

# Spikes & Spasms

The TremorAction.org Newsletter

NOVEMBER 2012

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## WELCOME TO THE NOVEMBER ISSUE!



November is the transition month between fall and winter. Tremor Action Network is also in transition. TAN is in the process of completing a re-designed website. Building a website in a new platform takes time-consuming planning. TAN's "Redirection" is now in the testing phase before going live. Testing the migration of content involves spending more time that may mean this is the last newsletter for 2012. Knowing this, the November issue is packed with knowledge for a better understanding of living with movement disorders.

Hokuto Morita, M.D., returns with another article on animals and neurologic disease. Dr. Morita introduces Spikes & Spasms subscribers to dogs and tremor. Steve Retterer also comes back to report on his Deep Brain Stimulation procedure for both Parkinson's and essential tremor. Andrea Goldstein, RN, TAN Director of Education, addresses TAN's participation at 2012 Annual Meetings. P. Cullinane, School of Medicine, National University of Ireland Galway shares his poster abstract on ET patients' quality of life, presented at the 16th Movement Disorder Society International Congress. Leyla Williams of the Center for Digital Research and Scholarships announces the launch of the new movement disorders journal, TOHM. Kathleen Welker, caregiver for an in-home hospice patient, provides two Kaiser Permanente resources for ways to relax. Romert, the Essential Otter Advocate gives you a peek into his whereabouts.

On September 14, 2012 Tremor Action Network granted \$5,000 to support publication of the Tremor and Other Hyperkinetic Movements (TOHM) Journal. The TAN scholarship will be used to cover the full article-processing fee for any author publishing specifically on the subject of tremor research who cannot afford to pay the fee.

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## A Neurology patient's best friend: not letting sleeping dogs lie or shaking dogs shake

By Hokuto Morita, M.D.

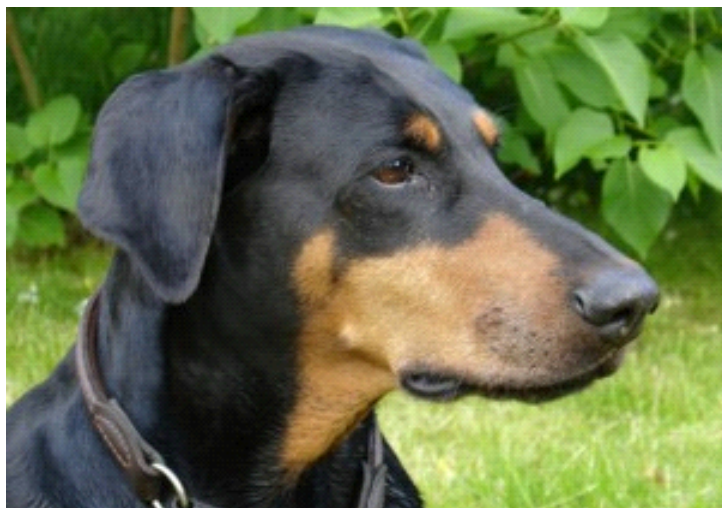


Photo taken from University of Bern Institute of Genetics:

[http://www.genetics.unibe.ch/content/rubrik/dobermann\\_head\\_bobbing/index\\_eng.html](http://www.genetics.unibe.ch/content/rubrik/dobermann_head_bobbing/index_eng.html)

It is widely known that dogs or other pets benefit the healing process in patients with all types of disease. Most large hospitals or medical centers have some form of pet therapy program. Recently, dogs have become our best friends in more ways than we have imagined. Beyond companionship, happiness, and love some of our furry friends have actually provided some key insights into neurologic disease. This has come about from collaborations between veterinarians and clinicians in looking at neurological diseases that are prevalent in certain breeds of dogs, diseases that in some cases resemble human neurological disorders.

### Dogs and neurologic disease

Probably the most stunning example of a genetic discovery in dogs that relates to human disease relates to a group of sleepy Doberman Pinschers. In 1999, Stanford scientist and current director of the Stanford Center for Narcolepsy, Emmanuel Mignot, capped a tour de force of work by identifying a gene responsible for the sleepiness in these Dobermans. The story of the sleepy Dobermans starts almost 30 years earlier. In the early 1970s, Dr. William Dement, considered by some to be the father of sleep research and author of the popular book "The Promise of Sleep", identified a group of Doberman

Pinschers and Labrador Retrievers that would spontaneously doze off in the middle of activities and sometimes collapse when they got excited, such as when they were being served food. We know these as some of the classic signs of a condition called narcolepsy. Dr. Dement established a breeding colony for these dogs at the sleep research center to study narcolepsy. Dr. Mignot, a narcolepsy researcher from France, traveled to Stanford and inherited this colony in the 80's and initiated what many scientists thought was a foolhardy task at the time - Identifying the gene associated with the narcolepsy in dogs. He did just that after many years identifying mutations of a gene called Orexin receptor 2 causing the sleepiness in these dogs. Perhaps even more surprising, at about the same time, in parallel research done by Dr. Yanagisawa at the University of Texas Southwestern who was looking at genes that were thought to be important for feeding behavior in mice found that when his mice were bred to have an absence of this gene, called Orexin, the mice also had altered day/sleep cycles and would suddenly collapse. The gene turned out to be one that directly interacts with the gene identified by Dr. Mignot. Subsequently, problems in these gene products were then identified in many humans with narcolepsy.

In science, there are at times reciprocal relationships between animals and man. An interesting example of this has recently emerged in epilepsy research. In this case, dogs trying to detect seizures in patients and in reverse, researchers trying to detect seizures in epileptic dogs.

A research collaboration between researchers at the Mayo Clinic, University of Pennsylvania, and Neurovista Corporation have created a novel implantable device wirelessly linked to an external recording unit which is currently being tested in dogs with canine epilepsy. Certain dogs are prone to epilepsy that shares a lot of characteristics with human epilepsies that are difficult to control with medications. The goal of this type of work would be to try to predict seizures before they happen. A practical application of this type of work is that if an epileptic patient knew that they were going to have seizure in advance they could take precautions or perhaps even try to abort the seizure by taking extra medications. On the flipside, there has been a small but growing interest in the possibility of seizure alert dogs- that is, dogs that have been trained to alert to or respond to seizures in patients. This is usually predicated on the idea that there may be subtle behavioral changes in patients who are about to have

a seizure although this is not known for sure. Other theories hypothesize dogs having keener senses and detecting changes in respiratory rate, heart rate, odors, or other such features. This area has been fraught with controversy however and there have only been a few limited studies. It remains to be seen if seizure alert dogs are practical.

