

# Spikes & Spasms

The TremorAction.org Newsletter

AUGUST 2011

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## WELCOME TO THE AUGUST ISSUE!

Again! Tremor Action Network was one of very few movement disorder advocacy organizations in attendance at the One Mind for Research Forum. Andrea Gardner, RN represented TAN. Andrea is an expert at translating technical medical jargon for laypersons to easily understand. Her 2 articles include 3 days coverage of a welcome reception, symposiums, special presentations, a networking dinner and closing remarks. Andrea's personal thoughts (in italics) are a combination of knowledgeable facts and intuition that make us think outside the box. **A diagnosis of ET and other movement disorders is no prevention for the onset of Alzheimer's and other disorders of the brain!!!**

Articles on PMD and PTSD by Doctors Stephanie Golder and Betsy Seifter parallel the One Mind for Research theme. So does the soldier's response on serving in the Army. Lindsay McGrath's article encompasses mind, body and spirit. The Congressional Neuroscience Caucus and Letters are reminders that strong support is needed to advocate for neuroscience research. Income at Risk demonstrates how vulnerable people with disabilities are in tough economic times. Romert enjoyed another visit with Patrick Kennedy!

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## 2011: A Neuro Space Odyssey Day 1

By Andrea Gardner, RN

Fifty years ago [President John Kennedy](#) envisioned "a man on the moon." Taking a cue from history, President Kennedy's nephew [Patrick Kennedy](#) has launched an ambitious science plan.

Unlike his uncle's outer space mission, Patrick's goal is directed at "inner space" - the exploration of research in neuroscience. Tremor Action Network (TAN) accepted Patrick's **Member of Congress** invitation to come to Washington, D.C. on July 29, 2010 to discuss his plan for "unlocking the mysteries of the brain." TAN featured the former Congressman's POA in the OCT 2010 issue of [Spikes & Spasms](#) (pg. 15,16). [One Mind For Research](#) evolved from this meeting of ideas.

On behalf of TAN I accepted a second Kennedy invitation to join Patrick, co-chairman Garen Staglin, leading neuroscientists, clinicians and other advocates for three days (May 23 through May 25) of symposiums and special lecture presentations.

*Forum highlights and personal thoughts (in italics).*

### Sunday

I was the first advocate to enter the Sheraton Boston

Café Apropos for the Welcome Reception. It gave me the opportunity to discuss wine and mental health with Garen, his wife Shari and son Brandon. [Staglin Family Vineyard](#) hosts an annual benefit that has raised over \$114 million for mental health research. Garen is the co-founder of the [International Mental Health Research Organization](#).

### Monday

A very early wake-up call for breakfast in the Back Bay room, followed by the 8:00 am to 5:30 pm punctual Forum schedule.

Garen opened the Forum by describing a "personal journey" with his son Brandon. He repeated the word [stigma](#) several times to define Brandon's brain disorder.

*Movement disorder patients with the symptom of tremor can identify with Garen's desire to break down the barrier of discrimination.*

#### • Introduction

[Steven Hyman](#) introduced the **Ten-Year Plan for Neuroscience: From Molecules to Brain Health**. The Plan has 3 major points:

- 1) The diagnosis and treatment of brain disorders requires understanding the most complex organ, the human brain.
- 2) Living longer dictates desired solutions. The burden of brain disorders is a global toll.
- 3) Investment in neuroscience and fields such as genomics, optics and magnetic resonance imaging will speed up discovery and treatment of brain diseases.

#### • Perception

[Takao Hensch](#) followed Dr. Hyman, asking attendees to keep 2 phrases in mind:

"Neurons that fire together wire together."  
-Donald O Hebb

"If you have wiring together you must also have a way to disconnect connections."

-Gunther Stent

#### • Collaborative Effort

[Husseini Manji](#) shared Sandra Day O'Connor,\* Stanley Prusiner and Ken Dychtwald's [New York Times](#) Op-Ed on Alzheimer's to emphasize a neurodegenerative disease that will triple by 2050. However, neuroscience is being perceived as the riskiest investment for pharmaceuticals. It basically costs 1.8 billion dollars to get a drug to market. Hundreds of millions of dollars can be spent on a drug that fails. Dr. Manji, the 3rd speaker to use the Forum's buzzword [siloed](#) stressed, "Neuroscience expertise is scattered and the approach to research is fragmented." He believes there is definitely a need for "open collaboration" in neuroscience.

***\*Those with tremor may know that the retired Supreme Court Justice is diagnosed with essential tremor (ET). Only off-label drugs are available for ET patients at this time. How will an FDA approved drug for ET ever get marketed with such staggering costs to develop one?***

#### • Mapping the Brain

[Karl Deisseroth](#) explained what optogenetics is - using light to control the brain by stimulating or inhibiting brain cells. His laboratory findings are helping he and other researchers to better understand Parkinson's. Optogenetics in mice may pave the way for stimulating the surface of the brain instead of the current treatment of invasive Deep Brain Stimulation surgery. [The New York Times](#) featured an article the week before the Forum that is helpful for understanding optogenetics.

***On January 16, 2010, over a year before Dr. Deisseroth's presentation, TAN Tweeted: "Technology hope 4 curing movement disorders. Have U heard of optogenetics-the promise 4 less invasive treatments?"***

#### • Alzheimer's Disease

Patrick introduced Congressman [Edward Markey](#) who founded the Alzheimer's Caucus after his mother passed away from the disease. The Alzheimer's research budget can't keep up with the dollars being spent on care.

