Spikes & Spasms

The TremorAction.org Newsletter APRIL | JUNE 2008

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WELCOME TO THE APRIL | JUNE ISSUE!

The TremorAction.org Newsletter features new and updated articles from our Sponsors: Allsup, Alseres Pharmaceuticals, Cleveland Medical Devices, Solstice Neurosciences, and Professionals: Esther Baldinger, MD, Diana Herring, MN, ARNP, Jerome Lisk, MD, Bob Myer, MS and Tim Moore, SSDI Advocate.

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

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**

Essential Tremor Survey

By Esther Baldinger, MD

Spikes & Spasms Note:

This survey was funded by Tremor Action Network.

Disclaimer: *The results should not be taken as medical advice or endorsement of any specific treatment. Please consult with your medical provider for any discussion or decisions related to your own condition. -* ***Esther Baldinger, M.D.***

Thanks to all of you who responded to the first essential tremor survey. In the three months that the survey has been open, 550 responses have been received! As a qualifier a web site survey is not representative of the general population and can only be the first step to controlled scientific study. While this type of survey can't provide definitive answers, your responses are very valuable in determining future paths for study. We are refining these findings into a shorter and more focused follow-up survey that will be coming soon.

What follows is a summary of the results with a discussion of the answers that I feel are most pertinent.

When asked the age at which you first noticed shaking of your hands:
39% said before the age of 20.
13.4% ages 20-29
11.6% 30-39
15.3% 40-49
12.4% 50-59
6.4% 60-69
2.9% 70 and above

Slightly more than half (51.4%) of the respondents noticed a hand tremor by the time they reached age 30 and less than 10% of respondents developed a hand tremor after the age of 60. WE MOVE a web site for the "education and awareness for movement disorders" states the mean age of onset of ET to be 45 years. An epidemiological evaluation by Dr. Louis and Dr. Dogu published in 2007, found only 14% of a general population showing tremor before the age of 30 and 58% later in life. Dr. Bain in a study of ET patients in the United Kingdom in 1994 found the most common age of onset of tremor to be 15 years and if tremor was to develop it did so by the age of 65 years. That study seems closest to our findings. So for people with ET, early onset of hand tremor is to be expected and onset of hand tremor after the age of 60 is infrequent.

About half of the respondents had head tremor. Of those, the onset of head tremor irrespective of whether there was a tremor at another site was:
12.5% under 20 years
15.8% ages 20-29
17.0% ages 30-39
23.4% ages 40-49
19.2% ages 50-59
8.7% ages 60-69
3.4% 70 years and above

Most respondents developed head tremor between the ages of 20 and 60 with the greatest number developing head tremor in their 40's. Young onset, that is under the age of 30 years, occurred in nearly 30% of respondents. Very few had the onset of head tremor when they were older than 70 years. Most people developed head tremor at the same time or after the onset of their hand tremor. The questions did not separate those people who developed head tremor alone or as the first symptom of ET. This is something that needs to be studied.

Voice tremor was found in 155 people of the group or just over one third.
15.1% under 20
15.6% 20-29
14.0% 30-39
19.0% 40-49
20.1% 50-59
11.2% 60-69
5.0% 70 and above

Current medical literature notes voice tremor beginning after age 50. This survey finds that voice tremor can occur

at any age even in the very young. It appears that the people with voice tremor also have tremor at another site, however, that question was not specifically asked. In addition, many people noted the onset of voice tremor within the same decade as either head or hand tremor, but the order of the onset was not requested and needs to be studied.

Jaw tremor was present in 113 people of the group or slightly less than one fourth.
10.7% under 20
15.0% 20-29
16.8% 30-39
22.1% 40-49
15.9% 50-59
12.4% 60-69
7.1% 70 and above

Jaw tremor has been associated with advanced ET, but our survey shows it can begin at all ages. In an evaluation of jaw tremor in ET patients by Dr. Louis et al in 2006, jaw tremor was associated with older age, more severe action tremor of the arms, and the presence of head and voice tremor. About 20% of people with jaw tremor in our survey appear not to have voice tremor and a smaller number do not have hand tremor. Again this is an area that needs more study.

"Slightly more than half (51.4%) of the respondents noticed a hand tremor by the time they reached age 30."

As expected, tremor interfered with function and caused embarrassment across all ages.

67.6% of all respondents said a relative had tremor. Of those, 33.3% answered father, 34.4% answered mother and 30.3% answered sibling.

93.1% of respondents identified themselves as Caucasian. Nearly every country in Europe was listed as a country of origin of the tremor side of the family with England, Ireland and Germany being cited most often.

There was no relationship between ET and any school subject. Most people's best subject was English and their worst was mathematics. Many people said that they were good at everything, especially spelling (78%), grammar (82%) arithmetic (74%) and reading (88%). Only 38% said they were good at complex math. 41% sing and 35% play a musical instrument.

People with ET do all kinds of work, remarkably including tasks, which require fine and extremely fine hand coordination. 73% said that they were "good with their hands" before the tremor interfered with activities and only 12.3% describe themselves as being "all thumbs." Sadly, a good number of people wrote that they had to change their work or retire because of tremor. 84% are right-handed. 58% exercise on a regular basis with walking as the exercise of choice for 84% of them.

26% said that they were exposed to chemicals, but no substance or group of substances that were listed stood out as being common to this subgroup of people with ET.

The great majority of people with ET are non-smokers (83.5%). Of the 16.5% who do smoke, 33% smoke one pack a day or more and the remainder smoke less than one pack. 54% drink alcoholic beverages. 47% answered one drink per day, 33% answered two drinks per day and 20% answered more than two drinks per day. What was not asked was whether alcohol was being used to improve tremor.