It is often beneficial to have animal models of disease both for learning about the disease and for screening potential treatments. Dogs are generally not practical animal models as they have long lifespan, care intensive, and they have a special place in the human heart. It would not be considered kind or ethical to breed certain disease traits as is performed in yeast, flies, worms, fish, and mice. However, preexisting conditions that have naturally become more prevalent as a result of breeding for the purposes of owning pets can be useful for the study of those conditions.

### Dogs and tremor

Head tremor has been noted in several dog breeds including boxers and bulldogs among some. Anecdotally, there are a plethora of youtube videos taken by owners showing examples of different kinds of head tremors. In addition, there are many different types of tremor syndromes in dogs, perhaps the better known of these is shaker dog syndrome. Just as in humans, there are many different types of tremors seen in animals. The question has been posed by patients and physicians alike, whether there is an animal form of essential tremor and if these can shed any light on what scientists know about essential tremor. It's hard to know if any of these tremors is at all related to essential tremor in humans but there have been a few studies.

Recently, a head tremor in the Southern Sea Otter, Goldie, was examined by a group of researchers at Columbia University led by Dr. Elan Louis in collaboration with the Monterey Bay Aquarium. They found that Goldie's head tremor and pathology resembled several aspects of essential tremor and published their results in the journal Movement Disorders in 2004. An article about this study appeared in the June 2005 edition of the Spikes and Spasms newsletter. More recently, a group of researchers and veterinarians from Germany have undertaken a large

scale study in Doberman Pinschers with head tremor with the goal of characterizing the natural history, inheritance, and clinical characteristics of their head tremor. In the November 2011 issue of the journal Movement Disorders, research led by veterinarian Dr. Martina Wolf and Dr. Andrea Fischer of the Center of Veterinary Clinical Sciences at Ludwig-Maximilians-University of Munich examined an inherited episodic head tremor syndrome in Doberman Pinscher dogs that in some ways resembles some aspects of essential tremor.

The research team recruited Doberman Pinschers for their study by putting announcements on their clinic home page and in internet forums between 2009 and 2010. In the end, they were able to recruit 87 dogs that met the criteria of their study. Information on these dogs were collected through interviews with owners, questionnaires,

videos, and basic blood lab studies and examination. Five of the dogs had more extensive neurologic examinations including MRI, spinal tap, and electromyography.

One consequence that essential tremor patients are quite familiar with is that in about 20-26% of the dogs in this study, there seemed to be distress after the episode of head tremor and

owners noted that their dog seemed to be tired, ashamed, tried to hide, or in need of affection afterwards. In some cases the dogs even tried to stop their head tremor with their paws or by pressing their head against an object.

Though the head tremor exhibited by these Dobermans resemble essential tremor in some ways, there are some key differences and the authors note this. One of the key differences is that the head tremor they observed was episodic or what some clinicians call "paroxysmal", meaning that it is present for limited durations and not constant whereas the tremor in essential tremor patients tends to be constant, though it can be minimal and only apparent with exacerbating factors. In these particular dogs, head tremor was only seen with a median of every 60 days and median duration was about 3 minutes though could range all the way up to 3 hours. In addition, in about two thirds of the dogs, these head tremors could be distracted or interrupted if the owner pet or talked to the dog. In almost 40% of the dogs, the head tremor had a particular precipitant like stress, fatigue, illness, or excess

**"A particular gene in these breed of dogs could potentially shed light on causes of head tremor in humans."**



excitement. It was also noted that in some cases head tremor was accompanied by abnormal posturing of the head, a symptom familiar to some patients with dystonia. It might be the case that the head tremor seen in these Dobermans is actually closer to other types of head tremor including dystonic head tremor or some of the paroxysmal dyskinesias.

The symptoms did appear to be familial or hereditary as the pedigrees of 60 of the affected dogs could be traced back to one common sire in the 1960s. One of the most exciting aspects of these findings is that if a particular gene were identified in these breed of dogs, it could potentially shed light on causes of head tremor in humans, much like the sleeping dogs' effect on narcolepsy research. Researchers would then screen that particular gene in available pedigrees to see if there were any possible links to essential tremor or other tremor disorders.

Will we see some of the same types of reciprocal relationships in essential tremor that we have seen in dogs with narcolepsy or epilepsy? Will we learn more about treating tremor in dogs and will we learn more about our own tremor from dogs? It remains to be seen, but perhaps the dog will become a patient's best friend in ways that we have not imagined.

To learn more about the study of head tremor in Doberman Pinschers please visit

[http://www.genetics.unibe.ch/content/rubrik/dobermann\\_head\\_bobbing/index\\_eng.html](http://www.genetics.unibe.ch/content/rubrik/dobermann_head_bobbing/index_eng.html)

## About the Author

Hokuto "Hok" Morita M.D. is currently a third year Neurology resident at the Mayo Clinic. He has had tremor since the age of 5. He finishes his Neurology residency in 2013 and will start a Movement Disorders fellowship at the University of Florida Movement Disorders Center in July 2013.

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[An inherited episodic head tremor syndrome in Doberman pinscher dogs.](#) Wolf M, Bruehschwein A, Sauter-Louis C, Sewell AC, Fischer A. Mov Disord. 2011 Nov;26(13):2381-6.

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## Dual Diagnosis: essential tremor and Parkinson's Part Two

By Steve Retterer

I have always had shaky hands. My friends in high school would ask me why I was so nervous. As I grew older, I was aware of my tremor but it never seemed to get in my way. I got good at stabilizing my hands when doing dot etching at work. Then Parkinson's disease reared its ugly head. As time passed, there was always something extra that would leave doctors scratching their heads.

