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In Motion

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14 April 2006 Volume 2, Number 1

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Welcome to *In Motion*!

Welcome to our 2nd issue of ***In Motion*** from Care4Dystonia, Inc. We have received an immense amount of feedback regarding our re-inaugural February issue along with offers to assist in the further development of *In Motion*. Please continue sending us your feedback, comments, story ideas and suggestions to us, so that we can improve on each future issue. Feel free to forward *In Motion* to others affected by dystonia, whether it is generalized, focal dystonia or even another movement disorder. This issue once again is packed with wonderful information and we'd like to thank each contributor for making this issue even better.

Beka, RN, C4D

Ask Linda

Dear Linda:
I have cervical dystonia which has spread to my right arm and hand. I fear disease progression and that dystonia will take over my entire body. What am I going to do then? Can you offer me some advice on how to deal with my fears? I'm afraid. Dystonia has already taken so much from me.
Thanks,
Cathy,
Modesto, CA

Dear Cathy:

Fear can be cervical dystonia's worst enemy. By allowing fear to overtake your mind and body you are creating more tension and stress on your neck muscles, therefore creating more spasms and twisting, which may be the result of your dystonia spreading to your right arm and hand.

Most of us, whether we have dystonia or not will fear something from time to time. This is relatively normal for each of us. To me, typically fear represents "an opportunity to make changes in our lives or to discover ways to view things differently". The key is to understand where the fear is coming from and addressing the issues head-on.

In your case your fear is that the cervical dystonia is spreading and that it will progress to a point of causing severe disability. Initially I suggest you learn some deep breathing and meditation techniques to learn how to relax your mind. Also, if you hope to heal from any illness or medical condition you must believe in your heart that you can do so. As you begin to relax your mind, you will then be able to focus more on healing your body. As you meditate, breathe deeply focusing on relaxing your neck and shoulders by pulling down your shoulders with each breath and also pulling your chin in toward your chest. Keep this up for a couple of weeks to a few months.

Category of Links

The ACAM
Link to the ACAM org described in our Feb Chelation Article.

Longevity Nutritionals
Site about nutritional supplements offered via the Fratellone Group in NYC. Learn additional information about Chelation Therapy as discussed in Feb!

Along with the deep breathing and meditation you may also want to do a few gentle neck exercises that help with relaxation and range motion.

As your neck and shoulders begin to relax you should see the stress and tension easing from your right arm and hand. I do not feel that dystonia actually spreads throughout the body like cancer does where cells change and mutate. Muscles compensate for each other. When one is not working properly another muscle takes over causing unnecessary stress and strain which contributes to additional spasms and twisting. This I believe is the case with your hand and arm.

I hope by learning how to relax your mind this helps ease many of the fears you have about your condition. Please feel free to email me at **Linda@portraitsindetermination.com** if you would like further clarification or need additional support.

Impact of Disability and Dystonia:

IT'S SAFE to say that sex particularly interests a lot of people!

Often people look at someone with a disability and think, "I wonder can s/he?" Let's say you're male for the moment, if you can't walk, the attitude is "well, nothing else works". And that's totally wrong.
People often talk about "the disabled" as if they were some homogenous group stuck away in a corner, completely separate from every other sector of society. And, of course, they're not. They're just ordinary men and women trying to get on with their lives. But in the area of sexuality, people with disabilities lose out pretty badly.
First of all, whether or not you have a disability, we're all bombarded from TV and magazines with this so-called perfect body. Whatever that is, I don't know. I often say to an audience, "If there's anyone here with a perfect body, or if there's anyone 'normal', would they mind standing up." No one ever has in all the years I've been speaking publicly.
Men with disabilities often find it easy to attract women. It sounds like I'm bragging, but when I was younger and less grey, women hung around and clung to me and when - no pun intended - the matter of sex arose, it was, "Oh shit, this wasn't on the agenda." I've often heard women say that they feel comfortable with gay men, and I think likewise there are a lot of women who feel comfortable in the company of men with disabilities.
Statistically, more men with disabilities go into relationships than women. I think in the case of women what happens is that men either look at them with curiosity, or else think, "She hasn't got a hope of getting a man", so they'd make an approach and if it works, it works. But the worst thing I could possibly imagine is anybody going into a relationship because they feel sorry for someone. You might as well write the script for a disaster movie, because there's no love there, it's all pity.
A person with a disability can be an appendage to somebody else. People will say, "Isn't it wonderful the way she looks after Paddy. She brings him everywhere." All the time in all sorts of walks of life your abilities are being diminished, and likewise your sexuality is being diminished and demeaned. The assumption is that if you have a disability you are deaf, dumb, you have a mental handicap, are asexual and basically an idiot!

