

# Spikes & Spasms

The TremorAction.org Newsletter

APRIL | JUNE 2009

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PS: Let Spikes & Spasms know what you think. Feedback is welcome. Share your personal experiences with Tremor Action Network, PO BOX 5013 Pleasanton, CA 94566

## WELCOME TO THE APRIL | JUNE ISSUE!

The TremorAction.org Newsletter features new and updated articles from our Sponsors and Partners: Allsup, Alseres Pharmaceuticals, Cleveland Medical Devices, Dana Foundation, Getting Hired, and Professionals: Jerome Lisk, MD, Dr. Larry Neznanski, Dr. Mona Reeva, Terri Sterling, MSP, and Fernando Hernandez, dystonia Advocate.

We thank our sponsors, partners and professionals for their support and encourage you to visit their websites.

Welcome new sponsors Cherry Blossom Enterprises and Pacific Writing Instruments!

Tremor Action Network connects "the bench to the tremor patient" through innovative clinical trials, studies, therapeutic, diagnostic, biopharmaceutical and assistive technology products. TAN supports and promotes research in an effort to help find the cause, treatment and cure.

Enjoy reading Spikes & Spasms brought to you by Tremor Action Network and Sponsors

## ET vs PD

By Jerome Lisk, M.D.

Tremor is defined as a rhythmic, involuntary, oscillating movement of a body part occurring in isolation or as part of a disease. Parkinson's Disease (PD) and Essential Tremor (ET) fall in the category of movement disorders. Tremors can occur at rest, with posture (holding an object) or with action affecting the head, arms legs, and voice. These disorders are not diagnosed by blood tests or imaging (MRI or CT) but help rule out secondary reasons for tremor.

Essential Tremor (ET) is also known as familial tremor or benign essential tremor. Essential tremor is the most common tremor disorder and ten to twenty times more prevalent than Parkinson's Disease (PD). The tremor frequency is different in Parkinson's Disease and Essential Tremor. More than sixty percent of the time there is a positive family history in Essential Tremor. In Both diseases the tremor intensity can worsen in response to fatigue, physical or mental stress (anxiety), caffeine or performance situations.

The onset of tremor in ET usually starts in both arms and then spreads to the rest of the body. ET can start at any age but is more common above the age of 65. In PD the tremor begins in one arm first then spreads to the other arm. The tremor of ET is more prominent with action and posture than with rest as opposed to PD where the resting tremor is more prominent than the postural and action tremor. Essential tremor nearly always affects the hands (~95% of patients) but also affects the head (~34%), face (~5%), voice (~12%), trunk (~5%), and lower extremities (~20%). Isolated head or voice tremor is never found in PD. Sometimes the tremor of ET can be lessened temporarily by alcohol; however, not in PD. Slowing of physical movement (bradykinesia) and Rigidity occur in PD not in ET.

Patient with ET can usually have a normal gait (walking) but

also may have unsteadiness with gait. Those with PD have a shuffling gait that starts off with shorter than normal stride, stooped posture, difficulty turning when walking, decrease arm swing and tremor while walking in the more affected arm.

Parkinson's Disease (PD) is also called primary or idiopathic Parkinson's Disease and is characterized by muscle rigidity, tremor, a slowing of physical movement (bradykinesia). PD usually develops after the age of 65, 15% of those diagnosed are under 50. PD is caused by a loss of dopamine producing neurons in the brain. Only 10% of those with Parkinson's Disease have a strong family history. The tremor in PD is referred to as a "pill rolling tremor". Patients also have facial masking in PD unlike ET. Early signs are decreased sense of smell, constipation, muffled speech and REM Behavior Sleep Disorder (RBD). In REM (rapid eye movement) Behavior Sleep Disorder patients can act out their dreams which can consist of talking to fighting in their sleep sometimes hitting their bed partner. REM

Behavior can occur 10-15 years before the symptoms of Parkinson's Disease. Those with RBD are at high risk for developing Parkinson's Disease.

Secondary Parkinson's Disease can be caused by medications, head trauma, Normal Pressure hydrocephalus or other medical disorders. These other Parkinson syndromes can mimic Idiopathic Parkinson's Disease making diagnosis difficult. The medications in PD are usually not effective in Secondary Parkinson's Disease. Deep Brain Stimulation Surgery is done for Primary Parkinson's Disease not Secondary Parkinson's Disease, so an accurate diagnosis is important.

Tremor disorders can be difficult and challenging to diagnose by physicians that may even have several years of experience treating patients with ET and PD. Many patients are not referred to a fellowship trained

**"It is very important to get an accurate diagnosis because the medications and surgical treatment to treat both are very different."**

movement disorder neurologist (a neurologist with specialized training in movement disorders by an accredited neurology residency program) until their symptoms worsen significantly. It is very important to get an accurate diagnosis because the medications and surgical treatment to treat both are very different. For example, the surgery (Deep Brain Stimulation) that is done for both of these disorders is in different parts of the brain. For surgical evaluation it is important patients to be evaluated by a neurologist that has been fellowship trained in movement disorders. Early treatment and diagnosis is very important to delay functional disability.

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### About the Author

Dr. Jerome Lisk treats patients with Parkinson's disease, essential tremor and dystonia in addition to spasticity in multiple sclerosis, cerebral palsy and other neurological disorders. He is heavily involved in local Parkinson's and essential tremor support groups, and in teaching nurses and therapists about spasticity.

Dr. Lisk obtained his M.D. from the Medical College of Virginia, in Richmond, followed with an Internship at UCLA/Charles Drew Medical Center, his Neurology Residency at the University of Texas at Dallas and the University of Texas at Houston, and the movement disorder fellowship (UT MOVE) in the medical and surgical treatment of movement disorders.