**When people ask me how long will it last, I answer, "Today is enough for me."**

As the Parkinson's became stronger, so did the essential tremor. It was as if Parkinson's was opening the gates. Parkinson's is noted as a resting tremor. Essential tremor is an action tremor. My tremor never stopped. For a while I took medicines for both. It was a relief to stop the internal tremor that went through my lungs, stomach and voice. Then the medicines started fighting with each other. I was the battleground. I was forced to stop taking the Primidone that had done so much good. Now, the internal tremor I had lived with for years became external almost overnight. Sinemet the gold standard for Parkinson's treatment would only help for a short time. Sleep became almost impossible. Sleeping was the only time the tremors stopped. I was in trouble and I knew it.

A trip to Vanderbilt in Nashville, TN brought me a ray of hope. If the Parkinson's could be controlled with DBS then

there were options. Cutting back on Parkinson's medicine might make it possible to go back on Primidone. If all else failed, a second surgery into the ventrolateral thalamus (Vim), with two more leads with another stimulator was possible.

The 24 hours before surgery are horrible. You have to go without any medicine. I was so nervous sleep was impossible. The next afternoon at 1:30 pm I was wheeled into surgery. My confidence in this team and the doctor was such that I took a nap while they drilled through my skull. They placed 4 leads with 4 positions on each one, 16 spots to test on each side. This is the time to be wide-awake; helping the doctor judge the best spot for your leads. It includes 32 questions, testing your vision, and checking your movement and tremor. After a night in the hospital, home I went (funny thing they won't let you drive yourself home).

After 2 weeks back to the hospital for the stimulator implant under the chest muscle, just below the collarbone (this hurts a lot more than lead placement).

Another 2 weeks go by and it is time to get "turned on." How will I be after this? This had been the longest month of my life. The time has come 5 months after the first phone call and so many

tests I can't remember them all. With a touch of a stylus it is on. With a bit of adjusting I feel the tremor stop. I can stand up easily, walk, and I have some voice back.

This is beyond my expectation. I remember the doctor stopped by after the lead placement surgery. He said, "You will be pleased with the results." That is such an understatement! How do thank someone who has given you another chance at life?



So here I am, 21 months later, after minor adjustments. Things are better than the day they first turned it on. Before surgery I was taking 1400-1600 mg of Sinemet a day. After surgery, taking only 300 mg a day. I did take some Primidone for a few weeks, right after surgery, but now no Primidone like I initially thought. The surgery stopped the tremor. My hands are better then when I was a teenager. I still have some toe curling and numbness on my face. BUT, when people ask me how long will it last, I answer, "Today is enough for me."

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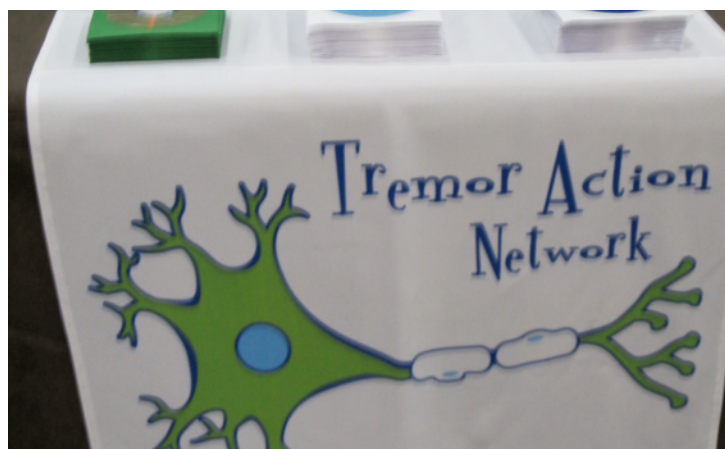
### About the Author

This is Steve Retterer's second article for Spikes & Spasms. His first article appeared in the [September/October 2008 issue](#). Steve's voice chat for Parkinson's patients has become Google's #1 [Parkinson's Chat Room](#). He is an avid photographer, and his backyard is a photogenic landscape for wildlife.

Steve's Parkinson's Chat Room now has its own Facebook page.

<https://www.facebook.com/Parkinsonschat>

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## Tremor Action Network Report Card

By Andrea Gardner, RN

TAN Director of Education

Movement Disorder Society member

TAN's collaboration with [HopeNET](#) on Essential Tremor Awareness Surveys™ offers the opportunity to view Tremor Action Network exhibiting at and/or attending meetings in a different way. The collection of survey information increases our awareness of how essential tremor (ET) is presented at annual meetings.

In the first ET awareness web-based survey, Questions #27, #28 and #29 addressed the importance of ET research, and the dissatisfaction of ET research not being funded like Parkinson's and dystonia. 56.8% responded that Parkinson's and dystonia receive more publicity, followed by 25% thought Parkinson's and dystonia patients and their respective advocacy organizations advocate more. Trailing at 16.9% was the response that researchers are less interested in ET.

### 64th American Academy of Neurology (AAN) Annual Meeting

*April 23 - 26, 2012 New Orleans LA*

Researchers presented approximately 134 Parkinson's poster abstracts, 32 dystonia abstracts, and 10 ET abstracts. An inquiry is warranted as to "Why" there is a disparity in the number of ET abstracts presented v. Parkinson's and dystonia abstracts. Are researchers truly less interested in ET? Is there truly less funding for ET research? Is there truly less interest by NIH/NINDS, pharmaceuticals, biopharmaceuticals, assistive technology

companies and other industries in funding ET research? Or, is less ET research funding attributed to the challenge researchers face in recruiting ET patients for clinical studies?

Six of the 10 ET abstracts were authored by Elan Louis, MD. ET abstracts re-visited prevalence of ET in Spain, the personality profile of ET patients, the reliability of the ET tremor scale, TETRAS, cerebellar dysfunction in ET, ET described with Lewy body, Purkinje cell loss and swellings (torpedoes) as an abnormality in the ET cerebellum, and the Lingo-1 variant in ET. Newer abstracts highlighted apathy in ET, dystonia and Parkinson's patients, head tremor improvement in ET patients after DBS, and the FUS/TLS gene identified in a large ET family.

Conclusions expressed more apathy in PD patients, but unlike PD, apathy has not been associated with ET and dystonia. Also, it was suggested, "the mutations in the FUS/TLS gene are rare in a sample of ET cases in North America." The [APTES](#) organization is quite excited about the possibility of the association between ET and the FUS/TLS gene as a cause of ET.

