered during the summer, helping local kids develop a love for sports and sportsmanship. He even managed to hold down a part-time job. “This shows how he is able to juggle many responsibilities and still be successful at them all,” noted Laurie Allison, Austin’s high school English teacher.

Austin doesn’t allow his ET to hold him back. Although he might struggle to keep the cereal on his spoon before a hockey game or hit the correct app icon on his iPad, his determination and positive attitude will carry him far.

The IETF is pleased to offer Austin an academic scholarship to North Dakota University where he will continue his education in engineering.
Katie Merrill is passionate about art and ET awareness. Having essential tremor has forced Katie to think creatively, to develop innovative solutions to her own artistic problems. As a digital arts student at Kansas Wesleyan University in Salina, KS, Katie had to figure out how to film and photograph her subjects, despite her shaky hands. She uses plastic shopping bags to hold her camera, using its own weight to steady the lens. “You hold the handles of the bag and the weight of the camera helps steady it,” Katie explains, “I call it the Dillon’s-Bag Steady Cam”.

And through her art, she strives to create awareness. She has already completed one project that offered viewers a photographic representation of how ET impacts daily activities and wrote an editorial article for the school newspaper during National ET Awareness Month. Earlier this year, she even gave a humorous yet informative speech on ET and was awarded first place at the National Pi Kappa Delta Speech and Debate Finals in Kentucky.

Essential tremor can cause a fair amount of frustration for anyone, but Katie refuses to let it get the best of her. “I run into an array of problems,” she said, “but there is no problem that has been thrown at me that I haven’t been able to solve yet”. This is Katie’s second IETF scholarship. With her can-do attitude and creative thinking skills, she will definitely go far.

One winter day when school was called off due to poor weather conditions in Cincinnati, OH, Jackson Burton decided to learn how to play Pink Floyd’s “Wish You Were Here”, including the intricate and complex guitar solo. He spent hours focusing on hitting the right cords with the right inflection. His trembling hands made this already difficult task even more challenging. In the song, Roger Waters expresses feelings of alienation and mistrust of those around him. This was something to which Jackson could definitely relate.

Jackson used to get terribly embarrassed when he was called to the whiteboard to write out the solution to a math problem, or when he was instructed to point out a specific location on the big wall map. It took a lot of introspection for Jackson to come to terms with his shaky hands. “I had to be humble,” remembered Jackson, “I had to realize that my friends and classmates were not there to persecute me, but to support me.” He made the choice to respond to their inquiries about his shaking hand in a more positive way; using humor as an ice breaker and a way to make new friends.

As he enters his freshman year at the University of Cincinnati, he will build on the determination and self-confidence he used to learn new songs and make new friends. The IETF is delighted to assist him on his journey.

Katie Merrill

Jackson Burton
IETF Funds Three New Research Studies

Each year researchers with an interest in studying the various aspects of essential tremor are encouraged to submit scientific proposals for grant funding from the IETF. Below are the three studies funded by the IETF in July 2016. The IETF only seeks proposals addressing the nosology, etiology, pathogenesis, or treatment of essential tremor, or other relevant topics. To date, your donations have provided more than $1 million in ET research funding.

Your research donation could make the difference between critical research being funded, or being turned away. Every donation, no matter the size, counts. It’s not too late to help us keep research moving forward, please make your research donation today!

Double-blind, Placebo-control, Cross-over Trial of Cannabidiol for Essential Tremor

Principal Investigator: Dr. Fatta Nahab, University of California, San Diego

A critical need exists to identify possible treatment options that produce less negative side effects and can be brought to market quickly. Dr. Nahab has found a significant number of his patients experiment with alternative therapies, due to their dissatisfaction with the current medications available. However, over-the-counter options and those perceived as “natural”, have little or no data to support their safety or efficacy.

In this study, Dr. Nahab will investigate a specific cannabinoid (CBD), one of the many chemicals in marijuana. The central hypothesis is CBD will reduce tremor amplitude while being well tolerated and safe for patients. Dr. Nahab’s hypothesis has been formulated on the basis of his team’s own preliminary data and in consultation with Dr. Adrian Handforth’s group, which is actively studying cannabinoids in the Harmaline model of ET. Dr. Handforth’s research was funded by an IETF research grant in 2015. Results obtained from this study will provide the critical knowledge needed in order to request additional funding from the National Institutes of Health (NIH) for a drug development program of CBD for ET and develop more targeted medications.

Application of Smartphones/Smartwatches in Diagnosis and Treatment Monitoring of Essential Tremor

Principal Investigator: Prof. Gregor Kuhlenbäumer, Kiel University, Germany

The analysis and quantification of tremor is achieved by using a tremor measuring
device called an accelerometer. However, accelerometry is not widely available, and only a few centers have them. Modern smartphones usually contain three sensors which might be suitable to analyze tremor: (1) an accelerometer, (2) a gyroscope, and (3) a magnetometer. The data from these sensors can be used to aid in the diagnosis of tremor disorders and to monitor tremor treatment.

The aim of this proposal is to test a variety of smartphones, to see if they can accurately measure tremor in ET patients and assist in their treatment. Smartphones are available to most people and could provide short-term tremor measurements. It is well known tremor intensity fluctuates from day to day and during the day. Therefore, accurate self-monitoring of tremor might be helpful to physicians assessing treatment options and effects.

