Spikes & Spasms

The Tremoraction.org and Care4dystonia.org Newsletter DECEMBER 2005

IN THIS ISSUE

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WELCOME TO THE DECEMBER ISSUE!

T'is the Season!

Dear Readers:

December is the month when our thoughts turn to celebrations. Tremor Action Network and Care4Dystonia, Inc. wish you a Joyous Happy Holiday Season, and also Hope for better treatments and cures for all movement disorders in the coming New Year.

As we share this Spikes & Spasms issue with you, full of informative articles, we encourage you to share our newsletter with others; especially, those who are in need of comfort and encouragement - at this time of the year.

Good things come in all shapes and sizes! We wish to give Thanks to both Athena Diagnostics and Solstice Neurosciences, for their generous, individual donations to our quarterly newsletter. Their separate contributions give recognition to Spikes & Spasms as a premier resource for people with movement disorders.

Warm Wishes,
Kathleen & Beka

Enjoy reading the December - Holiday issue brought to you by Life In Motion coalition members Tremor Action Network and Care4Dystonia, Inc. The LIM Campaign will continue through 2006.

Cherry-Pit-Pac®

By Darcy and Mark Shawver

Cherry-Pit-Pac®, a unique heating pad and cold pack made with cherry pits, is Mother Nature relieving aches and pains naturally.

When warmed in a microwave oven for approximately two minutes, a *Cherry-Pit-Pac* becomes a comfortable and safe portable non-electric heating pad (no electro-magnetic fields), that conforms readily to the shape of the body. The hot Pac provides soothing and penetrating heat. The heat lasts for about 20-30 minutes, which is the time recommended by most health-care professionals.

Cherry-Pit-Pac is a natural, effective way to relieve muscular aches and pains, stiff joints, sore muscles, cramps, headaches, stress, tension, and much more.

Cherry-Pit-Pac is a natural, effective way to relieve muscular aches and pains, stiff joints, sore muscles, cramps, headaches, stress, tension, and much more.

The round, small smooth pits settle into the curves of the body, allowing for heat or cold to penetrate deeply. *Cherry-Pit-Pac* is not heavy on the body, and can also be used as a soothing massager when gently rolled against the body. The massaging action increases blood flow, and helps with circulation. *Cherry-Pit-Pac* works great on the feet too, and is a super stress-reliever after a hectic day.

If moist heat is desired, sprinkling a bit of water on the Pac prior to heating will achieve a desired effect. When chilled in the freezer, *Cherry-Pit-Pac* is a convenient, comfortable and gentle cold pack.

Cherry-Pit-Pac is washable, does not have a food odor when heated, and will not deteriorate over time with each successive heating. Made in the USA, *Cherry-Pit-Pac* is a registered medical device with the FDA.

Cherry Blossom Enterprises guarantees "*you'll feel better!*" Satisfaction is guaranteed. Visit Cherry Blossom Enterprises online at: http://www.cherrypitpac.com , or stop by the Gatlinburg, TN retail location, *So Very Cherry*, 601 Glades Rd., Shop #11, Gatlinburg, TN 37738.

For further information, send an email to: cherrypitpac@aol.com, or call the toll free number: 1-800-519-0999.

About the Author

Cherry Blossom Enterprises, Inc. is a family owned business that has been making the *Cherry-Pit-Pac* for over 13 years. We learned that cherry pits were used in Europe many years ago, being warmed on the wood burning stove. Our family is from Michigan, which is one of the major sources of cherries in the world. We began making the *Cherry-Pit-Pac* initially to help relieve headaches without medication. We made some for friends and family, who then wanted some for their friends and family! Today, we have thousands of satisfied customers who have shared their stories of how the *Cherry-Pit-Pac* has made a difference in their lives.

Straight Answers to Serious Questions:

Healthcare Responsibility

By Nancy Muller, R.T., C.R.T.

I'm going to stray a little bit from my normal format of questions from readers and I'm going to address a scenario we all experience with medical offices and their staff.

I recently had a situation of my own that really did motivate me to write this article about the need for taking responsibility for your healthcare and not depending upon the office staff to make sure you get what you need. The key word is "follow- up".

How many times have you gone to the doctor, he or she orders tests for you or you need to see a specialist, and whether you have an HMO, PPO, Indemnity plan, or Medicare and a supplement, you find yourself sitting and waiting days, weeks, and the worst case scenario, months to be able to have these tests performed or a consult made in a timely manner?

In short, if you don't act as your own advocate, you can jeopardize your health and well being needlessly.