Newsworthy is that the Parkinson's Disease Foundation, AAN Research Fellowship and GlaxoSmith Kline supported 3 ET abstracts.

### 1st One Mind for Research Annual Meeting

*May 23-25, 2012 Los Angeles CA*

Lights, Camera, Action! Star power included Garen Staglin of Staglin Family Vineyard, Los Angeles Mayor Antonio Villaraigosa, former Congressman Patrick Kennedy, retired Vice Chief of Staff of the U.S. Army General Peter Chiarelli, financier and philanthropist Michael Milken, journalist and author Maria Shriver, actor Glen Close and Robert Klein, "one of Time Magazine World's 100 Most Influential People of the Year" for 2005.

The One Mind meeting held on the UCLA campus emphasized an agenda presented at the 1Mind4Research 2011 symposium in Boston MA. Familiar buzzwords and phrases translational research, stigma and silo were used often. The Canadian psychologist Donald O. Hebb's statement, "Neurons that fire together wire together," was re-visited by the Wiring the Mind panel. Neuroscience research was re-introduced as being a risky investment for pharmaceuticals.



One Mind for Research CEO Peter Chiarelli presented how the 10 Year Strategic Plan will be operated, beginning with prioritizing TBI, PTS and Multiple Sclerosis. Parkinson's appeared on a power point slide in small lower case letters, dwarfed by other diseases abbreviated in huge upper case letters. Perhaps the abbreviation for Parkinson's, PD, was unknown to the slide's graphic designer, and/or Parkinson's Disease was added to highlight movement disorders in general. Neither essential tremor nor dystonia were projected on the slide.

Stanford University neurosurgeon Jamie Henderson, well known leader in Deep Brain Stimulation (DBS), was a presenter on the panel, Engineered Minds. Dr. John Donoghue of Brown University introduced Dr. Henderson with a short film of a Parkinson's patient that had undergone DBS. Dr. Henderson didn't specifically address DBS. He spoke about robotic devices that could improve the performance of controlling prostheses for paralyzed cervical spinal cord injury patients. It would have been more beneficial for movement disorders Parkinson's, essential tremor and dystonia, if Dr. Henderson could have discussed his knowledge and experience in stereotactic neurosurgery (DBS).

Michael Thompson, of PricewaterhouseCoopers (PWC), presented the Real Economics of Brain Disorders. Parkinson's was presented as a brain disease, but not essential tremor nor dystonia. The total cost of movement disorders was not taken into consideration.

Ger Brophy of GE Healthcare was part of the panel, One Mind Program for TBI-PTS. GE Healthcare has a strong platform for diagnostics in neurology. DaTSCAN was presented as an image on a slide, but just a few words were spoken about DaTSCAN as targeted SPECT imaging for Parkinson's.

TAN had the privilege of dining with Louis Ptacek of UC San Francisco and Emmanuel Mignot of Stanford University at UCLA Chancellor Block's residence. Kathleen Welker and Dr. Hokuto Morita met with Dr. Ptacek some year's prior at his UCSF Mission Bay campus office. Drs. Ptacek and Mignot were presenters on the panel, The

Executive Mind: Rhythms/Sleep. Disturbances in daily rhythm of sleep have body-wide implications. Sleep and circadian rhythms affect health and disease. Sleep is very complex. Dr. Ptacek shared much has been learned from the fruit fly, mice and families. Dr. Mignot has studied narcolepsy for 20 years. Narcolepsy is one of the few disorders where sleep is impaired. Dr. Mignot studied narcolepsy in dogs. Like Dr. Ptacek's gene studies in families, Dr. Mignot isolated genes in narcoleptic dogs helped to understand narcolepsy in humans. Dr. Mignot's research suggests "the immune system" has an association with narcolepsy, and perhaps some cases of Parkinson's as well.

TAN was on the same airport shuttle with panel presenter Scott Small of Aging Minds. TAN asked Dr. Small of Columbia University what he thought of essential tremor as a neurodegenerative disease. Dr. Small seemed skeptical that essential tremor is being considered as a neurodegenerative disorder.

**"Is there truly less funding for ET research?"**

Take Two, Déjà vu! Very few movement disorder patient advocacy organizations a.k.a. American Brain Coalition (ABC) members attended the meeting. Other than TAN and the Dystonia Medical Research Foundation,

there was Robin Elliott of the Parkinson's Disease Foundation, who is also the ABC Chair. Robin departed the second day, but Katie Sale, ABC Executive Director, graciously made herself available to answer questions and make the necessary introductions. To paraphrase TAN's summary of the 2011 One Mind for Research meeting in Boston, "just a few strategic partners aren't enough for movement disorders to succeed within the Ten-Year Plan for Neuroscience." A concerted effort has to be made by ABC and its movement disorder members in order for movement disorders to be part of the 2013 One Mind meeting agenda.

The 2nd Annual One Mind for Research Annual Meeting will be hosted by Johns Hopkins University in Baltimore, MD, May 14-16, 2013

**Disclosure:** TAN hasn't covered every session presented during the 3 day meeting, Tremor Action Network invites readers to view the One Mind for Research first annual meeting videos at: <http://1mind4research.org/highlights-2012->

[one-mind-research-first-annual-meeting-may-23-25-2012](#).

**16th Movement Disorder Society (MDS) International Congress Parkinson's Disease and Movement Disorders**  
*June 18-21, 2012 Dublin IR*

It's no surprise that there are less attendees at an annual MDS meeting than the AAN annual meeting. Diagnosing and treating movement disorders is a sub-specialty within the field of neurology. After completing a residency in neurology, neurologists can enhance their skills with a fellowship in movement disorders.

The specialization in movement disorders carries over to the MDS meeting. The sessions, teaching courses and workshops are more detailed, and the abstracts have more of a theme; in particular, poster abstracts on Parkinson's. The event venue is more intimate.

The number of abstracts presented at the Dublin meeting totaled **1598**. Guided poster tours took place each day that lasted approximately 1.5 hours. The MDS abstracts were categorized by topics. Like the AAN meeting, the Parkinson's abstracts at the 16th International Congress far exceeded the number of essential tremor and dystonia abstracts. Essential tremor was categorized as "Tremor," and/or sub-categorized under topics such as Pediatric movement disorders, Clinical electrophysiology, Rating scales, Neuroimaging, Surgical therapy, Other movement disorders, and Genetics.