More than half (57%) of the group sleeps 7-8 hours most nights, but nearly half (46%) of the respondents said they had some difficulty with sleeping. In the general US population sleep disorders occur in about 1 in 6 people or about 15%. In our survey the reasons for this difficulty were listed as pain, sleep apnea, depression/anxiety, the tremors, medication effects, need to urinate, and

frequently "don't know why." This high rate of sleep disorders is another area that needs further study.

80% like particular foods with vegetables and cheese each getting more than 50% of people citing these as their favorite foods. 54% said they try to avoid sweets.

Allergies were common in the group with 57% saying that they were allergic to substances. Most common was pollen (63%), medications (46%), dust (45%), food (21%), and insect bites (16%). In evaluating the average US population the prevalence of allergies is listed as 9-16%. So the group of people with ET has a much higher rate of allergies. How this relates to ET is an area that needs study.

When asked do you have pain, 61% said yes with the majority having pain in their neck, back and shoulders. 59% said they have headaches now or had them at some time in the past. These numbers are higher then in evaluations of random groups of people, but studies on pain distinguish between acute pain that resolves, occasional pain and chronic pain that is present every day for three months. The questions on pain were too general to be compared with published findings. This needs to be addressed in the future.

Hearing problems were reported by 26% of our group. Hearing problems have been associated with ET. A 2007 study published by Dr. Benito-Leon and colleagues in Spain reported 38.7% of people with ET having hearing loss compared with 29.4% of controls matched for age. A Baylor College of Medicine study found 16.8% of ET patients used hearing aids and that more severe tremor was associated with more severe hearing disability. This survey reveals fewer hearing problems than reported elsewhere perhaps because many of our respondents are younger and have less severe tremor. Whether other studies have over-represented the number of people with ET who have hearing problems is an area for further study.

Balance problems were present in 42% of the group, dizziness in 36% and falling episodes in 19%. These numbers are large and occurred across all age groups. Many people who had dizziness denied hearing problems. Balance/gait disorder in ET has generally been overlooked in the medical literature. A study by Dr. Stolze and colleagues published in 2001 looked at 25 patients with ET and advanced intention tremor and found abnormalities in gait similar to people with cerebellar disease. People with mild hand tremor or tremor in other sites have not been studied. This is another important area that needs more information.

Vision was reported to be fair, good or excellent in 90% of the group. The sense of smell was fair, good or excellent in 94%. Loss of smell has been reported to be an early indicator of Alzheimer's disease. 88% said they do not have or have not had cancer. Almost one third have high blood pressure and/or high cholesterol, but heart disease was present in only 9% of the group, heart attack in 4%, and stroke in 4%. How these findings relate to ET is unknown. None of the medical literature regarding ET lists rates of heart disease, stroke or cancer in this group. More information is needed.

Thank you for participating in this survey and I hope you will participate again.

About the Author

Esther Baldinger is a practicing neurologist in Brooklyn, New York. She is an associate attending in neurology at the Long Island College Hospital, and an Assistant Clinical Professor of Neurology at SUNY Downstate Medical Center. Dr. Baldinger attended SUNY Downstate Medical College, graduating Magna Cum Laude and AOA in 1977.

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Tremor Can Be More Than Meets the Eye

By Joseph Giuffrida, PhD and Maureen Phillips

While most people know what tremor is when they see it, they may not realize that many different types of tremor exist and why it is important to recognize them. The current gold standard of visual assessment may be blind to subtle characteristics unique to different tremor types. Tremor is a common motor symptom associated with a number of neurological disorders. Defined as rhythmic, involuntary, to-and-fro movements of a body part, tremor is most common in the hands, but can occur in the arms, legs and head. Tremor can be an especially debilitating movement disorder symptom and make activities of daily living, such as dressing, eating and writing, difficult or sometimes impossible without the help of a family member of caretaker.

"CleveMed has developed a device called Kinesia™ that can be used to detect and monitor subtle differences in tremor characteristics."

Several movement disorders produce tremor as a motor symptom. The two most common are essential tremor (ET) and Parkinson's disease (PD). ET is a common disorder characterized by uncontrolled trembling of the hands and often involuntary nodding of the head. It is the most prevalent movement disorder, affecting nearly 10 million people in the United States alone. PD is a progressive disease associated with the destruction of brain cells that produce dopamine and characterized by muscular tremor, slowing of movement, partial facial paralysis and peculiarity of gait and posture. There are currently about 1 million people in the United States living with PD. Other diseases associated with tremor are multiple sclerosis, a chronic degenerative disease affecting the central nervous system; ataxia, the loss of ability to coordinate muscle movements; Huntington's disease, a genetic disorder that causes the degeneration of nerve cells in the brain; and multiple system atrophy, a rare degenerative disorder that causes symptoms similar to PD.

In addition to different disorders producing tremor, different tremor types may exist within a particular disorder, each with unique physical characteristics. Two of these important characteristics are amplitude and frequency. Amplitude refers to how big the movement is while frequency refers to the speed or rate at which the oscillation is happening. Rest tremor is one type that occurs when the affected limb is completely at rest. Resting tremors occur at a specific frequency, usually 4 - 7 Hz, and are most commonly associated with PD, but in some cases found in other movement disorders. Postural tremor occurs when a specific body part is held motionless against gravity, such as extending the arms out, pointing with the hands or sitting upright without back support. Postural tremor typically occurs at a frequency of 9 - 11 Hz and can be associated with PD, ET, multiple sclerosis and others. Other types of tremor include kinetic tremor, which occurs during a voluntary movement such as writing, drinking or eating and intention tremor, which is unique in that is occurs during a visually guided movement toward a target destination.

