Bishop Kelly High School Students
Engineer Better Tools for Tremor

IN THIS ISSUE: Dr. Paul Donohue Spirit of Hope Award Winner
My Story: Andres Deik | Focused Ultrasound Surgery Trial
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Children remind us how simple direct action can be effective when approaching a challenge. For instance, the simple but powerful act of 8-year-old Joy Schaaf (p. 29) to get friends and family involved in our cause. A child like Joy tackles a problem such as fundraising with ease while most adults hesitate to act. The students at Bishop Kelly High School (p. 16) provide hope through the research and development of new assistive ET products.

They display great courage, tenacity, and resolve with such fearless determination for helping by simply saying, “I have ET, this is what it is and here is how you can help.” They make it look so easy. Oh, the lessons we can all learn. We hope you enjoy the wonderful stories about our youth and draw as much inspiration as we did.

Dr. Paul Donohue’s articles on ET, published in his syndicated newspaper column To Your Health once or twice a year, draw thousands of hopeful people to the IETF to seek more information and resources. Dr. Donohue is this year’s recipient of the Shari Finsilver Spirit of Hope Award (p. 12).

The IETF thanks the many people who have made significant contributions to increasing ET awareness during March (and year-round) across the U.S. These stories (p.4) are examples of what each and every one of us is capable of doing. The stories inspired us. I know they will inspire you to reach out and do what you can to increase awareness.

Thank you for your financial support. Without your generous giving, we wouldn’t be able to continue funding programs that provide education, support, and research that will eventually lead to a treatment and a cure. So your monthly, quarterly and annual donations are greatly appreciated.

As some of our members have said, “$5 a month is about 17 cents a day; an annual donation is 8 cents a day or $2.50 a month. It’s such a small price to pay to help fund these important programs.” When we ask for another donation, please simply give what you can and not a penny more. Together, we only have one huge goal and mission - to help the 10 million people that live with ET each and every day.

Sincerely,

Catherine Rice
Executive Director, IETF
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Dr. Paul Donohue discusses his life’s work and ET awareness.

Cover Photo courtesy of Dr. Paul Donohue.
Graphic Design by Pete Dulin.
Confidentiality Statement: The IETF does not sell or share any member or non-member personal information, including physical addresses, email addresses and phone numbers.

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I have several family members affected by essential tremor. This might seem a perfect reason to become a neurologist, but I must admit that my passion for neurology, and movement disorders, arose years prior to me realizing their diagnosis. When I started medical school in 1999 in my native Barranquilla, Colombia, all my father had was a hint of a quiver in his lips and hands. This movement actually seemed to bother us more than it bothered him. I didn’t realize at the time that this tremor was going to progress and affect his life, and those of us who care about him.

I moved to the U.S. in 2007 after joining the neurology residency program at Beth Israel Medical Center in New York City. Around this time, I started to detect my father’s slow but steady decline. During residency I traveled home about once per year. Every time I visited I noticed changes that others had seemed to overlook. Just like weight gain or loss, it is easier to notice someone has changed when you haven’t seen them in a while. On the other hand, my mentors emphasized the use of keen observation skills as a neurologist. I think I was applying those skills in my father’s case.

Each year I noticed his action tremor getting more pronounced. I saw him struggling more with activities that most of us take for granted. An enthusiastic steak lover, he gave up ordering steak at restaurants. Attempting to cut the meat frequently resulted in the embarrassment (for him and those sitting with him, especially my grandmother) of having food everywhere other than on his plate or in his mouth.

His tablespoon quickly became nothing but a decorative item on his table setting. The only way he could have soup was by drinking it out of a mug that he tried to stabilize tightly between both hands, as if drinking hot cocoa on a cold winter night. Eventually this too became problematic. Since the idea of drinking soup with a straw seemed anything but appealing, he was forced to give up another of his favorite foods altogether.

In fall 2010, he finally relinquished the strong will that has always characterized him and decided to look for help. Finding a neurologist was easy. Finding correct medication became more challenging than any of us ever anticipated.

Unfortunately, the problems weren’t limited to the dining table. Shaving became quite challenging. Frequent cuts prompted him to buy an electric razor. Reading the paper wasn’t any easier, but neither was trying to find CNN on the television with his remote.

It was clear by that time that, like three of his five siblings, he had essential tremor. However, when I suggested the possibility of starting a medication, the reply I got was, “Why would I take another pill when I can just have some Scotch whiskey or beer and make the tremor stop?” That was the case until summer 2010, when writing and drawing simply became impossible.

Having been born decades prior to the digital revolution, his learning to use the 3-D design software Autocad was simply out of the question. Sadly, he had to retire from his job as an architect. Unfortunately, along with retirement came depression.

In fall 2010, he finally relinquished the strong will that has always characterized him and decided to look for help. Finding a neurologist was easy. Finding correct medication became more challenging than any of us ever anticipated. He was initially prescribed a beta-blocker, but his cardiologist forbade him from taking it given his history of a slow heart rate. He was then prescribed primidone. In spite of starting at a very low dose, he lost consciousness after the first time he tried it. He then experimented
with a benzodiazepine, which made no difference at a low dose, but caused him unbearable drowsiness and fatigue at higher doses.

Just when it seemed like he was running out of options, he was given a prescription for gabapentin. In his case, it made him somewhat sleepy at first but soon enough this effect dissipated and gentle increases in his dosing led to remarkable tremor control. Now he is again able to use a knife and a fork (granted he uses the special, heavy weighted silverware I found for him online) and has started reading *The New York Times* and sketching on his brand-new iPad. He is also able to dial again from his new cellphone, which has extra-large number keys that make it hard to miss one.

An optimist at heart, he continues to do quite well. Now 82, he looks forward to learning to use the new messenger application for his Facebook account. As for me, seeing him struggle and adapt so gracefully to his condition gives me all the motivation to continue to learn about essential tremor as I continue my training as a movement disorders specialist. With ever increasing public awareness, technological advancements for individuals with disabilities, continuous evolution of DBS, and exciting treatment alternatives coming down the pike, I am confident that the future will be even brighter for individuals like myself, who are at increased risk of someday developing this disease.
MARCH is National Essential Tremor Awareness MONTH

EssentialTremor.org

The IETF’s mission is to provide global educational information, services and support to those affected by essential tremor (ET), and to health care providers, while promoting and funding ET research.

During March, we encouraged volunteers, people with ET, their families, friends, and associates to help educate the public, including health care providers, educators, community leaders, and those undiagnosed with the condition.

