

Spikes & Spasms

The TremorAction.org Newsletter

SEPTEMBER | OCTOBER 2008

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WELCOME TO THE SEPTEMBER | OCTOBER ISSUE!

- Movement Disorders Awareness Month -

Congressman Danny K. Davis of IL introduced a simple resolution to "observe a movement disorders awareness month that would promote awareness, diagnosis and advocacy of movement disorders." On September 14, 2005 Representative Davis was the keynote speaker at the Life in Motion Movement Disorders Patient Summit in Washington DC, attended by patients, advocates, organizations and health care professionals. The Summit proclaimed the month of October as National Movement Disorders Awareness Month!

Tremor Action Network requests your participation to increase community awareness about movement disorders. This newsletter issue introduces readers to the [Dystonia Association South Africa](#), highlights finding Internet information, and pays tribute to movement disorders experiences authored by individuals living with cervical dystonia, essential tremor and Parkinson's disease.

For those who have not shared their personal experiences, you can "Tell Your Story" year-round at [WEMOVE](#).

Enjoy reading Spikes & Spasms brought to you by [Tremor Action Network](#) and [Sponsors](#)



Perception and Social Stigma

By William D Basher

Perception and social stigma are a combination of both our society and human nature.

In dealing with essential tremor for most of the 48 years of my life I have found people who I have known both privately and professionally to be for the most part understanding and supportive. However in showing both understanding and support people always feel the need to give advice and point out what they feel would be impossible tasks, and at times even with the best intentions discourage you from following your dreams.

At 15 years old I decided what I wanted to do. I wanted to make furniture, to be a wood worker, and one can imagine the reaction when I shared my aspirations with my teachers and parents. Handing a 15 year old a razor sharp chisel who, as one teacher put it "shakes like a leaf in a hail storm," was to them not only an impossibility it was just not rational.

These and other factors contributed to the discouragement of me pursuing my dream as a child. All through my childhood I was interested in some form of art, and as I aged I found myself becoming more and more determined.

"Perception and social stigma are a combination of both our society and human nature."

Kids can be cruel and some lessons learned during childhood stay with us forever. Such was the case with me during my school years. Kids bullying me, and having to give book reports standing up in front of the class became so frightful my grades slipped and my fear of a classroom was so bad I would not participate. No amount of persuasion from either my teachers or my parents was going to change that. That's when I entered high school and discovered a wonderful class called wood shop and man by the name of Mr. Fromer.

Mr. Fromer did something no one else had ever done; he did not baby me, nor did he react in a way that I had become so

familiar with by keeping me away from the machines. He treated me like everybody else. He seemed totally innocuous about my tremor and when I asked him about it he very simply stated, "I don't care if you shake," "do you?" That was it! Then and there I realized that allowing myself to give in to the opinions and intentions of people good or bad, whatever their motive,

was going to do nothing but keep me from reaching my goal, my desire and my dream.

As I became older I was still distracted by anything artistic around me. My mind was abuzz, like a rubber ball in a stone room bouncing in every direction. I took up drums and played in a band for almost 22 years. I worked restoring late 19th and early 20th century Street Cars, dabbled in Photography and Cartooning.

Earlier in life I also worked as a pressman running large offset presses, and at 19 years old came my first real taste of social stigma and it was also my first real experience with discrimination. I worked at a printing company when one day the owner noticed my tremor. He invited me into his office, closed the door and asked, "How often do you drink?" I stated that I did not drink, and tried to explain that I had this tremor since I was 5 years old. The next

day I found myself pulled off the press floor and was told my new duties were driving the van where it was safer for me. With certainty I was cautioned that I would eventually lose a finger or worse, and the company was just not going to take the risk. Needless to say I voiced my distain and was told if I did not like it then I could leave.

All these events and experiences are like anything else; they are lessons learned. And did I listen to the distracters? No! I continued unabated and now have become what I set out to do. My business is by word of mouth only and I make chests and tables hand carved to order, never letting my tremor get in the way.

Accomplishments and achievements in life always have a basis, a foundation as well as guiding influences that lead us to completion and fulfillment in life as a whole. My wife, Christina Kondratowicz, has helped me achieve just that. She has been my muse, her beauty both inside and out and the influences she has given me are reflected in my work. "Thank you" and "I love you" will never be enough for the imagination and exquisiteness she has given freely, and has always been there for me, telling me that having ET does not matter. She is right, it doesn't!

