

TREMOR TALK

For Donors of the International Essential Tremor Foundation

Issue 23 May 2017

BACK TO BASICS
ET 101

EXPLORING ET
Patient Survey
Results

When to Get
A SECOND
OPINION

NETA RECAP

Live to Tell
IN THE SPOTLIGHT
Kim Sutton's Story

 **iETF** International
Essential Tremor
Foundation

Your Voice for Essential Tremor

Thoughts from the Executive Director



As we head into the summer months, we have been very busy at the IETF since our last issue of *Tremor Talk*. Here's what's been going on.

March was National Essential Tremor Awareness (NETA) month, and we had another successful campaign with the support of our donors. With our direct mail appeal and a variety of events ran by our volunteers ranging from walks to bake sales, we have raised over \$27,000 (and counting) from 500+ donors. The NETA month t-shirts were such a big hit we had to order more. We have a few left over so if you are interested in one (for a \$30 minimum donation) please let us know.

The IETF has also been providing several educational opportunities to the ET community with more scheduled this year. During NETA month we hosted an ET Education Forum in Boca Raton, FL. The event went great with over 200 attendees and the support of our presenting sponsors Medtronic and Cala Health. The attendees

heard presentations on diagnostic and treatment options from Dr. Arif Dalvi and coping techniques from Ed Gray, a local occupational therapist. We also had several vendors sharing their products and services including GE Healthcare, the Tremor Education Center, Insightec, St. Jude's Medical, the Palm Beach Neuroscience Institute, and the Read-Steady Glove. We have two more ET Education Forums scheduled this year. We will be in Cleveland, OH on Aug. 26 and Sacramento, CA on Nov. 4. If you live in those areas we hope you can join us.

The IETF also hosted a webinar on March 21 on the "Diagnostic and Treatment Options for ET" presented by Dr. Cherian Abraham Karunapuzha (better known as Dr. K to his patients). If you weren't able to join us, a recording of the webinar is available on the IETF website.

The next installment of our teleconference series will be on June 13. Dr. Monique Giroux will be our speaker and her topic will be "Mindfulness: Coping with Anxiety, Depression and the Social Stigma of Essential Tremor." Registration information is included in this issue or check your mailbox or e-mail in the next couple of weeks for an invitation.

I will be representing the IETF at three national conferences

this year including the American Academy of Neurology in April, the Movement Disorder Society in June, and the American Academy of Family Physicians in September. Exhibiting at these conferences allows us the opportunity to raise awareness for the IETF and educate doctors on the resources we can provide for their patients.

And finally, I want to let everyone know one of our long-time staff members is moving on. Rebecca Dye has been with the IETF since July 2010 and is leaving us for a new opportunity. Rebecca was a tremendous advocate for the IETF and the ET community. She managed our support groups and volunteers along with being the point person for *Tremor Talk* and social media while being actively engaged in our marketing efforts. She will be missed, and we wish her luck in her new endeavor.

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.

Sincerely,

Patrick McCartney
Executive Director, IETF

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Contents

- 2 **Awareness** National Essential Tremor Month Recap
- 6 **Education** Back to Basics: ET 101; Upcoming ET Forum & Teleconference
- 10 **Health** Getting a Second Opinion When it Counts
- 13 **Support** Scholarship Winner Strikes a Chord
- 18 **Research** Importance of Research; Participating in Clinical Trials; Exploring ET: Patient Survey Results
- 24 **Foundation** IETF Teams with American Brain Coalition, Saying Goodbye to Two Board Members
- 26 **Honoraria and Memorials**
- 28 **Support Groups**

Feature

- 14 **Awareness** Kim Sutton - Live to Tell

For cabaret performer
Kim Sutton, singing is her
chance to tell her ET story **14**



Cover & Above: Kim Sutton



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 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.



National Essential Tremor Awareness Month 2017

ESSENTIAL TREMOR MAKES SIMPLE HARD.

It's not being able to button your shirt in the morning. It's not baking the family recipe ever again. It's not being able to give a toast at your daughter's wedding. But all that can change.

Essential tremor and the International Essential Tremor Foundation – everyone engaged in addressing the challenges of ET today while moving toward long-term solutions for tomorrow – become better known each year. But more must be done. Together we are stronger when it comes to increasing awareness and support for the millions of people living with ET every day.

This March, several people worldwide made the effort to join together to raise awareness. Their efforts – small but mighty – made one step toward changing the future of ET. On behalf of the IETF Board of Directors and staff, we thank everyone who took part in awareness month activities. From hosting awareness walks to teaming up with media for news coverage, dedicated people made an impact in communities all across the world.

NETA WALKS

Walks are an easy and fun way to get a community engaged while raising much needed funds. Although the IETF is a small organization, the supporters are strong. With their leadership, several awareness walks were organized in communities around the world. They accepted the challenge, and we could not be more grateful for their efforts.

Trinidad & Tobago NETA Walk

New support group leader Rebeca Noel hosted the group's awareness walk making them the first to ever raise essential tremor awareness in the communities of Trinidad and Tobago. With a sponsorship from National Gas Company, the group was able to design t-shirts for participants to show their visibility as families and friends walked together. The group raised \$430 (USD) making their first walk a big success.

Redding, CA NETA Walk

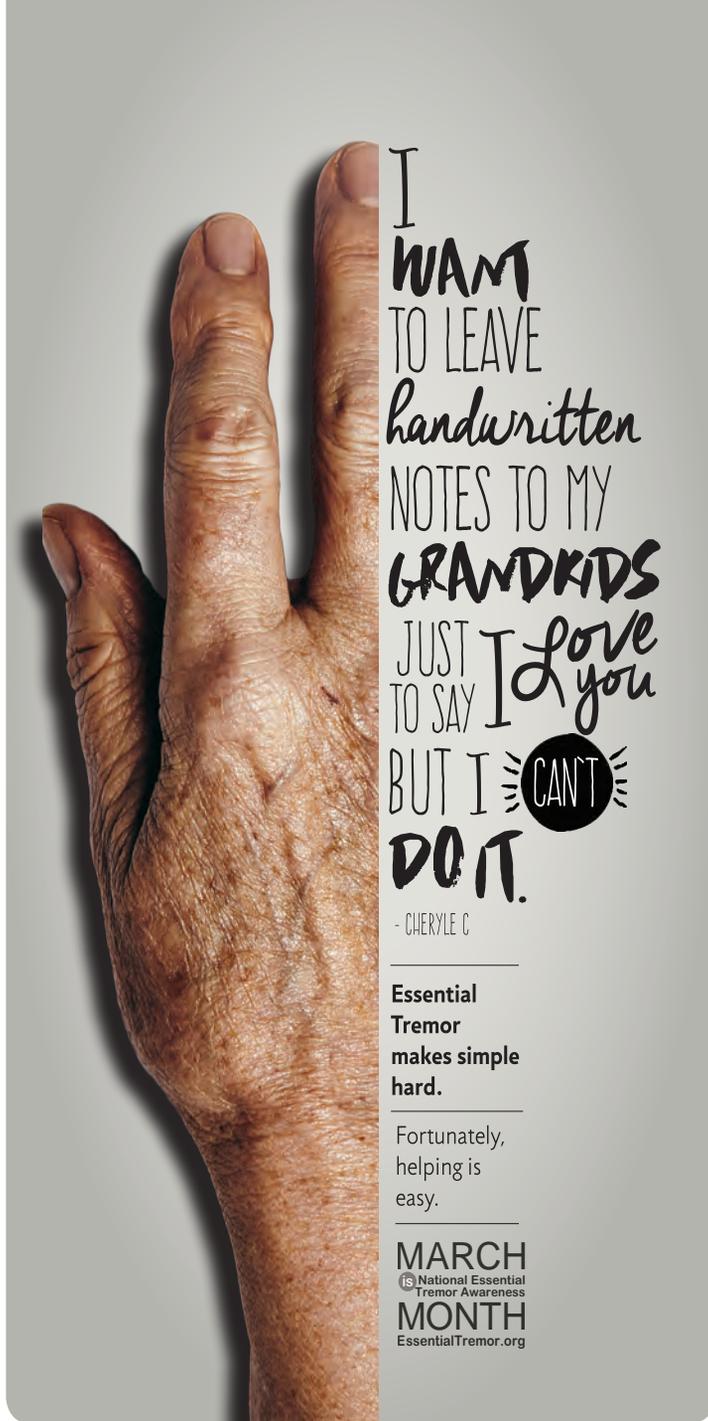
Rhonna Stacher of Redding, CA came forward again this year for her fourth annual community walk for ET awareness. Friends, family and coworkers joined together to walk around their local park, talk about essential tremor and build an ET community within their own.

Aurora, IL NETA Walk

Lynn Bernau, support group leader of not one but two ET support groups in the Chicago area, rallied her groups for their fourth annual "Shake, Rattle and Walk for Essential Tremor." The groups partnered again with



An excited young walk participant eager and ready to raise awareness for ET with her family in Trinidad & Tribago.



the local hospital and hosted their walk at the indoor walking track at Rush-Copley Healthplex. With a high visibility of many patients, they were able to raise awareness and hundreds of dollars to benefit the IETF.