Kathleen Welker exhibited on behalf of TAN, along with another U.S. advocacy organization, the [Dystonia Medical Research Foundation](#). Kathleen welcomed the second opportunity to exhibit next to the [European Parkinson's Disease Association](#), who looked after her when she came down with an intestinal virus. Europeans in general are more familiar with natural healing products sold over-the-counter. The EPDA team advised Kathleen to visit a Dublin pharmacy, where the local pharmacist had more discretion to discuss her symptoms v. a U.S. pharmacist.

TAN has highlighted key MDS abstracts to share with Spikes & Spasms subscribers, but unfortunately cannot share all in this article. Unlike the 10 ET abstracts featured at the AAN meeting, the MDS meeting presented 4x as many abstracts; approximately 45 essential tremor abstracts. Two of the abstracts have already been

included under the AAN meeting abstracts.

Tremor Action Network will feature more MDS ET abstracts on TAN's Twitter and Facebook pages.

**Essential tremor in children: Tremor onset at birth**

*I. T. Rossman, H. Brar, D. Ghosh (Cleveland, OH, USA)*

Authors reveal that ET in children at birth has not been reported until now, and suggest that consideration should be given to diagnosing ET in young children. According to the authors, ET is treatable in children.

**Bilateral thalamic Vim DBS for orthostatic tremor: New insights and literature review**

*C. Sidiropoulos, J. Schwalb, D. Taylor, J. Gorham, S. Bowyer, P. LeWitt (West Bloomfield, MI, USA)*

DBS programming failed to provide benefits to OT patient, even though some improvement has been achieved in a few cases of OT. Authors suggest more cases and longer follow up to define the benefits of DBS in OT.

**Deep brain stimulation in the caudal zona incerta and posterior subthalamic area is more effective than in ventral intermediate nucleus for various tremor control**

*T. Xie, J. Bernard, C. Ojakangas, U.J. Kang, V.L. Towle, P. Warnke (Chicago, IL, USA)*

Authors conclude cZi/PSA is more effective than VIM for tremor control, "including vocal tremor."

**Long term history of orthostatic tremor: A review of 50 patients**

*F. Di Biasio, S.L. Pullman, J.C. Corte's, Q.P. Yu, C. Hess, S. Fahn (Rome, Italy)*

Study aims to provide a better understanding of OT. Results from the study suggest OT predominantly affects females, shares an association with ET tremors, but does not respond to first-line ET agents. More finding are needed to precisely define the mechanisms of OT.

**Psychiatric manifestations in patients with essential tremor**

*N. Dragasevic, N. Kresojevic, A. Tomic, D. Pesic, M. Svetel, V.S. Kostic (Belgrade, Serbia)*

Patients were examined using the DSM IV criteria. Also used were depression-rating scales. Analysis of participants showed OCD, anxiety and depressive personality disorders. Authors conclude ET is more than a motor system disease.

**Accelerometric study of the effect of limb cooling on tremor in essential tremor patients**

*V. Evidente, J. Hentz, A. Duffy (Scottsdale, AZ, USA)*

Limb cooling with a 15C cold pack wrapped around a forearm for 10 minutes reduced tremor amplitude severity but not tremor frequency.

#### **Effects of zonisamide in essential tremor. Open-treatment trial**

*M. Mata, E. Garcí'a-Cobos, S. Al Hussayni, P.E. Bermejo, J.J. Lo'pez-Lozano (Majadahonda, Spain)*

The study group's mean dose of ZNS was 250 mg/day. ZNS significantly reduced participants' tremor.

#### **Impaired hearing in essential tremor**

*E. Eken, H. Kaleagasi, M. Unal, S. Bayram, E. Louis, O. Dogu (Mersin, Turkey)*

Study shows there can be an impairment inhibiting the functional transmission in brain stem of patients with ET.

#### **Cognitive motor interference during dual-task gait in essential tremor**

*A.K. Rao, J. Uddin, A. Gillman, E.D. Louis (New York, NY, USA)*

ET subjects' gait and balance worsened during dual-task walk and verbal test. The possible presence of cognitive motor interference suggests ET patients are at greater risk for falls.

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### About the Author

Andrea Gardner, RN, TAN Director of Education and Movement Disorder Society member, has been authoring articles for Spikes & Spasms since the premier issue, June 2005. Andrea's passions in addition to advocating for essential tremor include spokesperson for [DES](#), and Board of Director and member of the [Gateway Camera Club](#).

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# Tremor Severity is a Poor Predictor of Social Disability in Patients with Essential Tremor



NUI Galway  
OÉ Gaillimh

Cullinane P<sup>1</sup>, Browne P<sup>2</sup>, Leahy T<sup>2</sup>, McGovern E<sup>2</sup>, Counihan T<sup>1,2</sup>



Galway University Hospitals  
Ospidéal na h-Ollscoile Gaillimh  
UNIVERSITY HOSPITAL GALWAY  
MERLIN PARK UNIVERSITY HOSPITAL

<sup>1</sup>School of Medicine, National University of Ireland Galway.  
<sup>2</sup>Department of Neurology, University Hospital Galway, Ireland.

## Introduction

It has been estimated that 0.9% of the general population suffer from essential tremor (ET)<sup>1</sup>. This increases to 4.6% for those aged 65 years or more<sup>1</sup>. It is slowly progressive, increasing in severity by between 3.1% and 5.3% per annum<sup>2</sup>. Previous studies have shown, using generic scales, that patients with ET have a poorer quality of life (QoL) compared to control populations<sup>3,4</sup>.

## Objectives

1. To assess the impact of ET on quality of life, both qualitatively and quantitatively.
2. To determine the relationship between QoL and clinical measures of tremor severity.

## Methods

### Patient Selection:

Chart review (2005 – 2011)  
identified **152** potential candidates

Excluded those aged > 80 years

Remaining **132** invited to participate  
via letter

Non-respondents followed up with  
phone call

**50** agreed to attend clinic to  
participate

### Inclusion/Exclusion Criteria:

We used a modified version of the Movement Disorder Society Consensus Criteria<sup>5</sup>. Following the publication of an article from Quinn et al. we decided to remove isolated head tremor from the inclusion criteria<sup>6</sup>. This was the only modification.