### Contact Information

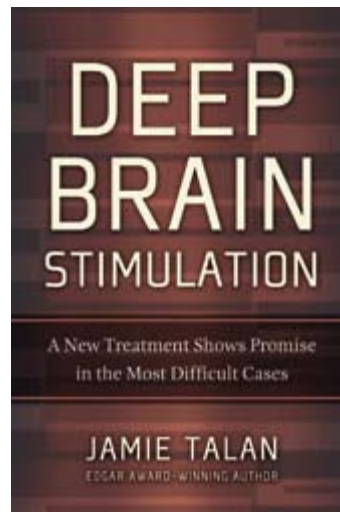
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## Deep Brain Stimulation Press Release

Contact: Leticia Barnes  
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"Deep brain stimulation opens a new horizon of therapies for many of the chronic brain ailments that trouble humanity..."

-**Dr. Mehmet Oz**, Vice chair and professor of surgery at Columbia University and author of *YOU: The Owner's Manual: An Insider's Guide to the Body that Will Make You Healthier and Younger*.

"...the fascinating story of deep brain stimulation and the hope that it offers in treating maladies of mind and brain."

-**Joseph LeDoux**, University Professor, New York University, and author of *The Emotional Brain and Synaptic Self*.

### Deep Brain Stimulation: A New Treatment Shows Promise in the Most Difficult Cases Jamie Talan

Publication date: March 27, 2009

UK Publication date: April 27, 2009

Cloth o 978-1-93259437-9

200 pages o \$25.00 o £17.50

Deep brain stimulation (DBS), a groundbreaking new medical technique that places electrodes in the brain, has begun helping thousands of people with Parkinson's disease and essential tremor for whom all other treatments have failed. Now, experimental research shows that DBS may

relieve the ravaging symptoms of a wide range of brain disorders, including obsessive-compulsive disorder (OCD), chronic pain, depression, epilepsy, dystonia, and chronic and debilitating headaches. The list of other grave conditions for which researchers are considering DBS is long, running from Alzheimer's disease to helping people with life-threatening obesity to lose weight.

In her accessible and timely new book, Jamie Talan, an award-winning science writer, explains how neurologists and scientists, some with little more than intuition to guide them, pioneered DBS and considers the risks and ethical challenges this brain surgery presents. In her carefully balanced telling, Talan movingly portrays the joy of patients successfully treated with deep brain stimulation, but also provides a cautionary tale of its failures.

*Deep Brain Stimulation* is for all readers fascinated by cutting-edge science, but is of special interest to patients, family members, and health practitioners who have seen the growing number of news reports about DBS and wondered about the successes and the risks of treating the intractable disorders with which they are coping.

Jamie Talan covered neuroscience for Newsday for more than twenty years, and is currently the science writer-in-residence at the Feinstein Institute for Medical Research in New York City.

Jamie Talan is available for interviews. Please contact Leticia Barnes at 202-216-2768 or [lbarnes@dana.org](mailto:lbarnes@dana.org) for more information.

**"Deep Brain Stimulation is for all readers, but is of special interest to patients, family members, and health practitioners."**



# CleveMed

■ ■ ■ Cleveland Medical Devices Inc.

## Keeping Score of Parkinson's Disease: UPDRS Challenge

By Maureen Phillips

Most patients with Parkinson's disease are used to the routine motor exam for evaluating the severity of their symptoms. You go to the doctor's office, do a few movements with your hands like holding your arms out or tapping your fingers, maybe get up and walk around or sit and stand. Then the doctor records a number, or a score, that indicates how severe he or she feels your symptoms are. This score is generated using a method called the Unified Parkinson's Disease Rating Scale, or UPDRS.

The UPDRS is a subjective scale where clinicians have patients perform tasks known to elicit motor symptoms, such as touching your nose, opening and closing your hand, or finger tapping. The clinician will watch as you perform these tasks and assign a 0 to 4 score based on how severe they feel your symptoms are at that time, with 0 being the absence of symptoms and 4 being the most severe symptoms. The UPDRS is the current gold standard for evaluating Parkinson's symptoms and similar rating scales are using for other movement disorders, such as the Tremor Rating Scale, or TRS, for essential tremor patients.

One current issue with these rating scales is that they are subjective and can sometimes prove inconsistent between clinicians, or between the same clinician at different times. To demonstrate this, CleveMed has created an interactive website called [UPDRS.CleveMed.com](http://UPDRS.CleveMed.com). This website asks you to rate Parkinson's motor symptoms similar to how a clinician would rate them. You will watch 12 videos, each

with an actual Parkinson's disease patient performing a task for evaluating tremor. Once the video is finished, you are asked to enter a score from 0 to 4, just as a clinician would, based on how severe you feel the patient's tremor was. When you are finished, the scores you enter are compared to the scores from two movement disorder clinicians for the exact same videos. This demonstrates the variability that can occur between clinicians for the same patient and how a method of objectively and consistently scoring symptoms could be very useful. Your scores are also compared to those generated by Kinesia, a device developed by CleveMed just for that purpose, objectively monitoring the severity of Parkinson's disease motor symptoms.

Kinesia is a compact wireless device that is worn on the hand of the patient while they follow video instructions that guide them through a series of tasks for evaluating tremor, bradykinesia (slowed movements or hesitations) and dyskinesias (wild, involuntary movements usually the result of a patient being overmedicated). When the patient evaluation is complete, the tasks for evaluating tremor are automatically scored on a 0 to 4 scale, and those scores correlate to the UPDRS. These evaluations can be done on a regular basis and the scores can be viewed in patient reports, allowing the clinician to look at changes in symptoms or fluctuations over the course of days, weeks or months. Having this type of information could assist the clinicians in a number of ways, one being better timing and dose of a patient's medication, potentially improving symptom control during the day.