There are many different diseases in which tremor is an associated symptom with tremor subtypes within those diseases. Since the neurological mechanism producing each of these tremor types may be different, the mechanism of action to treat the specific tremor may also differ. Much current research and drug development is targeted toward alleviating tremor which makes it a very important movement disorder symptom to carefully, objectively and accurately evaluate. Current medication options for reducing tremors include propranolol, primidone and other anti-convulsants or mild tranquilizers. Determining the correct timing and dosage of medication can be assisted by

monitoring the features of tremor in response to the drug. If symptoms are unresponsive to medication, or if the body becomes resistant to medication over time, surgery such as deep brain stimulation may be considered. There are several parameters of deep brain stimulation that can be adjusted after surgery that may impact tremor characteristics. Therefore, monitoring the quantitative features of tremor during tuning of these parameters may optimize a patient's treatment.

There has to be a method in place to judge the efficacy of treatment interventions being developed for tremor. Currently, clinicians use rating scales to rate tremor severity. In the case of PD, the Unified Parkinson's Disease Rating Scale is used and clinicians assign a score ranging from 0 to 4, with 0 being the absence of tremor and 4 being the most severe. Similarly, the Tremor Rating Scale is used to evaluate the severity of tremor in patients with ET using a similar scoring method. These scales provide guidelines for clinicians to visually assess tasks performed by the patient for evaluating different types of tremor. Clinicians then assign a symptom severity score based these criteria. An important issue with subjective rating scales is that clinician evaluations are subjective and can vary from visit to visit, or different clinicians may assign different scores for the same person. Also, the human eye may not be sensitive enough to detect very subtle changes in symptom characteristics such as the amplitude and frequency. For example, a study published in Neurology in 2000 by Dr. Roger Elble at the Southern Illinois University School of Medicine concluded the frequency associated with essential tremor decreases over time at a rate of approximately 0.06 to 0.08 Hz per year. While this decrease is too slight for a clinician to visually notice, it may be an important variable to understand that could provide insight into the neurological mechanisms of tremor.

Distinguishing tremor types and quantitative features is very important for research, clinical judgments and intervention efficacy. CleveMed has developed a device called Kinesia™ that can be used to detect and monitor subtle differences in tremor characteristics. Kinesia is a small wireless device worn on the patient's finger and wrist to monitor three dimensional motion.

Currently being evaluated in several clinical studies around the United States, this device is intended to help standardize tremor evaluations and provide clinicians with a tool to better quantify tremor features when the signs are too subtle for clinical differentiation alone. Improving and standardizing the clinical evaluation of tremor may ultimately improve the understanding of tremor subtypes, increase efficacy of interventions and maximize patient quality of life.

To find out more about CleveMed, The Division of Movement Disorders or our products, please visit our website at **http://www.CleveMed.com** or call us at 1-877-CleveMed (253-8363).

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Deep Brain Stimulation can help *dystonia*

By Diana Herring MN, ARNP

Diana Herring ARNP programming a dystonia patient. Photo courtesy of Dessie Bybee/NWH

How many of us appreciate the ability to move our bodies? To propel ourselves gently with our limbs, holding our torsos erect while maintaining our balance as we walk are actions we take for granted.

"Programming DBS leads implanted in the STN, or sub thalamic nucleus, can yield results more quickly than the Gpi."

Dystonia is a movement disorder, usually of unknown cause, that leads to abnormal posturing and the inability to move smoothly. A rare condition, it can be progressive and disabling for those affected. The symptoms consist of moderate to severe muscle spasms that are often sustained long enough to result in pain and awkward positioning. For example, torticollis is the most common localized form of dystonia; it is characterized by involuntary movements of the neck, often twisting to the side (rotation), or extended with the head facing up, or flexed with the head facing the chest.

Initially, these movements may be sporadic, but usually progress to a more constant or "gripping" quality. Any movement can be very painful, and ultimately the neck can become fixed into an abnormal position, making it difficult for a person to even move.

Some people with dysontia have involuntary jaw, tongue, or throat spasms that cause difficulty in talking or eating. Any part of the body can be affected, with dramatic and often bizarre movements of the head, neck, torso, arms or legs. Some movements are brought on by certain activities (picking up a book, being interviewed, walking, etc). Moving one part of the body can lead to abnormal posturing or movement of another area. "Sensory tricks," as innocuous as placing the hand to the cheek, often will stop the twisting of the neck; medical science does not know how this works. These "sensory tricks" may lose their effectiveness over time.

As many of us know, the first step is an articulate diagnosis, preferably from a movement disorder specialist. It is important to know if the movements are related to a particular cause. Medications, trauma to the head, and birth injury are examples of events that can lead to secondary dystonia. It is also important to know if dystonia runs in the family; a blood test can detect whether or not a person has the DYT1 gene mutation. This mutation tends to be more prevalent in early onset childhood dystonia.

Whether or not the cause of the disorder is known, the treatments may be similar. A variety of medications may be prescribed to help. These medications may, over time, lose their efficacy, or ability to work. Botox injections are usually quite useful to relax the tight contraction in the neck and upper back. These can be used for laryngeal or voice box spasms also. Given every 3 months by an experienced neurologist or health care provider, the injections can often stave off the most painful spasms, helping to align the head (in cases of torticollis) to a small degree for a short time. Significant improvement in 60% to 90% of patients with neck dystonia have been reported from Botox. Although individuals may find benefit, this may be less than they would desire and over the years may wane in effectiveness.

Sometimes after prolonged treatment the dystonia may

worsen, or not improve. Deep brain stimulation (DBS) is an approach for those patients who have tried medications and injections and are not experiencing relief of symptoms. The procedure is relatively safe and has been used on approximately eight hundred people world-wide. The benefits can be profound.