IETF Activities for National Essential Tremor Awareness Month

- Sent press release and media kit to national media
- Sent ET Awareness and The Scoop newsletter mailing to members, support group leaders, and healthcare professionals
- Posted ET Awareness materials for download at essentialtremor.org
- ET Awareness social media campaign (Facebook, Twitter) and email
- Sold ET Awareness bookmarks and bracelets
- IETF Washington, D.C. liaison Tom Bruderle contacted Congress
- Dr. Paul Donohue wrote about ET in syndicated newspaper column
- Distributed over 10,000 brochures to physicians so they can help spread awareness.
- Art in the Garden silent auction/fundraiser in San Francisco (3/31)
- Held ET Education Seminars in Kansas City and Philadelphia in March

Read more about Dr. Donohue on page 12.

ET Education Seminar in Kansas City

The IETF kicked off National Essential Tremor Awareness Month with an ET educational seminar Saturday, March 3, drawing 174 attendees from the greater Kansas City area.

Featured speakers from the Parkinson's Disease and Movement Disorder Center at the University of Kansas Medical Center were Director Rajesh Pahwa, MD, and Director of Research and Education Kelly Lyons, PhD. “Attendees had nothing but praise for Dr. Pahwa and Dr. Lyons. They found the information very beneficial,” says Carol Rucker, IETF Membership Coordinator. “Some even commented that they would like to have one of these events more often. The doctors shared a lot of information on research that the attendees were very interested in.”

Watercolor artist Fred Ekman donated his original art to the IETF for sale by silent auction at “Art in the Garden,” a Bay Area event hosted by the IETF to raise funds for essential tremor (ET) research and education.

“The mayor was very gracious and respectful to our group and read aloud every word on that certificate,” says support group member Betty Schwarz. “The event was special to us.”

Katy, Texas ET support group The Jewels of Katy join Mayor Don Elder, Jr. as he reads an official proclamation declaring March as Essential Tremor Awareness Month.
Eight-year-old Joy Schaaf in Greenville, Ohio took several steps to raise funds and awareness of essential tremor in her community. Read about her impressive accomplishments on page 29.

ET Awareness Arizona Proclamation
Chris Wertheim and Arizona support group leaders Jane Limbaugh (Sun Lakes) and Paul Leitch (Sun City) enlisted the support of State Representative Lela Alston to have the Arizona House of Representatives officially designate March as Arizona Essential Tremor Awareness Month. Congratulations!

For more updates on 2012 National Essential Tremor Awareness Month media coverage and events across the country, visit http://www.essentialtremor.org/NETA-Media-Coverage-and-Events.

Kansas State Representative
Kevin Yoder Speaks about ET in Congressional Record
“Mr. Speaker, today, I express my support and recognize March as National Essential Tremor Awareness Month.”
For the complete statement, visit:  http://capitolwords.org/date/2012/03/29/E488_national-essential-tremor-awareness-month

ABOUT REP. KEVIN YODER
On January 5, 2011, Representative Yoder was sworn in to serve his first term as part of the 112th Congress. Prior to being elected to Congress, Rep. Yoder served as a State Representative in the Kansas Legislature, representing Leawood and Overland Park. During the state’s recent economic crisis, he chaired the House Appropriations Committee.
Choosing to participate in clinical research is an important personal decision. 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 that you’re participating in the study?

Source: http://www.mayoclinic.com/health/clinical-trials/DI00033/NSECTIONGROUP=2

OTHER RESOURCES

CISCRP - The Center for Information and Study on Clinical Research Participation is a first-of-its-kind nonprofit organization dedicated to educating and informing the public, patients, medical/research communities, the media, and policy makers about clinical research and the role each party plays in the process.

www.ciscrp.org
www.ciscrp.org/patient/questions.html
www.ciscrp.org/patient/faqs.html
www.ciscrp.org/patient/educ_materials/index.html
Q&A: What are GABA Receptors?

Dr. Frédéric Calon is a biochemist-pharmacist and researcher at Laval University Medical Center in Quebec, Canada. He answers a question about GABA receptors from a reader with ET.

Question: Would you please expand on GABA receptors? What are they, what else do they do besides result in ET, and what good do they do? How could it happen that they are better or worse in their functioning? What does GABA stand for? How is it formed, grown, or developed?

Answer: GABA (gamma-aminobutyric acid) is an inhibitory neurotransmitter widely distributed in the neurons of the cortex. GABA contributes to motor control, vision, and many other cortical functions in the brain. GABA’s natural function is to reduce the activity of the neurons to which it binds.

GABA receptors are probably the most common kind in the mammalian nervous system. It is estimated that close to 40% of the synapses in the human brain work with GABA and therefore have GABA receptors.

GABA receptors are channel receptors. This means that when GABA binds to them, they change shape slightly to allow ions to pass through their central channel. This channel mainly allows negatively charged chloride ions to enter the neuron, thus reducing its excitability. Because of this property of the GABA channel receptor, GABA is classified as an inhibitory neurotransmitter, as opposed to excitatory neurotransmitters, such as glutamate, which augment the nerve impulses in the neuron.

It is thought by researchers that people with essential tremor (ET) have GABA receptors that show a decrease in their function as an inhibitory neurotransmitter, in a specific subregion at the core of the cerebellum called the dentate nucleus. As a result, this affects motor control and voluntary movement. Hopefully, GABA receptors in the dentate nucleus could be the target of specific drugs to alleviate tremor.

Focused Ultrasound Surgery

ABC World News with Diane Sawyer featured a story in late January 2012 on a study of MRI-guided Focused Ultrasound Surgery (FUS), a non-invasive, pain-free brain surgery. The television coverage generated significant interest in the surgery; however, FUS is only a study and not a treatment for ET.

Dr. Jeff Elias at the University of Virginia Health System is the principal investigator of one or more clinical trials investigating the use of Focused Ultrasound Surgery in Movement Disorders. In order to more efficiently communicate with patients who are interested in these trials, and to conduct an initial prescreening for these trials, the study team has developed a database.

Patients 18 years or older with a movement disorder are invited to be listed in the database. To participate, patients complete a questionnaire, either online or by mail, regarding clinical history relevant to clinical trial participation. Once your contact information is in the database, you will receive information about clinical trials as they become available. Please note that initial studies are small in size and enrollment may not be open at this time.

FUS TRIAL PRESCREENING DATABASE - University of Virginia IRB#16034.

To register in this database, go to: https://www.healthsystem.virginia.edu/focusedultrasoundtrial/. For more information, contact Johanna Loomba, Department of Neurosurgery study coordinator at FUSbrain@virginia.edu or call 434-243-1435, but email is encouraged.

ADDITIONAL RESOURCES

Study Information: http://clinicaltrials.gov/ct2/show/NCT01304758

Focused Ultrasound Foundation: www.fusfoundation.org/Essential-Tremor/essential-tremor
Many differences exist between essential tremor (ET) and Parkinson’s disease (PD), the former being at least eight times more common than PD.

Up to 20% of patients with ET may develop PD, and 10% report a family history of PD. However, whether ET is a risk factor for PD remains an unresolved and somewhat controversial issue. (Fekete R, Jankovic J. Revisiting the relationship between essential tremor and Parkinson’s disease. Mov Disord 2011;26:391-8).

