

# Spikes & Spasms

The Tremoraction.org Newsletter

MARCH 2006

## IN THIS ISSUE

- Early Success: The American Brain Coalition
- Mental Health: Q & A
- DBS Memoir: Matthew's Story
- My Journey With Botox A
- The Psychological Effects of Spasmodic Torticollis
- Romert: The Essential Otter

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## WELCOME TO THE MARCH ISSUE!



Tremor Action Network in partnership with the Society for Neuroscience and Dana Alliance supports and promotes the Eleventh Anniversary of Brain Awareness Week, March 13-19.

Brain Awareness Week (BAW) is a national and international campaign. Individual partners bring their own unique perspectives and messages about the brain.

BAW offers a rare opportunity to focus attention on movement disorders within the broader context of the brain and brain research. Tremor Action Network requests your participation to increase local community awareness about movement disorders. For more information on Brain Awareness Week activities, visit TAN's Brain Awareness web page.

**Enjoy reading the March - BAW issue brought to you by Life In Motion coalition member Tremor Action Network. The LIM Campaign will continue through 2006.**

Society for Neuroscience: <http://web.sfn.org/>

Dana Alliance: <http://www.dana.org/>

Brain Awareness:

<http://www.tremoraction.org/brainawareness>



## Early Success: The American Brain Coalition

By Katie Sale

In 2004, a small group of professional societies, patient advocacy groups, and foundations came together to form the American Brain Coalition (ABC), a non-profit organization that seeks to reduce the burden of brain disorders through public advocacy. Since that time, the ABC has recruited government agencies to join its cause, hired staff members, and retained the services of Washington, DC lobbyists Cavarocchi-Ruscio-Dennis Associates. While still relatively new, the ABC has grown to over 45 member organizations.

The ABC works with Congress to combat neurologic and psychiatric disorders. Among the ABC's goals are: 1) to advocate for research funding and progress toward effective therapies and cures for brain disorders; 2) to help build a health-care system more responsive to people with both acute and chronic brain disorders; and 3) to advance the understanding of the causes, impact, and consequences of neurologic and psychiatric illnesses in our society through advocacy to public officials.

The ABC hopes to achieve the same level of public awareness and support for diseases of the brain that have been realized by the American Heart Association for heart disease and the American Cancer Society for cancer. When the public begins to understand that 50 million of their relatives, friends, and neighbors are affected by diseases of the brain, we will attract the level of support for research and care needed to prevent, control, and cure these diseases.

The ABC's legislative focus for 2006 is meant to have broad appeal for all member groups. It has five main thrusts:

- To secure adequate funding for the biomedical research at the National Institutes of Health (NIH), since this is critical to furthering understanding disorders of the brain.
- To advocate for mental health parity in insurance coverage, so that treating mental illnesses is comparable to that of other medical conditions.
- To raise awareness of and support for the essential role of responsible animal research for future breakthroughs in the treatment of brain disorders.
- To improve the healthcare system to better serve people with chronic illnesses affecting the brain and mental health.
- To expand federal funding for embryonic stem cell research, which holds the promise of new treatments, and even cures.

The ABC is currently accepting applications for membership. We encourage organizations ranging from large non-profits to small, specialized advocacy groups, as well as government agencies to join. For more information, please visit the website at [www.americanbraincoalition.org](http://www.americanbraincoalition.org), or contact Katie Sale at [ksale@americanbraincoalition.org](mailto:ksale@americanbraincoalition.org).

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### About the Author

As Director of the American Brain Coalition (ABC), Katie Sale oversees the coalition's ongoing efforts, including ABC's membership recruitment, and interaction with members and leaders.

