

In Motion

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www.tremoraction.org

Welcome to *In Motion* !

Welcome to the April issue of In Motion. This issue is focused on Deep Brain stimulation, questions you should be asking about DBS, the FDA Adverse Effects, a new form of Yoga and Tai Chi and lots of news, and updates along with links to usable information. I hope you find this issue of value. Please forward it to your Support group members and others ! Share ! – beka, RN, MS, NP

Laughter and My Dance with Dystonia :

My dance with dystonia began fourteen years ago when I first learned I have spasmodic torticollis. For me, it all began with the *Twist* – an uncontrollable pulling of my head to the left. I received botox injections at the time of diagnosis, which eased the involuntary muscle contractions. I felt grateful. I was not in pain and was able to continue with my day to day life of raising three young sons, completing my bachelor's degree, teaching early education in a Montessori setting, and learning all I could about this obtrusive disorder that few had ever heard of, with no known cause, and no current cure.

I have wondered if dystonia is a reflection of genetics, trauma, stress or all of the above. Hereditary predisposition? My family tree consists of a variety of *movers and shakers* dating back to my grandmother, my mother, and now my aunt who was diagnosed last year with Parkinson's disease. Physical trauma? I have wondered about the swing set that fell on my head at the age of six. I have experienced essential tremors in my hands as early as the age of seven. Stress? Yes, we all deal with varying levels of stress on a daily basis. However, it was not until the loss of four family members in a close period of time, including my father passing of cancer two days before our third son was born, that I felt the pull of life changing.

Remember doing the *Jerk*? Now I am truly dating myself, indeed, back to the sixties. At this time, however, the *Jerk* is the dystonic tremor in my head. I remember a day of shopping. I was feeling well, thinking I was doing just fine, when a young child shopping with her mother shouted out, "Mom, why does that lady's head shake like that?" The mother of the child was obviously embarrassed and rushed away. I wanted to chase after her and say, "Hey, the child asked a good question. Please, let me answer it!" You see, I will do almost anything for a little understanding! I have done much since that day and look forward to the day of greater public awareness. I applaud Beka for all she is doing with such grace and compassion.

I am fortunate to have a loving family, supportive friends, knowledgeable doctors, and informed physical therapists...and I know I am on a spiritual journey. So begins the *Waltz* with the Spirit of God as my partner. I have experienced the loneliness of a dark night and the pain in silent moments. I have released certain ideas about my life and embraced others by taking them in hand, drawing them close, and taking one step at a time. As I can no longer ski, I snowshoe. As I can no longer teach, I volunteer. As I can no longer do it all, I ask for help as needed. In releasing one aspect of my life,

Category of Links

Make a Voluntary Donation

Oral Med Side-Effect Chart

Physical Therapy webpage

Kids in Motion

The Dr. Oz webpage

Moving Series Online

New Cosmo Awareness Movie

New DBS Brochures now available

Magnets continue to be available

Updated Blogs by persons with movement disorders on our Artistic page !

Dystonia screensavers can be found on our Media Page !

Alice Cooper promotes Dystonia and Essential Tremor !

Submit Your Stories for our June Issue.

Next Issue : RN battles Neurologists

Tips on Managing with DyT1 dystonia and Disability Views

And.....?

space is created for the enhancement of other aspects of my life. Pleasure can be found within the experience of them all. Once I accepted myself as all that I am, dystonia became the danseuse. So I move ahead and find comfort in knowing that in quiet moments of solitude, I am never truly alone, and even in pain there can be joy. Joy lies in the gift of choice. I choose to believe, to have faith in purpose, and to take full responsibility for my happiness and healing. I choose to thoughtfully, persistently, with aplomb continue to *rock-n-roll* to my individual beat of dolor and joy.

One way of experiencing conscious joy is practicing and teaching laughter yoga. Laughter yoga involves simple, playful exercises to promote laughter for medicinal benefits while utilizing yoga breathing techniques. Laughter Yoga began in 1995 when Dr. Madan Kataria, a family physician in Bombay, India, was writing an article, "Laughter – The Best Medicine", for his monthly health magazine. His desk research led him to discover an overwhelming body of scientific literature that described, in great length, the proven benefits of laughter on the human mind and body. In particular, he was very impressed by American journalist Norman Cousins' book, Anatomy of an Illness, and the research of Dr. Lee Berk of Loma Linda University. Dr. Kataria decided to field-test the impact of laughter on himself and his patients. What started out as a study of five has grown to over five thousand laughter yoga clubs all over the world. Laughter is good medicine for many good reasons. It strengthens the immune system and releases endorphins that can ease muscular spasms of the body, to name just a few. To learn more about the benefits of laughter or to find a group near you, please check out www.laughteryoga.org.

Souza wrote, "Dance as though no one is watching you". For all of us with dystonia, may our dance be light, even as others are watching.
Sharon Hampton, Certified Laughter Yoga Instructor

Sharon Working in Mexico !



Building in Mexico

Next Pic – Sharon at Work !



My Theory on Dystonia :

My experience with Dystonia is very different than anyone else seemingly. Mine developed about 9 months after having Bell's Palsy, (my 7th cranial nerve was damaged by an attack of the herpes virus and regrew incorrectly - aberrant regrowth of the nerve). It started in 1997 with my eyebrows jumping up and down and my right eye involuntarily closing, it has since spread all over my body. After realizing that Western Medicine did not offer a suitable answer for me, my wife (a career RN) and I tried many forms of alternative medicine looking for answers. None of that (chiro, acupuncture, holistic, therapeutic touch, etc., etc.) was much help either. Where we did finally have some success was using science. We decided to go in that direction after observing that my spasms seemed to be caused or intensified by "electrical things" such as fluorescent lights, electric ovens, vacuum cleaners, etc. etc. We figured maybe if we approached that aspect from a scientific point of view we might make some progress. Working with electrical engineers, we developed 2 methods of getting relief from spasms. The first was using a concept in physics called a Faraday Cage to create an energy-free environment in which my spasms disappear. Attached are pictures of a home-made version I use and a professionally built model that I own and have used in the past. Here's a link to info on the professionally built model - <http://www.ets-lindgren.com/page/?i=DEI-Screen>. So I then had a way of getting total relief any time I wanted, and that changed everything.