**"Your scores are also compared to those generated by Kinesia, a device developed by CleveMed just for that purpose."**

CleveMed is currently completing research studies to expand the use of the Kinesia device for multiple applications. In the future, we plan to include automated scoring for other symptoms outside of tremor, such as bradykinesia and dyskinesias and we are looking into using the device for other movement disorders, such as essential

tremor. We are also evaluating the use of the device in patient's homes, which may provide better care for people who do not live near movement disorder clinics or hospitals. One of CleveMed's research goals is to provide better means of symptom evaluation, whether it's in the home or at the clinic, and help improve the quality of life for the millions of people currently living with movement disorders.

Everyone is encouraged to visit [UPDRS.CleveMed.com](http://www.clevelandmed.com) and take the UPDRS Challenge to see how you fare against other clinicians. If you would like to learn more about Kinesia, you can visit our website at [http://www.clevelandmed.com/products/kinesia\\_overview.shtml](http://www.clevelandmed.com/products/kinesia_overview.shtml).

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### About the Author

Maureen Phillips is a Biomedical Applications Specialist with CleveMed. Any questions or comments about the article, CleveMed products or current research can be directed to her by email at [mphillips@clevelandmed.com](mailto:mphillips@clevelandmed.com) or by phone at 216-619-5918.

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# ALSERES

PHARMACEUTICALS



## **ALTROPANE® POET-2 Program** - Alseres Pharmaceuticals Completes Enrollment in First Stage of the Altropane(R) POET-2 Phase III Program and Receives Special Protocol Assessment Agreement from FDA for Phase III Trial of Altropane®

Alseres Pharmaceuticals, Inc. is developing the Altropane® molecular imaging agent to aid in the early diagnosis of Parkinsonian Syndromes (PS). In February 2009, Alseres announced it had completed enrollment in the first stage of the Altropane pivotal Phase III clinical program, Parkinson's or Essential Tremor (POET-2). The objective of the first part of the program was to acquire the set of Altropane images which will be used to train expert readers for the Phase III registration portion of the program.

In April, Alseres also announced that it has reached agreement with the US Food and Drug Administration (FDA) under the Special Protocol Assessment (SPA) process for the Phase III protocol of Altropane Molecular Imaging Agent to aid in the early diagnosis of Parkinsonian syndromes including Parkinson's disease. A SPA agreement defines the size, design and analysis of clinical trials that will form the primary basis of approval. Alseres is now preparing to initiate two, parallel clinical studies enrolling up to 480 subjects in total which will be conducted at 30-40 medical facilities throughout the U.S. The results from the POET-2 program and data from more than 600 previous subjects will be included in the submission of a

**"Alseres is now preparing to initiate two, parallel clinical studies at 30-40 medical facilities throughout the U.S."**

New Drug Application (NDA).

There are more than 11 million people in the U.S. alone living with tremor disorders of which more than one million have been diagnosed with Parkinson's disease. These figures are expected to double by 2030. According to peer-reviewed publications, misdiagnosis rates for PS are reported as high as 35-50%. "Millions of people experiencing tremor symptoms currently have no objective means to determine whether or not they have Parkinson's Disease," Ray L. Watts, MD, John N. Whitaker Professor and Chairman of the Department of Neurology, University of Alabama at Birmingham stated. "There is a clear need to improve the process for earlier diagnosis of Parkinson's disease which improves patient outcomes and their ability to take advantage of neuroprotective therapies as they become available."

Altropane has the potential to be not only 'first-in-class' in the U.S. but, based on its superior pharmacological and imaging characteristics, to be 'best-in-class' in the world, addressing a multi-million patient population. Altropane is a molecular imaging agent that specifically and selectively binds

to the dopamine transporter (DAT) found on dopamine-producing neurons. Loss of these cells is the hallmark of Parkinson's disease. Altropane used in conjunction with Single Photon Emission Computed Tomography (SPECT) imaging could be useful to distinguish Parkinsonian from non-Parkinsonian tremor: Parkinsonian patients would have reduced Altropane binding, due to fewer DAT sites, and thus reduced activity in the SPECT image. The superior pharmacodynamics of Altropane suggests that it will fit well with current and future SPECT imaging practices with minimum patient inconvenience.

## Bishop Kelly HS Engineering Design: NED Challenge

Submitted By Dr. Larry Neznanski

### Spikes & Spasms Note:

*The 6 minute SHAGS - Bishop Kelly High School video can be viewed at: <http://www.tremoraction.org/videos-1.php>. Special credits and thanks to Joanne Gunther and her video production class.*

The Bishop Kelly High School Engineering Design Class travelled to Washington, DC on February 25-27 to compete as one of the five national finalists in the National Engineering Design Challenge sponsored by the Junior Engineering Technical Society. The challenge is to research, design, and build a working prototype device to help people with severe disabilities succeed in the workplace. Teams submitted drawings and photos of their designs in a report detailing how they reached their design solution. 250 teams registered for the Challenge. Bishop Kelly was selected as one of the 28 semifinalists from a field of 100 designs submitted from across the country. The design team submitted a six minute video describing the prototype design in additional detail, and was selected as one of the five finalists invited to Washington to compete at the National level.

**"Bishop Kelly's device, SHAGS, accommodates all the commonly used syringes, needles, and vials."**

Bishop Kelly was awarded second place and a \$1500 prize for The Most Outstanding Engineering Design. In addition, the team received two additional awards. The first for The Most Innovative Use of Technology sponsored by the American Society of Mechanical Engineers, and second for The Best Application of Rehabilitation Engineering Design Principles sponsored by the Rehabilitation Engineering and Assistive Technology Society of North America.