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## Mental Health: Q & A

By Mona Reeve

### Spikes & Spasms Note:

*Introducing a new Column! Mona Reeve, PhD, MPH, LCSW will write a column that focuses on mental health issues for readers beginning with this issue. Readers are invited to ask questions that Dr. Reeve will work at answering. Topics include and are not limited to mental health concerns that are specific to us with movement disorders as well as other more general questions. Dr. Reeve will respond to the questions directly in the newsletter. Sometimes a specific question will be combined with others when the topic is similar and can be answered in one column.*

I first began to notice my tremor while in my late 30's early 40's and didn't pay much attention to it as movement was intermittent and transient. One therapist that I saw suggested ignoring it and holding my head in my hand while leaning my elbow on a chair's arm. When I finally got up the courage to seek medical assistance I consulted with a friend who is an occupational therapist to obtain the name of a good neurologist. I made the appointment and was in his waiting room for two hours before he saw me for five minutes and charged me \$100. He handed me three prescriptions that were for a barbiturate, a sedative and atenolol, saying that I could try all of these and see which one, if any helps, adding: "And by the way, alcohol can also help."

These experiences were a number of years ago and today I believe there are more enlightened health practitioners who really are looking for causes, remedies and their patients' well being in supportive and caring ways. Today I wouldn't spend two hours waiting for any health practitioner and I would suggest that you don't either. Nor would I pay anything for five minutes of a practitioner's time.

We are deserving of the time and energy and effort of any

**Sound mental health includes feeling a sense of personal power that we utilize in our everyday living and reflects in our overall health.**

practitioner that we choose to see. Why would I say that? Because I, too, am a health professional? No, because all of us, practitioner or client or patient deserve better treatment, if we are to feel that we are getting the best care possible. In seeking remedy for whatever health condition we have, we require and must request caring and support from the people we seek to help us.

Requiring sound health and mental health care is a responsibility that is grounded in our sense of our selves. Finding the best care possible is also our responsibility that reflects who we are and how we feel. There are many resources in the health care community, and whom we seek or what kind of care is an individual decision. Making the

most of the resources available to us is always our responsibility and provides us with good feelings that when undertaken help whatever condition we may have. Sound mental health includes feeling a sense of personal power that we utilize in our everyday living and reflects in our overall health.

I want to conclude this introductory column with "Five Good Things" written by Jean Baker Miller, MD, who along with two other women founded a new psychological theory over 25 years ago now called Relational and Cultural Theory.

"Growth fostering relationships empower all people in them." They are characterized by:

- 1) A sense of zest or well-being that comes from connecting with another person or other persons.
- 2) The ability and motivation to take action in the relationship as well as in other situations.
- 3) Increased knowledge of oneself and the other person(s).
- 4) An increased sense of worth.
- 5) A desire for more connections beyond the particular one.

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## About the Author

Dr. Mona Reeve has been in the field of health and human services for over 40 years and recently retired from providing psychotherapy to individuals, couples and families. She continues to offer mental health consultation, and personal and professional coaching. Dr. Reeve can be reached at [mreeva@comcast.net](mailto:mreeva@comcast.net)

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## DBS Memoir: Matthew's Story

By Matthew Miller

I've had essential tremor as long as I can remember, but it took until 1995 for someone to diagnose me. The diagnosis was bittersweet. I finally knew what I had was real, but I was told there was no cure and that treatment options were pretty limited.

I gave up on taking medications, because of both ineffectiveness and side effects. I resigned myself to believe that I was just going to have to live with a disease that offered no positive treatments.

In February 2005 I attended an IETF seminar with my partner, Ray. We were surprised to find about 80 people in attendance. I had never known anyone else with this disease so this was quite a surprise.

Deep Brain Stimulation (DBS) was presented as a surgical option. The DBS demonstration involved two individuals. Each person held out their arms. Both individual's arms shook violently, and then the neurologist touched an object to their shoulders. Magically, their shaking suddenly stopped. I remember my eyes filling with tears immediately thinking, "This just cannot be real." But it was. I was seeing it live! There was now another option and I wanted to know more about it!!!

