

...What's Your Take on Dystonia Research Today ? Where should it be headed ? Are we going in the right direction ? Send us your thoughts today via our email : infoc4d@aol.com and we'll post them on our site.



In Motion brought to you by www.care4dystonia.org

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Welcome to *In Motion* !

Welcome to this issue of In Motion. We have tightened this issue to include two "Your Stories "; one focusing on the use of Alternative Care and the second detailing pain management with Methadone, a controlled substance. Other topics included in this issue: Massage Therapy, Reading Food Labels, Caregiver resources, Website Updates, Our Food for Thought View, and DRD- dopamine Responsive dystonia. We hope that you will find this issue of value. Feel free to send us your comments, suggestions, and story ideas.

Beka- RN,MS, NP Founder

Website Updates

We have added new items to our dynamic and popular website. We now have a simple, but informational Publication page, A You Tube Video page where you can watch the Flash Ad that will be posted on www.youtube.com; excerpts from the Moving Series with information on how to purchase both books are now available online, a creative Send an E-Card page and a "Are U at Risk?" for cervical dystonia interactive page have all been added or are in the process of being added to the website. We've also listed our Milestones since our arrival in 2000.

As of the release of this newsletter we have had over 35,000 unique visitors to our website since its launch on April 1st 2007. We hope to continually improve it so that it serves You.

My Story: Nance's Story

Beka,

This will be in a couple of parts as my computer sometimes likes to turn itself off. About 10 years ago I started getting a 'tingling sensation in the lower left part of my brain. Then I would sometimes just 'fly' to the left. I got pretty good at making up lies and excuses for that one! At the time I was producing theatre, doing the job of 5 realtors and restoring an old Victorian for a flip house. Most of the work was being done by me; plastering, painting scraping of tons of wall paper, caulking etc. My neck started to turn right and I started in w/ the pain. I figured that it would all go away once things settled down in my life. I was embarrassed and tried all sorts of excuses when someone would ask what was wrong w/ my neck. When it came time for a hair cut, I would just go out and find some cheap chain place so when I was asked I could say that I was tremoring and had a very stiff neck. Finally the 'day of truth' came out.

This wasn't going away and I went to a wonderful young woman doctor. I hadn't been

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Editor : Beka

to a doctor in 10 years. I got into the little white room, started crying and said 'what the heck is this'? She said 'I don't know, but if you stick w/ me we can figure it out'. Actually she thought that I'd had a stroke, but didn't tell me that, and sent me for a CAT Scan. The good news...my head came back empty. Then I started searching. The turning ended up being a severe pulling to the right. I had to use my hand to keep my head straight. My search for answers took me to an Ortho's office. My lord, that was a very painful day! While I was in the little white room the receptionist came in and told me that the doctor said that she could talk to me. She had a 3 page print out from the internet, and proceeded to ask me a few questions. She asked how old I was and I told her 48. How long had this been going on and I said 2 years. She pointed to the paper that said usually starts at age 46. Family tremors? I said yes my father and uncle had shaky hands and 2 aunts had shaky heads. She pointed to where the paper said 'history of family tremors'. Then she said 'are you Irish'? Bingo!

She said what I am about to tell you isn't good news, but I was sent as a gift to you today then proceeded to tell me about ST because she had it. I rushed to my doctor w/ paper in hand and she prescribed lorazepam. My lord, I could at least function a bit again! I started getting ready to see the neuro by getting neck scans etc and was so ready for Botox... The neuro confirmed the dx. and proceed w/ Botox. It hurt a little but I told her 'if I say ouch, just ignore me and keep going'. We waited and waited and nothing happened. Tried again and again, nothing. She tried the 'wrinkle test' and it worked great (as a matter of fact, 6 years later and the wrinkle isn't back!). I went up to Boston and was offered all sorts of surgery but always said no and doctors up there injected me also. Nothing. Oh, I was also put on, 5 mg of clonazepam a day. I was in constant pain and had to go on disability and got it on the 1st try.