***Movement disorder researchers are beginning to associate ET with neurodegenerative diseases. Elan Louis and Hiral LaRoia have co-authored a paper that***

***suggests ET in association with Parkinson's and Alzheimer's. Felix Bermejo-Pareja published [Essential Tremor - A Neurodegenerative Disorder Associated with Cognitive Defects?](#) He profiled case studies that propose ET is associated with a risk for dementia.***

#### • Translational Neuroscience Opportunities

[Francis Collins](#) highlighted various NIH opportunities in areas such as innovation - new imaging technologies, and turning basic science discoveries into translational clinical applications. He envisions hundreds of existing compounds "in freezers and pill bottles" finding new uses.

***Is there a "Valley of Death" compound that could be used for developing an FDA approved drug for ET? It seems ET is the only movement disorder without a FDA designated drug.***

#### • Genetic Revolution

[Eric Lander](#), Co-chairman of President Obama's Counsel of Advisors on Science and Technology emphasized, "Understanding the basis of disease is a critical foundation for diagnosis and treatment."

***The obvious is the limited number of therapeutic possibilities for ET because of no gene discovery. Gene symbols LINGO1 and LINGO2 are being explored, but at this time there is no specific genetic marker like there is for Huntington's Disease to map ET.***

#### • Neural Interfaces

[Leigh Hochberg](#) was informative and very entertaining with his dry wit, but the topic on brain computer interfaces helping "locked-in" people who are unable to move or unable to speak didn't seem applicable to movement disorders.

***Assistive technologies are needed to silence the abnormal involuntary muscle movements and contractions in people with movement disorders.***

### • Neurobiology of PTSD

Former Senator [Max Cleland](#) provided a wonderful analogy of post-traumatic stress disorder (PTSD). He likened PTSD to riding a spooked horse, "thrown and dragged along the ground with no control over the horse that is off and running." [Elizabeth Phelps](#) addressed the neurobiology of fear. Dr. Phelps stated that many people can identify with PTSD symptoms after a traumatic event, but the symptoms go away for most.

*TAN members and website visitors have shared fear and worry, in particular traumatic incidents associated with their tremor. Many have commented on "re-experiencing the trauma, feeling depressed, losing interest in enjoyable activities, difficulty sleeping, being startled easily, feeling on edge;" all symptoms described by Dr. Phelps. Perhaps the brain studies on fear should be extended to movement disorder patients.*

### • Closing Remarks

[Gene Block](#) invited everyone to attend the 2012 One Mind for Research Forum that UCLA will host.

### • Fenway Park

The evening event was at Fenway Park! A networking dinner followed a tour of the oldest MLB stadium that featured a special presentation by 5 speakers representing the [Center for the Study of Traumatic Encephalopathy](#), a collaborative venture between [Boston University School of Medicine](#) and [Sports Legacy Institute](#).

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## About the Author

Andrea Gardner, RN wears many hats - member of the [Gateway Camera Club](#) Board of Directors, founder of the Minerva Book Club, knowledgeable oenophile, administrator and [spokesperson](#) for [DES](#), and essential tremor advocate. Andrea is a contributing Spikes & Spasms author, and has been a Jordan Rich [WBZ NewsRadio](#) guest on behalf of TAN. She is an expert at translating technical medical jargon for laypersons to easily understand. Andrea is reorganizing TAN's education program.

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## 2011: A Neuro Space Odyssey Day 2 and 3

By [Andrea Gardner, RN](#)

### Tuesday

#### • Treatment Development

Garen Staglin introduced [Mark McClellan](#) who reinforced Dr. Manji's lecture on treatment failure during the development process, confirmed there is a 30% failure rate in drugs developed for neurologic conditions. Dr. McClellan believes collaboration helps improve development science and the regulatory process (FDA).

#### • Emotion and Motivation

[Maurizio Fava](#) shared a personal loss - his mother's recent passing from Parkinson's complications declaring, "Every family in America has been affected or will be affected by neuropsychiatric diseases." [Helen Mayberg](#) noted depression is co-morbid with many conditions including neurological disorders. Dr. Mayberg used Deep Brain Stimulation for Parkinson's to point out that "brain targets for movement disorders" laid the groundwork for pioneering DBS for depression. She emphasized, "The effect of stimulation will be lost if not continuous." Dr. Mayberg stressed DBS is for patients with no options. *DBS "after" no options is in contrast with seminars for essential tremor (ET) and Parkinson's (PD) patients that propose DBS be considered "before" testing all the options. Wonder if numerous calls and emails to TAN about DBS programming issues are related to turning off the stimulation to conserve the battery?*

#### • A Wake-Up Call for Baby Boomers

[Meryl Comer](#) reinforced Congressman Markey's statistics that more money (billions) is spent annually on Alzheimer's care v millions for research. According to Ms. Comer Baby Boomers are motivated not to notice the diagnosis of Alzheimer's. She quipped, "We are the BOTOX generation." Ms. Comer showed photos of celebrities that have passed away from Alzheimer's, but their obituaries may have said "something else" because of that word Garen

opened the Forum with, "stigma." She acknowledged it took President Ronald Reagan's courage to give Alzheimer's a face. A compelling video of Ms. Comer and her husband showed what its like to be the patient victim and the caregiver for 17 years.

*"Something else" sounds familiar... Actress Katharine Hepburn and 60 Minutes Andy Rooney. [General Douglas MacArthur](#) camouflaged his tremor. [University of Florida Center for Movement Disorders and Neurorestoration](#) gave TAN permission to share the article with Patrick and other Forum presenters. As previously mentioned, recent findings support an increased risk of Alzheimer's in association with ET.*

#### · Learning and Memory

[David Holzman](#) talked about the importance of understanding the early detection and treatment of Alzheimer's.

*Asked Dr. Holzman during the Q&A why there was so little emphasis on ET at the conference. Referred to ET as a neurodegenerative disease. Dr. Holzman answered he wasn't aware of "that finding." Shared Dr. Felix Bermejo-Pareja's article as a reference.*

#### · The Blasted Brain: TBI

[Kevin Kit Parker](#) provided interesting information on what happens to the brain during an IED detonation, but the subject matter didn't seem relevant in association with movement disorders.

