

# Spikes & Spasms

The TremorAction.org Newsletter

DECEMBER 2013

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SEASON'S  
GREETINGS!



WELCOME TO THE  
**HOLIDAY ISSUE!**



Warm wishes for

*Healthful  
New Year!*

Tremor Action Network & Romert

## Spikes & Spasms Editor Note: Beverly Anita Helmholtz-Parenti Scholarship

2013 is an unusual year for The TremorAction.org newsletter. It is the first time in the 8-year history of the newsletter that only 1 Issue - this Holiday one, has been published in a calendar year. Generally, Spikes & Spasms issues are featured quarterly.

The newsletter was placed on hold to care for Beverly Helmholtz-Parenti. My mom fought the good fight for almost 3 years, just what you would expect from a survivor. Her battle with "failure to thrive" ended on November 7.

Beverly's family on her mother's Native American Indian side has inherited essential tremor. Symptoms of ET seem to worsen in our family with each new generation. I had high expectations of being the last family member to inherit ET, but cousins that are daughters of my mom's late brother (Henry A Helmholtz passed away 23 days after his sister on November 30) have recently shared they have hand tremors. Like me, one cousin is a Baby Boomer. Her sister is 18 years younger than I. Unfortunately; the Tremor lives on in our family.

Andrea Gardner, RN, TAN Director of Education, and Jeannine Parent, Beverly's sister-in-law, have made donations to TAN in my mother's name. Also Carol Helmholtz-Weber, Beverly's sister, and her children Dan, Tina, Augie, Ric, Peter and Joe, have made a donation on behalf of my mother to the [Tremor Journal](#), the open-access, peer-reviewed medical journal focused on non-Parkinsonian tremor that Tremor Action Network supports with an annual scholarship. When someone dies you want to keep his or her memory alive. I can think of no finer gift to honor my mother's life. My mom is gone from my sight but not from my heart. She cared deeply for the advancement of essential tremor research.

Please consider joining Andrea and my Aunt Jeannine in making a [tax-deductible gift](#) to a yearly scholarship in my mother's name. The goal is to raise a minimum of \$1,000 annually. The scholarship will be awarded to an investigator of essential tremor.

Thank you for your consideration. Wishing you a Happy New Year!

Kathleen

**"When someone dies you want to keep his or her memory alive."**



Beverly & Kathleen SEP 2013

## Congressional ET Advocate: Meeting with Congressman Scott Perry

By Nannette Halliwell

On October 25 I met with Congressman [Scott Perry](#) and Bob Reilly, his deputy chief of staff at the Congressman's York County District office. Congressman Perry represents Pennsylvania's 4th District.

I began the meeting by talking about Michael J. Fox being the face of Parkinson's Disease, and how his fame has brought attention and research. I shared when people hear "essential tremor" or "ET," they think, "What?" I talked about the disease itself, not being Parkinson's, not being a disease of just the elderly. I told Congressman Perry and Bob about my family, my grandmother having it in her late teens, me at 39, and my son at 14. My tremor cooperated on "show and tell." It was moving and shaking!

I addressed the 1-Octanol and Octanoic Acid clinical trials. The disruption by NINDS of the Octanoic Acid trial was what prompted me to contact Congressman Perry's office. I explained that alcohol dampens tremor, and Octanol is like alcohol without side effects. I shared that no drugs have been developed and FDA approved for ET, and that all drugs prescribed for ET with the exception of Propranolol (Inderal), developed for hypertension, are "off label."

I requested Congressman Perry to raise awareness of ET, increase funding for drug research, specifically Octanol. I asked him to join the [Congressional Neuroscience Caucus](#) spearheaded by [Congressman Earl Blumenauer](#) representing Oregon's 3rd District, support the White House focused [NIH Brain Initiative](#) (BRAIN), and to share [Tremor Action Network DVDs](#). I supported my requests with various articles I printed for the Congressman, including the 2013 specific diagnostic code [G25.0](#) for essential tremor, that for the first time the International Classification of Diseases did not code as an "unspecified

tremor." I told Congressman Perry that if someone mentions "movement disorder" he should ask if they are including ET. If the answer is No, ask why. I asked him if he came across someone in a public role that has ET to encourage this person to step forward and be the face of ET.

Congressman Perry responded that he sees Congressman Blumenauer on a daily basis while in DC. He said he would speak with him about ensuring that ET is included whenever movement disorders are mentioned. The Congressman also said he would contact NIH. He explained corresponding with NIH has to be done in writing, and that a response from NIH may take 3-4 weeks. The deputy

chief of staff Bob Reilly was very aware of ET, except he knew it as "benign tremor." Bob's family has an inherited prevalence for ET.

I voiced how I hope to start an ET support group. The response was overwhelming. Congressman Perry and Bob offered their communication services in terms of helping to

publicize my advocacy efforts through the [Congressman's Facebook page](#) and email list on anything I do. Bob gave me his contact information and asked me to keep in touch with what I am doing to raise awareness for ET.

All in all, I thought my meeting with Congressman Perry and his Deputy Chief of Staff Bob went well. I was able to hit on everything in my notes. For my first foray into public advocacy, it wasn't too bad!

## Congressional ET Advocate: Response from NIH/NINDS

By Nannette Halliwell

On October 28, 3 days after my meeting with Congressman Scott Perry, I received an email from his deputy chief of staff Bob Reilly thanking me for meeting with him and the

"I addressed the 1-Octanol and Octanoic Acid clinical trials."



Congressman and following up on the documents I provided. Bob was fact checking the information I gave him on the [Octanoic Acid study](#), asking for any other background information before he reached out to NIH. I replied to Bob on November 12 with additional information from Tremor Action Network. There were two Octanoic Acid trials, with results received for the first study - [Double-Blind, Placebo Controlled Pilot Study of Octanoic Acid in Essential Tremor](#), but not for the second one -

[Dose Escalation Study of Oral Octanoic Acid in Patients With Essential Tremor](#). I suggested to Bob that he contact [Dr. Mark Hallett](#), principal investigator of the Octanoic Acid study. I recommended that he and Congressman Perry let Dr. Hallett know that the Congressman would be willing to help Dr. Hallett advance research on Octanoic Acid for development as the first official drug for ET. I shared my tremor had been particularly bad the last two weeks, even with medication. My husband had to help me with cooking for our family. I had to resort to using a tablespoon to eat with because the food wouldn't stay on the fork. I emphasized that we really need drug research specifically for ET. We need solutions for our disease, not drugs that were intended for something else that just happen to help ET.

Bob responded on November 15 that he had made the written inquiry with NIH on behalf of Congressman Perry. He advised me it usually takes 3-4 weeks to get a formal response.

On November 20 I received another email from Bob Reilly, sharing the response from NIH. In Bob's own words, "I will say that this is more timely and comprehensive than most responses we receive. I hope you find it helpful. I have alerted NIH that I may have follow-up questions from you after you've had a chance to review the material."

Mr. Reilly,

Your letter to Pat White on NIH essential tremor (ET) research

and the use of octanoic acid as a treatment was forwarded to me, and I'm happy to provide you with information that I hope will be helpful to Rep. Perry's constituent, Mrs. Halliwell.

The National Institute of Neurological Disorders and Stroke (NINDS) leads NIH research on essential tremor, which is the most common neurological movement disorder. Dr. Mark Hallett, Chief of the Human Motor Control Section at the NINDS Intramural Research Program in Bethesda has carried out a number of studies on octanoic acid and related compounds as treatments for ET. These studies included an early-phase clinical research study that was completed in July 2012 and published in the journal *Neurology* in March 2013 (<http://www.ncbi.nlm.nih.gov/pubmed/23408867>).