Though certainly not without some risks, this surgery is well worth considering, using the services of an experienced DBS team. Each candidate is carefully screened to make sure that he or she has the best chance of benefiting. It is important to understand that in the past about 50% of people undergoing DBS had lasting success with a decrease in dystonic symptoms. The amount of benefit can vary. The most widely used part of the brain to implant the DBS stimulator has been the Globus Pallidus interna (GPi), hence the statistical information available tends to correspond to GPi placements. The benefits are increasing statistically as more centers implant DBS for dystonia, with percentages of dystonia patients who benefit reaching 80%. There is a variable degree, or amount of benefit, in each individual.

The sub-thalamic nucleus (STN) is another area of the brain that has shown promising results as a location for the DBS stimulator. This is a target that has been used for years in DBS for Parkinson's; now we are seeing some good outcomes for dystonia patients who are implanted in the STN. One advantage to STN placement is more immediate symptomatic relief, and in some cases improved outcomes over GPi placement in adults with primary localized or generalized dystonia who do not have the DYT1 gene mutation.

Here is one case study: Ms. P came to our DBS clinic last summer. She was only able to hold her head held tightly flexed forward with her chin to her right chest and shoulder in a fixed position. She explained that the problem started about two years previously with occasional spasming of the right neck muscles, accompanied by related pain, including headaches. Her condition then worsened. Eventually, her neck got "stuck" onto the right shoulder. After diagnosed with localized, primary dystonia, she underwent Botox injections that helped her to some extent for "a few days" at a time. She also was given medications for pain and to help relax the muscles.

However, treatment worked poorly. Being a young mother of two children, she described her condition as "horrible". Even her voice was "tight" sounding. She was worked up according to the usual DBS protocols here at our clinic. An MRI was obtained of her brain to make sure there was no structural problem such as a tumor or evidence of brain abnormality. Although dystonia cannot be "seen" on a typical MRI scan, other abnormalities can be "ruled out". She then saw our neurosurgeon and subsequently underwent other tests such as a neuropsychological exam as is our protocol for all candidates considering DBS. She was evaluated for specific motor scoring on a number of dystonic "scales" (scoring of degree and location of abnormal posturing) by our trained physical therapist familiar with dystonia. Mrs. P. was filmed to capture her current state of dystonia, documentation to be used as a comparison after DBS surgery. Other typical pre-operative tests were done to make sure she was healthy for surgery.

She underwent DBS surgery with our team while under general anesthesia. Patients with another movement disorder, Parkinson's disease, remain awake during DBS surgery. However, dystonic positions of the head, neck, or upper back can make it virtually impossible for most dystonic patients to remain conscious while undergoing DBS. Their movements typically interfere with the surgery as they often involve the head itself. So going to "sleep" contributes to a smooth and safe procedure.

Waking shortly after completion of the surgery, Ms. P spent one night in the hospital, closely monitored. She went home the next day and returned later the same week for a second surgery to implant the battery. The battery was connected to the DBS brain lead by an insulated wire tunneled under the skin, behind the ear and to the chest wall battery. Everything is under the skin and fat layers.

After waking from surgery, she sat up and had something to eat. The DBS programmer came in to turn on the new DBS system. Settings for the DBS unit initially were very low. Ms. P went home and returned two weeks later for follow-up. At this visit, the DBS settings were evaluated for benefit; this is done by testing each of the four contacts at the tip of the lead, turning them on one at a time, and evaluating for maximum efficacy. The advantage of using the STN as a target is that sometimes we can see beneficial results even while testing in the clinic.

Once determined, the DBS programming parameters were more finely tuned, allowing at least three to four weeks between sessions to see what the full effects might be on the patient's neck and head position. Ms. P could turn her head more readily over time and she also was able to hold her head more upright. As she visited the DBS clinic over the next few months (she had the other side of the brain implanted four weeks after the first side), the DBS team watched as she walked into the clinic each time in a more upright position. Finally, after two to three months of methodical and careful programming, the patient was able to hold her head in a near normal fashion most of the time. This was a great change from her previous trouble of having her head positioned onto the right shoulder tightly most of the time. She was able to decrease her pain medication and her voice became stronger. Her family and friends were amazed, while she herself was very appreciative.

Programming DBS leads implanted in the STN, or sub thalamic nucleus, can yield results more quickly than the GPi (GPi programming can take months for even initial benefits). In Ms. P's case, as in those of many other dystonia patients, we have implanted into the STN at our center, the results are good. And they occurred within weeks of surgery.

We have implanted with DBS nine people in total, with localized to generalized dysontia, all non-DYT1 primary dystonia (not related to another cause such as trauma and not the genetic variant) with DBS. Of these, seven have had remarkable benefits. Two patients had more modest benefits; of these, one had other medical conditions that led to some decline (the decline not a result of dystonia itself) and the other patient has had benefits that wax and wane, although he feels better and moves less erratically than he did prior to surgery.

For many reasons we have found that DBS can make a huge difference in our dystonia patients' quality of life, and we are excited and happy to be able to offer this surgery.

About the Author

Diana Herring MN, ARNP is a Deep Brain Stimulation Programmer. She coordinates the DBS program at Northwest Hospital & Medical Center in Seattle, Washington. Northwest Hospital & Medical Center has a study approval for implanting dystonia patients with DBS, granted by the Western Institutional Review Board. Ronald Young MD and Steve Klein MD work as our investigators. Currently the study has spanned four years. Diana may be reached at (206) 368-5935 or via email at **dherring@nwhsea.org**.

SOLSTICE NEUROSCIENCES

MYOBLOC™ University

New Online Learning Tool Fills the Knowledge Gap on Botulinum Toxin Type B for Cervical Dystonia

Solstice Neurosciences, Inc. Launches a Self-Guided Lesson as Prep for In-Person Workshops

Malvern, PA, USA - December 12, 2007 - In recognition that physician comfort and knowledge with techniques around botulinum toxin injections lead to the best results for patients with cervical dystonia (CD), Solstice Neurosciences, Inc. (Solstice) has created MYOBLOC™ University, an online, self-study resource that incorporates new learning technology. The course integrates multi-dimensional, life-like animation throughout the content - with anatomy based on real patients with CD and actual injection technique demonstrations with Myobloc® (Botulinum Toxin Type B) Injectable Solution. The course can be accessed at http://www.myoblocuniversity.com.