This is why I want to encourage everyone to take action immediately and not let the grass grow under your feet. When I worked in the medical field, I always treated my patients like I wanted to be treated. Unfortunately, that's not the case nowadays.

Let's take the instance of the HMO, everyone's nightmare!! Your doctor orders a procedure, but it has to go through the IPA first to authorize it. The buck starts at your primary physicians' office. The staff must submit a referral to the IPA, they should approve it and you should be making your appointment. Easy, right??? Wrong!!!!! It seems as if your request gets lost in the system somewhere, probably on someone's desk under a stack of un-processed requests, and weeks pass and nobody knows what's going on.

This is even the case when trying to get into a specialist for a consultation, no matter what kind of insurance you have, the whole process starts in your doctors office, and usually that's where the ball drops right off the bat. God forbid you should need surgery and that is even more stressful trying to get referred and approved.

Okay, this is my sure cure for taking matters into your own hands and taking charge of your healthcare. If YOU don't do it, nobody else will.

The minute you leave the examining room, you go to the front desk and the girl gives you a song and dance about calling you back when they get things arranged. You should start right there asking questions. How long will it take to get the referral, how long before I can get an appointment, when are you going to call me back? Be sure you get the name of the person you first talk to and the date you spoke with them.

Give the office maybe 3 days to get the process going. If you don't hear back, call the office. Ask to speak to the original person that made all their ridiculous promises to have you taken care of in no time. If this person gives you a song and dance, immediately ask to speak to that person's supervisor. If you get no satisfaction from the supervisor, the next step is the office manager. And if push comes to shove, you tell them you want the doctor to call you back. Absolutely do not take no for an answer. If you find it necessary, call that office every single day and take one more step up the chain of command. They will get so sick of hearing from you; they will take care of your situation just to get you off their backs.

It's unfortunate that this is the norm within the system, but there is no reason you can't beat the system. You have to take control and you have to be firm. Don't settle for a verbal battle with a front desk receptionist, go to the supervisor.

You have to understand the mentality of the staff of a doctor's office. With HMO's the pace is fast, and it's get em in and get em out!!! It saddens me that so much has been lost in that important aspect of care and compassion in patient care.

We are always given a copy of our "patients rights" when we go to the doctor or hospital, yet we don't seem to benefit from those "rights". You cannot let anybody walk all over you. You have to stand up for yourself and make sure things happen in a timely manner.

In short, if you don't act as your own advocate, you can jeopardize your health and well being needlessly. Take charge of your healthcare. When you have conversations with office personnel, be sure you document the conversations, dates, and times. You don't have to be nasty, but you must be firm so they know your not one to take lightly. This is the same road to go down when waiting for test results. In some cases, your well being is at stake, and time could be of the essence in taking needed action. Don't be afraid of taking charge of your healthcare as the staff will respect you rather than put your needs aside.

Whenever I have situations in my personal life that I feel would be helpful to my readers, I prefer passing my wisdom on to all of you, in hopes of being able to make a difference in your life.

Don't forget I'm always available to everyone that needs my help. You can call me at **(951)926-3677** or e-mail me at **NMuller406@aol.com**. If you would like to write, you can send your letters directly to **Tremor Action Network** or **Care4Dystonia, Inc.** to my attention, and they will forward them on to me. Please provide me with material to do a good informative article next quarter.

About the Author

Nancy Muller is a Registered Radiologic Technologist with a specialty in orthopedics. She is past president of the National Spasmodic Torticollis Association. Nancy has a forum in the NSTA Magazine devoted to an up front and personal forum of questions from members. She is a West Coast Liaison for C4D, and on the Board of TAN. She herself has had Spasmodic Torticollis for over 20 years. Nancy is an advocate for support and education of both the public and medical profession.

Company Profiles: Who's Who ?

By Beka Serdans, RN, MSN

Athena Diagnostics, Inc.

Athena Diagnostics develops and sells assays used to diagnose, evaluate, and monitor neurological functions. The company has a staple of more than 80 tests which are used to detect such conditions as Alzheimer's disease, nerve disorders of the arms and legs, and genetic mutations associated with Huntington's disease, dystonia, and some forms of mental retardation. They have also developed tests for immune system functions, which can be early-warning signs of some cancers. Hospitals and laboratories submit patients' tissue or fluid samples directly to Athena Diagnostics for testing: the company also markets its products directly to neurologists.

View the test for the DYT1 gene at http://www.athenadiagnostics.com and Botulinum Toxin Type B at http://www.myobloc.com.