I spent the next few months researching DBS, checking out websites, talking to people on message boards and finding out all I could. I was absolutely sold, but I still wanted to know everything before pursuing the surgical

procedure. In June I met with the neurologist who diagnosed me in 1995. I blatantly stated, "I want DBS surgery!" He did not seem to have any issue referring me to a neurosurgeon. He commented, "Well you seem to know everything and it does not look like there is anything else I can tell you." The following week I visited with both the neurosurgeon and another neurologist, who would be my programmer. They echoed, "Well it looks like you know all you need to know." The surgery was scheduled for September.

Then came the waiting. There is a lyric in a song, "The waiting is the hardest part." It is oh so true! I was aware that the risk factor of DBS surgery is low, but the 3% risk still haunted me for days on end. I paced and cried, experiencing insomnia and anxiety attacks. The three month wait was overbearing. To all who are going to have DBS, I recommend spacing your surgery a little closer. However, during the wait time I was inspired by a woman featured on Good Morning America. Seeing the joy DBS brought to her life I told myself, "If she can do it, so can I!" She said at the end of the segment, "If I can help just one person overcome essential tremor then I'll be happy." Well, she did just that!!! She gave me the courage to go forward, and I will be forever thankful to her.

I talked to all my family and friends. I received no support from my family, with the exception of my brother asking questions. I got all the love and support from my friends, everyone on the Yahoo DBS Surgery Message Board and my partner, Ray.

September 8th came. I was asked to arrive at the hospital at 5:45 am. Ray and I sat, waiting for what seemed like an eternity. I was absolutely terrified. I felt like I was going off to "The Chair," after sitting on death row. The admitting nurse called my name and Ray and I followed her to a room where she gave me the "low down" on what was to happen. She was very kind and informative, taking Ray's cell phone number to call him with updates. I put on the hospital gown and we were escorted to pre-op.

Pre-op is a large bustling room filled with all those having

any type of surgery. I was put in a hospital bed. Ray given a chair by my side comforted me, because I was still scared to death about what was to come. I had told my neurosurgeon's nurse that I wanted aggressive pain management practiced at all times; to please put me to sleep as much as possible. Thankfully, that's exactly what happened. I was given a "relaxer" which calmed me down. I'm not sure how much time passed at this point because I fell asleep, with Ray holding my hand. I was awakened by the neurosurgeon and the neurologist, who actually found it humorous that I was sleeping. It wasn't like I got a great night's sleep! I had not had food or water since the night before. I would have given anything for a glass of water!!!

Finally, they took me to put on the dreaded halo. I don't remember anything, because I was put to sleep. They woke me up for the MRI and CT scans. I remember being kind of disoriented, because I could only see to the right or left of me. The halo was on and it had bars coming across my face; like waking up in a jail cell. The only thing I really remember was being transferred from the bed to the MRI. The next thing I remember is waking up in an extremely cold operating room.

I think there were about 10 people in the room, milling around, doing whatever it is they do. There was loud rock music playing. A nurse wrapped me in a warm blanket, and that was like Heaven. Between the knock out drugs and a warm blanket, I was feeling just fine. The halo didn't seem to bother me. I knew it was on, but I felt nothing. The neurosurgeon talked to me, and then I was asleep again.

I was awakened. I looked left and right. I realized that my head was anchored. I could not move it in any direction. I was comforted by a voice from my neurologist asking me to stretch out my left hand, to grasp a plastic cup with water and a lid on it. I didn't even know they were "in." In my head that is, until they told me. Wires were inside my brain and the search was on for just the right spot.

**This is my Kodak moment,  
"the big light at the end of  
the long tunnel."**

This is my Kodak moment, "the big light at the end of the long tunnel." I held out the cup, turned it side to side, and realized I was not shaking. I brought it up to my mouth, and again I could do it without trembling! I immediately felt my eyes well up with tears. I began to sob. How I wish they would have let Ray in the O.R. with me, to see what I did for the first time ever. I thought about my parents, and wanted so bad for them to witness this moment. I heard people behind me asking what was wrong. I remember telling them, "I'm perfectly fine; it's just that I've never been able to do anything like this." I kept sobbing. I heard a voice say, "He's getting pretty emotional...We've hit the right target...Put him back under."