Grand Rapids, MN NETA Walk

Allison Dyke, the young beauty pageant contestant featured in a past issue of *Tremor Talk*, and her mother Julie, organized their third annual NETA walk at the local YMCA in Grand Rapids, MN. Walkers raised \$265 while sponsorships from Spectrum

Health and Mercy Health brought in \$750, totaling the overall amount to over \$1,000 in funds raised. More than 50 participants were able to test out different products specifically designed to help those with movement disorders while a local healthcare provider presented ET information to the public.

OTHER ACTIVITIES

Walks aren't the only way to raise awareness. There are countless ways to make an impact in new personalized and creative ways. Sometimes, however, it's hard to know where to start. The IETF provides the online guide to DIY Fundraising to make raising awareness easy and fun. You can download the guide and find other helpful awareness materials at www.essentialtremor.org/AwarenessTools.

To demonstrate all the different ways you can raise awareness, just see the ways people have done their part. People from all over the world hung awareness month posters, shared information on Facebook, and talked to their friends, family, and even complete strangers about ET all for raising awareness. All it takes is a little time and deep commitment to make a difference.

Information Table

Elizabeth Materazzo from Rural Upstate, NY works at her small-town hospital where they host a "Casual for a Cause" event. At this event, she set up an information table packed full of posters, pins, and educational handouts to educate patients and coworkers about ET while accepting donations for the IETF.

Media Coverage

Bob Kolquist from Abilene, TX, reached out to his local TV station to share his story. He appeared on the morning show at KTAB4U to

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speaking about ET and the importance of NETA.

DIY Cinnamon Roll Fundraiser

Kathy Nondorf from Highland, WI loved the cinnamon rolls at the local bakery Renaissance Farm. She reached out to the owner and created her own fundraiser selling the cinnamon rolls for ET awareness. Because her husband has ET, she and her coworkers have always wanted to show support for the IETF in some way. So they chose the most delicious way. They sold the cinnamon rolls to friends, family, coworkers, and everyone they could and raised nearly \$2,000.

London's ET Awareness Day

Jackie Farrell from Cheam, Surrey in the United Kingdom teamed with the National Tremor Foundation (NTF) to host an ET Awareness Day at Central Hall Westminster. Central London's largest conference venue is

a prime location opposite of Westminster Abbey and adjacent to the Houses of Parliament and Big Ben. With such high visibility from sightseers, Jackie and the NTF encouraged visitors to pop in during the afternoon for chat and tea while listening to speakers talk about how to start support groups in their communities and how to raise awareness in their daily lives.

Volunteer Program

Divy Bhatia from New Dehli, India has made great strides in bringing ET awareness to India. He fully launched a new volunteer program to mobilize people with ET to educate and engage the community. The group has begun plans to organize a walkathon around different colleges of Delhi University through the help of college societies. "[The Volunteer Program] went well, earlier there were only three, and then it went to nine. But seeing nine volunteers talking about ET freely and thinking about ideas on how we can target audiences and spread awareness was a great feeling," Divy said.

Although the program is newly developed, volunteers have already tackled many diverse projects. One volunteer is building an ET India webpage and a video about ET, targeted to Indian audiences in



both Hindi and English languages. Another is developing a short film about ET education. Others are creating a database of neurologists and movement disorder specialists with whom they can work with in the future to spread the word about ET in Delhi - a database which has never existed before in India.

Facebook Fundraising

Facebook now has a new charitable giving feature allowing anyone and everyone to raise funds for the IETF on their personal page. Both Elizabeth Bell Materazzo and Christine Taylor raised over \$1,000 just by adding the button to their page and asking friends and family to make a tax-deductible donation directly through Facebook. To add the button, click Fundraisers in the left menu of your News Feed. Click Create Fundraiser and search for International Essential Tremor Foundation. Then choose a cover photo, fill in the fundraiser details and click Create. Raising funds for ET has never been easier.

March may be over, but with your help, we can make the everyday challenges of ET a little easier by raising awareness. With the help of people like you, we know we can make a difference. ☺



Allison Dyke (above) shows off her sponsorship support. Kathy Nondorf (top right) and her fellow Lands' End coworkers raised nearly \$2,000 from cinnamon roll sales.



To learn more about how you can raise awareness all year round, visit www.essentialtremor.org/awarenesstools.

Leading a Support Group

Everyday, people with ET face challenges others find hard to understand. But no matter how much ET interferes with the usual way of life, it is not a hopeless situation. And YOU can be the important person to guide those who do feel hopeless toward positive personal change through a strong supportive system. The need for empowering support groups is greater than ever. Starting one in your community can be fulfilling and personally rewarding. And it's easier than you think.

The IETF's well-established volunteer program gives support group leaders the resources they need to thrive. With a training manual, DVD, and educational materials, everything you'll need to start a group and maintain it effectively over the years is at your fingertips.

What you can expect as a leader

Every support group leader is provided with:

- A training guide and DVD
- Accurate and timely news on research initiatives and treatment options

- Free educational materials
- Group listing on the IETF website
- A global team environment

What the IETF expects from you.

- Volunteers must be professional with the highest integrity.
- Groups must maintain an active support group, and meetings must be open to everyone.
- Leaders must have a working email address.
- Leaders must be themselves, be passionate and have fun.

The IETF is looking for leaders on the frontline who can be our voices. With your help, we can increase ET awareness, provide positive, friendly and nurturing environments, and make our ET community stronger. You can make an impact, and the IETF will be here to help you every step of the way. ☺



To learn more about support groups, visit www.essentialtremor.org/volunteer.

New Creative Content Volunteer Position

The IETF is searching for a few dedicated individuals to take on a new, exciting position. The new creative content volunteers will research and write content for the IETF's blog, *tremortalk.org*. This high-level volunteer position is a great opportunity to help educate the ET community and general public about this condition. Volunteers can work from home, and it requires only 2-4 hours per month. Be a part of a very special, select group of volunteers who can truly make an impact on the ET community.

Responsibilities

- Research and write creative content for the IETF's blog, *tremortalk.org*.
- Fulfill time commitment and meet deadlines consistently.
- Act as a representative of the IETF when writing for the organization, and respond to blog comments appropriately.
- The ability to participate in occasional creative team conference calls as needed.
- Record and report volunteer hours to the IETF monthly.

Qualifications

- Creative writing or professional writing experience strongly preferred.
- Superior command of the English language.
- Strong attention to detail.
- Ability to meet deadlines while working independently, with minimal supervision.
- Interest in scientific research with the ability to translate complicated information to a lay audience.
- Access to a computer with writing software, the Internet, and a valid email address.
- Firm understanding of ET or a willingness to learn.

If interested, please submit your resume and two writing samples (no more than two pages each) in a single e-mail to info@essentialtremor.org, with Creative Content Volunteer in the subject line.

Back to Basics

ET 101

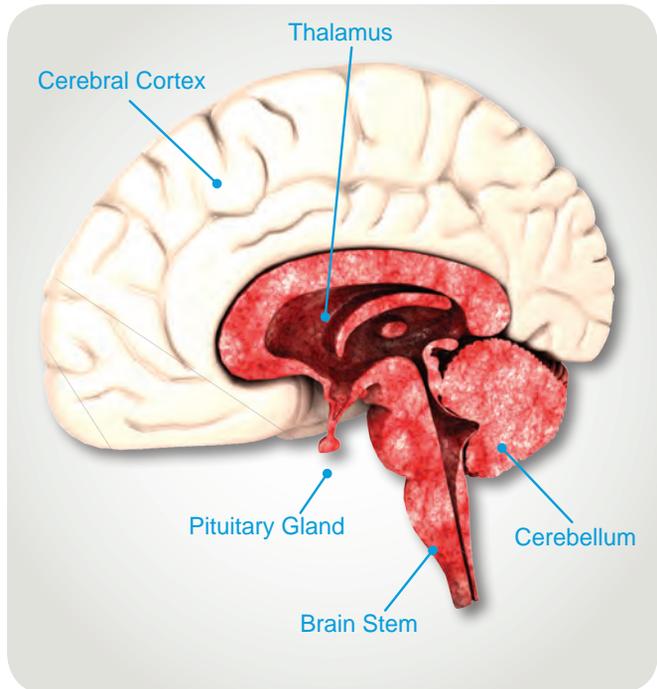
Sometimes it is all you can do to remember the name of the condition, let alone all the ins and outs that go with it. Whether you are newly diagnosed or have been living with essential tremor for decades, it is good to have a working understanding of your condition, so you can make good decisions about your health, today and as your tremor progresses.

What is Essential Tremor?

Essential Tremor (ET) is a neurological condition. Neurology covers the brain, spinal cord, and nerves which make up the nervous system, and despite how the term sounds, it has nothing to do with nervousness or anxiousness. When something goes wrong with a part of your nervous system, you can have trouble moving, speaking, swallowing, breathing, or even learning. With ET, it is kinetic (action) movement that is impacted.