### Scales:

- QoL was assessed using the quality of life in essential tremor questionnaire (QUEST)<sup>7</sup>. This is a validated, ET-specific QoL scale.

- Tremor severity was measured using the Fahn-Tolosa-Marin tremor rating scale<sup>8</sup>. Part A (tremor amplitude in various parts of the body) and Part B (patient performance on writing, drawing and pouring) were used to calculate the total score.

### What happened in clinic?

	<b>Background Information</b> <ul style="list-style-type: none"><li>• Basic demographics</li><li>• Family history, alcohol responsiveness</li></ul>
	<b>QUEST questionnaire</b> <ul style="list-style-type: none"><li>• Validated; 30 item; 5 subscales</li><li>• Increased score = Increased dissatisfaction</li></ul>
	<b>Modified Fahn-Tolosa-Marin rating scale</b> <ul style="list-style-type: none"><li>• Validated</li><li>• Parts A &amp; B</li></ul>
	<b>Narrative-based interview</b> <ul style="list-style-type: none"><li>• Face-to-face interview; open questions; unformatted</li><li>• Written down during interview</li></ul>
	<b>Statistical interpretation: PASW v18</b> <ul style="list-style-type: none"><li>• All tests 2-tailed</li><li>• p-value &lt; .05 considered statistically significant</li></ul>

## Results

### Patient demographics:

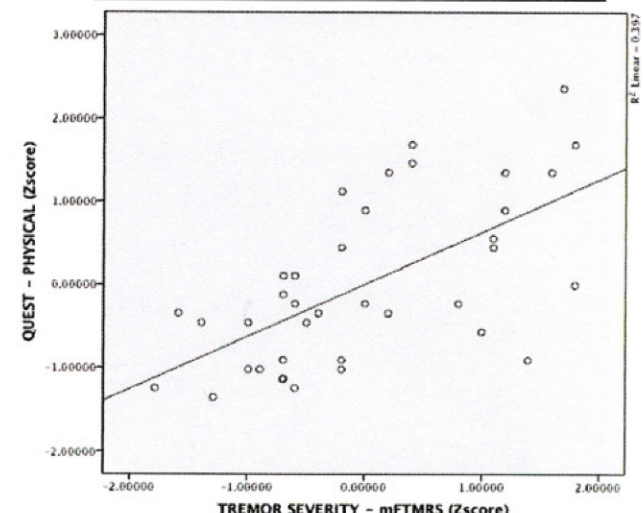
- 38 patients met criteria
- 58% male
- Mean age in years: 61 (±17)
- Mean duration of tremor in years: 21 (±19)
- Right handed: 92%
- + Family history: 79%
- Alcohol responsive: 50%
- Mean QUEST-SI: 14.3 (±10.3)
- Mean mFTMRS: 22.9 (±10.1)
- On treatment: 29%

### Patient narratives: the common issues:

THEME	SUBTHEME
SOCIAL IMPACT	Embarrassment when eating out/ at social event
	Tremor gets worse if people are looking at it
	Avoiding situations because of tremor
	Tries to hide tremor/ stay in background
	Misconceptions about cause of tremor
	Misinterpreted as sign of nervousness
PHYSICAL IMPACT	Difficulty speaking in public
	Tremor worse if anxious or nervous
	Difficulty drinking/ carrying cups or glasses
	Difficulty eating/ spilling food
	Difficulty writing
PSYCHOLOGICAL IMPACT	Difficulty performing intricate tasks with hands
	Tremor causes nervousness & anxiety
	Worried it may be something more sinister
	Worried that the tremor will get worse
IMPACT ON CAREER	Worried what others think of the tremor
	Changed job/ course because of tremor
	Has affected career path chosen
ATTITUDES & COPING	Passed up opportunities because of tremor
	Feels that he/she copes well with tremor
	Has it so long is used to it by now
	Gets help from others to do certain things
	Family & friends make allowances for tremor
	Explains to people about tremor
	Feels tremor is dismissed as not a serious problem

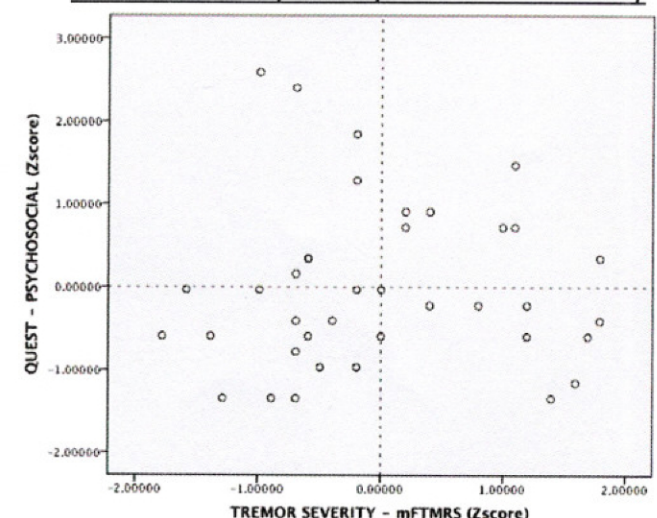
## Does tremor severity correlate with QoL?

Tremor severity vs. Physical disability



Spearman's rho	Strength	p-value
.660	Moderate	.001

Tremor severity vs. Psychosocial disability



Spearman's rho	Strength	p-value
.095	Weak	.568

## Conclusions

- Serious physical, social and psychological disability is common in patients with ET.
- Tremor severity correlates well with the physical impairment but tells us little about the psychosocial disability experienced by this group of patients.
- These findings are not only relevant to clinical practice but may also be useful in interpreting the results of clinical trials, both medical and surgical.

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## New Movement Disorders Journal Breaks From the Mold

By Leyla Williams, Communications Coordinator  
Center for Digital Research and Scholarship

Unlike other journals in the field of movement disorders, Tremor and Other Hyperkinetic Movements (TOHM), an open-access, peer-reviewed medical journal, centers on tremor and hyperkinetic movement disorders, giving home to clinical observations and research in this area. TOHM, a newcomer to the field of movement disorders, has launched with ten new articles at <http://tremorjournal.org>. The Center for Digital Research and Scholarship (CDRS), TOHM's publisher, provides editorial support, software, design, and hosting for the journal.