The company was founded in 1986 and resides in Boston. Within their mission statement one of Athena's goals is to serve patients by educating (1) physicians to confidently diagnose and manage patient disorders, (2) other healthcare personnel to utilize services in a convenient way, and (3) payers to understand the value of the services Athena provides. To that end, Athena actively seeks out opportunities to improve on their skills, to offer the physicians, the healthcare personnel and the payers' help, to try new things, and to achieve excellence in all their work within diagnostic genetic testing.

Regarding dystonia, the best example of an inherited generalized form of dystonia, is the association with the DYT1 gene. According to Drew Stringfellow, Athena's Movement Disorder Product Manager: "We licensed the DYT1 gene in 1998 from MGH. Dr. Laurie Ozelius was the discoverer, and is now at Columbia University. We got involved because it fit our company values and mission of improving the quality of patient's lives through the best possible diagnostics."

The DYT1 gene is responsible for early-onset generalized dystonia. The DYT1 gene codes for a previously unknown protein, named "torsionA," which has significant similarities to the heat-shock proteins. Found in virtually all living organisms, the heat-shock proteins help cells recover from stresses including heat, traumatic injury, and chemical poisoning. Until now, no human disease has been associated with these proteins. In people with early-onset dystonia, the DYT1 gene has a mutation that causes the deletion of three "letters" or nucleotides called GAG in the genetic code. This GAG deletion results in the loss of an amino acid, called glutamic acid, which is a component of the torsionA protein. This relatively minute change in the torsionA blueprint apparently causes critical changes in the function of the protein. The role of the torsionA protein is currently unknown, but somehow this defective protein disrupts communication among the neurons responsible for movement and muscle control, leading to the symptoms of early-onset generalized dystonia. (Source: Dystonia Medical Research Foundation, 2005).

Testing for the DYT1 gene is available from Athena Diagnostics. You can learn more about this test for dystonia via the website: http://www.neurocast.com/site/content/sessions_Dystonia.asp

Specifically, NeuroCAST is an innovative, internet-based educational program designed by Athena Diagnostics, Inc. to bring patients current information about delicate issues in the early and accurate diagnosis of neurological disease. Please visit the company's website at: http://www.athenadiagnostics.com to become informed about genetics testing for dystonia.

Solstice Neurosciences

A lovely shade of green marks the MyoBloc website, created by Solstice Neurosciences. Solstice is an emerging biopharmaceutical company focused on the development,

marketing and distribution of MyoBloc, botulinum toxin Type B.

Botulinum toxin is a "powerful" molecule. In the 1940s it was developed by the U.S. and other countries as a biological weapon. The toxin was not and has never been used as a weapon. Instead, it is the first biological toxin to be licensed for the treatment of human diseases.

At much lower doses, it can temporarily alleviate neurological disorders. When used to treat movement disorders such as dystonia and essential tremor, tiny amounts of the highly purified toxin are injected directly into the targeted muscle or gland. Therapeutic blockage lasts from one to six months depending on the medical indication and the individual, but eventually the nerve endings recover and again begin to release acetylcholine. To maintain the therapeutic effect, additional injections may be needed, often every 3-4 months when given for dystonia and essential tremor.

Of interest, in the late 18th century, Justinus Christian Kerner, an accomplished poet and physician in Southern Germany, was the first to recognize the potential therapeutic uses of botulinum toxin. The toxin, produced under anaerobic conditions, is a potent food-borne poison that causes botulism. An outbreak of botulism in Southern Germany in 1815 among people who had eaten uncooked blood sausage, led Kerner to publish two years later a precise description of botulism's symptoms- -from blurred vision to progressive muscle weakness, culminating in respiratory failure. Although he was wrong about the cause- -he believed it to be a fatty acid- -Kerner postulated that minute quantities of the disease-producing substance might be able to treat disorders of the nervous system.

It wasn't until 1897 that Pierre Emile van Ermengem, a Belgian professor of bacteriology, discovered the responsible bacterium. And, what was once known as Kerner's disease was renamed botulism from the Latin "botulus" for sausage.

Botulinum toxin was isolated from the bacterium in the early 1900s. In the 1920s, Herman Sommer at the University of California, San Francisco, isolated botulinum toxin Type A as a stable acid precipitate. In 1946, Edward J. Schantz and colleagues at the University of Wisconsin purified Type A in crystalline form.

In 2000 Solstice Neurosciences acquired exclusive rights for Myobloc from the Elan Corporation, then known worldwide as NeuroBloc. Myobloc®/NeuroBloc®(Botulinum Toxin Type B) Injectable Solution, is the only Type B available to patients and their physicians. FDA-approval was also acquired specifically for the use of MyoBloc for cervical dystonia.