I was awakened again and asked to do the same thing with my right hand. I could hear the static from the speaker every time they moved the wire around; the electro-static from my cells firing. My right side was very stubborn. After a few tries with the cup, and being put under twice, they hit the target on the third try. I could hold the cup with my right hand, turn it side to side, without

shaking. I began to sob again exclaiming, "I cannot believe this is happening! Did you see that?" I was saying it to anyone that would listen!!! Then I heard a voice say that I'm at about the tenth hour, and the next time I wake up I'll be in the ICU. I remember saying to the voice that I thought it was only about 10:00 am. It was actually after 6:00 pm!

The voice told the truth. I opened my eyes and the nurse was asking me to tell her to rate my pain from 1-10. I told her it was about an 8, and within seconds she was shooting Morphine into my I.V. I asked the nurse if she had a mirror. She brought me one and I was blown away! You could hardly see the incisions, but I sure felt them!!! I now wish that my head had been completely shaved instead of leaving the majority of my hair. I'd insist on this. I looked like I'd been in a minor car accident, but felt like I'd been in a major one. The head pain was very sharp and intense. Thank the Gods

for Morphine!

I fell asleep and when I woke up, standing over me holding my hand was my friend Carol. Noticing that Carol was holding my left hand, I gripped her hand and told her to resist me. I turned my hand left and right and she began to cry with me, both of us realizing that the surgery worked!!! Carol located Ray for me, and we shared the first moment of me not shaking anymore. Many friends came to see me, and I was just in awe at everything that had happened on the first day.

I tried to eat some fruit, but the stomach, the organ of digestion, is the last part of the body to wake up after surgery. I give thanks to all my ICU nurses. They took excellent care of me! I remember waking up several times throughout the night. My head drilled and carved open did not exactly make for a comfortable night's sleep.

Ah the next morning; the morning you wake up and are just glad to be alive. The nurses were again checking on me, every half hour or so, shooting me up with Morphine when I asked for it. I was taking it all in. I was still in disbelief. I kept turning my hands and arms side to side, to witness myself not shaking anymore. The honeymoon phase was in full swing!

I was sent home around 2:00 pm. Not bad, considering I just had holes drilled into my head and wired for sound!!! I was eager to leave the hospital to try all the things I could not do before. My friend James picked us up. My head felt every pothole in the streets of Seattle.

Before the surgery, Ray and I purchased DVD's of movies that I had liked from my childhood. I have to say our idea was good for the recovery phase. The movies were of great comfort; made me feel safe and secure. Also, Ray waiting on me hand and foot. I hate being waited on, but I really don't know what I would have done without Ray.

For home recovery, there are a few necessities:

1) shower cap for keeping your head dry; 2) Hibiclens

surgical soap; 3) hand sanitizer; 4) clean bed sheets and pillow cases; 5) gauze bandages and tape for second surgery; 6) clean garments.

Don't fool yourself into thinking you can do much. The head pain and the fatigue will keep you down for a while, so plan on taking at least two or more weeks off.

I had scary thoughts about the second surgery. If I hurt this bad now, how was I going to feel after having two plastic objects buried in my chest and wires tunneled through my head, shoulders and neck? I told myself that I had gotten through the most dangerous part of DBS and now I was about to go through the most painful part; as if it could get worse. Well, it did indeed in some ways. The second procedure was scheduled for September 15th. Same drill. The next thing I know, I'm back in recovery. It was about a 4-5 hour operation. I woke up and my chest hurt like heck. The soletras felt big and bulky. I could feel the wires in my neck running all the way up to the sides of my head.

Again another bumpy ride home, feeling worse than before. Insist on a sufficient supply of pain killers. For me, it was Percocet hydrocodone. A good alternative is Tylenol PM, so you can sleep at night.

