

In Motion

brought to you by www.care4dystonia.org

1 December 2007

Volume 2, Number 7

In This Issue

- Welcome
- Blepharospasm M/M
- Sally's Story : DRD
- Use of TENS Units
- ST Mini-Story
- Hypnosis
- Meiges Syndrome
- Topamax ?
- Merz Trial: NT201
- The Oz Effect
- UCSF Movement Disorders Program
- Brain Detector
- How well do You know your Nonprofit ?
- Dealing with Voice
- Updates and News
 - Dysphonia Campaign
 - Website Stats
 - PurTox
 - Clinical Connections
 - LIM Update
- Medical Disclaimer

Category of Links

www.myobloc.com

www.dystoniastudies.com

Welcome to *In Motion* !

Welcome to the Holiday issue of In Motion. This issue is packed with the stories of people living with dystonia, DRD, Alternative care, Blepharospasm, Hypnosis, lots of news, blog sites, and updates along with links to usable information. ~ *beka*

Marcellin's Story : Blephaospasm

The Story of Marcellin Chiasson, Port Hawkesbury, Nova Scotia

In 1996, I was hit with Blepharospasm and Oromandibular Dystonia. (Of course, I didn't know that's what it was at the time). For several years, I went from doctor to doctor not knowing what my problem was and whether I would ever get better. In 1982, I had had 2 major operations for Colon Cancer. From 1992 to 1994, I suffered from Meniere's Disease which is fluid in the inner ear causing me to lose my balance, making the road spin if I was driving and at times, making me violently sick to my stomach. Then in 1995, I took a medium/mild heart attack and at one point, I was told things did not look well and for me to discuss any future plans I might have with my family. So when I was hit with functional blindness, twisting face, trouble chewing and swallowing food and twisted neck in 1996, I was a complete mess. Like many other patients, I was tossed from doctor to doctor who had absolutely no clue what was wrong with me. The ironic thing about my condition is that my eyes would open if I played the fiddle, operated my chainsaw, or walked into a doctor's office which made the diagnosis worse because all tests including CT scan and MRI did not show anything abnormal. To this day, I give thanks to my family doctor, Dr. James Collins, for believing in me and giving me his undivided support. I have read so many stories of family doctors not believing their patients and telling them it was some type of psychological problem. After about my 8th doctor, he gave me a proper diagnosis and started a treatment which meant I was given Injections of Botox and later tried about 10 different kinds of medication for my Blepharospasm. None worked. I found out about a surgery (Myectomy) which was performed by Dr. David Jordan, Oculoplastic Surgeon, 340 McLeod Street, Ottawa, Ontario, K2P 1A4 (Tel 613-563-3800). He removed my upper eyelid muscles and now I can do many normal things such as driving my car. Before the operation, I had to hang onto the wall to go to the bathroom. Dr. Jordan gave me a new lease on life and I will be eternally grateful to him.

As for my Oromandibular, Dr. Jordan said that this was out of his specialty and directed me to Dr. Barclay, Neurologist. She gave me medication which seemed to arrest that part of the Dystonia, however, the medication has side effects. I have short bouts of mild confusion, bouts of short term memory loss, fatigue, etc. However, the side effects still allow me to do things I could not do before I took her medication.

What else can I say was helpful to my condition? I would have to say that my faith in God, keeping a positive outlook and the many prayers of family and friends. As I began to get better, I wanted to help others faced with this terrible Dystonia.. At one point, I

out our Oral Med Page
online !

New NT201 Webpage
online at
www.care4dystonia.org.
Check it out !

Cosmo Awareness Program
now in effect !

Free Cosmo Postcards- 740
have been distributed
since October 1st 2007.
Have you done your share
in promoting Awareness ?

was the leader of Atlantic Canada for the Canadian Dystonia Medical Research Foundation, however, I resigned when, in my opinion, their total attention was directed to the raising of funds and in my mind, Patient Support did not have the importance it should have. When I met Beka Serdans through the Internet, she was like a breath of fresh air. Her motto was and remains "Care until Cure", which was exactly the type of person I could support and work with. There is no membership fee to belong to her group and her focus is with patients, awareness and most recently patient education. We are grateful that she has shared her own experiences with us and as an active nurse, she has the best interest of patients at heart. She is the founder of the following Web Site

www.care4dystonia.org . I can be contacted at :
Tel: 902-625-1811 or e-mail at marcellin.chiasson@ns.sympatico.ca.

Marcellin Chiasson, 26 Tamarac Drive, Port Hawkesbury, Nova Scotia,
B9A 3E7

My Story : Sally's Story

Ok, here it is...a bit long..in my own words....

I have dopa responsive dystonia (DRD). My dystonia began along my right arm, shoulder and leg during sleep when my brain tried to go from nonREM to REM. The dystonia was so strong that when my jaws clamped during sleep, a tooth on the right side of my face was loosened. I also had some dystonia during the day - twisted posture, right hand pumping, slow writhing motion while talking, I would fall if I was surprised by anything while walking such as a dog suddenly barking close to me. All of this had been occurring since early childhood though it was much milder at first, worsening gradually. I was able to do well in school though never up to my abilities; I served four years in the US Navy, advancing from a seaman recruit to second class petty officer and was awarded a Good Conduct Medal. VA benefits plus savings enabled me to go to university where I earned BS and MS degrees. This may seem irrelevant, but it's not. Please bear with me.

I married, and I was able to work in my field for a few years, then I did part time work in a related field, but by 1998 I could no longer work at all. My sleep deprivation from lack of REM which had always been serious, worsened so that I couldn't stay awake long enough to drive myself to work. I couldn't stay awake at my desk. I couldn't remember anything - passwords, project details, names, my telephone number, my address. I couldn't figure anything out anymore. I would go home after a few hours of work, stumble through the door, closing it but leaving it unlocked, fall on the sofa with my winter coat and boots still on, and sleep for hours only to be woken up by my right arm and leg suddenly folding hard against themselves, the right side of my trunk trying to fold itself over down the center of my chest, and my right jaw clamping hard enough to loosen that poor tooth.

The first time I went to a doctor with a specific dystonia symptoms was in November 1974. For the next 30 years, I presented myself with the symptoms of dystonia from one doctor to doctor to doctor to doctor. It went on and on. Their clinical and verbal responses made no sense. Though I was able to describe in detail the dystonia that was occurring when I was sleeping, no one would ever let me say more than one, maybe two sentences. Some of them yelled at me, some laughed, some sneered. I remember two physicians who simply got up and

Contact Us

www.care4dystonia.org

Editor : Beka

walked out before I had finished my first sentence. I did every test they asked of me, I took ever medication they gave me, I paid all of them every penny they demanded of me, but no one would ever let me even describe what my symptoms were .