Contact Us

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Editor : Beka

Co-Editor : Linda

HOW CAN THE SITUATION BE IMPROVED?

I THINK there has to be a fundamental change in people's attitudes to disability and sexuality generally. You shouldn't necessarily separate the two; you have to take a person as a whole being.
As for the 'cult of perfection' thing. The fact of the matter is that I have a disability. And I've become used to managing life from a different viewing angle. Being in a wheelchair is a great way of spotting women's bottoms, for example.

Apart from education, another area that could change is media representation showing pictures of people with disabilities exuding a sexy image. Positive imagery, rather than this negative collection box type mentality. In every walk of life people tend to look to role models. And if somebody with a disability turns out to be a sex symbol, there will be other people who say "jaysus ", if she or he can do it, then I can too.
The culture we live in is strange. You meet these so-called trendy liberals and you get a pain in you're behind listening to them waffling on and on. But when you want to promote some sort of positive image around disability and sexuality, they say it could be very embarrassing. There's a lot of prejudice out there still.
People with disabilities often have low self-esteem. 80 per cent of people with disabilities are unemployed in Ireland, so they can't go out and buy the trendy clothes they'd like. But at the same time, I have more perfumes than my wife! I am as vain as be-damned! And I'm not ashamed of that. I think it's great. I try and project an image. People are often afraid to admit that they're proud of themselves; I think that is a shame.
What's in play is a "medical model" of disability based around hospitals, wheelchairs, crutches. What we really need is a "social model" of disability, which is an entirely different animal, because it basically says you, get out there, you socialize, and you interact with other people.

People with disabilities are going to have to educate themselves, and I would have no hesitation in using the phrase 'getting off their backsides' and being more positive, and take pride in how they look. Don't be afraid go out there and play the game.

By Paddy Doyle

www.paddydoyle.com

Website Updates:

Due to the interest in alternative-complimentary medicine, we have created a web page specific to these modalities, beginning with Yoga and Herbal Medicines for pain. We hope you find the information of value.
http://www.care4dystonia.org/Camcare.htm

About Our Sponsors

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

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

The Brain- Neurotransmitters:

Nutrition and the Brain
Part 1
Basic Neurobiology
Robert Pastore, Ph.D., The Fratellone Group, NYC, NY USA

Unfortunately the main understanding of nutrition and the brain focuses on the fact that the brain requires glucose to function properly. Though that is an accurate statement, the fundamentals of nutrition and the brain doesn't begin with glucose at all. It begins with the main communication, and body building blocks, the amino acids.

The way amino acids interact in the brain is an absolutely fascinating science. Once a basic understanding of nutritional neurobiology is grasped, it might change the view one has of amino acids and ask the question "what is an essential amino acid?"

Eight amino acids are generally regarded as essential for humans: tryptophan, lysine, methionine, phenylalanine, threonine, valine, leucine, and isoleucine. Two others, histidine and arginine are essential only in children. This is what I was taught in school. Then I started practicing, and noticed this may not be the case. Let me explain.

Neurotransmitters are chemical messengers that are used to relay, amplify and modulate electrical signals between a neuron and another cell. Though there are many, the common ones include acetyl choline, dopamine, norepinephrine, epinephrine, GABA, and serotonin.

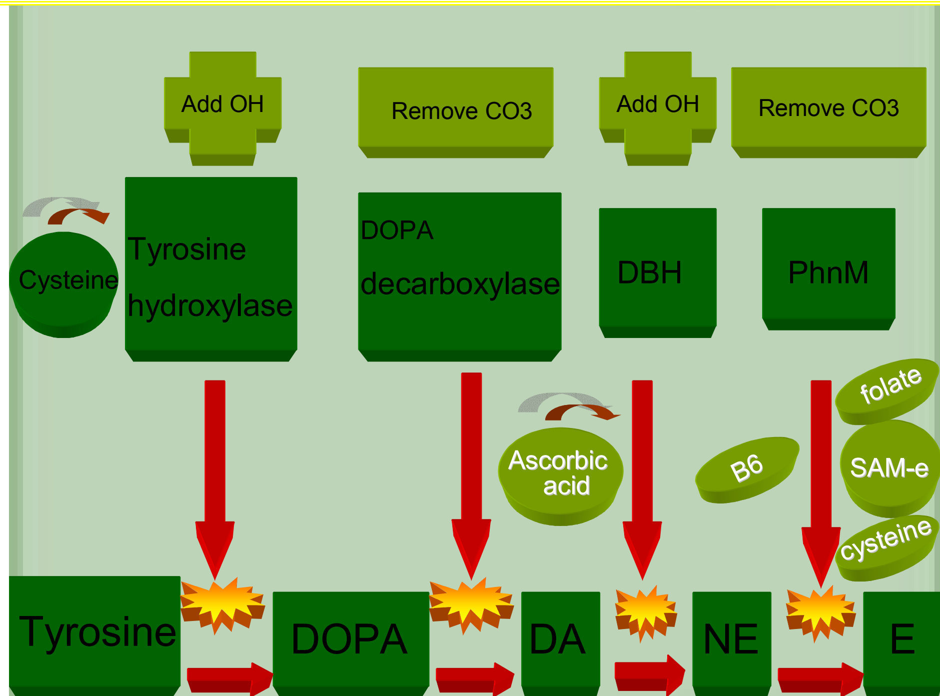
Dopamine, norepinephrine and epinephrine are constructed from the nutrient soup inside our cells via the following pathway.