Norepinephrine’s Effects on the Cerebellum and Role in Tremor  
Principal Investigator: Dr. Esther Krook-Magnuson, University of Minnesota, Minneapolis

Propranolol is a beta-blocker and is the most widely used medication for the treatment of essential tremor. Dr. Krook-Magnuson’s hypothesis is propranolol’s actions are centrally located, working on a region of the brain known as the cerebellum, and slowing the amount of norepinephrine released. Norepinephrine is a neurotransmitter. Think of it as a city bus that moves information from the brain to various locations/stops in the body. Propranolol slows the bus down during its travels, helping keep your hands more steady. But Dr. Krook-Magnuson proposes if we can influence our norepinephrine bus where it is built, in the nuclei of the brain known as the locus coeruleus, rather than when it’s cruising through the body, it will reduce tremor.

Further, she proposes the effects of norepinephrine on tremor depend on the dose — specifically, she believes it will have bidirectional effects. In other words, the levels of norepinephrine introduced at the factory could cause our norepinephrine bus to come flying out of the gate like a bullet train or slowly head out at more of a Model T pace. Either way, the findings from this proposal would resolve the controversy surrounding propranolol’s location of action in the brain and provide new options to help reduce tremor.

Visit www.essentialtremor.org/research/ietf-funded-research for more information on past IETF funded studies.
The Human Motor Control Section (HMCS) is my research unit in the Intramural Program of National Institute of Neurological Disorders and Stroke (NINDS). The Intramural Program of a National Institutes of Health (NIH) is the part of the institute which conducts research in Bethesda, MD. Our main goal is to understand the pathophysiology (changes associated with or resulting from disease) of different movement disorders and, if appropriate, to translate findings to therapies. ET research has been one of the major activities of the HMCS. Some of our current projects are described here.

One confusing issue is exactly how ET is defined. While there are clinical and research definitions available, everyone agrees they have problems. In order to understand anything about a disorder, the patients studied must all have the same condition. If the definition is not sufficiently refined and the subjects really have different disorders, the chances of finding answers are much less. This is particularly true in the field of genetics. While ET often looks like it is transmitted by a powerful autosomal dominant gene, where about 50% of an ET patient’s descendants may develop ET themselves, it has been very difficult to find any gene mutations. We have been studying families for some years trying to find causative genes. Like everyone else, we have largely failed.

In relation to genetics, the methodology is also advancing. In the past we have used a technique called linkage analysis. Linkage is the tendency for genes and other genetic markers to be inherited together because their location is near one another on the same chromosome. However, this analysis is limiting and the results can be misleading. We are currently using a method called “next generation sequencing”, to determine the genetic basis of ET. Whole genome sequencing (the process of determining a complete DNA sequence) and whole exome sequencing (technique for categorizing all the information created in a genome) will help us better understand how genes play a role in the development of essential tremor. Utilizing this strategy, we hope to finally see more success in finding the culprit gene(s).

We know one ET look-alike is exaggerated physiological tremor; that is, normal tremor worsened by factors such as caffeine use or anxiety. There are clinical neurophysiology tests that can usually distinguish between ET and exaggerated physiological tremor. We now utilize these in our studies so we exclude subjects with exaggerated physiological tremor.

Another confusing issue is dystonic tremor. Dystonia is a condition involving involuntary muscle contractions, which lead to abnormal postures of body parts. Patients who have dystonia may also have tremor, and this tremor often looks like ET. Moreover, families of patients who have ET often have family members who also have dystonia. So there is some relationship there but certainly some differences. We are now engaged in a relatively broad study to try to identify similarities and differences between dystonic tremor and ET. We are studying patients who clearly have one or the other. Studies include Tremor characteristics, voluntary movements, response to brain stimulation, sensory function, and neuroimaging. In these studies, we will likely learn more
about the genesis of ET as well as seeing its differences with dystonic tremor.

A major effort has been devoted to therapeutic development. A basic issue in this field is how tremor is measured. It is necessary, of course, to have a good measurement technique to know whether a particular therapy has been beneficial. We have studied different methods of tremor assessment including a scientific measurement of spiral drawing. These studies have been valuable, but a problem with measurement has always been the variability of ET over the course of a day. Hence, a single time point measure might not capture the best measure of severity. In this regard, we are also piloting some devices such as wearable movement sensors for long term monitoring of tremor – that is, over several days at a time. Such measurements should, theoretically at least, be the best way for a physician to make a tremor assessment.

The oral “therapy” which is most effective for ET is ethanol, an alcohol with two carbon atoms. However, not everyone reports they respond, so this is another inconsistent feature in ET patients that is not wholly understood. Ethanol has many interactions, so it is not clear how it works when it works. In a project led by Dr. Dietrich Haubenberger, who is actually now leading all the work on ET done in the HMCS, we have tried to identify which patients respond and which don’t. His results show virtually all patients do respond, but there is some variability in the amount of response. Interestingly, there is little correlation between patients’ impression of their response and their actual response. The next stage of this investigation is to understand the mechanism of response when it occurs, and those studies are just getting started now.