The very lowest point for me came in the spring of 2003. I traveled 1500 miles from my home in Alaska to a large well known hospital in Seattle to see yet another neurologist, who wouldn't let me speak as seemed typical by now, and I demanded to know why no one would let me say anything. He had me fill out an MMPI questionnaire, which is a simple standardized psychological test consisting of 500 questions. I filled it out in good faith. I answered each and every one of those questions truthfully. It was evaluated by a psychologist who did not interview me in person except on paper. The results showed no psychological problems. Because the MMPI score showed no psychological problems, the neurologist concluded that I had a psychological problem so deep that I was unable to appreciate it, that I had personality abnormalities, and that I was unable to say what I was thinking and feeling . Ergo, the neurologist concluded, there was no need to listen to me describe my symptoms. This he wrote out in his report, signed, and mailed to every hospital that has my I chart-medical records in the Pacific Northwest, Alaska, and to my health insurance company.

BUT that's not all. He told me that there was no doubt that I had been sexually abused as a child. When I told him that it didn't make any sense, and that I hadn't been sexually abused, he laughed and said I was the most repressed woman he had ever seen. When I insisted that I really hadn't been sexually abused, that the accusation made no sense at all, he said that I must be hiding a deep horrible secret about my family and he wondered what it was.

Back home again, I immediately went to two psychologists, one male and one female, to find out if it could be true that I was sexually abused and have only lots of memories of fun with my entire, extended family, like fishing and hiking, picking berries and building a sailboat and sailing it at the lake. They both took the time to interview me and said no, the current consensus is that it may be possible to repress memories of the actual sexual abuse, but all the memories surrounding it are not repressed. They said that when small children are abused, they get hurt and require medical treatment. Then the police are involved. That all creates memories. When older children are abused, they remember the responses of other adults. Moreover, they both said, people with deep psychological problems due to childhood sex abuse don't have memories of family fun. Instead they have lives that are full of problems. They leave a long trail of angry people behind them wherever they go. They don't get medals due to good conduct, they don't earn Bachelor of Science and Master of Science degrees. They don't have happy, long lasting marriages. Both psychologists agreed with me, that the neurologists' conclusions made no sense at all. But I had to find a doctor who willing to listen to those psychologists.

For a full year, from Spring of 2003 to Spring 2004, I got no medical care at all. The two doctors I saw during that time could not get past the neurologist's report declaring me unable to say what I think and feel. They would not speak to the two local psychologists I had seen. They did not even take my blood pressure anymore. They did nothing to find out what was wrong with me. I was absolutely convinced that I would never again get any health care and that there was nothing I could do. I knew then how much doctors had failed me, I knew it was because of their psychological issues with childhood sex abuse, and the grief I felt for the loss of my adult life was the most intense emotion I have ever had.

Spring 2004 I tried one more doctor. I was very sick and close to being unable to help myself. I laid everything out for her to see and I gave her a

About Our Sponsor :

We are extremely grateful for the support of Solstice Neurosciences, Inc. for recognizing the value of this educational endeavor.

You can learn more about our sponsor on our website where we have a page devoted to them and potential new future sponsors.



list of my symptoms that I had written on a piece of paper. I gave her the signed forms permitting her to talk to my two psychologists. As I talked, I remember writhing around towards the right, and bending in two, not at my waist but just below my ribs. She let me speak! I told her about sleep, how sharp, hard painful movements woke me up 4, 5 times a night, and how sleep deprived I was. I showed her the seven ganglia I had in my right hand from all the hand pumping I did. I was in so much pain from the ganglia and the tendinitis in my right arm, shoulder and leg, and the neuroma in my right foot. She let me keep on talking. Then she prescribed sinemet. I didn't know it was dopamine. She didn't say what it was and I was way beyond caring about anything at that point.

When I took the sinemet, it was a miracle. It was astounding. Within an hour I was able to hold my upper body straight. My hand was still, I stopped writhing; I stopped pressing my right foot sideways on the floor. I actually had a short dream that night and there was no dystonia waking me up in the middle of the night..

It's been 3 years now. It took a year and a half for my brain to learn to sleep all the night through and have dreams about familiar people and events, mixed up, of course. I received physical therapy, I did lots of exercises and almost all of my tendinitis is gone, the ganglia are all gone, the neuroma in my right foot is even gone. For the first time since 1974 I am pain free. Even that tooth has settled firmly back into its place in my jaw is gone. The part that hurts is that sinemet was available in 1974. All that suffering for 30 years: the pain, the sleep deprivation, and the loss of my profession didn't have to happen. I was able to tell doctors all along what they needed to know to make an accurate diagnosis. I lost most of my adult life as those doctors just looked the other way. I did manage to get my degree, it was my only chance to have the university education that I wanted so much, but I had to do it while suffering severe sleep deprivation and pain. Those doctors cost me and my husband tens and tens of thousands of dollars.

About that neurologist's report claiming personality abnormalities, it seems there's nothing I can do about that. His word against mine. The neurologist didn't need any hard facts to prove his claim, but there's nothing I can say that will now prove that I don't have a personality abnormality or some deep hidden psychological problem. His comment about my hiding a horrible secret about my family, I regard as a threat and harassment. Once a family gets smeared with accusations of sex abuse of children, it's impossible to undo the harm. I can't even complain to the employer of that neurologist, that well known Seattle hospital, because I won't risk harming my innocent family. My two psychologists say that a person's life is where the proof lies, and I try to take comfort in that. I take my sinemet 3 times a day and I have never felt even a twinge of resentment because I have to set aside the time and attention three times a day to take them. I don't forget to take the sinemet either. I don't mind the cost. I just wish I could be free of the report that took away from me my human right to speak for myself.

Use of TENS Units : Is it 4 You ?

Yes, I have my own TENS unit and sometimes even wear it at work. A TENS is a battery-powered device, which is not much bigger than an iPod, and is typically used by a trained physiotherapist. But any physical therapist should be able to teach you ow to use one. To get one - it is covered by health insurance, you just need a doctors prescription, usually bought at health supply stores.

TENS electrodes are placed on the area where you are experiencing pain which then allows the electrical current to be absorbed into the painful area. It is not a magic

cure and the TENS unit doesn't work for everyone but there's has been a lot of success with the TENS unit reducing the amount of pain experienced in most people. I use it for low back pain but some times use for shoulder pain.

Some health care providers believe the electrical current scrambles the pain signals sent from the area of pain to the brain and so the brain doesn't think it should hurt there anymore. It is thought that nerves send the messed up messages to the brain and because of the pain signals getting confused the brain no longer sends pain messages back down to the area in the back that hurts. Other healthcare professionals believe the TENS stimulates the production of endorphins, the body's natural painkillers and so this results in the reduction of pain. Regardless, TENS Units can help reduce pain levels if used correctly.