ET impacts the thalamus, located deep within the brain. The thalamus relays sensory information from receptors in various parts of the body to the cerebral cortex. The cerebral cortex is that wrinkly, squiggly part that covers the outside of the brain, and its job is to process different types of sensory information.

So if a person reaches for a cup, a sensory impulse travels from the body surface towards the thalamus, which receives it as a sensation, a need to pick up the cup. This sensation is then passed onto the cerebral cortex for interpretation as touch, pain, temperature or in the case of ET, a need for a movement that will pick up the cup. This is where things start to go badly for those with ET. And although it is not completely



understood why or how, the information sent from the thalamus telling the hand to grab the cup gets confused and involuntary movements, in the form of tremor, is added to the mix.

Although many people first notice ET in their hands, it can affect many different areas of the body, such as the arms, voice, head, face, legs, and feet. Some people even note the feeling of an internal tremor, as if their intestines are having a mini-earthquake. And because ET is progressive, you may notice your symptoms increase or even spread to other areas of the body as you age. However, the rate of progression is very individualized, even within family groups. So, unfortunately, there is no way to know if and when your tremor may progress.

Although the average age of onset is mid-40s, any one at any age can develop ET, even infants. ET knows no gender, race, sex, or religion. It is an equal opportunity effector.

There is a 25-35% error rate in diagnosis among general neurologists treating tremor.

Diagnosis

There is no blood test or scan that will give you a definitive diagnosis of ET. Diagnosis usually comes down to family history, a physical exam, and ruling out other possible causes of tremor, like Parkinson's disease, substance abuse, or a dietary deficiency. According to the *Journal of Neuroscience*, there is a 25-35% error rate in diagnosis among general neurologists treating tremor. That is why it is so important to see a movement disorder neurologist when seeking a diagnosis.

Movement disorder neurologists have to go through special fellowship training in the 20 or so conditions that can cause tremor in a person. Therefore, they are well-versed in tremor and have a better chance of making a positive diagnosis.

Medications

The first thing to remember when it comes to treatment for your ET is there is no magic bullet, no magic pill that will make your tremor go away forever. Actually, there is no medication out there specifically designed to treat ET. So what we are left with are medications which were designed to treat other conditions, which

happen to have the happy side effect of tremor reduction for some people. So no, your doctor is not crazy for putting you on blood pressure medication for your tremor. Blood pressure medications also known as beta-blockers, such as propranolol (Inderal®), have been found to help reduce tremor for some people. This medication is often tried first as it has a low occurrence of side effects and is the only medication approved by the FDA for the treatment of ET.

Sometimes physicians may try an anti-seizure medication like primidone (Mysoline®) if a person is unable to take or tolerate beta-blockers. This medication can have some problematic side effects, but they usually go away with a little time and patience. When this medication is used for ET, it is given in a much lower dose than it would be prescribed for seizure disorders.

If a person also has anxiety associated with their ET, benzodiazepines might be helpful. Also known as "benzos", anti-anxiety medications may be useful in people who do not respond to

other ET medications. However, these medications are usually less effective and can lead to dependency. It is important to consult with your treating physician before stopping any of these medications, as you may experience withdrawal symptoms.

Surgeries

Only 50% of people who try medications to help control their ET find it helpful. For those who do not respond to the common medications and whose tremor has become debilitating, surgical options might be in order. Brain surgery is a serious thing, so be sure to get all the information you can in order to make the right decision for you and your family.

In 1997, Deep Brain Stimulation (DBS) was approved by the FDA for the treatment of ET. DBS has a high success rate with up to a 90% reduction in tremor. This procedure does not destroy brain tissue and is completely reversible if negative side effects should occur. In DBS, lead wires are implanted into the brain, and an electrical signal from the device interrupts the signal from the thalamus telling the hand, arm, or whatever to move.

In July 2016, the FDA approved a new surgical option called Focused

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Ultrasound. Although still in its infancy, this procedure offers patients the option of a surgery free of cutting. Ultrasound waves travel through the skull, leave all the bone and tissue undamaged. At the point where the waves converge in the thalamus, a great deal of heat is generated, thus burning a hole in the tissue making it so the signal from the thalamus can no longer reach its destination. Focused Ultrasound is not reversible and does permanently destroy brain tissue. Although the procedure is still relatively new, many patients find success in the operation. It is very critical to discuss your options with your neurologist, neurosurgeon or movement disorder specialist before making a decision that's best for you.

Other Options

Medication and surgery are not for everyone. Some people choose to make lifestyle changes in order to help keep tremor at its lowest rate. It is known stimulants like caffeine and nicotine can make tremor worse, so cutting out coffee and soda, and quitting smoking may help keep your tremor at its usual state.

It is also known stress and anxiety can also make tremor worse, so doing things that help you de-stress will also help your tremor symptoms. Activities such as yoga, meditation, exercise, and deep breathing help the body relax during stressful times. It is good to keep in mind, however, adrenaline may also put your tremor into overdrive, so be sure to plan for a little extra cool down time if you use exercise as a stress reliever. In no way should you allow ET to limit your physical activity.

There are also devices on the market you can use to help you accomplish your everyday tasks more easily. Some people find weighted utensils, specialized writing tools, or a variety of gizmos and gadgets that can be found all over the internet. A few minutes on elderstore.com or thegrommet.com, and you will find all kinds of innovative products you didn't even know existed.

It is important to be well-informed about your condition, but it is just as important to be supported while living with it. The IETF strives to bring you the latest information and research, so you can make the very best decisions about your health. And when you need support, check out our support groups (listed in the back of this publication) or our Essential Tremor Awareness Group on Facebook (www.facebook.com/groups/5884699022). Share your challenges and successes with a group of friends who truly understand what it is like to live with essential tremor.

And don't forget the importance of talking to your doctor. If you have questions about your treatment options, medications, assistive products or new technology, make a list of questions and take it with you to your next appointment. Together, you and your doctor, can find the right options for you so you can live your life to its fullest, even with essential tremor. ☺



Learn more about essential tremor including diagnosis, treatment and surgical options at www.essentialtremor.org/about-et.

ESSENTIAL TREMOR EDUCATION FORUM

**SATURDAY
AUGUST 26, 2017**

CLEVELAND, OH • LOCATION TBD

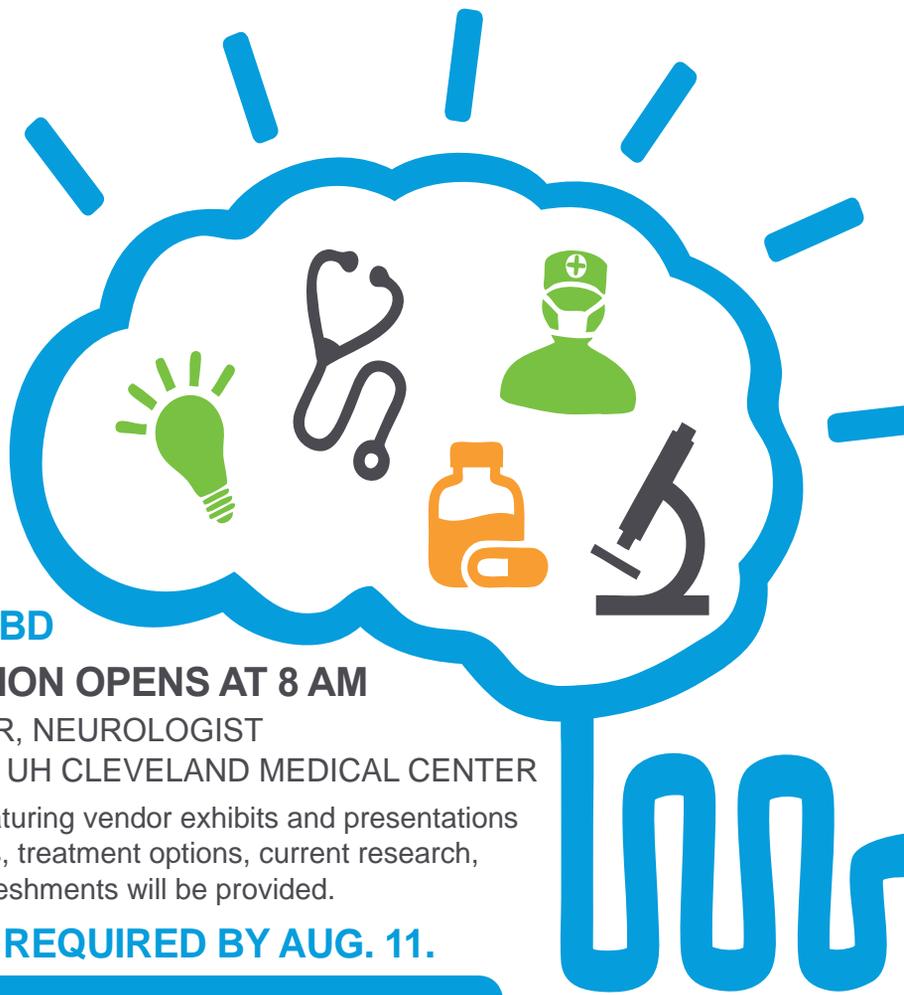
9:00AM - 12:00PM • REGISTRATION OPENS AT 8 AM

FEATURING: DR. BENJAMIN L. WALTER, NEUROLOGIST
MEDICAL DIRECTOR, DBS PROGRAM, UH CLEVELAND MEDICAL CENTER

Join the IETF for a free educational forum featuring vendor exhibits and presentations by local ET experts on the diagnostic process, treatment options, current research, assistive devices, coping tips and more. Refreshments will be provided.