Bishop Kelly's device, named the Syringe Holder and Guidance System (SHAGS), is designed to help Marla Sheehan, a local nurse, to continue to practice her

profession. Marla has essential tremor, causing her hands to shake such that drawing and measuring medicine from a vial into a syringe can be difficult and dangerous. SHAGS greatly reduces this problem and accommodates all the commonly used syringes, needles, and vials.

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### About the Author

Dr. Larry Neznanski, Bishop Kelly High School Physics teacher, has been awarded the 2009 Siemens Foundation Award for Advanced Placement Physics due to his dedication and exemplary teaching and the success rate of Bishop Kelly students on the AP exam.

Congratulations to Bishop Kelly Engineering Design Class teachers/coaches Dr. Neznanski, Dr. Guy Hudson, and the ten outstanding students participating in the Design Challenge: Lauren Naughton, John Feusi, Sam Kosydar, Dan White, Cory Miller, Clint Taipale, Josh Letsinger, Jessica Burlile, Alfredo Bravo-Iniguez, and Ryan Schmidt.

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## Getting Social Security Disability Benefits Isn't Simple, Even After Approval

Allsup explains important help representatives provide when SSDI benefits hit roadblocks

Belleville, Ill. - March 24, 2009 - Even after getting approval for Social Security disability benefits, people can run into hurdles before those funds start arriving, according to Allsup, which represents tens of thousands of people in the Social Security Disability Insurance (SSDI) process each year.

"Problems and errors with dates, lump-sum payment amounts and regular monthly benefit amounts can occur once SSDI benefits have been approved," said Jim Allsup, CEO and founder of Allsup, which provides financial and healthcare-related services to people with severe or permanent disabilities that prevent them from working. "The issues create more headaches for the claimant, who already may have waited years for these benefits to begin.

"That's where a company like Allsup steps in—we are driven to ensure that the details of your case and that your SSDI benefits are accurate," Mr. Allsup said.

SSDI is a federally mandated insurance program overseen by the Social Security Administration (SSA) that operates separately from the retirement and SSI programs. SSDI provides monthly benefits to individuals who are under full retirement age (age 65 or older) and who can no longer work because of a disability (injury, illness or condition) that is expected to last for at least 12 months or is

terminal. Individuals must have paid FICA taxes to be eligible. More details are provided in the "SSDI Overview" on Allsup.com.

### Hurdles To SSDI Benefits, After Approval

A number of factors can create confusion and obstacles to receiving those funds once SSDI benefits are awarded.

In Allsup's 25 years of providing representation to claimants, their specialists have helped people with disabilities resolve issues relating to their date of application, their onset date of disability, and a number of other factors that can tie up the eventual receipt of lump-

sum payments and benefits. This saves time for you and ensures your benefits begin correctly and at the earliest time possible.

"The SSA is coping with huge amounts of paperwork, a tremendous amount of data and thousands of claims for people," Mr. Allsup said. "It's not surprising that there are going to be a

number of details that have to get finalized so someone's benefits can begin. In some cases, mistakes happen that can cause tremendous problems for claimants."

Allsup's representatives have identified and resolved a number of circumstances for claimants, including experiences such as the following:

- A woman who was awarded SSDI benefits but whose claim was listed with an incorrect application date. Claimants who eventually are awarded benefits will receive a lump-sum payment that dates back to when they first applied for SSDI benefits. In cases where that date is incorrect, someone could be paid less or more than they are owed.
- A man who was awarded SSDI benefits for only one year, when those benefits should have been ongoing.

**"Allsup's representatives have identified and resolved a number of circumstances for claimants."**

There are claimants who receive benefits for a specific period of time ("closed-period benefits"), such as a year or two. Allsup finds and corrects cases where the benefits should be ongoing and mistakenly are listed as benefits for a limited time period.

- A woman whose benefit start date was calculated incorrectly, meaning she would have missed several months of benefits. Claimants who are awarded SSDI benefits do not receive those benefits until five months after their date of disability; known as the date of entitlement to cash benefits. Sometimes errors in dates can result in several months of lost benefits unless they are corrected.

"These are all cases where Allsup stepped in to provide the correct information and made sure that our claimants were getting what they deserved," said Mr. Allsup.

Choosing representation from a company like Allsup means that people with disabilities have someone working on their behalf to get through the SSDI process, including the post-award process when those cash benefits begin, he said.

Allsup specialists communicate with SSA officials through phone calls and correspondence. They monitor the progress of your SSDI case throughout the process, including the time period after award and through the steps of lump-sum payments and regular monthly benefits.

There are a number of additional benefits to choosing representation. For more insights and guidance to help you with your SSDI application, visit "Choosing Disability Representation" and "Why Allsup."

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## About the Author

Allsup, Belleville, Ill., is a leading nationwide provider of financial and healthcare related services to people with disabilities. Celebrating its 25th anniversary in 2009, Allsup has helped more than 110,000 people receive their entitled Social Security Disability Insurance and Medicare benefits. Allsup employs more than 550 professionals who deliver services directly to consumers and their families, or through their employers and long-term disability insurance carriers. For more information, visit [www.Allsup.com](http://www.Allsup.com).

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**gettinghired.com**

Careers & Community for People with Disabilities

## GettingHired.com, Connecting Jobseekers with Disabilities with Jobs

By Jim Lunny

As stated well by the National Organization on Disability, "by any measure, lack of participation in the workforce is among the most critical issues facing working-aged people with disabilities.<sup>1</sup>" The latest data on the employment picture for people with disabilities released by the U.S. Bureau of Labor Statistics tells us that much work remains to be done to increase the rate of participation of people with disabilities in the workforce.

Statistics from BLS on the employment status of people with a disability for March 2009 indicate the following:

- For the portion of the U.S. population 16 years of age and older, people with disabilities constitute 11.4% of the population, yet only 3.8% of those who are employed.
- The employment rate for people with disabilities, 16 years of age and older, is only 19.8%, in contrast to an employment rate of 64.6% for all people in

this age group with no disability.