It had been demonstrated some years ago that one possible means of ethanol action might be to influence a particular mechanism in a part of the brain called the inferior olivary nucleus. Studies of this mechanism in animals showed other alcohols, with more carbon atoms, had a stronger effect. Hence, it occurred to us that studies with these longer chain alcohols might be therapeutic without the ill effects of ethanol. We began our studies with octanol, an eight-carbon alcohol. Work over a period of years showed octanol could be effective, as predicted. However, when we studied its metabolism in the body, we found it was rapidly altered to octanoic acid. Subsequently, we have studied octanoic acid, and the first studies in ET patients showed octanoic acid was safe and well tolerated, and has the potential benefit of tremor reduction. Unfortunately, at this time, octanoic acid breaks down too quickly in the body to be clinically practical. We are anxious, however, to pursue further studies and are awaiting development of better ways of formulating the octanoic acid so it can be taken like a regular therapeutic drug.

It is possible to dampen tremor in a body part with mechanical means. This has been demonstrated recently with the success of the Lifeware® spoon, which was
developed with NIH-support. Tremor of the arm is a complicated mechanical problem with multiple segments (upper arm, lower arm, hand, fingers), and hence to develop better mechanical damping, the details of the movements of all segments of the arm need to be measured and then modeled. We are now assisting Dr. Stephen Charles of Brigham Young University and his PhD student, Adam Pigg, to gather the kinematic data they need to do the modelling.

Many persons participate, and have participated in the past, in the HMCS studies. Dr. Dietrich Haubenberger, who is also a member of the IETF’s Medical Advisory Board, is now leading the ET studies at NIH. Dr. Camilo Toro has been working with us with spiral analysis and genetics. Dr. Lev Goldfarb is also working on the genetics. Dr. Pattamon (Oh) Panyakaew is doing the work on dystonic tremor compared to ET.

The NIH is a national resource, and we have had patients participate in our studies from all over the United States. We are grateful to them; clearly patients are crucial collaborators in our research studies. We cannot make progress without them.

Mark Hallett, MD, is the Co-Chair of the IETF Medical Advisory Board, and Chief of the Human Motor Control Section at the National Institute of Neurological Disorders and Stroke, part of the National Institutes of Health, in Bethesda, MD.
It is said laughter is the best medicine. But is it really? Does laughter have any real therapeutic benefit? If you laughed at the joke above, even a little, research says you just did something wonderful for your health. In a review of the available clinical data on the subject, Dr. Ramon Mora-Ripoll, medical scientific director at Organization Mundial de la Risa, in Barcelona, Spain, reviewed all the available scientific research to learn to what extent laughter benefits both physiological (physical) and psychological (mental) health.

In ancient times, philosophers such as Plato and Aristotle would not allow laughter during their teaching sessions, as they believed laughter clouded the mind’s ability to think logically, in addition to finding it morally objectionable. But laughter seems to have its origins much further back in our human history. Laughter is part of what makes us human. Both humans and apes (chimpanzees, bonobos, gorillas, and orangutans) laugh when tickled, suggesting laughter derived from a common primate ancestor. At just six weeks old, babies begin to smile and shortly after begin to giggle. So laughter is clearly a very primitive reaction to stimulus.

Today, researchers like Dr. Mora-Ripoll are trying to understand how this primitive reaction benefits the body and mind of modern man. Dr. Mora-Ripoll reviewed health-related laughter research from a wide variety of medical areas, from dermatology to dentistry, oncology to obstetrics, to determine what health outcomes directly relate to laughter. And the results are nothing to laugh about.

**Physiological Benefits**

Amusement, humor, and laughter have numerous positive effects on the body and impact a wide variety of systems: muscular, cardiovascular, respiratory, endocrine, immune, and central nervous system. The main impact of laughter can be described as having the following effects on the body:

- Laughter exercises and relaxes several muscle groups.
- Laughter improves respiration and may improve oxygen saturation levels.
- Laughter stimulates circulation. When combined with exercise, it may be effective in the long-term lowering of blood pressure.
- Laughter decreases stress hormones, such as Cortisol, which can increase sugars (glucose) in the bloodstream.
- Laughter increases the total leukocytes (white blood cells) in the blood, thus boosting the body’s immune system defenses.
- Laughter increases a person’s ability to manage and tolerate pain.
- Laughter increases mental function.

**Psychological Benefits**

How laughter impacts mood, behavior, and relationships has been studied much more extensively than how it impacts the physical systems of the body. Laughter is often used by people as a way to cope with difficult or uncomfortable stressors or as a means to enhance
personal relationships. When explaining essential tremor, many people will begin their description of the condition with a joke. Something like “I bet you didn’t know I’m James Bond’s personal martini assistant,” or “If I ever decide to go to medical school, I’ve already got the illegible handwriting thing down.” A quick quip seems to put everyone at ease and communicate to the listener you are okay and a deep level of concern is not really necessary ... and you can say it all with just a little joke.

The mental health benefits of laughter can be summarized as such:

- Laughter reduces stress, anxiety, and tension and relieves the symptoms of depression.
- Laughter elevates mood, self-esteem, hope, energy and vigor.
- Laughter enhances memory, creative thinking, and problem-solving abilities.
- Laughter improves personal interactions, relationships, attraction, and the feeling of closeness.
- Laughter increases friendliness and helpfulness, and builds a foundation for group identity, solidarity, and cohesiveness.
- Laughter promotes a general feeling of well-being.
- Laughter improves a personal overall quality of life.
- Laughter intensifies amusement and is absolutely contagious.¹

Types of Laughter
There are several types of laughter; however there are only two types that seem to directly impact health: genuine or spontaneous laughter, and self-induced stimulated laughter. Spontaneous laughter is beyond one’s control and is triggered by outside stimuli (such as a funny movie or a book of witty limericks). Self-induced laughter is triggered by the individual, without any outside stimuli required. Some people would say spontaneous laughter is “a real laugh” whereas self-induced stimulated laughter is a “fake laugh”. What is truly fascinating is the brain can’t tell the difference between these two types. Therefore, one can conclude the health benefits of laughter can be felt by those who belly laugh for real and by those who are totally faking it, in exactly the same way.