COST IS FREE! REGISTRATION REQUIRED BY AUG. 11.

**VISIT [WWW. ESSENTIALTREMOR.ORG/SEMINARS](http://WWW.ESSENTIALTREMOR.ORG/SEMINARS)
OR CALL 888.387.3667**



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Tuesday, June 13, 2017

12pm Pacific • 1pm Mountain • 2pm Central • 3pm Eastern

Topic:

Mindfulness: Coping with Anxiety, Depression & the Social Stigma of ET

Speaker:

Monique L. Giroux, MD, Movement Disorders & Integrative Medicine Specialist,
Medical Director Movement & Neuroperformance Center at Englewood & Fort Collins, CO

Facilitated by Patrick McCartney, IETF Executive Director

**Register online at www.essentialtremor.org/seminars
or call us at 888.387.3667 to reserve your spot.**

Choosing the Right Doctor

Getting a second opinion when it counts



When you go to the doctor, you expect answers. Trusted, reliable answers. Being diagnosed with a life-altering condition can be difficult, confusing, and overwhelming as you navigate through information, treatment options, and the healthcare system. But how do you know if you've been diagnosed correctly or are making the right treatment choices?

Taking the time to learn about your condition, getting a second opinion or perhaps even a third, and weighing your options is a reasonable approach to managing your ET. Healthcare is a service industry, and your doctor should be there to listen and adhere to your needs. You, the patient, are the consumer. If you have trouble understanding your provider, or feel rushed or disrespected, trust your

gut. Consider seeing another provider.

Second opinions don't hurt, and in fact, may even help

Imagine you have a loud grinding sound coming from your car. You take it to the shop, and your mechanic says it's nothing. But yet, you never hesitate to get a second opinion in that case. So why do patients hesitate to get a second opinion on the most important commodity they own—themselves.

Statistics show over one-third of adults in the U.S. will never seek a second opinion. And almost 1/10 of newly diagnosed patients rarely or never truly understand their diagnosis. A second opinion simply means you are consulting with another doctor to confirm a diagnosis and/or find possible different treatment choices available to you.

Proactive decision-making will give you a greater degree of control over your treatment. Decisions regarding your health should be made after you have been thoroughly informed about your diagnosis, prognosis, and available treatment options. As a patient, it never hurts to get a second opinion. Keep in mind doctors are human, and they too can make mistakes or be faced with unusual or challenging cases. When the first doctor's opinion is the same or similar to the second doctor's, your confidence will be increased.

While second opinions may be awkward for the doctor and patient at times, studies have shown 30 percent of patients who sought second opinions for surgery and 18 percent of those who were required to obtain a second opinion by their insurance company found the two opinions were not in agreement, according to Patient Advocate Foundation. These studies are one more reason why you need to make sure you are educated properly to make the best decision for your health.



Choosing a physician

As you choose a physician, whether it be for a first or second opinion, it is important to think about what is most important to you. Asking good questions will help you assess whether you're getting the best possible answers to your questions.

- Is it important to you to know how long the physician has been treating ET, or how many people with ET they have treated?
- Is the amount of face time spent during your appointment important?
- Do you want to see a doctor who is also active in ET research or clinical trials?
- Is it important to you that your provider is open to discussing alternative and complementary therapies?

Giving some thought to your necessary criteria will help you choose a provider who is right for you.

Be an informed consumer and arrive for the second opinion with all of your previous medical records, contact information about the first physician, insurance card, list of prescribed medications and allergies, and any diagnostic test results.

What will it cost me?

Assuming it is medically necessary, most insurance plans will pay for at least part of the cost while Medicare will pay 80% of the cost. As a matter of fact, if the second opinion doesn't agree with the first, Medicare will pay 80% of the cost of a third opinion. Patients that belong to a Medicare

Health Maintenance Organization (HMO) are entitled to a second opinion, but some plans require a referral from your primary care physician, and like most HMO treatments, you must see an in-network physician. To learn about second opinions call 1-800-MEDICARE (1-800-633-4227) or for specific rules by state for a second opinion you can visit www.medicare.gov/coverage/home.asp.

Call your insurance provider before going for any treatment or second opinion to prevent any confusion or denial of the bill. You need to know exactly what will be covered, such as an out of network provider, any testing that may be required, and what your responsibilities are before seeking the second opinion. Diagnostic tests can be very costly, and many insurance providers will not pay for them if they were completed for the initial diagnosis. You always have the right to have copies of the tests you already had done, and they can always be used with different physicians.

Patient Self-Advocacy

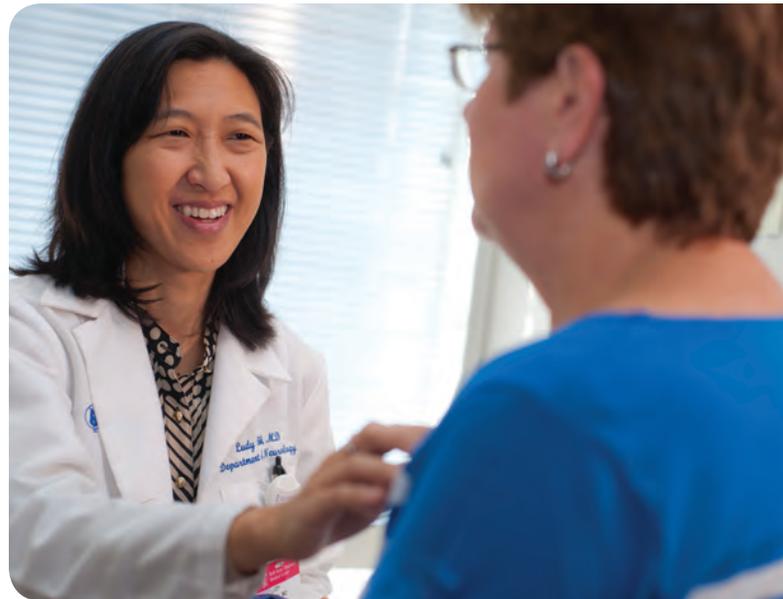
Getting a second opinion is important not only for correct information, but also to increase a patient's confidence in their care. If someone has a physician who says, you know what, there's really nothing more I can do for you; your condition is progressing, and your treatments aren't working right now. Then any patient should be very skeptical about that answer and look further. No patient should settle for a doctor who subsides on their care and well-being, thus the importance of self-advocacy. The pro-active patient is not there for

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the doctor to fix them or to just simply tell them what to do; they are there to get information so the patient AND the doctor can make informed decisions together. A good doctor understands your right to be well-informed and should support a second opinion.

You, the person with ET, know who you are. You know how your life has been and who you've been. You know who you were before being diagnosed. You know who you have been over the last number of years as things have changed. What things you've lost. What you're missing. So only you can question, is there something that can fill those gaps in and bring me back closer to the quality of life I was living before, to that full meaning my life had? There are so many other aspects of living with ET that don't just have to do with the disease process and treatment, but that reach out into so many other aspects of a person's life. Your healthcare provider should be trusted a partner in your efforts to manage this life-altering condition.



When you have questions about the accuracy of your doctor's diagnosis or the appropriateness of their recommended treatment, you shouldn't feel powerless. A second opinion can help put your mind at ease. After all, when your health is on the line, such decisions could have significant and lifelong effects. ☺



Learn more about finding an IETF-verified ET specialist in your area at www.essentialtremor.org/find-a-physician.

TIPS

- ☺ Learn to use your tremor-free hand for as many activities as possible, including writing.
- ☺ Use your tremor-free hand to steady your trembling hand and use two hands when possible.
- ☺ Keep your elbows close to your body when performing tasks as a way to help control hand tremor.