The second was to use a frequency generator to set up an electric field across my body which will, in many (not all) environments, control the spasms. That method is not foolproof, works 50-70% percent of the time, so it's not perfect, but it does allow me to go many places and do many things that I would not otherwise be able to do. The generator fits in my pocket and the selected frequency travels down 2 wires that I attach my pants pockets on either side. Here's a link to the model I'm using - <http://www.testequipmentdepot.com/bk-precision/signal-generators/3001.htm?gclid=CPnZsMWEspECFQL4gAod4jr2MQ>.

The concept is really pretty similar to DBS, except that the signal is constant rather than pulsed and is not directed at a specific target area. It doesn't require brain surgery or anything implanted in the body, so it's non-invasive. Unfortunately, I haven't been able to get either the DMRF or BEBRF to look into either of my methods to see if they might have some benefit for other patients. Even more importantly, other patients don't seem to have any interest in the ideas either, which I can't quite figure out. Maybe if I put together a decent website, I can generate more interest in these methods that work for me.

Contact Us

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Editor : Beka

The other thing that I always recommend that patients consider is removing the metal fillings from their mouth. That made a HUGE difference for me. At a later time, I'll share my thoughts on why I think that's important, I've given you enough info here to chew on for awhile.

More Thoughts from Tom :

Hi Beka,

I can address your observation that "the more stimuli I get, the worse I get".

But first we need to define "stimuli". I'll assume it means activity that your senses (sight, sound, smell, touch) are aware of. So for example, if I was in the middle of a large grassy field, surrounded by a lot of barking dogs, children running around screaming, a battery powered boom-box blaring loud music, etc., you would say that there were "a lot of stimuli". If I were in a busy airport with tons of people moving around, intercoms announcing flights, etc., you would say that there were a lot of stimuli. However, for me, my condition would be completely different in the airport than out in the field, I would have all kinds of spasms in the airport and I would have no spasms in the field. Why? Because none of the stimuli in the field involve any electrical energy (other than the battery powered boom-box, which would emit a very small field), whereas the airport has all kinds of energy emanating from any restaurant equipment, lighting systems, security screening equipment, luggage conveyor belts, radar, etc., etc.

So although both locations involve lots of "stimuli", only the stimuli involving electrical energy would have any impact on me. So I would theorize that the same might indeed be true for you, that it is not simply "more stimuli", but the type of stimuli that really makes the difference.

One of the frustrating issues for me with the Blepharospasm people is that approximately 50% of them have concluded that fluorescent lights aggravate their eye spasms much more than other lighting systems, such as incandescent or halogen. The assumption is always that it is because they are "so bright". My own experience is that fluorescent lights can cause me to have terrible eye spasms regardless of whether I can even see the light or not, which means that brightness has nothing to do with it. It is well known in industry that fluorescent lighting systems emit non-visible energy frequencies that can interfere with the proper flow of data down a cable. Therefore I don't think it's a stretch to assume that they could also interfere with the proper flow of data in a neurological system, particularly one like mine that has been impaired. So in that case, others assume that the negative "stimuli" is the brightness of the light, whereas I would say that the negative stimuli is the non-visible frequencies emanating from the system. So it's important not only to recognize a stimuli, but to determine what aspect of that stimuli is really the issue.

Another example would be "loud noises". Many blepharospasm and dystonia patients will make the statement that "loud noises" set off their spasms. But what I always want to know is, what is the source of the loud noise? I never react to sound coming out of my TV or stereo, no matter how loud it is. I can listen to organs on my stereo at very loud levels and never react to it. But put me near an electric organ and my body goes crazy. The sound is the same, the volume is no different, but the way the sound is created is completely different, and is what determines whether I react to it or not.

Since you probably have some good medical connections, one interesting experiment you might want to try would be to go inside a shielded MRI room with all the MRI equipment and everything else possible shut down and compare your condition in there with your condition in the rest of the hospital or imaging center. An MRI room is a shielded room usually made of solid copper. The concept is the same as the screen

room I sent you the info on, it just uses solid metal instead of screen. With nothing running inside the room, it is essentially an energy free zone. You might be surprised at how significant the difference in your condition is inside the room vs. outside. Then again, there may be no difference at all, who knows, but that would be one way you could easily test one of my theories to see if it applies to your situation.

You are also welcome at any time to come to my house in Sarasota, FL and try my screen room here !

That's all for now. Glad to know you are putting some thoughts into my ideas rather than just dismissing them, as many other smart people with a background in the medical industry have done, in spite of the fact that everything I am talking about is based on fairly basic concepts in science and physics.

TomSpasm from the BBs, Florida.

Beka's Update on her DBS - Part 3:

Inside DBS: The Real Deal

Well, the last time I wrote to you about my experiences with DBS was in 2005 and 2006 for Dystonia, Inc. I've now passed my 3rd year anniversary, 2007, a year filled with chaotic, chilling and unexpected but indecisive emotions, along with social and physical changes. To be honest, many of you have written asking "How are you?", yet I have been somewhat reluctant in answering many of your questions pertaining to DBS. This is primarily because I haven't wanted to dash hopes and dreams about DBS being a potential treatment for **all** persons with dystonia, but truthfully there are no guarantees or set rules and outcomes to the procedure. But, as a nurse, and, now nurse practitioner, reviewing the Nurses' Code of Ethics I have to be honest and truthful. You will read about events that you don't want to hear, emotions that you did not expect, and coping with disabilities from me : some of which may not have been expected. But I'm not as strong as everyone thinks or has concluded! I too am a patient with dystonia just like who those who are reading this Part 3 of " Beka's DBS Journey ".

