

July 2011

Dear Friend of the IETF,

A few weeks ago we did an impromptu Facebook survey, asking how you react when a stranger asks about your tremor. Out of the 199 people who responded, 78.8% said they come right out and explain what essential tremor is. This is very encouraging! We are often asked why so many people are completely unaware of this condition when it affects the lives of millions. The answer is plain and simple; ET is not life-threatening so the sense of urgency is just not there. But this anecdotal survey shows that awareness is spreading because you are talking about it. Essential tremor may not have celebrity spokesperson, but we have something better ... we have you!

The key is to keep on talking. Talk to your friends, family and co-workers about essential tremor; pass on a **bookmark**, a **bracelet** or brochure. Not only will it relieve you of the stress of trying to keep your tremor under wraps, but chances are (statistically speaking) they already know someone with ET. Whether you're a teacher, business owner, construction worker or professional dog walker ... you're the face of ET ... you're our celebrity ... and it is your collective voice that can change the world for the next generation. So, keep talking!

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### Octanoic Acid Study Produces Desired Results

Many essential tremor patients have noticed a reduction in tremor when they drink a glass of wine or have a cocktail with dinner. Many neurologists actually encourage essential tremor patients to have a drink in social situations to help ease their tremor temporarily and take the edge off any social anxiety they may be feeling as a result of the condition. But why does a moderate amount of alcohol have such a noticeable effect on ET?

Researchers are exploring the answer to that and many other questions right now. Today, researchers are studying Octanoic Acid, a metabolic byproduct of alcohol (1-octanol), for use as a new treatment option for those with ET. This treatment is not available to the public as of yet, but the initial study results are very promising.

**Read More: (<http://essentialtremor.org/read.asp?docid=862>)**

According to a report published in *Medscape Medical News*, a small proof-of-concept study suggests safety and some potential benefit in terms of efficacy from administration of octanoic acid, a metabolite of the long-chain alcohol 1-octanol, in patients with essential tremor (ET).

A single dosage was well tolerated. The primary desired outcome, postural tremor power measured by accelerometry at 80 minutes, was not met; however, a greater benefit was seen for later periods out to 5 hours.

"We did have some suggestion that there is efficacy, that there is some superiority for octanoic acid in secondary outcome parameters, which mainly are at later time points,"

says study author Dietrich Haubenberger, MD, from the National Institutes of Neurological Disorders and Strokes (NINDS). Haubenberger explains that the octanoic acid begins to take noticeable effect later than expected, anywhere from two and a half hours to five hours. The strongest effect for the right hand was recorded even after five hours.

Alcohol has been long identified as an agent that provides temporary relief from tremor symptoms for patients with ET. Of course, regular use of alcohol to treat ET presents problems. Studies have shown that 1-Octanol, a type of alcohol that is rapidly converted to octanoic acid, is effective in providing tremor relief. Researchers suggest that octanoic acid may be the active substance.

The study, designed to test the safety, efficacy and action of drugs in the body, was conducted to objectively measure tremor rather than functional outcomes or clinical scores.

Dr. Rodger Elble, of Southern Illinois University School of Medicine, is an ET researcher and member of the IETF Medical Advisory Board. As co-moderator of the study session, Dr. Elble remarks that “this was only a single-dose study, and the efficacy of octanol/octanoic acid needs to be confirmed in a longer randomized, placebo-controlled trial.”

At this point, it remains unclear from the study whether all ET patients respond to this treatment or only those that respond to ethanol, a form of alcohol.

These findings were presented at the Movement Disorders Society 15th International Congress of Parkinson’s Disease and Movement Disorders.

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## Tulips for Tremor: A Roadmap to Hope

Okay Montana, New Mexico, South Dakota and Nevada ... your spot on the map is looking pretty bare! As an addition to our Tulips for Tremor campaign, this year we are commemorating every Tulips donation with a mark on the official IETF map! Every dollar donated funds desperately needed research to find better treatment options and an eventual cure for this life-altering condition. Funds from this campaign also provide additional resources to help spread ET awareness. Show your support and make your mark! And when your children and grandchildren no longer have to face a life of challenges with ET, you’ll be glad you did.

### **Check out the Map**

**(<http://maps.google.com/maps/ms?msa=0&msid=206010476996827964328.0004a1d4e36a15544155a&ie=UTF8&ll=36.684424,-96.901474&spn=21.932327,52.906036&source=embed>)**

**Make a Tulips for Tremor donation** (<http://www.essentialtremor.org/Donate-to-Tulips-for-Tremor>)

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## Genetic Research May Have Found Culprit Genes

The exact cause of ET is unknown. That is why the treatment options available are so limited and the medications used are not specifically designed to treat essential tremor – they just happen to have the happy side-effect (for some) of tremor reduction. It's hard to treat a condition when you're not sure what is causing it. But as research in the field continues, and with a grant funded by the IETF, some interesting advances in identifying the genetics behind the condition are coming to light. Two genes, LINGO-1 and LINGO-2, are being explored to see if the proteins they produce are the cause of rhythmic shaking you know all too well.

**Read More:** (<http://www.essentialtremor.org/LINGO-1-Study>)

A new study by the Banner Sun Health Research Institute examines *Neuropathological and Biochemical Substrates* for Essential Tremor. Dr. Holly Shill, Director, Cleo Roberts Center for Clinical Research, Christopher Center for Parkinson Research, leads the study which is funded by the IETF.

The cause of essential tremor (ET) is unknown but recent findings have shown genetic links to the genes LINGO-1 and LINGO-2. This project will deal with the next stage of these studies by confirming whether the proteins that these genes make are abnormal in ET affected brains. This will be done by studying brain tissues taken from ET patients and comparing them to brain tissues from unaffected subjects using biochemical techniques. The researchers hypothesize that abnormalities in the nervous tissue of the cerebellum, a region of the brain responsible for clinical manifestations of essential tremor (ET), are due to alterations in levels or distribution of LINGO-1 and/or LINGO-2 proteins. This research project will be the first to investigate the detailed neuropathological and biochemical role for LINGO in relation to ET.

This project will build on the hypothesis that ET is a degenerative disease where the cerebellum is the primary pathological site. This project has access to one of the largest collections of ET brain tissues from subjects that were extensively studied both while living and after death. By this approach, we will be able to identify which genes and proteins are abnormal in ET and therefore can start to plan ways to treat this disease in a focused manner.

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### Giving from the Heart

Margaret Mead said, “Never doubt that a small group of committed individuals can change the world. Indeed, it's the only thing that ever has.” She was so right. A small group of committed individuals in Katy, TX decided to do something that would allow a small group of friends to get together on a regular basis and do something good for a worthy cause. Their solution was to design and sell jewelry as a fundraiser for essential tremor research. What the group received was much more than tired, shaky hands and donation checks ... Read this story and more in our next issue of *Tremor Talk*, the IETF member magazine. Not a member? **Join the IETF** and find inspiration in stories of determination and perseverance from people just like you.

**Become a member**

(<https://www.essentialtremor.org/SiteResources/Data/Templates/WebFormLayout2.asp?docid=677&DocName=Become%20a%20Member>)

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