My neuro wasn't me to wear elbow pads to cushion my elbows, but vanity wouldn't let me do that. I finally quit tiring and using Botox after 5 years and my pain was horrid. Both of my doctors begged me to go to pain management, which I did. He asked if I'd ever heard of methadone. I said 'of course, it's for heroin addicts' right?' He said that it has a bad reputation because that's what most people think, but it is a pain killer that you can use for a long time. I started taking it and right away started feeling less and less pain and suddenly my head, little by little started going straight! My husband and I had decided to move to Florida as the cold weather was tough on my neck. Our house was a drafty old Victorian on Narragansett Bay in RI and would never heat up in the winter. I started w/ 10 mgs of methadone for the 1st 2 years and last year went up to 20. I have never gotten high of the slightest buzz from it. It goes directly to the pain. No one really knows why it straightened out my neck. My feeling is that it let the muscles in my neck ease up. I'm not 100% pain free, but I don't bang into door frames anymore and no longer get black eyes from open kitchen cabinet doors! My walking is somewhat gingerly. I am more that grateful that after 7 years of trying, something worked! Thanks for listening to my story. Nance

My Story No. 2: Lori Allen

I believe dystonia moved into my life at a young age, with scoliosis being the main symptom. But it didn't really reveal itself as an entity to be dealt with until I was in my 40's. That was when I thought I hurt my neck and shoulder planting a heavy hibiscus. But this time was different...usually the chiropractor could adjust me and I'd be better again. However, the pain and tightness in my neck and shoulder just continued to worsen and evolve, with movements and posturing beginning.

I found myself getting shuffled back and forth from chiropractor to orthopedic surgeon to neurologist. They would do an exam, order a test, try a treatment, and still be baffled, so they'd send me back to the other specialist. Finally, the neurologist sent me to a Movement Disorder Specialist who finally gave me the diagnosis of dystonia two years after my neck symptoms started.

Shortly afterward, my symptoms seem to spread to my leg. After injecting my neck with Botox three times, the neurologists decided that the results of my injections weren't very successful and that there were just too many muscles spasming to continue with Botox. So they tried giving me stronger doses of some medications I had tried earlier with no success. One of them, Clonazepam, worked for the longest period, about 1½ years, before I had to be weaned off it because it wasn't working anymore.

A neurologist I was seeing sent me to Johns Hopkins Hospital in Baltimore to see a Movement Disorder Specialist. He asked me psychological-type emotional, family history questions. He filmed me walking. After a short physical exam, he gave me his recommendations:

- ❖ Get the DYT1 gene test.
- ❖ Get started with physical therapy.
- ❖ Get weaned off of Clonazepam.
- ❖ Go to a psychiatrist to be evaluated.

I did the first three suggestions, but I refused to go to a psychiatrist because I felt my symptoms were the result of a neurological disorder that had been with me all my life and I didn't have any emotional or psychological problems other than any normal person's experience with occasional mild depression. This was to me a physical problem, not a psychological one, and I deeply resented his insinuations and questions. I realized this must be his standard way of evaluating dystonia patients.

When I returned to the neurologist who sent me, he read the report and insisted that I go to a neurological psychologist. I repeated to him that I didn't need a psychologist and my problem was not "in my head," and that it started with scoliosis when I was young. He stated that he would not treat me again, or give me any Botox, unless I first agreed to be evaluated by the psychologist. So I stopped going to him.

I went for about 2 years without a neurologist. Then I was referred to my present Movement Disorder Specialist, with whom I am very satisfied, and he finally gave me the diagnosis of Generalized Torsion Dystonia. I don't have DYT1 dystonia. But I think one day they will discover I have some other dystonia gene.

There are no drugs that help my symptoms. I have tried many different alternative therapy modalities over the past eleven years:

Chiropractic: Worked great in my teens, 20's, and 30's. Now I have too much arthritis in my neck and my muscles contract when touched.)

Potassium supplements: Experimented with, keeping a daily log, actually helped symptoms for 3 weeks, and then stopped.

Sphingolin: This is an extract in capsule form made from Bovine Spinal Cords. Read about these helping autistic children, so I thought it was worth a try. This too helped for 3 weeks, and then stopped working.

Chiropractic Neurologists: Wow, very "different" type of exams and treatments. I went to two different ones. The one I went to on a regular basis, had me squeeze hand exercise balls to stimulate my brain on the opposite side, and had me try to balance on a wobble board, and gave me a TENS unit.