The day after surgery, Dec 31, 2004, I woke up with a stiff neck due to the heaviness of the Halo frame that had tied me down to the Operating Room table for 12 hours. Yet, there was no occipital, ripping or searing "back of the head" pain, and I recall thinking "this is really spectacular". I can live normally, and so I did for the first 6 months after DBS surgery with programming beginning 2 weeks after my stitches were removed and cerebral (brain) swelling had resolved. I looked normal, typical, natural, and ordinary, just like every other person on NYC streets (But in truth, who really looks normal in NYC!!). No one could tell that I had a movement disorder, so my neurosurgeon, Dr. Mike and I went to work and garnered even more media coverage with NBC, CBS, and Nursing Journals on a national level. Life was good. I felt good, decent, blameless, and worthy.

Yet, as time went by, programming became more difficult and time-consuming. Finding those right, "optimal" settings became tricky, complex, difficult, and would cause many side-effects including leg dragging, loss of speech, hoarseness, loss of verbal understanding (expressive aphasia that is seen in stroke patients), gait difficulties, and tingling of the limbs (paresthesias) during the 30-90 minute sessions. Dr. Mike and I continued to try and find the right settings, and with time we eventually did in late 2006. But it was a tiring, strenuous, exhausting, wearing, laborious, and arduous time. Anyone not expecting this during programming is being unrealistic about this process. Worrying about the Halo Frame and loss of hair is meager compared to the

aftermath of DBS Surgery.

At times I wanted to give up. There was also something else that was occurring each time settings changes were made by early 2007 - signs of depression would develop about a week after DBS reprogramming. Suicidal thoughts came about – it was almost as if a key was being switched on and off in my brain that controlled these emotions. I landed in a psychiatrist's office - one who had no idea what DBS was or how it worked. But research was coming out reporting cognitive changes in patients with DBS. The antidepressant Zoloft was tried for 30 days, followed by Effexor XR, even though I knew of the risk the drug had with the possibility of worsening my Dystonia. It was a risk I had to take. Two choices - medication therapy or jumping into the East River. I developed an obsession with the East River, and was constantly being saved by Dr. Mike's telephone calls. The East River obsession was one that I rarely shared with colleagues, family or even friends including others with dystonia. After all , what was I going to say to others with dystonia- would they understand ?

Feelings of darkness, hopelessness, doom, gloom, and despair continued for several months in 2007. My mother called to check on me practically everyday for months. My younger sister had moved to LA, California; thus family support existed overseas or a long 7 hour drive away. I was disappointed that programming was now an ongoing issue. Then BOOM! We found the right settings and for 9 months I was able to work solely in the Open Heart Unit with Dr. Mehmet Oz, MD, without any programming at all. Ahh- life was good again. My mood improved as I worked and traveled. I rode a bicycle twice in Aruba, although I once steered into a vehicle, in the process ripping up my knee. Yet without thinking, I recall jumping into the Atlantic Ocean off the coast of Aruba with a bloody knee, not realizing that I was likely to attract sharks!

By September 2007, I really had no complaints except those associated with the current nursing shortage, which was reaching a crisis level. I felt stagnate and burned-out in my job. It had been a long, rocky, and winding road. Soon I began to hear from nursing colleagues that DBS had changed me, tweaked my brain in the process, and somehow altered my personality. What could I do? Had I really changed personality-wise? I really can't tell you if this is true or not today. Physically, the feelings of doom had left me with immense weight loss – I was down to 110 pounds, at a height of 5'8"! Some said that I was now perfect for walking down a runway as a fashion model. Foolish!!!

Effexor XR was slowly tapered, which led to an increase in dystonia symptoms, pain, sensory tricks, and DBS headaches. Klonopin became the drug of choice for me again. Difficulties walking again became routine, and crossing NYC streets without being hit by a yellow cabby became a risk. Planning life became a routine again. Sleeping on ice packs to diminish the pain became a norm. Heat did nothing for me. I had to bring a soft cervical collar back out of the closet. In reality, Dystonia had been waxing and waning for the past year, yet everyone else with dystonia wanted to desperately know "how well DBS was working for me?". I would really limit my answers in my return emails. I desperately wanted DBS to last and I tried to ignore the return of symptoms.

After all, I had not experienced any lead breakages, wire breaks, lead migration, infections, or battery changes. Yet, by late 2007 and early 2008 with each programming session, we noticed that I required less and less voltages to obtain sensitization to the settings. In fact, 1.5 volts was as high as we could now go without inducing horrible side effects, "electrical-like jolts", which was surprising considering that at the start of surgery I had begun at 3.5-3.7 volts bilaterally. Scientific papers were now describing the loss of optimal DBS effects occurring between years 3 and 5 for all 3

disorders – Parkinson's, Tremor, and Dystonia. This was utterly disappointing, a loss, defeat, failure, and 100 % unexpected. Twisting returned along with a diagnosis of Thoracic 6 thru 10 disc degeneration and fractures. Back pain!

As I read the book "Neurotic Adventures of a Law Student", I was forced to face the fact that there was a very good possibility that DBS might not last as long as my battery would. I had faced the "Neurotic Adventures of DBS", but failure had never been in the picture. Nor had I even been told that failure was a possibility. So, what now? My last programming session resulted in two high jolt-like electrical shocks. I thought I had been electrocuted! I recall leaving the office, finding myself in a cereal aisle of a local bodega, crawling into bed and not waking up for 26 hours. You could say I got plenty of sleep. I suspected I had experienced a sub-clinical seizure of some sort since I had no recall of being in the supermarket. Generally, having brain fatigue and brain fog is not an uncommon experience after a programming session. This was in November 2007. We have not programmed me since that time relying on oral medications and botulinum toxin type B- MyoBloc.