**"NINDS is currently seeking a partner to continue the octanoic acid study."**

The NINDS Intramural work with octanoic acid was most recently supported by an industrial partner in addition to NINDS. That company was sold and the new company has decided not to continue supporting the work. The NINDS is currently seeking a new industrial partner to continue the work in the future, and discussions are underway. An industrial partner will provide expertise on drug formulation, which is necessary in order to bring a new product into clinical use.

The NIH Extramural Research Program, which supports investigator-initiated research at academic, medical, and other biomedical research institutions throughout the United States, also supports research on essential tremor. The National Institute on Deafness and Other Communication Disorders (NIDCD) is funding a randomized, placebo-controlled study of octanoic acid for the treatment of essential voice tremor that is currently recruiting patients. The [ClinicalTrials.gov](#) entry [NCT0186525](#) provides information on that trial.

([ClinicalTrials.gov](#) is searchable by the public and is continually updated as new trials supported by NIH and the private sector are registered.) NINDS funded researchers also are investigating improvements to deep brain stimulation therapy, which the FDA has approved for use as a treatment for essential tremor. The NINDS Small Business Innovation Research (SBIR) program has also supported projects relevant to essential

tremor. For example, an SBIR funded small company has brought to market a spoon that applies active cancellation technology (as in noise cancelling headphones) to stabilize movement from tremor, which helps people with tremor feed themselves. The International Essential Tremor Foundation recently highlighted this device on their webpage (<http://www.essentialtremor.org/read.asp?docid=960>). In addition to research on therapies and assistive devices, NIH, of course, continues to support studies to better understand the underlying causes of essential tremor, including genetic contributions, which may pave the way for new treatment strategies by NIH or the private sector.

Information on all research grants awarded by the NIH is available by searching the NIH RePORTER database at <http://projectreporter.nih.gov/reporter.cfm>, which is updated as new projects are funded. Entering the words "essential tremor" in the "Term Search" field will yield a list of research grants for that disorder. The results provide the name and affiliation of the principal investigator of each project as well as links to other useful information, including summaries of each project and published articles, patents, and other results. Other publicly accessible NIH databases that may be useful include [Medlineplus.gov](http://www.nlm.nih.gov/medlineplus), which provides general medical information for the public and information on specific disorders, including a page on tremor at <http://www.nlm.nih.gov/medlineplus/tremor.html>, and [PubMed.gov](http://pubmed.gov), which is a searchable database of articles in the more technical scientific and medical literature.

Please let me know if there is any additional information we can provide.

-Bob

**Robert Zalutsky, Ph.D.**

Office of Science Policy and Planning

National Institute of Neurological Disorders and Stroke

National Institutes of Health

I responded that I did have an opportunity through Kathleen from TAN to try the spoon. I can see where it may be of some help but it is \$295.00. That is really going to be out of the price range for many people. Also, if there

are any public sessions, briefings, meetings or whatever that pertain to essential tremor, I would like to attend.

Bob called me right before Thanksgiving, to let me know that he would follow up with a call to Dr. Hallett. He said he was going to ask Dr. Hallett to notify him when there was anything going on the HILL about ET. He would convey to Dr. Hallett that he would like to have someone from the Congressman's office attend, and that he would also let Dr. Hallett know that Congressman Perry has a Constituent (Me!) that would like to be there as well. Bob was glad to hear that I was writing articles to encourage others with essential tremor to advocate.

I do encourage other people to step out of their comfort zone and do what I did, Advocate! I do encourage Constituents from the other 49 States to use my articles as templates for advocating on behalf of essential tremor. You definitely have my permission! It's not as difficult as one may perceive. The House works 2 weeks in DC followed by a 1 week "Constituent Work Week." Eric Cantor, Representative for Virginia's 7th District and House Majority Leader, implemented the 2 weeks on, 1 week off in 2012. Congressman Cantor refers to the 1 week off as, "work periods." Please contact your Congressman's office to make an appointment to see them when they are Home.

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## About the Author

Nannette comes from a strong family history of ET on her mother's side. Nannette was diagnosed at 39. Nannette has decided to advocate for ET research because if she hears the phrase "movement disorder" not including essential tremor, she will go mad and take her family with her.

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COLUMBIA UNIVERSITY  
MEDICAL CENTER

## NEW RESEARCH STUDY NEEDS VOLUNTEERS - GABA IMAGING OF ESSENTIAL TREMOR

Dr. Elan Louis and colleagues at Columbia University have undertaken a new research initiative. The objective is to use new advanced imaging methods to learn what is happening in the brains of people with ET. We are calling on the assistance of the ET community to help us complete this groundbreaking, NIH-funded research. Interested candidates would comply with the following criteria:

1. You have been diagnosed by a doctor as having ET (rather than dystonia, for example).
2. You are at least 70 years old.
3. You did NOT have brain surgery for ET.
4. You do NOT have any metals in your body (pacemakers, stents, prosthesis, etc.) - this would contraindicate performing an MRI scan of your brain.
5. You do NOT receive treatment with primidone or topiramate.
6. You are willing to have two interviews (one now and one in 3 years) with us at Columbia Presbyterian Medical Center. During each interview, after some questionnaires, an MRI scan of the brain will be performed. Each interview/scan will last approximately 3 hours.
7. You are willing to consider becoming a brain donor in the future. We would discuss this further with you.

Participants will be compensated \$125 after each interview (total compensation after completing the two interviews: \$250).

If you are interested, send an email to: [nch2101@cumc.columbia.edu](mailto:nch2101@cumc.columbia.edu) or call (212) 305-8513.

Thank you all!

**Nora C. Hernandez, M.D.**

Clinical Research Coordinator

**G.H. Sergievsky Center**

**Columbia University Medical Center**

630 W168th St. P&S 16

NEW YORK, NY 10032

## TOHM Journal

By Leyla S. Williams, Communications  
Coordinator Center for Digital Research and  
scholarship

### Spikes & Spasms Note:

*In November, TAN had the pleasure of attending a CDRS/TOHM staff meeting with Elan Louis, MD, MS, Editor-in-Chief of TOHM, and CDRS [staff](#) - Leyla Williams, Mark Newton, Eva Cunningham and Kerri O'Connell. It was with profound delight to meet and observe these young professionals, efficiently engage in a no time to waste discussion with Dr. Louis. They were even in sync with their laptops. TAN noticed during the Power Point Presentation that they all use MacBook Air!*

*Tremor Action Network is a source of support for the TOHM Journal. TAN provides a link to the Journal on both the Welcome and Publication pages of the website.*

**"Journal focuses on non-Parkinsonian tremor published by CDRS."**

[Tremor and Other Hyperkinetic Movements \(TOHM\)](#), is open-access, peer-reviewed medical journal focused on non-Parkinsonian tremor published by the [Center for Digital Research and Scholarship \(CDRS\)](#). The journal was accepted in March 2013 for inclusion by [PubMed Central \(PMC\)](#), the [National Institutes of Health's](#) repository for peer-reviewed primary research reports in the life sciences.

TOHM, a newcomer in the field of movement disorders, was launched by CDRS in August 2011 at <http://tremorjournal.org>. The journal is set apart from other journals by its liberal article length policy (full-length articles may be up to 5,000 words) and its rapid turnaround time.

**FIRST DECISION**

**3.25**

*submission to first decision in weeks*

All articles archived in PMC are indexed in [PubMed](#), which comprises more than 22 million citations in its database for biomedical literature. For journals, PMC submits article citations to PubMed as soon as their articles are live in PMC, after any publisher-specified embargo period. Citations usually appear in PubMed within 24 hours of submission to PMC. TOHM has no embargo period, so all articles from the journal are deposited immediately upon publication.

TOHM has published 91 articles since launching in 2011, with the number of submissions growing. The journal's website has been visited nearly 15,000 times since its 2011 launch. For TOHM, being indexed in PMC will enable the journal's content to be more readily discoverable and, the editor-in-chief expects, attract even more quality submissions.