Solstice Neurosciences is founded on vision and values: striving for excellence and innovation, committed to teamwork and service, and respectful of integrity, courage and passion. To learn more about Solstice Neurosciences, visit their website at http://www.solsticeneurosciences.com.

MyoBloc employs a dedicated team, available to assist with medical information and product and reimbursement support. To learn more about MyoBloc, visit http://www.myobloc.com.

About the Author

Beka Serdans, RN is Founder of the non-for-profit organization of Care4Dystonia, Inc. She is also a writer having published two books detailing her journey with dystonia. Currently Beka is authoring a third book " Walk a Mile in My Shoes " describing her adventures and mis-adventures around the world incorporating personal accounts with Deep Brain Stimulation, which she under-went surgically for own dystonia in December 2004. One of the highlights this year has been collaborating with TAN on multiple projects for her. She will complete cer-tification as an Adult Nurse practitioner in April 2006. To contact her she can be reached via the email : infoc4d@aol.com.

Highlights of the 19th Annual Symposia: The Etiology, Pathogenesis and Treatment of Parkinson's Disease and other Movement Disorders

By Beka Serdans, RN, MSN

On a sunny (September 25th 2005) day marked by vivid blue skies, both TAN and C4D Founders Kathleen Welker and Beka Serdans, respectively, had the opportunity to attend a Symposia presenting the latest research developments on a variety of movement disorders in San Diego prior to the 130th Annual American Neurological Association three day Meeting. The following are highlights on a variety of subjects pertaining to essential tremor and dystonia as presented by basic scientists and researchers.

Special recognition to Julie Ratzloff from the ANA for making it possible for TAN and C4D to attend the 19th Annual Symposia, and also exhibit at the 130th Annual ANA Meeting.

Focus on Essential Tremor

1) The Tolerability and Efficacy of Sodium Oxybate (Xyrem®) as a Treatment for Ethanol-responsive, Medication-refractory Myoclonus and Essential Tremor. (*Key Author - S.J. Frucht, Columbia University Medical Center*).

Twenty (20) patients with ethanol (alcohol)-responsive, but medication-refractory myoclonus and essential tremor were enrolled in a study to evaluate the use of the drug sodium oxybate (Xyrem®) as a potential treatment for both disorders. The researchers concluded that Sodium Oxybate was effective in all 20 patients with mild transient side-effects being dizziness, headache, emotionality, nausea, sedation and gait disturbances. Side-effects resolved with appropriate drug dosing changes. Significant improvement in kinetic and postural tremor and myoclonic symptoms were seen with functional improvement in daily living activities in all 20 patients.

2) Olfaction in Twins Discordant for Essential Tremor. (*Key Author -A.R. Chade, The Parkinson's Institute of Sunnyvale, CA*).

A reduction in the sense of smell (Olfaction) is an early sign of PD yet there have been conflicting results in previous studies that have addressed the relationship of smell and essential tremor. Using twins with ET, research findings concluded that smell identification was not reduced in twins with ET when comparing them with twins free of neurological disease.

3) Essential Tremor Pathology: A Case-Control Study from the Essential Tremor Centralized Repository. (*Key Author-E.D. Louis, Columbia University*).

The goal of this study was to examine the pathology of ET using post-mortem brains donated for research purposes via the IETF. Ten (10) cases were assessed and it was noted that 60 % of the ET cases had Lewy bodies; 40 % of the cases on the other hand exhibited typical mild degenerative cerebellar changes. Findings from this study suggest that two pathological changes may be present in those diagnosed with ET.

4) Tremor as a Sign of Neurotoxicity in Welders: The Bay Bridge Cohort. (*Key Author: W.C. Koller, University of North Carolina, Chapel Hill*).

This interesting study examined a group of 49 welders who had been exposed to high levels of manganese while working on the Bay Bridge for 15.5 months. It was noted that 73.8 % (39 welders) had tremor; 27 of the 49 exhibited a mild to moderate form of postural and kinetic tremors. Other complaints included sleep disturbances and fatigue. No other neurological findings were noted in this particular study group. The authors concluded that exposure to high levels of the metal manganese may in fact lead to neurological dysfunction such as tremors.

5) Unilateral Cortical Stimulation in Essential Tremor. (*Key Author-R.Pahwa, University of Kansas, Kansas City*) .

Two (2) patients with severe disabling hand tremors underwent unilateral (one-sided) cortical brain stimulation with a newly developed implantable and programmable device under general anesthesia. Despite the lack of adverse effects, unilateral cortical stimulation proved to be ineffective using the specific programming parameters allowed by this new implantable device. Obviously further research is warranted.

