Spikes & Spasms

The Tremoraction.org and Caret4dystonia.org Newsletter SEPTEMBER 2005

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PS: Let Spikes & Spasms know what you think. Feedback is welcome. Share your personal experiences with Tremor Action Network, PO BOX 5013 Pleasanton, CA 94566 or email: tremor@tremoraction.org and infoc4d@aol.com

WELCOME TO THE SEPTEMBER ISSUE!

JUNE ISSUE FEEDBACK

Please sign me up right away. You're providing an invaluable service to us with tremors and dystonia. - **Debbie**

Wow! and I mean WOW!!! What a terrific resource! I delayed dinner so I could read the whole newsletter!
- **Nanette**

Thank you so much for this newsletter. It gave me a sense of not being alone. - **Katie**

BRAVO! The new newsletter is marvelous and I look forward to receiving future issues. Like many that suffer with ET, I didn't know what "it" was for many years.
- **Hilary**

Very good job and useful information. All who contributed should be praised in the release of this little gem. - **Jan**

My compliments to the authors! - **Marla**

The Goldie article was absolutely fascinating and so well researched. - **Mike**

Enjoy reading the September issue brought to you by **Life In Motion** coalition members **Tremor Action Network** and **Care4Dystonia, Inc.**

WE MOVE Launches Life in Motion Awareness Campaign

Tremor Action Network and Care4Dystonia, Inc. are pleased to join a coalition in support of WE MOVE's *Life in Motion* awareness campaign. This nationwide initiative is designed to raise awareness about movement disorders and improve the quality of care for the estimated 40+ million Americans who are living with these disorders, including essential tremor, Parkinson's disease, dystonia, restless legs syndrome, spasticity and others.

Fifty patient advocacy organizations, foundations, and professional societies have joined a coalition in support of the *Life in Motion* campaign. Like WE MOVE, coaltion members are committed to raising awareness about movement disorders, emphasizing the importance of early and accurate diagnosis, and illustrating available treatment options.

Healthcare professionals and people living with movement disorders are encouraged to visit the online Life in Motion Resource Center.

Life in Motion launched at the AAN meeting in Miami on April 11th. Campaign initiatives have already resulted in over 50 million media impressions. Efforts will continue through 2005 and will include media outreach, public service announcements, and community outreach highlighting real stories of people living with movement disorders. Additionally, through the efforts of the Life in Motion campaign, the initiation of a Movement Disorders Awareness Month is expected to be announced for October. Activities to promote awareness of movement disorders will surround this announcement.

If you are interested in participating in *Life in Motion* or contributing a story of a person living well with a movement disorder, we encourage you to contact WE MOVE at **wemove@wemove.org**.

Healthcare professionals and people living with movement disorders are encouraged to visit the online Life in Motion Resource Center where they will find information and support resources including…

- downloadable fact sheets about movement disorders
- database of national movement disorder advocacy groups and foundations.
- a video depicting what life is like with a movement disorder
- downloadable brochures:
  - *Managing Your Life in Motion*, a practical tool to help patients more effectively communicate with their healthcare team.
  - *Life in Motion* campaign brochure

To learn more, please visit the Life in Motion Web site at:
http://www.life-in-motion.org

Or call the toll -free number:
866-LIM-3136 (**866-546-3136**)

The Life in Motion campaign is funded by an unrestricted educational grant from Allergan.

About the Author

Since 1991, WE MOVE has been educating and informing patients, professionals, and the public about the latest clinical advances, management, and treatment options for neurologic movement disorders. WE MOVE believes that increasing knowledge and understanding promote timely, accurate diagnosis, and up-to-date treatment, resulting in a better quality of life for individuals affected by these often devastating conditions.

WWW.WEMOVE.ORG

The *Life in Motion* is a campaign supported by WE MOVE

The Ultimate Gift

By Dona Salerno

My grandfather and father have had tremor for as long as I can remember, as well as an aunt and a few uncles. In most families, there are topics that are just not discussed. For mine, this was that issue.

My grandfather, Casimier Wojakowski, has had tremor since he was forty years old. Five out of six of his siblings had tremor. My father has had it for most of his life, and I was about ten years old when I noticed that my hands trembled like my dad's. Since it is so widespread in my family, it is an accepted trait of my family tree. It never even raises an eyebrow. Instead of being unusual, the opposite became true; those of us with steady hands became the odd ones!

It was not until my symptoms became magnified at the age of forty that I realized that there was a name for what my body was going through, and I needed to do some serious research. Being a science educator, I knew that my best source of information was the Internet. The moment that I discovered the name, essential tremor (ET), was both one of relief and determination. The "beast" now had a name. I knew that I had a great amount of work in front of me.

One of the most chilling pieces of research was the fact that "children have a 50% chance of inheriting..." Oh, my God! What was I thinking? How could I do something about this? I have a Master's in Science! There has to be something proactive that I can do to help. That's when my Internet search intensified and led me to Tremor Action Network (TAN). One of the members of TAN's Message Board was discussing Columbia University's Brain Bank for people with Essential Tremor. Dr. Elan Louis, medical researcher who established the brain bank for ET, is one of TAN's medical advisors. Now I was impressed. I joined Tremor Action Network to learn everything that I could.