"MYOBLOC™ University is for busy physician specialists who want to expand the scope of treatment options for their patients with cervical dystonia, and for those seeking a comprehensive review of the condition and the role of botulinum toxin type B," said Eric J. Pappert, MD, assistant professor of neurology and director of the Parkinson's Disease and Movement Disorders Program at the University of Texas Health Science Center in San Antonio, Texas and Vice President, Medical & Scientific Affairs of Solstice. Dr. Pappert led the development of MYOBLOC™ University.

"New Online Learning Tool Fills the Knowledge Gap on Botulinum Toxin Type B for Cervical Dystonia."

CD is often a disabling and painful movement disorder that requires life-long management. Also known as spasmodic torticollis, it is a condition that primarily affects the cervical area of the neck. While the exact cause of CD is unknown, scientists believe the problem originates in the basal ganglia area of the brain that is instrumental in movement. The treatment goal is to lessen symptoms of spasms, pain and impaired posture, and to improve functionality.

"A broad range of treatment options are often needed to address the symptoms of cervical dystonia. The botulinum toxins are considered the primary and most effective form of treatment, which makes it critically important for physicians to be experienced with both forms of botulinum toxin available here in the U.S.," noted Dr. Pappert.

The multi-media content covered in MYOBLOC™ University includes:

· Detailed overview of the clinical presentation and diagnosis of CD -- with video depictions demonstrating abnormal movements and which muscle are involved

· Review of currently available treatments - oral medications, surgical options, injections with botulinum toxin, and complementary therapies

· Fundamentals for dosing and muscle injection techniques when using MYOBLOC to reduce the severity of abnormal head position and neck pain associated with CD

· Patient case studies that illustrate the challenges and potential solutions in managing CD patients

· A post-test for participants to gauge their understanding of the materials presented

Upon completing the online lesson, physicians can request in-person training with MYOBLOC, which is available through Solstice in a variety of venues. The company's overall goal is to support physicians who care for CD patients - ranging from neurologists to physiatrists to anesthesiologists and pain management physicians. MYOBLOC™ University does not offer continuing medical education credits.

About the Authors

About MYOBLOC

Myobloc® (Botulinum Toxin Type B) Injectable Solution is indicated for the treatment of patients with cervical dystonia to reduce the severity of abnormal head position and neck pain associated with cervical dystonia.

Before administering MYOBLOC, physicians should consult the full Prescribing Information.

The most frequently reported adverse events with MYOBLOC are dry mouth, dysphagia, dyspepsia, and injection site pain. These adverse events are generally mild to moderate, transient, self-resolving, and more common with higher doses.

For full Prescribing Information, please visit **http://www.myobloc.com**.

About Solstice Neurosciences, Inc.

Founded in 2004, Solstice Neurosciences, Inc. is a biopharmaceutical company focused on the development, manufacturing, sales and marketing of specialty products. Solstice's first product, MYOBLOC, represents the only botulinum toxin type B currently available to physicians and patients. MYOBLOC is sold in the United States and approved in Canada. It is also distributed and sold in the EU as NeuroBloc. MYOBLOC is indicated for the treatment of patients with cervical dystonia (CD) to reduce the severity of abnormal head position and pain associated with CD. For more information about Solstice Neurosciences, Inc., visit **http://www.solsticeneuro.com**.

Myobloc® and NeuroBloc® are registered trademarks of Solstice Neurosciences, Inc.

[**Editor's Note:** for access to current course offerings, users must register on website; users can access site regardless of medical credentials.]

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Huntington Movement Disorders Program

By Jerome Lisk, MD

The Movement Disorders Program at Huntington Hospital is dedicated to providing the best diagnostic, therapeutic, palliative, and supportive care to patients with movement disorders, with emphasis on the treatment of Parkinson's disease, dystonia, essential tremor, and complex movement disorders. We utilize a multidisciplinary approach to address the diverse needs of our patients and their families. This includes a neuropsychologist, a neurophysiologist in the OR monitoring cases, and physical, occupational and speech therapy. Patient care begins with an in-depth evaluation by one of the movement disorders specialists and continues through discussion of diagnoses, necessary evaluations, pharmacological and non-pharmacological therapies, surgical options and ongoing support. Our main objective is on improving the quality of life for both our patients and their families. The multidisciplinary approach is important so that, in essence, patients have one-stop shopping - we can address all of their needs in our program.

"Our main objective is on improving the quality of life for both our patients and their families."

In addition to diagnosis, evaluation, treatment, and ongoing support, patients may be able to participate in research which furthers our knowledge of these disorders and will hopefully one day lead to enhanced therapies or possibly cures for people suffering from these disorders. We also try to work with different local and national Parkinson's organizations in helping patients with Parkinson's disease.

We help patients with all aspects of education when in comes to movement disorders including the pharmacological and non-pharmacological treatments and other facets of movement disorders. I believe in being there for those patients, caregivers, and families whose lives have been affected by Parkinson's, essential tremor, dystonia and other movement disorders. If we are unable to provide certain services that someone is looking for, we direct them to an organization that can help them. We help people directly or indirectly through local and national organizations that we have working relationships with. Currently we are developing relationships with Parkinson's Alliance, Team Parkinson's, The Tremor Action Network, The National Parkinson's Foundation, The American Parkinson's Disease Association, The Parkinson's Resource Organization, The Parkinson's Action Network and The International Essential Tremor Foundation.