You cannot get your chest incisions wet for about eight days. You must change the dressing on your chest daily. When you sleep, be sure your bed sheets, pillow cases and garments are clean. Cleanliness is for fighting infection. Watch for any blood on the pillow cases, as this is an indicator that you still need to be very watchful for infection. Always keep your hands clean with a hand sanitizer; especially, your finger nails. You will want to scratch your head a lot. Don't scratch with your finger nails. Use Hibiclens when you wash your hair and chest incisions.

The second healing is just as challenging as the first. The two go together, because you are still healing from the first surgery. The head doesn't just hurt now, but your

chest as well. Two major surgeries will zap your energy. Count on being short of energy, and getting daily headaches for about three months. Watch out for depression. Your mood will swing in all different directions. Be aware where it's coming from and what is causing it, to dismiss any negative feelings as quickly as possible. Look at the positives! You may not be turning cartwheels anytime soon, but the feeling inside every time you do something you could not do before brings it all home.

Programming sessions with the neurologist to set your soletras/kinetra are non-invasive, and can be a little boring as well as draining. One can hold their arms out in front of them only so long before fatigue sets in. Some of the surges you get can be some of the most pleasurable feelings, but a little frightening at the same time. Kind of like bungee jumping; great rush but still a little scary! You'll leave the sessions with a whole new life in front of you and a joy I cannot even begin to describe. I run home and try all kinds of things. I still can't believe it's real. Every day is a new discovery of skills that you knew you had, but could never use them. Don't let non-productive programming sessions get you down. A great deal of patience is required because it may take many time to get the setting(s) right.

Programming has indeed worked for me. I'm at 98% reduction on both right and left hands, and 90% reduction in the head tremor. With more sessions to come, it may get even better. Remember to be patient! It's a good idea to keep a log book/journal of your tremor and how your body is feeling every day, so you can show your neurologist each time you go in for programming.

For me the pain, the temporary loss of youthful energy, the depression; all are a small price to pay for the benefits of DBS. All the bad things will last only a few months to get a lifetime of, for lack of a better term, normalcy. I realize that my experience has been painful, but life altering. I like to use the words, "silent cheer." You want to dance, shout, and jump around, but you can't. Just remember, that time is also coming soon.

I now feel a moral imperative to help anyone that is about to embark on a DBS journey. In addition to having the support of other fellow DBS'ers, it's a very good idea to make sure your support system at home/work is well in place. Once you decide to move forward, make sure you have someone to take care of you at home. Don't try to be the independent fool. Have someone with you at all times during your recovery. Choose more than one person so that others can give your primary caregiver a rest when they need it.

We share a common disease among one another, but our experiences will be very different. I feel very fortunate in mine. I can say that this was a success, even though I'm not done yet. Keep moving forward and if all goes well, your world will become still and peaceful.

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### About the Author

In keeping with his obligation that, "I feel a moral imperative to help anyone embark on a DBS journey," a streaming video of Matthew's February 23, 2006 TV interview with NBC's (King5 Seattle) Evening Magazine reporter Kim Griffis, can be viewed at: <http://www.king5.com/eveningmagazine/>. The title of Kim's interview with Matthew is Controlling tremors with a push of a button.

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### My Journey With Botox A

By Nancy Muller

#### Spikes & Spasms Note:

*BOTOX® botulinum toxin type A may be useful to treat essential tremor (voice or head).*

I was diagnosed with Spasmodic Torticollis, also called Cervical Dystonia in 1988, and have been treated with Botox ever since my diagnosis. I was in the original Botox-A trials at UCLA Medical Center during its research phase and shortly after I started in the program, it was approved by the FDA for treatment of ST. I have been treated for the last 18 years every three months with injections, other than a short period of time after I had surgery in 1999, at

which time I had a Selective Cervical Denervation and I did not require treatment for about a year. Unfortunately the symptoms again required additional treatment with Botox-A injections.

Research of more than 100 years has expanded the knowledge of botulinum toxin type A from the identification of the bacterium *Clostridium botulinum*, which is the bacterium that causes food poisoning (botulism). In the 1960's, the muscle-relaxing properties were investigated for the use of realigning crossed eyes. According to Allergan Pharmaceutical, which is the company that manufactures and distributes Botox A, these early studies paved the way for treating other conditions caused by overactive muscles, such as blepharospasm, strabismus, hemifacial spasm, spasmodic torticollis, oromandibular dystonia, urinary retention, spasmodic dysphonia, stuttering, and voice and head tremors.