1. Tyrosine hydroxylase (adds an OH group) converts and amino acid L-Tyrosine into L-DOPA. This is called the rate limiting substance in catecholamine synthesis because if it is not present, the reaction will not continue. So there must be a mechanism to request from our genome appropriate levels of L-Tyrosine synthesis when needed. Cysteine makes up the sulfur group at the heart of heme-thiolate, the key enzyme that catalysis tyrosine hydroxylase.

2. DOPA, formed by hydroxylation of L-tyrosine, is then converted into dopamine by DOPA decarboxylase (take away a carboxyl group).

3. Dopamine is then converted into norepinephrine by DBH, dopamine--beta--hydroxylase (add a hydroxyl group to the beta carbon). Ascorbic acid is involved.

4. Norepinephrine is then converted into epinephrine by phenyl ethanolamine--N--methyltransferase (PhnM - add a methyl group to the amine group on the alpha carbon). L-cysteine, folate, B6 and SAMe are involved in that enzyme reaction.



This graphic above illustrates what the basic formation of catecholamine synthesis within the human brain.

In clinical practice, I'm finding many patients are presenting with sulfur amino acid type deficiency symptoms such as delayed gastric emptying time, sensitivity to their environment such as in the condition environmental intolerance, better known as multiple chemical sensitivity, increased anxiety, sleeplessness, poor appetite.

When I hear those symptoms, I immediately request a neurotransmitter urine test to identify a base line measurement. If I notice low dopamine, or elevated norepinephrine with poor conversion to epinephrine, I think L-cysteine and L-tyrosine may be "conditionally essential" amino acids in this particular patient, and they might benefit from their supplementation.

Epinephrine helps stimulate the opening of the pyloric sphincter, allowing food contents to leave the stomach and enter the duodenum. Excess norephinephrine increases sensations of anxiety and sleeplessness. Low dopamine is usually associated with depression, poor focus, poor memory, low energy.

Though I'm being very basic here, and there are virtually hundreds of reactions induces by each neurotransmitter, it does indeed make you notice the effects of nutrition on the brain.

Let's take a look at serotonin production in the human brain. On a very basic level, the essential amino acid L-tryptophan meets with the enzyme tryptophan hydroxylase to form 5-hydroxytryptophan. The enzyme 5-HTP decarboxylase, initiated via B6, catalyzes 5-hydroxytryptophan into serotonin.

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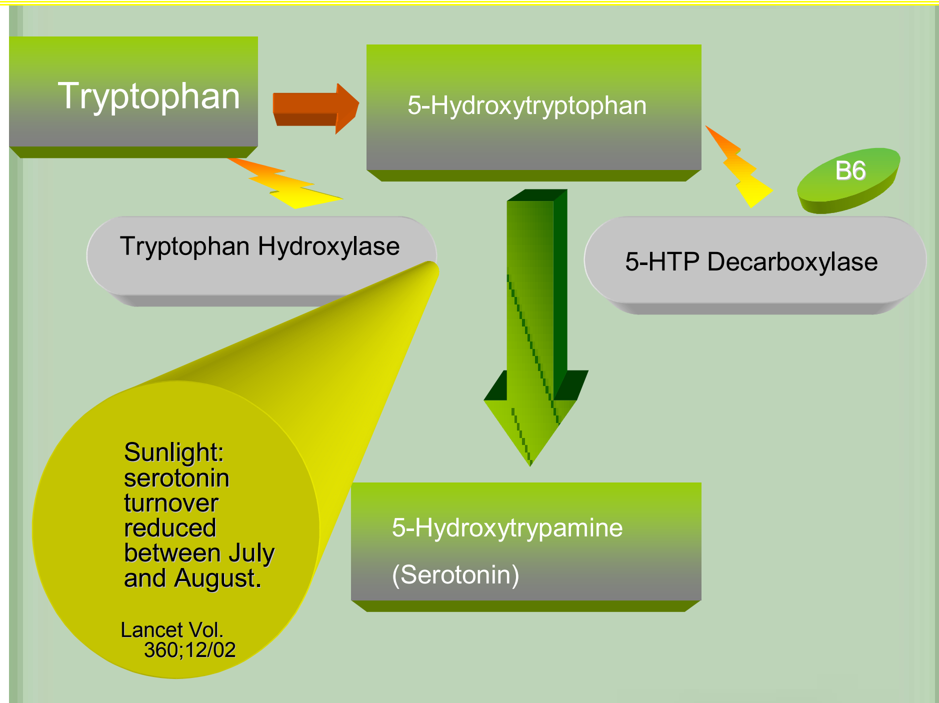
Patrick Fratellone, MD