#### · Movement

[Peter Sack](#) spoke about Parkinson's. Mr. Sack acknowledged he spent a lot of time trying to hide his symptoms, questioning why he had to have a disease that people could see. Mr. Stack asked the Forum attendees to tear down the silos by collaborating with one mind for research. [Howard Federoff](#) called attention to Parkinson's as not strictly a disease of the motor system. It also involves non-motor systems depression and dementia. He used a graph that showed the growth of Parkinson's in China is staggering. Dr. Federoff discussed [Heiko Braak's](#) proposal that PD begins outside the central nervous system

and then progresses to involve it.

*ET research hasn't begun to scratch the surface in comparison to PD. There is little data on economic burden and genes. Why is PD accelerating in China? Could it be that emissions from combustion, smelters, and incinerators with little regulation expose the Chinese people to environmental toxins that have been linked to PD? Surprisingly, the FDA approved diagnostic test [DaTscan](#) that can help with early diagnosis of Parkinson's Disease and may differentiate PD from other movement disorders such as ET was not mentioned, even though NIH Director Dr. Collins referred to new imaging technologies as 1 of the opportunities for neuroscience.*

#### · The Future of Medical Innovation

Former Congressman [Dick Gephardt](#) talked about his [Council for American Medical Innovation](#) that he feels has made progress with policy makers. He coined "neurology is the black hole of medicine." His steps for going forward are in alignment with other speakers, in that research entities have to share discovery information, and the FDA needs help from the private sector for reform.

#### · Closing Remarks

Patrick Kennedy's final call to action was personal. He paid tribute to his mother for confronting the prejudice and stigma associated with her disorder. Patrick asked all in attendance to help with "the race to inner space."

#### · Halfway Home: [the movie](#)

Forum guests were treated to an advanced screening of the documentary film that focuses on the issues military personnel face returning home from the theater of war. Narrator Martin Sheen, director Paul Freedman, [Sergeant Tommy Rieman](#) and Day 1 panelist Max Cleland held a discussion following the screening. Sergeant Rieman highlighted his redeployment to Iraq eased his suffering from PTSD.

*Curious on how the [Department of Veterans Affairs](#) assesses and treats PTSD.*

Wednesday

[American Brain Coalition](#) (ABC) co-sponsored the morning One Mind Panel Presentation in conjunction with the One Mind for Research Forum. The almost 2 hour event was formatted for patient advocates that may not have attended the two Day Forum. The 1st Panel included new faces, NINDS Director [Story Landis](#) and FDA

Commissioner [Margaret Hamburg](#), but the panel presentation New Developments in Translational Science: Compounds to Cures was well covered on Day 1 and 2 by Dr. Manji, Francis Collins and Mark McClellan. The 2nd Panel featuring Patrick, former Congressman [Jim Ramstad](#), [Brandon Staglin](#), and [Mary Woolley](#) presented The Public Face of Mental Health. Mr. Ramstad who collaborated with Patrick on the Mental Health Parity and Addiction Equity Act shared "1 in 3 Americans are afflicted with a mental health disorder." Mary Woolley's repetitive theme was "create political will" to end mental health stigma, and advance brain research. Brandon is a very genuine person. It was a privilege to speak with him several times

*ABC Chair [Joseph Coyle](#) paraphrased depression expert Helen Mayberg by stating, "Co-morbidity, that is the coexistence of more than one diagnosable disorder, is not the exception, it's the expectation." A diagnosis of ET and other movement disorders is no prevention for the onset of Alzheimer's and other neurological disorders. But...*

*Very few movement disorder patient advocacy organizations that are members of the American Brain Coalition (ABC) were in attendance. Other than TAN counted 2. Movement disorders will continue to be a challenge without a broader collaboration. Just a few strategic partners won't do. A more synergistic effort is needed for movement disorders to succeed within the Ten-Year Plan for Neuroscience.*

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## About the Author

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## DALLAS BRAIN & WELLNESS INSTITUTE



### Psychogenic Movement Disorders

By Dr. Stephanie Golder

Psychogenic Movement Disorder (PMD) is officially categorized as a Medically Unexplained Symptom (MUS). This condition manifests itself most commonly as a conversion disorder. A conversion disorder with psychogenic movements is defined by the DSM-IV as a movement disorder that cannot be explained by organic damage to the nervous system; conversion disorders are thought to have a psychological origin, and in contrast to factitious disorder or malingering, the symptoms are not intentionally produced or feigned.

Because of the broad nature of this definition, PMD serves as an umbrella term for a variety of movement disorders when there is no neurologic or other medical indication to explain symptoms. PMD can present as tremor, myoclonus, dystonia, chorea, bradykinesia, tics, athetosis, ataxia, or other movement disorder. Neurologists and psychologists alike are often stumped by PMD. In recent years, the disorder is receiving greater attention, as PMD patients are estimated to account for 2-3% of all patients in movement disorder clinics.

The emotion center in the brain is very tightly linked with the motion center in the brain, and if there's an emotional disturbance, the body can react with motor symptoms. Vanessa Hinson, MD, director of the Movement Disorders Program at the Medical University of South Carolina in Charleston, states that with the correct explanation of symptoms and guidance toward the appropriate treatment, 99% of PMD patients accept the diagnosis and become actively involved in treatment.

Hinson adds, "I often make the analogy that on a small scale, if someone who is supposed to speak in public is nervous, their hands might start shaking, or if they're embarrassed, their face might get red, so emotional feelings can translate into physical symptoms." She said that most patients are receptive to the analogy and understand what she is saying.