There was also something else Dr. Mike and I had observed over the last year that had to do with electromagnetic forces. I had worked in settings that contained an immense amount of electrical equipment and outlets, especially the Open Heart Unit where caring for a patient with an "artificial heart " was the norm. Physical electrical forces in each of the other 4 ICUs I worked in were completely different, and each affected me and altered my settings, thus bringing about a return of symptoms over time. This phenomenon too was unexpected. But, it is something to take notice of today.

As I finish this portion of my journey, I want to reiterate that each person's journey with DBS is different. What I have experienced is not what YOU may experience. There is no-cookie cutter recipe for DBS or dystonia today. But you need to be aware that programming is the greatest problematic issue that goes along with the procedure. Anyone telling you otherwise is minimizing this problem. You will have "highs and lows". DBS will not be a "cure" for your symptoms. Also, be aware that you may require new and old meds to manage certain cognitive, physical and emotional effects. Socially, life can improve to a certain extent, but unreasonably high expectations can be detrimental, especially when dystonic symptom breakthroughs can occur at anytime. Physical adjustments include simply feeling comfortable, and developing an inner sense of peace with an implantable device within the physical environment - your workplace, area of leisure etc. It took about 2.5 years for me to feel safe and fearless with the device and this new hardware in my brain that could go awry at anytime. I also have learned to avoid certain environments along with the strength and impact of electromagnetic fields on my individual settings. I don't use a cellphone. Ipods and Walkmans are out of the question for me. What lies ahead I'm not so sure - a rechargeable battery? I'd rather have programming improvements, which actually leads me to wonder about the Advanced NeuroStimulator created by the "other DBS company " found on www.ans-medical.com.

In a matter of speaking , DBS is still in its scientific infancy phase. An abundance of long-term research studies do not exist, yet I'm sure due to the costs related to DBS, these studies will be required by Health Insurance companies for coverage of this Humanitarian Aid Device; it is not yet FDA-approved for dystonia. I think for now I have given enough "food for thought" and I thank Dystonia, Inc. for allowing me to openly write about MY experiences with DBS. Parts 1 and 2 of my Journey can be read on the www.spasmodictorticollis.org website under the "treatment center " icon. I realize that some of you may have hoped for a happier outcome, but I have been forthcoming and honest in telling you MY story with DBS. Become Educated about the procedure !

About Our Sponsor :

We are extremely grateful for the support of Solstice Neurosciences, Inc. and Mentor Corp. 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.

But remember to Take One Day at a Time. New Adventures Await you each day.

Links : www.parasphotography.com/beka.html DBS Foto Essay

Part 1 – Beka’s Journey at

http://www.spasmodictorticollis.org/treatmentCenter_DBSBeka.cfm

Part 2 – DBS Revisited

http://www.spasmodictorticollis.org/treatmentCenter_DBSDBSRevisited.cfm

Both Parts 1 and 2 can now also be found on the DBS webpage of

www.care4dystonia.org

Top 55 DBS Questions : Don’t go Empty-handed before a DBS Evaluation

What to ask about DBS- the procedure :

1. What is Deep Brain Stimulation ? Can you explain it to me in simple non-medical terms ?
2. Do you have a sample model of the device and hardware to show me ?
3. Is there an age limit to having DBS ? How old has the oldest-youngest persons been that you have operated on – what were their outcomes ??
4. What are the risks involved in DBS ? Percentages ?
5. What are your infection-hemorrhage-stroke- rates ?
6. What precautions do you use post-operatively to minimize the risk of infections ?
7. How long will the procedure be ? (Ask about time, etc.)
8. Will I be awake during the procedure ? (until the IPG placement)
9. What are the risks associated with general anesthesia ?
10. If the procedure will be performed with me being awake, what sedative medications (ie. Versed, Fentanyl, Valium etc.) will be used ?
11. What anti-emetics (anti-nausea ie. Zofran) will be used in the Recovery Room ?
12. Will pain medications be available to me after the procedure ? If so, what ?
13. When is the pre-DBS MRI performed ? Under controlled sedation ?
14. When is the post-CT Scan of the head performed after the procedure ?
15. Which device would be better for me – the Soletra or Kinetra ?
16. How visible will the IPG be ?
17. What is the battery life for the Soletra ? Kinetra ?
18. Will the leads be placed bilaterally and where ? STN area ? GPI ? Thalamus ? Or a combination of those areas ?
19. Where do you place the IPG – subclavicular area , abdomen ?
20. Please explain the micro-lesioning effect ? How will that affect me post-operatively ? How long does this effect last ?
21. What will the length of my hospital stay be ? 24 hours or more ?

22. How many incisions will I have ? How do I care for them when discharged from the hospital ? What are signs of infection ? Staphylococcus ? Redness ? Discharge ? When can I remove the dressings ?
23.

This information has now been formatted into a readable, informative tri-fold brochure. Contact us if you would like free copies of the brochure.

Linda's Story - OMD :

March 2006, that's when I was diagnosed with oromandibular dystonia but the symptoms started several months earlier. I noticed that I was having some difficulty with forming words clearly and thought that I was becoming lazy with my diction. I searched the internet for examples of alliterations that I could say aloud and went on numerous speech therapy websites. At the time I was Manager of an Intensive Care Unit and needed to speak clearly as I was often conducting meetings, meeting with staff, interviewing recruits and various other tasks that required me to speak clearly. I noticed at first that if I chewed gum or had a candy in my mouth my speech was clearer and although I have hated chewing gum all my life I resorted to it. It was embarrassing to conduct a meeting with gum or candy in my mouth. (These tricks were only temporary and no longer worked when my dystonia progressed.)

In desperation I called my family physician to let her know that I was having trouble speaking. She asked me to go to the Emergency department at the hospital as she thought I was having some symptoms of a stroke. In the Emergency my blood pressure was elevated and at first they did think I had a stroke. I had a CT scan which was inconclusive but did suggest an area near the basal ganglia that may be a stroke. I followed up with an MRI which was normal. I saw a Neurologist in March and after a series of tests to rule out numerous diseases a diagnosis of Oromandibular Dystonia was made. Since then I have had to give up my position of ICU Manager as my dystonia progressed making speech inaudible and I was having facial grimacing and excessive tongue movement. At the time a secretary working on my unit was diagnosed with cancer and seeing her go through chemotherapy, surgery and eventually death made me keep my diagnosis of dystonia in perspective.