I was quick to fill out the application to donate brain tissue if it could help find a cure. I broached the subject with my parents concerning my grandfather. As one might expect, I received a flat out, "NO!" I dropped the issue with my parents and chose to discuss it with grandpa the next time I saw him in person. It was such a personal request that I wanted to speak to him directly and plead my own case.

I called Columbia and spoke to Sarah Borden who is Dr. Louis's assistant. She was more than willing to deliver the necessary forms to my home in Chicago. Not only did I receive the packet, Sarah sent them through over-night mail. I would now have them to take with me that weekend when I went to Michigan to visit my grandfather for his 90th birthday party. She acted in such a professional manner and was available to answer all of my many additional questions. She made the process seamless.

This may sound like a strange present, however, to my family, with a long history of the movement disorder essential tremor; it was huge.

It was a very sensitive and personal moment when I asked my grandpa if he would consider donating his brain tissue to the ET research repository after his death. After seeing my tremor and acknowledging my father's, he commented that it had run very strongly through our family. For the first time the floodgates opened and we were discussing the forbidden topic, Tremor.

I trembled with emotion as I waited his reply. He looked up at me with his typical grin and devilish glint in his eye and quipped, "Well, I won't be needing it anymore, so you can have it!"

He agreed to donate a small portion of his cerebellar brain tissue upon his death to the Columbia University Brain Repository in New York. This may sound like a strange present, however, to my family, with a long history of the movement disorder essential tremor; it was huge. The Wojakowski family currently has four living generations with this disease.

Despite the hardships of ET, my grandfather Casimier Wojakowski did not let them get in his way. He was in the U.S. Coast Guard during the 1930s, owned and farmed 200 acres of land, raised dairy cows, owned and flew a private airplane, began a gravel business on his acreage in the Upper Peninsula of Michigan.

My grandfather became one of our nation's foremost experts on the best procedures and techniques on how to down our annual National Christmas Tree, and he had that honor seven years in a row. His essential tremor did not deter him, but it was always present. Grandpa has led a rich and varied life, and it makes me proud that he is still willing to give -- this time in the form of brain tissue donation.

P.S. I love you, Grandpa. Thank you for your selfless gift to me, your grandchildren, great grandchildren, and to future generations of people who suffer with essential tremor.

About the Author

Dona Salerno received her Bachelor of Arts in Education in 1987, the same year she was married. She had a son in 1989 and a daughter in 1993 while finishing her Master's degree in Science. After college graduation, her first job was teaching gifted first grade through sixth grade students in the subject area of Language Arts. Then, over the years, she secured self-contained classroom positions in grades 4, 5, 6, and upon completion of her Master's, 8th grade science.

She is currently on temporary disability leave and spends her time advocating for TAN.

Boston Life Sciences, Inc.

Parkinson's or Essential Tremor Trial (POET)

Boston Life Sciences, Inc. (BLSI) is the sponsor of the POET clinical trial, designed to determine the effectiveness of the investigational molecular imaging agent, ALTROPANE®, and the Single Photon Emission Computed Tomography (SPECT) imaging, in differentiating Parkinsonian Syndrome tremor from non-Parkinsonian or Essential tremor.

The POET trial is a multi-center, open-label, out-patient, clinical trial that includes both male and female patients between the ages of 18 and 80. Patients from this trial are referred by an internist, general practitioner or neurology clinic. If the patient meets the various eligibility criteria, SPECT imaging will be scheduled. When the imaging is completed, the patient will return to the site for follow-up testing and an appointment with a Movement Disorders Specialist (MDS). The MDS will perform a clinical evaluation of the patient and provide an independent patient diagnosis without reference to the results of the imaging test. The results of the SPECT imaging will remain blinded until the completion of the trial.

It is estimated that approximately 140,000 individuals per year present to their physician with new, undiagnosed movement disorders such as Parkinson's Disease and Essential tremor.

It is estimated that approximately 140,000 individuals per year present to their physician with new, undiagnosed movement disorders such as Parkinson's Disease and Essential tremor. In 2002, the European Journal of Neurology reported that there is a 20-30% misdiagnosis rate in the early stages of Parkinson's disease. Other publications have reported even higher rates of misdiagnosis. The accurate differentiation of Parkinsonian from non-Parkinsonian tremors has important clinical implications in terms of initiating effective treatment, minimizing unnecessary treatment side-effects by reducing the number of inappropriately treated patients, and providing a more accurate prognosis for patients and their families. The efficacy of ALTROPANE® would represent the first in a new class of highly-selective CNS diagnostic molecular imaging agents that has the potential ability to assist the clinician in making this important differentiation.