TENS unit: For me the TENS unit was ultimately unsuccessful due to the increasing number of muscles I had spasming. I was constantly changing the batteries and developed a severe rash from the electrode pads. They sell a special adhesive for those who develop a rash, but it never did stick well enough, so the pads were always falling off.

Although it didn't work for my generalized dystonia, it might be successful for those with cervical dystonia. You cannot use it in conjunction with Botox injections though. So this is an idea to be discussed with your doctor if other methods aren't

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

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working.

Massage Therapy: Felt great but seemed to actually make the muscles tighten up even more within the short drive home. Had to stop going.

Physical therapy with physical therapists: most of the exercises they gave me for my neck, range of movement and isometrics, were and still are very helpful. Didn't like or try some of the other more extreme exercises, such as hanging my head off a bed and trying to raise my head.

Over the door traction unit: a chiropractor got me one of these units, thinking my problem was caused by my small bulging cervical disc. To this day, I don't know if using this ever made a difference one way or the other.

*Aquatic personal training: I would very strongly advise any person with any type of dystonia try this. Aquatic therapy is fantastic. Exercising in the water, stretching, working with aquatic equipment for strength training, is so much easier than exercising on dry land. The water keeps you buoyant, gives you some easy resistance, and feels great. Especially if you can join a health club that has a heated pool that you can use throughout the year.

*Personal Training: Try to find a well-trained, experienced personal trainer who has preferably worked with neurological disorder clients before, even if they've only dealt with Parkinson's patients. A good personal trainer can be expensive, but if they can offer you some advice on how to keep your muscles in good shape, it will be well worth the money.

*Stretching, light weight training, swimming, or water jogging, rolling on large exercise balls, walking on treadmills, using the elliptical cross trainer machine, riding a stationary bike, and lots of other strengthening exercises you can do on the floor in your home...these are just some of the helpful and necessary tools I use on a daily basis to alleviate some of the pain and spasm I experience every day.

Isometric exercises for the neck and arms work really well to strengthen the neck muscles and counteract the spasms.

In short, my best advice for anyone with dystonia can be summed up in one word: EXERCISE. It keeps me going, so I keep it going. Just remember to stretch before and after.

Essentials I have on hand:

Electric Massager
Heat/cold gel packs
Heating Pad
Muscle cream/gel
Soft cervical collar
Velcro lumbar support

Exercise equipment I use:

1. Light hand weights
2. Wobble board (balance board): I stand on this and wobble side to side and back to front or just try to balance on it. I also lie with it under my pelvis to help straighten out my lower back and I do pelvic tilts on it.
3. Styrofoam cylinder: for "foam rolling" or myofascial release. Myofascial Release and Yamane Ball Rolling are interesting to learn about. I usually do foam rolling for my legs several times a day.
4. Theracane: cane shaped, with extra knob-shaped ends to press on knotted muscles until they "release."

5. Large inflatable exercise ball. Great for stretching out the kinks in your spine.
6. Treadmill: regular walking is great for the whole body.

Extra note:

It is very important that you find the most comfortable pillow and mattress that support your neck and back without causing discomfort. Like Goldilocks, you'll have to experiment to find the one that's "just right" for you. A good night's sleep is essential to feeling your best during the day.

Best Regards - Lorri

Massage Therapy:

The Benefits Of Massage

What exactly are the benefits of receiving massage or bodywork treatments? Useful for all of the conditions listed below and more, massage can:

- Alleviate **low-back pain** and improve range of motion.
- Assist with shorter, easier labor for **expectant mothers** and shorten maternity hospital stays.
- Ease medication dependence.
- Enhance **immunity** by stimulating lymph flow—the body's natural defense system.
- Exercise and stretch **weak, tight, or atrophied muscles**.
- Help **athletes** of any level prepare for, and recover from, strenuous workouts.
- Improve the condition of the body's largest organ—the skin.
- Increase **joint flexibility**.
- Lessen **depression and anxiety**.
- Promote tissue regeneration, reducing **scar tissue and stretch marks**.
- Pump oxygen and nutrients into tissues and vital organs, improving **circulation**.
- Reduce **post surgery adhesions and swelling**.
- Reduce **spasms and cramping**.
- Relax and soften injured, tired, and **overused muscles**.
- Release endorphins—amino acids that work as the body's natural painkiller.
- **Relieve** migraine pain.