Further study is needed in this area to fully understand how the brain processes laughter, but laughter as a therapy has been gaining popularity in recent years.
Laughter clubs and laughter yoga are becoming more and more popular around the world, as people learn the remarkable benefits of laughing.

Modern science has somewhat dismissed laughter as real therapy because it is seen as a distraction, unprofessional, or a form of alternative medicine. But there seems to be real benefit in it. Plus, it is something pretty much everyone is capable of doing, without the need for any expensive equipment or pharmaceuticals. There are almost no negative side effects to laughter and there are only a handful of medical conditions which would make laughter inadvisable. So as long as you are not fresh out of surgery or force yourself to laugh so hard you pass out (laughter-induced syncope), you should be able to reap the very real medical benefits of laughter. And who knows, you might even make a friend or two along the way. 😊

References


How do you tell the story of a master storyteller?

I suppose we could start with the laundry list of accomplishments, titles, awards, and accolades.

We could cover his education or the theory behind the genius. But that really doesn’t tell much of a story.

So I guess, in order to tell his story, we have to start it like all good stories do ...
Once upon a time there was a young man with dreams and ambitions which far outweighed the structure and rigor of academic life. He had been bitten by the comedy bug early and wanted nothing more than to perform and make people laugh. So with less than a year left before graduation, the young man chose to leave university life behind and head out into the wide world on his own.

It took a bit for Adam McKay to find his way. In between odd jobs that helped pay the bills, he did stand-up and became a member of Chicago’s Improv Olympic group where he began to find his comedic groove. But all the while, on-stage and off, his hands shook. It was strange to him, even after he had done numerous performances and stand-up gigs, his hands still shook. It was just a little and it wasn’t a real problem, but it was curious. Adam didn’t feel nervous,
but he assumed nervousness must be the problem. So he worked even harder to be better prepared and keep himself steady.

At 26 years old, Adam was a member of The Second City, a well-known improvisational comedy group, best known as Chicago’s first ever on-going improvisational theater troupe. It was a good gig. He felt the electricity of the crowd, the excitement. He was prepared to absolutely kill ’em. But there he was, full of confidence under a blazing spotlight at a huge Second City premiere and his hands trembled. And it was more than just a little shake. Out of nowhere, his hands just trembled.

In the early 90s, Adam auditioned for Saturday Night Live. It was a big move and another great opportunity. But he didn’t make the cut. He was turned down as a performer, but they loved his writing. His writing was hysterically funny, yet timely and poignant; a difficult balance to find. He contributed some sketches, skits, and shorts before becoming SNL’s lead writer for three seasons. It was during this time, in around 2000, Adam decided it was time to learn more about his shaking hands.

As a writer for SNL, there was nothing to be nervous about. There was no live audience any more, no butterflies in the stomach, no spotlight. But yet his hands continued to shake. When he mentioned it to his doctor, at a routine appointment, his physician dismissed it as stress. There were tight deadlines and pressure, but this shake felt like something more to Adam. However, following his doctors instructions, he did what he could to help decrease his stress levels. He started to exercise regularly and take better care of himself. But again, the tremor never went away. It actually began to get worse.

As he was writing the script for the blockbuster hit Anchorman: The Legend of Ron Burgundy with Will Ferrell, Adam sought answers from a movement disorder neurologist. He was diagnosed with essential tremor. But at the time, he was so busy he didn’t have much time to think about what having essential tremor meant for him or for his future. He was given a prescription for a beta-blocker and told to have a cocktail during social situations, to help calm the shaking. The beta-blocker didn’t seem to help much, but the alcohol did.

Adam often wondered what was wrong with him. Why couldn’t he seem to get it together? He would look at all the talented and funny people around him and wonder how they all managed to be so steady, so calm, while he seemed to be completely losing it. The little voice in his head began to berate him with constant reminders of his inadequacies, and his shaky hands reinforced the voice. His thoughts became obsessive and negativity ruled his mind. His tremor was in control. He tried to hide the shake, but that only seemed to make it worse. He began to avoid social gatherings, allowing his tremor to dictate his social schedule. And in Hollywood, that’s not a good idea. Dinner parties are where business gets done and contacts are made. Adam was missing out on not only the social aspects of Hollywood life, but also on opportunities.
Internally he was seriously struggling. But on the outside his life seemed idealic. He had directed his second co-authored movie with Will Ferrell, *Talladega Nights: The Ballad of Ricky Bobby,* which opened at No. 1 at the box office and grossed more than $47 million in its first week. This should have been a time of great celebration, but for Adam, this is when it all came to a head.

At 35 years old and at the height of his career, he was drinking too much and happy too little. He knew he had a problem with his tremor. With the love and support of his family, Adam decided to seek help. He started to see a therapist to quiet the little voice in his head and a neurologist to learn more about essential tremor. Slowly, he started to feel better, started to feel like he was more in control. By the time he was working on *Anchorman 2,* he had quit drinking (to ensure it wouldn't become a problem) and was actively practicing mindfulness.