TENS units can send varying amounts of electrical current depending on how it is configured.

Regardless of the fact that you can actually buy one of these for yourself, that's not really the best idea since a trained physiotherapist has been trained in evaluating the situation and establishing the correct settings based on your needs. Don't rush it, there is no reason to increase the settings on the TENS in hopes of getting relief of the pain sooner... it just doesn't work that way.

Some believers of the transcutaneous electrical nerve stimulation device think that these units work exceptionally well for some back pain sufferers. A lot of us with dystonia have back pain! Even though some people don't feel like they got all the relief they were looking for with the TENS unit, it does appear that many people who have used these units do report enough of a decrease in pain that it does appear to be beneficial. Research continues as scientist try to learn the exact benefits of back pain sufferers using a TENS.

Resources : arthritis.about.com/od/assistivedevicesgadgets/g/tensunit.htm
en.wikipedia.org/wiki/Transcutaneous_Electrical_Nerve_Stimulator

My ST Story: A Mini-Story

I finally was diagnosis with Cervical Dystonia (Spasmodic Torticollis) this past February. I have had the tremors on and off since July 1999. I saw many, many neurologist in my home state of North Carolina. Unfortunately, in Nov. of 2006 my tremors became so bad that I had to take a medical leave of absence from work, and still not able to return to work. After visiting Baptist (wake Forest) Medical Center in Jan. 2007 and seeing their movement disorder specialist, I left the appointment in tears because I still had no diagnosis. My husband got online and contacted John Hopkins's Bay view Medical Center and got me in to see Dr. George Ricaurte. Within 15 minutes I had a diagnosis and finally some hope. Well, the doctor at Baptist refused to treat me with Botox because "he did not feel comfortable treating me". So I now travel 2 and 1/2 hours to Charlotte, NC to receive my Botox injections. This is just a mini story of what I have gone through.- K.B

Alternative Care: Hypnosis

Hypnosis is a social interaction in which one person responds to suggestions given by

another person (the hypnotist) for imaginative experiences involving changes in perception, memory, and the voluntary control of action.

Researchers have been interested in biological correlates of hypnotizability as well as in those that can be measured by paper-and-pencil tests. Although hypnosis is commonly induced with suggestions for relaxation and even sleep, brain activity in hypnosis more closely resembles that of a person who is awake. The discovery of hemispheric specialization, with the left hemisphere geared to analytic and the right hemisphere to nonanalytic tasks, led to the speculation that hypnotic response is somehow influenced by right-hemisphere activity. Studies employing both behavioral and electrophysiological mechanisms have been interpreted as indicating increased activation of the right hemisphere of the brain among highly hypnotizable individuals, but positive results have proved difficult to replicate and interpretation of these findings remains controversial.

Hypnosis is influenced by verbal suggestions, which must be interpreted by the individual in the course of responding. Therefore, the role of the left hemisphere of the brain should not be minimized. One proposal is that hypnotizable individuals show greater flexibility in using the left and right hemispheres in a task-appropriate manner, especially when they are actually hypnotized. Because involuntariness is so central to the experience of hypnosis, it has also been suggested that the frontal lobes (which organize intentional action) may play a special role. A better understanding of the neural substrates of hypnosis awaits studies of neurological patients with focalized brain lesions, as well as brain-imaging studies (e.g., PET, fMRI) of normal individuals.

Resources : http://www.institute-shot.com/hypnosis_and_health.htm
<http://www.hypnosis.com/>
http://www.dilbertblog.typepad.com/the_dilbert_blog/2007/07/hypnosis.html
www.hypnosis.org/

For more Info about Alternative Care , [contact www.MapleHypnosis.com](http://www.MapleHypnosis.com)

Are You aware about our Awareness Magnets. Contact us and we'll send as many as you wish at no cost. Help spread the word about dystonia. We have already distributed 41,000 of them since last year !!

DYT1 Gene testing available thru www.athenadiagnostics.com

Meiges' Syndrome: Chewing Motions?

Meige's syndrome presents with a combination of upper and lower facial motor dysfunction, including eye closing spasms and oromandibular dystonia. While the pathophysiology of eye closing spasms has been extensively studied using the blink reflex and other trigeminofacial reflexes, very few studies have been carried out with regard to the abnormal perioral movements. We hypothesized that action-related dystonic features could be revealed by the analysis of the semiautomatic rhythmic movements required for chewing and swallowing. A total of 7 patients with Meige's syndrome that complained of chewing problems and 7 age-matched healthy volunteers were studied. Subjects were instructed to munch and swallow a small muffin while surface electromyographic (EMG) activity of masseter (MAS) and orbicularis oris (OOr) of the dominant side was recorded. In healthy subjects, MAS and OOr showed a rhythmic alternating phasic EMG pattern during chewing, which changed to a tonic cocontraction of both muscles during swallowing. Mean duration of MAS and OOr EMG bursts was, respectively, 297 +/- 28 msec and 328 +/- 29 msec. Patients exhibited the following alterations: excess duration of muscle activity, frequent cocontraction, loss of rhythmicity during chewing, and abnormalities in the chewing to swallowing transition phase. These abnormalities, similar in type to those encountered in other forms of focal dystonia, may be the expression of an abnormal motor control of basal ganglia over mastication-

Check out our New Site Map. Let us know what more information you would like us to add.

Our New YouTube webpage !

New Navigation System coming to our Site !

Disorder Society.

PMID: 15390039 [PubMed - indexed for MEDLINE]

Resources :

<http://www.neuro.psychiatryonline.org/cgi/content/full/14/3/355>

<http://www.blepharospasm.org/meige.html>

Can You tell me about Topamax?

Topamax is primarily used for migraine Headaches and seizures. It is not FDA approved specifically for dystonia but then neither are many of the other neuro drugs used to treat symptoms such as Baclofen, Artane or even Klonopin!