Although many people with disabilities may not be able to enter the workforce, it is clear that with the proper support and resources, many more than are currently employed would be able to enter the workforce, and ultimately seek and secure employment. Again as well stated by the National Organization on Disability, "the unemployed disability population represents a willing resource that is vastly underutilized and that would largely welcome the opportunity for independence and self-reliance provided by employment."<sup>2</sup>

Although the employment rate for people with disabilities remains stubbornly and unacceptably low, there is a need for qualified workers in many sectors across the United States, and the need for qualified workers is expected to grow enormously in the future. And, as NOD reminds us, there are significant bottom-line reasons for employers to hire these workers from among the ranks of people with disabilities, with research showing "that people with disabilities have lower rates of turnover and absenteeism and 70% of workplace accommodations can be made for less than \$500."<sup>3</sup>

The good news is that there is a new private sector initiative that is leading the effort to close the employment participation gap for people with disabilities while helping employers meet the challenge of finding qualified workers. GettingHired.com was launched in November 2008. We are a national employment and networking portal that uniquely connects job seekers with disabilities, employers committed to hiring job seekers with disabilities, public and private agencies providing services to the disabled community, including disabled veterans, departments providing disability and career services at institutions of higher education, and disability advocacy groups. You can visit us at [www.gettinghired.com](http://www.gettinghired.com).

**"More than 16,000 individuals have registered, at no cost, with GettingHired.com as Jobseekers."**

**GettingHired.com's mission is to create sustainable employment growth and opportunities for people with disabilities.**

More than 16,000 individuals have registered, at no cost, with GettingHired.com as Jobseekers. The Jobseeker functionality provided by GettingHired.com includes access to a robust suite of career development tools designed to prepare individuals to enter the workplace, to connect with peers and mentors, and to find a multitude of career opportunities. These fully accessible career building tools include:

- Career Compatibility Assessments
- Cover Letter and Resume Building Tools
- Video Interview Training
- Video Resume and Profiles

Through the GettingHired.com social networking platform, people living with disabilities are able to participate in the social media landscape via the GettingHired.com web forum, blog and articles. Here, Jobseekers can connect with peer mentors who also have disabilities to discuss an array of relevant topics, including employment and career concerns. In addition,

Jobseekers have full access to the directory of Service Providers, and are able to search this directory to locate organizations that can assist them with the services they need in their community to be successful in their job search and continued employment.

Over 300 organizations providing services to people with disabilities have already joined the GettingHired.com community, at no cost, as Service Providers. They are utilizing the network to extend their outreach to other providers of services, to local employers, and to individuals in the community who need their help and the services they provide. Many of these Service Providers are providing employment services to people with disabilities and are

using the resources available at [GettingHired.com](http://GettingHired.com) to augment their work and assist their clients through the full career assessment and job search process. Once these individuals obtain employment, the network of Service Providers remains available to assist the new employee and support employment success.

[GettingHired.com](http://GettingHired.com) has an active outreach program to disabled students graduating from universities, colleges and other institutions of higher education across the United States. We are working with career services and disability services departments at these institutions to encourage the registration of their students as Jobseekers. We are working to help ensure that these students have an opportunity to be fully considered for all of the exciting positions for which they are qualified.

Our Employer partners are committed to hiring the most qualified candidates, regardless of disability, to meet their critical human resource needs. These companies recognize that it is good business to specifically consider qualified applicants from among the ranks of people with disabilities, and know that [GettingHired.com](http://GettingHired.com), as the largest employment and networking portal for jobseekers with disabilities, is the best place to find this talent. The [GettingHired.com](http://GettingHired.com) portal is of course fully Section 508 compliant and accessible to all jobseekers with disabilities. Employers are partnering with [GettingHired.com](http://GettingHired.com), having recognized that in many cases, their career sites are not similarly accessible, and as a result they are losing out on access to a whole pool of talented candidates. Employer partners pay an annual subscription fee to join the community to post all their open positions and to have access to the portal technology that actively works to match qualified workers with specific employer needs. We are currently listing thousands of positions across the country.

The [GettingHired.com](http://GettingHired.com) Advisory Council is comprised of experienced leaders from national advocacy organizations and charter member subscribing employers. The Advisory Council helped guide the efforts of the company through

the design and launch of the portal, and continues to play an active role in providing insight and advice.

One of the significant needs that has been identified in recent years, necessary to increase the participation rate of people with disabilities in the workplace, is a forum for connecting jobseekers with disabilities and employers, seeking the most qualified workers, who are committed to hiring from the ranks of people with disabilities. [GettingHired.com](http://GettingHired.com) is pleased to have taken the leadership role in providing this forum. Please visit us at [www.gettinghired.com](http://www.gettinghired.com).

1. National Organization on Disability website, [www.nod.org](http://www.nod.org), April 3, 2009
2. National Organization on Disability website, [www.nod.org](http://www.nod.org), April 3, 2009
3. National Organization on Disability website, [www.nod.org](http://www.nod.org), April 3, 2009

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### About the Author

Jim Lunny is the Vice President of Workforce Development Solutions for [GettingHired.com](http://GettingHired.com), with responsibility for working with service providers and advocacy organizations and for further raising awareness of the resources available at [GettingHired.com](http://GettingHired.com) to jobseekers with disabilities. Jim has been with the organization since February of this year. Prior to this, he served as Vice President Unit Administration for Recording for the Blind & Dyslexic, a national nonprofit organization based in Princeton, New Jersey.

