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In Motion

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www.rewiredforlife.org

Redefining Dystonia

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Welcome to *In Motion* !

Welcome to the June issue of In Motion. This issue is packed with the stories of people living with dystonia, Medicare Updates, Fall Prevention Info, spasticity information, questions you should be asking about DBS and lots of news, blog sites, and updates along with links to usable information.

beka

Mary Beth's Story :

I fell off a horse back in 1984..the horse dragged me when the saddle fell off during an equestrian riding course I was taking as a non-traditional student in college. I fractured my pelvis, hurt my back and my neck. A year of physical therapy and pain management helped but as I go older (now 61) the pain in back and neck became worse. Had disc surgery two years ago and then we set to work on my neck. Dr. had a hard time with me because the MRI and injections showed little and did nothing for me...except the MRI showed I had arthritis...when my head started bobbing just a bit, the neurosurgeon called the "specialist" using Botox and asked her to see me.

She is known as the Botox Queen around Emory and Atlanta, because not too many physicians use or know about Dystonia symptoms. But as I said, I found a great Dr. now and I go every 3 months gaining very good range of motion and pain free...then slowly it comes back and I can hardly turn my head either way and the pain is extreme...especially if I try to sit at a computer.

But I'm just so grateful they found it. A diagnosis..but I would say...the machine found it, the Dr. suspected it when nothing else worked. Hope that helps for others to know.

Take Care
Mary Beth

Medicare Updates :

In case you missed the news, 2007 brought some new preventive benefits and changes to existing preventive benefits under Medicare. Knowing what Medicare will pay for, how often, and whether coinsurance and deductibles apply to how you are covered by Medicare.

A New Benefit and Some Changes

In general, the Medicare statute provides coverage only for diagnosis and treatment of an illness, injury or impairment of a body part. However, through a series of legislative changes over the years, the Medicare program now covers a broad range of preventive and screening services for Part B beneficiaries.

The most recent addition to the list of covered benefits took effect Jan. 1, 2007, when Medicare began paying for preventive ultrasound screening for abdominal aortic aneurysms for at-risk beneficiaries as part of the Welcome to Medicare physical. The screening will be available to men age 65 to 75 who have smoked at least 100 cigarettes in their lifetimes, individuals with a family history of abdominal aortic aneurysm and any other individuals recommended for screening by the United States Preventive Services Task Force guidelines. The *FPM* encounter form for Welcome to Medicare physicals has been updated accordingly; it is available online in the *FPM* Toolbox at <http://www.aafp.org/fpm/20060900/medicarepreventiveexam.pdf>.

Two other changes to Medicare's preventive services coverage are important to note:

- Medicare expanded the bone mass measurement benefit by increasing the

number of patients who qualify due to long-term steroid therapy. For these beneficiaries, Medicare reduced the dosage equivalent required for eligibility by one-third, from an average of 7.5 milligrams per day of prednisone for at least three months to 5 milligrams.

- Medicare exempted colorectal cancer screening from the Part B deductible, eliminating a potential financial barrier to using this benefit.

For more information about Medicare preventive benefits, you can access the prevention page on the Centers for Medicare & Medicaid Services' Web site at http://www.cms.hhs.gov/preventioninfo/01_overview.asp. You can also download a copy of the *Guide to Medicare's Preventive Services* at <http://www.medicare.gov/publications/pubs/pdf/10110.pdf>.

K. Moore, Medscape

Contact Us

www.care4dystonia.org

Editor : Beka

Preventing Falls :

About Preventing Falls

Many older people wish to live an active and independent life but a serious fall can shake their confidence.

The National Preventing Falls programme encourages healthy ageing through practical advice and exercise resources that help strengthen muscles, increase flexibility, improve balance and maintain independence.

How can I stay steady on my feet?

Falls are often the result of many different factors. Make sure you are aware of the following:

Exercise – Exercising regularly can keep you fit, healthy and help to reduce the risk of falling.

Keep feet healthy – Foot pain and other foot problems contribute to an increased risk of falls. Talk to your chiropodist about keeping your feet healthy and wearing the correct type of shoes.

Medicines – Some medicines can make you dizzy and increase your risk of a fall. If dizziness is one of the side effects of any medication you are taking, or if you take more than four different medicines, ask your GP or pharmacist for a medicines review.