The graphic above depicts the said conversion of the essential amino acid L-tryptophan into serotonin. Note the added study from the Lancet regarding sunlight. To summarize, researchers found that vitamin D stimulated from sunlight exposure increases serotonin synthesis. Many patients with seasonal affective disorder have been receiving vitamin D therapy after measurements of 25 hydroxy Vitamin D levels were assessed.

There actually is a hierarchy of neurotransmitters and like everything else in the body, they strive to work together. The following graphic depicts that visually.

The Neurotransmitter Hierarchy of the Catecholamine and Serotonin Systems

- Serotonin:
  - The Master Neurotransmitter controlling catecholamines
- Dopamine:
  - The Serotonin Modulator assuring the function of Serotonin
- Both Serotonin and Dopamine have to be present in adequate concentrations for the catecholamine system to function.

Serotonin plays a major role in not only the health of the brain and our sense of wellbeing, but also the health of the digestive tract and its efficiency of digestion.

In part 2 of Nutrition and the Brain I will discuss the "Second Brain" and the role of the mitochondria in the brain.

www.pastoreformulations.com

Note:

I asked Dr. Pastore to write the above article as it enhances the issue and question of "Why there is no cure for dystonia yet and other major neurological disorders?" It is obvious form Dr. Pastores' article that the brain is very complex with many highly involved pathways, neurotransmitters, mechanisms of action, signaling that all seem to interact and cross-react with one another etc. This only reinforces the notion that : **One single point of damage in the brain can play and create immense havoc on the entire nervous system leading to such disorders as dystonia and other neurological disease**. - beka

Ten, 9, 8, 7, 6 Sec…Lingual Dystonia

19 October 2002, joking with the anesthetist, I never dreamt that the surgery I was having would impact my life so profoundly.

In March I had been admitted to hospital with a painful and swollen tongue and was prescribed anti-allergy medications. After two days of torture, the "allergic reaction" diagnosis was proved incorrect when the infection inside my tongue found its way to the surface with a lot of vile and bloody pus. The Consultant Maxilla-Oral Surgeon saw me the next day and explained that I most likely had a "thyroglossal cyst" requiring surgical excision. Infections of the tongue are life-threatening because it can swell to the size of a small football! I accepted the Consultant's advice to have the surgery; apparently the procedure would be straightforward and simple (If a doctor ever tells you that, my advice is to get a second opinion!)

When the anesthetic wore off, as expected, I was in some discomfort, and it would be a week before the swelling went down. I left hospital after two days with paracetamol pain killers and returned to work after two weeks. Even though I had difficulty speaking, I expected this to slowly improve. However, after four weeks I began to notice a new discomfort, the tongue muscles were starting to spasm.

My dystonia is a sustained contraction of the many lingual muscles that intensifies with speech. At first I could shake it off by simply relaxing, but after a further week it was present from the minute I awoke. The discomfort was intense because the tongue is the most sensitive part of the body. At first I didn't make the connection with speech; all I wanted was to be able to form words correctly. I practiced talking to myself or reading aloud and the more I talked the tighter the muscles became. I would be

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reduced to a state of agony, with pain all the way down my throat and barely able to make any intelligible sound. The pain only subsided when I slept, when I could get to sleep because my tongue had a mind of its own thrusting against my teeth uncontrollably. I later discovered that when eating the spasms eased and I could talk quite easily, this was the infamous sensory feedback phenomena.

I returned to the clinic (actually ER a few times) for an explanation of what was going on but the Consultant did not have an answer, he was baffled. The Maxillo-Oral clinic do a lot of tongue surgery for cancer patients and the Consultant said that even people with half their tongues removed never had my problem. His guess was that the spasms would settle after a few months and he recommended the drug tegretol. He also told me that further pathology revealed the so-called "cyst" (1x2 cms) had been a very rare birth defect!