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## New Tremor Action Network Sponsors

### Cherry Blossom Enterprises

#### Spikes & Spasms Note:

TAN Advocates met Darcy, co-owner of Cherry Blossom Enterprises, during a 2003 seminar in Gatlinburg, TN. The Advocates purchased every Cherry Pit-Pac shape offered, with the exception of the new product, "Hand Warmers." For those that embrace complimentary therapy, keep Cherry Pit-Pac in mind for spasms and muscle contractions. The Cervical-Shaped collar spells relief for aches and pains from head tremors. The Original Pac is useful for many ailments. TAN has witnessed the alternative therapy and comfort Pit-Pacs bring to cancer patients.



**Cherry Blossom Enterprises, Inc.** is a family owned business that has been making and distributing the Cherry-Pit-Pac for almost 15 years.

Cherry-Pit-Pac®, a unique heating pad and cold pack made with cherry pits, is a natural effective way to relieve muscle pain and spasms, stiff joints, sore muscles, cramps, headaches, stress, tension, and much more. A Cherry-Pit-Pac is a comfortable and safe portable non-electric heating pad that conforms readily to the shape of the body. The hot Pac provides soothing and penetrating heat. It reduces inflammation and swelling when used as a cold Pac.

Visit Cherry Blossom Enterprises at:

[www.cherrypitpac.com](http://www.cherrypitpac.com) for further information, testimonials, and more great products!



### Pacific Writing Instruments

#### Spikes & Spasms Note:

PenAgain was well received at the AAN 60th Annual Meeting, the Movement Disorder Society 12th International Congress, and the ANA 133rd Annual Meeting. Private practice neurologists, academic institution movement disorder specialists, and nonprofit organizations requested dozens of pens for their patients.

The story of PenAgain™ stretches over 20 years in the making. The original idea and design surfaced while the inventor and owner of Pacific Writing Instruments was still a young teenager. Colin Roche has lived his dream in making PenAgain a reality.

The Y-shaped pen and pencil are designed for the index finger to rest in a cradle. The unique ergonomic design allows the hand to become more involved, reducing the stress of gripping pens and pencils with just the fingers. PenAgain may be effective for writer's cramp and hand tremors. Twist 'n Write pencil for children is helpful for fine motor skills.

For further information and testimonials visit Pen Again at [www.penagain.com](http://www.penagain.com).



## Dystonia (and other movement disorders as ET, PD, etc.) from inside

By Fernando Hernandez

I've been living together with dystonia ever since I was a child, a fact I do believe entitles me to speak about it from my own view. They were tough times indeed for me and my closest circle, caused by the scant knowledge available concerning this disease back in the 70s. In fact, the worst thing for me was the hard process, with endless proofs and tests (some of them very painful) and treatments, before a final diagnosis. It came after having been checked by different medical teams in some places and hospitals throughout Spain.

Since then things have fortunately changed a lot in many aspects, specially for those who are carriers of DYT1 gene, now very easy to diagnose through a single and specific genetic test. I must say I got my definitive diagnosis recently, in 2007, being 42, when I finally decided I should face (again) my disorder in a say "constructive" way."

**"I had to admit a slower speed when facing many of the challenges in life, although it didn't mean I had to resign myself."**

I think it is really important to properly consider dystonia, taking into account the rest of diseases existing. We unfortunately know most of the cases have no cure, but it is also true dystonia is not a mortal illness anymore. Furthermore dystonia implications or consequences are very often incomparable with blindness, cancer, immunodeficiency, and so many other diseases that exist. I think TD patients, when facing such a delicate situation as their disease, should try and consider themselves in a world where many people put up with conditions much harder than theirs in their lives. When I am asked about my life and my familiar situation I usually answer the same: "we go through in sporting attitude." In fact, I think I should face my life exactly this way even if I was a healthy person, trying to win every single daily match and also

accepting every defeat when occurring. Something probably easier to be said than to be accepted!

Which kind of limitations does TD, ET or PD cause? Both physical and psychological; being the second one (in my opinion) much more difficult to treat and be treated. At least, this is my own experience.

If we talk now about physical limitations we must consider the lack of ability for acts which require skilfulness (writing, playing guitar, handling things) as a determining factor, as it is the difficulty to coordinate movements when walking. When time goes by it is very usually the locomotive system that deteriorates gradually, mostly the articulations, and then discomfort and pain come to appear

even in a chronic way one usually gets accustomed to.

Symptomatologic treatment for dystonia is usually carried out by prescription of medicines. However, there is a series of personal tricks which can be, at least sometimes, more useful than any other treatment. In fact, the key relies on understanding there are two different ways of doing

things: normal way and our way, and we must be conscious the only difference between them is usually nothing but "aesthetic" manners. Accepting things the very way they are becomes the first step to try, just to try, to move forward. A task; again, not easy to carry out.

I remember myself hiding in my own shell for years, maybe a whole decade, only dealing with my personal circle of friends and family, and without any interest of meeting other people. I was a young boy who probably was saved by the only useful alternative solutions that I met: a couple of hobbies I almost became a specialist of. At that time I tried (not very successfully) a lot of medicines which even would affect my behaviour in some way or another for a long period of time. I was conscious somehow I had been restricting my own human potential and capabilities and refusing any opportunity from life. Fortunately there came a day I managed to get my act together and finally

understand very clearly these key things:

- The only way out for me was accepting my own situation as it was.
- Moreover, those who really loved me would also accept me and my special circumstances.
- My personal "difficulties" couldn't definitely ruin my life.
- I had to admit a slower speed when facing many of the challenges in life, although it didn't mean I had to resign myself.

Indeed, the main limitations seem to be psychological, and sometimes cyclic and full of ups and downs that are very difficult to deal with.

Far from introducing myself as an example of anything but, as I said before, someone aiming to share his own experiences with people who may find them helpful or beneficial, I thought it would be interesting to briefly outline my own profile, as an open invitation for other people to share their experience. I mean to stress there is a whole lot of things which can be done and must be tried though, of course thankfully acknowledging the help and understanding of the environment we are bound to rely on in such a special way.