"The past fifteen months have seen our journal launch, the website receive hundreds of submissions, and CDRS publish groundbreaking articles by leaders in the field of movement disorders. Now that TOHM is being indexed in PubMed, it confirms our center-stage place in the area of non-Parkinsonian movement disorders. That the indexing will allow for even greater visibility of these articles and impact of our research is extremely exciting," said journal Editor-in-Chief [Elan D. Louis](#).

CDRS' Director [Rebecca Kennison](#) commented on TOHM's inclusion in PMC: "This is an important breakthrough moment for TOHM. Being included in PMC and indexed in PubMed will enable TOHM to continue to grow and confirms its prestige in providing an international platform for experts and specialists in the field of hyperkinetic movements. We continue to be honored to partner with Dr. Louis and his team and congratulate them on this milestone."

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## About the Author

As CDRS' Communications Coordinator, Leyla Williams manages partner relationships, oversees outreach and publicity efforts, and grows and maintains the Center's online presence. Prior to joining CDRS, Leyla worked in her hometown of London in nonprofit communications, campaigns, and political fundraising. Leyla has a B.S. in Psychology from the University of Birmingham, UK.

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## Genetic Variation in Essential Tremor Research

Abstracts By David H. Tegay, DO

### Spikes & Spasms Note:

*Dr. Tegay contacted TAN in May 2010, requesting assistance with posting the research study on the genetic causes of essential tremor, and help with recruiting patients for the study. Eleven days later Dr. Tegay let TAN know that, "We are getting a very quick and good response through the recent TAN postings and may reach our recruiting limits for this first phase of our study." Mary Jane Donnelly's support group in New York, and members of the TAN Yahoo Tremor Group were the enthusiastic participants of this study that included enrollment in an ET Questionnaire, submission of 2 Cheek Swab kits, and documentation of ET diagnosis.*

*TAN corresponded with Dr. Tegay in October, 2013 to learn that, "There certainly were some interesting things on array that were detected but much needs to be validated more rigorously, with the caveat that the results need further validation." Dr. Tegay anticipated creating a new study using a different approach because of, "Development of newer technologies which would allow greater ability to explore genetic associations." Dr. Tegay offered to share 2 Abstracts he presented at the American Osteopathic Association Research Conference, and the Society Neuroscience Annual Meeting.*

*TAN had a luncheon meeting with Esther Baldinger, MD in NY on November 5 to discuss Dr. Tegay's project. Dr. Baldinger was interested in the genetics of ET, and new approaches worthy of pursuit.*

*TAN appreciates Dr. Tegay sharing his Abstracts and his access to resources that can be advantageous in candidate gene identification. ET patients that participated in Dr. Tegay's "first phase of his study" will be pleased to read his Abstracts and learn about his future endeavors.*

### Essential Tremor: Candidate Gene Identification Using Microarray Comparative Genomic Hybridization

**Authors:** Rahmat Balogun, B.S., OMS III, NYCOM, Old

Westbury, NY; Brian Hallas, PhD, NYCOM, Old Westbury, NY; Enrico Fazzini, DO, PhD, NYCOM, Old Westbury, NY; Eli Hatchwell, MD, PhD, SBUMC, Stony Brook NY; David H. Tegay, DO, NYCOM, Old Westbury, NY.

**Hypothesis:** It is hypothesized that Essential Tremor (ET) may be caused by previously unrecognized genomic Copy Number Variations (CNV's). The aim of this study was to identify and catalogue pathologic CNV's in a cohort of ET subjects in order to identify novel ET candidate genes, provide a more accurate means for diagnosis and risk stratification, and allow rational therapeutic development. This was accomplished by genome wide and ET pathway focused CNV analysis, using microarray Comparative Genomic Hybridization (aCGH).

**Overview of Research Design:** This was a pilot study designed to capture CNV distribution in a cohort of subjects with clinically confirmed ET. CNV's identified in the ET cohort was compared to normal cohorts to delineate statistically significant differences in CNV distribution and enable candidate gene identification.

**Materials and Methods:** After obtaining IRB approval to perform a CGH on DNA samples from 40 subjects with ET using standard fluorescence based protocols on a customized oligonucleotide aCGH platform (Agilent), 3 m resolution scanning and Agilent feature extraction software generated data files. Agilent DNA analytics software was then used to identify significant CNV's. Significant CNV's were ranked on a 6-point scoring system to prioritize validation and further study. Points were assigned to CNV's in 2 categories based on significance of genes to ET pathogenesis and CNV frequency within the normal population.

**Results:** A number of significant CNV's have been identified in ET subjects, receiving priority scores of 5 or greater, including CNV's containing the following ET candidate genes: Potassium Channel, Calcium-activated, intermediate/small conductance, Subfamily N, Member 2 (KCNN2) and PARK2. CNV analysis and validation is ongoing

and identification of a number of additional high-priority CNV's is anticipated based on the degree of already identified genetic heterogeneity.

**Conclusions:** A large number of previously unrecognized significant CNV's exist within the ET population, many harboring promising candidate genes. Further characterization and elucidation of mutation frequencies within these genes is necessary to determine their ultimate significance to ET. Downstream studies must include analysis of candidate genes in large numbers of normal controls and validation in independent ET cohorts along with assessment of pathways to determine realistic targets for future interventions.

***Presented at the 2010 OMED American Osteopathic Association Research Conference***

**Title:**

**Exploring shared genetic pathways to essential tremor and Parkinson's disease**

**Authors:**

\*R. A. BALOGUN<sup>1</sup>, B. H. HALLAS<sup>2</sup>, E. A. FAZZINI<sup>3</sup>, E. HATCHWELL<sup>4</sup>, D. H. TEGAY<sup>3</sup>;

<sup>2</sup>Neurosci., <sup>3</sup>Intrnl. Med., <sup>1</sup>New York Col. of Osteo. Med., Old Westbury, NY; <sup>4</sup>Med., Stony Brook Univ. Med. Ctr., Stony Brook, NY

**Abstract:**

Essential tremor (ET) is one of the most common movement disorders and is characterized by a slowly progressive postural and/or kinetic tremor, usually affecting both upper extremities. Although the pathophysiology of essential tremor is poorly understood, there is known to be a significant hereditary component. While a limited number of genetic risk factors have been associated with ET (e.g. LINGO1) the specific genetic determinants remain unknown in the majority of cases. Recently, common single nucleotide polymorphisms (SNPs) in LINGO1 have also been associated with Parkinson's disease (PD) suggesting a shared pathophysiologic basis. It is thus hypothesized,

that additional genetic variations (either within LINGO1 or putative candidate genes) may be associated with a shared genetic predisposition to both ET and PD. Microarray comparative genomic hybridization (aCGH) has proven to be a robust platform for the genome-wide delineation of the contribution of copy number variations (CNVs) to both rare and common disorders, with increasing genomic resolution facilitating rapid candidate gene identification. CGH can thus be used to identify novel candidate genes that may be associated with ET and further interrogated for their contribution to PD pathogenesis.

With IRB approval, aCGH was performed on DNA samples from a PD cohort using a custom designed whole genome and pathway targeted oligonucleotide microarray (Agilent) to identify significant CNVs and enable candidate gene identification. This protocol was repeated with an independent ET cohort to extract similar CNV data and perform between group comparisons. Data was analyzed to identify both novel candidate genes within significant CNVs associated with ET and regions of shared CNV between ET and PD. Preliminary data analysis demonstrated apparent overrepresentation of heterozygous PARK2 deletion in the PD cohort versus reported normal population CNV frequency, also present in subjects with ET. Further delineation and validation of PARK2 contribution to PD and ET will be presented along with sequencing data for rare genetic variants in known genetic associations such as LINGO1.