By February 2003 the pain was becoming unbearable; I had taken very little of the tegretol after reading about the side effects. Anyway, why was I being given medication for epilepsy! His next idea was to try me on dothiepin which is an anti-depressant used in the clinic to relax muscles and reduce pain! So now I was supposed to take anti-depressants? No way!

This was not only having a negative impact on my life, but it was affecting the whole family in particular my wife. One day, I was so demented by the discomfort that my son contacted the GP who prescribed diazepam to calm me down. It was the first drug that gave me any relief. I knew that it would because by this time my research on the Internet pointed to dystonia. I went back to the Clinic and told the Consultant what I had read. He was aware of dystonia, but had no professional experience of the disorder. He recommended that I should see a neurologist, but the waiting list was six months, in the meantime he referred me to the hospital Pain Specialist.

The Pain Specialist turned out to be quite a character. He mentioned morphine, and then he suggested that I could try cannabis! Finally, he said that I was suffering from a pain syndrome, and botox might help by breaking the pain/spasm cycle. The Consultant in the clinic told me that they regularly used botox on facial muscles (accident victims), but had never applied it to a tongue. He was prepared to offer the treatment but said that I would be something of a "guinea pig", and the results would be unpredictable. I was afraid of what might happen and declined.

By the end of March the pain was so bad that I was forced to give up my regular job and was transferred to work where I didn't have to use the telephone all the time. My GP reluctantly continued to prescribe diazepam though not on repeat prescription, he was afraid that I might sue him if I became addicted!

My thoughts darkened, could I live with this for the rest of my life? Here was I on a beautiful sunny day, in unrelenting pain. I resolved to try and end it all. Fortunately, it is not that easy and things can go wrong leaving one alive but brain damaged. Also I didn't want to inflict it on the family. After a few weeks I began to think positively again and I made a private appointment with a neurologist.

The Neurologist asked me a lot of questions and did some physical tests to

rule out common disorders, this only took about 20 minutes! He then announced that I had a focal dystonia caused by the trauma of surgery. My heart sank, because I knew what the prognosis was; only a percentage of people get remission. He recommended that I should continue with a higher dose of diazepam, up to 15mg/day, and to start neurontin. I could also try any of the other drugs used for dystonia through my GP. He did not recommend artane due to its side effects, nor did he recommend botox because it is too risky for the tongue. His final advice was to try to get on with my life!

Diazepam and neurontin was a good combination for me. Much of the pain may have been due to nerve damage, which was eased by the neurontin. By the end of May I felt confident enough to go back to my old job, with my new meds and the sensory trick I had discovered. My dystonia is also sensitive to what is going on in my brain, e.g. when focusing on a specific task the contractions tend to subside, but as soon as I start talking they return. The meds wear off in the evening and I can survive social occasions with the help of a glass or two!

The GP was never happy about prescribing diazepam and I asked him to change it to klonopin which I found works better. Although they are both benzodiazepines, it must be diazepam that has the bad press. The GP confessed that with 30 yrs experience in a large practice he had never seen a case of dystonia, and I think he is still a bit skeptical! Did I suffer brain damage from the aesthetic? Was the Pain Specialist close to the truth regarding pain/spasm pathways to the brain? Is it just the local nerve damage interfering with normal sensory feedback? Who knows?

In conclusion, I was very angry with the doctors, they had led me into a mess and didn't have the experience to recognize or treat the disorder. I had to do most of the initial research myself and then try and convince them! Had it not been for the information I found on the Net, my suffering would have been prolonged.

The general medical communities need to be made more aware of dystonia.
Patients have to be proactive in finding effective treatments.

I have overcome the anger now, mostly by expressing it in a support group environment, and accepting my condition. Also, my case is relatively mild compared to what others suffer. All new sufferers say the same thing, "I want my life back". **I would like to say that I have got my life back, but I haven't, rather what has happened is that my life has been changed and I have adapted. It is sink or swim, and I have learned to swim and regained a measure of happiness. One door closes and another opens, and I realize that I have found new meaning in my life by being actively involved in a support group. We must all start helping ourselves and getting involved in the fight against dystonia.** I am still hoping for a remission though…1, 2, 3, 4 5yrs?

Robert
United Kingdom

Distinguishing Tremors?

Distinguishing the Various Forms of Tremor

Tremors are rhythmic, involuntary muscular contractions characterized by oscillations (to-and-fro movements) of a part of the body. The most common of all involuntary movements, a tremor can affect various body parts such as the hands, head, facial structures, vocal cords, trunk and legs; most tremors, however, occur in the hands. Tremors often accompany neurological disorders associated with aging. Although the disorder is not life-threatening, it can be responsible for functional disability and social embarrassment.