Stress is a major precipitating factor in PMD. A vital aspect of healing is to identify the specific stress factors that may be responsible for the motion symptoms. It is important that the patient understands that the movement symptoms are real and actual; the emotional and motion centers of the brain function together, and in the cases of PMD, it is as if these centers have crossed in their response. Helping patients understand that physical brain function is largely responsible for their symptoms offers them dignity and freedom to accept that there is a physiological component to their diagnosis. This is so important toward healing!

At [Dallas Brain & Wellness Institute](#), we strive toward helping our clients find physical, emotional, and spiritual healing. Our integrated approach involves counseling, neurofeedback therapy, and Hemispheric life coaching. This approach is different from traditional treatment, in that we involve neurofeedback therapy. When significant stress, depression, or anxiety is present, physical changes occur in the brain. PMD patients experience motor responses to this stress, depression, and/or anxiety. Through neurofeedback, the brain waves are influenced back to a normal state, allowing the client to experience significant reduction or elimination of the symptoms that are responsible for their condition.

As the brain heals, the client meets regularly with a counselor to discuss precipitating factors, employ effective coping skills for stress and anxiety, monitor changes as healing takes place, and address other issues that may be involved in their current symptoms. The counselor, neurofeedback therapist, and client work together toward the client's wellness.

As we near the end of neurofeedback therapy, we transition from counseling to Hemispheric life coaching. We guide the client to address the future with increased confidence and balanced decision-making skills. This integrated approach to wellness guides our clients toward physical, emotional, and spiritual healing. Hope becomes a meaningful part of the future!

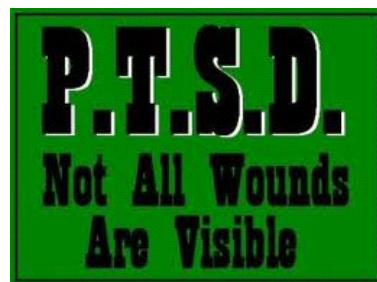
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### About the Author

Dr. Stephanie Golder and her partner Mindy Fritz offer an integrated approach to wellness that incorporates neurofeedback, counseling, and Hemispheric life coaching. Their website, <http://brainandwellnessinstitute.com> is a reliable source for information on a host of issues from anxiety/depression, ad/hd, autism, migraines, movement disorders, ptsd, and many other conditions. The FAQ's page includes a great explanation on neurofeedback - what it is, how it works, how successful it is.

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**DALLAS**  
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**INSTITUTE**



## PTSD - Symptoms and Treatment

By Dr. Stephanie Golder

### Is it PTSD?

Are you wondering if you or someone you love is suffering with post-traumatic stress disorder, PTSD? Read to find out and to learn how to get help toward real healing!!!

There are many symptoms of PTSD that have been grouped by health professionals into 6 specific criteria. A person does not need to experience all the symptoms to be diagnosed with PTSD, but factors from each criterion are evident to help form a diagnosis of PTSD. Criteria A-F, listed below, are outlined in the 4th edition of the *Diagnostic and Statistical Manual of Mental Disorders, DSM-IV*.

#### Criterion A

A person must have experienced a traumatic event where **both** of the following occurred:

- The person experienced, witnessed, or was confronted with an event where there was the threat of or actual death or serious injury. The event may also have involved a threat to the person's physical well-being or the physical well-being of another person.
- The person responded to the event with strong feelings of fear, helplessness, or horror.

#### Criterion B

The person experiences **at least one** of the following re-



experiencing symptoms of PTSD:

- Frequently having upsetting thoughts or memories about a traumatic event.
- Having recurrent nightmares.
- Acting or feeling as though the traumatic event were happening again, sometimes called a "flashback."
- Having very strong feelings of distress when reminded of the traumatic event.
- Being physically responsive, such as experiencing a surge in your heart rate or sweating, to reminders of the traumatic event.

### Criterion C

The person experiences **at least three** of the following avoidance symptoms of PTSD:

- Making an effort to avoid thoughts, feelings, or conversations about the traumatic event.
- Making an effort to avoid places or people that remind you of the traumatic event.
- Having a difficult time remembering important parts of the traumatic event.
- A loss of interest in important, once positive, activities.
- Feeling distant from others.
- Experiencing difficulties having positive feelings, such as happiness or love.
- Feeling as though your life may be cut short.

### Criterion D

The person experiences **at least two** of the following hyper-arousal symptoms of PTSD:

- Having a difficult time falling or staying asleep.
- Feeling more irritable or having outbursts of anger.
- Having difficulty concentrating.
- Feeling constantly "on guard" or like danger is lurking around every corner.
- Being "jumpy" or easily startled.

### Criterion E

The symptoms described above must **have lasted for more than a month**. If the symptoms have lasted for less than a

month, you may have another anxiety disorder called Acute Stress Disorder.

### Criterion F

The symptoms described above have a great negative impact on your life, interfering with physical health, work or relationships.



### So you are diagnosed with PTSD. Now what?

It is very important to understand that a comprehensive approach to healing is vital to help the person struggling with PTSD to gain the greatest benefit from treatment. To this end, it is important to recognize that someone who suffers from PTSD must address both the emotional and physiological aspects of this disorder.

At [Dallas Brain & Wellness Institute](#), we strive to walk alongside those struggling with this disorder as they unlock their pain and greet the future with hope! Through counseling and neurofeedback, the client heals experiences healing both emotionally and physiologically.

### The Emotional Aspect of Healing from PTSD:

The negative memories, associated fears, and the adverse emotions related to the trauma(s) that cause PTSD can be overwhelming to process for the person struggling with this disorder. Therefore, counseling is a vital component to healing. At Dallas Brain & Wellness Institute, with the assistance of a counselor, the client addresses the impact of the trauma on one's life, identifies and processes specific emotions and fears still attached to the pain, learns to disengage from those emotions and fears that

have developed based on the trauma, and moves into the future with hope and anticipation of good things to come!