Although inconvenient, annoying, frustrating, and often embarrassing dystonia was not going to kill me and it is something that you can live with. I have been prescribed numerous medications to help alleviate the symptoms of my dystonia but unfortunately due to side effects have been unable to tolerate them. Currently I am taking a very small dose of Tetrabenazine and have had two series of botox injections. In October 2007 I had 10 milligrams injected into my tongue and last week (Jan. 2008) had 10 milligrams injected into my tongue and 45 milligrams injected into both sides of my jaw. I do think that my speech is clearer since the injection and that makes me happy. It is just unfortunate that the effects only last about 3 months and then I will have to go for further treatments. Along with the meds and botox I go for a facial massage every two weeks, and have started some physiotherapy on my neck and face as well as some acupuncture.

I have been truly blessed with a loving, supportive family, great friends and co-workers who have made living with this disease possible. When my speech is garbled they just continue on with conversations as if they understood everything I said. When I have excessive facial movements and my tongue protrudes they just wait until I am over the spasm and continue on the conversation.

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 over 42k of them since 2006.

Perhaps they will come up with a cure for dystonia in my lifetime and if they do I, as well as millions of others, will be eternally grateful. Until they do I live with my dystonia a day at a time.

Linda P., RN

ADA Disability and “Asking for Accommodation” ?

What do you do if your Employer refuses to Accommodate you and your disability ?

The Americans with Disabilities Act (ADA), along with its regulations, is a complex and detailed federal law. A full discussion of your “loaded questions” is beyond the scope of this column, but I can make some general comments. It might be helpful for you to search for past Brent’s Law columns for other information and general responses to previously submitted ADA questions.

It would also be helpful for you to review a document, Enforcement Guidance: Reasonable Accommodation and Undue Hardship under the Americans With Disabilities Act (2002), available at www.eeoc.gov/policy/docs/accomodation.html. The document clarifies the rights and responsibilities of employers and individuals with disabilities regarding the issues of reasonable accommodation and the concept of undue hardship (for the employer).

For example, the document categorizes the three types of reasonable accommodation, one of which is a modification or adjustment to the work environment, or the manner or circumstances under which the position held or applied for is customarily performed, that would enable the qualified individual with a disability to perform the essential functions of the position. Such adjustments might include job restructuring or acquiring or modifying equipment. The touchstone of “reasonable” accommodation, according to the Guidance Document, is that it is “feasible” or “plausible.” Moreover, the individual with a disability must inform the employer that an accommodation is needed.

The only statutory way an employer cannot provide a reasonable accommodation for a qualified individual if it would cause “undue hardship” to the employer. This term is defined as a significant difficulty or a significant expense. The Equal Employment Opportunity Commission makes such determinations on a case-by-case basis.

If you believe you have not been reasonably accommodated in your workplace, you should consult with a nurse attorney or attorney in your state who works with employees and is familiar with this federal law. He or she can explain your specific rights in your specific situation concerning a reasonable accommodation, and, if not provided, remedies under the act. ~ Carol Brent, RN JD, Nursing Spectrum 2008

To file a Disability ADA Claim against an Employer visit www.eeoc.gov

FDA Device Approval :

On June 26, 1996, FDA issued a final rule to carry out provisions of the Safe Medical Devices Act of 1990 regarding humanitarian use devices (HUDs). This regulation became effective on October 24, 1996. **An HUD is a device that is intended to benefit patients by treating or diagnosing a disease or condition that affects fewer than 4,000 individuals in the United States per year.** A device manufacturer's research and development costs could exceed its market returns for diseases or conditions affecting small patient populations. FDA, therefore, developed and published

this regulation to provide an incentive for the development of devices for use in the treatment or diagnosis of diseases affecting these populations.

The DBS device for Dystonia is listed on the webpage below. Please become informed.

The regulation provides for the submission of a humanitarian device exemption (HDE) application, whichMore info can be read at :

<http://www.accessdata.fda.gov/scripts/cdrh/cfdocs/cfHDE/HDEInformation.cfm>

FDA Newsletter : <http://www.fda.gov/cdrh/fdaandyou/index.html>

What is an Adverse Event ?

An adverse event is any undesirable experience associated with the use of a medical product in a patient. The **event is SERIOUS** and should be reported when the patient outcome is:

Death

Report if the patient's death is suspected as being a direct outcome of the adverse event.

Life-Threatening

Report if the patient was at substantial risk of dying at the time of the adverse event or it is suspected that the use or continued use of the product would result in the patient's death.

Examples: Pacemaker failure; gastrointestinal hemorrhage; bone marrow suppression; infusion pump failure which permits uncontrolled free flow resulting in excessive drug dosing such as in an Insulin pump.

Hospitalization (initial or prolonged)

Report if admission to the hospital or prolongation of a hospital stay results because of the adverse event.

Examples: Anaphylaxis; pseudomembranous colitis; or bleeding causing or prolonging hospitalization. (Now reportable to the Joint Commission)

Disability

Report if the adverse event resulted in a significant, persistent, or permanent change, impairment, damage or disruption in the patient's body function/structure, physical activities or quality of life.

Examples: Cerebrovascular accident (stroke) due to drug-induced hypercoagulability; toxicity; peripheral neuropathy.

Congenital Anomaly

Report if there are suspicions that exposure to a medical product prior to conception or

during pregnancy resulted in an adverse outcome in the child.

Examples: Vaginal cancer in female offspring from diethylstilbestrol during pregnancy; malformation in the offspring caused by thalidomide.

Requires Intervention to Prevent Permanent Impairment or Damage

Report if you suspect that the use of a medical product may result in a condition which required medical or surgical intervention to preclude permanent impairment or damage to a patient.