I listed most of the meds used for dystonia on this page

www.care4dystonia.org/index.php/dystonia/treatment-for-dystonia/oral-medications

Most of the drugs used in dystonia is based on trial and error, and are used as off-label use. I can't see any reason for not trying the drug although for some people it can worsen facial tics and rarely dystonia.



www.topamax.com

The Merz Trial:

Visit <http://care4dystonia.org/index.php/nt201-toxin/>

The Oz Effect:

On Nov 2nd 2007 I and my neurosurgeon, Dr. Mike Kaplitt, MD, PhD and scientific advisor of C4D found ourselves sitting in the studios of "Oprah and Friends XM " ready to discuss dystonia with Dr. Mehmet Oz, MD. As a CTICU RN I have worked with him for the past 9 years. We sat in comfortable beige chairs as Dr. Oz drank a green colored liquid concoction that looked like green bile. Dr. Mike and I couldn't help thinking the same thing. During the interview we covered multiple aspects of dystonia : misdiagnosis, symptoms, treatments, toxins (Botox, MyoBloc, NT201 and PurTox), multiple forms of dystonia, DBS selection for PD, tremor and how location of DBS leads differs for dystonia and gene therapy. We also added the need for more diverse research monies. Personally, I couldn't help it, but say that "Dystonia sucks. It ruins lives, goals, hopes and dreams ". And I let Dr. Mike take over from there. XM Satellite Radio has close to 6 million listeners. Dr. oz actually spelled the word dystonia out for listeners. Overall a great experience. Wonder what he will say now that I have mobilized over 15k newsletter subscribers of www.care4dystonia.org and he'll be receiving plenty of Thank You emails. ~ beka

**Have you seen our
New Flash Video ;
Making waves on
YouTube !**

About UCSF Movement Disorder Program:

PROGRAM PERSONNEL

NEUROSURGERY

Philip Starr, MD, PhD
Paul Larson, MD

NEUROLOGY

Alec Glass MD
William J. Marks Jr, MD
Jill L.Ostrem, MD

NURSING

Monica Volz, RN, MS
Susan Heath RN, MS
Elaine Lanier RN, MS
Robin Taylor, RN

Basal Ganglia Research : Krys Bankiewicz Ph.D., Alastair Martin, Ph.D

OVERVIEW

The UCSF Center for the surgical treatment of movement disorders offers comprehensive neurosurgical and neurological management for patients undergoing surgical treatment for Parkinson's disease (PD), dystonia, and tremor. All program staff specialize in movement disorders. Since the launch of the center in 1998, we have performed 800 deep brain stimulator (DBS) electrode implants, including all major surgical targets: the sub thalamic nucleus (STN), the globus pallidus internus (GPi), and the thalamus.

OUTPATIENT CARE BY AN INTEGRATED TEAM

Patients are evaluated and managed in a weekly interdisciplinary clinic where the patient is seen by both a movement disorders neurologist and a movement disorders neurosurgeon in the same visit. Following implantation of deep brain stimulators, integrated management of stimulator settings and medications, including botox therapy, is offered by our movement disorders neurologists.

INNOVATIONS IN SURGICAL TECHNIQUE

UCSF is a proven leader in microelectrode-guided neurosurgery, the standard approach to implantation of deep brain stimulators. In addition, we are experienced with novel technical approaches to DBS implantation, including frameless techniques and interventional magnetic resonance imaging (iMRI). With frameless DBS surgery, the patient does not have to wear rigid frame attached to the skull for the duration of surgery. With the use of iMRI, surgery is performed within an MRI unit providing high-quality images of the brain during the surgery. Patients may have DBS implants performed under general anesthesia, rather than awake as is necessary with the standard approach. Using iMRI, images of the brain are can be obtained at any point as surgery progresses, so as to confirm accurate placement of the electrode and the absence of bleeding complications.

ACCESS TO CLINICAL TRIALS AND NOVEL THERAPIES

We participate in several funded clinical trials to refine existing surgical procedures or to test new approaches. These include a large multicenter trial of DBS for Parkinson's disease, and Phase I and Phase II (investigational) trials of gene therapy for Parkinson's disease. We have the largest experience in the Western United States with DBS of the globus pallidus for dystonia.

RESEARCH

Our research projects aim to improve surgical outcomes, develop new treatments for movement disorders, and better understand brain physiology in movement disorders. Using a database of DBS electrode locations and clinical data, we are able to correlate exact DBS electrode placement with clinical outcome so as to determine optimal electrode position. Analysis of physiological signals recorded in the operating room contributes to understanding the organization of the basal ganglia, and

the abnormal signals responsible for movement disorders. Our MR physicists and basic scientists are developing novel means of delivery of biologic agents, such as vectors for gene transfer, to the brain.

CONSULT REQUESTS CAN BE SENT TO:

Diane Hollander, Clinic Coordinator
Department of Neurosurgery
400 Parnassus Avenue, Box 0350
San Francisco, CA 94143
415-353-2071 (phone) 415-353-2889 (fax)

The UCSF Movement Disorders Center provides comprehensive care for patients of all ages with dystonia. Our team includes fellowship trained movement disorders specialists with significant experience utilizing chemodenervation treatments (botulinum toxin) for the treatment of dystonia, including cervical dystonia, blepharospasm, hemifacial spasm, task-specific dystonia (including musician dystonia, writers cramp, and hiker's dystonia) and other less frequently encountered forms of dystonia. Dr. Mark Courey, the director of the UCSF Voice Center, has substantial experience utilizing botulinum toxin and surgical approaches for the treatment of spasmodic dysphonia. Drs. Philip Starr and Paul Larson, neurosurgeons specializing in the treatment of movement disorders, work very closely with the movement disorders neurologists and are among the nation's most active and well respected surgeons in the treatment of dystonia utilizing deep brain stimulation (DBS). In addition, Dr. Nancy Byl is a widely respected and highly published physical therapist with significant experience using strategies for sensorimotor retraining in the treatment of dystonia. She has additionally worked in collaboration with Dr. Michael Merzenich in order to create animal models of dystonia.

Movement Disorders Neurologists

Jill L. Ostrem, MD (Botox, DBS)
Graham A. Glass, MD (Botox)
Chadwick W. Christine, MD
William J. Marks, Jr., MD (DBS)
Michael J. Aminoff, MD (Botox)
400 Parnassus Avenue, 8th Floor
San Francisco, CA 94143-0138
Patient Appointments: (415) 353-2273
Fax: (415) 353-2898

Neurosurgery

Philip A. Starr, MD, PhD
Paul S. Larson, MD
400 Parnassus Avenue, 8th Floor
San Francisco, CA 94143-0350
Patient Appointments: (415) 353-7500

Physical Therapy

Nancy Byl, PhD
Physical Therapist
Professor, Physical Therapy & Rehabilitation Science
Affiliate, UCB/UCSF Graduate Group in Bioengineering
1318-20 7th Avenue, Box 0736
San Francisco, CA 94143-0736

(415) 476-3452
Fax: (415) 502-0323

ENT

Mark S. Courey, MD

Professor
Director, Division of Laryngology
Director, UCSF Voice Center
Department of Otolaryngology - Head and Neck Surgery
Patient Appointments: (415) 885-7700
Fax: (415) 885-7800

Brain Detector and PAIN:

Handheld Monitor Can Detect Subtle Brain Injury

10.04.07

Researchers at the New York University School of Medicine, New York City, have developed a handheld device that can detect subtle brain damage immediately after concussion. The sophisticated yet simple-to-operate device, the researchers say, may prove especially useful on the battlefield or the football field, enabling brain damage to be detected almost immediately after mild head injuries. Such damage is often overlooked or misdiagnosed, even with an advanced imaging technique like computed tomography (CT), say the researchers.