### **The Physiological Aspect of Healing from PTSD:**

The person suffering from PTSD may experience significant success through counseling, and they may lead a successful and relatively happy life because of ongoing efforts to grow and heal from the associated trauma(s). However, many of these sufferers from PTSD still struggle from a variety of physical issues: high blood pressure, body temperature dysregulation, chronic pain, chronic fatigue, fibromyalgia, migraines, Reynaud's phenomenon, nausea, severe muscle tension, irritable bowel syndrome, insomnia or other sleep disorder, depression, asthma, anxiety, a weakened immune system, and/or a host of other conditions. Many times, even the patients' doctors are stumped as to why these people, who may appear physically healthy, do, in fact, have so many different conditions. These patients are not hypochondriacs; the symptoms are real and actual. These physical conditions are related to the physiological condition associated with PTSD.

When someone develops PTSD, there is an actual, physical change that takes place in the brain. These changes have a critical effect on the proper functioning of the parasympathetic nervous system. Over time, this dysfunction begins to affect various body systems, and physical symptoms appear and often spiral out of control! Many patients are told there is little that can be done for this ... outside of medication to attempt to control or reduce symptoms. Unfortunately, a medication for one issue may exasperate another issue, and before you know it, someone suffering from the physiological effects of PTSD is on any number of medications and doing their best to manage the side effects.

### **Healing the Brain/Healing the Body:**

At [Dallas Brain & Wellness Institute](#), we utilize neurofeedback to help the brain heal from the physiological effects of PTSD! The brain of the person suffering from PTSD produces very significant amounts of

high beta waves (undesirable and associated with fear and anxiety) and very little amounts of alpha waves (necessary and associated with calm and relaxation). These alpha waves are also vital for the parasympathetic nervous system to function optimally. Through neurofeedback therapy, high beta waves are greatly reduced and alpha waves are increased throughout the brain. The result is a brain that learns to function effectively, a body that heals from the associated physical conditions/symptoms and learns to tackle stress appropriately, and a hopeful person who begins to experience tranquil, peaceful emotions that had long ago eluded him or her!

## Trauma and Illness

### A trip to the dark side

By Betsy Seifter, Ph.D.

#### Spikes & Spasms Note:

The book [After the Diagnosis: Transcending Chronic Illness](#), led TAN to Julian and Betsy Seifter's blog on [Psychology Today](#). Tremor Action Network is grateful to Dr. Betsy Seifter for responding to our email. The Seifter's understanding of PTS symptoms in association with chronic illness is analogous to Dr. Stephanie Golder's PTSD approach, in treating the brain and body. We thank Dr. Seifter for granting permission to reprint the December 15, 2010 article for viewing only.

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"[Trauma](#)" means injury, from the Greek "to wound or pierce"; in its root sense, it's a blow to the body, but as anyone who's watched Oprah knows, it also refers to emotional wounds. What begins in the body often spreads to the mind; in [post-traumatic stress disorder \(PTSD\)](#), a physical assault triggers a mental disorder involving hypervigilance, numbness, [depression](#), [anger](#), flashbacks, social withdrawal.

Chronic illness is traumatic on both levels--the physical, obviously, but also the mental and emotional. People who are ill very often display classic symptoms of post-traumatic [stress](#), even if they don't have the full-blown disorder. Some who are ill develop a veil of impenetrability--you can't see in (and it's possible they can't see out). Others are in chronic combat mode--"you talkin' to me?"-- and still others spend all their time on the lookout for the next symptom or exacerbation. In *After the Diagnosis*, Cathy, with her undiagnosed [fibromyalgia](#) and her hypersensitivity to pain; Beverly, who was angry,

obsessed, and given to far-fetched explanations involving someone-or-other's malfeasance; Bill, who claimed he was fine as he resisted any argument in favor of further treatment--all show symptoms of traumatic stress. It's no surprise that illness can end up running the show, in some sense, when the pain of being sick is so difficult to bear.

Patients who do well with their illnesses may simply be lucky--the symptoms aren't that bad, or can be well controlled--or they may be temperamentally [resilient](#), inclined to forget their deficits. But for some, it might be better not to shrug off problems, but rather to acknowledge the dark side. By recognizing the traumatic aspects of illness the ill person can potentially break

through denial, modulate obsession, lessen rage. Group therapies for people who've been in battle or sexually assaulted have in common a "telling" of the trauma, which robs it of some of its power to haunt; support groups for the chronically ill have a similar expressive function, as patients trade stories of their symptoms, surgeries, and treatment regimens. And a

consequence of this "being in touch" with the pain-with the anger, preoccupation, sadness- can sometimes, over time, be a road to putting the illness in its place. It is part of life, sometimes overwhelmingly so; but it might not have to be all of life.

"People who are ill very often display classic symptoms of post-traumatic stress."

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#### About the Author

Betsy Seifter, Ph.D. is a teacher, editor, writer and co-author of [After the Diagnosis](#).

She graduated from Swarthmore College and received her doctorate in English literature at Columbia University. She is also co-author of *The McGraw-Hill Guide to English Literature: William Blake to D.H. Lawrence*, volumes I and II.

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## Serving in the Army with Essential Tremor (ET)

### Spikes & Spasms Note:

*Ever since TAN's knowledge of the Fussell v Georgia Ports Authority decision, we've been interested in safety officers and military personnel in association with a diagnosis of ET. The Eleventh Circuit stated, "A fellow officer's ability to draw his or her gun and accurately shoot it is a self-evident requirement in protecting fellow officers in a variety of situations."*

*One of the search engines provides a community page where web visitors can ask and answer questions. TAN came across a Q&A that peaked our interest. We contacted the former soldier, extending an invitation to share any additional comments.*

### Q: Can I go into the military with ET (Essential Tremors)?

"I'm very interested in going into the Air Force. I have a mild case of Essential Tremors and I'm a little worried I will be disqualified from joining. It is not noticeable when I'm calm, but when I become nervous and you stare at my hands for more than a second, you can notice."