Your brain sends electrochemical messages to your muscles to make them contract and move, and the message is transmitted from a nerve to the muscle by a substance called acetylcholine. When too much acetylcholine is released, muscles become overly active and spasm or tense up. Botox A works by blocking the nerve from releasing acetylcholine. The muscle spasms stop or are greatly reduced and you are able to receive some relief from the symptoms. Botox is not a cure, and used only to treat the symptoms.

In my case, the symptoms were greatly relieved and I was able to function in a fairly normal manner for many years. I was on Botox A for about 12 years until I became immune. But that is an incredible amount of time to be able to function normally and get good relief from the symptoms. I had virtually no side effects from the injections. On occasion I might have a little weakness and heaviness to my neck but that was pretty much it. Over a period of time you

get used to being injected because there are so many benefits to using the drug. Many people take oral medications in addition to the Botox injections, but its personal choice in regard to the degree of your symptoms.

One thing you must realize when having Botox injections, is that you won't always have the same results with each treatment. Sometimes the effects are dramatic; especially, with the very first time you are injected, and also those times where there is a big lapse of time between injections. I feel this is the best treatment we have and you need to hang in there and not get discouraged if you don't have the same results each time you are injected.

I also encourage being injected by a neurologist that specializes in movement disorders and that they use the EMG (electromyogram) to monitor the activity in the muscles when injecting Botox. Some of the muscles can be injected simply by sight, but the majority of them do require the use of the EMG.

**When too much  
acetylcholine is released,  
muscles become overly  
active and spasm or  
tense up.**

In regard to insurance coverage of these treatments, Medicare definitely pays for a portion of the charge and then if you have a supplemental plan, they should also pick up some of the cost. A great deal of insurance companies do cover treatment, especially for Spasmodic Torticollis. One way to find out if your insurance company covers treatment is to call the toll free number, 1-800-530-6680. Some people that do not have any coverage could possibly qualify for the Botox Patient Assistance Program, and this program is available to all patients who lack insurance coverage and demonstrate financial need.

The effects of the Botox injections normally last about 3 months before needing to be treated again, and normally you will start to feel results from the injections about 2 weeks after the treatment. The best way to minimize your chances of becoming immune to Botox A is to try and tolerate the lowest possible dosage that can be tolerated.



When foreign proteins, like botulinum toxins, enter your body, that's when antibodies may form, and if this is the case, you may no longer respond to treatment. But all is not lost because if you are immune to Botox A you can be injected with Botox B, which is called Myobloc. This is exactly what happened to me about 6 years ago. The test for the antibody is to inject a small amount of Botox above the eyebrow. After a few days if you are able to wrinkle your forehead you have the antibody, but if there is no wrinkle, you are not. It's a very simple test and it's worth knowing if you have the antibody because then you can go on to the next step and receive Myobloc.

Myobloc will be the next leg of my journey, which will be featured in the next edition of Spikes and Spasms. If anyone would like to contact me regarding this article or any additional information about Spasmodic Torticollis or Botox feel free to either write me at [nmuller406@aol.com](mailto:nmuller406@aol.com), or call me at my home number at 951-926-3677.

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### About the Author

Nancy Muller is the past president of the National Spasmodic Torticollis Association. She has a column in the NSTA Magazine devoted to an up front and personal forum of questions from members. Nancy has a published chapter in The Spasmodic Torticollis Handbook, authored by Drs. Pathak, Frei, and Truong. She is a contributing author and editor of Spikes & Spasms. Nancy is on the Board of TAN.

For more information on Allergan and the product BOTOX® botulinum toxin type A, visit: <http://www.allergan.com/site/>.