Examples: Acetaminophen overdose-induced hepatotoxicity (toxic liver) requiring treatment with acetylcysteine (Mucomyst) to prevent permanent damage; burns from radiation equipment requiring drug therapy; breakage of a screw requiring replacement of hardware to prevent mal-union of a fractured long bone.

Source : www.fda.gov

You must remember that many patients taking drugs etc. often have multiple illnesses and other health problems, thus one always has to take into account the entire clinical picture of the patient. They may have other problems that can lead to any of the above events as well. Therefore, be careful in assuming the worst when reading an FDA Adverse event or a research report about such an event.

The Other “DBS Company “:

Advanced Neuromodulation Systems, Inc. (ANS), the company sponsoring this clinical trial, is the technology leader in implantable neurostimulation therapies. ANS has nearly 20 years of experience, numerous technological firsts, multiple awards for excellence in product design and business, and more than 25,000 patients in over 25 countries with similar ANS neurostimulators for chronic pain management. ANS’ goal is to improve the lives of the millions of people around the world who suffer with disabling pain or nervous system disorders. To learn more about ANS, visit www.ans-medical.com.

Visit www.poweroverET.com

Visit www.poweroverPD.com

Dystonia will be undergoing clinical trials as well in the near future by ANS.

Letters To Dr. Oz :

Dear Dr. Oz,

The last few years of my life were like a nightmare. The smallest amount of exercise or stress or even stretching upon waking in the morning would set the muscles of my feet pulling my toes into unbearably painful positions, my feet would curl and twist and my legs and back would flex until it felt as if my bones were breaking. One night I was awakened by a headache and accidentally stretched a leg and instead of stopping at my lower back, the uncontrollable spasming and pain crawled all the way up to my head and face. Sitting in the recliner chair I was forced to sleep in, I was bent into a back-bend from which I could not move, screaming in agony, my head pinned to the back of my shoulders. I spent 6 hours like this before I allowed my husband to take me to the ER where I was told I was a drug seeker. The spasms were treated but I was left

writhing in the bed in agony for another 10 hrs from the severe migraine that had awakened me the night before. Scared to death because twice a drug test showed the presence of barbiturates which I had never taken, I went home tagged as a drug seeker and horrified at what had happened. I learned later that the medication the doctor gave me caused the positive barbiturate test, but that tag remains. An MRI later showed 3 herniated discs in my neck. While in the hospital for an unrelated surgery, I again had an episode in the presence of doctors and nurses. It wasn't until another year passed that the continuing uncontrollable spasms and pain were diagnosed and I began treatment with a tiny yellow pill. This tiny yellow pill which contained levodopa and carbidopa changed my life. Further treatment with B vitamins from a malabsorption issue has made even more of a difference.

My life today is liveable because I finally got that diagnosis. I will not be defined by dystonia, but I have learned how to live with it. I am more creative because I must think outside of the box to get thru the day. I cannot do the things I used to do like riding my beautiful champion Arabian horses, but I can go into their stalls at night and listen to them nicker, feel their warm breath and the tickle of a whisker on the back of my neck and feel content. When I see the fields beyond my house sparkling with billions of tiny green lights in the summer, I awaken my children at midnight so they too can experience the wonder of the flight of masses of fireflies, lighting the pasture like daybreak. Dystonia gives me great pain, but it also gives me this, and I am richer for it.

Dr. Oz, I had seen too many doctors to begin counting, over several years before my Dystonia was diagnosed. I was told everything from epilepsy to a psychiatric disorder and forced to live with this for years, and I am not alone. **Thank you Dr. Oz** for doing this upcoming show on Dystonia. There are so many people who have gone mis-diagnosed or un-diagnosed, and you are giving them hope... *Hope to begin trying again to live the life that they had dreamed of living before dystonia reduced them to people just struggling to survive.*

Gratefully and Warmly Yours,
Ellen Schnakenberg

A Note From Beka :

As we moved into this new Oz media venture, I would like to sincerely thank the many supporters of dystonia and this newsletter to include: Allergan, Inc.; Solstice Neurosciences, Inc.; Medtronic, Inc.; We Move; Dystonia Association of Kentucky; and Tyler's Hope.

I have reviewed everyone's comments from the 10 minute/10 Question Dystonia Survey that was released on Feb 4, 2008. We received an impressive 243 completed surveys. I understand the overwhelming desire that many of you have for new information about dystonia including new medications and updated research to eventually find a cure. In preparation of each newsletter I scan all of the major medical websites and neurology journals for new information. It is very disappointing that there truly is very little information about new therapies for dystonia or any new pharmaceutical agents. My goal and desire is that each of us continue to advocate for the advancement of dystonia research so that we may obtain the funding to develop more effective forms of therapies.

Pain and Exercise :

Physical conditioning in chronic pain patients can have immediate and long-term benefits, according to a new study presented at the American Academy of Pain Medicine

24th Annual Meeting.

A frequent co-morbid condition of chronic pain is profound physical deconditioning, which results from inactivity. "People with chronic pain don't want to exercise — the main reason is that they are in so much pain," the study's lead investigator, Amy M. Bureson, PsyD, from the Cleveland Clinic Foundation, in Ohio, told *Medscape Neurology & Neurosurgery* here. "We were hoping this [study] would show people how important exercise is." Source : Medscape News, 2008

Links :

Advanced Approaches to Chronic Pain Management Resource Center
Anxiety Disorders Resource Center
Depression Resource Center
Integrative Medicine Resource Center
Mental Health and Psychiatric Nursing Resource Center

American Academy of Pain Medicine 24th Annual Meeting- 2008

Stem Cell Review :

The Physical Therapy of Mice and Men

A therapy using embryonic stem cells helped restore muscle function in mice with Duchenne muscular dystrophy, the most common form of muscular dystrophy in children, U.S. researchers say.