About the Author

William D Basher was born in Washington DC. He has achieved his childhood goal in becoming an Artisan, despite "best intentions advice" that essential tremor would keep him from pursuing his dream of carving wood. Mr. Basher is the Lead Carver of Artisan & Associates. His any form of Art interests which began as a child include but are not limited to music, poetry, trains, photography and cooking.

"Two cents' worth"

By Elizabeth James

Why is it that the people who suffer the most complain the least? Why is it that once we have a name of a disease we now begin to live this label?

"I have Essential Tremor and Cervical Dystonia."

It came to me the other day as I was having uncontrollable spasms I could focus on the parts of my body that are not in pain. What a concept!

My mind is not in pain, my heart is healthy, my feet still work, and I can talk. I am NOT my disease, what can I do to help others?

I always want to help others but not in supporting them to complain and become their disease. This kept going through my mind as I realized if I let go of the "poor me" I have some diseases that will not kill me. Why didn't I go out dancing when my neck was not in spasm?

Are you finding yourself giving up pleasures in your life?

Are you feeling isolated because you are embarrassed or feel you can no longer function in society?

Is your identity now what you have and NOT who you are?

At this point, I had choices. What did I do to help someone else today? What did I do in order to make my symptoms seem lessened?

I found Yoga, mediation, swimming, and changing my attitude actually changed how often I felt disabled. I feel lucky, even blessed that my medication cocktail works for me. I can dance, I can walk, and life is out there waiting to be lived, NOW.

Once the chapter of our "disease story" has been accepted, we have the responsibility to create the life we

wish, when symptoms become severe, we have "other" options. There are always options. We also have responsibilities. Are we really doing the best we can?

Did I eat right? Sleep enough? Did I try to stretch, relax, and feed my mind with thoughts of appreciation? Did I help someone else?

If I answer no to these... no surprise, I feel more identified with my disease and less connected to living.

Nothing like helping someone else, even you, to help take some of the discomfort go away. If you have one minute or one hour of relief, Dance, Sing, enjoy, hold a puppy, help someone else who is worse and be happy for that moment, that hour of relief.

My guess is you will have more times of relief and fewer symptoms.

Just like me, we are all doing the best we can... or not... Either way, we are NOT our disease. We do have healthier choices.

Thank you TAN for all you do to help spread awareness with compassion and hard work, for all your efforts at keeping people informed, keeping the word out there for all to find comfort. TAN gets better and better. I pray each of us finds comfort and appreciation for actually having a place that works so very hard for the cause.

About the Author

Elizabeth James is the Number #1 Advocate for those with essential tremor and cervical dystonia. She has served two terms on Tremor Action Network's Board of Directors, Moderated TAN's online support group Tremor and WEMOVE's ET Discussion Forum. Elizabeth Chaired TAN's first Shaking the World to Find a Cure fundraiser in collaboration with John Spenger's Bistro Blends of Napa Valley, and with Dona Salerno organized TAN's participation in the Life In Motion Letter Writing Campaign. Tremor Action Network received a grant in recognition of Elizabeth's and Dona's efforts at getting TAN Advocates involved in the Campaign.

"We are NOT our disease. We do have healthier choices."

Dystonia Association South Africa

By Gisela Stanek, National Director

Spikes & Spasms Note:

The Dystonia Association of South Africa is currently in the process of producing an informational public service announcement to be aired on South African television stations. Gisela Stanek contacted Tremor Action Network after viewing TAN's "Quality of Life" DVD. TAN and the Dystonia Association have pledged to work together, and to cite Gisela, "I feel that the more we know about each other's work the greater the benefit for the patients."

WHAT IS DYSTONIA?

Dystonia is the name given to a group of movement disorders which are characterised by sustained muscle contractions causing twisting and repetitive movements or abnormal postures. Such dystonic spasms may affect one or more parts of the body, or the whole body. They are frequently painful, but disappear in sleep. Dystonias are often misunderstood by the public and may be misdiagnosed by medical professionals not familiar with the condition. They can affect all ages and ethnic groups.

The symptoms are often transient, and can be mistaken for emotional or psychiatric disorders. Intellect, personality, emotions, sight, hearing, sensation and sexual function may be quite normal, but may be inhibited by the affliction.

WHAT CAUSES DYSTONIA?

The cause of these abnormal movements is thought to stem from the basal ganglia area of the brain which controls muscle activity. Some Dystonias can be caused by the use of Neuroleptic drugs. Some are hereditary.

About the Author

Gisela Stanek is the National Director of the Dystonia Association of South Africa. To learn more about the Association please visit <http://www.dystonia.org.za>. The "About Us" web page provides details on when the Association was founded, the Membership and Newsletter, and lists the organization's Administration. The Dystonia Association incorporates essential tremor, Tourette's Syndrome, and other movement disorders under their umbrella.