Check your eyesight – Eye tests are free if you are over 60. Make sure you book a regular eye test with your local optician and discuss the use of your glasses.

Home safety – Take the time to think twice when doing tasks that might be more hazardous. Be aware of the risks around your home, such as standing on chairs or stools to reach high or awkward places, or stretching to change a light bulb. Always take care on the stairs and make sure you have good lighting, especially around stairwells. Talk to your GP if you have any concerns.

Vitamin D – Vitamin D helps keep bones healthy and strong. It is found in some foods but is mostly formed by the action of sunlight on the skin.

Osteoporosis – The chance of developing osteoporosis increases as we age. Keep your bones healthy by eating a diet rich in calcium and vitamin D and taking regular, weight-bearing exercise. Discuss osteoporosis the next time you visit your GP or nurse.

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.



What should I do if I fall?

- Get help and try not to panic: Try to attract attention by banging on the floor or wall. Use your personal alarm or call 999 if you can reach a phone.
- If you can't get help and you are not hurt, try to get up: A lot of the problems people experience after a fall come from lying on the ground for too long and getting cold. If you can't get up, use a piece of sturdy furniture to try and pull yourself up.
- Keep warm: If you're unable to get up, tense your arm and leg muscles and cover yourself with a coat or whatever you can find to keep yourself warm.

The importance of having your fall assessed

Always tell your GP if you have a fall as there are a number of things that can be done to reduce your risk of falling and maintain your independence. You should be offered a 'falls risk assessment' by a trained healthcare professional.

This may be done at the doctor's surgery or you may be asked to go to a specialist clinic. The aim is to uncover anything that might make you more likely to fall and to see if there are specific things that can be done to help.

The check should:

- Include one or more simple tests to see if your balance and walking could be improved in some way.
- Check on whether there are things in our home that may be a hazard.
- Assess the medicines you take.
- Check on your eyesight and glasses.
- Find out if you have any fears about falling.
- See if you have any foot pain or problems.
- Check on whether you are at risk of osteoporosis (brittle bones).
- Test how well your body's nervous system is working and whether you have problems with memory.
- Explore unexplained blackouts or faints.

The doctor or nurse will then devise an overall plan around these issues to help you reduce your risk of falling in future. The National Institute for Clinical Excellence (NICE) has produced a free information booklet on falls for older people, their families and caregivers. **Visit the NICE website** to download a copy.

Prescription Basics:

How to read and understand your prescription

1. It is a part of the process of becoming an informed patient who understands as much as possible about the medications he is taking. The first step starts in the doctor's office. Be aware that you understand what medication is prescribed for you, how often and how it should be taken, and for how long. If you are not sure about the dose, ask specifically if you should continue the medication once the symptoms subside.

2. Some drugs such as antibiotics, should be continued for a small time, even if all the symptoms have disappeared. Other drugs should be discontinued when the symptoms subside. Make sure that you understand your dosage schedule, any precautions you need to take to prevent or reduce possible side effects, and how you should alter your normal eating or drinking habits while you are taking the medication.

3. You should also learn what side effects are to be expected, as well as which ones are within the 'normal' range and which ones are signals that you need to consult your doctor again. Be sure that you know and understand all of these facts before you leave your doctor's office.

Follow all the steps given above properly.

Step 4

Keep a track with your pharmacist about how to take this medication:

It makes a great difference whether you take the drug before a meal, after a meal, or along with it, the effectiveness of it depends on the directions for its use. Your pharmacist can help you understand directions such as 'take with fluid,' 'as directed'. you may not only take water, but also you should take milk or fruit juice. Some diuretics, should be taken with orange or citrus juice or tomato juice to decrease potassium loss, since these foods contain natural potassium. Also, you should check the number of doses per day if your prescription simply says 'as needed'

Take all the details about your daily diet that includes foods, beverages or other drugs:

it is important as it involves risk factors such as some drugs interacting negative even dangerous ways with tobacco, alcohol, certain foods, or drugs you habitually take like aspirin. Ask your pharmacist about all these, even if you have already discussed with your doctor. You may have neglected to mention that you will be traveling and taking an anti-nausea medication, or that you will be going to a dinner party where alcohol will be served. There are many drugs that interact dangerously with alcohol. If you are taking oral contraceptives, be sure to mention the type and ask if you should continue to take it along with the new medication. If the pharmacist says no, check with your doctor about an alternative birth control method that can be used safely with the medication.