The Huntington Movement Disorders Program implants the majority of the Deep Brain Stimulators for neurologists at UCLA. We are also currently working with UCLA in research projects and hopefully there are many more to come. I also look forward in working with USC.

I believe providing a program where physicians spend a lot of time with their patients, explaining, educating and making patients feel that they are an integral part of their care plan is important. We want every experience to be a good one. Here at Huntington we are able to spend more time with patients than physicians might be able to at larger academic centers and we can provide them more personal access to their physicians. Patients do not have to wait months to be seen. We hear all the time that patients appreciate the time and VIP treatment given in our program, which can not be given at a major academic center. Private practice and research/academics is seldom found in medicine, however, here at The Huntington Movement Disorders Program we have the best of both worlds. We are always on the cutting edge, keeping up to date on the latest literature on movement disorders. We also attend national meetings and discuss cases in a multidisciplinary conference twice a month.

Cal Tech is the leader of scientific research in California and one of the top research institutions in the United States. Like Cal Tech, we are committed to research and

have developed a relationship with Cal Tech, which allows us to collaborate with some of the greatest minds in the country.

About the Author

Dr. Jerome 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. Dr. Lisk treats patients with Parkinson 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.

For more information about the Huntington Movement Disorders Program, please visit **http://www.huntingtonmovementdisorders.com** or contact Jennifer Birch, NP by email: **jennifer@pacifichillsneurosurgery.com** and phone: (626) 535-9552.

ALSERES
PHARMACEUTICALS

Alseres Pharmaceuticals Initiates the ALTROPANE® POET-2 Program

Alseres Pharmaceutical recently initiated and enrolled the first subject in the initial stage of the ALTROPANE® Parkinson's or Essential Tremor - 2 (POET-2) Phase III clinical trial program. This subject was enrolled at the University of Alabama, Birmingham trial site under the direction of Principal Investigator Dr. Ray L. Watts, MD, Professor and Chairman of the Department of Neurology.

> **"The POET-2 program is a two-part clinical trial program that is beginning with a clinical study in seven centers."**

ALTROPANE is a diagnostic molecular imaging agent being developed to aid in the differentiation of Parkinsonian Syndromes from non-Parkinsonian or Essential tremor. Currently, tremor disorders are diagnosed by subjective clinical evaluation which, according to the Canadian Journal of Neuroscience, is associated with an error rate among general neurologists of 25% to 35%.

Alseres believes that ALTROPANE has the potential to help doctors more accurately diagnose tremor to minimize the side-effects of unnecessary treatments. ALTROPANE may also provide diagnostic support to monitor disease progression and the effects of emerging therapeutics.

The POET-2 program is a two-part clinical trial program that is beginning with a clinical study in seven centers to acquire a set of ALTROPANE images which will be used to train the expert readers. This is the customary requirement for clinical trials of molecular imaging agents. The second part of the planned POET-2 program involves two concurrent, multi-center Phase III trials of approximately 150 subjects each using the optimized ALTROPANE imaging protocol.

The seven sites that are enrolling subjects in this imaging study are: University of Alabama, Birmingham, AL; University of Arizona, Tucson, AZ; Cedars-Sinai Medical Center, Los Angeles, CA; University of Florida, Gainesville, FL; Dartmouth-Hitchcock Medical Center, Lebanon, NH; University of Texas, Houston, TX; and UT Southwestern Medical Center, Dallas, TX.

For more information on this trial please visit: http://www.clinicaltrials.gov/ct2/show/NCT00596908?term=altropane&rank=2

About the Author

Alseres Pharmaceuticals is a biotechnology company engaged in the research and clinical development of biopharmaceutical products for the diagnosis and treatment of Central Nervous System disorders. Alseres shares a commitment to find a better solution and make it available to those who need it most. To find out more about Alseres Pharmaceuticals, please visit **http://www.alseres.com** or call (508) 497-2360.

ALTROPANE® is a registered trademark of Alseres Pharmaceuticals.

Trace Center

By Bob Meyer, MS

More and more, touch screen based "kiosks" are filling in where people used to work - airline counters, the express lane at supermarkets. For some users, these kiosks can be easier to use since you make a selection directly on the display. For others, using these technologies can be an intimidating and difficult if not impossible task. In order to understand the effect of these technologies on users with motor control disabilities, a research study is currently under way at the Trace Research & Development Center. A part of the College of Engineering, University of Wisconsin-Madison, the Trace Center was founded in 1971 and has been a pioneer in the field of technology and disability.

"Eight of the accessibility features included in Windows Vista were originally developed by the Trace Center."

Trace Center Mission Statement: To prevent the barriers and capitalize on the opportunities presented by current and emerging information and telecommunication technologies, in order to create a world that is as accessible and usable as possible for as many people as possible.

The Trace R&D Center was formed by a group of students in 1971 to address the communication needs of people who are nonspeaking and have severe disabilities. The Center was an early leader and innovator in the field that came to be known as "augmentative communication" (a term first coined by the Trace Center).

As the personal computer emerged, the Trace Center became a leader in making computers accessible to people with all types of disabilities. In 1984, the Center served as a coordinator for the nationwide Industry-Government Initiative on Computer Accessibility. The computer design guidelines developed through this effort were used as the basis for many industry guidelines and accessibility standards.

During the 1980s and 1990s, the Trace Center worked directly with the computer companies to integrate disability access features into their standard, mass-market products. As a result of this work, disability access features are incorporated directly into most operating systems and environments today. For example, eight of the accessibility features included in Windows Vista were originally developed by the Trace Center. MouseKeys, StickyKeys, FilterKeys (RepeatKeys, SlowKeys, BounceKeys), ToggleKeys, SoundSentry (renamed "Visual Notifications"), and ShowSounds (enhanced and renamed "Captions") originated at the Trace Center, and have been included by Microsoft in all of its operating system releases since Windows 95.