Contact Information:

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"I feel that the more we know about each other's work the greater the benefit for the patients."

The Botulinum Toxin Dream

By Terri Sterling

The rhythm of my soul moves in waves like the bobbing of my head, going left and right, unsure of what direction it wants to stick. The rhythm changes with the muscle spasms of my twisting Cervical Dystonia but my mind remains clear, bright, and filled with motivation to fill my ever expansive dreams. I try to read a book but the bobbing of my head and the twisting of my neck causes the letters, words, and sentences to become scrambled and confused. I lose my place and mix sentences from different lines together resulting in humorous stories or tears of frustration. I move on to my art studio.

I stand in my art studio, before my 8 foot easel, moving my whole body to the rhythm of my soul with each painted stroke, until a picture of pure emotion rises out of the blank white stark canvas or until my neck muscles are too tired to let me complete my mission on this beautiful golden night. I slowly lay down my head to rest my neck, find myself falling asleep, and start dreaming of another painting where my head is shaking in front of curious toddlers who are searching for answers. My mind is filled with unfinished paintings I have been dreaming of every night because my body can't keep up with the demands of my imaginative flights. I get dressed and go to my day job.

I sit before my clients of all ages, responding with the appropriate words, and hoping my life story brings them the inspiration they need to find the muse in their lives, so they too can reach the highest imagined goal, which would bring them peace and happiness.

Today I receive the Botulinum Toxin, which pulses through my neck as the needle is slowly drained into each muscle resulting in comfortable paralyzation and more energy to fill my dreams, hopes, and painterly inspirations as my head

turns back to the center of my body. I write each morning of the energy around me, the flowers in full bloom, and the amazing friendships formed because of this movement disorder and hope that it outweighs the negative interactions I have experienced.

Public places present their difficulties as people around me see the weaving of my head because of the Cervical Dystonia and threaten to hit me as they misread my body language. A recent visit to a public bathroom resulted in a threat of potential danger because my head shakes to its own musical rhythm and looks like I am saying "No" when I am not. I explain my disorder but wish I didn't have to defend myself as the Toxin wears off. I remind myself of

how thankful I am for places like the Tremor Action Network and wish I knew about them when I first had Cervical Dystonia (CD).

My CD started at age 16, went untreated and misdiagnosed until 23 when I went to the Robert Wood Johnson Hospital and saw a UMDNJ movement disorder specialist. I was

first treated with numerous medications but the side effects were too much for me. I decided to attend college full time, earned a Masters in psychology, and began treating clients. I first received Botulinum Toxin in 1991 and the results were and continue to be remarkable. I am grateful for my doctors' help, Botulinum Toxin, and the people involved in research. Without their help I would be lost.

"I am grateful for my doctors' help, Botulinum Toxin, and the people involved in research. Without their help I would be lost."

About the Author

Terry Sterling is a trained Creativity Coach with 14 years of experience. She is the owner of Inspiration, a private coaching business. For more information visit her website at http://www.freewebs.com/terris_inspiration/.



Dual Diagnosis: essential tremor and Parkinson's

By Steve Retterer

Spikes & Spasms Note:

"Can essential tremor increase my risk for other illnesses?"

"Essential tremor (ET) is linked to other illnesses. Other movement disorders, such as Parkinson's disease, have been associated with ET. However, more people with ET get Parkinson's disease than those in the general population. This may be due to the fact that some people diagnosed as having ET are initially incorrectly diagnosed, and subsequently turn out to have Parkinson's."

Source: Cleveland Clinic Health Information

http://my.clevelandclinic.org/disorders/Essential_Tremor/hic_Essential_Tremor_Basics.aspx

"Emergence of Parkinson's disease in essential tremor: A study of the clinical correlates in 53 patients. Patients with essential tremor (ET) may develop Parkinson's disease (PD); however, few studies have examined the clinical features of this combination syndrome. Fifty-three patients with ET-PD were studied and compared to 53 PD and 150 ET patients. The co-occurrence of the two diagnoses in the same patient may be mechanistically related."

Source: Minen MT, Louis ED

Jefferson Medical College, Philadelphia, Pennsylvania, USA

(c) 2008 Jul 10 Movement Disorder Society

Researchers estimate that 4% to 5% percent of people aged 40 to 60 have essential tremor. The closest estimate I could find for Parkinson's in the same age group was about 1% to 1.5%. It stands to reason that if you take 1000 people that have essential tremor, about 1% to 1.5% may also have Parkinson's since they are different diseases.