Stem cells are the body's master cells, acting as a source for the various cells and tissues in the body. Those taken from days-old embryos, called embryonic stem cells, can produce all of the body's cell types.

"The problem had been that embryonic stem cells make everything," says Rita Perlingeiro, PhD, of the University of Texas Southwestern Medical Center in Dallas, whose study appears in the journal *Nature Medicine*.

"We know with embryonic stem cells, you have to find a way to pull out the cells you want," Perlingeiro says. "How to dig them out – that is the problem."

Perlingeiro's team experimented with stem cells taken from mouse embryos. Mice in the study lacked dystrophin, a protein that is lacking in humans with muscular dystrophy. At 3 months, the mice showed no signs of tumors. Tests showed the muscles were significantly stronger than in untreated mice with the condition and they performed better than other mice in tests of coordination.

"We have now looked for over four months, and there has been no tumor formation," Perlingeiro says. "We're very excited to see the fibers were green – and you could see dystrophin."

Perlingeiro says her team hopes eventually to develop a stem cell therapy for humans with muscular dystrophy using a new approach for making human stem cells from reprogrammed skin cells.

Source: Reuters Health

More on Stem Cells – Do they have a Role in treating Dystonia ??

With stem cells, "one could treat diseases that are caused by the loss of a particular cell function or tissue function," says John Leavitt, PhD, an analyst for Tolland, Conn.-based Nerac Inc., a research and advisory firm. "If you have stem cells that can differentiate

into that missing or defective tissue, then, in theory, you can [begin] cell replacement therapy, where you replace the defective cells with the healthy cells, [which] would then be able to regenerate the defective tissues.”

Patients, such as stroke survivors and individuals with neurodegenerative diseases, suffer long-term disability with conditions that may continue to worsen over time, despite intensive regimens of therapeutic rehabilitation. Hospice care facilities are filled with patients whose conditions have already surpassed the rehabilitation methods administered by conventional therapies, and concern for the quality of life of these patients is ever present with healthcare workers.

“When you think of the diseases that might be addressed first [with stem cells], it’s the neurodegenerative diseases like Parkinson’s and Alzheimer’s,” says Leavitt. “Spinal cord injury is another key area. In the news, we heard about Christopher Reeve and his wife, Dana, and also Nancy Reagan essentially pleading for more stem cell research. It’s because the general belief is that spinal cord injury and/or Alzheimer’s disease could be addressed.”

Stem cell therapy may provide the key to survival and the quality of life that is often denied to patients, whether in hospice care or struggling with immobilizing injuries and cancers. In hospital settings, one of the most difficult aspects of recovery is rebuilding the muscles that have been destroyed or have atrophied as a result of an accident or long-term illness.

“Hopefully with stem cell therapy, the need of hospice care would likely decline because the diseases could potentially be cured,” says McAllister. “However, in patients with diseases without a cure, stem cell therapies could be used to preserve mobility and function – for example cancer patients. Stem cell therapy can be used to promote muscle growth or prevent muscle atrophy.”

An Industry in Flux

Many professionals have expressed lingering concerns that the entrance of stem cell therapy into the mainstream will result in a shrinking range of therapeutic specialties.

One cannot help but imagine the drastic changes to the current methods of therapy, in light of a possible near future when therapists are no longer racing to preserve patients’ dwindling motor and cognitive functions. Instead, they may work with patients to adjust to their stem-cell formed organs, nerves, and/or limbs.

“I don’t foresee – anywhere in the near future – that a patient is going to be transplanted with a limb grown in a petry dish, but if it does happen, you are going to need months of various kinds of therapy to re-establish the neuro-connections to allow for even basic movements,” says Lionel Bissoon, DO, founder of the American Board of Mesotherapy, who consults clients in New York, Florida, and California.

What stem cell therapy may yet have to offer the gamut of different therapy specialties is a chance to revisit those patients deemed beyond the point of rehabilitation.

Contrary to the idea of downsizing the therapeutic industry, stem cell therapy may eventually expand the industry to its widest margins, as more patients formerly confined to nursing homes, intensive care units, and hospice care could find themselves struggling to adjust to restored bodily function. *Stem cells may one day be able to repair a person’s physical disabilities*, but therapists will be more crucial than ever to assist in the array of mental adjustments needed to restore health.

“I believe what you will see in the future are therapists specializing in the needs of

people undergoing stem cell transplant,” says Bissoon. “And, there may eventually need to be more specialized therapists for these stem cell patients who need more high-endurance rehabilitation – they may need more fine motor skill tuning than even the stroke patients. I really believe that therapists are going to have to become more specialized within the next 10 years to handle the needs of stem cell patients.”

While stem cells may be decades away from the kind of restoration that science fiction authors are foretelling for the coming age, stem cell therapy, nevertheless, has enormous potential to expand, if not revolutionize, the way in which healthcare professionals approach and assess therapeutic rehabilitation. The controversial research of today may be the very technology that advances the therapy field of tomorrow.

— **Bob Stott, Therapy Times 2008**

DBS Update :

Deep Brain Stimulation May Improve Memory

Deep brain stimulation (DBS) surgery, which is currently used to treat Parkinson’s disease and other movement disorders, is now being studied for its potential to treat a variety of conditions. For example, DBS of the hypothalamus has been used to treat cluster headaches and aggressiveness in humans, and stimulating this area influences feeding behavior in animals.

A new study finds that hypothalamic DBS performed in the treatment of a patient with morbid obesity unexpectedly evokes detailed autobiographical memories. The study appears in a recent online issue of the *Annals of Neurology*.

Conducted by Andres Lozano, PhD, MD, BSc, MD, BMedSci, FRCSC, professor of neurosurgery and Canadian research chair in neuroscience, and his team at the Toronto Western Hospital in Ontario, the researchers examined a 50-year-old man with a lifelong history of obesity in whom a variety of treatment approaches had failed.

While they were identifying potential appetite suppressant sites in the hypothalamus by stimulating electrode contacts that had been implanted there, the patient suddenly experienced a feeling of “déjà vu.”