Step 6

Always keep all the information about activities that you should avoid or restrict:

some drugs contain warnings on the label that you don't drive or operate equipment or machinery as it causes drowsiness and slowed reactions. Even if your medication does not carry such a warning, ask anyway. Drowsiness is a common side effect and, in a driver, can be lethal. Also ask if you need to restrict travel or exposure to the sun since some drugs cause photosensitivity i.e. sensitivity to light or the sun, and you may suffer an uncomfortable rash and side effects.

Step 7

You should also know about the time limit of the drug that you are taking at present and when to discontinue:

The time limit depends on your need to take a medication, varying with your condition and the drug itself. In some cases, one should stop the drug as symptoms disappear to minimize side effects or to avoid tolerating the drug. In other cases, you should continue taking the drug for a specific time regardless of your symptoms, in some special cases, such as kidney infection, the treatment is long-term, and you'll take the medication for several weeks or months.

Step 8

You should be aware of the possible side effects:

If the doctor has spoken to you about the possible side effects, then also check again with your pharmacist the most common side effects of this drug. Write down the list if you don't remember; the expected, rare one, not cause for concern and serious. For example, the drug phenylbutzone causes a blood disorder, one of the first symptoms is a sore throat; thus, your pharmacist will tell you to check with your doctor if your throat becomes sore in the course of taking this medication.

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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 6,000 of them since the launch of our April 1st 2007 new website. We now have a new design that matches our website colors and logo !

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Step 9

You should learn to store your medication: -

And lastly, while taking your medications, before you leave the drugstore or pharmacy, ask the pharmacist how to store the medications. It is important because many drugs lose potency becoming inefficient and useless, due to improper storage.

Source : <http://www.healthepic.com>

Use of Phenergan : A Case Study

Hi Beka :

I would appreciate any information on the appropriateness of treating a dystonia that occurred after a 21 year old man experienced a sudden severe acute dystonia after taking 80mg of geodon twice daily for several days. I am a nurse on the unit that he is hospitalized at. This was one of the worst neuroleptic-induced dystonic episodes I have witnessed in many years of nursing on a psychiatric unit. The dystonia was characterized by abnormal positioning of his mouth, jaw, and neck along with abnormal positioning of his limbs and a jack-knifed position from the waist. The psychiatrist on call ordered phenergan (promethazine) 25mg intramuscular to be given. I had experience with a family member that received phenergan IM and developed a dystonia and her internist instructed her that it was fairly common for this to occur and advised her to list it as an allergy from then on.

After calling the psychiatrist back and questioning this order and asking for Cogentin to be ordered instead this is what my patient received. It took approximately 15 minutes for the IM Cogentin to take effect resolving his dystonia and I monitored his airway and stayed with him throughout. What happened the next day at work was that the psychiatrist was upset with me for questioning his order for phenergan and insisting this is used all the time to treat acute dystonia. He insisted he expected me to administer this in the future when he orders it even though I explained my worries as I had seen my sister develop a dystonia with phenergan. If the dystonia worsened this young man could have developed airway impairment I am afraid. If you have any information regarding the treatment of acute dystonia with IM phenergan I would appreciate it.

THANK YOU,
Belinda Staten

RN,C

This nurse stood by her patient and acted as an advocate for them. Thank each nurse you meet Today. They will cherish it, just you will.

Spasticity not Dystonia :

Spasticity is a form of muscle overactivity. A spastic muscle is one in which a muscle resists being stretched out, and the resistance to stretch is greater the faster the muscle is moved. Spasticity is often used as an umbrella term for other forms of muscle overactivity that often occur at the same time in the same patient.

Description

Spasticity occurs following damage to the neurons, or nerve cells, that send signals from the brain to the muscles to cause movement. These neurons, which run from the brain through the spinal cord, are called upper motor neurons, and damage to them produces an upper motor neuron syndrome. The upper motor neuron syndrome may be caused by stroke, traumatic brain injury, spinal cord injury, multiple sclerosis, or numerous other less common causes of damage to the motor neurons. Damage to the brain occurring prior to or shortly after birth is called cerebral palsy (CP), which is the most common cause of an upper motor neuron syndrome in children.