As ET progresses, tremor frequency (number of repetitions per second) may decrease; however, tremor amplitude (magnitude/strength) may increase. Increased amplitude is associated with a decreased ability to manage fine, discrete motor tasks.

The characteristics listed in the table can help differentiate between parkinsonian and essential tremor, but a medical professional should be consulted for proper diagnosis.

In those with PD the most disabling symptoms are generally slowness, stiffness and problems with walking and balance, although tremor can also cause some disability. In PD, writing often becomes very small (micrographia) and therefore difficult to read.

The large majority of disability in patients with ET is a direct result of the tremor interfering with many daily activities. The severity of ET can vary greatly with some patients having a very mild tremor and therefore minimal to no disability to others who have such a severe tremor that they cannot perform the majority of their daily activities. The writing of a person with ET tends to be large and tremulous rather than slow and small as in PD.

Anxiety can increase ET and PD.

In addition to medications and botulinum toxin, deep brain stimulation is a therapeutic option for those with severe disabling ET or PD.

ET is often associated with a strong family history (familial tremor), but no specific ET-related gene has been identified.

A special picture or scan of the brain that measures the uptake of dopamine, such as DaTscan, can help to differentiate between ET and parkinsonian tremor. Dopamine is depleted in patients with parkinsonism but not in patients with ET; therefore, scans showing depletion in dopamine are most likely parkinsonism and normal scans would suggest a more likely diagnosis of ET. These scans are used as a tool to help the physician make an accurate diagnosis in difficult cases.

The information above is intended to describe the fundamental differences between ET and PD. To obtain a diagnosis, please consult a neurologist, preferably a movement disorder specialist.

Prepared by IETF Medical Advisory Board Members Arif Herekar, MD, Chairman and Head, Department of Neurology, Baqai Medical University; Joseph Jankovic, MD, Professor of Neurology, Distinguished Chair in Movement Disorders, Director, Parkinson’s Disease Center and Movement Disorders Clinic, Co-Director, Parkinson’s Disease Research Laboratory, Baylor College of Medicine, Department of Neurology, Houston, Texas; and Kelly Lyons, PhD, Research Professor of Neurology and Director of Research and Education for the Parkinson’s Disease and Movement Disorder Center at KUMC; and President, IETF Board of Directors.

<table>
<thead>
<tr>
<th>Parkinsonian Tremor Signs &amp; Symptoms</th>
<th>Essential Tremor Signs &amp; Symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>High amplitude. Lower, slower frequency.</td>
<td>Low amplitude. Amplitude is more variable, ranging from barely perceptible tremor to a high amplitude tremor. Higher, faster frequency.</td>
</tr>
<tr>
<td>Mostly seen at rest.</td>
<td>Mostly seen during action.</td>
</tr>
<tr>
<td>Generally involves slow movements (bradykinesia), rigidity (stiffness), and problems with walking or balance.</td>
<td>Tremor is primary symptom – slowness, stiffness and walking and balance problems are not commonly seen.</td>
</tr>
<tr>
<td>Rarely a family history (&lt;10%).</td>
<td>Family history of tremor reported in the majority of patients (&gt;50%).</td>
</tr>
<tr>
<td>Resting and postural (re-emergent); postural tremor observable after mean latency of 5 sec; rarely kinetic.</td>
<td>Postural, kinetic; postural tremor immediately observable; resting tremor less common.</td>
</tr>
<tr>
<td>Onset generally at ages between 55-65.</td>
<td>Onset most common in middle age but can occur at any time in the lifespan.</td>
</tr>
<tr>
<td>Usually starts on one side of the body and progresses to the other side; usually remains asymmetrical.</td>
<td>Usually affects both sides of the body initially (bilateral; symmetrical).</td>
</tr>
<tr>
<td>No effect on consumption of alcohol.</td>
<td>Alcohol often improves tremor.</td>
</tr>
<tr>
<td>Usually improves with levodopa treatment.</td>
<td>Improves with primidone and propranolol in some cases.</td>
</tr>
<tr>
<td>Hands affected more than legs, voice and head almost never affected.</td>
<td>Hands predominantly affected, but tremor also present in the head and voice; rarely in the legs.</td>
</tr>
<tr>
<td>Worsens with emotional stress.</td>
<td>Worsens with emotional stress.</td>
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Research Study Announcements

Brain Changes Study in People with ET or PD, Clinical Research at the Parkinson’s Disease and Movement Disorders Center at Beth Israel Deaconess Medical Center

Beth Israel Deaconess Medical Center in Boston is conducting a research study to study brain changes in people with essential tremor or parkinsonian tremor. The study will involve participating in one study visit. During the study visit researchers will assess tremor in the clinic using neurological history and exam and sensors attached to computers. Volunteers will also be asked to have blood drawn for genetic testing. If subjects are eligible, during the visit, a brain MRI exam will be performed in the MRI suite. Researchers will measure changes in brain structure to see if they are related to essential tremor or parkinsonian tremor.

You may be eligible for this study if you have a diagnosis of essential tremor or parkinsonian tremor with tremor in your hands and/or other body parts, are not pregnant and have no medical devices or metal in the body which are not MRI-compatible. Healthy control volunteers are needed and you may be eligible if you do not have tremor and are between the ages of 21-80. $75 is paid to you for each study visit completed as well as parking reimbursement.

Please call 617-667-9890 or email jmille12@bidmc.harvard.edu for more information.

Octanol Research Study - Dose Escalation Study of Oral Octanoic Acid in Patients with Essential Tremor

The National Institute of Neurological Disorders and Stroke (NINDS) in Bethesda, Maryland has extended its study on the effects of 1-octanol, a food additive similar to alcohol, that has been shown to improve tremor in some people and had few side effects. 1-octanol is converted to octanoic acid, and research suggests that octanoic acid itself might suppress ET with no significant side effects such as drunkenness. Researchers want to see what dose of octanoic acid is most useful in reducing ET.

Eligibility: Individuals at least 21 years of age who have ET that responds to treatment with alcohol. Participants must be able to stop taking certain ET medications during the study.

Design: This study requires three visits. Visit 1 is a screening visit that will take up to 5 hours. Visit 2 is a 2- to 3-day inpatient admission to the National Institutes of Health Clinical Center. Visit 3 is a followup outpatient visit 1 to 2 weeks after the hospital admission. At the screening visit, participants will have a physical exam, neurological exam, and medical history. Blood and urine samples will be collected. Participants will also have an alcohol dose test to measure the tremor’s response to alcohol. For the study visit, participants will enter the hospital for testing. Participants will have the study drug and test the tremor’s response to it. Frequent blood samples will be collected 1-2 weeks after leaving the hospital, participants will have a final followup study visit. Blood samples will be collected.