On set, he was really, really shaky. He was a little concerned about what his staff and other people might think. His agent showed up one day when Adam was particularly shaky. Although embarrassed, Adam proceeded to explain essential tremor to him. And the most amazing thing happened -- the agent looked at him and said, “I have ADHD. We all have stuff...” and quickly moved the conversation along, making no other mention of it. It was liberating. The simple mention of the condition took all the anxiety away for Adam. And he quickly found, to his surprise, the more he mentioned it the more he found that the only one who really cared about his shaky hands (and now his shaky head, as well) was him.

So when he began working on his most recent adaptation, the Academy Award winning film *The Big Short,* he was sure to explain his essential tremor to his staff right off the bat. He even encouraged his assistant director to be open with the crew about it, so everyone from the painting supervisor to the Foley mixer understood what Adam’s shake was AND what it wasn’t. Being open and honest about ET helped Adam keep his mind in a healthy place, and enabled him to focus on the job at hand—telling a great story.

At 46, Adam is one of the best know and widely admired writer/directors in Hollywood. His ability to bring out

“Adam is a gifted filmmaker and comedy maker. He has had a rare kind of success directing and producing, and someone else in his position might have become comfortable, or overconfident, or lose their sense of empathy—but because he struggles, because he has an ongoing relationship, in a sense, with his essential tremor, he is more engaged and compassionate than ever.” - Shira Piven

Continued next page >>>>
research

the very best in the actors, create complex characters that make you laugh, and cry, and want to seriously punch a banker in the face (in the case of The Big Short) is just part of what makes him great. He is also incredibly funny in his own right, perfectly approachable, and very, very smart. He is a loving husband and a positive role-model for his daughters, Lily (11) and Pearl (16). He is also, now, an advocate for essential tremor.

As Adam plugs away on his next adventure (he’s currently directing a new pilot for HBO) he will continue the process of being kind to himself and keeping that little voice in the back of his head, in the very, VERY back of his head; where it belongs. He may write with a shaky hand, and direct with a shaky head, but there is nothing shaky about his resolve.

... and he lived happily ever after.

The Tremulous Hand of Worcester

Life in 13th century England was tumultuous. Duke William II of Normandy (William the Conqueror) had secured the English throne in 1062 and promptly ousted much of the native English aristocracy, replacing them with his own French counterparts. The new Norman society was set up like a pyramid. At the top of the pyramid was the king. Below him were the barons and then the knights. At the very bottom of society were the peasants. Most peasants were serfs; they worked the land for their lord. And at the heart of every town and every village in England was the church.

The middle ages are known as a time of great piety in England, a time when the Catholic Church stood center-stage for every community event. The church acted as a place of worship, a hostel for travelers, a hospital for the sick, and a church library. However, there was a great disconnect between the church and the common people. Everyone was expected to attend mass each Sunday; however, the service was delivered in Latin, a language the common man would not understand. The common person would have spoken English, but was most likely unable to read or write. To complicate matters further, the Norman bishops and lords and ladies of the aristocracy spoke a Norman version of French.

During this time, a scribe, most likely a monk, lived and worked at Worcester Cathedral Priory in England, overlooking The River Severn. He spent his days translating documents from Old English into the language of the day, Middle English or French and later, Latin. Thousands of his notes and edits can be seen in at least 20 different books, covering a wide and unique array of subjects from church history to herbal medicine. This scribe is famous among modern scholars not only because of his interest in translating unusual documents, but because he is the oldest known writer affected by tremor. He is known as “the Tremulous Hand of Worcester”.

For years, scholars have wondered about the cause of the scribe’s shaky writing. Dr. Deborah Thorpe, Postdoctoral Fellow at the Centre for Chronic Diseases and Disorders at the University of York, and Dr. Jane Alty, Movement Disorder Neurologist at Leeds Teaching Hospital NHS Trust, took a closer look at the scribe’s handwriting to try and determine what type of tremor he had. The results of their joint neurological and historical analysis were published in the August 31, 2015 issue of Brain.

There were many aspects of the scribe’s life that were unknown to the researchers. He left no written record...
If you look closely at the individual letters, you can clearly see a rhythmic shake, indicative of essential tremor. Photo credit: Mr. Christopher Guy, Worcester Cathedral Archaeologist. Reproduced by permission of the Chapter of Worcester Cathedral (U.K.). F174-F38r.

of his personal life, so it is unknown if his tremor was isolated in just one hand or if other body parts were also affected. They also do not know his age, although the researchers maintain he was most likely of advanced age, but seemed to remain sharp in his later years, with no sign of dementia or cognitive decline. They do know, however, his tremor probably precluded him from being employed as a regular manuscript copiest. His work seems to have been centered around making these older, archaic works more easily understandable to his French/Latin-speaking colleagues.

The researchers carefully evaluated and analyzed the Tremulous Hand’s writings, noting changes as he aged. They were able to rule out numerous other possible causes of the tremor, such as writer’s cramp, dystonia, ataxia, and Parkinson’s disease. Factors such as a regular amplitude and frequency, a distal rather than a proximal tremor, steady pressure on the tip of the writing implement, and the absence of micrographia (small handwriting) all lend to a diagnosis of essential tremor.