In addition to its rolling submission policy and open access policy, which set it apart from other journals in the field, TOHM has a rapid turnaround time. Indeed, the current turnaround time from submission to first decision is only 26 days (3.7 weeks), echoing that of prestigious open-access journals such as PLoS One. TOHM uses an iterative publishing process and therefore does not have fixed deadlines. In addition, TOHM's online format permits more liberal word limitations than other journals. TOHM's open-access quality allows for greater visibility of its papers and, in turn, increased impact of its research.

Professor of Epidemiology and Neurology at Columbia University, Elan D. Louis, MD, MS is the founding editor of the journal. Dr. Louis' research interests include degenerative diseases of the central nervous system, with an emphasis on tremor disorders. Dr. Louis has written over 300 peer-reviewed articles and has been invited to author editorials and reviews for journals such as Annals of Neurology, New England Journal of Medicine and Lancet. TOHM also features an illustrious editorial board with a

wide range of leaders in the field of movement disorders.

TOHM has evolved from a mere conversation about a journal to become a reality for the editor. "When I first started talking to CDRS about their journal services, launching TOHM as a journal was just an idea. Over the last year and a half, we've worked together to launch the journal, receive submissions, and finally publish the journal's first set of articles. Making TOHM an open-access journal will allow for greater visibility of these articles and, in turn, increase the impact of our research, which is enormously exciting," said journal Editor-in-Chief Elan D. Louis.

CDRS is delighted to announce the launch of TOHM's first ten articles. "It has been a pleasure to continue to partner with TOHM, which provides an international platform for experts and specialists in the field of hyperkinetic movements, and gives center stage to clinical observations and research in the area of non-Parkinsonian movement disorders. We are honored to have had the privilege of working with TOHM to bring their first set of articles online and look forward to our continued partnership," said CDRS Director Rebecca Kennison.

**"Tremor Action Network  
granted \$5,000 to  
support publication of  
TOHM."**

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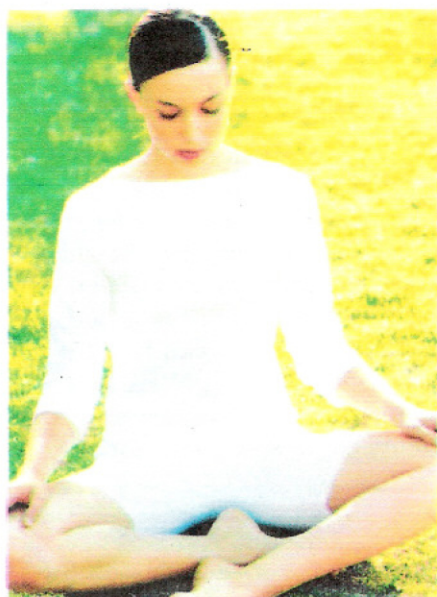
### About the Author

Leyla Williams is Communications Coordinator for the Center for Digital Research and Scholarship.

The Center for Digital Research and Scholarship (CDRS) partners with researchers and scholars to share new knowledge. Using innovative new media and digital technologies, CDRS empowers Columbia's research community with the online tools and services necessary to make the most of scholarly communication, collaboration, data-sharing, and preservation. More information about our services and projects is available at <http://cdrs.columbia.edu>. CDRS is part of the Digital Programs and Technology Services division of Columbia University Libraries/Information Services.

Contact Leyla Williams at 212-851-7338, or send an email to: [lwiliams@columbia.edu](mailto:lwiliams@columbia.edu)

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There are many ways you can relax. Deep breathing, muscle relaxation, and the relaxation response are simple and good for your health.

**R**elaxation has many benefits. It can help you feel calmer, think more clearly, and relieve stress, headaches, and tight muscles. Whether you want to take a break from a stressful day or manage your stress for the long-term, a regular relaxation practice can really help you get back to a calmer state.

There are many ways to relax. Three common methods are: deep breathing, progressive muscle relaxation, and the relaxation response. When learning these skills, it is important to find a quiet place where you won't be disturbed. Try to practice for 10

or 20 minutes once or twice a day. It may take two to three weeks to fully develop these skills, but once you have trained your mind and body to relax, you'll be able to get the same relaxed feelings quickly.

## Deep breathing

When it is done with purpose, deep breathing can help calm you down. It can help you let go of stress and worries and focus quietly on the present moment.

### *How to do deep breathing*

Place both hands on the lower part of your stomach and inhale so that your belly pushes gently against your hands. Your stomach muscles should be relaxed. Then, gently push with your hands as you exhale slowly. If it helps, imagine a balloon in your stomach that inflates when you inhale and deflates when you exhale. Practice this several times. When you breathe out, try to imagine tension and stress leaving your body; say to yourself, "I am feeling relaxed and calm."

Here are some important tips for practicing this skill:

- Wear loose, comfortable clothing and find a quiet, relaxing place to practice.
- Start practicing for just one to two minutes. Slowly increase your practice time up to five minutes. Practice several times a day.
- In the beginning, it may help to practice deep breathing while lying down on your bed or on the floor. Lie on your back, bend your knees, and place your feet comfortably apart.

- If you feel lightheaded, dizzy, or anxious, you may be breathing too deeply or too quickly. If this happens, stop practicing for a moment and breathe normally until the symptoms pass. Try inhaling and exhaling through your nose to prevent hyperventilation.
- As you progress, practice deep breathing in a variety of settings (e.g., sitting at your desk, waiting in line, or watching television).
- Be patient and gentle with yourself.

## Progressive muscle relaxation

The body responds to tense thoughts or situations with muscle tension, which can cause pain or discomfort. Progressive muscle relaxation will help you reduce stress and become more relaxed. It involves tensing and releasing each muscle group to create a deeper sense of relaxation. It can also reduce feelings of anxiety. You can use a recording to help you go through all the muscle groups, or you can follow the instructions below. Progressive muscle relaxation often helps with stress-related health problems and can help you fall asleep.

**Note:** If you have fibromyalgia or myofascial pain syndrome, check with your health care professional before practicing progressive muscle relaxation.