Scholarship Winner

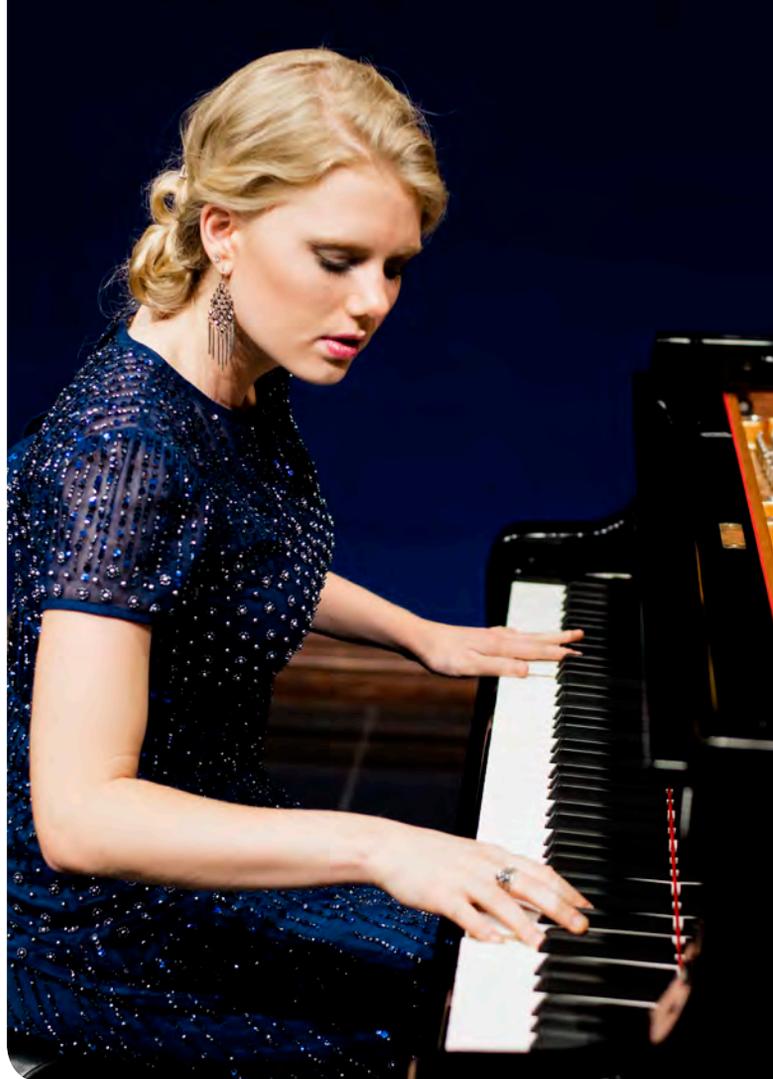
Strikes a Chord

The hustle and bustle of the room grows quiet as she begins, one note at a time, gradually building until her fingers are gracefully gliding over the keys and the music soars. Not a person in the room would know the same hands that craft flawless, classical music, would also have ET.

Former IETF scholarship recipient, Carilee Fore began playing piano at only 6 years old. Playing hours and hours on end, pouring out thoughts, feelings, and emotions through the music she loved. However, at age 9, she became frustrated when she kept missing the notes she knew inside and out. Her parents had noticed her shaking hands for a while, and since her father had essential tremor, he, unfortunately knew she had it too. “I was very frustrated, overwhelmed and didn’t totally realize the implications it was creating for me. ET was definitely cramping my style,” Carilee said.

Despite her diagnosis, Carilee didn’t let it stop her. She continued to play in numerous competitions and performances, working harder than ever before to tame her tremor. Performing in front of large audiences can be nerve-racking for many, but Carilee’s confidence just couldn’t hide her tremor. “People thought I had stage fright. I looked out in the crowd and would see pitiful, sympathetic faces staring back at me,” Carilee said. “‘We’re not judging you, we’re rooting for you’ they said, which made me feel pathetic.”

Carilee has been told her whole life, being a pianist was a bad idea while having ET. Her lifelong dream of being a piano performance major in college was slowly disappearing. She searched for new avenues to explore and decided to become an education major at Dallas Baptist University in Texas. After only three months, she decided her passion was in performing. She couldn’t deny it. So she switched her major to piano performance, began taking medication to help her ET, and from there, she thrived.



Former IETF scholarship recipient Carilee Fore completes her final senior recital and achieves her dream of becoming a piano performer.

In Spring 2014, she was awarded an IETF Scholarship Award. “Getting the IETF scholarship not only helped financially, but also helped with my confidence. It gave me the assurance I could do this.”

Three years later, as she finishes the last note in her senior recital performance, she feels relieved and satisfied. She accomplished her goal. But what makes her the most proud is she realizes she’s ready to move on. Piano performing was her dream. And she did it. But knowing her ET will progress, she’s ready to explore a career her ET can handle as she studies for her master’s degree in International Management at the University of Texas Dallas.

“I never let ET choose who I was or what I really wanted out of life. It was just a roadblock, and although I know piano performing isn’t realistic in the long-term, I have a better piece of mind knowing I did my best,” Carilee said. ©





LIVE TO TELL

IN THE
SPOTLIGHT
WITH
KIM SUTTON



I have a tale to tell

Sometimes it gets so hard to hide it well

I was not ready for the fall

Too blind to see the writing on the wall

As the house lights dim, she comes to the stage; the spotlight blazes down, her fair skin glows under the hot lights. This is where she was born to be, front and center. Her voice rings out clearly as the program begins, singing the songs of her youth and her life. She is there to take her audience on a journey through theatrics and music. She wants every member of her audience to have a taste of what it is like; to live to tell with essential tremor.

Kim didn't start out as a cabaret singer. She started her career serving her country in the Navy. Later, she became a full-time mom to two wonderful, little girls. As her girls grew, she began to notice a slight trembling in her head. But with two little ones and a busy schedule, it was easy to pass off the shake as being due to a lack of proper rest or low blood-sugar. She would make sure to keep moving as she spoke or had conversations, believing she was "disguising" the tremor as nervous energy.

Because her little shake was nothing more than a slight embarrassment and annoyance, she went on with her life, giving it little thought. Her mother had died at only 47 years old from cancer. So it was just her and her siblings left to attend to her father. About the time she noticed a tremor beginning in her hands, her father was diagnosed with multiple sclerosis (MS). MS is an unpredictable, often disabling disease of the central nervous system that

disrupts the flow of information within the brain, and between the brain and body. Tremor is symptom of MS. It is a less common symptom of the disease, but a possible symptom nonetheless. A tremor caused by MS can occur in various parts of the body due to damage in the complex nerve pathways that are responsible for coordination of movements.

Kim was afraid she had MS. She was in denial. It was fear that kept her from seeking treatment and fear kept her ignoring her tremor. Whether she realized it or not, even before she had ever sung a note or touched a mic, she was already on stage. Every interaction, every conversation was a mini play; a time to fake, hide, block and bridge. When in public, she was performing. The only respite was the solitude of home and family.

Kim's children grew into fine young ladies and left the nest to begin their lives. And as painful as losing your children to their adult lives is, the pain of losing her father to MS was unbearable. So quickly her life seemed to be turned upside down. She had been Super Mom for so long, attending every meeting, cheering at every practice, and offering heart-felt applause at every ear-splitting concert. And now, the house was quiet. There were no costumes to sew or uniforms to wash. There were no doctor's appointments with Dad or lunch on the way. There was just Kim.

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With her sadness getting the best of her, she started therapy. Her therapist walked her through the loss of her parents and the perceived loss of her children. She grieved. For some time, she grieved. But such things don't have time limits. And as she came to accept the loss and see the light at the end of the tunnel, her therapist challenged her with something she had not considered in some time ... herself. Her entire life had been spent in the service of others, and it was time to find something that was hers and only hers. She needed to find something she could pour herself into and grow.

It was singing she landed on. She had never sung in front of an audience before, at least not an actual audience; children and the family pets with a hairbrush microphone didn't count. So with no real experience she auditioned for a cabaret class.

Cabaret is a form of entertainment featuring music, song, dance, recitation, and/or drama. It is mainly distinguished by the performance venue, which might be a pub, restaurant, or nightclub. Performers interpret the music, weaving their own unique style to the lyrics thus allowing the audience to experience the music in a completely different way. The intimacy of the cabaret setting allowed Kim to connect with the audience as she sang her story. Within 10 weeks of beginner classes, she was performing before a real audience with a real microphone.

It was time to
find something
that was
hers ... and
only hers.

It was about this time her tremor also started to become a real problem. It had progressed. She had moved from denying her tremor to concealment. On stage, she noticed her own trembling and did everything she could to hide it. She was embarrassed and felt foolish for being so nervous, even though she didn't really feel nervous. Kim really thought she was doing a good job containing the shake and concealing her secret. Until one night, after a show, a physician from the audience approached her. "How long have you had essential tremor?" he asked.

Kim had never heard of essential tremor until that fateful moment. She discussed the condition with him and learned just enough to know she needed to see a movement disorder neurologist for a positive diagnosis. She realized there are other possible causes of her shaking, other than MS. She went home and told her family about the encounter and revealed her secret. Only, it really wasn't much of a secret. They had all noticed her head and hand tremor for years. She was floored. All this time she thought she was doing such a good job covering it up, when in reality she only made it worse and more noticeable.

She decided to go to the one neurologist she knew and trusted, the one that had taken care of her father. A few tests. A few questions. And there it was, a diagnosis. Essential tremor.