The device, called BrainScope, is based on the studies of E. Roy John, PhD, professor of psychiatry and director of the Brain Research Laboratories (BRL) at NYU School of Medicine.

In the late 1970s, John discovered how to translate EEG tracings – recordings of the brain's electrical activity on an electroencephalograph – into numbers called quantitative EEGs (QEEGs). A significant advance, QEEGs gave scientists an objective and standardized way to assess cognitive functions.

John has devoted much of his career to the study of QEEGs and their clinical applications, in the process collecting and analyzing brainwave recordings from about 20,000 patients. Using this database, the world's largest; John established normal ranges for QEEGs across the life span and correlated deviations from these norms with a wide variety of neurological disorders, including concussions. This evidence provides the scientific basis for BrainScope.

BrainScope consists of an adhesive strip, containing six electrodes, which are connected to a mini-computer that resembles an oversized iPod. After a suspected head injury, a first responder affixes the electrode strip to the patient's forehead. The device automatically collects a sample of the patient's EEG and computes a large number of QEEG feature search of which are compared to a databank of normal scores. Within minutes, BrainScope's color display indicates whether any of the patient's brain functions deviate from normal.

It is not uncommon for mild-to-moderate concussions to go unnoticed, because they cause no visible wound and symptoms like nausea quickly resolve. "The subtle brain dysfunction associated with such concussions is often invisible even to sophisticated imaging scanners, including CTs and MRIs," says John. "Moreover, such scans must be

carried out in a hospital, and are typically performed hours or days after the initial injury, which delays treatment.”

“With a BrainScope, one would see the effects of a concussion right away, providing unequivocal evidence of injury and timely guidance for medical intervention,” says Leslie Prichep, PhD, professor of psychiatry at NYU School of Medicine and a longtime collaborator of John’s.

The device is intended to be used as a triage instrument in a variety of settings, including battlefields, sporting events, emergency rooms, and clinics. John is particularly concerned about reports of the high number of concussive brain injuries caused by improvised explosive devices in Iraq, and the possibility that there are many homeless combat veterans with undiagnosed brain injuries caused by these devices. “BrainScope could be used on the battlefield, improving the chance that soldiers with less obvious brain injuries will receive proper care,” he says.

After the death of former NFL defensive back Andre Waters, who committed suicide last year after suffering numerous concussions, teams at all levels of sport have begun to pay more attention to brain injuries. In the future BrainScope could assist clinicians in determining an athlete’s level of recovery and readiness for safe return to competition after concussion, says John.

Source: New York University Medical Center (2007)

(Wonder if this would help in post-traumatic dystonia ?)

How Pain Affects the Brain :

Anybody who’s tried to concentrate on work while suffering a headache knows that pain compellingly commands attention – which is how evolution helped ensure survival in a painful world. Now, researchers have pinpointed the brain region responsible for pain’s ability to affect cognitive processing. They have found that this pain-related brain region is distinct from the one involved in cognitive processing interference due to a distracting memory task.

Researchers at the University Medical Center Hamburg-Eppendorf in Germany published their discovery in the July 5 issue of the journal *Neuron*.

To search for the region responsible for pain’s ability to usurp attention, the researchers asked volunteers to perform a cognitive task involving distinguishing images, as well as a working memory task involving remembering images. The researchers asked the volunteers to perform the tasks as they experienced different levels of pain caused by the zapping of their hands by a harmless laser beam.

During these tests, the volunteers’ brains were scanned using functional magnetic resonance imaging (fMRI). In this widely used analytical technique, harmless magnetic fields and radio waves are used to scan the brain to determine blood flow across regions, which reflects brain activity.

The researchers’ experiments identified a brain region called the lateral occipital complex (LOC) as the cognitive-related area affected by both “working memory load” and pain. This finding was expected, since the LOC is known to be involved in processing images.

The researchers next sought to identify the brain region by which pain affects the functioning of the LOC. They theorized that the best candidate for this region was one

called the rostral anterior cingulate cortex (rACC). This region is known to be involved in the brain's processing of pain, and it is part of the anterior cingulate cortex, which plays an important role in "executive" functions such as attentional control. These structures are located deep in the brain in the region of connection between the two hemispheres.

Indeed, the researchers' fMRI scans indicated that the rACC is, indeed, the brain center through which pain influences the LOC. By contrast, they found a working memory load affects the LOC through a different region, the inferior parietal cortex.

The researchers noted that the modulation of visual processing by pain that they observed in their fMRI studies is behaviorally relevant, because as their fMRI scans showed pain affecting the LOC, they also observed a parallel impairment of accuracy in subjects' recognition of the images.

Source: Cell Press (2007)

How well do You Know your Non-Profit? :

Sunday, October 28, 2007 (SF Chronicle)

Charitable organizations presume too much

Susan Alexander

When did I become a member of groups I never knowingly joined?

Maybe I'm mistaken, but I always thought that the word "member" meant that one had purposefully joined a club or similar entity. Joining such a group can be a good idea. For example, membership in a social club offers a range of pleasant benefits, like golf, swimming or dining in an exclusive setting.

Being a member of a professional organization generally offers career-oriented perks, along with help climbing a possibly shaky ladder to professional success. And then there's membership in a political party, which has always meant sharing an outlook (more or less) on public policy.

But now it seems that my charitable instincts have turned me into a "member" of a host of other groups. Charities to which I've donated a few stray bucks have anointed me as a member, and they are now pursuing me to "renew" my membership!

Jeez, I didn't realize that when I sent Oxfam a small donation I would suddenly become a "member" of that admirable group. But apparently I did, because here's an envelope it recently sent me, announcing that there are "10 reasons to renew (my) membership"!

The Make-a-Wish Foundation, another commendable organization to which I've donated a small sum on occasion, has now written me to ask for more. The shocker is the envelope's threat that this is my "final 2007 renewal notice." But please tell me, Make-a-Wish folks, when exactly did I join in the first place?

Yes, I'm a softie, and I have perhaps foolishly sent dribs-and-drabs donations to a wide array of worthy groups that tug at my heart. But please let me know, Nature Conservancy, NARAL and Southern Poverty Law Center, why doing that constitutes "membership" in your organization? And yes, Juvenile Diabetes Research Foundation, you do such wonderful work on behalf of kids with diabetes. But seriously, all I did was send you a check or two. Yet now you've sent me a "2007 renewal reminder."