“We did this research by applying modern day medical knowledge to the 800-year-old manuscripts,” Dr. Alty remarked. And together, Drs. Alty and Thorpe solved this medieval mystery. “Research on neurological disorders is always looking for the earliest possible bio-marker of any disorder,” Dr. Thorpe added. “So anything that can help detect or analyze those conditions are useful.”

It appears the Tremulous Hand spent a good many years working as a scribe at the Priory, even going back and correcting errors in his own works, later in life. No one knows exactly who he was or what happened to him when he could no longer hold his quill. But we do know he probably had a lot of the same challenges and frustrations people with essential tremor do today. But he seems to have managed an impressive and prolific career. And his legacy continues in each shaky word penned in margins of the manuscripts he touched.
Essential Tremor & The Role of Alcohol

by Dr. Fatta B. Nahab

The journey of most individuals with essential tremor includes early confusion about their diagnosis, questions about the long-term implications of having ET, uncertainty about its treatment, and frustration by the slow pace of new research. Another commonality I hear from many of my patients is the advice given to them by the first physician who diagnoses them with ET to “have a drink on occasion” if they want to reduce their tremors at a restaurant or in other social environments. This directive is based on the idea that ET is alcohol-responsive or alcohol can suppress tremor. While this is likely true, there is much about this topic we do not fully understand. Let’s review what we do know…

After receiving some professional validation that alcohol may suppress their tremors, individuals often ask “what type of alcohol is best?” It’s important to clarify what we mean by alcohol since it means different things to different people. To a chemist, alcohol is any chemical compound with an oxygen and hydrogen atom attached. In common parlance, however, alcohol in adult beverages specifically refers to ethyl alcohol or ethanol. In this circumstance, all alcoholic beverages have ethanol though the quantity depends on the proof or percentage of ethanol contained. It therefore, makes no difference what type of alcohol is consumed, only the volume needed to produce a clinical effect. In our research studies, we typically use 80 proof liquors (40% ethanol) since the volume of liquid is smaller than the equivalent amount of wine or beer.

Moving beyond the trivial details of alcohol is the question of whether alcohol is a reasonable option for the treatment of ET. For many years, the ET community relied on anecdotal reports or surveys that asked individuals whether they felt alcohol improved their tremors, and 50-70% of individuals did report improvement (Kohler 1994). While this may seem significant, it was unclear whether this meant some people had no response or whether they were simply unaware of the improvement. To address this question, several recent studies have attempted to objectively quantify the alcohol response while recognizing ET severity can vary fairly significantly throughout the day (Hopfner 2015). The findings showed people with ET across the board had the greatest reduction in tremor about 60 minutes after alcohol intake, though by the next morning individuals developed “rebound tremors” or tremors that were worse than before alcohol. This study made other interesting observations, including finding no differences in alcohol response among genders, with age of onset, or family history of ET. The study also found a very loose relationship between the degree of actual response and people’s perceived response. This latter observation, individuals with ET have difficulty judging changes in their tremor, has been seen in other studies as well.

With this information in mind, the tremor suppression properties of alcohol remain limited by its short duration of effect, the occurrence of rebound tremors, the intoxication concerns, and potential for abuse. Some experts in the field (myself included) have argued the alcohol response can be helpful in differentiating ET from other similar disorders, though it’s important to acknowledge most disorders are made worse by anxiety and this feature also responds to alcohol. While the degree of response may vary among the various disorders, this remains an area that requires further study.

Recognizing the use of alcohol in ET has both risks and benefits. Researchers have focused on trying to better understand its mechanism of action. Based on the work of many scientists, we know alcohol has widespread effects throughout the entire brain and the body. Among alcohol’s numerous potential mechanisms are its ability reduce communication between cells through so called “gap junctions” and lead to reduction in the ability to propagate an unwanted signal like tremor. Alcohol also acts on various parts of the GABA receptor, which has inhibitory effects on the brain. Regardless of the exact mechanism(s), efforts are underway to
develop medications that are better targeted to reduce tremor while attempting to minimize side effects such as intoxication, addiction, or the short duration of action.

One example of this effort is the research being carried out on 1-octanol or its metabolite octanoic acid by the National Institutes of Health group led by the Co-Chair of the IETF’s Medical Advisory Board Dr. Mark Hallett. In these preliminary studies, both agents demonstrated good tremor suppression properties, did not cause intoxication, and had considerably longer durations of action than ethanol (Nahab, 2011; Haubenberger, 2014). Despite these exciting findings, challenges remain in finding optimal formulations and determining long-term safety and efficacy.

Our current understanding of how ET and alcohol interact remains incomplete. As this knowledge increases, we will gain further insights into how ET develops and also what targets future treatments should focus on.

Fatta Nahab, MD is an Associate Professor of Neurosciences at the University of California, San Diego, and a member of the IETF’s Medical Advisory Board.

Ethanol, also commonly called alcohol, ethyl alcohol, and drinking alcohol, is the principle type of alcohol found in alcoholic beverages, produced by the fermentation of sugars by yeasts.

Octanol also known as 1-Octanol is a fatty alcohol. Many other isomers are also known generically as octanols.

Caprylic acid is the common name for the eight-carbon saturated fatty acid known by the systematic name octanoic acid. Its compounds are found naturally in the milk of various mammals, and as a minor constituent of coconut oil and palm kernel oil.
Patients with essential tremor do not have many treatment options. Current medications for tremor control are only effective in about half of patients. Those who are significantly debilitated may seek surgical alternatives like deep brain stimulation (DBS) or gamma knife thalamotomy. A promising new approach called focused ultrasound is now another option for patients to consider.