Focus on Dystonia

1) Factors associated with Decreased Quality of Life in patients with Dystonia. (*Key Author-H.H. Fernandez, McKnight Brain Institute, Florida*).

The goal of this study was to determine the factors associated with disability in patients with dystonia. 64 patients with an average age of 55 were evaluated and participated in questionnaires. The strongest predictor of decreased **physical** quality of life was lack of energy and tiredness. Confusion, depression, anxiety and lack of energy was directly associated with a decreased **mental** quality of life.

2) Functional MRI in Writer's Cramp. (*Key Author -V.K. Hinson, Medical University of South Carolina, Charleston, SC*).

It has been reported that the basal ganglia were thought to play a primary role in the pathophysiology of focal dystonia; however recently additional studies have suggested cortical sensorimotor abnormalities instead. Functional MRIs were performed on a small group of patients and it was noted that brain activation patterns were different in those with focal dystonia which may represent a change in movement strategy or impaired sensory integration.

3) Is Focal Task-specific Dystonia Limited to the Hand and Face? (*Key Author-S.J. Frucht, Columbia University Medical Center, NY*).

Focal task-specific dystonias of the hand include writer's cramp, musician's cramp and face embouchures dystonia. The researchers described two individuals who exhibited signs of focal task specific dystonia involving the legs. Focal dystonias of the hands and face have been thought to be linked to performance of skilled activities requiring years of practice and attention. These two cases may represent that focal task specific dystonias can affect any body part or limb and perhaps may be automatic in nature.

4) A Comparison of Mood profiles across Parkinson's disease, ET and Dystonia Patients. (*Key Author-K.M. Miller, University of Florida, Gainesville*).

351 PD patients, 59 with ET and 90 dystonia patients were evaluated using the Beck Depression Inventory Scale and a Visual Analog Mood Scale for the presence of depression and other mood disorders. Sadness and tiredness appeared to be more prevalent in PD patients as compared to ET and dystonia patients. There were no significant differences in any of the 3 patient populations, even when comparing age, education, and symptom duration.

5) Dystonia and Tremor associated with a duplication in the Chromosome 1q32-q42 Region. (*Key Author-R.L. Rodriquez, University of Florida, Gainsville*).

The first ever case report of a patient with dystonia and tremor was associated with duplication in a specific chromosome. Could it be that multiple movement disorders are genetically related after all?

About the Author

Many of you have been contacting the Founder of C4D regarding Deep Brain Stimulation. You can read how Beka is doing after DBS and dealing with programming online at **http://www.care4dystonia.org/narrativeDBS.htm**.

You will also find "50 Questions to ask about Deep Brain Stimulation" before undergoing the procedure on the C4D website.

Beka recommends the link to "Never Die a Nerve" by Jeanie Brown at:
http://usa1.ebooks.com/ebooks/book_display.asp?IID=155645

Adrift at sea, the essential otter awaits a name....

By Aleah Mahan

The article, *Animal Tremors: Of Mice and Men…and Marine Life*, which appeared in the June issue of *Spikes & Spasms*, inspired Tremor Action Network and I to collaborate on a cartoon strip that would feature a "Goldie" - like otter, experiencing the challenges of daily living with a dual-diagnosis of essential tremor and dystonia.

Oscar Wilde wrote, *Life imitates art far more than art imitates Life*. As an editorial cartoonist, I visualize his quote; especially, with the first-hand knowledge that individuals from the online Yahoo! Tremor Health Group have been diagnosed with both related movement disorders. I was also inspired by the Life In Motion campaign, where I learned that, "A patient with a movement disorder may visit more than 15 doctors over the course of five years before receiving an accurate diagnosis..."

Please help name the otter, orphaned at http://tremoractionotter.blogspot.com/.

I 've created an orphaned southern sea otter, living with essential tremor and dystonia, off the Pacific Coast of California This otter gets by with a little help from friends at the Monterey Bay Abalone Research Center, T.A.N. http://www.tremoraction.org/. and C4D http://www.care4dystonia.org. Friends are a necessity, but a name is more so! The otter's interests are: shellfish, classical music, classic rock music, blue grass, Bogart movies, and naturally swimming. The otter also enjoys reading War and Peace.

The otter is orphaned at http://tremoractionotter.blogspot.com/. Underneath the otter's home is another link - Comments, that allows you to stop by and participate in the contest to give the otter a name. There are blog directions for you to follow:

1. Either click on the link http://tremoractionotter.blogspot.com/, or type the link address into the server's web address field, and click on Go.