Nonetheless, what I do consider really important is the chance of convincing people going through well known periods of gloom so often caused by dystonia, that people under similar or even worse circumstances have tried and pursued things in social, labour, emotional, academic fields, and they haven't been put off and have actually enjoyed, in an almost "normal" way, this chance of facing these challenges.

Married since 1996, and father of a son of 11, I cannot say my sentimental life has been different to any other person from my generation. Besides, I am the engine which drives a family in which, despite my so evident limitations, I am not the only one with motion difficulty (my wife suffers multiple sclerosis). On the other hand, being myself a DYT1

gene carrier, my little son (symptomless for the time being) is my major concern, although there is no reason to be alarmed.

So here I am trying to share the keys of my experience, what I call a positive approach to dystonia and other movement disorders, but also to any other chronic, incurable, or similar disorder.

I use to say that, of course, I am not a model of anything, and I also say I trust those people who help you with an extra bit of understanding, something so really expensive to get these days. Understanding, in my opinion, is the best medicine to deal with.

In a simple way, and absolutely far from any interest but showing my own experience, I have spent a long time, months, designing and developing a web space from which I try to help sharing very carefully the best of me in a practical way, and considering not only physical aspects but animics too.

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## About the Author

Fernando's website that he graciously claims "is not his really but belonging to sick people," is visited from almost every country in the world. He credits personal effort and the support and patience of his family and friends for maintaining his website.

The author says he strongly feels people who suffer any kind of movement disorder are definitely special ones, the same way than other people who put up with any other illness conditioning their lives in a similar way. He defends that further than the evidence of the physical limitations that people with dystonia, essential tremor, Parkinson disease, etc. show, it is really more important to consider what their minds usually hide.

So there he is trying to undress his experience and thoughts for "we all."

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## How much do I believe in me?

By Terri Sterling, MSP

How much we believe in ourselves will determine how successful we are at fulfilling our dreams. The only thing that stops us is the limits we place on ourselves about what we can and cannot achieve. We decide that other people are right about us and lose our way down some dark and boring bane road. We each allow the public's view of the disabled to shatter our happiness, and joyful expectations of the life we want to achieve.

I have dreamed for years of becoming a full time artist, creating art with other people, switching careers, but I too was guilty of not believing in myself enough. Instead of becoming the artist, I am meant to be; I chose the safe road and became a mental health therapist. I chose this road because I was so afraid my \*Dystonia would progress that I would not be able to control my own body to paint the images I dreamed of every night. This limiting fear took me down a road that worked but also blocked me and limited my ability to succeed in the art field that I loved. I was so afraid that I would lose this deep love of mine that I buried a part of me by avoiding the issue. I became a therapist which was not as healthy for me; I then became a Creativity Coach, which is healthier for me and for the people I serve, but I have been missing something in my life and know that I have much more to offer myself. I intend to become the artist that I am meant to be. I now have almost every thing in place including the education, information, savings and art supplies, but I do not have studio space right now. I intend to find some art space that is reasonably priced. I also know there are grants that I can apply to and shows I can enter that will help support me. I know there are galleries that will accept my work. I have learned a lot in the last two years about the art world and now the question becomes how much do I believe in me.

Recently, while looking for a suitable day job that would fill

my soul and make me want to run to work, I came across an incredible program called A.R.T., which stands for Art Realization Technology. This is no ordinary program because it believes in that disabled artists can create the work they dream of even if they are paraplegics, have multiple complex medical issues that would stop most people, some are unable to talk, and have developmental delays. Now you would think that someone who cannot move could not create art but in this program, the disabled artist can, by "borrowing" another person's body. The disabled artist points with a laser or indicates what color paint they want to use, points at the size brush they want to use, and shows the "tracker" what shape they want to paint. The "tracker" is a person who agrees to have zero

influence over the disabled artists and the outcome, but is willing to have the artist "borrow" their body or physical abilities to move. The Tracker physically creates the painting by following the instructions carefully and not commenting or interrupting what the artists wants. This method gives the disabled artists a visual voice, which allows them to be heard by the

public instead of ignored, as if they do not matter. These beautiful artists have had several shows, were on CBS, and one of them sold a painting for \$1,500. If they can do it, then so can we.

The difference is that each of these artists did not place limits on themselves. They found their voices by using Tim Lefans' \*Artistic Realization Technology Program; he is very humble to have been able to help them. Tim, the founder of this program, was not disabled when he started it, and was an artist who had visited their school. Tim is now going blind due to a medical problem. He continues to paint and create sculpture in New Jersey. I saw their video, from the CBS show, and cried because someone out there was going to let me have my voice no matter had bad this Dystonia gets. My soul was moved by the deep commitment they have for each other and for their art. I too can have a voice no matter what happens to me.

**"I too can have a voice no matter what happens to me."**

I will be meeting this incredible group of artists next week and I hope they accept me into their community as a tracker. I will be incredibly humble to be in their presence and it will not be me influencing them but them influencing me. It will help me to become more prolific, more creative, and freer of my own self-induced limits and to find that creative voice that I have caged in for too long.

How much do you really believe in yourself?

\* Dystonia is a rare movement disorder that causes our bodies to become distorted or twisted. I have muscle spasms in my neck that causes my head to turn to the left and makes it difficult to write. I receive Botox every three months, so that I can write like any normal person; I am in less pain and my neck and head are pointed straight.

\* I became a mental health therapist and have been practicing in this profession for 14 years. I have been a Creativity Coach for five years and will continue to be one in this healthy field. I love working with clients but have not enjoyed the negative politics or prejudice acts that I have seen exhibited in the psychology and social work field.

\* Tim Lefans' Artistic Realization Program information and video can be found at [www.artrealization.org](http://www.artrealization.org). Please watch his video. I hope it moves you as much as it has moved me.