A Powerful Ally

There's no denying the power of bodywork. Regardless of the adjectives we assign to it (pampering, rejuvenating, therapeutic) or the reasons we seek it out (a luxurious treat, stress relief, pain management), massage therapy can be a powerful ally in your healthcare regimen.

Experts estimate that upwards of ninety percent of disease is stress related. And perhaps nothing ages us faster, internally and externally, than high stress. While eliminating anxiety and pressure altogether in this fast-paced world may be idealistic, massage can, without a doubt, help manage stress. This translates into:

- Decreased anxiety.
- Enhanced sleep quality.
- Greater energy.
- Improved concentration.
- Increased circulation.

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 38,000 of them since last year (2006).

Not bad - don't you think??

- Reduced fatigue.

Furthermore, clients often report a sense of perspective and clarity after receiving a massage. The emotional balance bodywork provides can often be just as vital and valuable as the more tangible physical benefits.

Profound Effects

In response to massage, specific physiological and chemical changes cascade throughout the body, with profound effects. Research shows that with massage:

- Arthritis sufferers note fewer aches and less stiffness and pain.
- Asthmatic children show better pulmonary function and increased peak air flow.
- Burn injury patients report reduced pain, itching, and anxiety.
- High blood pressure patients demonstrate lower diastolic blood pressure, anxiety, and stress hormones.
- Premenstrual syndrome sufferers have decreased water retention and cramping.
- Preterm infants have improved weight gain.

Research continues to show the enormous benefits of touch—which range from treating chronic diseases, neurological disorders, and injuries, to alleviating the tensions of modern lifestyles. Consequently, the medical community is actively embracing bodywork, and massage is becoming an integral part of hospice care and neonatal intensive care units. Many hospitals are also incorporating on-site massage practitioners and even spas to treat post surgery or pain patients as part of the recovery process.

Increase the Benefits with Frequent Visits

Getting a massage can do you a world of good. And getting massage frequently can do even more. This is the beauty of bodywork. Taking part in this form of regularly scheduled self-care can play a huge part in how healthy you'll be and how youthful you'll remain with each passing year. Budgeting time and money for bodywork at consistent intervals is truly an investment in your health. And remember: just because massage feels like a pampering treat doesn't mean it is any less therapeutic. Consider massage appointments a necessary piece of your health and wellness plan, and work with your practitioner to establish a treatment schedule that best meets your needs.

Review the [clinical research studies](#) examining the benefits of massage.

Review massage information from the [National Center for Complementary and Alternative Medicine](#), a division of the National Institutes of Health.

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

Check out the following website: www.amtamassage.org/ (The American Massage Therapy Ass.)

Patricia's Story with the use of massage :

I have what may be cervical dystonia, at least this is what my neurologist says. I'm in denial, but worrying. At first, my head leaned to the right and I could not move it to the left or hold it up. I went to a chiropractor, thinking it was due to a dislocated disc. After numerous treatments, he

Highlights of our Next
issue :Dec 2007

This is "your issue "
**Contribute your
thoughts , feedback,
suggestions, stories,
humor to this end of
the year issue !**

suggested the neurologist. I didn't like the botox treatments the neurologist suggested. I went to a spa and got deep Swedish massage. This has helped a great deal. I'm almost functional. I can now hold my head up and have greater strength in my neck. But I still have the strange automatic turning of the head to the right that is almost uncontrollable. I still hold out hope that I merely need to let the blood flow get into those tight muscles and let them heal. Then, I hope they will regain their strength and I will recover from this embarrassing ailment. I have been struggling for three years now, but have found the greatest relief through massage. ----Pat H., Bayonne NJ

Reading Food Labels:

Grocery stores are packed with aisle after aisle of different types and brands of foods. The food label can help you to make sense of how to choose healthy foods. Here are some tips on how to use the food label to choose foods low in saturated fat and cholesterol.