2. Underneath the cartoon, there is a link that ends with the number of comments. Click on the link "comments."

3. On the next pop up, on the right hand side, is a field that says, "Leave Your Comment."

4. Type your comment in that field.
5. Choose "Other" for identity.
6. Type in Name.
7. Type in word verification answer.
8. Click on "Publish Your Comment."

The Yahoo! Tremor group members have been asked to choose the winner of Name the Orphan Otter contest. The otter in fairness to gender prefers a unisex name! Only one name per contestant. Please feel free to leave more than a name. Say Hello to the otter with your personal blog. The otter has a PROFILE!!! The winner will receive a gift from Cherry Blossom Enterprises, valued at $50.00. The winner will be able "to choose their $50 gift" from an array of products, available for viewing at: http://www.cherrypitpac.com/. Read about Cherry-Pit-

Pac, featured in the first article of this newsletter.

About the Author

Aleah Mahan is an editorial cartoonist from Northeast Kansas. She has published a weekly cartoon in the Westmoreland Recorder for 9 years.

Aleah began her cartooning career by drawing amusing events that would take place at her various places of employment over the past 20 years. While working as a Sheriff's Office dispatcher, Aleah would draw cartoons of the often comical events that took place in that county and then post the cartoon up for all to enjoy. This is where her cartooning was discovered by the new publisher of the Westmoreland Recorder, who in turn, offered her the opportunity to create a cartoon strip for his paper. The title of Aleah's cartoon for this paper is, "Pott. Cownty." Pott. is short for Pottawatomie, which is the name of the county the paper covers. Aleah's cartoons often depict cows experiencing life's amusing events, thus the "Cownty," in the Pott. Cownty. Visit **http://pottcownty.blogspot.com** to view Aleah's cartoons.

Aleah became affiliated with Tremor Action Network by joining an internet message board associated with ET. Aleah's mother was diagnosed with ET over 20 years ago, and her grandfather suffered from it, undiagnosed for most of his senior years.

Aleah makes her home in Paxico with her husband, Mike, and dogs, Sparky and Pogo, and cats, Jinx and Milo. She has a grown daughter and son, a stepson who is a junior in high school, and 2 grandsons (ages 8 and 1). Aleah is an active volunteer at the Cat Association of Topeka and the Pottawatomie County Caring Hearts Humane Society.

Still Waiting:
The Pitfalls of SSDI

By Nancy Muller and Jennifer Seghers

Nancy Muller, author of "Social Security Disability," interview with Jennifer Seghers on the trials and tribulations of applying for Social Security Disability.

Nacy Muller: Jennifer, what conditions do you have that prompted you to file for Social Security Disability?

Jennifer Seghers: I have essential tremor, chronic vertigo, and chronic headaches.

NM: When did you file your application for disability?

JS: April 30, 2003.

NM: Did you file the paperwork on your own or did you hire a Social Security disability attorney?

JS: I initially filed the original application on my own.

NM: Were you informed at the time of filing that barring a denial of the claim and subsequent appeals, the processing of the claim would take approximately one to six months?

JS: I don't believe I was. There is no local Social Security office where I live. I reside in a rural area of North Dakota. The nearest office is 120 miles away. A chronic condition of vertigo prevents me from driving long distances. I was aware that I could schedule an appointment in person, by phone, and/or complete the application online. I chose an appointment by phone, because my vertigo prevents me from sitting in front of a PC monitor for any length of time. Also, with hand tremors, I would need assistance to help me complete the online form. Social Security makes it clear that if another person "completes and signs the Internet application," there might be delays in processing the application.

NM: Does Social Security require you to provide information separate from the application?

JS: Yes. You have to complete a Disability Report, Authorization to Release Records, and a Work History Report.

NM: Was your claim accepted or denied?

"Hopefully, my Hearing establishes precedence for people applying for SSDI because of ET..."

JS: Denied. I wasn't given a specific reason. I was informed that I could appeal the denial through the next phase called Reconsideration.

NM: Did you file for Reconsideration?

JS: Yes. I received a second denial stating, "I could perform jobs that exist in significant numbers in the national economy," as long as the work did not require fine motor skills.

NM: What is the third step in the process since you were again denied?

JS: I would now have to file for a hearing with an Administrative Judge.

NM: Did you continue to do your own filing at this point?

JS: No, I decided obtain an attorney to handle this phase.

NM: What does the attorney charge for his services?