ALTROPANE® is a molecular I-123 based imaging agent that binds with high affinity and specificity to the dopamine transporter (DAT). DAT is a protein found on the surface of dopamine producing neurons in the brain. Since most forms of Parkinsonian Syndrome (PS) result in a decreased number of dopamine producing cells, it would be expected that these patients also have fewer DATs. As a result, when ALTROPANE® is administered to patients with Parkinson Syndrome, its binding is substantially diminished as compared to patients without PS but exhibiting symptoms similar to PS. This marked decrease in ALTROPANE® binding in patients with PS is the basis for its potential use as a diagnostic test distinguishing Parkinsonian Syndrome tremor from non-Parkinsonian or Essential tremor.

For more information about the POET trial, please visit the POET web pages at:
http://www.bostonlifesciences.com/trials/poet/index.html

Or e-mail BLSI at **trials@bostonlifesciences.com**

About the Author

Boston Life Sciences, Inc. (BLSI) is a development stage biotechnology company engaged in the research and clinical development of novel diagnostic and therapeutic solutions for central nervous system (CNS) diseases.

ALTROPANE® is a registered trademark of Boston Life Sciences, Inc.

Portraits in Determination

an interview with Beka Serdans, R.N.

By Linda Furiate

Spikes & Spasms Note:
Millions of people diagnosed with movement disorders, and "approximately 140,000 individuals yearly living with symptoms of undiagnosed movement disorders," can physically and emotionally identify with this empowering interview (television program transcript) about cervical dystonia.

Linda Furiate: Beka, thank you for being here and thank you for coming down from New York. As mentioned in the opening you and I both have a movement disorder called cervical dystonia, which affects the muscles in the neck. I have had the condition for about 10 years and you have suffered from it for about 15 years. I want to talk about what it's like to live with cervical dystonia, some of the treatment options and how we have managed to cope with this condition. In December 2004 you made a pretty radical decision to undergo a 10 hour surgery to have a deep brain stimulator implanted. Where were you emotionally from a level of tolerance with the muscle spasms and the twisting that led you to have brain surgery?

I think that when we have a movement disorder, it's the whole sensory thing. We feel like something is staring at us, something is looking at us, and sometimes that can set us off.

Beka Serdan: My symptoms from June to December just progressed and I knew something had to be done. I had reached a point of no return and that was the option that I chose.

LF: What had you done prior to the surgery? Give me a brief history of some of the treatment options you did use that led you to that and how symptomatic were you?

BS: Well symptomatically if you are eating on the floor that is pretty symptomatic, if you are eating puréed dinner for Thanksgiving that is rather symptomatic. I had constant pain, constant twisting, constant pulling. I started off using oral medications, trial of medication, using any type of medication you could imagine for any neurological disorder, meaning from Parkinson's to tics to tremors to spasticity. From there we went onto BOTOX, which is botulinum toxin A, from there to Myobloc which is botulinum toxin B, which actually lasted practically 10 years for me which wasn't bad and then I developed antibodies to that one. Then we decided one more drug in June of last year (2004) and then I said that's it, its time for surgery.

LF: You are a registered nurse, you work in the neuro-ICU, briefly in a sentence or two describe to me what you believe cervical dystonia is and what do you feel the genetic factor is?

BS: I don't really know if there is a genetic component to cervical dystonia. I don't know if it's a muscular disorder or if it's a sensory disorder or whether it's a global brain disorder, I don't know. There really aren't clear cut answers regarding dystonia.

LF: What does your body tell you that it is?

BS: My body tells me it's a neuro disease.

LF: And why do you feel that way?

BS: Probably because of my medical background.

LF: How has cervical dystonia impacted your dreams?

BS: It has robbed them. It destroyed them.

LF: What were some of your dreams when you were younger?

BS: Going to medical school, being accepted into medical school, being robbed from that. Issues of marriage, having children, that is always an issue for anyone and everyone but I think it's even more so when you have dystonia, particularly when there possibly could be a genetic component. I don't know whether there is or not for our type. And loss of freedom.

LF: Going back to the marriage and family thing, what is it like dating with cervical dystonia? Here we are all twisty and spastic, just the thought of getting dressed can be overwhelming, how do you feel about the whole dating scene and putting yourself out there when you know you have this movement disorder?

BS: First of all you have to realize that people who have movement disorders tend to become socially isolated, so many of them do not even enter into the dating scene. For me I have dated some people, here, there, but not commitments, because often the opposite sex is afraid of committing to someone who has a chronic illness. Do I take care of them for the next 80 years or however long they are married? That is a big choice that they have to make.

LF: What's one thing you wish you could do, physically, that you have not been able to do as a result of having your symptoms?

BS: Bicycle. When I went into surgery I had four goals: One was to go to Rome and ride a moped which I did. My other goals include going to Israel, riding a bicycle and walking in high heels.

LF: Do you feel that riding that bicycle is something you are going to be able to do in the very near future?

BS: I hope so, I mean I don't know. I've tried riding my bicycle and it hasn't turned out quite yet. Maybe I just need time to re-adjust.

LF: So when you say you were riding your bicycle and it hasn't turned out, what happened?

BS: Well I came out of the bike shop, he gave me a test run with the bicycle, I did fairly well with it and then I ended up taking it home. I rode partially home and well, I ended up running into a few people.

LF: Did you say "excuse me, I'm sorry?"

BS: No not really, not in New York City, people don't do that.