There are many types of tremor and several ways in which tremors are classified. The most common classifications are by behavioral context and position. There are five such categories of tremor:

1. Resting. Resting or static tremor occurs when the muscle is at rest, for example when the hands are lying on the lap. This tremor usually stops during deliberate movement and is often seen in patients with Parkinson's disease. While commonly referred to as 'pill rolling' tremor of the hands, it can also affect the head, trunk, jaw and lips. It is often associated with other symptoms such as generalized slowness of motor activity, rigidity and postural instability.
2. Postural. Postural tremor occurs when a patient attempts to maintain posture, such as holding the hands outstretched. Postural tremors include physiological tremor, essential tremor, tremor with basal ganglia disease (also seen in patients with Parkinson's disease), cerebellar postural tremor, tremor with peripheral neuropathy, post-traumatic tremor, and alcoholic tremor.
3. Kinetic. Kinetic or intention (action) tremor occurs during purposeful movement, for example during finger-to-nose testing.
4. Task-specific. Task-specific tremor appears when performing goal-oriented tasks such as handwriting, speaking, or standing. This group consists primarily of writing tremor, vocal tremor, and orthostatic tremor.
5. Hysterical. Hysterical tremor, or psychogenic tremor, occurs in both older and younger patients. The key feature of this tremor is that it dramatically lessens or disappears when the patient is distracted.

Drugs can also cause tremor. The list includes caffeine, fluoxetine (Prozac), haloperidol (Haldol), lithium, methylphenidate (Ritalin), metoclopramide (Reglan), phenylpropanolamine, pseudoephedrine, theophylline and valproic acid.
If shaking or trembling has been present for less than 2 years, it may be caused by temporary conditions such as:

- Increased anxiety or stress
- Certain medications
- Caffeine excess or caffeine withdrawal
- Nicotine or smoking excess nicotine withdrawal

- Alcohol excess or alcohol/drug withdrawal

Such shaking or trembling could also be caused by conditions such as:

- Endocrine imbalances
- Electrolyte imbalances
- Hormonal imbalances

Our June Issue :

- The Brain and Nutrition Part 2
- Focus ST
- Posttraumatic dystonia
- Dysphonia
- Coping
- Psychological Effects (One Man's Remarkable Story and Advice with each of the above topics)

If shaking or trembling has been present for two or more years and you do not have an endocrine or hormonal imbalance, you may have essential tremor or Parkinson disease. An estimated 5 million Americans are affected by essential tremor, a neurological disease characterized by an uncontrollable shaking of the limbs, in particular the arms and head. Unlike resting tremor associated with Parkinson's disease, symptoms of essential tremor are noticeable during movement, such as lifting a cup of coffee.

The causes of essential tremor disease remain unknown, and current therapies are either partially effective or carry undesirable side effects. In more than half of the cases, essential tremor is hereditary. In the group with an inherited type it is transmitted as an 'autosomal dominant' trait, meaning that children of an affected individual will have a 50 percent chance of also developing the disorder. Both men and women are equally affected by essential tremor. The usual age at onset is in the 40s, but it may also occur as early at the teens. When tremor begins in the elderly, it is sometimes referred to as "senile" tremor. Scientists at the University of North Carolina at Chapel Hill may have identified the genetic basis underlying essential tremor disease, the most common human movement disorder. The discovery comes from studies involving a strain of genetically altered mice that show the same types of tremor and similar lack of coordination as people affected by essential tremor.

This animal model of the disease might prove useful for screening potential treatments, reported Morrow, associate director of UNC's Bowles Center for Alcohol Studies and professor of psychiatry and pharmacology in UNC's School of Medicine.

"We believe that these mice could explain one etiology, or origin, of essential tremor disease in humans because of the marked similarities between the mouse model and the human disease," said Morrow, who led the study team.

Reports of the findings appear red in the March 2005 issues of the Journal of Clinical Investigation. The symptoms in GABA-A receptor alpha-1 deficient mice had the same properties as those in people who suffer from essential tremor, suggesting to the authors that the mice might respond to drugs used to treat human patients.

"Very low doses of alcohol are effective at ameliorating tremor in human patients. Interestingly, we observed the same effect in these mice – they are exquisitely sensitive to alcohol," said Morrow.

Additional compounds that ease the symptoms of essential tremor in humans, such as the anticonvulsant primidone and the beta-blocker

propranolol, also had partial alleviating effects in the mutant mice.

"The work by the Morrow group clearly implicates the GABA system in human essential tremor," said Dr. Kirk Wilhelmsen, associate professor of genetics and neurology at UNC. "These mice provide a framework for further pharmacologic study of essential tremor and currently are the best available model for the condition." Future studies will examine essential tremor patients for polymorphisms or variations in the DNA sequence that might adversely affect GABA-A receptors.