Visit [www.essentialtremor.org/octanol-research-study](http://www.essentialtremor.org/octanol-research-study) for inclusion and exclusion study criteria.

Contact(s): Patient Recruitment and Public Liaison Office, Building 61, 10 Cloister Court, Bethesda, Maryland 20892-4754. Toll Free: 1-800-411-1222. TTY: 301-594-9774 (local), 1-866-411-1010 (toll free). Fax: 301-480-9793. Electronic Mail: prpl@mail.cc.nih.gov

BYU Upper Limb ET Study - Characterizing Essential Tremor in the Shoulder, Elbow and Wrist

Steven Charles, PhD of Brigham Young University, Provo, Utah, is currently recruiting patients with essential tremor to participate in an experiment investigating the control of upper limb movements. The goal of this research is to better understand the movement impairments associated with essential tremor and improve assistive and rehabilitative devices for patients with this disorder. Subjects who participate in our experiment will be asked to make a number of upper limb movements under different conditions, freely or in interaction with objects or a robot, while recording various movement characteristics such as motion, force, and/or muscle activity.

The experiment consists of one session lasting less than 2 hours, is completely non-invasive, and is performed in the research laboratory of Steven Charles, PhD, on the campus of Brigham Young University. Only those who are 18 or older are eligible to participate. If you are interested in participating in this experiment, please contact Steven Charles at skcharles@byu.edu or (801) 422-7369.
My Participation in ET Research

David Van Fleet has had essential tremor (ET) and has been aware of the tremor nearly all of his life, but especially since high school and college.

“During an engineering drawing class my freshman year in college, the instructor asked me to draw a straight line freehand,” recounts David Van Fleet, who has pronounced tremor in both hands and slight tremor in his head and neck.

Van Fleet realized that something was wrong, but he wasn’t diagnosed with essential tremor (ET) for over thirty years. Currently, he works as a professor of management at Arizona State University in Mesa, Arizona.

“I have tried all or virtually all of the usual medications and while they help the tremor, the lethargy and dizziness are unacceptable side effects for a university professor. So for the past several years I have been off medication entirely.”

No longer able to reliably take notes by hand, he now uses a computer and taught himself to use his left hand for many tasks. Throughout his life, Van Fleet has actively supported ET research and has participated in several studies both at the National Institute of Health and at Mayo Clinic. He participated in the octanoic acid study conducted by Dr. Dietrich Haubenberger which was reported in the Fall/Winter 2011 issue of Tremor Talk.

“I recently had the opportunity to become a participant observer regarding medical research,” says Van Fleet. “Specifically I became a subject in a drug study at the National Institutes of Health (NIH). Before going into the details of my experience, some background would be useful.”

Research Study Background

Essential tremor (as opposed to Parkinsonian or other forms of tremor) responds to alcohol (ethanol). For some people with ET, a drink or two may reduce tremor. Because alcohol is addictive and damages the liver, it is not prescribed as a way of treating ET.

A search for an organic compound similar to ethanol—that might yield reductions in tremor without negative side effects—led to 1-octanol which doesn’t have the effects of intoxication. Researchers have observed that 1-octanol is changed to octanoic acid by the body.

“I participated in a study of octanoic acid,” says Van Fleet. “This was a Phase I/II study for safety and effectiveness. Phase III and IV (for effectiveness, risk, benefits, and optimum use) studies will follow depending on these study results.”

No compensation was offered for the study, but the NIH did cover travel and lodging expenses for Van Fleet and his wife Ella for the first two visits from September 27 through October 3.

“There also is no immediate benefit to me but hopefully the study will lead to better treatment such as lessening tremors with few side effects,” says Van Fleet. “Further, octanoic acid can be administered in pill form so a stronger dose with time release could be made available to provide longer reductions in a person’s tremor.”

The NIH ET Testing Experience

Van Fleet arrived on a Sunday afternoon and settled into his hotel. He was admitted at the National Institute of Health (NIH) the next morning. On Monday, he completed paperwork and later underwent tests for urine, blood, and EKG. After his vital signs were taken, a nurse and Dr. Dietrich Haubenberger checked Van Fleet’s tremor.

“Dr. Codrin Lungu, the official doctor overseeing the study, also came by and did a very brief check,” says Van Fleet.

After lunch, Van Fleet was tested to establish a base line for his tremor. He was wired with ten electrodes and two wrist sensors to measure tremor and
run a battery of tests. He says, “The tests start with the hands in front, then hands under the nose, and then touching from nose to the doctor’s finger back and forth with each hand.”

Van Fleet drew spirals with each hand, recorded a handwriting sample, and tried to barely touch an X on a piece of paper. Other steps involved video recording his hands immobile for two minutes, keeping his hands immobile again while wearing weights, drawing spirals on a computer, and finally pouring apple juice from one cup to another with each hand.

For the alcohol portion of the test, Van Fleet drank one small bottle of vodka in orange juice and waited twenty minutes. The earlier actions were repeated. He says, “They decided that one drink was enough to establish that alcohol did indeed reduce my tremors.”

To evaluate the aftereffect, the battery of tests was repeated every twenty minutes for three hours to determine how long the effect remains. The wrap-up involved memory and cognition tests to establish that the subject was not intoxicated.

Two days later on Wednesday, Van Fleet returned for a second hospital visit. After admission, he had a peripherally inserted central catheter (picc) line inserted from around the elbow and up a vein to the top of the heart. The picc line remained inserted for the following two days.

“The picc line insertion was done by a major in the National Health Service Corps,” says Van Fleet of the 45-minute procedure. “He used ultrasound to locate the best vein, numbed the area with Xylocaine®, covered everything with protective dressing, inserted the line, and then used an x-ray to verify that it was properly placed.”

Van Fleet and his wife had dinner in his hospital room before she returned to the hotel. After a late evening snack, Van Fleet’s vitals were taken and he went to bed. At midnight, a glucose drip was inserted into the picc line and he began a 12-hour fast.

On Thursday, Dr. Haubenberger arrived and attached electrodes after Van Fleet’s vitals were taken in the morning. A nurse conducted the same battery of tests as on Monday with vitals checked and blood drawn via picc line every hour. The testing cycle ran every twenty minutes with the experimental drug or a placebo administered from 5:30 AM until 8:30 AM. More tests followed from 9-11:30 AM. Van Fleet recalls being bored at points, but he chatted with the nurse and doctor at intervals about a variety of subjects to pass time.

At night, a nurse arrived to take Van Fleet’s vitals and again at midnight a glucose drip was inserted into the picc line. The patient began another twelve-hour fast.

Friday morning’s routine duplicated the previous day’s schedule. The picc line was removed after lunch. Once Van Fleet’s blood results showed that he was back to normal, he was released from the hospital.

After viewing local sights, Van Fleet and Ella flew home. During his third and final visit to the NIH, Van Fleet had more vitals taken, blood work done and a final debriefing by a nurse and Dr. Haubenberger. Afterward, he flew back home to Phoenix.