### A: Hello.

"I had been serving in the army for 3 years as a combat soldier, and to say the truth sometimes I regret it.

There are few reasons for it:

The first is the humiliation I had to go through a lot of times, especially at shooting practice. I can't even start to try and tell you how embarrassing it was to be in that situation (although you probably know). And you probably know that after physical stress or lack of sleeping the tremor gets worse.

The other thing that really depressed me was the fact that

I am a smart and a sharp person, but because of the tremors the commanders thought I was weird (oh by the way I didn't tell them I had et cause if I did they wouldn't let me stay there). So no matter how hard I tried, I couldn't exploit my potential so really it felt like I'm wasting my time.

Another thing is the fact that in those 3 years I could have tried to find a cure, but instead I think that some of the things I had gone through made the coping with the ET harder.

I'm sorry if this is disappointing you. Maybe you are mentally stronger than me, but I really think that you should concentrate on getting better."

**"I have found out that the saying "everything is possible" does not apply."**

### Invitation Response: On the day I was recruited, I had two options:

The first was to tell the truth, or as I did and as I do so often - to lie.

I did so for the same reason I lie so many times - I wanted to be normal. I didn't declare that I had ET, and so began my Via Dolorosa (Way of Suffering) to become a combat soldier.

The hardest period was the training. It was a time of daily basics, coping with lack of understanding, shame and fear, humiliation from few peers and even by some of the commanders, and what bothered me equally - the pity stares and whispers.

My most remembered incident happened in the shooting range when one of the senior commanders started laughing and shouting in front of everyone because I was shaking while I aimed the rifle to the target (of course that only made me shake harder). The only thing I could think about besides not crying was the dilemma whether or not to move the gun from the target and stick the barrel in my mouth.

Even today I find myself thinking a lot about that day. I

was 18 at that time and I was at the peak of my self-determination of who I was and who I was going to be.

The period of military service is supposed to be a time of self-development of the personality and of the potential, but for me, and this is what hurts me the most, it was not so.

I find myself thinking a lot of times that not only I had not progressed nor fulfilled my potential, but also that I lost some of the belief in myself.

I have found out that the saying "everything is possible" does not apply to me, no matter how hard I would try or want it. It's a hard feeling, a feeling of helplessness and lack of control.

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### About the Author

A "truthful and caring individual" who wishes to remain anonymous.

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## Spirited Movement Foundation Retreat

By Lindsay McGrath

### Spikes & Spasms Note:

*This article is adapted from a piece written by reporter Nancy White that originally appeared in the **Cohasset Mariner** Newspaper.*

When Lindsay McGrath, director of The Spirited Movement Foundation, a four year old non-profit based in Massachusetts, came down with cervical dystonia years ago, it meant she could not move her neck.

Lindsay went from doctor to doctor in search of the answer as to why her neck muscles were in spasm and she couldn't control her movements. Her condition - her head was basically lying on her right shoulder - made it hard to be around other people and she was in constant pain.. There was tremor in her neck too, especially when she was tired or stressed. There was also isolation and fear.

After Lindsay got her diagnosis and began medical treatment, she began to do research into movement disorders. And through that research she discovered that people living with movement disorders have little in the way of community.

Lindsay, a trained hospital chaplain, decided to do something: she wanted to help others in the same position, suffering from similar pain and isolation.

In 2008, Lindsay founded The Spirited Movement Foundation. The organization offers interfaith spiritual retreats for people living with movement disorders and their family, friends and caregivers. The retreats provide community and offer activities like adaptive yoga, tai chi, massage and therapeutic dance that can help improve

quality of life.

"What we offer is a complement to the medical treatment people get. Once you leave the doctor's office it can be a pretty lonely journey," Lindsay said, adding for some attending a Spirited Movement retreat is the first time they meet other people who live with similar conditions.

The Spirited Movement Foundation has hosted five retreat events and maintains a website filled with informative, inspiring blog postings, prayers, videos and more at <http://www.spiritedmovement.org>.

**"The organization offers interfaith spiritual retreats for people living with movement disorders."**

"There's a real hunger for community, and we are committed to meeting it," Lindsay said. "It's important to find the tools you need to feel better. We want to help people do that in a way that brings joy into their lives."

For more information on The Spirited Movement Foundation visit [www.spiritedmovement.org](http://www.spiritedmovement.org) or call (781) 385-9401.

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### About the Author

Lindsay McGrath, M.Div. is director of the Spirited Movement Foundation. She holds a Master of Divinity degree from Boston University School of Theology and is trained in spiritual direction and pastoral counseling. A former hospital chaplain, Lindsay founded Spirited Movement in 2008.

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## Congressional Neuroscience Caucus

### Spikes & Spasms Note:

*On June 13, 2011 TAN urged patient advocates to ask their Members of Congress to join the Congressional Neuroscience Caucus.*

*This article is adapted from American Brain Coalition contributors Katie Sale, Executive Director, and Allison Kupferman, Government and Public Affairs Director.*

On June, 23, 2011, Dr. Joseph Coyle, chair of the American Brain Coalition, welcomed more than 90 attendees—over half from congressional offices—to the first-ever Congressional Neuroscience Caucus briefing. The Caucus was established last year by co-chairs Reps. Cathy McMorris Rodgers (R-WA) and Earl Blumenauer (D-OR) to promote a better understanding of how the brain develops, functions, and ages. **The Caucus also seeks to raise awareness about the millions of Americans afflicted with neurological disorders or mental illnesses.** Dr. Coyle launched the briefing by thanking the co-chairs for their leadership in establishing the Caucus and the Society for Neuroscience for their sponsorship. He then spoke about the background and mission of the ABC, which is a coalition of more than 60 patient and professional organizations concerned with disorders of the brain, that span from Autism to Alzheimer's and the plethora of disorders in between. **Dr. Coyle discussed the complications caused by comorbidity. For instance, many individuals with Parkinson's disease cite depression as their most disabling symptom.** The American Brain Coalition works with its members to advocate for policies where there are shared interests. Dr. Coyle emphasized that when the

**" As a member of ABC, TAN urges you to encourage your Representative to join the Caucus."**

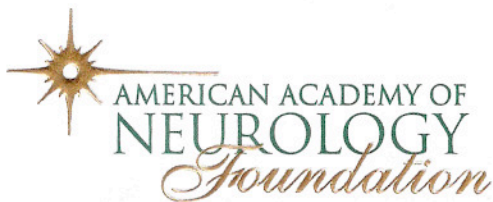
community speaks with one mind and one voice, we have a greater impact.