**How Focused Ultrasound Works**

Most people are familiar with ultrasound being used to “see” unborn babies and other areas inside the body. These same sound waves are applied in focused ultrasound. The technology uses multiple beams of sound all directed on one spot to generate heat, much like how a magnifying glass focuses beams of sunlight to burn a hole in a leaf. The patient has their head shaved and wears a helmet during treatment that contains the transducers that deliver the ultrasound beams. The sound energy travels through the skin, skull, and brain to heat the target tissue without harming nearby tissue. The destruction of the target tissue interrupts circuits of the brain responsible for tremor.

How are the doctors able to see into the brain? They use an MRI (magnetic resonance imaging) machine. The patient lies inside the MRI tube for the entire procedure so the physicians can visualize the brain, validate they are targeting the correct region, and monitor the exact amount of heat being applied. Patients are awake during the procedure, talking with the medical team as they assess progress in reducing the tremor throughout the process. Directly following the procedure, tremor has been shown to be reduced by 47% in a majority of patients.

**Picking the Right Treatment for You**

Is this treatment for everyone? Just like any surgery, patients who seek focused ultrasound must be evaluated to see if their diagnosis, medical history, and symptoms match the treatment criteria. It is not a one-size-fits-all approach.

According to study results recently published in *The New England Journal of Medicine*, the technology comes with benefits and risk considerations. The procedure does not require an overnight hospital stay. The benefits can be felt immediately, with patients recovering rapidly and quickly returning to activities of normal life (usually the next day). There is no need for the neurosurgeon to drill holes in the head or implant a pacemaker and wires in the body. Focused ultrasound offers a reduced risk of infection and blood clot formation, and no exposure to radiation. Finally, it offers relief without the need for periodic adjustments.

Considerations for choosing focused ultrasound include the understanding that it permanently destroys part of the brain—the results cannot be undone—and the treatment effect is not adjustable. The treatment is currently considered safe to treat just one side of the brain, so it reduces tremor on one side of the body (usually the dominant side). The procedure may take several hours of lying completely still inside the MRI machine. Some patients may experience temporary pain, dizziness, or nausea during the procedure. There is also

**FDA Approves New Surgical Option for ET**

The U.S. Food and Drug Administration has recently approved a new treatment for essential tremor—it’s called focused ultrasound. Now that this approach is available in the U.S., Canada, and many other parts of the world, let’s explore how it works, the potential benefits and considerations, and where to get treatment.
a chance patients could experience side effects, such as gait disturbance or numbness.

Where to Get Treatment
Focused ultrasound is currently available to treat essential tremor at several leading academic medical centers in North America, Europe, and Asia. The Focused Ultrasound Foundation (www.fusfoundation.org) and Insightec (www.insightec.com), the company that makes the device, have lists of treatment sites around the world. The Focused Ultrasound Foundation is engaged in funding research for essential tremor as well as expanding the use of this technology to treat patients with other neurological disorders, including Parkinson’s disease, epilepsy, brain tumors, obsessive-compulsive disorder, depression, dystonia, and Alzheimer’s disease.

North American Treatment Locations:

Stanford University Medical Center
Stanford, CA
Contact: Evalina Salas (650) 724-4131
tremorstudy@stanford.edu
Neurosurgeon: Casey Halpern, MD

University of Maryland Medical System
Baltimore, MD
Contact: Charlene Aldrich (410) 328-5332
caldrich@smail.umaryland.edu
Neurosurgeon: Howard Eisenberg, MD
Neurologist: Paul Fishman, MD

Brigham and Women’s Hospital
Boston, MA
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hgalvin1@partners.org
Neurosurgeon: G. Rees Cosgrove, MD

Weill Cornell Medical College
New York, NY
Weillcornell.org/parkinsons-disease-movement-disorders
212-746-4966
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Ohio State University Neurological Institute
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I currently direct the Movement Disorder Program at Barrow Neurological Institute in Phoenix. I did my undergraduate degree in electrical engineering and completed a fellowship in motor physiology. I have been in the “business” of movement disorders since 1999 when I finished my neurology training. I was initially drawn to neurology because I am fascinated by the logic of the circuitry of the nervous system. Neurology is a field where you can usually simply talk with a patient and their family, exam them, and have a pretty good idea of what is happening, without the need for a lot of testing. Movement disorders, specifically essential tremor, are even more that way. If you are good at listening to the patient and can categorize their movement problem accurately, you are well on your way to trying to help them. I like the idea that I can see the tremor, describe what I see, and put it in a category. It appeals to my logical engineering brain.

I also have essential tremor in my family. I remember as a young child watching my grandfather struggle with simple tasks such as eating and drinking. I also noted after his evening cocktail his hands were pretty steady. This combination of personal and intellectual interest has led me to want to study essential tremor.

My particular focus in ET research has mainly been in the pathogenesis of ET; how the condition is developed and what mechanism(s) are involved. My hope is with a better understanding of what is underlying ET we can
then develop better, more effective treatments. I had the opportunity to work in the Arizona Study of Aging and Neurodegenerative Disorders (ASAND), in Sun City, AZ. Sun City is one of the first and largest retirement communities in the country. The main focus of ASAND is to study the neurology of aging.