Here are some tips that will help you to stick to your low saturated fat, low cholesterol diet:

Free. This claim means that a food contains no amount (or a very small amount) of these nutrients: fat, saturated fat, cholesterol, sodium, sugar, and calories.

- **"Calorie-free"** means fewer than 5 calories per serving.
- **"Fat-free"** means less than 0.5 grams of fat per serving.

Low. This claim can be used on all foods that can be eaten often without going over the limit for one or more of these nutrients: saturated fat, cholesterol, fat, sodium, and calories.

- **"Low-saturated fat":** 1 gram or less per serving.
- **"Low-fat":** 3 grams or less per serving.
- **"Low-cholesterol":** 20 milligrams or less and 2 grams or less saturated fat per serving.
- **"Low-sodium":** 140 milligrams or less per serving.
- **"Low calorie":** 40 calories or less per serving.

Other words that mean "low," include: "little," "few," and "low source of."

Lean and extra lean. These claims can be used to describe the saturated fat and fat content of meat, poultry, and seafood and game meats.

- **"Lean":** less than 10 grams of fat and 4.5 grams or less of saturated fat, and less than 95 milligrams of cholesterol per serving.
- **"Extra lean":** less than 5 grams of fat, less than 2 grams saturated fat, and less than 95 milligrams of cholesterol per serving.

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

Resources :

www.fda.gov/opacom/backgrounders/foodlabel/newlabel.html

www.kidshealth.org/kid/stay_healthy/food/labels.html

www.lifeclinic.com/focus/nutrition/food-label.asp

Caregiver Resources:

1. www.aarp.org
2. www.thecaregiverzone.org
3. www.caregiving.com
4. www.ncoa.org
5. www.nfacares.org
6. www.wellspouse.org

DRD- Dopamine Responsive Dystonia : A View

There may be many errors that result in dopamine responsive dystonia. The only real way to know for sure is to do the test. Sinemet is an old drug. Many people have been on it for years. It does come with some side-effects, but over time they tend to diminish. Being late for a single dose quickly reminds me that I am a much more comfortable and happier person while on this drug. There is absolutely no question that it is worth the expense and the hassle for me to get any level of improvement at all. When all else fails, ask your children if they think that it is worth it. They are the ones who are going thru the experience. One shouldn't force a person to take a med for the rest of their life, but you shouldn't take one away from them either. Someone with Dystonia feels powerless enough without having decisions like that made for them and without their input, no matter their age.

I appear to be responsive to Dopa-related meds like Sinemet also. Dystonia is a stubborn creature though; it doesn't follow rules very well. Some people will be very responsive to the meds and it happens almost immediately, where others may respond only to higher doses and only after a longer period of trial. **Dealing with any chronic condition becomes all about patience and very little about understanding I'm finding.** When I got my diagnosis as an adult, my doc told me he didn't have a lot of time to discuss it with me, and told me to look it up on the internet. When I did several searches, my symptoms didn't seem to really match any of the dystonias, so I actually blew that doc off for a year while I continued to suffer and get worse. Now I understand that everyone is different, so I can't expect my body to react like anyone else's. I try to be and stay informed and have an ongoing dialog with my Neuro.

Thankfully your kids have you to be their "warrior" and lead them thru this experience. They truly are blessed. They will be watching you for clues on how they should be reacting and feeling about this though. You are more than their warrior, you are also their teacher. It's okay to show them that you are afraid for them as long as it's tempered by the encouragement that every step is getting them closer to finding out and being able to fight what is happening to them. This gives them power, which is something they feel they don't have much of.

Power is hope. Of course you don't want your child (ren) to have dystonia!! There's not a person here that wouldn't breathe a sigh of relief if you came back and told us they were wrong.

Yes, Dystonia is difficult. Any chronic condition is. Anyone who tells you otherwise is lying to you. There is a definite mourning process that you have to go thru (and sometimes revisit) after a diagnosis. There are a lot of success stories though, at least I'd call them success stories, and you can read them all over the internet. We were dealt a crappy hand of cards, but it's our choice whether we want to take that and be miserable, or just have fun because we're playing the game.