Both essential tremor and Parkinson's cover a wide range of symptoms, but there are specific differences. One major difference is that they originate in different places in the brain, and treatment options for both are different.

For years I would tremor/vibrate when under stress. I thought it was my own form of anxiety attack. I really did not think much of my hands shaking since they have for most of my life. They shake slightly both resting and moving. I have read many stories where doctors aren't sure if symptoms like mine are Parkinson's.

My story is so different! I broke my finger at work and went to the worker's comp physician, who said that I needed to see a neurologist. My immediate response was, "For a broken finger?" His reply, "No, you have additional problems." I had been having some trouble with stiffness in my wrist, sometimes numbness down my arm, and noticed that my arm sometimes didn't swing much.

I scheduled an appointment with a neurologist who performed a few office tests and said I had PD, with a closing remark, "See you in 6 months." After searching and studying information on the Internet, I made another appointment with the same neurologist and asked, "Why does my neck and arm (wrist) hurt so much?" Grudgingly, the neurologist commented he might need to do a few more tests, but echoed, "You still have Parkinson's." He then sent me home with a video exercises tape for very advanced Parkinson's.

Deciding a second opinion was needed I went to another neurologist who walked into the exam room, looked at me for several moments and asked, "Have you ever been diagnosed with Parkinson's?" He was very thorough,

scheduling many medical tests to confirm and rule out anything else. After the diagnostic testing was done he stated that I showed all the classic signs of Parkinson's. After a year of treating me he retired.

So on I went to the third Doctor, a Movement Disorder Specialist. During all this time I kept mentioning the Medicine just did not seem to help the vibration that I lived with all my waking hours and sometimes in the night. It did help with the leg, arm and hand movements, but with constant body vibrations I was always extremely tired.

The MDS did check with my sister's neurologist to check on any family related movement disorders. He eventually started thinking that some how I was not taking the medicine properly. Then it was decided that my body was resistant to the medicine. I believe that I was over medicated, which was starting to affect my health, giving me double vision and other known side effects of Parkinson's drugs. Without the Parkinson's medicine I can barely talk above a whisper and sound drunk. Also, walking any distance is very difficult. Eventually Parkinson's gave me balance problems that forced me into disability.

With disability came a move to a new state for financial reasons, and of course I had to find another neurologist! I will never know if I was on so much Parkinson's Medicine that the 4th neurologist could see the essential tremor, or that the essential tremor had finally become strong enough on its own to show, or he just listened more to what I had to say. The new neurologist felt that a great deal of my trouble was coming from essential tremor. He had me try Primidone, and within 15 minutes the vibration that I had felt for the last 5 years stopped. I am now taking less than half of the Parkinson's medicine I was prescribed. The Primidone interacted with some of the Parkinson's medicine, so after a bit of experimentation my neurologist was able to find a combination that greatly reduced my constant body vibration and tremors.

The quality of my life has greatly improved since both conditions have been treated. I just hope that through my

experience others won't have to suffer as I did.

"He had me try Primidone, and within 15 minutes the vibration that I had felt for the last 5 years stopped."

About the Author

Steve Retterer joined TAN's online group Tremor in May 2008, and has been very kind and compassionate, sharing his knowledge and experiences with over 700 members. Steve and his great good friend Lindy host a voice chat for Parkinson's patients, and they are working with Tremor Action Network to develop a voice chat for essential tremor and related neurological movement disorders. Lindy and Steve vouch that voice chat works wonderfully, and believe is more preferable because of the difficulty members have with word processing. A tremor "spells trouble" when typing, and voice chat can make for a more user-friendly way to participate in movement disorders discussions.

Congratulations to Steve on his photo "Foggy Sunrise" (not shown), chosen as an image for the 2009 Creativity and Parkinson's Calendar. Steve never picked up a camera until after his diagnosis. To paraphrase Steve, "We lose some but gain in other areas."

How to Understand Searching for Information on the World Wide Web

By Mona Reeva, PhD, MPH, LCSW Owner of Green Mountain Artistry

Frequently I sit down at the computer to look for information. This has become so common a process that if a new word comes up, or I want to recall a piece of history, my first thought is - let's google it.

Google, one of the search engines on the world wide web, is a great place to get information. Though not the only search engine available, it has become one of the more popular ones.

If I want to find other search engines, I can write "search engines" in my google find bar and click with my mouse on the go or arrow button, and up comes a list of many of the search engines.