Research Study Reflections

It took two years to get final approval for this study. “That involved reworking it to meet NIH’s very high standards,” says Van Fleet.

The NIH sets standards and requirements above and beyond what might seem sufficient. For example, the third visit could seemingly be done by having a local doctor do the blood work and EKG and then conduct the debriefing over the phone.

“But labs that do blood work are not 100% identical. So there could be some unexplained variance if different labs were used,” says Van Fleet. “In addition, the NIH and the Food and Drug Administration feel that the researcher should personally see and talk with each subject before releasing them from a study. It may be more expensive but provides greater reliability and confidence in the final results.”

Van Fleet learned about evidence-based medicine from this experience. “Naturally enough researchers would be advocates of the use of current best evidence in making medical decisions. That evidence would include the results of their research,” says Van Fleet. “It is interesting that the concept of evidence-based decision making has grown from medicine to management.”

In the end, Van Fleet completed his role in the research study and “came away with very positive impressions about the state of medical research of this type.”
Dr. Paul Donohue

This year’s Shari Finsilver Spirit of Hope Award recipient Dr. Paul Donohue writes a daily column titled *To Your Health* that is syndicated to more than 175 newspapers. The question-and-answer series is one of the oldest health columns in North America, having first appeared in the 1950s. Dr. Donohue took over the series thirty years ago.

Dr. Donohue is board-certified in his primary specialty, internal medicine, the specialty that emphasizes diagnosis and non-surgical treatment of illnesses. He also is board-certified in the subspecialty of infectious diseases.

He graduated from the University of Michigan Medical School in Ann Arbor, Michigan. He has a master’s degree in public health from Tulane University in New Orleans and did advanced work on infectious diseases at the University of California, Davis. After completing medical school, he served two years in the Army Medical Corps and 18 months as battalion surgeon in the 173rd Airborne Brigade during Vietnam. He was awarded two Bronze Stars, one of which was for valor during combat.

The International Essential Tremor Foundation presents the Shari Finsilver Spirit of Hope Award to Dr. Paul Donohue in recognition of his ongoing effort to educate the public and raise awareness about essential tremor (ET).

Dr. Donohue’s syndicated newspaper column *To Your Health* frequently addresses questions about ET from readers. His column reaches a nationwide audience where they learn about the condition and understand that they are not alone.

Addressing ET openly gives people hope that they can be properly diagnosed, get treatment, learn more about the condition from the IETF, and find support from others with ET.

Each year, the Shari Finsilver Spirit of Hope Award is presented annually to the person that embodies Shari’s spirit and commitment to combating ET, supporting the IETF, and spreading hope to those with ET and their loved ones. Shari was the first recipient of this prestigious award.
What drew you to the field of medicine and public health originally?

Dr. Donohue: My intention in going to medical school was to become a psychiatrist. After four years of school, I realized psychiatry was not for me. I chose internal medicine as best suited to me.

You have written the column To Your Health for nearly two decades. Have the nature of questions from readers changed over that span?

Dr. Donohue: The nature of the majority of questions has stayed the same—heart disease, kidney disease, high blood pressure, diabetes and all the common illnesses. Things that changed during my newspaper career were newly described illness. I’ve actually been writing the column for three decades. I started well before anyone knew of AIDS and other infectious diseases like West Nile Fever. Those are only two examples. The introduction of new techniques like coronary artery surgery along with the introduction of new medical devices like the heart defibrillator brought questions that were new to the public, doctors, and me.

Do you find that readers are more knowledgeable today given access to online information about medical conditions and treatments?

Dr. Donohue: People are much more knowledgeable today. They’re exposed to discussions on all medical ailments through TV — professional medical discussion, news programs and dramatic programs whose theme is based on medical topics.

Is misinformation problematic for consumers seeking health advice and treatment from online or other sources?

Dr. Donohue: Since Internet information is often provided by people with little to no training and since the printed word on a computer screen tends to have an aura of infallibility, lots of misinformation is widely distributed. On the other hand, lots of good information is transmitted by people with impressive credentials. You have to be careful who is saying what.

After writing the column for so many years, why do you continue this work?

Dr. Donohue: I continue to write the column because it’s given me an opportunity to stay up-to-date in many fields and to affect the lives of more people than I would ever see in a private practice. I like to study medicine.

What is the most rewarding aspect of your role as a columnist? And the most challenging?

Dr. Donohue: The most rewarding aspect of being a columnist is to hear from people who sought treatment for an illness they didn’t realize they had or for an illness they thought they had but did not. The most challenging thing is try to stay current with the latest treatments and newly recognized conditions.

Essential tremor is a condition that affects an estimated 10 million people in the U.S. Yet, it is still not well known or diagnosed accurately. How can the public learn more about the condition and/or receive proper diagnosis of ET?

Dr. Donohue: If it weren’t for the International Essential Tremor Foundation, the number of people who know nothing of this illness would be a hundred times larger than it is. My uncle had essential tremor. Even after I became a doctor, he insisted he had Parkinson’s disease. Nothing I said would convince him otherwise. It still amazes me how many people recognize Parkinson’s disease and how relatively few people know about essential tremor, a more common disorder. I believe more doctors are now diagnosing this illness and that’s how the general public will learn about it.

In the spirit of hope, what thoughts can you share with the many people that have ET, a condition that can be treated but not cured at this time?

Dr. Donohue: I wish people with this condition would recognize it for what it is, usually an eminently treatable disorder even for those with the most disabling tremor. I think that will happen in a realistically short time.
Lauren Gray of Gainesville, Florida attends the University of Florida, College of Veterinary Medicine. Her scholastic activities include roles as the Treasurer and Vice President of the Student Chapter for the Association of Shelter Veterinarians. As an undergraduate, she also served as President and Vice President of the Pre-Veterinary Medicine Club in subsequent years.

Gray has explained to others for years that she is not nervous or jittery because of caffeine. Her shakiness is due to essential tremor. She didn’t know this fact for most of her life, including the clinical portion of her veterinary education where she performed spay and neuter procedures on dogs and cats.

As the shaking in her hands progressed and affected fine motor control, she grew concerned about her ability to perform as a veterinarian. “Being accepted into veterinary school is no small feat, but I worked hard through my undergraduate program to graduate cum laude with a degree in zoology. I felt as though nothing could hold me back from my dream. It is for that reason that the progression of my seemingly benign hand tremor was so scary for me.”

Gray met with a neurologist that diagnosed her as having ET. With medical treatment, the tremor is now intermittent and generally does not hinder her abilities. Confidently, she views her professional career ahead with bright prospects.

“To this day, I have successfully completed two canine spays, two canine neuters, two feline spays and nine feline neuters including my own cat, Otis (pictured above). I am confident that ET will not hinder my future, and I will go on to be a very successful veterinarian.”