The other forms of muscle overactivity common in the upper motor neuron syndrome are:

- Clonus, a relatively slow rhythmic contraction and relaxation of a muscle, typically occurring after a stimulus such as movement or while attempting to hold the muscle still. Clonus can be mild or severe in intensity.
- Spasms, strong and sustained contractions of muscles, which are often painful.
- Increased reflexes, in which the normal reflexes (such as knee extension in response to tapping) are greatly exaggerated.

Together, all these forms of muscle overactivity can cause significant disability in a patient, interfering with dressing, bathing, feeding, mobility, and other activities of daily living. The upper motor neuron syndrome also involves weakness and loss of dexterity, which may be even more disabling to the patient, and may be much less amenable to treatment.

Clinical patterns and problems

Spasticity may affect any muscle or group of muscles, but common patterns are often seen. Each causes its own set of impairments. For instance, the forearm may be drawn up and in toward the chest, making it difficult to put on or take off a shirt. The thighs may be pulled close together, not only making dressing difficult, but narrowing the base of support for standing and walking. The fingers may be clenched tight, driving the nails into the palm and preventing access for cleaning, resulting in infections and skin breakdown. One of the most common patterns is termed equinus, in which the calf muscles tighten, preventing the ankle from flexing completely and leading to walking on the toes.

When the muscle that is overactive is also very strong, it can lead to more severe complications, including partial dislocation. Hip dislocation is a common complication of spasticity in cerebral palsy. A constant imbalance in the forces across a joint due to spasticity can cause the bone to form new tissue in response, leading to bony deformities.

Inactivity brought on by disability can lead to a host of other problems, including pressure sores, osteoporosis, respiratory infections, and social isolation.

Resources :

www.exploringspasticity.com/exploringspasticity/explore/whatis.html

www.zanaflexcapsules.com/consumers/index.asp?section=6

www.exploringspasticity.com/

Photo By Sheri Todd 2007



Forever in Time

For additional Sheri Todd Photos visit the site :

<http://new.photos.yahoo.com/bisto52/album/576460762401898440>

Biologics News :

In 1978 , researchers at the biotech company Genentech did something that never had been done before : They manipulated bacteria into making human insulin. Insulin became the first pharmaceutical biologic- a protein made biologically, by living organisms, instead of chemically. The same theory or concept is now being applied to neurotoxins. The FDA has not supplied guidelines to pharma companies on how to achieve approval of generic insulin and other proteins.

The FDA now says that it no longer plans to issue guidelines for any biologic medicine which includes NEUROTOXINS = Botulinum toxins. Instead , the FDA has announced that it will develop global guidelines applicable to ALL biologic generics , from insulin to the latest super proteins. Generics will not be forced to repeat the exhaustive clinical testing that drugs go through to receive FDA approval for use in humans.

On Feb 14, 2005 Rep. Henry Waxman of California, Rep. Emerson, Schumer, Pallone and Clinton introduced H.R 1038, the " Access to Life-Saving Medicine Act " which will establish a process thru which the FDA will be able to approve lower cost copies of generics- biopharmaceuticals.

To learn more read

www.henrywaxman.house.gov/issues/health/generic_biologics.htm
for details.

Updates and News

June is Here ! Were you ready for Dystonia Awareness Week ?

Events- News :

- C4D donated Auction Items to Dystonia, Inc. and the Dystonia Ass. of Kentucky (autographed AC 360 books and Actor autographed TV scripts from All My Children).
- Press releases were sent to major TV networks, PR newswires, Univision and other forums.
- DBS segment has been re-aired on MSNBC. (June 05)
- C4D placed an Ad for Awareness in **www.movementdisorders.org** journal-newsletter.
- C4D Brochure has been completed and is now available.
- C4D Flash Video Movie is under development!
- **[Http://www.parkinsonsappeal.org](http://www.parkinsonsappeal.org)** began PSAs on DBS in the UK
- NJ Golf Event **<http://www.njdystoniagolf.org/>**