LF: I think one of the hardest things for me that has had a big emotional impact, I have become symptomatic two times, I have had cervical dystonia about 10 years, two major times when I have become symptomatic is when my sister had her babies. When the babies were really little it was really uncomfortable and hard for me to hold them and not fear that I was going to drop them. It has had this emotional impact in that I will never be able to get that time back.

LF: Do you think people are staring at you?

BS: Since the surgery probably less. After surgery for 4 or 5 weeks I had no hair, I shaved my entire head so obviously there was a staring component regardless of whether you had a movement disorder or not. I don't know who was worse, men or women, women would often blatantly, particularly in New York that is filled with who looks better and who doesn't, you always get

stared at.

LF: I asked that on an emotional level too, I think when we have a movement disorder and I have heard this from many people, it's that whole sensory thing, we feel like something is staring at us, something is looking at us and sometimes that can set us off. We could be perfectly fine and then all of a sudden we get this sense that, oh my God, someone is looking at me, it just kind of throws this dagger into our neck that sets off the feeling. Would you say you feel that same way as to the aspect of people staring at you?

BS: Yeah, yeah. Even at work, working in an open heart unit with patients who were awake following surgery, all they would ask is "what's wrong with your neck?" Or families would ask real blatantly and that would set off symptoms and then of course I would have to rearrange an entire room so that the patient and the equipment would be into my range of view.

LF: How does that make you feel when someone asks "what's wrong with your neck?"

BS: It makes you feel lousy. At first I didn't have an answer because I didn't know what dystonia was. It took 5 years to get a diagnosis. I had dystonia already when I was age 18, 19 years old with tics and facial type movements and vocal cord involvement. I didn't know so for 5 years I went around telling everybody at work I had a crooked neck, stiff neck or I wore a cervical collar. Patients and family would stare and say why the heck is she wearing this collar. And then finally I got a name to the condition, then I began explaining I had this disorder dystonia and then at first they didn't know about it. Then as time progressed and as Michael J. Fox with him having Parkinson's disease that sort of helped clarify things, ah, a movement disorder.

LF: You talk about being 18, 19, I hope you don't mind telling your age, you are almost 40, I am in my mid-40's, the average age of onset is typically 35-50 age range. You say you started having tics when you were 19, 20 years old - when you were in Germany and you were standing on Track 13, which you reference in your book, when you first noticed the head turning, how old were you then?

BS: About 24, 25 then it progressed, it got worse and then it seemed like I went into a remission in 2003 and whether that was related to alternative medicine, I'm not sure or long-term use of the botulinum toxin, which studies do show long term use can produce remission. I do not know if remission exists or not and things got worse again, so it's been a cyclical type thing.

LF: I don't necessarily think in terms of remission, I think in a reduction and/or elimination of symptoms.

BS: I never had an elimination of symptoms.

LF: Yes, you did, because when you were doing the BOTOX and the Myobloc you were actually doing fairly well for a while until the antibodies kicked in.

BS: I never had an elimination of symptoms because elimination to me means completely gone.

LF: Eliminations means eliminating them to the point of not being so severe.

BS: Okay, I will agree on that.

LF: I don't think we can totally get the rid of the condition but can eliminate or cut back on the symptoms where we are not as symptomatic.

BS: Yeah, yeah.

LF: Because when I think of remission I think in terms that it's gone. I don't think that's a viable thing at this time.

BS: Exactly.

LF: How do your emotions play into your having a good day or a bad day in terms of your dystonia?

BS: I think dystonia is such a cyclical type disorder, you have good days and bad days and that reflects on your overall mood. You know you wake up with it and you go to sleep with it, what you do in between waking up and sleeping is a different story and that obviously depends on your mood and your emotions. I think there have been times when there has been depression, feeling helpless, hopeless particularly about the issue of a cure, waiting for one, being told there was one in a sense when there wasn't one, that really could put you down in the dumps.

LF: So, does dystonia cause depression or does depression cause dystonia? What came first the chicken or the egg?

BS: Well that's a good question. We know from a research standpoint that some anti-depressants, medications that will induce a form of dystonia for people that have been prescribed them and then years later they develop dystonia. Then there are other cases they develop dystonia first and are put on anti-depressants to treat the depression. So knowing which one comes first is a tough one.

LF: What are some of your little idiosyncrasies as a result of having cervical dystonia? For me, for instance, when I walk in to a restaurant I want to make sure I am sitting at a certain place at the table so I have people at the correct side of me.

BS: When I walk down the street I always try to have people walk on the left side of me because it minimizes spatial orientation. Other things would be sitting on the left side of the bus so I wouldn't have to worry about turning my head this way. Changing a patient's entire room, IV equipment anything and everything, their beds in order when I walk into the room everything would be into my line of sight. Those are the little things and then of course there are the sensory tricks where you are leaning against the wall or your hands are up like this (around the neck) and you don't know what to do and that is the way you walk either down the street and you just keep on going.

LF: Where do you find your strength and how do you cope with living with this condition?