Some of these groups have even issued me "membership cards," complete with member numbers. And a few have gone over the edge and sent me membership "statements" that strongly resemble bills. I just got one from amfAR, the Foundation for AIDS Research. C'mon, people! Do you think that scares me into sitting down and writing you a check?

Truthfully, I resent being lumped into the category of "member" by groups like these, with which I have no real connection other than a desire to add a small amount to their coffers. Being threatened with a "final renewal reminder" doesn't induce me to respond. On the contrary, it makes me wonder about the professional fundraisers these groups must hire. Do their ominous reminders work on anyone? They certainly don't work on me. Instead of loosening my purse strings, they encourage me to tighten them. The threatening envelopes get tossed into my recycling more often than not.

All this tossing makes me think hard about the charitable world today. For one thing, I've been warned about an insidious trend. It appears that if you donate only a small amount, charities tend to sell your name to other groups, so you can then be hounded by 10 or 12 charities instead of just one. "Your name is worth more to these charities than the \$25 you give them," a friend confided. If that's true, it simply compounds the problem. And it seems to account for the plethora of solicitations I find in my overstuffed mailbox every day.

While I'm at it, I'll go further and denounce some of the other tactics these groups employ. Even those that don't call me a "member" are guilty of some pretty odious practices. For starters, I am now the recipient of endless "free gifts." The proliferation of address labels has gotten totally out of hand. My daily mail includes countless address labels from groups I've never even heard of. I've received enough of these labels to last at least two more lifetimes, and that's assuming I never move from my current address.

Other freebies include ballpoint pens, note pads, greeting cards and calendars - many more than I can ever use (and many that are so unappealing that I never would use them). Most of them end up in a charity donation bag (one hand washes the other?) or, even worse, the trash, adding to our overflowing landfills or our overburdened recycling centers. Honestly, I'd much prefer that these groups spend my cash differently. Hey, please use that money to search for a cure, actively fight racism, and directly lift women out of poverty. Note pads and calendars? I can buy that myself.

Some of us have gotten wise to this endless pursuit of donations, with repeated requests arriving bi-weekly. **Web sites now exist on the Internet to tell us how most charities operate.** For example, Charity Navigator (charitynavigator.org) evaluates charities, trying to distinguish among them by giving four stars to those that have an efficient operation, while poorly run charities, which spend too much of their revenue on fundraising and other administrative costs, garner only one or two stars. Maybe this kind of ranking isn't perfect, but these Web sites have helped me weed out some of the groups I used to support. If enough of us did that, we might have an impact on the most deplorable tactics.

The solution for me may be to become **more selective**. Instead of making small donations to a wide range of worthy groups, I may focus on a handful of them and send a larger check to each. But I fear that my name may stay on the same old mailing lists ad infinitum, adding pounds and pounds to recycling as I continue to toss.

This blizzard of charity solicitations has to stop. Where I once was charitable, I am now more likely to be hostile, vowing never to contribute a dime to most of the charities that pursue me with such zeal. **Don't these groups realize that they have literally reached a point of no return?**

Susan Alexander is a freelance writer based in San Francisco. Contact us at insight@schronicle.com.

Copyright 2007 SF Chronicle

Dealing with Voice:

Lessons learned in a communication group at the University of Arkansas, Fayetteville, and offer people with serious communication problems a way to redefine who they are on their own terms.

When stroke or disease damages the ability to understand or use language – a condition known as aphasia – more is lost than words and sentences. Since people express who they are through conversation and other communication, aphasia can mean a loss of self, what University of Arkansas researcher Barbara B. Shadden, PhD, has called “identity theft.” Shadden is a professor and director of the Speech and Hearing Clinic in the College of Education and Health Professions at the university.

Shadden and sociologist Patricia R. Koski, BA, MA, PhD, have applied sociological theory to illuminate the process of a communication group for people with aphasia. An article about the results of the group, “Social Construction of Self for Persons with Aphasia: When Language as a Cultural Tool is Impaired,” appears in a recent issue of the *Journal of Medical Speech Language Pathology*. Koski is an associate professor in the department of sociology and criminal justice and associate dean of the University of Arkansas Graduate School.

Theorists in a number of disciplines agree that “language, talk and communication are critical elements of the ongoing construction of self,” the researchers wrote. When people with aphasia are involved with the medical system, their role as patients reshapes their life stories. Often they begin to see themselves as powerless, incompetent and socially marginal.

“The way you create yourself is that you tell a story,” Koski says. “Think of how you present yourself to other people. You tell a story. It’s not just a presentation of self – it’s a creation of self.”

“But if something happens to that communication tool that lets you tell that story,” Shadden says, “then how do you do it? How do you create yourself? What do you do if your tool has failed you and others don’t know who you are?”

In 2004, a communication group was created at the University of Arkansas Speech and Hearing Clinic as a way of “transforming communication strategies learned in individual therapy into a broader social context.” While communications professionals in the group facilitated discussion, everyone participated on an equal footing, which created very different relationships than are typically seen with the medical model.

“The medical model is a very comfortable model,” Koski says. “There’s you the professional, and there’s that other person the client. You treat the client. You have power, you are separate, and you don’t have to take a risk. This support group was based on the assumption that there was fundamentally no power difference.”

Shadden had always taught her clinical students that they were dealing with a person first and a disorder second. With the communication group, she says, “We were trying to put some teeth into that.”

The group was a place for people with aphasia to use the cultural tools available to tell the story of who they had been and were becoming. A cultural tool is more than the act of speaking and using language. Cultural tools include, among other things, beliefs, assumptions, values, posture, gestures, facial expressions – and assistive devices. For

people who have lost their ability to use language, assistive devices may involve computer programs or other people.

"Being articulate is a really important tool in our society. Being able to express things well with a voice is an incredibly important tool," Koski says.

"That idea of voice, not in just the literal sense, but the idea of 'having a voice,' is really about having a self. You can't separate the two," Shadden says.

The logistics of the communication group were simple. People were seated in a way to maximize social support and communication. For example, a woman who could write but not speak was seated next to a man who could read and share her writings with the group. Group members selected personal biographical discussion topics ranging from the first kiss and first car to vacations of the past and future. Topics were selected well in advance to give everyone time to prepare. Facilitators were active and equal participants in the discussion, presenting their own personal story along with everyone else.

Shadden and Koski use the example of Jack to show the impact of the group process. A stroke had left him able to say little more than "uh huh" and "no" while also communicating through facial expressions, various vocalizations and drawing. Eight years after the stroke, Jack and his wife both expressed anger and frustration and seemed to be focused on what he was unable to do. He had an assistive tool that he avoided using.