## 2010 Society for Neuroscience Annual Meeting

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### About the Author

David Tegay, D.O., F.A.C.M.G., joined the New York Institute of Technology in 2007, and participates in various administrative committees in the School of Osteopathic Medicine. He is involved in ongoing research studies about the genetics of Parkinson's disease, essential tremor, autism, Facioscapulohumeral Muscular Dystrophy, and rare genetic syndromes such as Toriello-Carey syndrome.

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## Can Stabilizing the Trunk Help those with Essential Tremor: Anecdotal Evidence Exists!

By Cynthia Gibson-Horn, PT

Recently I had the opportunity to meet and have lunch with Kathleen Welker, the founder of Tremor Action Network. While we were discussing the application of Balance-Based Torso Weighting (BBTW)<sup>®</sup> on balance and mobility, she asked if I had ever noticed if BBTW could change tremor. Clinically I had seen it improve tremor in the trunk, arms and hands in people with stroke, Parkinson's disease and ataxia. However, I had never seen a patient with essential tremor.

Trunk and extremity weighting can be found in the literature dating back to the 1970's. Studies by Morgan note improvement in tremor with weights placed on the wrists of patients with many diagnoses including those with essential tremor (1-2). Treatment results show wrist weighting were immediate and appeared to be patient-specific in the amount of weight required to calm or reduce the tremor. Weights were added two ounces at a time; too much weight resulted in increased tremor. Patients with moderate to severe tremor were helped the most. Today, the practice of extremity and trunk weighting still exists as a therapeutic approach in some clinics. To assist with eating, individuals with tremor may use weighted utensils, and more, recently a tremor canceling spoon.

Years ago I realized that placing small amounts of weight strategically on the torso or trunk could have profound effects on balance and mobility in a patient with Multiple Sclerosis (3). That one session, with one patient, has developed into a researched evidenced-based assessment and treatment called Balance-Based Torso Weighting or BBTW. The difference between past weighting and BBTW is the specificity of weight placement. BBTW is currently under investigation in people with MS in a NIH grant

awarded to Dr. Gail Widener PT, PhD, and Dr. Diane Allen PT, PhD. The results look promising. In phase one, immediate improvements in gait speed were demonstrated as well as increased time on single limb stance and less time on double limb stance. In other words subjects were more likely to be on one leg during walking than on both, which is indicative of improved stability. Same session changes in gait speed and balance have been demonstrated previously in randomized controlled trials in MS and Parkinson's disease at Samuel Merritt University in Oakland, California (4-5).

As part of the BBTW assessment a trained clinician determines directional imbalance in both static positions

as well as dynamic testing. During dynamic testing perturbations or nudges to the torso are applied to determine where a patient loses their balance. Rotational symmetry is also tested. Once an individual's directional loss and asymmetry are determined, small amounts of weight are placed on an assessment vest in locations to decrease directional loss or

asymmetry. After the weights are placed the clinician assesses to determine if the individual has improved function in standing, walking, coordination, writing, speech and other essential functions. Think of it like balancing a tire. When your tires are out of balance the car shakes. When the tires are balanced immediately the car moves with better control.

We know that stabilization of the torso is important for walking as the head arms and trunk are responsible for about 70% of one's body weight (3). If the 70% of the body is out of balance the legs will have difficulty. As for function in the arms and legs if they are attached to a stable core they often function better. A common saying in physical therapy is proximal stability equals distal mobility.

The improvement seen with BBTW is immediate upon

**"I love immediate measurement tools and immediate improvement so I was game to try it with Ms. Welker!"**

application within a matter of seconds or minutes. This is hard to believe, but it is what actually happens. In some way the sensory system picks up the information from the weights via the skin, muscles or joints, etc. and the patients has better motor control immediately. At least 80% of patients receive immediate improvement. I like to think of the amount of improvement in reference to baseball. A small percentage of players hit home runs which is very exciting. More often patients are getting base hits to first, second and third. However, the odds are better than baseball with BBTW.

If the patient decides that the improvement is enough, they can acquire their own BalanceWear® device. BalanceWear is a semi custom garment that is available to patients with all kinds of disabilities. Patients from 9 months old up to 92 year olds with a variety of different diagnoses have benefitted.

While having lunch with Ms. Welker, she mentioned a way to test whether BBTW affected tremor. She showed me a Tremor App on her iPhone that was developed by Lift Labs. The Lift Pulse application immediately provides a 10 second calibrated recording measurement of tremor frequency and amplitude. I love immediate measurement tools and immediate improvement so I was game to try it with Ms. Welker!

Ms. Welker demonstrated the tremor app and took her baseline measurements of her right and left hand on her iPhone. After obtaining her tremor measurement I tested her balance using the BBTW methods described above. She had rotational asymmetry, which meant I could turn her one way more than the other. She also demonstrated loss of balance posterior loss and to one side more. Three  $\frac{1}{2}$  pound weights were placed on the assessment garment to stabilize the torso. We re-measured her tremor with the Lift Pulse tremor app. On the dominant left hand the tremor measured 1.56 Cm before BBTW and 1.24Cm after BBTW; a 21% improvement. On the right hand her tremor decreased from .69Cm to .31Cm; a 55% improvement. This treatment occurred in a 20 minute session.

I have seen many patients with tremor in all parts of their bodies. In many we note a difference in the tremor with BBTW but have been unable to measure. The Lift Lab Tremor App is great for showing these differences in the upper extremity.

BalanceWear is a noninvasive immediately effective tool that patients can access through clinicians trained in the Balance-Based Torso-Weighting Technology. So many things in medicine are complicated requiring surgery or pharmaceuticals which may have negative side effects. With BalanceWear one knows right away if the treatment is working. Later if a patient isn't doing well they can just take the garment off. There are no known negative side effects known.

It gives me great satisfaction to assist those with disability...making their lives a bit easier.

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## About the Author

Cynthia Gibson-Horn is a physical therapist who developed the Balance-Based Torso-Weighting technology and the BalanceWear product line. In 2010 she co-founded Motion Therapeutics to bring BalanceWear products to patients. Cynthia teaches Balance-Based Torso-Weighting to clinicians throughout the US. She is instrumental in research regarding Balance-Based Torso-Weighting® and the balance correction product now known as BalanceWear®. The garments cost between 795.00 to 950.00 US dollars. Insurance coverage varies.

For more information on BBTW and BalanceWear or to see where trained clinicians are located see [www.motiontherapeutics.com](http://www.motiontherapeutics.com)

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## Smart Spoon that Feels Essential Tremor

By TAN Advocates

A new kind of sensor, a spoon that feels essential tremor (ET), has been developed by [Lift Lab Designs](#). The [LiftWare spoon](#) is part of a new generation of sensors. The only downside of the spoon and the sensor manufacturing industry in general is, the cost. The good news is, the selling price should go down as the demand increases for the spoon and other number of sensory devices.

TAN acted in the capacity as an unpaid patient advocacy organization consultant to LiftLabs from March through September 2013. According to Anupam Pathak, MS, PhD, founder, "TAN has been immensely supportive, encouraging, and insightful along our journey of developing and refining our technologies." TAN introduced Dr. Pathak and his products to movement disorder specialists and physical therapists throughout the United States.

In June, TAN made a presentation of the spoon to support groups that attended a 2-hour ET Conference at Holy Cross Hospital in Silver Springs, MD. In July, TAN recruited patient advocates in the San Francisco Bay Area to work with LiftLabs rapid testing a beta spoon. In September, TAN shared the spoon with Stephanie Fertig who leads the Small Business Program at NINDS. She had not seen the spoon since awarding the SBIR grant to develop it. At the NINDS Nonprofit Forum attended by TAN, Ms. Fertig discussed the spoon in the [NIH videocast](#) at 1:12:10. Unfortunately for awareness of ET, Ms. Fertig referred to the spoon as, "technology being sold for Parkinson's Disease." Dr. Pathak's Abstract, presented at the 2013 American of Academy Neurology (AAN) meeting in San Diego, specifically focuses on the spoon's design for ET patients.