Rep. Earl Blumenauer expressed his strong support for neuroscience research, citing it as the next frontier. The Congressman mentioned the high cost of neuropsychiatric disorders to families and to society. Additionally, he said that the Neuroscience Caucus is meant to address brain disorders more broadly, although there are many diseases associated with the brain that have their own Caucuses. He emphasized that this Caucus is all-encompassing in order to facilitate a broader vision and discussion. The

Congressman said that brain disorders touch every family at some point in time and that there are vast opportunities for us to understand more. Finally, Rep. Blumenauer said that brain disorders have healthcare and policy implications, and perhaps this broad issue will serve to unite Members of Congress. Additionally, Rep. Blumenauer made a statement on the House floor, explaining the Caucus

and expressing his support for neuroscience.

**As a member of the American Brain Coalition (ABC), Tremor Action Network "urges you again" to encourage your Representatives to join the Congressional Neuroscience Caucus. ABC provides CapWiz, an online legislative action center, to make it as easy as possible to contact your Representatives. Please visit: <http://capwiz.com/americanbraincoalition/home> There will be a blue "Take Action!" box. Click on "Urge Representatives to Join Neuroscience Caucus" and follow the steps.**



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*St. Paul, Minnesota*

June 1, 2011

Kathleen Welker  
Tremor Action Network  
PO Box 5013  
2525 Glen Isle Avenue  
Pleasanton, CA 94566

Dear Kathleen,

On behalf of the American Academy of Neurology Foundation, thank you for your support for the First Annual Brain Health Fair in Honolulu, Hawaii.

The Brain Health Fair's success is primarily achieved by the hard work and commitment of its supporters and volunteers. We recognize your valuable contribution to this event and we appreciate your willingness to take part in this new venture. The support and feedback we've received from volunteer health associations, local health care and medical organizations, and the general public has been overwhelming. It is thanks to the fruitful collaboration of these entities that we were able to exceed all expectations and bring patients, their families, physicians, and the curious public together to gain a greater awareness about neurologic health and safety.

Thank you again for your support. We hope you enjoyed participating in this extraordinary event.

Sincerely,

Christine Phelps  
Deputy Executive Director

cc: Amy Nostdahl, Program Manager, Education Programs



# Tremor Action Network

## Shaking the World to Find a Cure

June 24, 2011

Contestants of the 2011 International Brain Bee  
Department of Neural and Pain Science  
University of Maryland  
650 W Baltimore Street  
Baltimore, MD 21201

Dear Contestants,

Congratulations! As winners of the Local and National Bees, what an accomplishment to be invited to the International Championship in Florence, Italy.

Leonardo da Vinci was born in the region of Florence. He is well known for painting the Mona Lisa and The Last Supper. However as a scientist da Vinci made an important contribution to neuroscience with his notebooks on different tremors. He noted,

“How nerves sometimes operate by themselves without any command from other functioning or soul. This is clearly apparent for you will see paralytics and those who are shivering and benumbed by cold move their trembling parts such as their head and hands without permission of soul, the soul with all its forces can't prevent them from trembling.”

Leonardo passed away on May 2, 1519. Four hundred ninety-two years later there are treatment options for essential tremor and tremor related neurological disorders such as Parkinson's disease and cervical dystonia, but little is known about the etiology.

On behalf of Tremor Action Network I sincerely hope your motivation to learn about the brain does not end in Florence. My nonprofit and other patient advocacy organizations that provide services to tremor patients are counting on you to pursue careers in neurological science to solve the medical mystery of tremor.

Enjoy your time in Florence! May the Renaissance City that has had a historical impact on science, have a lasting influence on your career choices.

Sincerely,  
Kathleen Welker  
Tremor Action Network



## Income at Risk: Unemployment Rates Rise Sharply for People with Disabilities

*Unemployment rate for people with disabilities highest in nearly two years!*

*Social Security disability applications significantly higher than first quarter...And a year ago.*

**Belleville, Ill. - July 25, 2011** - During second quarter 2011, unemployment rates for people with disabilities spiked and continued to outpace the unemployment rate for other workers, according to a quarterly study by Allsup, a nationwide provider of Social Security Disability Insurance (SSDI) representation and Medicare plan selection services.

**The Allsup Disability Study: Income at Risk** shows that for second quarter 2011, people with disabilities experienced an unemployment rate more than 80 percent higher than people with no disabilities. Specifically, the unemployment rate for April 2011 through June 2011 averaged 15.7 percent for people with disabilities, compared to 8.6 percent for people with no disabilities, according to non-seasonally adjusted data from the U.S. Bureau of Labor Statistics (BLS). Additionally, on a monthly basis, the June 2011 unemployment rate for people with disabilities reached 16.9 percent. This ties the highest recorded monthly rate, set in August 2009, since the BLS began reporting unemployment for people with disabilities nearly three years ago.

"While people with disabilities continued to face employment challenges, it appeared earlier in the year that there was a slight easing, but that has now diminished," said Paul Gada, personal financial planning director for the

Allsup Disability Life Planning Center.