"In my discipline people think if you get the right computerized device into someone's hands that will solve the problem. That's the easy part," Shadden says. "Figuring out what they can and can't do is easy. Figuring out what they will or won't do is hard. What matters about a tool is what you do with it."

Over the course of a year and a half, Jack responded to the group story-telling exercises and the good-humored support by engaging in more complex explanations of his feelings. He was transformed "as he found his voice and was able to share his life story." Subsequently, when faced with the life-threatening result of a medical test, he was able to discuss it with the group and later with his wife.

"For the first time, they began to communicate about how they wanted to live their lives in the face of this threat. During the course of this transformation, his wife appeared to be picking up her life story as well, as anger abated and her life story expanded beyond being married to an angry man who had had a stroke."

Source: University of Arkansas, Fayetteville

Updates and News:

Clinical Trials for Dystonia : Currently there are about 25 clinical research trials associated with dystonia- use of MyoBloc, deep brain stimulation, focal hand dystonia, EMG use in dystonia, diagnosis and history of neurological disorders. You can find more info about participating in any of these studies by visiting this website :

<http://www.centerwatch.com/>

<Http://clinicalconnection.com>

Sent to us from Alice :

<http://articles.mercola.com/sites/current.aspx>

Sweet Misery, A Poisoned World - FDA Aspartame Conspiracy - 6 of 9

September 28, 2007 By Video Clip

Are You Looking For Some Hope & Comfort In A Troubled World?

September 28, 2007 By Video Clip

How Mercury Kills The Brain

September 28, 2007 By Video Clip

Glen's Blog: Glen's Poetry can be found on our Artistic Webpage.

[http://ganolen.wordpress.com/.](http://ganolen.wordpress.com/)

We have passed out over 41k Awareness magnets since Jan 2006. We thank everyone for their help! It could not have been done without you!

Mentor Announces Initial Patient Injections in Phase III Study for PurTox(R) Botulinum Toxin Type A

SANTA BARBARA, Calif.--(BUSINESS WIRE)--July 3, 2007--Mentor Corporation (NYSE:MNT), a leading supplier of medical products for the global aesthetic market, announced today that initial patient enrollment and treatment in its pivotal Phase IIIa study of PurTox(R) for the reduction of glabellar rhytides (frown lines) by intramuscular injection took place on June 29, 2007. ***PurTox is a purified botulinum toxin type A neurotoxin.*** Mentor had previously announced that it received Food and Drug Administration (FDA) approval for its Phase IIIa study protocol and that it anticipated the initiation of this study during its first fiscal quarter.

Joshua H. Levine, President and Chief Executive Officer of Mentor Corporation, commented, "This is a significant step in our long-term growth strategy to expand our presence in facial aesthetic medicine. We believe these Phase III clinical studies will support a successful FDA approval and validate the benefits of a purified toxin." "We are very excited to be participating in the Phase III studies," said Dr. Corey Maas, Principal Investigator and head of The Maas Clinic in San Francisco. "The early results of the safety and efficacy of PurTox demonstrated in the Phase II study are extremely promising as they relate to aesthetic outcomes for our patients."

In addition, **Mentor continues to make substantial progress in its Phase I clinical study for the therapeutic indication of treatment of pain associated with adult onset spasmodic torticollis/cervical dystonia. Multiple cohorts of patients have been treated and follow-up is ongoing.**

Send in your Winter Pics and we'll post them for you !

LIM Updates :

Here is a brief overview of what's been going on with the program.

The LIM campaign has continued its media activities to raise awareness of movement disorders. In 2007, the LIM programs generated 17 million media impressions in print and broadcast outlets. Additionally, this year the program hosted four LIM Movement Disorder Experience Center events, partnering with various hospitals, including the University Hospitals Case Medical Center (Cleveland), University of Minnesota Medical Center, Swedish Medical Center in Seattle and University of South Florida. These exhibits were attended by more than 600 people, including patients, consumers and healthcare professionals, all of whom express appreciation for the event and for the education about movement disorders. As we have done in the past, the LIM and coalition group materials were distributed to all attendees.

As you probably know, if your organization would like media support surrounding an event/activity you should reach out directly to WE MOVE/LIM program. Should you have a need for this service, please email Melissa Gordon at mgordon@ccapr.com. www.life-in-motion.org

Website Stats 2007:

- 2005 Unique Visitors to our Site : 30,521
- 2006 Unique Visitors to our Site : 41,363
- 2007 Unique Visitors thus far (11-11-07) : 51,747
 - Daily Average per day : 142 visitors

Top Countries who visited our Website for 2007 :

United States, Chine, UK, Russian Federation, Germany, Australia, France, NZ, Korea, Japan, Switzerland, South Africa, India, Spain.

Dysphonia Association embarking on a 60k Research Fundraising Campaign. Learn more at www.dysphonia.org. **They have reached the half-way mark !**
Congrats to them !

The U.S. FDA issued a public health advisory to alert healthcare professionals, patients and their caregivers of reports of death and other serious side effects from overdoses of fentanyl in patients using fentanyl transdermal (skin) patches for pain control.

Deaths and overdoses have occurred in patients using both the brand name product Duragesic and the generic product. Some patients and healthcare providers may not

be fully aware of the dangers of this very strong narcotic painkiller. *The directions for using the fentanyl skin patch must be followed exactly to prevent death or other serious side effects from overdosing with fentanyl.*

Read the entire Med Watch safety summary, including links to the public health advisory, healthcare professional and patient information sheets and the drug information page at

<http://www.fda.gov/medwatch/SAFETY/2005/safety05.htm#Fentanyl>.

Source: Med Watch (2007)

Is Something Around ? A Cold ? The Flu ? Dystonia ? Visit www.WhoIsSick.org

DBS Video : http://youtube.com/watch?v=DgVg8X_ChIY

Our Video : <http://www.youtube.com/watch?v=auTIZnbVJSY> Are You at Risk for Dystonia ?

FROM READERS

Beka,

Once again, and forever-more, please know that you are much loved and adored and appreciated for what you have done for dystonia here and elsewhere. Getting this to happen was HUGE, but I know that you already know that. If you can, please share with me, what kind of hate mail would someone send to another who tries only to help those of us suffering from this painful disorder? What could someone think was negative about this kind of interview?? I am beyond understanding...

I personally haven't even heard the interview, but am already sending your note on to those who know of my DRD, hoping they might join in with notes of thanks to Dr. Oz. They do not suffer themselves, but yet do so by proxy. Dystonia affects us all.

Again, thank you so much for all that you do.

...and again, CONGRATS!!!