Dopa responsive dystonia has a treatment that is easy and effective-- in the world of dystonia we are really the lucky ones! Your kids' lives don't have to be spoiled by dystonia unless that's how you want them to be. They can even be enriched! Because now you will have to make plans to do fun things, you will appreciate the experiences more and in the end may end up doing MORE fun things with your kids and family. Your kids will learn to live their lives deliberately and with strength and creativity that many other people never find their entire lives. Our lives are much more than what we are able to do or not do. **We need not be defined by our disease unless we choose that path. To live with Dystonia is not so much living with a disability as it is to live creatively. Always you must be thinking of a new and better way to do something. We learn to think outside the box and we're better, smarter people for it.**

I think that those of us who feel we live a good life concentrate on having a particular attitude of focus. The key in that is that we are able to focus beyond what is immediately in front of us. When we get angry, we focus that on doing the constructive things instead of destructive. **Our attitudes are those of builders and dreamers who can see past the mundane and every-day, not fighters who concentrate on the unfairness of what they have lost.** !! And losing things along the way, I have personally learned that I have gained much more as a result. I can no longer ride my beautiful horses for more than a few minutes without spasms forcing me back on the ground, but those few minutes have become my heaven and have enriched me more than the thousands of hours I rode before. Before I felt exhilaration in the feel of riding, but now, I long each day for the sounds they make, the smells and the touch. I breathe in the sweet smell of clover and soil and skin as my cheek lies on a smooth shoulder, and it changes me.

Feeling the breath of my mare on my neck gives me a feeling of completeness that I didn't take the time to notice before. It's so much more than that though. I set my alarm for midnight so I can go outside and see our field absolutely throbbing with the green light of fireflies dancing in the still darkness, and feel content to watch them with excitement, wonder and emotion that most people forget they can feel. Because we have to make a deliberate effort to do things, we appreciate them so much more. Your children's lives will be different with dystonia, but they can also be beautiful, and even enriched. I feel sorry for those who see a caterpillar walking across a leaf and don't feel compelled to watch him for a moment and wonder what he is thinking.

E (Ellen in Missouri) Generalized Dystonia

What's this? An Opposing View on Methadone use

Hi Beka :

I just wanted to write to let you know about my experience with methadone. I was sent to a pain clinic in Dallas TX where they decided to place me on methadone. This was very detrimental to my progress. All of a sudden I was worse. Although my pain was better I was not able to control my muscles and the depression it created was unbearable. I was on this drug for 11 months until I went to a new neurologist who happens to do research for dystonia. She immediately said I must get off this drug. She explained to me that it was actually making things worse which I kept telling them but know one was listening.

It took me several months (3) to get off this drug because it is extremely addictive. I hope that your articles show the negative side of this drug so that others will not go through what I did. I used to be a nurse with a very active life, but now I'm having to learn to live differently. I have cervical dystonia and facial dystonia, which affects my self esteem and my abilities to move freely but God is good, **I'm learning to appreciate the little things in life**. Well I just felt that I should give my 2 cents worth on this drug. Keep up the good work, this site has been a God send to me.

Sincerely,
Pam W.

Updates and News

Clinical Trials for Dystonia : Currently there are about 44 active 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/>

THERAPISTS CAN NOW PUT A WIDE VARIETY OF ASSISTIVE TECHNOLOGY TO WORK FOR THEIR CLIENTS WITH DISABILITIES

EVAS has teamed with Dell™ to offer Plug & Play Computer-Based Assistive Technology Solutions for people who are visually, physically, hearing or learning disabled.

EVAS' Assistive Technology Solutions are tools that can be used to gain independence - an independence which can open the doors to educational or employment opportunities and a better quality of life.