## *How to do progressive muscle relaxation*

Pick a place where you can stretch out comfortably, such as on a pad or carpeted floor. Tense each muscle group for 4 to 10 seconds (hard, but not to the point of cramping). Then release the muscle and give yourself 10 to 20 seconds to relax. Try to relax each muscle group a little more deeply each time you do this exercise.

## *How to tense muscle groups*

- Hands: Make a fist.
- Wrists and forearms: Extend your arms and bend hands back at the wrist.
- Biceps and upper arms: Make a fist, bend arms at elbows, and flex biceps.
- Shoulders: Shrug them.
- Forehead: Wrinkle it into a deep frown.
- Around the eyes and bridge of the nose: Close eyes as tightly as possible. (Remove contact lenses before beginning this exercise.)
- Cheeks and jaws: Grin from ear to ear.
- Around the mouth: Press lips together tightly.
- Back of the neck: Press head back against the pad or supporting surface.
- Front of the neck: Touch your chin to your chest.
- Chest: Take a deep breath, hold it, then exhale.
- Back: Arch your back up and away from support surface.

- Stomach: Suck your stomach into a tight knot.
- Hips and buttocks: Press your buttock cheeks together tightly.
- Thighs: Clench hard.
- Lower legs: Point your toes toward your face, as if trying to bring them up to touch your head.
- Lower legs: Point your toes away and curl them downward at the same time.

## Relaxation response

The relaxation response slows the heart rate and breathing, lowers blood pressure, and helps relieve muscle tension. It can help you slow down, reduce stressful feelings, and refocus your thoughts.

*Technique (adapted from Herbert Benson, MD):*

- Sit quietly in a comfortable position with your eyes closed.
- Become aware of your breathing. Breathe slowly and steadily; breathing from your belly and not from your chest.
- Each time you exhale, say the word "one" (or any other word or phrase) silently or aloud. Or, you may choose to fix your gaze on a stationary object. Any mental stimulus will help shift your mind away from distracting thoughts.
- Continue this for 10 to 20 minutes. As distracting thoughts enter your mind, don't dwell on them. Just allow them to drift away.

- Sit quietly for several minutes until you are ready to open your eyes.
- Notice the difference in your breathing and your pulse rate.

Don't worry about becoming deeply relaxed. The key to this exercise is to be passive, to let distracting thoughts slip away like waves on the beach. Practice for 10 to 20 minutes once or twice a day, but wait for at least two hours after a meal. When you have set up a routine, the relaxation response should come with little effort.

## Additional resources

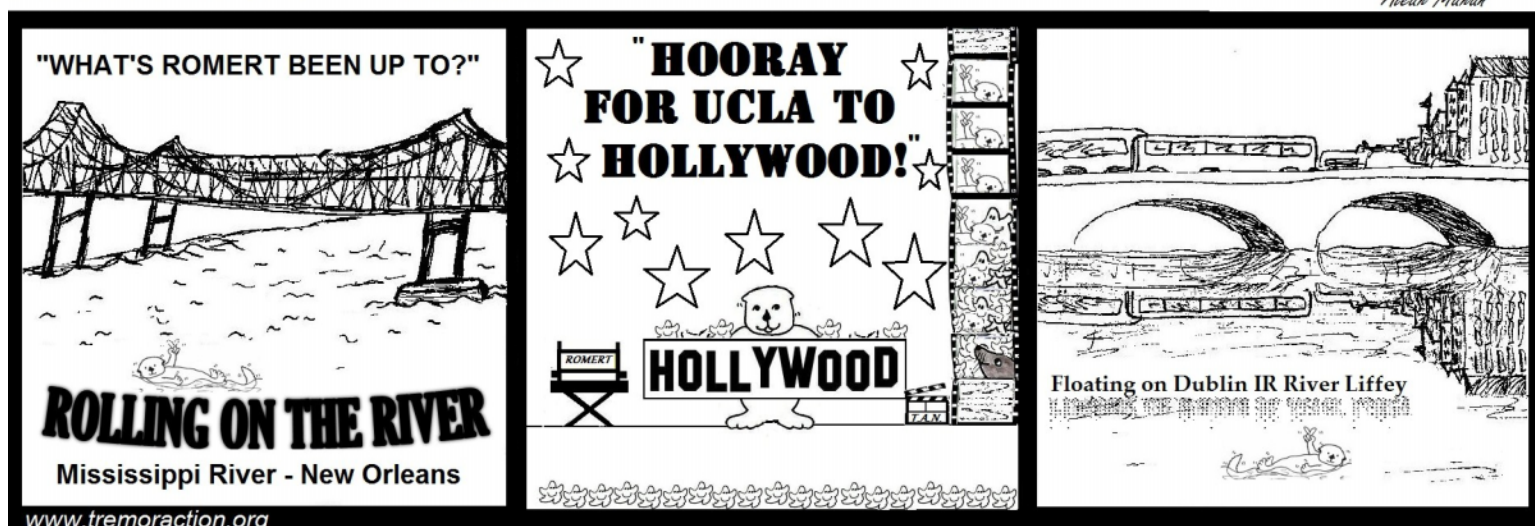
- Connect to our Web site at [kp.org](http://kp.org).
- Visit your facility's Health Education Department for books, videos, classes, and additional resources.
- Want a customized online stress management plan? Check out our HealthMedia® Relax™ Healthy Lifestyles program at [kp.org/healthylifestyles](http://kp.org/healthylifestyles).
- Try out our Health Coach Stress Less Program at [kp.org/mindbody](http://kp.org/mindbody).
- If you are hit, hurt or threatened by a partner or spouse, this can seriously affect your health, including your ability to manage stress. There is help. Call the National Domestic Violence Hotline at 1-800-799-7233 or connect to [ndvh.org](http://ndvh.org).

This information is not intended to diagnose or to take the place of medical advice or care you receive from your physician or other health care professional. If you have persistent health problems, or if you have additional questions, please consult with your doctor. If you have questions or need more information about your medication, please speak to your pharmacist. Kaiser Permanente does not endorse the medications or products mentioned. Any trade names listed are for easy identification only.

## What's Romert Been Up To?

**Romert** The Essential  
Otter  
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