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## The Psychological Effects of Spasmodic Torticollis

By Karen Frei

There are many psychological aspects of spasmodic torticollis ranging from social stigmata to coexistent psychiatric disease such as depression. However, this aspect of ST is difficult to assess and many people with ST tend not to want to discuss this aspect of their disorder. Consequently, psychological effects are not well studied.

One of the ways we measure overall effects a disease process may have on one's life is to use a Quality of Life scale. Quality of life is a term that describes functionality - physical abilities, cognitive and mental abilities and the person's sense of well being. If you are functioning well, you have a good quality of life. There are several domains that are considered with a Quality of Life scale including intrinsic factors, extrinsic factors and disease related factors. Intrinsic factors come from within the person such as self esteem and self criticism. In other words, how happy you are with yourself. Extrinsic factors include your environment such as social support and socioeconomic status. Disease related factors include disease duration, severity of disease and the response to treatment. The combination of scores from each of these domains provides the final score that is thought to accurately reflect the effects of the disease on one's life. In general the greater acceptance of the illness and social participation in combination with the lesser degree of social stigma, anxiety and depression produces a higher Quality of Life score and an improved ability to cope with the disease.

A study performed in Austria (Muller et al, 2004) reported the impact of ST comparable to other chronic neurological conditions such as multiple sclerosis, Parkinson's disease and Stroke. People with ST tended to have a greater disability in the mental health scores in the Quality of Life scale. One study (Gundel et al, 2001) reported that 75% of those studied with ST had some form of psychiatric disorder. Social phobia appears to be the most common, followed by depression and anxiety.

Social stigma is a major problem with ST. ST is a visible condition. Other people can see the physical disfigurement - the head tremor or twisted neck. This produces a perception of stigma and self-consciousness, feeling unattractive, apologetic, feeling different from others. As a result there is an avoidance of others. One of the Quality of Life studies found stigma to be affecting all aspects of life including social, private and working lives.

Social phobia can also result. Social phobia is defined as an excessive fear of scrutiny or embarrassment suffered by persons facing participation in seemingly conventional social interactions. This leads to social avoidance and a lack of participation in pleasant activities. One study found that over 50% of those with ST had some form of social phobia.

Once a person begins to isolate themselves avoiding social activities it is easy to see that depression can develop. The sense of stigma from ST compounds the depression. Depression has been reported to occur from 24 - 47% in those with ST. Pain may be a major factor in depression and treatment with botulinum toxin tended to decrease the depression. There is a theory that depression seen in those with ST results from the combination of a sense of disfigurement, self depreciation and social embarrassment. However, depression may be related to ST disease pathophysiology, in other words may be a part of the disorder, or depression may be a preexisting condition and may have developed in the absence of ST.

Anxiety is also commonly reported to occur in 40% of those studied with ST. Anxiety is a chronic sense of nervousness, unease and fear. It may be related to social phobia and/or depression.

It is easy to understand why ST produces several psychological effects including social stigma, social phobia, depression and anxiety. ST is a chronic illness- it does not go away. As such it shares common features with other chronic illnesses such as cancer, multiple sclerosis or Parkinson's disease. Chronic illness may result in pain, fatigue, stress and can also lead to depression. Other common ST stressors with chronic illness include: uncertainty of the future, uncertainty of disease course, physical disability, a loss of independence and financial difficulties especially when unable to work. ST also provides additional stressors including: a loss of body image, a loss of self-esteem and dignity, a loss of sexuality and intimacy and a loss of social contacts and social phobia. Signs of excess stress from ST and/or chronic illness

include sleep disturbance, fatigue, body aches/ pain, anxiety, irritability and tension.

Since ST is a chronic illness and will not go away, the only way to live with this condition is to develop effective coping strategies. Coping is to deal competently with a situation or problem. Upon learning of the diagnosis, one goes through similar stages to learning one has a terminal illness. This was studied and described most effectively by Elisabeth Kubler-Ross and includes: Denial, Anger, Bargaining, Depression and finally Acceptance. The remainder of the article will describe these stages and effective coping strategies.