- Bachmann-Strauss Golf Invitational <http://www.dystonia-parkinsons.org>
 - DyStonia, Inc Red Vest Golf Event <http://www.spasmodictorticollis.org>
 - Dystonia Association of Kentucky "1st Annual Dancing with the Kentucky Stars" Benefit Gala & Silent Auction was held on June 9 2007. <http://www.dystoniaassociation.org>
 - Childrens' & Family Dystonia Symposium August 07 <http://www.dystonia-foundation.org>
 - CD by Billy McLaughlin, a musician affected by focal dystonia , released. Proceeds of sales go to DMRF.
 - Since our new websites April 1st launch date, we have already distributed over **6,000 Awareness Magnets**. *Remember, they are free. Simply send us your address and the quantity you would like to distribute around the world.* We'll be happy to send them to you. Write to infoc4d@aol.com. 1k just were delivered to South Africa !
 - Movement Disorders Society Meeting held June 07 Istanbul, Turkey. For more info, visit <http://www.movementdisorders.org>
-
- <http://www.life-in-motion.org> continues its Tour. Could they be coming to your town ? Learn more at their site.

Are You coming to the DySTonia, Inc Baltimore Symposium. Beka will be there with an educational table ! Meet her there this coming Sept 2007 !

- Dystonia Fundraiser : Louiseville Support Group
- DMRF National Garage Sales during Awareness Week in June.

Clinical Trials for Dystonia : Currently there are about 34 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.clinicaltrials.gov>

Patient Selection Criteria change for N201 Toxin studies – visit www.dystoniastudies.com for more information.

MS Community :Research Blog on Multiple Sclerosis

We, at The Patient Connection, are currently running a research blog or online discussion on the subject of current treatment options for Multiple Sclerosis. We are seeking the opinions of both people have had or have family members with MS. In particular we are interested in your experiences of Tysabri or other treatment regime

We would love it if you could share your story or just post useful resources for sufferers, caregivers, and family members

To participate please go to

<http://www.thepatientconnections.com/blog.asp?uid=15>

The blog is anonymous and easy to use so I'd like to thank you for

your contribution in advance.

Best wishes
Belinda
The Patient Connection

Tyler's Update :

My son, Tyler Staab, has recently lost some weight because of his dystonia. He has a hard time chewing and it makes his eating difficult. He tries really hard but sometimes it makes it worse when he tries so hard. He was just given a feeding tube to try to help relieve some of the pressures of eating as well as put some weight on him. The thing that I will not forget during this process is his continued positive attitude and jovial demeanor. Tyler asked if he could go swimming when he got the tube in and the doctor responded by saying yes but people may stare because of the tube sticking out. Tyler just looked at the doctor and said, "doc, have you seen me walk yet, people already stare." I am very proud of how Tyler is handling these very difficult things. Everyone can learn from how he handles hard times. I am his father and look up to him at times.

Rick Staab
Tyler's Hope for a Dystonia Cure www.tylershope.org

Allergan Profits

For the quarter ending March 30, 2007:

Allergan's total product net sales were \$872.4 million, which includes \$165.2 million of product net sales acquired in connection with the Inamed acquisition. Total product net sales increased 41.8 percent, or 40.0 percent at constant currency, compared to total product net sales in the first quarter of 2006.

BOTOX(R) product net sales to between \$1,125 million and \$1,160 million. (2007)

DBS Updates :

Many of you have requested additional **information about DBS**. You can find Top 10 Questions and Answers regarding DBS, written by Okun, Hernandez and Foote of the University of Florida at these links :

Should Patients See a Movement Disorders Neurologist?
<http://mdc.mbi.ufl.edu/candidate/candidate-MDneurologist.htm>

The Need for Well Trained Interdisciplinary Teams
<http://mdc.mbi.ufl.edu/candidate/candidate-allcenters.htm>

How Do We Accomplish Large Population Screening?
<http://mdc.mbi.ufl.edu/candidate/candidate-largepop.htm>

What Kind of Commitment Does DBS Require?
<http://mdc.mbi.ufl.edu/candidate/candidate-commitment.htm>

Additional Links can be found on our website " What's New " web page.

DYSTONIA HEALTHCARE TREND SURVEY TO BE RELEASED> PLAN ON PARTICIPATING.

Beka's blogs on www.care4dystonia.org via Medscape.

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 continue to recognize this issue as a start of that – New Horizons ! We also have been updating our website on a fairly regular weekly basis. Visit the site often as you just might find some new and interesting news ! Best Wishes for the Summer !- **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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