She started treatment right away. First the standard, propranolol; but she couldn't tolerate it. Then she tried the second option, primidone; but it made her too sleepy to function. She even tolerated Botox® injections in her neck to help dampen her head tremor, but they never really worked either. After a year of Botox®, with only slight results, Kim's doctor explained her other option. Deep Brain Stimulation.

The name sounded like a Swedish massage for the brain. But as her doctor described the procedure, the idea of having her head shaved bald, holes drilled in her skull, and wires implanted in her brain was

In her caberet show “Live to Tell”, Kim Sutton celebrates her life with an eclectic musical set that samples 48 tunes by Madonna. Sutton recounts her childhood, years as a sailor, DBS brain surgeries and her life “living in the moment”.

far from appealing. Kim went home that day sad and scared. She discussed her doctor’s recommendation with her family and close friends. The girls were not in favor. The procedure had definite risk, and they felt their mom should try to live with the tremor, accept it as part of who she is.

It’s not a choice you make overnight.

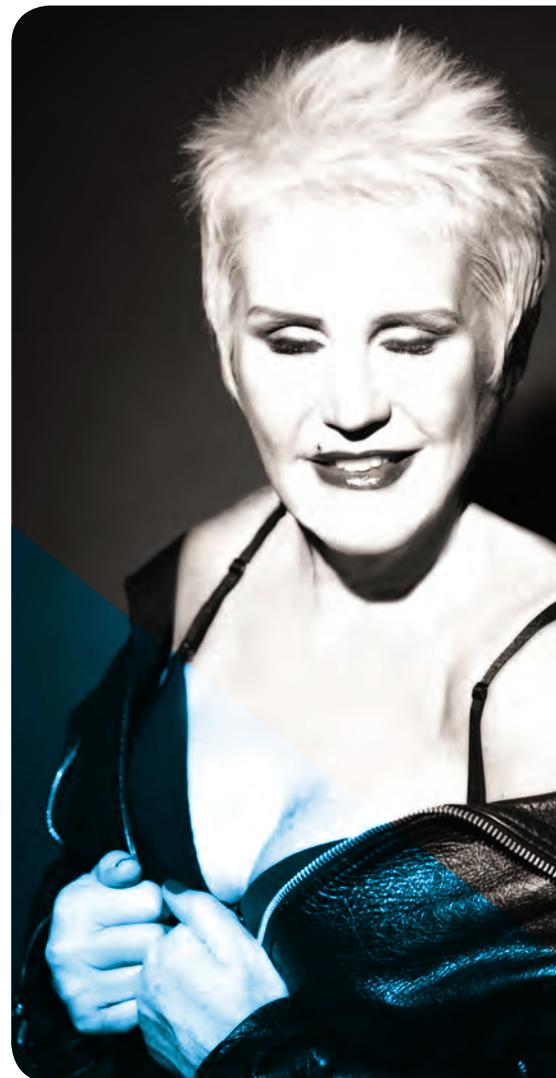
Kim had a gig in Greece. She allowed herself time to consider her options; consider the life she wanted to live. She had already won the 2015 Best Show Award from *Broadway World* for her work in “Anchors Away.” But could she maintain her quality of life? That was the real question. It was beside an old lighthouse, looking out across the clear blue waters of the Aegean Sea when she made her choice. Yes, she could accept her condition. Yes, she could live with it. Many people do. But that would mean sitting idly by watching her cabaret dreams crumble with every progression of symptoms. It was in her head, her hands, her voice, and even her legs on occasion; and she would not accept something she had the power to change. She decided she would have the surgery.

She wanted to set an example for her children. Acceptance is important in life, in things you cannot change. But she wanted them to see there is also value in calculated risk, and living life to the fullest.

And for Kim, the calculated risk paid off. She had a successful surgery about a year ago with minimal side-effects. She said she knew even before she was wheeled to the recovery room that the procedure was successful. She could hold up her hand, and it was steady.

Today, Kim is pretty much tremor free. Even her vocal tremor is greatly diminished. And although she is living “in the moment” and no longer suffers the symptoms of ET, she won’t forget her journey. Her most recent endeavor was a bold new show, “Live to Tell,” at the Laurie Beechman Theatre in Manhattan. This show celebrates her life with an eclectic set, sampling 48 songs by the pop icon Madonna. In her show, she describes her life as a sailor, mother, and essential tremor patient through her heartfelt interpretation of the music. Kim’s performance was so well received dates were readily added to her contract.

Like most people with ET, Kim wants to educate others about essential tremor and help those suffering in silence, trying to hide their shake to know they are not alone. ☺



The Importance of Research

The high quality of medical care we have today is built upon years of effort by physicians, scientists, and other medical professionals exploring the causes and potential treatments for diseases and conditions. The tireless effort of these professionals has made many once life-threatening diseases and conditions just a memory.

The future of medicine has never been so bright. Advances in treatments are being announced every day that can help eliminate or improve the life of patients suffering from chronic, life-altering and threatening diseases. New drugs and treatments options are in development in medical facilities and labs across the nation—all that could have the potential to improve the lives of individuals and entire communities.

However, there is still much work to be done.

Essential tremor is a common but misunderstood disorder affecting the lives of millions of Americans. Patients are affected in different ways and respond to treatments in varying degrees. Overall, tremor and tremor-related disability tend to get worse with time. Dr. Ludy Shih, movement disorder specialist and clinical investigator, identifies two specific aspects which are driving the need for ET research:

- A. The need for more effective and better tolerated medications for tremor.
- B. The ways the common clinical features of ET should lend us clues to the understanding of tremor.

The Need for ET Medications

Tremor medications currently used are a byproduct of research and development on other neurological conditions, like epilepsy. Because little is known about how tremor works in humans and how it might be manipulated successfully, pharmaceutical companies have little incentive to develop a robust product development program for tremor.

The Need for Understanding Tremor

ET cases are familial; giving us hope genetic mutations can be identified that will reveal basic knowledge about how tremor works in humans, similar to what the discovery of genes causing Parkinson's disease has done

for that field. If we are fortunate, genetic mutations may reveal a chemical target that can be manipulated with the right drug, or they may reveal a more complex mechanism rooted in nervous system development or even neurodegeneration, although this latter point is quite controversial.

Dr. Shih's research at Beth Israel Deaconess Medical Center is focused on two areas. One goal is to attempt to identify patients who have subtle physical brain changes that may be associated with a more rapid progression of tremor-related disability.

They are also trying to identify whether there is any association with genetic variations in a gene called LINGO1 that is not seriously defective in people with ET. But instead, this LINGO1 gene may contain slight variations that help contribute to the development of ET in a patient.

Dr. Shih and her team's second goal is to work collaboratively with other centers through the North American Essential Tremor Consortium to build a robust, data-rich repository on a large group of patients. This repository could help classify and identify biological markers of tremor that might help enrich current genetic studies on ET. Genetic techniques have advanced significantly over the years, but there are many forms of tremor. Each may have their own mechanism and

methods of treatment. Therefore, careful clinical characterization may still be necessary in order to make “finding the needle in a haystack” more productive.

The Need for You

The many different approaches to research provide corresponding insights. Clinical trials and research studies can deliver important information about the effectiveness and adverse effects of medical interventions by controlling the variables that could impact the results of the study. However, feedback from real-world clinical experience is also crucial for comparing and improving the use of medicines, medical devices, and diagnostics.



Science today is also changing rapidly and becoming more complex, so no single researcher or single site can bring all the knowledge to develop and validate medical innovations or to ensure their safety. This makes the need for more research even greater so information can be shared between institutions and researchers which can lead to more answers faster.

This is where you come in. You can help drive research by volunteering to participate in these types of studies. According to the Institute of Medicine (US) Committee on Health Research and the Privacy of Health Information, one of the main reasons why individuals do not participate in research is lack of knowledge about the availability of clinical trials. Clinical trials are a key research tool for advancing medical knowledge and patient care.

The IETF regularly lists current recruiting research studies on our website at www.essentialtremor.org/research/research-recruitment. These studies (no matter what phase they are in) are the first step to learning more about ET. By participating in these studies, you can help drive research and information sharing among researchers.

Research studies of all types are important to finding the cause of ET, better treatment options and possibly even a cure. However, it is important to remember the significance of research is not always to just find the answer, but to also find what IS NOT the answer. It can seem discouraging when a study finishes, but the intended methods were disproven. But by eliminating any factor, no matter how big or small, we can narrow our search towards more discovery and understanding of ET.

So now is the time to accelerate research breakthroughs that will change the world for you and millions of others with ET. Whether you participate in research studies or donate to IETF-funded research initiatives, your continued support is crucial to sustaining our research efforts and making even more breakthroughs in the future. ©



To learn more about ET research and IETF-funded research, visit www.essentialtremor.org/research.