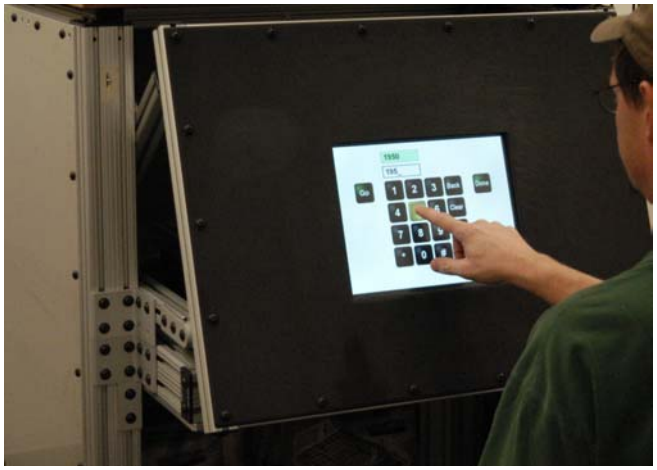
As technology became more pervasive in the workplace, education, entertainment, and daily living, Trace's research and development efforts have focused on universal design of information and communication technologies, so that they are more accessible and usable by elders and people with disabilities.

In October 2003, the National Institute on Disability and Rehabilitation Research (NIDRR) of the U.S. Department of Education, awarded a five-year, Rehabilitation Engineering Research Center (RERC) grant to the Trace Research & Development Center, University of Wisconsin - Madison.

The overall focus of the Universal Interface and Information Technology Access RERC is on accessibility and usability of current and emerging information technologies. This includes access to information content in its various forms, as well as access to interfaces used within content and by electronic technologies in general.

The desired outcome of this work is a seamless integration of the various technologies used by individuals with disabilities in the home, the community, and the workplace. The RERC includes a broad research and development program, as well as training, technical assistance, and dissemination activities.

One component of this research, currently underway, is the usability of touch screen based information kiosks. These kiosks are turning up in more and more locations like airline check-in counters and self-service check-out aisles in supermarkets. Most research regarding touch screen design and use involves tests using younger subjects without disabilities. In the current study being conducted at the Trace Center, we are focused on learning what differences exist relating to touch screen use for users with both gross and fine motor control issues. As part of this we have invited adult users with essential tremor, Parkinson's disease, multiple sclerosis, and cerebral palsy to take part in the testing.



The study uses a Trace Center designed kiosk which allows the researchers to change the look of the touch screen by altering button sizes and spacing. While it is being used, we measure the force, timing and accuracy data of the users in order to satisfy one of the goals of this project - to come up with a set of basic functional characteristics of users with fine and gross motor control disabilities. Eventually, this information may enable designers of touch screen based technologies to use the combination of factors that gives all users the best possible chance to use the device successfully.

For more information about the Trace Center and its projects, visit our website at: **http://www.trace.wisc.edu**

About the Author

Bob Meyer, MS is a graduate student in the Industrial and Systems Engineering Department at the University of Wisconsin-Madison and works for the Trace Center on the touch screen project.

Allsup provides true help to people with disabilities

Answers to your questions about Social Security disability Allsup (http://www.allsup.com) started in 1984 and was the first enterprise of its kind - focused on helping people with disabilities make it through the complex process of receiving Social Security Disability Insurance (SSDI) benefits. Since then, we have helped nearly 100,000 people with disabilities nationwide receive the benefits they deserve.

At the same time, applying and receiving benefits has not gotten easier. Each year, 2.5 million people apply for disability benefits through the Social Security Administration (SSA). Two out of every three applicants are initially denied.

"Top 10 tips for breaking through the backlog."

Today, there are more than 750,000 people whose disability cases are pending before the SSA at the hearing level. These individuals and their families may end up waiting months and sometimes years to receive benefits. The difficulty of receiving SSDI is one factor behind Allsup's recent release of our top 10 tips for breaking through the backlog. These tips are based on our representatives' expertise and hundreds of years of combined experience supporting applicants:

1. Determine eligibility. To be eligible for benefits, claimants must have been disabled before reaching full retirement age (65-67) and meet the Social Security Administration's definition of disabled, which generally means being unable to work due to a medically determinable mental or physical impairment expected to result in death or last for at least 12 months. Individuals must be under age 65 and also have worked and paid into the program for five of the last 10 years. (Obtain a free evaluation to determine eligibility by visiting http://www.allsup.com/disabilityGuidelines/criteria.aspx)

2. File immediately. If an initial claim is denied, Allsup notes that the wait for an appeals hearing now takes an average of 512 days. There is no time to lose.

3. Obtain doctor's agreement. Claimants need written medical confirmation of their qualifying conditions when they apply. According to Allsup, not having a doctor's agreement when filing could delay the process a month or more.

4. Get help. Filing for disability benefits is a complicated process akin to preparing a difficult income tax return. Allsup emphasizes that the earlier applicants seek help, the more support they can get to help put them back on the right track.

5. Prepare an accurate medical record. A comprehensive factual record is required to convince the government to provide benefits.

6. Establish your work history. Compile records of dates and tenure of previous employment. As noted above, individuals must have worked for five of the previous 10 years to qualify for benefits.

7. Meet deadlines. If benefits are denied at any stage of the process, claimants have only 60 days to file an appeal. If the deadline is missed, the process starts over from the beginning.

8. Reduce spending. The long wait for benefits means that people lose their savings, their cars and sometimes even their homes. Cut out unnecessary spending as quickly as possible and prepare for the long haul. And don't use credit

cards. Allsup reminds applicants that high-interest debt will add to long-term problems. There may be other, more affordable options for handling expenses.