BS: Cry a lot on the phone with my mother. I think it takes sheer will, I think it takes determination. I think it takes a lot about researching the disorder, learning enough about the disorder, learning enough about psychology, about depression, anxiety, self-image, self-worth. If you have had a good foundation with your self-image, self-worth beforehand it can be less destructive but if you come out of a family that doesn't have that strength you could end up doing very poorly emotionally with the disease.

LF: What would you say your supports systems are?

BS: My mother is the key support system. My two sisters, my one sister she doesn't know how to react to the disease. She's afraid of "catching it" even though I don't have the genetic form. My other sister she is pretty cool about it. The rest of the family is relatively cool about it, they have read my books, they looked at the website, so they know and they have self-educated themselves.

LF: How important is it to continue working?

BS: I have continued working through all of this. People

are constantly amazed with how I continue working through this in an ICU setting, as an ICU nurse which is very intensive labor wise. Its very heavy work, you are always short staffed. Assignments are heavy and I think it has just taken sheer will to go in every single day and go in to give care to other people.

LF: Why do you think you do that?

BS: To try and escape my own issues with dystonia.

LF: And to support yourself.

BS: Yeah, financially.

LF: We have to work, even though we may have a disability, we have to work.

LF: Beka, you are known as one of the biggest advocates for dystonia and about 3 years ago you started your own foundation, called Care 4 Dystonia, that supports people with all forms of dystonia. What's your motivation for the foundation and what keeps your going?

BS: My motto with dystonia is care until a cure, because we are a long way from a cure. That is basic science that is basic molecular science, we are a long way off from that so that is my motto. I think in terms of the foundation it focuses on four things: patient care - meaning the quality of medical care, meaning the diagnosis and treatment of dystonia. There have been people who have been to 26 physicians to be diagnosed with dystonia other people have gone 17 years undiagnosed. Is that right or wrong? Then obviously there is public awareness, collaboration and education. Those are my four goals, improving those four goals. It's not raising money for research, because other people can do that. My goal and as a nurse from a nurse perspective - that's what nurses are good at. Nurses are good at care, not at cure, cure is what medicine and physicians do, but nurses' care and there is a huge difference between the two.

LF: Do you see yourself one day being able to open your own center?

BS: I certainly would love that. If I had the adequate funding and correct help, yeah, - a multi-disciplinary center that caters to dystonia or to movement disorders in general with dystonia being within it. Having a social worker, a nutritionist, a psychologist, a physical therapist, occupational therapist, even those types of people who can help with social disabilities, financial issues, that's what's needed for movement disorders. It's being done by a few pioneering centers to a certain degree, but it not reaching everyone, it's not accessible by everyone.

LF: What's the best thing about having cervical dystonia?

BS: That's very hard to say because I am at a different stage regarding cervical dystonia, because I am relatively symptom-free right now. With the disease, it opens up your mind to those who are disabled, those who are different, those who are viewed by society as different because I think we as a society need to start recognizing people who are different whether they look different, whether they act different or whether they think different, whether they talk different and whether we are doing that at this point, completely, I am not sure.

LF: What message of hope and inspiration can you provide to those who are watching this program that have cervical dystonia or really any disability, what message of hope and inspiration can you provide to them in order for them to get through their day?

BS: Each person has their own cross to bear, each day brings something new whether it is positive or negative, it's how we utilize what we are given that day for the better. It's the hope that we all need, I think that is what everyone should be doing.

LF: Beka, we are out of time. I really appreciate you coming down from New York and helping spread a little bit of awareness for cervical dystonia.

About the Author

Spikes & Spasms subscribers know Linda rather well, from reading her *Ask Linda* column. To view Linda's television video of her interview with Beka Serdans - *Living with Cervical Dystonia*, please visit:

http://portraitsindetermination.com/media/index.html

New Software Cages Mice

By Nico Cuppen and Nick Allen

Using a computer mouse is almost impossible for people with tremors. Many people associate tremor with Parkinson's disease, but tremors are also associated with other neurological disorders, including essential tremor (ET), multiple sclerosis (MS), and stroke.

London-based Tunic Software has developed a software program - *MouseCage*, which compensates for hand tremors when using a mouse. *MouseCage* is simple to use, installs in seconds, and requires no additional hardware.

This is how it works:

MouseCage (patent pending) features a special Guide cursor that provides visual feedback by showing actual hand movements. The Windows cursor takes an average of this motion and automatically moves to where the mouse user intends to click.

MouseCage features a special Guide cursor that provides visual feedback by showing actual hand movements.

Nico Cuppen, co-founder of Tunic Software explains: "getting two independent cursors to appear on the computer screen proved quite a challenge. At first sight it might seem a straightforward thing to do, but up until now it has been regarded as a pretty unusual thing to want to do!"

An innovative feature of *MouseCage* is its "Cage" key. When the user is near or on target, the mouse can be Caged by pressing a user-defined key on the keyboard. Caging the mouse greatly reduces the cursor motion for accurate clicking. Pressing the Cage key a second time locks in the mouse, stopping all motion. The user can click in their "own time." The Guide cursor even changes color to indicate when the user is in the Caged or Locked mode.