Participating in Clinical Research

Choosing to participate in clinical research is an important personal decision. A clinical trial offers an opportunity to try a new therapy, but a person needs to understand and consider the benefits and risks before agreeing to be part of any study. The Mayo Clinic offers a list of questions to ask and understand the impact before participating in clinical research. Before you agree to participate in a clinical trial, know the answers to these questions:

- Who is in charge of this study?
- Do the people running the study have a vested interest (conflict of interest) in the outcome?
- What is this study trying to find out?
- What will be expected of you?
- Is it possible that you might receive a placebo?
- What benefits or risks can you expect if you take part in this study?
- How long will the study last?
- What happens if your condition gets worse during the study?
- Can you continue seeing your own doctor during the study?
- Will you need to pay for any part of the study, including doctor visits and routine tests?
- Who pays if you're unexpectedly injured during the trial?
- How will your participation in the study affect your daily life?
- What happens at the end of the study?
- Will you be told the results of the study? When?
- Who will know you're participating in the study?

Current Recruiting Studies

Brain Activity Measurement Study Using EEG New York City area

The ET research team at Columbia University, headed by Dr. Sheng-Han Kuo, is looking for people in the New York City area with ET to study their brain activity using an electroencephalogram (EEG). Must have had a diagnosis of ET for more than three years.

Contact: Dr. Shi-Bing Wong at 212-342-3753 or email sw3162@cumc.columbia.edu.

RULET Study of Non-affected Family Members Nationwide

Dr. Elan Louis at Yale University is spearheading an NIH funded research initiative aimed to better understand the lifestyle habits of essential tremor families. The research team is now interested in meeting with the parents, brothers, sisters, and children of people with ET. Family members must not have ET and be at least 40 years old.

Contact: 203-785-2086 or email rulet@yale.edu.

McGill University Genetics Study International

Researchers at McGill University in Montreal, Quebec, Canada are conducting the largest genetics study of ET patients ever. They require 10,000 participants affected by ET. It is open to anyone who has ET even if you have not been officially diagnosed by a physician. Must be at least 16 years old. No travel necessary.

Contact: Email ET.Genetics.Rouleaulab@gmail.com.

Brain Changes in ET Patients Study Boston/New England area

Researchers at Beth Israel Deaconess Medical Center are hoping to learn more about brain changes in people with ET using noninvasive brain stimulation called transcranial magnetic stimulation and brain imaging. They are recruiting healthy people with ET between the ages of 18 and 75. You must not have a medical device or metal in the body which are not MRI-compatible.

Contact: 617-667-4746 or email Cashton@caregroup.org.



Learn more about recruiting research studies in your area at www.essentialtremor.org/research/research-recruitment.

Exploring ET Patient Survey Results

Dr. Kelly Lyons is not only President of the IETF Board of Directors, she is also a Research Professor of Neurology and Director of Research and Education at the Parkinson's Disease and Movement Disorder Center at the University of Kansas Medical Center in Kansas City, KS. In collaboration with Rajesh Pahwa, MD, also at KU Medical Center, and with funds provided by the Melching Tremor Fund, Dr. Lyons set out to better understand the current diagnostic and treatment patterns in people with essential tremor (ET) in order to improve the care of many people she sees impacted by this life-altering condition.

The team put together a simple 16-question survey. The survey asked questions about how people were diagnosed, what types of symptoms they have, and what treatment options they have tried. The survey was emailed to everyone on the IETF's email list, via the online survey company Survey Monkey. Using a software system, like Survey Monkey, to send out the survey and receive the responses makes accumulating and organizing the raw data much easier. And since nearly 3,000 people participated in the survey, there were a lot of data to compile.

What We Learned

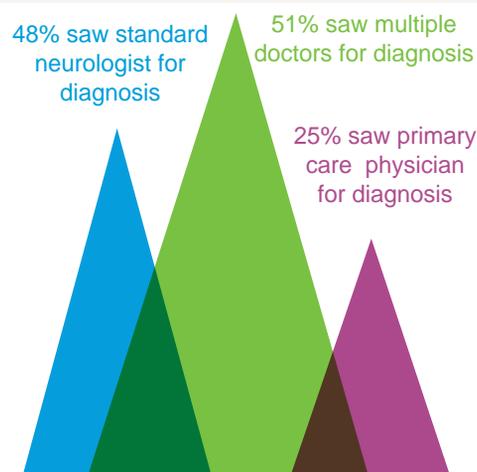
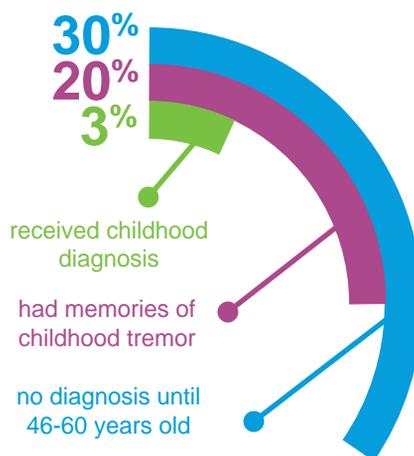
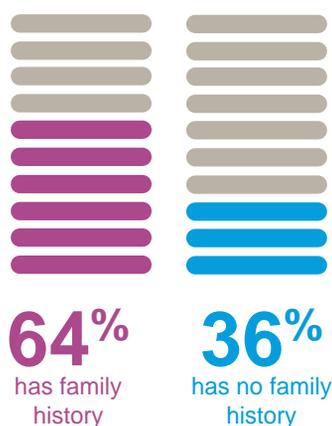
The average age of the respondents was 65, although the range went from 6 years all the way up to 98 years

old. Interestingly, a majority of the respondents, 61 percent, were women. So the survey may show a slight female bias.

When it comes to diagnosis, the majority of people, 48 percent, saw a standard neurologist for a diagnosis, while 25 percent were diagnosed by their primary care physician or family doctor. More than half had to see multiple doctors in order to get an accurate diagnosis of ET.

But what is really interesting is nearly 20 percent of respondents remembered having tremor as a child or young person under the age of 15. But only around three percent received a diagnosis while that young. More than 30 percent of the people surveyed said they didn't get a diagnosis until they were much older, between the ages of 46 and 60. Obviously, there needs to be more awareness and education among pediatricians and other healthcare providers about this condition, as there seems to be many people, adults, and children alike, suffering quietly with undiagnosed or misdiagnosed tremor for a good part of their lives.

Essential tremor is often hereditary, meaning it seems to be passed down from generation to generation through genetics. This survey definitely falls in line with the current data with 64 percent of respondents



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noting a family history of the condition. That means, however, 36 percent of people who took the survey have no known family history of ET. Unfortunately, it is still unclear what the exact cause of ET is, thus it is still not understood why some people have a strong family history of ET and others just seem to come up out of nowhere. It is hoped the genetic research being conducted at Yale University and other educational institutions will shed more light on this question in the future.

The areas of daily life people said they had the hardest time with were writing—80, drinking—68 percent, eating—67 percent, holding or carrying things—66 percent, and typing on a computer or moving a computer mouse—64 percent. Basically, anything requiring fine motor skills is negatively impacted by the tremor. And with so many people facing challenges and frustration while doing simple, everyday tasks, more than 64 percent shared they were embarrassed by their tremor. The embarrassment felt by so many ET patients can lead to anxiety and/or depression. Some people go so far as to become isolated in their homes because they cannot bear to face judgmental eyes of the general public.

As far as treatments go, the beta blocker propranolol was by far the

most common treatment used by those surveyed, with 35 percent saying that is the medication they take. Only 20 percent are taking the seizure medication primidone, the second most common medication option.

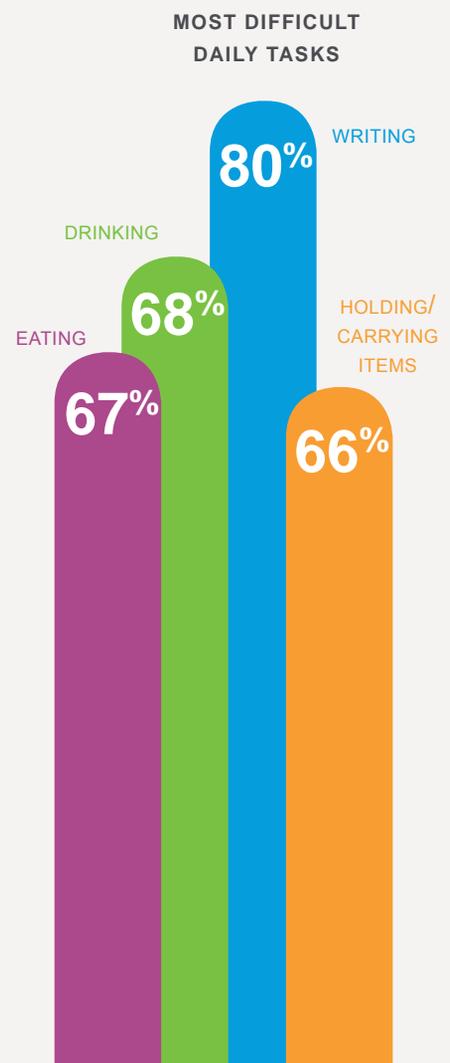
These survey results are very much in line with the current literature. The American Academy of Neurology guidelines state, “Propranolol and primidone are not helpful for 30 percent to 50 percent of people.” Astonishingly, 32 percent said they are on no treatment at all for their tremor. Almost half said they stopped treatment due to unwanted side effects or because it didn’t seem to be working. One has to wonder if a tailored treatment was available, one designed specifically for ET, would so many people be living without treatment? One also has to wonder if lack of treatment is related to a lack of awareness of the various treatment options available for ET.