Effective treatment of tremor requires distinguishing this type of movement disorder from other movement disorders. Without being seen and examined by a movement disorder specialist, the cause of your tremor may be difficult to determine. Please note that it is extremely important to obtain an accurate diagnosis before trying to find a cure. Many diseases and conditions share common symptoms: if you treat yourself for the wrong illness or a specific symptom of a complex disease, you may delay legitimate treatment of a serious underlying problem. In other words, the greatest danger in self-treatment may be self-diagnosis. If you do not know what you really have, you can not treat it!

Risk factors for Tremors:
Dehydration
Mercury Toxicity
Hyperthyroidism
Stress
Anxiety
Hypoglycemia
Abnormal magnesium levels

Key Points to Remember

For simplicity's sake, remember three types of tremor:

A. Parkinsonian tremor (or "resting," "pill-rolling," or "extra pyramidal tremor")

B. Intention (or "cerebellar tremor"), and

C. Action (or "kinetic tremor").

Although in theory these are easily defined and distinguished, such is not always true in practice. The Parkinsonian tremor is typically a coarse (i.e., relatively large amplitude) tremor, present primarily at rest, with a frequency typically of 4-6 Hz. Generally, this tremor improves or may disappear when the individual is carrying out an action, i.e., on intention. The typical Parkinsonian tremor is present in the hand (so-called "pill-rolling tremor" -- to be demonstrated) or in the forearm where it takes the form of alternating supination and pronation. Parkinsonian tremor in the hand is commonly noticed when the patient is walking. In contrast, action tremor is of lower amplitude (i.e., finer) and of higher frequency, 8-10 Hz. It is absent when the body part is at "rest," but appears when the limb assumes a posture that requires effort to maintain (e.g., outstretched arms). Action tremor may be "physiologic," drug induced (caffeine, stimulants, etc...); stress-induced, or representative of essential tremor

(see below). It is rarely due to identifiable pathology. Intention tremor is typically absent at rest. Although visible with sustained posture, it is markedly increased on intention (during a movement), and the amplitude of the tremor increases as the target is approached. This type of tremor virtually always indicates pathology of the cerebellar hemispheres or their efferent or afferent connections, and is most commonly seen in multiple sclerosis or brain injury victims.

For more information about ET go online and read the latest research updates on **www.tremoraction.org**.

Additional Link Info:
http://www.aafp.org/afp/990315ap/1565.html
http://www.medical-library.org/journals3a/essential_tremor.htm
http://www.esnpn.org/JOUN/41-1/15.HTM
http://brain.oxfordjournals.org/cgi/content/abstract/124/9/1765
Http://www.emedicine.com

Basic Definitions you should Understand:

The following terms are commonly used to describe certain motor signs typical of movement disorders:

1. Chorea: refers to rapid, irregular, relatively small amplitude, random-appearing, rather continuous, non-stereotyped jerks, usually of the distal limbs.

2. Athetosis: A wormlike, writhing, twisting movement, typically of the limbs.

3. Choreo-Athetosis: A mix of 1 and 2.

4. Tremor: Rhythmic, oscillatory movements, usually of the limbs (when noted in trunk/head this is often called Titubation). Tremor is described in more detail as above.

5. Dystonia: "Abnormal tone" Involuntary, sustained, patterned, and often repetitive muscle contractions of opposing muscles. Results in twisting, spasmodic or other abnormal postures of many body parts. For example, involuntary turning of the head by neck muscle contraction is referred to as Torticollis. When there are repetitive twisting head movements, it is referred to as spasmodic torticollis.

6. Tics: These are semi-involuntary, (often compulsive), repetitive, stereotyped movements (e.g., facial grimace, eye squint, head flip, etc...). A Tic that involves muscles, the contraction of which produces a sound, is known as a Vocal Tic (e.g., grunt, sniff, cough, snort, etc.). Tics can be suppressed by the individual but at the expense of an inner emotional tension that compels the individual to make more tics later. Stereotypes are like tics but are not associated with this "inner tension" and are very common in "normal" people (e.g., twisting hair with fingers, drumming fingers, wiggling leg ... movements that your sibling might make to annoy you during a long car ride).

Source : **www.wemove.org** and **www.medline.com**

Distinguishing Dystonic Tremors

Dystonic tremors are quite variable in their presentation and on some occasions can look like essential tremor. They are, however, seldom seen in isolation and usually are associated with dystonic posturing. The tremors are also sometimes somewhat more irregular than what is seen with essential tremor. Because essential tremor and dystonia tremor may look the same, and both can be genetic, the question was recently asked whether patients with essential tremor might carry an abnormality at the DYT1 locus. This has been found not to be the case although the actual gene for essential tremor has not been identified.