According to Nick Allen, co-developer: "The Cage key allows the user to take tight control of the mouse on demand, and Tunic Software trials have shown that people find the Caging concept both intuitive and empowering. There is a degree of satisfaction in hitting that Cage key and finally getting the mouse to slow down."

MouseCage employs a tremor-detection feature that switches the computer between normal operation and *MouseCage* driven operation, depending on the user's pattern of hand movements. Nico Cuppen explains: "Even with *MouseCage* running, a person without tremor can use the mouse, because the Cage key and other functions are designed to work in the non-tremor mode. **All users can take advantage of the *MouseCage* features if they need a little more control.**"

At present, *MouseCage* is available for Windows 2000/XP. For further information, or to download a trial version, visit:
http://www.mousecage.org/

About the Authors

Tunic Software's *MouseCage* is the result of an Anglo-Dutch collaboration between British physicist Nick Allen, and Dutch software wizard, Nico Cuppen. Tunic Software is so named because it was set up by "Two Nics."

Nick conceived the dual-cursor concept in 2004, along with an algorithm that would work rapidly enough to deal with the millions of mouse events that occur during a computer session. However, the concept and a potential algorithm would remain just that, until he teamed up with software expert Nico to form Tunic Software and bring *MouseCage* into existence.

Better Health and Nutrition for Life with Dystonia

By Linda Rafferty

Because of hectic schedules, not feeling well (mentally and physically), the convenience of fast foods, and every day toxic stress, it is unlikely we eat a healthful diet; even without the ravages of dystonia.

Our digestive system may be already compromised from a variety of factors, including aging, over-the-counter and prescription meds, smoking and lack of exercise. In addition, our constant spikes and spasms create a buildup of lactic acid which results in pain and fibrous (hard/tough) muscles. Worry burns up calories, and poor diets make it almost impossible to replenish our bodies. Making optimal nutritional choices can improve our day to day lives. It can take a while, but it is well worth the effort. Make those calories count!

Our constant spikes and spasms create a buildup of lactic acid which results in pain and fibrous muscles.

Choose organic foods when possible to reduce toxicity.

Publix, Target, Wal-Mart (grocers) now have an organic section for fresh produce, and even Mott's has organic applesauce in the canned fruit section. Organic farms have strict guidelines for processing dairy products, produce, grains, etc. No toxic pesticides or antibiotics are used, and produce is grown in nutrient rich soils.

Choose calcium-magnesium rich foods such as dark green leafy vegetables (kale, collard greens, etc.), low or non-fat soy products, and/or low or fat free yogurt (if you tolerate dairy). Calcium - magnesium acts as a nerve nutrient involved in the electrical transmission of muscles.

Limit carbs to lower your glycemic variety such as whole grains.

Can't give up white rice? Converted rice has a lower glycemic index (lower glycemic foods help with blood sugar regulation). Baked sweet potatoes are a better choice than the traditional white baked potato.

Protein sources can come from lean chicken and turkey, fish, egg whites, soy, whey and yogurt. Protein is required for all cell growth, and insures strong skin, hair, nails, bones, connective tissue and skeletal muscles.

Add protective EFA (essential fatty acids) to your diet. They are found in salmon, mackerel, and a variety of nuts; especially, walnuts. EFA are essential to the body, and must be obtained from the foods we eat. The greatest concentration of EFA is found in the brain.

Eggs are not the enemy. Eaten in moderation they are a valuable source of amino acids, essential fatty acids (EFA), and vitamins and minerals. Egg whites are an excellent source of protein.

Green teas are loaded with powerful antioxidants called polyphenols. Antioxidants improve the immune system and repair cellular damage. Drink lots of **purified, filtered or distilled water** to assist your body in eliminating toxins. Use this water when making teas!

Great **snacks** are Luna or Zone Bars (available just about anywhere including Wal-Mart). Include a **digestive aid** to your diet to boost absorption of nutrients.

Supplements can fill the gaps even good diets often leave, but be certain to use a high quality, well-balanced product. Test your supplements. They should dissolve (in a glass of water) within 30 minutes. Rapid disintegration is vital so the nutrients can be quickly absorbed into the bloodstream, and the benefits are rapidly available to our cells.

Try a soy **protein** smoothie. Just put in a blender with juice, or distilled water or ice, or non/low fat soy milk. Add a

banana or other favorite fruit, even a touch of cinnamon. The possibilities are endless! When choosing soy protein, make certain the manufacturer indicates whether the soybeans used in the product have been water washed (processed) and not alcohol processed.

If you have been exposed to long-term toxic stress and/or if your diet has been in a nutrient-poor, caloric-burning state for an extended period of time, making the above changes can help refuel your body. ***Remember your body deserves the improved health and vitality that will follow!***

About the Author

For 25 years, Linda Rafferty has provided bookkeeping and accounting services for small businesses. In 1980 a personal health challenge spurred her passion for nutritional and wellness therapies. In addition to her bookkeeping practice, Linda is a dual-licensed aesthetician (skin care specialist), a Nutritional and Wellness Educator©, and a published author. She has had cervical dystonia (spasmodic torticollis) since 1986. Linda is a member ST/Dystonia, Inc., DMRF (Dystonia Medical Research Foundation), Mississippi Gulf Coast Dystonia Support Group and AARP.