JS: The case is taken on contingency, and by law he can

only receive 25% of back benefits or the cap $ amount. The lower amount is what the attorney receives, which is also determined by the administrative judge if there is a favorable decision.

NM: How long did you have to wait for a Hearing to be scheduled?

JS: From the time of the application, almost two years. The Hearing was held on April 7, 2005.

NM: If you had to repeat the process, would you have hired an attorney from the inception of your claim?

JS: For me personally, No. It is my understanding that 90% of the time you receive a first denial, followed by a second denial (Reconsideration). Individuals have shared that Social Security representatives advise you not to obtain an attorney until the Hearing. I know of people who used attorneys and paralegals as soon as they became disabled. These individuals did not benefit from having legal professionals complete and file their paperwork. I know of others who had no assistance and received SSDI on the first try. In my honest opinion, it's "the luck of the draw." However, I must admit I would have experienced less stress if I had hired a lawyer to take the steps I took alone!

NM: Do you feel your attorney was instrumental at your Hearing?

JS: Definitely! The lawyer contacted the treating physicians, knowing precisely what to request from them; meticulously organized my medical records; collected statements from family members, friends and Tremor Action Network. The Administrative Law Judge commented during the Hearing that I belonged to a support group for people diagnosed with essential tremor. The ALS received that information from Tremor Action Network.

NM: On what findings was it determined you would receive a favorable decision?

JS: The ALS listed 8 Findings. Number 3 was the most favorable for people diagnosed with essential tremor! The ALS stated, "The medical evidence establishes that the claimant has severe essential or familial tremor…" Hopefully, my Hearing establishes precedence for people applying for SSDI because of ET, even though the ALS noted that "the impairment is not listed in, or medically equal to one listed in Appendix 1 to Subpart P, Regulation Number 4." The ALS mentioned, "The closest impairment is Parkinson's." I responded, "Essential tremor is a cousin to Parkinson's!"

NM: Were you satisfied with the decision the judge made in your case?

JS: Yes and No. Yes that there is evidence to support essential tremor as a disability. No, in that unlike other States, North Dakota must issue a written decision; up to four months after the Hearing. One of my online support group members from Tennessee received a favorable decision at the Hearing. My written decision was not signed and dated until August 31, 2005; more than four months after the Hearing. Also, I have yet to receive the "back pay" from the time I was officially declared disabled on August 20, 2002.

NM: I understand you were also eligible for SSI (Supplemental Security Income), which is based on financial need. How does this benefit you?

JS: During the period between August 20, 2002 and the decision date, I qualified for both SSDI and SSI. My attorney notified me that it was determined that I met the income, resources, and other requirements for supplemental security

income payments. The lawyer cannot receive a percentage from the back pay, until it is released to me! I contacted the field office, who nicely told me I had to wait my turn. The office finally contacted me on October 31. I have to provide tons of paperwork before I get my back pay for disability. I have to find all income receipts and bank statements from the time I applied. I wish I would have known this before. Neither my attorney nor the Social Security office informed me.

NM: In closing, at what point are you at regarding your case?

JS: I'm receiving my monthly SSDI benefits, but I'm still waiting for the back pay from 2002. The pitfalls of SSDI!

About the Authors

Nancy is past president of the NSTA, and has had ST for over 20 years. You can read more about Nancy by reading her article, *Straight Answers to Serious Questions*.

Jennifer is the co-chairperson for TAN's *ET Advocate Council*. For more information on the Council's initiatives for promoting ET awareness, contact Jennifer at **jseghers@tremoraction.org**. Independent of TAN, Jennifer is also the moderator/owner of the *Yahoo! Tremor Health Group*. For further details about Yahoo's online support group, email Jennifer at **essential_tremor@yahoo.com**.

Consensus Conference for Essential Tremor

By Hokuto Morita

On October 20-21, 2005, 70 scientists with an interest in Essential Tremor research descended on the Embassy Suites in Bethesda, Maryland to attend the first ever Consensus Conference for Essential Tremor. The goal of the conference was to bring together ET researchers and specialists to form a coordinated plan for future research. The meeting was funded by a grant from the National Institute of Neurological Disorders and Stroke (NINDS) with additional funds coming from Jazz Pharmaceuticals, International Essential Tremor Foundation, Medtronic Inc., Merck & Co., Inc., and the US Army Medical Research & Materiel Command. The meeting was divided into several different topics including: diagnosis and clinical assessment, epidemiology, pathophysiology, genetics, and treatment. TAN representative Hok Morita participated in the meeting and reports on some meeting highlights:

NIH researchers called for more use of DNA repositories and increased use of current animal models for drug screens.