Conclusion

It is very clear there is a real need for increased awareness of ET to improve the diagnostic process. Many people had to see multiple doctors in order to receive a diagnosis and almost one-third are not followed by a physician.

It is also clear this community needs more effective treatments with fewer side effects. One-third

of people surveyed are living without treatment yet many experience significant disability in performing daily activities due to their ET. Additionally, tremor is an embarrassment to the majority, impacting social and emotional health as well as physical. New tools and adaptive technology needs to be developed to address the quality of life issues surrounding ET. And with your help, through more research support, we can take a step closer. 



Learn more about ongoing ET research at www.essentialtremor.org/research.



President's Club

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 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.

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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The decision to support a nonprofit organization is personal and should be carefully thought out. International Essential Tremor Foundation Planned Giving can help you think strategically about how to support the organization that is important to you.

There are many ways to make a gift. But with just one simple sentence added to your estate or financial plans, you will help the IETF continue to fund research, increase awareness, and provide educational materials, tools, and support to those affected by ET for years to come. Once you know all the possibilities, you may discover the ability to bring about a greater impact than you ever imagined.

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PLEASE CONTACT THE IETF'S EXECUTIVE DIRECTOR AT 888.387.3667 OR EMAIL INFO@ESSENTIALTREMOR.ORG FOR MORE.



Washington Update: American Brain Coalition



The IETF works with many organizations to advocate at the federal levels for increased ET research, access to quality care, long-term services, and general public awareness. All to make a better life for you and the millions of Americans living with ET.

One of the key organizations the IETF teams with is the American Brain Coalition. The American Brain Coalition (ABC) is a non-profit organization comprised of 85 non-profit and for-profit members. These members are many of the leading patient advocacy and voluntary health organizations, as well as professional neurological, psychological, and psychiatric associations. The ABC and its members represent the 50 million Americans with disabling brain disorders, including essential tremor, and are a significant portion of the stakeholder community in the field of neuroscience.

Together with ABC, we seek to advance the understanding of the functions of the brain, and to reduce the burden of brain disorders through public

advocacy with the Congress, the administration, and with the general public.

Exciting and innovative brain research initiatives are taking place in the U.S. and across the world. The IETF works with the ABC to help researchers find new ways to treat, cure, and prevent many diseases of the brain, which includes the Brain Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative. This critical initiative is just one of the many programs that received funding through the 21st Century Cures Act. The Act, which was signed into law by President Obama in December 2016, provides \$4.8 billion in new funding for the National Institutes of Health (NIH). Of that funding, \$1.6 billion was earmarked for brain diseases, including essential tremor, Alzheimer's and Parkinson's disease.

The ABC is working harder than ever to keep this funding afloat with rumors of extreme NIH budget cuts from President Trump's administration, upwards to \$5.6 billion from the 2017 fiscal year budget, which would greatly impact the new funding designated from the 21st Century Cures Act. However, at this time, no specific details have been determined.

One way you can advocate for ET research is to make sure your local congress representative is a member of the Congressional Neuroscience Caucus. The Congressional Neuroscience Caucus was created to raise awareness about the brain—both healthy brains and those affected by psychiatric and neurological disorders, including ET. Contact your representative, ask them to become a member of the Caucus, and let your voice be heard to promote awareness and research for ET.

Everyday, we are all activists on the frontline, moving together and speaking with one clear voice to advance federal policies and programs that benefit you and the many other people living with ET. ☺

To learn more about the ABC and the BRAIN initiative, visit www.americanbraincoalition.org.



Saying Goodbye

Two Board Members Move On



Russ Rosen

The IETF wishes the best to two longtime members, Russ Rosen and Edward Block, as they retire from their positions on the IETF Board of Directors.

Russ Rosen joined the IETF board in April 2007 after his wife Arlene was diagnosed with ET and began to take a variety of medications. He was concerned about what she was experiencing, but with limited knowledge about essential tremor he wanted to explore opportunities to learn more about this disorder. After attending support group meetings in Dayton, OH, he began to better understand what his wife was experiencing. He was especially struck by the high level of emotional support and help with coping skills offered during the meetings.

As an IETF board member Russ served as secretary and treasurer during his time on the board. Russ was also always an advocate for building our support groups and trying to help as many people affected by ET as possible. In addition, he brought his strength as an individual with a master's degree in Social Work Administration and 25 years of experience working in the not-for-profit setting as a volunteer and a staff person working with boards of directors and committees, planning, managing and networking.

Edward Block joined the IETF board in December 1999 serving as secretary and vice president during his term on the board. With more than 30 years in the pharmaceutical industry, he led several drug development projects involving prescription and over-the-counter (OTC) products as well as transitioning prescription products to OTC. His experience includes international assignments, notably in the Pacific Rim.



Edward Block

Ed has ET and can trace it through several generations of his family. In addition, as a result of his professional expertise, he understands the limited options for treating the condition. The IETF relied on his understanding of drug development, including regulatory and political processes to help determine and reach both short- and long-term goals. Ed also brought experience in marketing/evaluating business development opportunities for potential ET treatment options based on credible medical research.

The board and staff would like to thank Russ and Ed for their service and commitment to the IETF and the ET community. They have played an integral role in establishing the IETF as the most accurate, reliable, and up to date source of information for essential tremor and have set the foundation as we continue to grow. ©

Honoraria and Memorials

Thank you to everyone who established memorials and contributed funds to honor loved ones on behalf of the IETF from December 16, 2016 to April 18, 2017. If your donation was processed after April 18, 2017, it will be listed in the next issue of *Tremor Talk*. (Honoraria or Memorials are listed in UPPERCASE, donors are listed in *italics*.)

HONORARIUMS

RICHARD COURTHEOUX
Ms. Lillian Courtheoux

GLORIA FISHFADER
Ms. Karen Hemmerling
Ms. Vicki Fishfader

SHARI FINSILVER
Joyce Keller & Michael Walch
United Jewish Foundation

SUSAN ISRAEL
Ms. Edith Snyder

TERRI LACEY
Ms. Ashley Hobbs

CALVIN LEE
Ms. Nanci Curtis

HAZEL NELSON
Mr. Timothy Nelson

RODGER NONDORF
Ms. Dawn Chiantello
Mr. Heer Dawg
Mr. Donald Decker
Ms. Joanne StLouis

JACH PETERS
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Ms. Dawn Bland

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Mr. Paul Skowronski
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LAURA STRAUSS
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Bob & Jo Smiley

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Ms. Patricia Conroy
Ms. Jennifer Hubbard
Ms. Jane Johnston
Ms. Mary Rowen
Ms. Elaine Seckler

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Mr. Robert Schultz
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PAUL R RICE JR
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Ms. Emily Wolff

FLORENCE RINGLEY
Ms. Lisa Booy

ESTELLE SALZMAN
Steve & Sue Bertenthal
Ms. Donna Seitz
Ms. Stacey Silverman

CLARICE SMOOT
Ms. Lisa Marsellis

DON VAN DYKE
Mrs. Faith Shaw-Holmes

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.

Did You Know?

The IETF offers
FREE resources for
healthcare providers
to share with their
patients.

The IETF depends on healthcare providers and physicians who specialize in ET to help those affected better understand their condition. Healthcare providers can order quantities of any materials the IETF has listed on the website at any time. At your next visit, let your physician know how the IETF can help them provide a wealth of quality information and support...at no cost to them.



Learn more about free resources at
www.essentialtremor.org/for-healthcare-providers

ET Support Groups

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Support groups are not intended to provide medical advice or be a substitute for qualified medical care. The IETF 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.

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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 www.essentialtremor.org/volunteer.

Best Wishes



Rebecca Dye

After nearly eight years of service, Rebecca Dye, Communications & Volunteer Program Manager, has sadly left her position at the IETF. She will be moving on to a new, exciting opportunity in her local community where she can use her strong skills to continue to serve people.

Rebecca has been a critical asset to the organization as she managed all volunteers and support groups globalwide. Her sincerity and dynamic personality made volunteers comfortable and greatly appreciated. She was also the point person for creating each and every issue of *Tremor Talk*. From collaborating with researchers and healthcare providers on story ideas, to writing and designing the issue cover-to-cover. Her dedication to detail and creative ideas made *Tremor Talk* an award-winning magazine.

Rebecca has always had a deep passion for not only the ET mission, but for always putting the people in the ET community first. The impact she made is one that will be treasured and never forgotten. She will be greatly missed. Join us as we wish her the best of luck for the future. ☺

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