Denial is a refusal to believe the diagnosis. "I have a muscle spasm. It'll go away with some hot packs and massage." Being told you have ST can be quite a shock, especially if you have never heard of such a disorder before. Chances are that you may not have known anyone else with this disorder. You will need to take your time, allow the information to sink in. Go ahead and get a second opinion. This will give you more information on your condition. As you already know, knowledge is power. Investigate this disorder. Find out what treatment options exist. Learn about ST.

Anger often follows denial. There is irritability and frustration. "Why is this happening to me?" At this stage physical activity can be helpful to release some of the negative emotions. Striking a pillow, running or starting a regular exercise program can be beneficial. Concentrate on maintaining optimum health.

Sometimes bargaining occurs and a person will attempt to change their condition through good works. This can be religious in nature and the person will attempt to bargain with their creator otherwise it can occur as a superstition or ritual. "If I get better I will dedicate my life to doing good deeds." While this can represent "magical thinking" and it is often difficult to negate this kind of thinking, planning ahead and problem solving can help to avoid becoming overwhelmed. Try to plan ahead, for example,

schedule your activities according to your abilities; don't schedule several doctor appointments in the same day. Problem solve - look for solutions, ways to overcome obstacles; for example, taking a break in order to prevent excessive fatigue.

Depression then sets in with feelings of hopelessness and helplessness. ST takes over your life. Depression can be serious and may require counseling and/or medications. If you have any thoughts of committing suicide or if the depression and bad mood lasts for more than one to two weeks, you must seek help from a psychiatrist. Do not wait or try to handle this on your own. For mild forms of depression try joining social activities. Attend your local NSTA support group meeting.

Finally acceptance occurs and effective coping can take place. Oftentimes this requires reorganization to include ST in your life and you will have a positive outlook physically, emotionally and spiritually. - A good Quality of Life!

Additional coping strategies include relaxation, meditation and biofeedback. Cognitive behavioral therapy can be used to improve negative thought patterns. The following are defense mechanisms and coping style some of which have been presented earlier. You can find your style or adopt some of the others.

**Affiliation** - turning to others for help or support

**Altruism** - gratification from helping others

**Anticipation** - anticipating consequences and considering realistic responses or solutions

**Humor** - using humor as a coping mechanism. An example is Norman Cousins who wrote the book "Anatomy of an Illness."

**Self-Assertion** - express feelings and thoughts directly

**Self-Observation** - reflecting on thoughts, feelings, motivation and behavior

In summary, most coping strategies allow you to gain control over your disorder. Acquiring knowledge about ST and positive thinking will help. Remember to discuss issues

with your doctor including your thoughts and feelings and questions regarding medications or treatment plans. Use available support networks including NSTA and other support groups, friends and don't forget your family! Your family, and that term is defined differently by each person, are a major part of your support network. Maintain communication with your family members and talk about your feelings and plans. You can even include your family members in support group activities. May all of you have a good Quality of Life!

#### References:

1) [Muller J](#), [Wissel J](#), [Kemmler G](#), [Voller B](#), [Bodner T](#), [Schneider A](#), [Wenning GK](#), [Poewe W](#). Craniocervical dystonia questionnaire (CDQ-24): development and validation of a disease-specific quality of life instrument. Journal of Neurology Neurosurgery and Psychiatry. 2004 May;75(5):749-753.

2) [Gundel H](#), [Wolf A](#), [Xidara V](#), [Busch R](#), [Ceballos-Baumann AO](#). Social phobia in spasmodic torticollis. Journal of Neurology Neurosurgery and Psychiatry. 2001 Oct;71(4):499-504.

3) [Urs and Corinna Rogger](#), [Coping with Dystonia](#) - a workshop presented at the European Dystonia Foundation Assembly in Basel. This can be found at the following internet address:

<http://www.dystonia-europe.org/europe/articles/Final%20Rogger.htm>

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Dr. Frei's professional and academic accomplishments are extensive and her biography can be viewed at: <http://www.pmdi.org/frei.html>.

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