For more detailed information, please visit Linda's website:

http://www.pathtogoodhealth.com/

New Technology: Home Monitoring of Movement Disorders

By Joseph P. Giuffrida

ParkinSense is a small, lightweight, wireless system used to monitor movement disorder symptoms

There are many movement disorders and a wide range of symptoms that can have a large impact on the quality of life for affected individuals. Movement disorders such as essential tremor, Parkinson's disease (PD), stroke and cerebral palsy can cause troublesome symptoms that make it difficult to complete activities of daily living. For example, in PD the symptoms of tremor, bradykinesia (slowed movements) and rigid joints can affect a person's ability to groom, eat and use a computer mouse. The inability to complete these and other daily activities can limit independence and societal participation.

Movement disorders can cause troublesome symptoms that make it difficult to complete activities of daily living.

Cleveland Medical Devices Inc. (CleveMed), located in Cleveland, Ohio has a division dedicated to quantifying movement disorder symptoms and providing home based therapy aimed at restoring function. The Division of Movement Disorders is developing a line of products that will record movement, restore control and enhance function. Funding provided by the National Institute of Health has allowed CleveMed to establish several programs that are developing clinical products focused on both improving the diagnosis and therapy of movement disorders and providing these patients with assistive devices.

One product, ParkinSense™, is currently being evaluated in large-scale clinical testing with PD subjects. The device is being developed to automatically rate the severity of PD symptoms. Parkinson's disease is particularly challenging to treat. Left untreated, a person with PD may have symptoms of tremor, slowed movements and rigidity. One medication, L-Dopa is commonly used to treat PD symptoms. If the precise amount of this medication is given to the patient, then the symptoms may subside. However, if too much of this drug is administered, then the patient may have wild, involuntary movements called dyskinesias. Therefore, there is a fine line concerning the dosage and the times at which the medication should be taken. Symptoms are typically evaluated by clinicians during an office visit using the Unified Parkinson's Disease Rating Scale. Additionally, patients are asked to keep journals at home to track how their symptoms fluctuate during the day. However, a small system that can measure symptoms while being worn by the patient throughout the day is likely to provide a better indicator for clinicians to determine the necessary adjustments to the medication dosage and timing.

The ParkinSense system consists of two small, lightweight units worn as a finger band and a wristband. Tiny sensors in the finger unit provide monitoring of three dimensional motions. The wrist unit provides battery power, memory and a radio for real-time data transmission. Additionally, electrodes may be placed on the skin and connected to the wrist unit to monitor muscle activity. The system may be worn by a subject throughout the day to record PD symptoms. Additionally, the system includes clinical evaluation movies on the computer monitor. At several times throughout the day, the subject may go to the computer and complete exercises that would normally be done in the clinic during a symptom evaluation. During the computer based evaluation, data is sent from the subject worn system through a radio link to the computer. Video feedback is provided to the subjects during the tasks. Data is processed and reports are sent to a clinician's office over the Internet. The clinician may then modulate a subject's medication intervention based on the results. By monitoring PD symptoms at home, we can provide greater insight into the complex fluctuation patterns of the

symptoms over time and in the subject's natural home environment. In addition to PD, this device could also be used to monitor symptoms of essential tremor.

CleveMed is researching use of the ParkinSense system described above as not only an aid in the diagnosis and medication dosing of patients with movement disorders, but also as an assistive device intended to facilitate their computer mouse control. Dependence upon computers has continually increased over time, yet a standard, handheld computer mouse will not operate properly for someone with severe tremor. Movement disorders symptoms may reduce voluntary control or create too much abnormal movement. CleveMed is developing a wireless computer mouse that could be moved around in space. Coupled with software algorithms that would detect and compensate for abnormal movements, a subject's computer cursor control would be restored.

Finally, the technology platform on which ParkinSense was developed can also be used for the treatment of movement disorders. Stroke and cerebral palsy patients, for example, are often left with paralyzed, weak or spastic upper extremity muscles. Studies have shown that greatly increasing the amount of therapy may help to "rewire" the brain and improve function in the affected limb. As such, CleveMed is currently researching home therapy options that would: 1) monitor motion and muscle activity to detect upper extremity therapy tasks, 2) apply functional electrical stimulation to paralyzed or weak muscles to assist with therapy tasks, 3) encourage patients to increase the amount of time spent on therapy through the use of interactive graphics programs, such as video games, that are more entertaining than traditional therapy methods, and 4) provide clinicians with feedback regarding the patients' therapy progress via the Internet. In providing these therapy options, intensive home-based therapy could then have the potential to provide greater patient recovery while reducing overall recovery time.

CleveMed's development of novel techniques aimed at greatly improving symptom information for doctors and researchers is aimed at improving functional results of medications and therapies for the millions of people affected with movement disorders. With the creation of our small, lightweight, wireless platform for recording motion and muscle activity, we hope to provide a variety of applications for the diagnosis, treatment and assistance of these patients.