"People with disabilities generally have higher unemployment," Gada said. "Those who have been searching in a market with minimal job growth may be out of work longer, their conditions worsening and their financial resources and employment prospects diminished."

The BLS also reported that 44.4 percent of individuals unemployed in June had been jobless for 27 weeks or more. This compares to 45.5 percent who had been jobless for 27 weeks or more during June 2010.

### Number of New SSDI Claims Jumps

After stabilizing in the first quarter, the Allsup Disability Study: Income at Risk shows that during second quarter 2011, the number of people with disabilities unable to work and applying for SSDI increased to 760,621, up nearly 6 percent compared with last quarter.

June 2011 applications of 287,287 contributed significantly to the second quarter increase and were 27 percent higher than a year ago. About 1.8 million SSDI claims are pending in the Social Security review process with an estimated average cumulative wait time of more than 700 days.

### Early Representation Critical To Receiving SSDI Benefits

People with disabilities may continue to seek employment only to find their conditions worsening to the point they are not able to return to work. They then may face many months or years attempting to secure their Social Security benefits. However, they can receive their SSDI benefits faster if they have representation from the beginning of the SSDI application process. For example, 55 percent of Allsup claimants are awarded benefits at the initial application level compared to just 35 percent nationally.

"People with disabilities are often already facing a

precarious financial and health situation," Gada said. "Delaying the SSDI benefits they have worked for and deserve puts them at even greater risk."

In addition to an earlier award, representation from the start of the Social Security Disability Insurance application process can help individuals:

**Find out before they apply if they are likely to qualify for SSDI benefits.** In evaluating a person's application, the Social Security Administration (SSA) follows a five-step sequential process and makes decisions based on medical documentation, work history, age and other factors. A representative can help them quickly evaluate their work history and medical information to determine before they apply if they are likely to qualify for Social Security disability benefits.

**Receive specialized expertise and hands-on help from the beginning.** Delays are often caused because people don't complete or inaccurately complete the necessary forms. Professional representation ensures expert, knowledgeable help in completing the application and Activities of Daily living forms.

**Avoid waiting in Social Security telephone and office lines.** A professional representative can handle the paperwork, answer questions and submit the individual's claim. For example, more than eight out of 10 Allsup claimants never need to visit an SSA office, easing what can be a significant hardship for many people with disabilities.

**Improve likelihood of getting their benefits.** Having a representative who makes certain the person is likely to qualify for SSDI benefits and then providing them support improves a person's likelihood of being awarded. In fact, Allsup has a 98 percent success rate among customers who complete the process with Allsup.

Anyone with questions about eligibility for Social Security benefits can contact the Allsup Disability Evaluation

Center at **(800) 678-3276** for a free disability evaluation.

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## About Allsup

Allsup is a nationwide provider of Social Security disability, Medicare and Medicare Secondary Payer compliance services for individuals, employers and insurance carriers. Founded in 1984, Allsup employs nearly 800 professionals who deliver specialized services supporting people with disabilities and seniors so they may lead lives that are as financially secure and as healthy as possible. The company is based in Belleville, Ill., near St. Louis. For more information, visit <http://www.Allsup.com>.

The information provided is not intended as a substitute for legal or other professional services. Legal or other expert assistance should be sought before making any decision that may affect your situation.

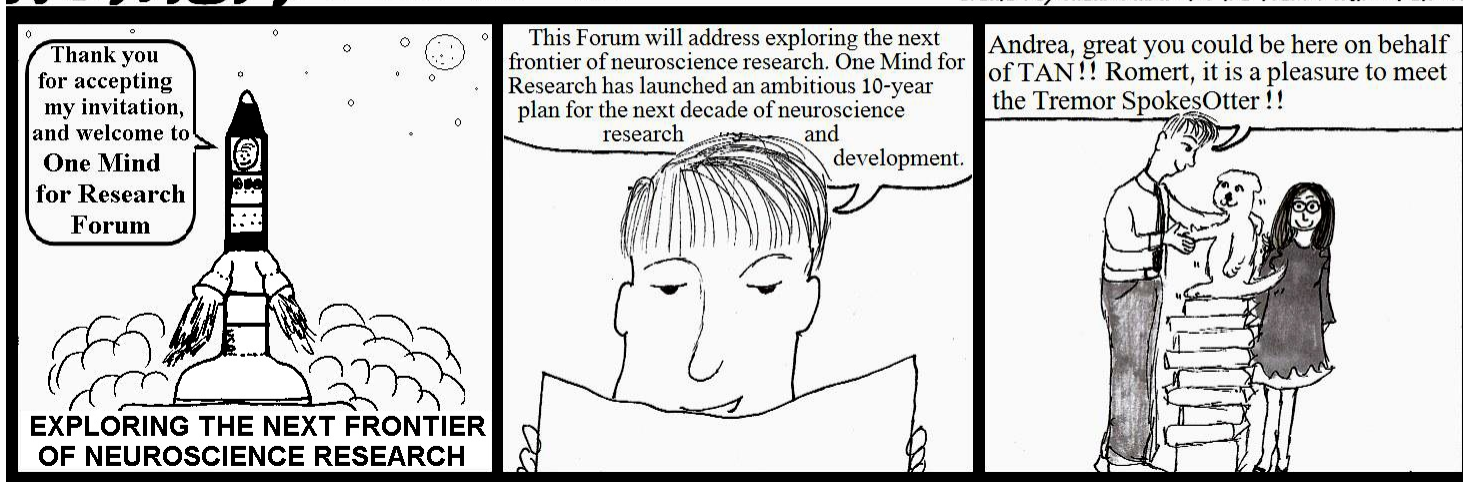
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# Spokes Otter goes to Boston

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

*Romert* the Essential Otter ©2011

*Created by Aleah Mahan for the Tremor Action Network*



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