**Neurology February 12, 2013; 80(Meeting Abstracts 1): S53.005**

"LiftLabs made some design changes as a result of working directly with TAN advocates."

### *S53 Dystonia and Tremor*

#### *Clinical Validation of a Handheld Assistive Device for Tremor (S53.005)*

*Anupam Pathak<sup>1</sup>, John Redmond<sup>2</sup>, Michael Allen<sup>3</sup> and Kelvin Chou<sup>4</sup>*

*<sup>1</sup>Lynx Design San Francisco CA<sup>2</sup> Lynx Design San Francisco CA<sup>3</sup> Lynx Design San Francisco CA<sup>4</sup> Neurology University of Michigan Ann Arbor MI*

**OBJECTIVE:** *To demonstrate the effectiveness of a handheld device on reducing tremor, using Active Cancellation of Tremor (ACT) technology.*

**BACKGROUND:** *Essential Tremor (ET) causes action tremors that can severely limit a person's ability to eat, resulting in decreased quality of life. A compact, handheld, battery-powered device is presented that stabilizes a spoon when shaken by an unsteady hand. The device employs ACT technology to sense motion, detect whether the motion is tremor, and move the spoon to cancel tremor.*

**DESIGN/METHODS:** *Eleven subjects (9M/2F) with ET performed three tasks (holding, eating, and transferring objects) using a spoon device with ACT turned on and off. Tremor amplitude during these tasks was measured using accelerometers embedded in the device. Tremor was rated clinically by a neurologist using the Fahn-Tolosa-Marin Tremor Rating Scale, and overall improvement was rated by the subject using the Clinical Global Impression Scale (CGI-S). Both subject and neurologist were blinded to whether the device was on or off.*

**RESULTS:** *With ACT turned on, tremor amplitude was reduced by an average of 72% in the holding task, 76% in the eating task, and 71% in the transferring task as measured with the accelerometer. There was significant improvement in tremor scores with ACT on compared to*

*ACT off in the eating ( $1.18 \pm 0.98$  vs.  $0.00 \pm 0.45$ ,  $p=0.003$ ) and transferring ( $1.18 \pm 0.75$  vs.  $0.27 \pm 0.65$ ,  $p=0.006$ ) tasks, but not the holding task. CGI-S was also significantly improved with ACT on versus ACT off with eating ( $2.45 \pm 1.51$  vs.  $4.27 \pm 0.47$ ,  $p=0.002$ ) and transferring ( $2.45 \pm 1.37$  vs.  $3.82 \pm 1.47$ ,  $p=0.04$ ).*

**CONCLUSIONS:** *The ACT assistive device can reduce tremor amplitude of a spoon when being used by individuals with ET. The tremor reduction is clinically evident and can make eating tasks easier, potentially improving an individual's quality of life.*

*Supported by: NIH SBIR grant 5 R44 NS 070438.*

**Disclosure:** *Dr. Pathak has received personal compensation for activities with Lynx Design. Dr. Redmond has received personal compensation for activities with Lynx Design as an employee. Dr. Allen has received personal compensation for activities with Lynx Design as a device designer. Dr. Chou has received personal compensation for activities with Medtronic, Inc., Merz Pharma, and Accordant as a consultant.*

## SPOON TESTERS:

TAN recruited 4 ET patient advocates living in the San Francisco Bay Area to test the spoon for a period of 2 weeks. Two advocates tested the spoon much longer, for up to two months. TAN requested each spoon tester to share their comments. Two of the advocates included additional comments on testing another LiftLabs product, [LiftPulse](#).

### #1

I would describe my tremor in my dominant hand (right) as moderate. That means I can eat with utensils more than half the time without problems. Less than 20% of the time I do have trouble getting food to my mouth with a utensil. While I've had trouble writing for 3 or 4 years, it's only been in the last 6 months that my tremor has started to affect the consumption of the food I eat. I have serious trouble filling out forms and writing a check.

The task I use a spoon for the most is my daily bowl of

cereal. I do eat soup a couple times a week. While I use a spoon to eat ice cream 5+ times/week, that doesn't seem to cause me as much trouble - maybe because the ice cream is solid and weighs more in the spoon.

When eating cereal with the Liftspoon, it actually looks odd if you look at your hand and spoon concurrently. You can see your hand shaking while the spoon is fairly stable. You wind up getting virtually everything on your spoon into your mouth. Most soups I eat are fairly thick and, again, Liftspoon came through. I don't eat enough "clear soups" (broth) to judge how the spoon would work with liquids.

While Liftspoon works very well, given a choice, I would rather have a "LiftFork." Most of my food is consumed by using a fork.

I do not think LiftSpoon would help if someone had a very bad tremor. I used to be ambidextrous when using eating utensils. My left hand is affected by tremor so much - I didn't even try it.

- Mike

### #2

Here's my take on the spoon TAN was kind enough to have me try out:

The spoon I used appeared to have a tremor of it's own, which apparently was the same frequency as my own right hand tremor. There was no noticeable change or improvement in the ease of eating with a spoon, using the LiftLabs Spoon. In other words, I couldn't tell whether the tremor was from my hand or from the spoon.

Also, I use a fork (or try) much more often than a spoon. I use spoons for my blueberry & yogurt breakfasts and the blueberries were popping off the spoon just as if I were using a regular spoon. I couldn't use the spoon to stir my evening hot chocolate because we were not supposed to get the stem of the "beta spoon" wet. I also tried holding the spoon in several different positions, but always got the

same results - flying food. I tried using the spoon about 10 of the 14 days I had it, but finally gave up when it was not doing the trick.

Sorry it didn't work out for me. I don't know if I just had a faulty spoon, or if all the spoons have a tremor of their own (which happens to match my own tremor). But thank you so much for the opportunity to try it out and would gladly be a test subject for any Lift Labs products in the future.

I do use the LiftPulse app on my iPhone already and it's good to have a record of the "shakes."

- Edie

### #3

The LiftWare spoon provided the opportunity to test it in restaurants. The tremor in my dominant hand (left) has finally caught up and overtaken the tremor frequency in my non-dominant hand, causing me to be selective with the types of food I eat. I can still use ordinary utensils with my right hand, but my left hand is beginning to struggle with regular flatware.

I purposely used the spoon in restaurants to see if other patrons would notice. No one did. (Sidebar: Sometimes tremor patients feel more self-conscious than they should. We need to remind ourselves that the digital age we live in has replaced "gawking" with "selfie;" the [Instagram](#) of being absorbed with oneself.)

I give credit to LiftLabs for developing an adaptive device that doesn't look out of the ordinary. In fact, the spoon is extraordinary! I didn't feel self-conscious using the spoon in public. The LiftWare spoon senses the tremor, but doesn't make noise in doing so. I ate Thai food in Berkeley's Gourmet Ghetto, and Mediterranean food in San Francisco's Mission District, without spilling any food on me.

In the comfort of my home I was more aggressive with testing the spoon at the dining table and in the kitchen. I didn't experience difficulty in using the spoon to scoop up

an assortment of chopped vegetables and sliced meat. I used the spoon in the kitchen to measure ingredients and fluids. I encountered no problems measuring sugar and coffee grounds. I was amazed how water stayed in the spoon without spilling. However, I do use a fork and knife more than a spoon. LiftLabs has plans to add attachments. Their website states, "several attachments coming soon." I encourage the company to design a fork ASAP. I use a fork more than any other utensil.

My favorite part of being a spoon tester was sampling Mike's homemade chocolate chip cookies, eating a chocolate croissant in the company of Edie and Lift Labs mechanical engineer Michael Allen at the Rustic Bakery in Larkspur Landing, and, the ferry rides from San Francisco's Ferry Building!