Brandon Affeldt of Westfield, Massachusetts plans to attend the University of Massachusetts-Amherst. He wrote about ET’s impact on his life.

“It does affect the way I compete in sports, write in school, speak in front of a crowd, and even complete everyday tasks like using utensils at the dinner table. Tremor may not shorten my life, but it causes monotonous tasks to become difficult and frustrating. Since being diagnosed, I have learned that through perseverance and especially patience, I am able to overcome the setbacks that constant hand tremor involves.”

His outlook on life with ET is mature, confident, and inspiring. “I have taught my body to become used to the constant shaking of my hands; it has become as much a part of me as my own name. In my heart of hearts I believe that essential tremor has given me an advantage over most people. Having it has taught me to become disciplined, patient and determined. I never take no for an answer, and I have a never-say-die attitude. I carry these attributes with me throughout every aspect of my life, and it has made me a stronger, more complete person.”
Stephen Remillard’s scholarship award will assist him in his goal of receiving a post-graduate Diploma of International Hospitality at Auckland University of Technology in Auckland, New Zealand.

He has worked to raise awareness and funding for essential tremor as well as other conditions through marathon running. He elaborates on this pursuit in his application essay.

“My goal and aspirations were to connect with individuals whose lives have been affected by ET and choose to use exercise and running to combat their symptoms. This idea was based on my love for running and my experience living with essential tremor.”

Remillard, who was diagnosed with ET at a young age, writes that teasing in elementary and high school because of his shaking hands and voice affected him socially. Yet, the greatest impact of ET involved his athletic pursuits.

“As a competitive soccer player for more than half my life, a winter sports enthusiast, a long distance runner and an all around healthy individual, I never figured a disorder like ET would stand in the way of my life endeavors. After graduating high school, I continued on to college to play soccer but decided that I was more interested in pursuing a military career. Unfortunately, this was not in my future. After several attempts of enlisting, I was medically rejected because of my ET.

“That experience ultimately changed my life path. I decided to return to school and eventually graduated with a Bachelor of Science in Business Administration. I am continuing to expand my education by studying abroad to receive a post-graduate Diploma in Auckland, New Zealand.”

Elisabeth Shabi of Canton, Georgia plans to attend Reinhardt University. She is an academic tutor for Cherokee FOCUS, a non-profit organization, pianist and choir member at her church, and a Georgia Social and Behavioral Sciences Club member.

In her application essay, Shabi listed many of her roles in life such as being a “struggling pianist with shaking hands.” She wrote, “When I confided to someone what was happening to me, that very wise person suggested that this was God’s way of telling me to calm down. I am convinced he was right.” “So now, when life is rolling over me, filling my heart with worries, and I look down and see my hands shaking, I sing. Three simple words sung by everyone’s old heroes: Let it Be. When it seemed as though tremor was just one more disaster heaped upon an already unmanageable pile of stress, I had to learn to accept it instead as a reason to take a deep breath and let the heartaches go. I’m still learning that I can’t always ‘fix’ everything, and that I can’t let my happiness or stability rest upon that of my loved ones.”

The IETF thanks our first generous scholarship donor Lillian Courtheoux. To learn more about the IETF Scholarship Program, download an application, or donate to the Program, visit www.essentialtremor.org/Scholarship or call the IETF at 888.387.3667.
Bishop Kelly High School’s Engineering Design team, based in Boise, Idaho, is developing two tools that may one day assist people with essential tremor (ET). MagWrite 2.0 is a device to help those with various types of tremor write more legibly. MagMouse is designed to work with a wireless computer mouse to lessen the effects of tremors while using a computer. These tools are being developed by the team as they participate in the 2011-2012 Lemelson-MIT InvenTeam program.

Each year the Lemelson-MIT InvenTeam Program awards grants to teams of high school engineering students. Thirteen Bishop Kelly students and two advisors, Dr. Guy Hudson and Dr. Lawrence Neznanski, comprise one of sixteen InvenTeams nationwide chosen for the exclusive opportunity to participate in the program. Each team receives grants up to $10,000 each to invent technological solutions to real-world problems of their choosing.

“The Bishop Kelly InvenTeam chose to develop magnetic assistive devices for people with tremor in their hands and arms, due to ET, Parkinson’s disease, or injury,” says Dr. Hudson.

This project consists of a nine-month process of designing and testing, followed by a debut of the finished prototype in June 2012 at the EurekaFest held at MIT in Boston. The IETF donated funds and is a co-sponsor of the engineering team.
InvenTeam students rely on inquiry and hands-on problem solving as they apply lessons from science, technology, engineering, and math (STEM) to develop invention prototypes. Interactive, self-directed learning coupled with STEM curricula are essential for experiencing invention.

Bishop Kelly has had an Engineering Design class since 2008 and has worked on assistive technology for persons with tremors each year. Participation in the InvenTeam program began in June 2011 when Dr. Hudson attended a training session at MIT. A month later, the students helped prepare the grant application with guidance from their advisors. For their current work, the students chose to improve on their original design for the MagWrite assistive writing device developed last year. Also, they are working on the MagMouse model.

“The nine-month research and development phase is where we are testing to ensure we have a complete, viable product,” says Bishop Kelly student Patrick Tavelli. “It consists of testing variables of the magnetic damping properties of several materials (we looked at copper and aluminum).”

“Also key in the development of the product during this time period are our prototypes. Using these early forms of our device, we catch little details that we missed evolving the product over time,” adds team member Taylor Takasugi. “We will shortly begin testing the new devices with volunteers who have tremors to see the effectiveness.”

The devices work by using the scientific principle of magnetic damping. “When a strong magnetic field moves over the surface of a conductor, eddy currents are generated which in turn create a magnetic field in the conductive surface,” says Tavelli. “This field opposes the motion of the moving magnetic field. This is ideal for damping tremors as the damping force is proportional to the speed of the tremor; the faster the motion, the stronger the damping force.”

Takasugi discusses magnetic damping for the MagWrite 2.0 and MagMouse devices. “We are testing this with and without other software solutions that lessen the mouse sensitivity.”

The team uses several testing methods to generate data and feedback for both devices. The first test measures the effect of damping by attaching the device (or similar jig) to a cord which runs around a smart pulley to a mass. In simple terms, a weight is dropped to pull the device across its base.

“We use this test to measure the effectiveness of various things; magnet size/strength, base material, base thickness, etc.,” says Takasugi. “The most important testing, though, will be with our volunteers who have tremors. We will look at ergonomics and perform a variety of qualitative and quantitative tests with them to look for improvement in writing legibility and ease of use.”

When the final prototype is completed, the team plans to take the device to an assistive living center near the school to, hopefully, obtain lots of data and user feedback.