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## About the Author

Terri Sterling is the owner of Inspiration, a private coaching business. For more information visit Terri's website at:

[http://www.freewebs.com/terris\\_inspiration/](http://www.freewebs.com/terris_inspiration/).

Terri is an artist and writer. Her artistic creativity, Creative Souls, can be viewed at: <http://creativesouls.wordpress.com/>.

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## Grief, Oh Grief!

By Mona Reeva, PhD, MPH, LCSW Owner of Green Mountain Artistry

"Grief is a strange and fearsome experience, and in its midst unusual behavior and thoughts can tenaciously take over and cloud judgment in our actions and words. We can lose sight of the love and compassion that is available, misinterpreting kindness and caring for other more complicated emotions."

This is part of a letter that I sent to my son and daughter in law after my granddaughter Rachael passed away at the age of 10 from a mitochondrial disorder. She was a wondrous child with a zest for life. As her disabilities began to emerge from this disorder, she demonstrated strength of character by continuing to pursue her interests.

Rachael's journey began when it was discovered that she was becoming deaf. She got hearing aids - one blue and one pink, to remind her in which ear the hearing aid belonged. With a sense of humor she pursued her piano lessons in spite of her hearing loss. When one foot began to turn under, she wore braces and went to physical therapy with a smile on her face making the best of it. When after coming home from basketball camp, she began to have pain in her chest and got more tired and breathless, she accommodated to the heart defect. And finally, the disease encroached on her brain stem.

I attended her memorial service held to commemorate her birth date and her passing. The service was well planned and beautifully done, reflecting the love and devotion her parents feel for her. She would have been 11 years old.

The sense of loss that we carry when we encounter a disability remains with us, sometimes through tears and sometimes relegated to the back of our minds and hearts only to emerge periodically to remind us again.

I have sustained no loss that matches the emotions I



encountered at the death of my granddaughter Rachael. While I have other grandchildren and a large and growing family, the loss of any grandchild or child would be devastating. There is a surreal sensation that emerges. Surreal in the sense that while I know it is true, I cannot truly grasp the reality.

In the society in which we live, models of "good health" persist, even though all of us, in one way or another carry health issues. Whether a disability is caused by a physical problem, or an emotional one or the death of a loved one, some are visible, some are not.

I often despair at the word "normal" since, frankly, I don't know what that means. After a lifetime of working with emotionally distraught people, and seeing loss amongst friends, coworkers, clients and family, it is too clear that "normal" has no real meaning. Not one of us conforms to any definition since every person has some loss to deal with over a lifetime - no matter the age. Perhaps this is really what "normal" means.

**"I often despair at the word "normal" since, frankly, I don't know what that means."**

We are among those whose disabilities are visible - shaking hands, head, voice, et al. Some of us take medications that mask to one extent or another, the motion that is different from those who do not have this. Some of us allow the shaking to be present, deciding not to stop the tremors. Sometimes I even forget that the tremors exist, until I see someone staring at me and I am reminded. I have had the experience of someone staring at me and when asked the other person will gather their polite forces and say "Oh I was admiring your hair". How nice! Maybe!

The thought that keeps coming back is to remind me that there are many kinds of losses. From the onset of a disorder, to the death of a person you love. Some are ongoing such as when you are taking care of a loved one who is ill and you watch the illness take hold; or when you watch a loved one in the dying process; or when health care is

unavailable; or when you aren't taken seriously as a caregiver.

Each one has serious effects and takes its emotional toll. No one loss is to be dismissed or compared or taken more seriously than another. All are serious and all have an aftermath that may vary in intensity, but nevertheless are present in our bodies, mind and soul.

Sometimes I wonder as I read the paper or watch the news, if I were to suffer a loss in which my whole family got wiped out by bombs, disease, natural disaster or any other multiple tragic event, I would not know how to create a truce with myself.

That is not within my personal experience, yet it is within the historic context of this country and definitely the planet. We therefore end up with repeated national loss when we honor the fallen from war on different holidays, or when we mark the anniversary of a disaster in which we honor a person or persons. An

opportunity is given to again feel our losses, and we can renew connection to our family and friends who have died.

In my family we will have an annual day of remembrance for Rachael, as I have for my parents, my brother, family and friends who have gone before me. We light candles. We honor all on Yom Kippur, the day of mourning in the Jewish faith. And I will always hold a special place of honor for my granddaughter who brought delight to my senses, a relationship of mutual respect and trust, and who lives on for me in my soul.

The other day I was sitting in an easy chair looking out the window to our garden and saw a squirrel on the top of the fence reach down to take a clipping of new growth from a climbing rose that was just beginning to emerge. While I was watching this I noticed a number of juncos take turns with lesser goldfinches feeding at the niger thistle bird



feeder, and one Oregon junco bathing in the bird bath. The garden was beginning to show evidence of its spring comings, while some winter flowers were open casting a spell of white blooms across the area. In my fantasy I saw Rachael dancing along the pathways admiring the comings and goings of the birds and squirrel and as I awoke from my dream state, I started crying. How could I not?

This article was written in memoriam for the loss of my granddaughter Rachael. You can see her lovely face and the foundation that was set up on her behalf and on behalf of all people suffering from mitochondrial disorders by going to [www.rachaelsgift.org](http://www.rachaelsgift.org)

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### About the Author

"Mona Reeva is in her second career creating one of a kind handicrafts in jewelry, knit scarves and photographs including photo note cards.

The result is a beautiful collection of crafts and photographs that demonstrate her life long experience and keen eye. These individually one of a kind items are available in her online store, Green Mountain Artistry, at <http://greenmountainartistry.com>"

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## The Essential Otter Advocate

<http://www.romert.blogspot.com>

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