- Kathleen

### #4

ET has been in my hands since the age of 10, and head since the age of 45. My tremor affects most every aspect of my life these days. I try to be an advocate and explain the shaking to those whom I meet in my daily activities. It is a fact of my life.

I tested the LiftLabs spoon device a couple of times during the development process.

Perhaps the device was at a stage of development that did not fit my tremor. The spoon did not seem useful to me at this time. The combination of head and hand tremor makes eating unusually difficult for me these days. I look forward to trying the spoon again to see whether improvements have been made that would allow me to benefit from its use.

My eldest daughter also suffers from ET (as did my mother and a brother). She volunteered to test the spoon as well, but the LiftLabs engineers found that her tremor was not advanced enough at her age to benefit from the spoon.

I'm definitely enthusiastic and excited about the LiftPulse tremor app from Lift Labs.

I am also very grateful for LiftLabs' generosity in making the app available to tremor sufferers for free.

I have installed LiftPulse on my husband's iPod Touch and it works great on that device.

I am able to track my tremor through various conditions in my life, such as high stress, totally relaxed, with medications and without.

I haven't had an opportunity yet to show it to my neurologist, but I anticipate his reaction will be of high interest.

I plan to get a smart phone in the near future. When I do I'll install the app on that device and have it close at hand at all times. I think it's an indispensable tool for tremor sufferers.

- Peggy

### Postscript

LiftLabs made some design changes as a result of working directly with TAN advocates. Mike suggested that the spoon's sensor be turned off when laying the spoon down. Edie and Peggy's daughter hand tremors made LiftLabs aware that an adjustment was needed for the spoon to feel more mild tremors.

After conversing with advocates on what worked and didn't, LiftLabs designed the "[thumbs test](#)" to assist ET consumers to determine if LiftWare will work for them.

LiftLabs [December blog](#) shares the prototype of the 1st attachment, a deeper spoon for holding liquids, and, the in-design-phase of a fork attachment. Technology per se is always about changes - improvements.



## MagnaReady Shirt

By Jane Applegate

### Spikes & Spasms Note:

MagnaReady shirt has received much media attention, but the Jane Applegate interview with Maura Horton is TAN's favorite. TAN spoke with Maura on the media coverage, and she requested TAN to include the CBS Morning Show interview with James Brown, featuring Hall of Fame MLB player Johnny Bench, Seattle Seahawks QB Russell Wilson, and her family.

TAN has 2 MagnaReady shirts, men and women, that will be given away at the beginning of 2014. More details to follow in the next TAN In Action alert

We thank Maura for granting permission to reprint the April 9, 2013 article for viewing only.

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A new men's shirt company is trying to tap into the nearly \$3 billion U.S. market for dress shirts with innovative designs and practical fasteners.

Its timing is good: men today are buying more shirts with collars and cuffs, according to NPD Group, a market research firm. In fact, NPD reports that sales in the men's dress shirt category jumped 13.49% to \$2.78 billion in the 12-month period ending Nov. 30, 2012. That's compared with a 2.26% increase in the overall men's shirt and sweater business during the same period.

Maura Horton, a children's clothing designer, told me she put her skills to work when her husband Don, was having trouble buttoning his shirts. Horton, who has Parkinson's disease, needed an easy-to-button dress shirt while working as an offensive coach for North Carolina State University. (He's no longer coaching the university team).

After buying and trying out a few poor quality shirts with Velcro® fasteners, Maura Horton got busy designing a high-quality, 100 percent cotton, no-iron dress shirt that fastens with tiny magnets hidden in a French placket. The

MagnaReady shirts, which sell for \$59.99, are designed to solve a big problem for men with a variety of health challenges.

Once she perfected the design, she searched on Alibaba.com to find magnet manufacturers in China. "It took six months to get the molds made right," says Horton. "We found that when you coated the magnets in plastic (to make them waterproof), it reduced the strength of the magnet."

Once she had the magnets in production, she found a shirt manufacturer willing to make the shirts. South Carolina-based Overton Apparel makes MagnaReady shirts in a factory in Honduras. "My husband was my test model," says Horton. "Now, however, he can't wear the magnetic shirts because he's had brain surgery to alleviate his symptoms and has a pacemaker."

Still, her husband's challenge was the inspiration for the new family business. Now, she plans to expand by adding a

line of kids' coats with magnetic fasteners.

Like most entrepreneurs, her biggest challenge was finding the money to start the business. She actually pitched her magnetic shirt concept and made it to the finals on Shark Tank, the hit show where entrepreneurs try to attract investors

Although she didn't find an investor on the show, the process led her to a private investor who has a family member with multiple sclerosis. The investor, who she declined to identify, invested under \$1 million to help her develop the shirts and pay the cost of filing for a patent on the design.

So far, Horton and her investor have spent under \$200,000 to get the business off the ground. "My dream is to sell the shirts in retail stores," says Horton. "Retailers

**"TAN has 2 MagnaReady shirts, men and women, that will be given away at the beginning of 2014."**

have not done their homework. They have big sections of 'plus size' clothing, but nothing for customers with disabilities. I guess disability clothing is not sexy enough, but it should have its own department."

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### About the Author

Jane Applegate is the author of four books on small business success, including *201 Great Ideas for Your Small Business*, (Bloomberg/Wiley). She's the founder of [TheApplegateNetwork.com](http://TheApplegateNetwork.com).

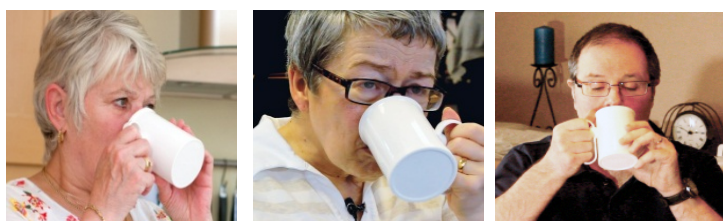
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## Inventor Designs Cup To Make Drinking Easier For Tremor

By Chris Peacock

### Spikes & Spasms Note:

Chris has published a [new video](#) featuring how handSteady® can be held for essential tremor.



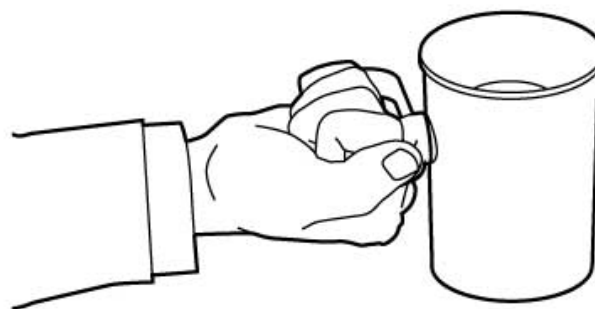
**handSteady® - the answer for people who struggle with standard cups due to tremor**

handSteady® is an innovative cup (launched in July 2012) designed specifically to assist people with tremor to drink easily. The key benefits include:

- Stays steady despite tremor.
- Tilts easily without needing to raise elbows.
- Large handle for a secure grip.
- Elegantly designed - looks like other cups.
- Comes with a unique discrete lid.
- Strong material & dishwasher safe.

Unlike other cups it has a rotatable handle, and this enables people with tremor to hold it in unique positions where tremor is minimal.

For example, the handle can be held with the elbow tucked in (to reduce tremor from the shoulder) and the forearm twisted so that the palm faces upwards. (See diagram below.) In this position, the forearm can't twist any further and so tremor can be minimal.



Tremor can be minimal if you hold the handSteady® cup's rotatable handle in this position.

Holding the handle in this unique position can enable you to carry the cup (perhaps a full cup?) from the kitchen to the lounge, and lift it to your mouth without spilling.

(You can try this at home with an empty cup - holding it at 90 degrees to see if your tremor is minimal here.)

handSteady® can also be held like a standard cup and can be tilted either by using the mouth to pivot the cup, or by holding the cup with two hands - taking the weight of the cup through the handle and tilting it with the other hand. It can also be tilted like a normal cup using your thumb to lock it in place.