“This will give us feedback on the finer points of the design; style, ergonomics, effectiveness, etc.,” says Tavelli. “We currently consult with Dr. Lauren Seeberger of the Boise Elks Hospital, an expert in tremors of all types. She has been very helpful in educating us about tremors and introducing us to clients willing to help with our testing.”

Product development has led to design challenges such as the arrangement of magnets in the devices. “Last year’s final prototype for the MagWrite suffered from an issue, we named ‘torquing,’ in which the front of the device swiveled in an undesirable manner when in use,” explains Tavelli. “To correct this, we had to experiment with several prototypes.
and new magnet arrangements; we feel we have addressed and corrected this in our latest prototypes.”

“Another hurdle was committing the time; with the majority of our team being seniors, college applications and fall semester courses drew a lot of energy and time away from this project,” says Takasugi. “Luckily, we were still able to continue researching and developing. Now that the fall semester is finished and college applications are turned in, the team is really stepping up efforts and we are making good progress.”

Working with funds granted by the Lemelson-MIT InvenTeam program, the Bishop Kelly team anticipates being able to produce several prototypes for testing and exhibition within budget.

They hope to produce an improved model of last year’s MagWrite device where the pen is attached to the writing device. The user simply engages the pen by squeezing the device. Another model would enable the user to still hold the pen or pencil with several fingers and grip the damping device to steady their writing. Finally, they will produce a model for the MagMouse.

“We will also be working towards reducing the cost of the final device as much as possible, an important aspect of the engineering design process,” says advisor Dr. Hudson.

The entire process has provided a hands-on learning experience of great value to the students. “I particularly have learned quite a bit about the engineering process and how things get done in the real world,” says Tavelli. “It has been great to learn this lesson: Things don’t happen by themselves. I need to get moving and work to get this done.”

He adds, “I have also found this course and our many projects and competitions to be inspiring, especially given the field I want to pursue in college is Bio-Medical Engineering.”

Overall, the student team is appreciative of the learning opportunity afforded by the grant and supporting sponsors. “We have been very lucky to participate in such a wonderful program, and it has been great to see how much we can do,” says Dr. Hudson. “Service to others is an important part of our school’s mission; working with assistive technology to help others helps us to fulfill that. We look forward to seeing where the next four months take us.”

To learn more about the Bishop Kelly Engineering Team and projects, visit http://bkengineeringinventeam.blogspot.com. About the Lemelson-MIT Inventeam Program: http://web.mit.edu/inventeams
Deep Brain Stimulation: A New Life for People with Parkinson’s, Dystonia, and Essential Tremor is a detailed overview of the many aspects of this surgery (DBS). The book, published in 2012 by DemosHealth, was written by Kelvin L. Chou, MD, Susan Grube, RN, MSN, and Para G. Patil, MD, PhD.

This book offers history of the procedure, how it works, what impact it can have on medical conditions including essential tremor (ET), health risks, complications, preparations, frequently asked questions, and long-term clinical and side effects. Chapters explore questions such as patient qualifications for the surgery and what to expect during the surgery.

The authors write: The best way for you to find out if you are a good candidate for DBS is to go to a center where they have a multidisciplinary team that specializes in the evaluation and care of individuals undergoing DBS.

The authors also examine when it is appropriate to consider DBS if medications are not controlling symptoms. They write: You should only consider surgery for essential tremor if:

1. You have tremors that limit your ability to do things.
2. You have tried at least three medications for essential tremor and none of them have worked, or you have had side effects that prevent you from taking higher doses.

The criterion of tremors that are limiting depends on several factors including age, daily activities, work roles, and other health issues. The authors specify: Because of the risk of surgical complications, you should only consider DBS if you cannot live with your tremors the way they are.

Chapter 3 comments on the relationship between dosage of ET medication and its effect on tremor. The chapter includes a table of common medications used for essential tremor with upper limits of the dose by which the authors would expect an effect on tremor. They write: If your physician has not prescribed the doses of these medications to the doses listed, you may consider going back to your physician to try higher doses before going for DBS evaluation.

Doses of Essential tremor Medications
- Clonazepam: up to 6 milligrams daily
- Gabapentin: up to 2700 milligrams daily
- Mirtazepine: up to 45 milligrams daily
- Primidone: up to 350 milligrams daily
- Propranolol: up to 320 milligrams daily
- Topiramate: up to 400 milligrams daily

DBS Selection Criteria for ET
Most DBS centers will consider you for DBS if:

1. You have a diagnosis of essential tremor, and your tremors limit or interfere with your activities.
2. You have not responded to high doses of at least three tremor medications.
3. You do not have dementia or active psychiatric illnesses.

The book discusses the DBS evaluation process by a movement disorder specialist for the surgery. A neurosurgeon that specializes in DBS surgery also conducts an evaluation and examination. The risks and benefits of DBS surgery should be discussed with you, and the neurosurgeon should also talk to you about the most appropriate target in the brain. At this visit, you should ask questions about the surgeon’s experience and complication rate. A neuropsychological examination considers any potential cognitive problems and mood disorders. Another step, magnetic resonance imaging (MRI) of the brain, aids the neurosurgeon in planning surgery and their approach.

The book explains that DBS centers may have differing practices. Ultimately, the authors state: We believe that the best outcomes are seen at a center that conducts a comprehensive evaluation prior to surgery. If you want to consider DBS and think it is appropriate for you, we would encourage you to seek out a DBS center that specializes in this type of procedure and make sure you feel comfortable with their approach.
This grant year, the International Essential Tremor Foundation has not received enough funding to support all fifteen promising ET research proposals we have received. It is imperative to nurture these researchers so they will continue to search for a cause that will encourage the development of appropriate medications and eventually a cure. If we don’t, they will turn their expertise and energy to other projects.

Research without funding is like a seed that gets no water or sunlight. It is a missed opportunity and one that may not return.

Your support, as well as the support of your family members and friends, are vital in order for the IETF to fund these projects.

Donate today. Call the IETF at 888.387.3667 with your tax-deductible donation in any amount. Or, visit www.essentialtremor.org/donate to support vital research now that can make a difference tomorrow.

Thank you for your support on behalf of the 10 million people in the U.S. with ET.
Thank you to everyone that established memorials and contributed funds to honor loved ones on behalf of the IETF from September 23, 2011 to March 31, 2012. If your donation was processed after March 31, 2012, it will be listed in the next issue of Tremor Talk. (Honoraria or Memorials listed in uppercase, donors listed in italics.)

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Essential Tremor is a neurological condition that causes shaking of the hands, head, and voice. Learn more.

• ET is often misdiagnosed as Parkinson's disease (PD), but it is eight times more common than PD.
• ET affects people of all ages.
• ET is often genetic.
• Eating, drinking, typing, grooming and writing is difficult, if not impossible, for people with ET.
• Many people with ET are embarrassed by their shaking and become socially isolated.