The meeting was marked by areas of progress and areas needing great improvement. By far, diagnosis issues proved to be the area with the most pressing needs. The reason why diagnosis is such an important issue is because it impacts every other kind of study, including genetics, pathology, and treatment. For example, if scientists are studying tissue or blood samples from families that they think have ET and it turns out that they don't have ET, then the whole study becomes worthless or worse, may lead them to erroneous conclusions. For this reason, several scientists called for improvements in diagnosis and tremor evaluation. At the meeting, several problems and barriers to diagnosis were identified. First, there has been a proliferation of various tremor rating scales without much consensus on relative advantages and disadvantages of each. This makes it difficult for those within the field to compare or standardize their results. In addition, it makes it extremely difficult for other scientists who have to choose among the many different scales. The consensus of the meeting called for a detailed examination of current rating scales, comparing the advantages and disadvantages of each to form a single universal rating scale that could be used by everyone. Universal scales exist for most of the major movement disorders, but ET has been lacking in this area. Previous attempts have been made, but this meeting called for more aggressive attempts.

One of the underlying reasons for such disagreement in the field is that ET is inherently difficult to diagnose. Dr. Elan Louis pointed out that even neurologists misdiagnose ET about half of the time. Although some of this is due to lack of awareness or exposure, this is not the only reason. ET may not be one disorder, but may be a family or spectrum of disorders, thus making it difficult to recognize. The lack of consensus and a truly universal scale compounds the problem. Meeting participants agreed that solving diagnosis issues was key for future progress.

NIH researchers Dr. Mark Hallett and Dr. Katrina Gwinn-Hardy called for more use of DNA repositories and increased use of current animal models for drug screens. There are presently a few mouse lines that shake. Some of these show characteristics that are in some ways similar to ET. Although these are probably imperfect models, it is hoped that by screening many drug compounds in these kinds of mice, that a compound that may help with tremor will be identified. Dr. Hallett talked about the value of such models and this is the approach that Dr. Adrian Handforth, TAN scientific advisor, has taken. Dr. Handforth has received funding from the Parsons Foundation to screen potential compounds in mice treated with Harmaline, currently the best animal model of ET.

Dr. Higgins presented his exciting work on ET genetic studies. Dr. Higgins has identified a polymorphism (a base

pair change in DNA) that seems to be associated with ET in a few of the families he's studying. He has shown an association with ET in these families, but it is not clear whether this change is causative and will require further detailed studies. Identification of genes was identified as another major goal of current studies. TAN is cooperating with Duke University's ET research project to help identify genes for ET.

Both the genetics studies and diagnosis issues are highly dependent on each other. In order to do meaningful genetics and pathology studies, accurate diagnosis is required, but the best diagnostic tools come from good biological markers, such as genetic or pathological markers. This may sound like circular reasoning and in some ways it is. Scientists have to try to get any foothold into the disease that they can. Some of the researchers at the meeting are doing this by tightening up diagnoses and sub-classifying ET, while several researchers are examining if physiological or imaging methods may help diagnose ET. Overcoming these challenges will require collaboration between experts across the fields. One of TAN's major missions is to bridge some of the gaps between these fields by attending clinical meetings as well as lab research-oriented meetings.

Dr. Elan Louis encouraged researchers to collaborate in calculating the true costs of the disorder. It's clear that ET can lead to considerable disability and lost work productivity. Calculating the economic impact will help grant reviewers and policy makers know the true impact of the disease.

Dr. Hallett showed a video of promising trials of Sodium Oxybate (Xyrem) which is currently being studied at Columbia and Jazz Pharmaceuticals for the treatment of movement disorders that are responsive to alcohol. This drug is currently approved for the treatment of narcolepsy with cataplexy. This drug has shown some very encouraging results; however, it will be studied cautiously and will be highly regulated due to the use of an almost identical compound by recreational drug users and past side effects. All current users of Xyrem are enrolled in the Xyrem Success Program for the aforementioned reasons.

The key recommendations coming from this meeting were:

1. Establish a reliable brain bank.
2. Identify genes for ET.
3. Establish a universal tremor rating scale.
4. Form collaborative networks with sharing of data.
5. Make a repository of cell lines from families with ET.

The meeting stimulated dialogue between many researchers and it is hoped that future meetings will bring news of exciting progress.

About the Author

Hokuto "Hok" Morita has had ET since age 5. He is on the Board of TAN and is currently a first year medical student at the Penn State College of Medicine. He plans to become a Movement Disorder Specialist.