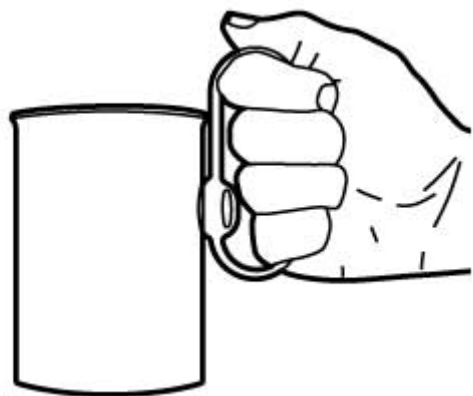
The rotatable handle technology enables people with to keep their elbows securely tucked in or resting on the table instead of raising them up (which can be unstable). See diagram below.



**handSteady®'s rotatable handle means you can drink securely despite tremor without raising your elbows**

The handle is large enough for up to four fingers, and because the handle rotates many people with tremor like to hold the handle upside down (see diagram below) when transporting it as

the centre of gravity is lower and it is more stable.



**You can hold handSteady®'s handle in many ways**

Everyone's tremor is different, so the handSteady® cup has been developed with Occupational Therapists to be highly versatile with the following features:

handSteady® has a specially designed lid that sits mainly below the rim of the cup, so that is hardly seen. It has a drink hole, which can also be used to hold straws.



**The handSteady® lid is very discrete and has a drink hole, but can also be used with a straw.**

The idea is that with handSteady® you can feel more confident because you're able to drink more easily despite tremor and the cup looks 'normal'.

### \*\*\*New way to hold handSteady for more grip

Basically the handle is turned upside down and the fingers are fed through the handle and wrap around the rim of the cup.

Chris Peacock (34 years of age) designed handSteady®

because a close family member suffers from tremor. He could see how tremor affects the activity of drinking and how this could negatively impact their life. As an inventor, Chris knew he had to come up with a solution.



**Chris Peacock, the inventor of handSteady**

So Chris worked with health professionals and people with tremor to develop and refine the handSteady®. Mary Ramsay from Scotland who suffers from Essential Tremor says, "I can now drink a full cup of tea for the first time in my life. I have had tremor since birth. I honestly don't know how I managed before handSteady"

It was at IBM where Chris was first taken seriously as an inventor. He then went to the Royal College of Art to do a masters design engineering to develop his skills in this area. Chris then set up a company "handSteady Ltd" to borrow finance and invest it in manufacturing the product in the UK to meet ISO9001 quality standards.

handSteady launched in July 2012 and has been featured by Forbes, Readers' Digest Canada, the BBC, The Guardian and Discovery News. People with tremor from around the world are now using handSteady® and we are receiving great reviews.

David Anderson from Wales says, "The product is wonderful and has significantly improved my life. Instead



of my wife having to feed me drinks when my tremor is bad; I can now do it myself."

Everyone's tremor is different, and whilst handSteady® is proving to be effective for most people who purchase it, it's not for everyone. That's why the handSteady team offer free worldwide shipping (it takes approximately 2 weeks to get to the States) and a 30 day money back guarantee.

handSteady® is not available in stores, but can be ordered directly from the manufacturers at [www.handSteady.com](http://www.handSteady.com) by credit card, debit card or PayPal. It is £39.99 which is approximately \$64. This includes free shipping and a 30 day money back guarantee. It's this price due to the expense of manufacturing the product and to ensure the business is around in the years to come developing and refining drinking aids that help people with tremor.

The 30 day 100% money back guarantee means you can try handSteady® at home, and if it doesn't work for you, you can send it back for a full refund. But if it does work for you, it could be a one-time purchase that you use for over an hour every day and one that could improve your quality of life.



handSteady® can be ordered at [www.handSteady.com](http://www.handSteady.com)

## Social Security Benefits for Disabled Widows, Widowers and Divorced Spouses

By Tai Venuti, MPH

Manager of Allsup Strategic Alliances

If you are unable to work due to a disability and are the ex-spouse or widow(er), of a Social Security Disability-insured worker, you may be eligible for [SSDI benefits](#).

Last year, the Social Security Administration (SSA) paid \$966 million to 92,000 individuals who qualified for Disabled Widow(er)'s Benefits (DWB) based on their late spouse's or ex-spouse's work record. The SSA refers to the wage-earning spouse as the "number holder," or NH.

### Are you eligible for DWB?

To receive DWB, a widow(er) must:

1. Have reached age 50, but not age 60.
2. Prove his/her [relationship](#) to the NH.
3. Prove disability using SSA's [disability standard](#)
4. Be found disabled before the end of a [prescribed period](#).

This is determined by a number of factors including the NH's date of death and the widow(er)'s age. The disability must have started before, or within seven years, of the worker's death, or within seven years from the claimant's last entitlement to mother's, father's or widow(er)'s benefits.

5. File an application.
6. Complete a disability report and sign medical release forms so SSA may obtain medical records.
7. Serve a waiting period of five full calendar months.

If you are a divorced spouse, you must meet the criteria above and have been married to the NH for at least 10 years.

If you are entitled to a retirement or disability benefit based on a monthly payment that equals or exceeds one-half the NH's monthly benefit, you are not eligible for DWB.

### What happens if you remarry?

Generally, widow(er)s or surviving divorced spouse claimants must be unmarried to qualify for DWB. However, if the subsequent marriage ends (by death or divorce), eligibility can be reinstated. Under certain conditions, the remarriage may be disregarded if:

- The remarriage occurred after the claimant reached age 50; and
- He/she was disabled at the time of the remarriage.

A widow(er) who has not remarried can receive survivor's benefits at any age if she or he takes care of the NH's child who is under age 16, or is disabled. Disabled widows and widowers aged 60 and over are eligible for the same benefit as non-disabled aged widow(er)s.

### Non-disabled widow(er)'s and surviving divorced spouse benefits

Currently, about five million widows and widowers receive monthly Social Security benefits based on their deceased spouse's earnings record. Widow(er)s benefits based on age (as opposed to disability) can start any time between age 60 and full retirement age.

### Government Pension Offset

If you receive a pension from a government job in which you did not pay Social Security taxes, the Government Pension Offset (GPO) may reduce your benefits by two-thirds of the amount of your government pension.

For example, if you are eligible for a \$1,000 per month Social Security spouse's or widow(er)'s benefit, and receive a monthly civil service pension of \$600, two-thirds of that (\$400) will be used to offset your SSA benefits, and you will receive \$600 per month from Social Security (\$1,000 - \$400 = \$600).

**"Currently, about 5 million widow(er)'s receive monthly Social Security benefits based on their deceased spouse's earning record."**

Some individuals are exempt. You can get additional information from the SSA's [Government Pension Offset](#) fact sheet.

### Help is available for SSDI claims

If you are disabled, under 60 years of age, and would like to learn more about qualifying for SSDI on your late or ex-spouse's work record, please call Allsup's Disability Evaluation Center at (888) 841-2126 or visit [Expert.Allsup.com](http://Expert.Allsup.com)

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### About the Author

As Allsup's manager of strategic alliances, Tai Venuti draws on her experience to develop and grow relationships with organizations that share the company's commitment to empowering people with disabilities to live lives as financially secure and healthy as possible.

In her role as manager of strategic alliances, Venuti works with organizations representing a wide range of constituents. Identifying and building strategic alliances allows Allsup and its partners to create new programs, leverage resources, support innovation, and better meet the specific needs of individuals.

Venuti previously managed national public health campaigns for the U.S. Department of Health and Human Services, and is an experienced presenter and panelist. She holds a master's degree in public health from St. Louis University, a bachelor's degree in journalism from Michigan State University, and is accredited by the Public Relations Society of America.