For more information on our movement disorders research and products, please visit **www.CleveMed.com** or call us at **1-877-CLEVEMED**.

About the Author

Joseph P. Giuffrida, PhD is the Director of the Division of Movement Disorders at Cleveland Medical Devices, Inc. in Cleveland, Ohio. His research focuses on developing clinical products for movement disorders including Parkinson's disease, stroke and cerebral palsy.

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Ask Linda

By Linda Furiate

Dear Linda:

I have had cervical dystonia for over ten years. I have found that at times I become very depressed. What recommendations do you have to help me move beyond my depression? I do see a therapist on a regular basis and feel I am in good hands with her, but I would like to know first hand how you may deal with overcoming depression since you also have cervical dystonia.

Kate M. - Des Moines, Iowa

Dear Kate:

The depression we may experience as a result of living with the symptoms of a movement disorder can at times be overwhelming. Often we find ourselves isolated from our friends, family and our dreams.

If we can rule out any psychiatric and organic reason, I feel depression may be a result of feeling as though we are not able to fulfill a dream or desire. How many times have we said, "Oh, I am so depressed, it's Saturday night and I am home alone, or Bobby didn't call me like he promised he would." Of course these are minor issues and the feeling of depression typically only lasts for a few moments. However, in some cases when we experience a prolonged period of time with numerous desires going unfulfilled, long term depression may occur.

Ways to avoid depression is to keep your mind occupied, rather than allowing yourself to focus on your condition or negative circumstances. This can be done by reaching out to friends and family, engaging in a hobby, or volunteering your time - even if it's just something you do from home. When you find yourself having to spend a great deal of time alone, develop a long term project such as watching all of the movies made with one of your favorite actors; organize your cabinets or dresser drawers; sort through all your clothes, getting rid of things you do not wear anymore; write yourself a love letter mentioning all of the things you love about yourself and what others love about you - re-read it often; or plan future events so that you have something to look forward to. The key is to keep your mind positively engaged.

An additional avenue that may help you move beyond your depression is to do something every day to aid in your physical and emotional well-being. By doing so, a few things may result: one, you may begin to feel better physically; two, you may begin to feel better emotionally; and, three, you may now be ready to pursue your dreams and desires, eliminating the depression for good.

I hope this provides the insight you are seeking.

Be well, Linda Furiate

About the Author

Linda Furiate is a personal coach, mentor, talk show host and author, helping individuals with physical challenges move beyond any and all obstacles to live a more satisfying life.

To learn more, log into:

http://portraitsindetermination.com

If you have a question for Linda, email her at:

Linda@portraitsindetermination.com

One question will be selected to appear in the Spikes & Spasms newsletter.

The Gift of Brain Donation

By Sarah Borden

Many people have never thought about brain donation before, either for themselves or for their loved ones. Talking about plans for a relative after they die can be uncomfortable or contentious. However, having these sensitive conversations and making important arrangements as early as possible can save families from the burden of last-minute planning. The Salerno family's experience with this is detailed in the previous article (*The Ultimate Gift*). Another family's recent experience with Columbia University's brain donation program can illustrate this. Their mother was an older adult who felt that research into her illness was a significant contribution that she could make. She wanted to help scientific research find a cause, begin to understand what approach new treatments should take, and most importantly help anyone in her family with the same disease. Her family had certainly never considered brain donation, so she made a point of talking about it with them and with the researchers. At first, her family believed that their mother's enthusiasm for brain donation was just another one of many things that she agreed to do. But when they had the face-to-face talk, it became clear that she believed in the legacy that she could contribute to scientific understanding by making this generous donation. They understood that this was not just another one of their mom's crazy ideas and the whole family felt positive about their mother's decision.

When they had the face-to-face talk, it became clear that she believed in the legacy that she could contribute to scientific understanding by making this generous donation.

From a researcher's perspective, the incredibly charitable donation of brain tissue is absolutely necessary to understand neurological disorders such as essential tremor. Unfortunately, brain banks across the world have very few brains of people with essential tremor, especially compared to other movement disorders such as Parkinson's disease. Both a lack of research funding for and public knowledge of essential tremor explain this. Elan Louis, a neurologist specializing in movement disorders, and other researchers at Columbia University have now started the first brain bank exclusively for essential tremor. With the support of Tremor Action Network and the International Essential Tremor Foundation, many people in the essential tremor community have expressed interest in participating in this research. The brain tissue that has been collected has begun to shed light on possible causes of essential tremor. If you or a family member with essential tremor are interested in learning more about brain donation, please write or phone Sarah Borden, the research coordinator.

Feel free to ask any questions:

Columbia University's Essential Tremor Centralized Brain Repository

Phone: (212) 305-8513

Email: tremor@columbia.edu

Address:

622 West 168th Street, P&S Unit 16

New York, NY 10032

About the Author

Sarah Borden is the research coordinator for the Essential Tremor Centralized Brain Repository at Columbia University. She is in the process of completing her Master's in Public Health degree at Columbia University and loves to talk to people about brain donation!

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