The patient reported the perception of being in a park with friends from when he was around 20 years old. And as the intensity of the stimulation was increased, the details became more vivid. These sensations were reproduced when the stimulation was performed in a “double-blinded” manner.

The contacts that most readily induced the memories were located in the hypothalamus and estimated to be close to the fornix, an arched bundle of fibers that carries signals within the limbic system, which is involved in memory and emotions. Stimulation was shown to drive the activity of the temporal lobe and the hippocampus, important components of the brain’s memory circuit.

At the first office visit – two months after the patient was released from the hospital – the researchers were able to induce and videotape the memory effects seen in the operating room by turning on the electrical stimulation.

They also tested the patient’s memory during and without stimulation and found that after three weeks of continuous hypothalamic stimulation, he showed significant improvements in two learning tests.

In addition, the patient was much more likely to remember unrelated paired objects when stimulation was on rather than when it was off. The researchers conclude that, "just as DBS can influence motor and limbic circuits, it may be possible to apply electrical stimulation to modulate memory function and, in so doing, gain a better understanding of the neural substrates of memory."

Source: Wiley-Blackwell, 2008

Updates and News

We thank those who have contributed their services and/or made donations and matching Gifts a possibility for Care4Dystonia, Inc. A Million Thanks to each and every one of you. ~ beka

We applaud the www.nstda.org in reaching their grant funding goals !

New Botulinum Toxin coming onto the Market ? PurTox- made by Mentor Corp. will be branching out into the cervical dystonia arena.

Visit the new www.medtronic.com site
Visit the new www.BOTOXMedical.com site
Visit the new **NT201** webpage on our site

DBS Systems :
www.activadbs.com (Medtronic)
www.ans-medical.com (ANS Libra)
www.neuropace.com (RNS System for www.seizurestudy.com)

Clinical Trials for Dystonia : Currently there are about 20 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/> or visit www.clinicalconnection.com

Poetry Watch : My Passion by Kathie Stehr

Poetry requires intensity.
I need to bring the burdens of my heart,
to my fingertips and write.
But my fingertips freeze,
the teardrops stop in my throat.
They never travel to my eyes
and spill on the page.

Dystonia is the thief.
IT robs me.
Passion requires intensity.
Intensity means feeling.
Deep feeling brings dystonia,
the thief,
in to steal.

IT makes the voice weak.
IT makes the head pull and shake.

The body draws up,
thoughts are forgotten,
buried under the pain.
Is it any wonder that we,
the victims of dystonia,
find difficulty in expressing
what we need to the most
Feelings of love
sadness, fear, joy, LIFE.

Valid Medical Online Sites :

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

<http://www.cancer.org/docroot/home/index.asp>

<http://dirline.nlm.nih.gov/>

<http://medlineplus.gov/>

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

<http://healthfinder.gov/>

<http://www.ncbi.nlm.nih.gov/sites/entrez/>

<http://www.mlanet.org/resources/medspeak/>

<http://well.blogs.nytimes.com/>

<http://www.asco.org/>

[Http://www.medscape.com](http://www.medscape.com)

You can visit Jenelle's CaringBridge site at

<http://www.caringbridge.org/visit/jenelle> (drug-induced dystonia)

From a Reader : Adult-onset primary dystonia

This is a rare subtype of focal dystonia. The symptoms remain localised to the trunk of the body, but may spread to involve the neck muscles. The dystonia does not spread to the leg. Unlike other forms of focal dystonia it is more common in men than women.

The twisting trunk movements have been likened to the Leaning Tower of Pisa, and the term Pisa syndrome is occasionally applied to these dystonias.

(OK, do we now google the Tower of Pisa when searching for Dystonia info online ???)

Latest C4D News :

1. Public Service Announcements featuring the Rocker, Alice Cooper, to be released in April on US radio stations. Dystonia and Essential Tremor Featured ! Our Thanks to Buckley Broadcasting
2. Oz DVDs will be available for purchase ONLY in April-May.
3. The Journal of Neuroscience Nursing will feature Dystonia and DBS once again.
4. New Dystonia Forum open at www.wegohealth.com. Beka will answer questions once a week. Join and Post !
5. Register for the Utah Dysphonia Conference www.dysphonia.org
6. Established Author Joel Goldman publishes new fiction novel.
7. American Nurse Today Journal to feature Dystonia article.
8. We continue to receive requests for magnets and postcards. We applaud those of you who have helped to create Awareness of Dystonia.

9. Applause to www.tylershope.org on creating grants for DYT1 studies.

Botulinum Toxin News :

- Continued FDA Debates on Botox and MyoBloc use
- http://www.businesswire.com/portal/site/google/?ndmViewId=news_view&newsId=20080303006541&newsLang=en
- Toxin spread into other muscles ? Ask Questions. Learn.
- <http://www.newsinferno.com/archives/2708>

Philanthropy News : The question is simple, what have we given in return to those who make financial donations to our organization? No, I don't mean little chotchkies or mailing labels.

Maybe it sounds backwards even, "they are supposed to give to us!" But giving, as in any relationship, is a two way street.

Here are three things that we, as a non profit organization, give back to our supporters:

Most of the people who give to our group do so because they have an interest in our mission and activities. One of the greatest benefits that we can offer is to help educate those with dystonia further about our cause- care "for" dystonia.

Donors give because it's something they feel they can do to help a cause they care about. Some of our supporters want to go a step further and appreciate any other resources that we provide such as one on one direction and guidance to a correct diagnosis.

The best thing WE do give you is successful outcomes based on our mission. We keep our mission and vision forefront in our minds and in our daily activities as we move forward and reply to all your emails!

If I have not replied to an email over the last 2 weeks , please accept my apologies, I will reply personally. I just began a new ICU job. Let's say - working the day shift has been a bit tough lately, especially if you're a night owl like I am ! I have updated the website for all of our readers.

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 – **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.

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