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## American Brain Coalition Board

By Andrea Gardner, RN, Director of Education

Tremor Action Network is pleased to share the [American Brain Coalition](#) (ABC) Nominating Committee selection of TAN to serve on the ABC Board for three years. TAN was on the ground floor of the ABC start-up in 2003 and 2004. TAN attended the 2003 Society for Neuroscience (SFN) Advocacy Workshop Meeting in New York City that was the catalyst for the evolution of ABC. TAN was present at ABC's first meeting held in conjunction with the 2004 SFN Meeting in San Diego. TAN was inducted as a nonprofit member during the 2005 American Academy of Neurology (AAN) Meeting in Miami. On behalf of TAN, Kathleen Welker served on the ABC Strategic Planning Committee.

The ABC is a coalition for bringing together neurological and psychiatric organizations that represent interested patients, families, and professionals to collectively advocate for increased support of research that will lead to better treatment, services, and support. The organization is also pressing for a national commitment towards finding cures for individuals with disabling neurological and psychiatric disorders. "ABC hopes to achieve the same level of public awareness and support for diseases of the brain that have been realized by the American Heart Association for heart disease and the American Cancer Society for cancer. Only when the public understands how mental illness and diseases of the brain affect millions of their relatives, friends, and neighbors will we attract the level of support for research and care needed to prevent, control, and cure these diseases. Each ABC member has a responsibility to network with colleagues in their field so that ABC can achieve this level of awareness."

TAN complies with ABC's "request for responsibility." TAN pays an annual fee of \$500 to belong to ABC. TAN

attends the 2 times a year membership meetings (Spring and Fall) and sponsored events. TAN was awarded the first ABC Advocacy Challenge Award. TAN features ABC articles in The TremorAction.org newsletter, and proactively shares ABC updates with tremor patient advocates.

TAN officially joined the ABC Board at the November 5 Fall Membership Meeting in New York City, at the main office of the Parkinson's Disease Foundation. Prior to the NY meeting, ABC's executive director Katie Sale invited TAN's liaison to the Board, Mr. Peter Muller, to sit in on conference calls.

**"TAN was on the ground floor of the ABC start-up in 2003."**

The following is a list of ABC membership meetings, board conferences and events that TAN has knowledge of. Mr. Muller, Kathleen Welker and I attending.

### [Spring and Fall Membership Meetings](#)

- Spring Membership Meeting: Bethesda, MD - February 28, 2013 (P Muller)
- Fall Membership Meeting: New York City, NY - November 5, 2013 (P Muller, K Welker)

### [Board Conference Calls](#)

- Monthly Board Conference Call - April 18, 2013 (P Muller)

### [Congressional Neuroscience Caucus Briefings](#)

- The Science of Mental Illness: Correlations between Mental Illness and Violence - March 18, 2013 (P Muller)
- The Brain Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative: The NIH Perspective - June 2013 (P Muller)

### [Items of Interest](#)

- BRAIN Working Group Meeting: San Francisco, CA - May 29, 2013 (K Welker, in-person)
- BRAIN Initiative Webinar for Patient Advocates - July 22, 2013 (P Muller, K Welker, A Gardner, RN)



- BRAIN Working Group Meeting: Boston, MA - July 29, 2013 (A Gardner, RN, phone)
- NINDS Nonprofit Forum: Bethesda, MD - November 10-11, 2013 (K Welker)

Attempts were made to reach Mr. Muller for additional information, but he was unavailable.

I look forward to assisting TAN with the ABC membership in 2014.

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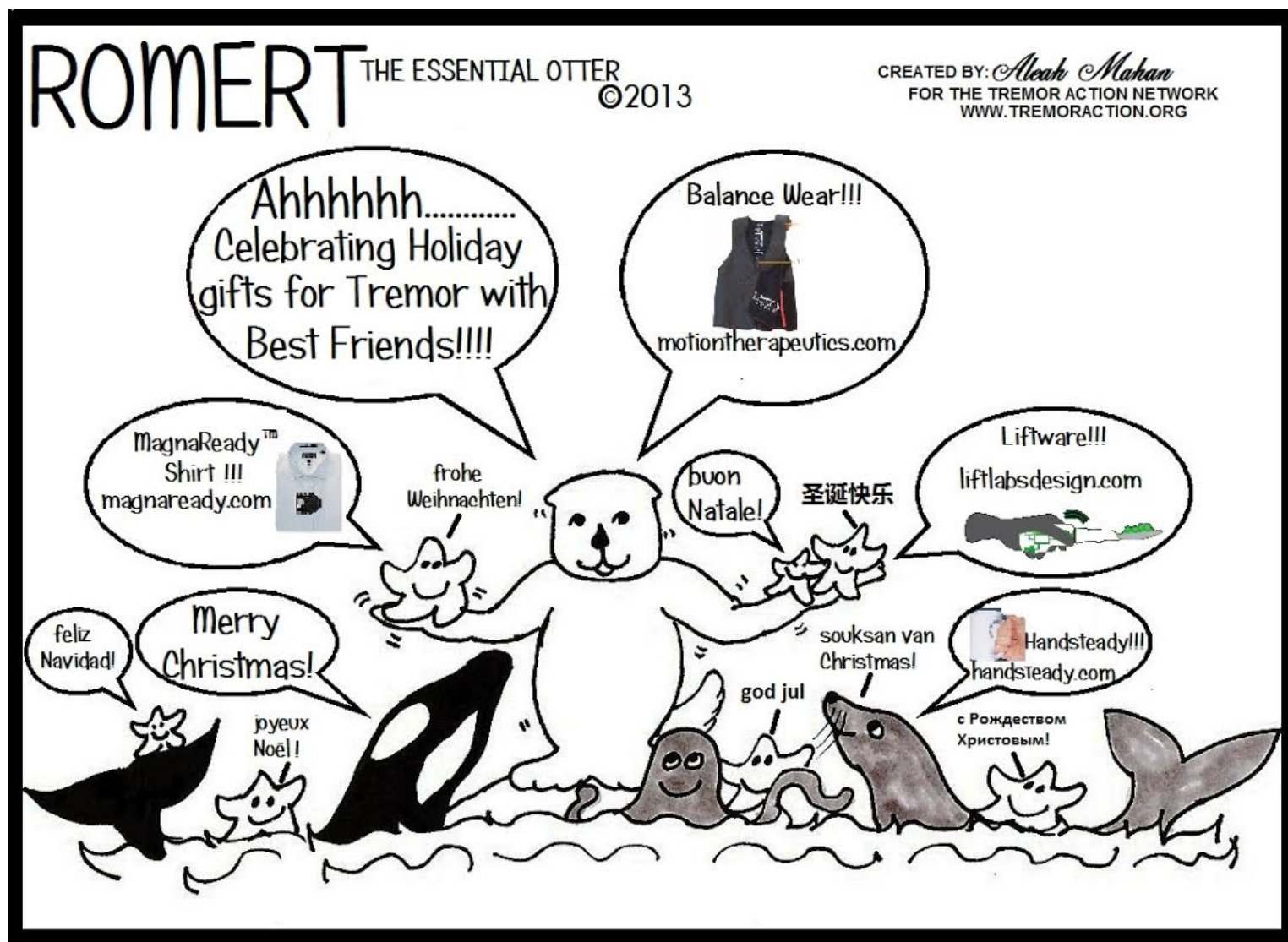
## About the Author

Andrea Gardner, RN wears many hats - photographer, knowledgeable oenophile, administrator and spokesperson for [DES](#), and essential tremor advocate. Andrea is a contributing Spikes & Spasms author. She is an expert at translating technical medical jargon for laypersons to easily understand. Andrea has held the position of TAN's Director of Education for over two years.

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# Romert's Tremor Gifts

The Essential Otter Advocate <http://romert.blogspot.com>



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