We examined people with Parkinson’s disease, Alzheimer’s disease, and what we call “healthy controls”. Within this latter group, there are a large number of people who had tremor. The average age of the people in the study is close to 80 years old. It has been fascinating to study ET in this population outside the typical neurology clinic. Some of them have what we might call “classic ET”, which means they often have long duration tremor, have a family history of essential tremor, and are bothered enough by it to seek out a doctor for treatment. These would be the typical patients I might see in my clinic.

However, there are many others who have tremor noted on their examinations but aren’t bothered by it (or maybe they are just tired of complaining about it) and do not bring it to the attention of their physician. I had one gentleman who had essential tremor since childhood and said “everyone in my family shakes,” but it did not bother him because he just assumed that is part of who he was. He had learned to work around it throughout his life and was coping very well. It was not even listed as a medical condition in his chart. I have seen others who had significant tremor upon examination and when I bring it to their attention, they did not realize their shake had a name, as they just assumed all old people shake. It is somewhat funny to see the same person for their annual visit the next year, note the tremor again, ask about it, and have them say “Oh yeah, you told me this was called essential tremor last year when I was in. No, it is still not really bothering me.”

This has led me to wonder more about whether all tremor we call ET is really the same condition. We have started our research with the idea it really is all the same, it really is all essential tremor. We lumped all the data together as we began reporting on some of the findings in our brain bank (a centralized collection of human brain tissue specimens used in brain research). Most of our folks have been older when they started noting their tremor because of the way they came into the program.

The studies have shown there is really no significant pathology in this group linking ET to Parkinson’s (PD), Alzheimer’s (AD), dementia, or cerebellar degeneration. However, over time, we have begun to wonder whether the different expressions of essential tremor we see are really one and the same tremor type or several different types. With funding from the IETF, we have slowly begun accumulating tissue samples in the brain bank of people who had early-onset tremor. Currently, we have nearly 100 who have come to autopsy. We continue to find no link between ET and either PD or AD, even as we add those with longer duration tremor. About half of our participants have clinically diagnosed tremor and the other half were diagnosed by us as they came through our research program. It is amazing how many people live with unrecognized tremor. It represents a perfect opportunity to really study how tremor starts and progresses, as well as whether there is a difference between early and late age onset ET.

I have been on the Medical Advisory Board for the IETF for many years now and only recently gotten involved as co-chair. I am looking forward to many years of continued involvement with the IETF. My hope is all the research in ET helps us understand the genetic component, what is actually happening in the brain with ET and, most importantly, what can be done to treat it. In the meantime, I am pleased to be associated with an organization that raises awareness for the disorder, funds research, and helps people cope with tremor on a daily basis.

Holly Shill, MD, is Co-Chair of the IETF Medical Advisory Board; and Director of the Lonnie & Muhammad Ali Movement Disorder Center at the Barrow Neurological Institute at St. Joseph’s Hospital and Medical Center in Phoenix, AZ.
Although every donation matters, regardless of size, those gifts of $1,000 or more annually go a long way to further the mission. The IETF recognizes and thanks all those who donate at this level by including them in the President’s Club. You are a hero to everyone affected by this life-altering condition. Thank you.

For more information about becoming a President’s Club member, call the IETF Executive Director (toll free) at 888.387.3667.

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After eight years of service, Carol Rucker, IETF Membership Coordinator and that friendly voice you heard on the other end of the line when you called the IETF office, retired in July. With a strong background in accounting and database management, Carol was truly an asset to the organization. She will be deeply missed. In retirement, Carol looks forward to doing all the things she just couldn’t find time for while working 40 hours a week. She has already booked up her social calendar with trips around the country to see old friends, dinner dates with her husband, shopping excursions with her daughters, and tickets to every sport her grandchildren participate in. It doesn’t look like she will be slowing down any time soon.

With Carol off and running, that left an open position at the IETF. Thankfully we were able to find a most competent and compatible replacement. Dawanna Fangohr (pictured above) comes to the IETF with more than 15 years experience in data management, finance, and accounting. Streamlining processes and increasing efficiency are high priorities for Dawanna. Plus, with an outgoing and friendly personality and an affinity for quality customer service, she is sure to be a valued asset to the organization as finance and database manager. Please welcome Dawanna to the IETF team.
Honoraria and Memorials

Thank you to everyone who established memorials and contributed funds to honor loved ones on behalf of the IETF from April 16, 2016 to August 15, 2016. If your donation was processed after August 15, 2016, it will be listed in the next issue of Tremor Talk. (Honoraria or Memorials are listed in **UPPERCASE**, donors are listed in *italics*.)

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Celebrate birthdays, anniversaries or special occasions with a gift “in honor of” family and friends. Or remember loved ones who have passed on with a gift in their memory. Making an honorarium or memorial donation is a great way to recognize those close to you, while supporting the mission of the IETF.

You can make your donation online at essentialtremor.org/ways-to-give or by calling the IETF office (toll free) at 888.387.3667.
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Support groups are not intended to provide medical advice or be a substitute for qualified medical care. The International Essential Tremor Foundation does not assume any liability resulting from participation in a support group. The opinions held by the support group leaders, attendees or presenters are not necessarily those of the IETF.
Are you looking for a support group but don't see one listed in your area? Consider volunteering as an IETF Support Group Leader, and help bring greater support and awareness to your community. Learn how to start a support group and keep it going for years to come at essentialtremor.org/volunteer.
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