E (Ellen in Missouri) on the forums

Dear Beka,

You have done nothing, but good for all of us, these idiotic people make me so sad, you definitely deserve and apology from each and every last one of them.

Please know that all of us with a heart do appreciate all that you do.

I know it's upsetting for you but these fools who don't see the good in what's being done here and are harassing you definitely should be so utterly ashamed of themselves, that they don't deserve any help from what you have gone out of your way to do for all of us.

Beka please know that you are appreciated, and respected.
If not for you and what your doing where would all of us with Dystonia be?

A lot more in the dark that's where!

I belong to a couple of different ST Dystonia groups via internet, magazines and e-mail and we should all be working together it is absolutely ridiculous that there is any type of animosity going on here.

So come on people, where is the common sense. Have they lost their minds along with having a crooked neck, give me a break here?

We are all in the same boat, we all hurt, we all get the embarrassing stares, and we all have had our lives changed.

These fools who have the unmitigated gall to harass you, need to just stand back open their tiny little brains and look at all the wonderful things you are doing for all of us.

Sorry but this makes me so angry at their stupidity, please don't let the bad apples spoil the whole barrel; you are an angel to the rest of us.

You take care, and from the bottom of my heart thank you for all you do.

Elaine Larson
Benefits/Workers' Compensation

www.myobloc.com

www.care4dystonia.org for NT201 Toxin info

Excessive Botox Use Cause for Concern

http://www.bottomlinesecrets.com/blpnet/article.html?article_id=43609

Hi Beka:

You are one of the best things that has happened to Dystonia. I cannot thank you enough for getting DR OZ involved with our disorder, it will give Dystonia some awareness that has been way too long in coming. DR OZ has a lot of credibility with the public. As far as the negative Emails you have been getting you certainly don't deserve it, so don't let it bother you. I think you're sweet as sugar for what you're doing and you certainly have my support.

My Very Best
Tony

Have We made a Difference in Your Life ? Someones' ?

As a dystonia organization/nonprofit we have never gone to our newsletter subscribers or others to ask them to consider making a difference in Care4Dystonia, Inc. C4D has always somehow sustained itself through the salary of our Founder. We have no paid staff or space. Yet, this year has been a year of major milestones for us.

Our major media milestone has been securing Dr. Mehmet Oz, MD to publicize dystonia for us and on behalf of those with dystonia to 6 million listeners on "Oprah and Friends " XM Radio.
Other milestones include :

- Launch of our new successful website with total unique visitors reaching over 51,000 as of the mailing of this email.
- Our Founder, Beka as an NP with a Masters degree, absolutely , continually answers every single email herself whether it be while working in the CTICU at Columbia at 3am or 3pm on a sunny afternoon. We do not believe in leaving patients in distress, without correct guidance or direction towards proper care and diagnosis.
- Dr. Michael G. Kaplitt, MD, PhD became our scientific advisor and has been promoting our Cosmo Awareness Program at Weill-Cornell.
- Over 41k Awareness Dystonia Magnets have been distributed worldwide.
- A new Dystonia video is now online and on YouTube.
- The Book " I'm Moving Two " has become a bestseller in independent book publishing with sales being returned to C4D 100 %.
- Growing list of Your Stories **online**
- Valuable Newsletter with over 15k subscribers
- O-Magazine has been captured for 2008.

Additional Milestones can be found listed on our website !

Your voluntary donation will enable us to assist those affected by dystonia ensuring proper diagnosis and treatment such that in the long run science will lead to a CURE. Let Dystonia Speak! The time to act is now. Get involved. Support Care4Dystonia today! If you believe in our activities and recognize them as being vital to dystonia, please consider making a Gift to us this year- 2007. Click here for our [Simple Donation Form](#) (PDF format)

To make a donation to Care4Dystonia, Inc., preferable by check (US Dollars, Euros accepted), please mail your contribution to:
 Care4Dystonia, Inc.c/o Serdans
 Suite 4F
 440 East 78th Street
 New York, NY 10075 USA

Care4Dystonia, Inc. is a nonprofit corporation. All donations are tax-deductible per US NonProfit 501c3 Status Laws. **Give Today !!**

View our Website for the BEST info from Addiction to dealing with Pain relief and other issues. Day to Day Tools for Living with Dystonia.

- 2007 ST Quality of Life Survey Highlights :
 76.9 % Female, 23.1 % Male
Average age of ST onset : 40 to 49
Pure Rotational Torticollis most common form
Least common form Retrocollis
First Sign or Symptoms at Onset : Involuntary turning , followed by PAIN
The Most bothersome symptoms is PAIN (43.5 %)
Pain most described as Continuous, Steady, Constant
47 % have associated limb dystonia such as writers' cramp, dysphasia follows this sx
37.7 % are social drinkers 1-2 drinks per day
14.6 % drink alcohol to relieve their symptoms
39.9 % do not feel that a cure will occur in their lifetime

Over 25 % are tired of waiting for a cure
Overall quality of life is factored as " Fair "
43% are no longer able to maintain their former lifestyle or hobbies.
Suicidal ideation +++++
Social isolation is felt by over 66 % of the participants (n= 169)
Close to 10 % no longer seek neurology care or ST treatment
Educational literature present in medical offices - not seen 63 % of centers
Overwhelming response - if educational sessions were offered would you attend - Yes >76 %, greater if the instructor had dystonia themselves
Interactive Education modules via a computer or DVD use +++++ (cost and ease of use an issue)
Transportation key issue to attending a Support groups
Support groups are no longer of importance :
Due ties with Fundraising (DMRF contracts)
Lack of attendance-time
Lack of quality speakers
Too much time and effort to organize
Disinterest- finding speakers
Lack of transportation and Location

Copyright. C4D 2007. Survey Results cannot be used without permission by C4D. CONTENT LIFTING PROHIBITED.

FINAL THOUGHTS: We recognize the amount of information that is available and needs to be conveyed to all of you. We hope that you will recognize this issue as a start of that – New Horizons! Best Wishes for the Holiday Season and Upcoming New Year! ~ beka of C4D

Medical Disclaimer: The information contained in this Web Site is for informational and educational purposes only. While it is based on professional advice, published experience, and expert opinion, it does not represent a therapeutic recommendation or prescription. C4D urges you to consult and obtain medical advice from a licensed, trained, and competent medical provider. Any decision to use a healthcare professional-medical care center-clinic listed on this Website is the sole responsibility of the patient-reader-user. Care4Dystonia is not liable for healthcare choices, decisions or possible-actual consequences of medical or surgical therapies made, sought or obtained by patients and others affected by any form of dystonia.

Copyright © All Rights Reserved 2006-7. C4D.