Dystonic tremors refer to dystonia and superimposed tremor .It is often worsened when the patient voluntarily moves in the direction away from the force of the contraction. Dystonic tremor may occur in the body part affected by the dystonia especially dystonic tremors with cervical dystonia. The tremors have a frequency of approximately 4 Hz to 7 Hz, are mainly postural, and kinetic without a rest component. The second type of dystonia and tremor is seen when the tremor involves a body part not associated with the dystonic segment. An example would be cervical dystonia in a patient with upper limb postural tremor. These tremors are generally resistant to pharmacotherapy, and they are best managed with local injections of botulinum toxin.

Source : **www.dystonia-foundation.org**

By beka serdans, RN

Updates and News

Your Feedback :

I just read my copy of the newsletter and was very impressed. I found it very informative, easy to read, and I enjoyed it. Thank you so much for bringing it back. I do have a question though, I was trying to access the message boards to talk to other people with focal hand dystonia, but I could not. I am slightly computer challenged, so if you could please let me know how to access this great section, I'd appreciate it. Thanks for you help.Warmly, E. P

Beka – The newsletter is simply wonderful Please thank your sponsors on my behalf. What a wonderful service. Exactly what we need today. – K.C

Hello Beka – I have read the newsletter and found it to be candid, open and refreshing. I can’t thank you enough for bringing In Motion back to us. - L.D

Please sign me up right away for the newsletter. I’d also like to receive 200 magnets as soon as possible. What a super way to raise awareness for dystonia (a crappy disease). - S.H

Jennele’s story about her pregnancy and dystonia gives me and my husband hope as we have been considering of having a child, but have

been afraid to because of my 3 year battle with dystonia. I'd like to write to Jennelle. Thank you for bringing her story to light. Reading it was an inspiration. – F.L

Beka – Can you help me understand publicity a bit more? Your newsletter is doing so much already for all of the rest of us. – A.G

Just to say ***thanks Beka*** you've opened a new dimension for me,
Thanks again.
Pat Twitty
Generalized Dystonia.
Durham England.

Hi
I have just read your online magazine and my thoughts are :
EXCELLENT
I am the sec of the British Charity ADDER. Looking forward to reading your next issue.

Pauline Dawson
Soc/ Sec
A.D.D.E.R , England

MyoBloc now developing a Reimbursement Program, visit **www.myobloc.com** today.

Clinical Trials for Dystonia: Currently there are about 23 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/

Radio News: You can listen to Dr. Patrick Fratellone, MD House Calls with Dr. Patrick Fratellone "via the link **Http://www.wwrl1600.commainframe.html** each Sunday afternoon - 2-3pm EST USA. Also available **on www.tribecaradio.net**. Learn more about Alternative Medicine!

Direct Questions about Chelating Therapy to **www.fratellonemedical.com.**

Botulism Toxin's Insidious Route Into Nerve Cells
http://www.biocompare.com/gonl.asp?id=118647

Neuroscientists Discover New Cell Type That May Help Brain Maintain Memories Of Smells
http://www.biocompare.com/gonl.asp?id=118648

New Film being made: REWIRED Healing Hands Fund and Film (Click to access story) Film being partially funded by the DMRF. A Surprise!

A Golfer's Blogs with ST : Golf ST Blogs (Click to access story)

For info about OMD visit the OMD Network at **http://www.dystonia-foundation.org/support/foundation.asp#16**

Please periodically check the *www.myobloc.com* website as they are developing a reimbursement program for those who receive these injections.

Need a complete guide to resources for dystonia – download your copy of **DeMystifying Dystonia** today at **www.care4dystonia.org- about dystonia webpage.**

Magnet Awareness Program

As of the release of this newsletter, since mid Jan 2006, C4D has distributed 6,435 refrigerator sized magnets, which has not only increased awareness of dystonia overall , but also has invoked wonderful participation from people and families affected by dystonia regardless of non-profit allegiance, type of dystonia involved, symptoms, and treatment chosen for a particular dystonia. As it is said, in Numbers there is Strength. We agree wholeheartedly and will continue with the Program! **Dystonia is Dystonia**. The word needs to be heard! May be we are making strides in dystonia unknowingly??? Uhmmm- your thoughts are welcomed at any time!

FINAL THOUGHTS: We recognize the amount of information that is available and needs to be conveyed to all of you. There is immense information available to learn about treatments and dystonia. Our February newsletter was an immense success. We applaud each of you who value this newsletter. We hope that you will recognize this second issue as a continuation of that special need and will forward it to others in need of this information. – 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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