ET Awareness Bookmarks
Bookmarks with ET facts printed on one side to raise awareness of ET. Share with friends, family and people at your physician’s office, hospital, library, school, office, or community center. Help the IETF to educate the public about ET.

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  - Basic Membership benefits plus
  - Reusable green IETF logo bag

- **$100 Silver Membership**
  - Bronze Membership benefits plus
  - IETF Anniversary Edition of Essays

- **$250 Gold Membership**
  - Silver Membership benefits plus
  - *ET: The Facts* by Drs. Mark Plumb and David Bain

- **$500 Platinum Membership**
  - Gold Membership benefits plus
  - Richard Crandell Music CD: Essential Tremor

- **$1,000 President’s Club Membership**
  - Platinum Membership benefits plus
  - One IETF apparel item

  Size: __________

Step #2: Member Information

In order to provide you with the most appropriate information on our products and services, please tell us a little more about yourself. **Please note: The IETF does not share or sell member information to any third party.**

Please check one: _____ Male   _____ Female   Do you have ET? _____ Yes   _____ No

Date of Birth ____________

At what age did you first notice signs of ET? _______   At what age were you diagnosed with ET? ____________

How many family members have ET?   Living _________   Deceased _________

How many generations of your family are affected by ET? (Living and deceased, including yourself) ________

Please check one:

- Asian, Pacific Islander _____
- Black _____
- Hispanic _____
- Native American _____
- Caucasian, non-Hispanic _____
- Other (please explain) _____

Over Please
Step #3: Additional Donation

Donation amount: $ ______________

I would like my donation to fund: (Please check one) Greatest need _______ Research Initiatives _______

☐ in honor of ________________________________ ☐ in memory of ________________________________

Please send an acknowledgement to:
Name: ______________________________ Address: ___________________________________________
City: ________________________________ State: _____ Zip: ________ Country: ____________________

Step #4: Gift Memberships

Add a gift membership for a family member or friend for only $15 per Basic Membership

Name: ______________________________ Relation to you: ______________________________________
Address: ______________________________ City: __________________ State: _____ Zip: ________

Name: ______________________________ Relation to you: ______________________________________
Address: ______________________________ City: __________________ State: _____ Zip: ________

Name: ______________________________ Relation to you: ______________________________________
Address: ______________________________ City: __________________ State: _____ Zip: ________

Step #5: Total Donations and Mail to the IETF

Name: ______________________________ Phone: (______) ____________________________

Mailing Address: ______________________________ City: __________________ State: _____ Zip: ________

Email: ________________________________ (By providing your email address you acknowledge that you wish to receive electronic communications from the IETF. You may unsubscribe at any time.)

☐ My check is enclosed (payable to IETF)         Charge my ☐ M/C ☐ Visa ☐ Discover ☐ Am Express

Card holders name: ______________________________ Acct #: ____________________________ Exp: _________

Billing address: ______________________________ City: __________________ State: _____ Zip: ________

Total Donation: $ ________________
An ET support group is an informal, self-managed, self-help group. It is not a therapy group or a 12-step program. It is run by and for people that have ET or that have a family member or friend who has ET.

An ET support group is a place to be you. The group is a place where people feel welcome and accepted, can talk openly and can exchange ideas about the challenges of living with ET. It is a place where privacy and confidentiality are respected.

An ET support group is a source of information and practical suggestions about ET and about the IETF. It is not a substitute for medical treatment or for personal or health counseling.

An ET support group is a circle of friends where people with ET and their supporters can listen, laugh and empathize together.

An ET support group is as unique as its members. The interests and capabilities of support group members vary greatly and change over time. Rather than a standard approach, each group offers the specific support its members need at any given time.

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For information on starting a support group in your area, contact:
Rebecca Dye / rebecca@essentialtremor.org or call toll-free 1-888-387-3667.
Inspiring Young Girl Spreads ET Awareness

Story and photography by Linda Moody. 
Reprinted courtesy of *The Daily Advocate*, Greenville, Ohio.

Originally published March 9, 2012 – Joy Schaaf, a third-grader at East Elementary in Greenville, wants the public to help her celebrate National Essential Tremor (ET) Awareness Month in March.

The 8-year-old daughter of Teresa and Raymond Schaaf, was diagnosed with essential tremor in the fall of 2010 at the age of 6. She has done and is doing things to make the public become more aware of the disorder.

Joy, according to her mother, was invited to speak at the board of education meeting last Thursday, and a book Joy penned last year will be read by her to her class this week.

It was her teacher last year that observed Joy shaking while doing fine motor activities.

“She’s not too severe yet,” said her mother. “She needs help pouring things and needs different accommodations.”

Joy has written to various media and has even asked the Darke County commissioners to make March Essential Tremor Awareness Month in Darke County. That will be signed soon.

She will also be setting up a table at the Swinging 8’s Square Dance Club on March 24 to pass out bookmarks and fliers about essential tremor. “I am going to put out posters around the county and read a book to my classmates that I wrote last year,” she said. “People can find my book at the Greenville Public Library and I donated one to the Springfield library. Eikenberry’s is going to put fliers in their grocery bags for me, and Bob Evans is allowing me to have a fundraiser April 13-15.”

She said if people would like to help with the fundraiser at Bob Evans in Greenville, they need to take her flier to the restaurant when they eat those three days. “Bob Evans will donate 15 percent to the International Essential Tremor Foundation,” she said.


She wants to try out for the East Echoes when she is a fourth-grader, and will sign up for cheerleading.

Her favorite subject is science, and she likes to read about cheetahs and leopards. “I can’t tell if my writing is shaky or not and I don’t think the teachers recognize it either,” she said.

At recess, she likes talking with her friends and playing freeze tag. Her evenings are spent doing homework and on Wednesdays, she goes to Logos Bible study at her church.

Joy used to live in Springfield and is now living in the Union City, Ohio, area, with their chihuahua, Princess Ginger.

ET, according to Joy in a letter to *The Daily Advocate*, is where people shake with their head, hands and voice.

“If a person has ET, they cannot control their shaking,” she said. “About 10 million people have ET in the United States. ET is not a disease like Parkinson’s. You can inherit it from your family and it is not contagious. Most people don’t know what ET is so I want to raise awareness for it.”

While ET is not life-threatening, it is a serious and progressive condition that can significantly affect a person’s quality of life…socially, professionally and emotionally. People with ET often have difficulty with everyday activities, such as getting dressed, drinking, speaking or writing.

It was noted that despite the numerous people directly affected by ET, there is still little awareness of the disorder. In fact, ET is often misdiagnosed as Parkinson’s disease, but ET is eight times more common than Parkinson’s.

Getting proper diagnosis for tremor is a key step in seeking treatment, managing the condition and raising awareness with others to foster understanding. It afflicts people of all ages, including newborns.
Look for information on our popular Tulips for Tremor annual fund raiser to benefit ET research initiatives and awareness programs.