9. Maintain health insurance. There will be a temptation to cut spending on insurance, but Allsup notes that even after individuals begin receiving disability benefits there is a two-year waiting period for Medicare eligibility.

10. Don't give up. The Social Security Administration denies more than 60 percent of all initial applications, but two-thirds of the people who appeal eventually will receive their benefits.

About the Author

Allsup is the nation's premier Social Security Disability Insurance representation company. Our representatives pre-qualify individuals to ensure eligibility, develop accurate factual records and represent applicants throughout the disability decision process. This allows the Social Security Administration to focus on issuing disability decisions and clearing backlogged claims. Four out of five Allsup applicants never deal directly with the Social Security Administration.

Today, the company has more than 500 professionals focused on helping individuals and their families nationwide gain the financial and health benefits they deserve.

Medical Record Documentation for SSDI

By Tim Moore, SSDI Advocate

Disability claims that have been filed with the Social Security Administration are adjudicated on the basis of what a claimant's medical records have to say about their condition. And for claims that are inevitably approved, the information contained in the records do the following:

1. Establish the onset date of a claimant's disability (necessary for the calculation of back pay benefits and for determining the onset of Medicare eligibility).

2. Establish a current state of disability (necessary for the approval of ongoing benefits).

Practically every person who files for disability benefits understands that their medical records will be used to determine whether or not they are approved. And every physician who becomes aware of a patient's disability application knows, or should know, that the information they furnish to the social security administration may play a large role in deciding the outcome of their patient's claim. However, beyond this, the vast majority of claimants and physicians know relatively little about the approval criteria used by SSA for disability claims.

"The vast majority of claimants and physicians know relatively little about the approval criteria used by the SSA."

So, how does one qualify for disability benefits from the Social Security Administration and what must a claimant's records demonstrate in order for this to occur?

For both Title II (Social Security Disability) and Title 16 (SSI Disability) benefits, a claimant must satisfy the following requirements:

1. They must have a severe condition (though SSA has little difficulty differentiating a severe impairment from a non-severe impairment, the process is, still, largely subjective).

2. For the condition to be considered disabling, it must have a duration of at least one year and, in that time, it must limit an individual's ability to work and earn at least a substantial and gainful income while in the performance of past work or suitable other work (as determined by one's age, education, work skills, and rated residual functional capacity).

Substantial gainful activity equates to a dollar amount in gross monthly earnings and this amount changes annually. However, for 2007, substantial gainful activity was considered to be $900 per month. This meant that in 2007 an individual who was approved for disability was either A) functionally limited to the extent that they could not work at all, or B) functionally limited to the extent that they could not work and earn at least $900 per month.

The Social Security Administration's definition of disability focuses on a claimant's ability to work. And, for this reason, disability adjudicators (disability examiners at the application and reconsideration levels and administrative law judges at the hearing level) look for evidence of functional limitations when reviewing medical evidence. Specific examples would include a claimant's limitations with regard to the ability to sit, stand, walk, stoop, crouch, reach overhead, lift more than a certain weight or grasp objects.

Unfortunately, most treatment notes and hospital records are lacking in this regard, i.e. they fail to document a claimant's functional limitations, past or present. Yet, this is exactly the type of information that the Social Security Administration is looking for when deciding claims.

What happens when a disability claimant's medical records fail to establish that they no longer have the ability to derive a substantial, gainful income from the performance of work activity? Their claim may be denied or they may be sent to a consultative medical exam, performed by an

independent physician, for the purpose of gathering additional documentation. Such exams, though, rarely result in the approval of a claim. And, in fact, in most cases consultative medical exams are scheduled simply to satisfy a "recency of evidence" requirement, thus allowing a case to be closed.

In actuality, one of the most effective tools for winning a Social Security Disability or SSI claim is the submission of a medical source statement from a claimant's treatment physician.

What is a medical source statement? It may take the form of a residual functional capacity assessment such as the RFC form used by the Social Security Administration (a multi-page check off form that allows a physician to address a claimant's functionality and limitations). Or it may be presented as a letter from a treating physician. In either case, however, it is vital that the form is sufficiently detailed to the extent that a claims adjudicator can determine what the claimant's limitations are in the opinion of the treating physician.

By contrast, letters from doctors that simply state "My patient is disabled and unable to work" have little value in the eyes of a disability examiner or a federal judge. The Social Security Disability system focuses on a claimant's remaining ability to work, despite their condition, and looks to compare objective evidence regarding a claimant's functionality against the demands of their past work and other types of work they may potentially be suited for. For this reason, an assessment of a claimant's functionality and limitations by a treating physician can be vital. This is particularly the case at the disability hearing level.

Should a physician submit a supporting statement prior to the disability hearing level? In some cases, this type of statement may be instrumental in winning a case at the initial claim and reconsideration levels. However, State Disability processing agencies (where disability examiners decide claims for the Social Security Administration) often do not give credence to the opinion of a treating physician, choosing instead to adopt the opinion of an agency unit physician (employed by Social Security) who has never treated the claimant, or the opinion of an independent consultative medical examiner (a physician who has performed an outside exam, lasting, perhaps, 10 minutes on average, and who, once again, has no history of treatment with the claimant).

By contrast, at the disability hearing level, attitudes toward statements provided by treating physicians are often remarkably different. And such a statement can certainly win a claimant's case, as long as the statement is in line with the physician's history of treatment with the claimant.

About the Author

Tim Moore's website, **http://www.disabilitysecrets.com** "distributes information that should be provided by the Social Security Administration representative taking the claim for SSDI and SSI benefits, but almost never will." According to Tim, "Social Security does not try to make this information clear or even understandable."

Tim also has a Social Security blog at **http://www.disabilityblogger.blogspot.com/** that offers an Archive of posts dating back to September, 2005 along with state statistics and links.

The Essential Otter Advocate

http://romert.blogspot.com/

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