Here is a list of a few:

- 1) www.google.com
- 2) www.search.yahoo.com
- 3) www.ask.com
- 4) www.answers.com

To get a tutorial on how to get information on the web, the following link or url is very valuable and will help in understanding how the systems work. Copy the url below and paste it in your web site search bar.

<http://lib.berkeley.edu/TeachingLib/Guides/Internet/SearchEngines.html>

The following is taken from the above link:

"How do Search Engines Work?"

Search Engines for the general web (like all those listed above) do not really search the World Wide Web directly. Each one searches a database of the full text of web pages automatically harvested from the billions of web pages out

there residing on servers. When you search the web using a search engine, you are always searching a somewhat stale copy of the real web page. When you click on links provided in a search engine's search results, you retrieve from the server the current version of the page.

Search engine databases are selected and built by computer robot programs called spiders. These "crawl" the web, finding pages for potential inclusion by following the links in the pages they already have in their database (i.e., already "know about"). They cannot think or type a URL or use judgment to "decide" to go look something up and see what's on the web about it. (Computers are getting more sophisticated all the time, but they are still brainless.)

If a web page is never linked to in any other page, search engine spiders cannot find it. The only way a brand new page - one that no other page has ever linked to - can get into a search engine is for its URL to be sent by some human to the search engine companies as a request that the new page be included. All search engine companies offer ways to do this.

After spiders find pages, they pass them on to another computer program for "indexing." This program identifies the text, links, and other content in the page and stores it in the search engine database's files so that the database can be searched by keyword and whatever more advanced approaches are offered, and the page will be found if your search matches its content.

Many web pages are excluded from most search engines by policy. The contents of most of the searchable databases mounted on the web, such as library catalogs and article databases, are excluded because search engine spiders cannot access them. All this material is referred to as the "Invisible Web" -- what you don't see in search engine results."

For a more complete listing of search engines, go to this link or url:

<http://www.internettutorials.net/engines.html>

There are also search engines that combine several other search engines that allow for a larger accumulation of information. For example www.dogpile.com will bring information from google, yahoo, live search and ask in one search.

If I want to find information about essential tremor, for example, as this is the kind of information that is useful to us, I will write essential tremor into the search bar and click on the web connection.

Let's say I use google.com. A multi page list comes up that I can search from. However over 500,000 items of information come up one of which looks like this:

"Essential Tremor Information Page: National Institute of ...Essential tremor (sometimes called benign essential tremor) is the most common ... Children of a parent who has essential tremor have a 50 percent chance of ... www.ninds.nih.gov/disorders/essential_tremor/essential_tremor.htm - 21k - Cached - Similar pages"

Searching through over 500,000 items of information can be a formidable task. So we can refine our search by thinking about what exactly do we want to know. For example, if I am interested in symptoms, I can write symptoms of essential tremor and search and what comes up on google are now only over 400,000 responses. Then I might briefly look through the first few pages to see if that satisfies what I want to find out about the symptoms of essential tremor. To further refine the search, I can write in head symptoms of essential tremor. Now I've reduced the number of returns to over 200,000 or I've cut the returns in half. You can further refine your search depending on what you exactly want to know, by reading a few of the returns and deciding what is the next piece of information that will work.

This means that we click on some of the returns from our search and that gives us hints about obtaining further information and leads us on an extended search. In the meantime as we read through several of the items, we find

names of organizations, chat rooms, support groups, names of specialists, etc that are or can be of use to us.

This is a remarkable process that can send us on a fabulous search through the world wide web to accumulate information that helps us in our own search for better health care, understanding and support.

Another way of gaining information is to create a google alert that can bring information directly to you on a daily, weekly or monthly basis on the topic of your choice. This is useful as you don't do the search, but the search comes to you from any number of places such as news, journals, blogs, etc.

I have been doing much research on the web, and have alerts coming to my email address on a regular basis. While I can get engaged in this process of finding information and forget that I really have a life away from the computer, I am so engaged that I often find this a worthwhile process.

I hope I have been able to share finding information in a way that enables you to find what you seek on the world wide web.

"Computers are getting more sophisticated all the time, but they are still brainless."

About the Author

Dr. Mona Reeva writes a column for Spikes & Spasms. After a successful career in human services Dr. Reeva has a new one, Green Mountain Artistry at www.greenmountainartistry.com that "is dedicated to creating, showing and selling unusual designs and handcrafted items."

The Essential Otter Advocate

<http://www.romert.blogspot.com>

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BY ALEAH MAHAN



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