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WEBSITE UPDATES

- *We have added excerpts from the Moving Series for reading online. Ordering information of both books can also be found on our Home page by clicking on the Moving Series Books icon. Unfortunately we cannot give out free copies to everyone as our budget is limited and is primarily based on our Founders' Employment Salary. We have recently sent out a number of free copies to individuals; however the costliness of doing so for every request is high for us. We hope that you will understand this decision. Copies are available on www.amazon.com.*
- *Our Avoidable Med List is now online along with new blog site listings.*
- *Our Top 55 DBS Questions continues to be the most popular of our all of our publications. Please read it carefully if DBS is your choice of treatment.*
- *For Info on Botulinum Toxin B , visit www.myobloc.com today.*
 - *New Survey on CD has been released on September 1st 2007 , closing 30 days later.. Your Participation will be valuable and vital once again.*

Our Awareness Magnets remain free of charge. Have you spread your share around the country? World? We are nearing the 40k mark !

Interested in Advocacy , visit www.dystonia-advocacy.org

DBS Film from www.lilafilms.com wins Humanitarian Award.

Care4Dystonia website has won a **Hope Award 2007**. The Hope Award is given to websites that offer positive support and encouragement to people suffering from chronic illnesses, and is awarded by IBS Tales. To be eligible for the Hope Award, websites must:

- offer accurate information and resources for patients
- encourage sufferers to search for new treatments and hope ;
- refuse to accept inadequate medical advice and doctors who tell us to "learn to live with it"!

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

16 grants were given to a variety of researchers, most focusing on the Torsion A protein by www.dystonia-foundation.org for 2007.

FOOD FOR THOUGHT :

The immediate and long-term stability of Care4Dystonia, Inc. rests on the growing number of people with dystonia who recognize their needs as well as the value of an organization. C4D generally strives to succeed based on our Founder's yearly salary as an ICU RN with ongoing new initiatives since 2000.

C4D does not send out solicitations for contributions via mail, post or otherwise. While voluntary donations are welcomed by C4D, our emphasis is on Setting the PACE – Patient Care, Awareness, Collaboration and Education. Although, realistically few of the dystonia nonprofits do not even "talk or share" one another's achievements to their own members whether it is media recognition or some other sort of achievement.

At C4D, we have continued to selflessly promoted the efforts of other groups in the area of awareness, patient education material, patient referrals, despite the ongoing drive for dominance by other groups. Without a doubt, collaboration is necessary verbally, but also needs to be seen in action, so that the lives of all people suffering with dystonia regardless of cause improves quickly.

What are your Thoughts on the current Dystonia nonprofit status. Should there be only 1 group ? Should Unification be emphasized ?

FIRING YOUR NEUROLOGIST :

Here are five ways to know when it's time to think about leaving your neurologist :

- 1. When your neurologist doesn't like it when you ask questions**
- 2. When your neurologist doesn't listen to you**
- 3. If your neurologist can't explain your illness to you in terms you understand**
- 4. If you feel bad when you leave your neurologist's office**
- 5. If you feel your neurologist just doesn't like you -- or if you don't like him or her**

"While Botox and dermal fillers are not surgical, they are still wholly medical procedures that require the experience and oversight of a physician specifically trained in cosmetic procedures of the face. A qualified physician is key not only to safety, but also to an aesthetically pleasing outcome." (the same theory applies to injections being given for dystonia)

Source : <http://www.injectablesafety.org>

Just for Fun...

"He has all the virtues I dislike and none of the vices I admire."
-- Winston Churchill

"I have never killed a man, but I have read many obituaries with great pleasure."
--Clarence Darrow

"He has never been known to use a word that might send a reader to the dictionary."
-- William Faulkner (about Ernest Hemingway)

"I've had a perfectly wonderful evening. But this wasn't it."
-- Groucho Marx


"I didn't attend the funeral, but I sent a nice letter saying I approved of it."
-- Mark Twain

"He has no enemies, but is intensely disliked by his friends." --
Oscar Wilde

"I am enclosing two tickets to the first night of my new play; bring a friend... If you have one." -- George Bernard Shaw to Winston Churchill
Churchill replied: "Cannot possibly attend first night, will attend second, if there is one."

"I feel so miserable without you; it's almost like having you here."
Stephen Bishop

"He is a self-made man and worships his creator." --
John Bright



"I've just learned about his illness. Let's hope it's nothing trivial."
Irvin S. Cobb

"He is not only dull himself; he is the cause of dullness in others."
Samuel Johnson

Submitted by a N- subscriber !

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 continuation of that - New Horizons! Best Wishes - C4D*

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