

Spikes & Spasms

The TremorAction.org Newsletter

JUNE 2007

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WELCOME TO THE JUNE ISSUE!

Tremor Action Network experienced the AAN progress at the 59th Annual Meeting in Boston when TAN met Esther Baldinger, M.D. TAN connects "the bench to the tremor patient" by featuring Dr. Baldinger's article, "Shakers and Movers," and also her AAN poster presentation, "An Open-Labeled Pilot Study of Riboflavin for the Treatment of Essential Tremor."

DYSTONIA AWARENESS WEEK is June 3-10, and DAW comes in all shapes and sizes! TremorAction Network requests your participation to increase local community awareness. TAN is educating the public about dystonia by sponsoring the June 7 Wayne County Action Program event in Lyons, New York. M.J. Donnelly and dedicated Advocates will present printed materials and demonstrate low-tech simulations to Wayne County volunteers to learn first-hand what it is like to cope with the day-to-day challenges of living with a movement disorder. Nancy Muller and Terri Sterling "in this issue" share their individual perspectives on living with dystonia.

Dr. Mona Reeva, returns with a profound article on "loss and grief," followed by TAN's other advocate Romert, extending an invitation to join the online support group Tremor!

Enjoy reading the June issue brought to you by **Life In Motion** coalition member **Tremor Action Network.**

Shakers & Movers

By Esther Baldinger, M.D.

Essential tremor is the most common movement disorder. Despite this fact, it is the poor orphan of movement disorders, with no drugs or other therapies specifically approved for the treatment of this condition. The currently used medications, predominantly propranolol, primidone and topiramate are only partially effective and have significant side effects. Many people with essential tremor have been disappointed when they visit their physicians and learn of the limited treatment options available.

As a neurologist who also suffers from essential tremor, I chose no treatment over the available options listed above. However, I was also searching for a solution because the daily lives of several members of my family were severely affected by ET. My mother would never go to a restaurant or share a cup of coffee with friends. I was intent on helping her and others like her, while avoiding a similar fate.

While on this quest, with myself as the initial subject, I discovered that high doses of Riboflavin (Vitamin B2) greatly improved my tremor without any side effects. I tried this therapy on 15 other people from age 50-90. 10 of the 16 patients, including me, showed a mild to moderate improvement in their tremor. This was associated with improvement in their ability to write, eat, drink and pour liquids in more than 50% of the patients. None of these patients reported any side effects, except for noting increased yellow coloration of their urine. When Riboflavin was stopped, the tremor returned to its prior level.

Because this study was undertaken with no placebo arm and with a limited number of subjects, I along with other physicians at the Long Island College Hospital in Brooklyn, New York are running a follow-up study to further assess

the effectiveness of Riboflavin for the treatment of ET. Any person willing to participate in this study should contact me at (718) 232-1570.

About the Author

Esther Baldinger M.D. is a practicing neurologist in Brooklyn, NY. She is an Associate Attending in neurology at the Long Island College Hospital, and an Assistant Clinical Professor of Neurology at SUNY Downstate Medical Center. Dr. Baldinger attended SUNY Downstate Medical College, graduating Magna Cum Laude and AOA in 1977.

“Essential tremor is the poor orphan of movement disorders, with no drugs or other therapies specifically approved for the treatment of this condition.”

An Open-Labelled Pilot Study of Riboflavin for the Treatment of Essential Tremor

Esther Baldinger, MD

Neurology, SUNY Downstate Medical Center and Long Island College Hospital

OBJECTIVE

Can high dose Riboflavin ameliorate Essential Tremor?

BACKGROUND

Essential Tremor, which has a genetic component, but no consistent pathology, may be caused by abnormalities in cellular energy production. Riboflavin is essential to the production of energy. The active forms FAD, FMN participate in metabolism, the degradation of drugs and toxins, and in activation of other vitamins particularly Niacin to NAD and NADP. Active transport brings Riboflavin into the blood-stream and a special carrier-mediated system brings Riboflavin into cells. If either mechanism is defective, then over supplementation of Riboflavin may ameliorate this defect.

DESIGN AND METHODS

16 subjects from the age of 50 to 90 with ET were treated with doses of Riboflavin from 400-800 mg in an open labeled fashion. There was no change in concomitant tremor medications, if any. Evaluations were made at 4 week intervals and if the response was inadequate, the dose was increased to 600 mg at 4 weeks and then 800 mg at 8 weeks based on the patient's subjective evaluations and the examiners observations, utilizing the clinical rating scale for tremor by Fahn, Tolosa and Marin.

RESULTS

10 of the 16 participants (2/4 with head tremor and 8/12 with hand tremor) had reductions in tremor severity. The improvement in TRS severity scores ranged from slightly improved (20%) to moderately improved (50%). Riboflavin was associated with enhanced ability to write, eat, drink and pour liquids in more than 50% of the patients. Physician ratings and patients own subjective evaluations were consistent with measured improvement. Riboflavin was well tolerated with no adverse events observed or reported.

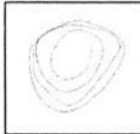


Figure left. 74 y/o male pt before treatment
Figure right. Pt on 800mg Riboflavin



CONCLUSION / RELEVANCE

Riboflavin may be beneficial in the treatment of ET and further evaluation is necessary using a double blind protocol.

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Demographic and Clinical Characteristics of Hand Tremor Patients

AGE	GENDER	CONCOMITANT TREMOR MEDS	RIBOFLAVIN DOSE	BASELINE TREMOR	TREATMENT EFFECT
50	F	None	800	Moderate	Yes*
50	M	Propranolol LA	400	Moderate	Yes*
50	F	Propranolol LA	400	Moderate	Yes*
66	M	None	400	Mid	No
74	M	None	400	Moderate	Yes*
75	F	None	600	Severe	No**
75	F	None	800	Severe	Yes*
75	F	None	400	Moderate	Yes*
82	F	Primidone, Propranolol, Topiramate	600	Severe	No
82	F	Primidone, Propranolol, Topiramate	800	Severe	No
87	M	Topiramate	600	Severe	Yes*
90	F	None	400	Moderate	Yes*

Baseline Tremor Scale	Mild Tremor Score 0.0-0.9
	Moderate Tremor Score 1.0-2.9
	Severe Tremor Score 3.0-4.0

*Yes=Reduction of Tremor Score 1 or More Grades
**Improvement by Half Grade in One Hand

Demographic and Clinical Characteristics of Head Tremor Patients

AGE	GENDER	CONCOMITANT TREMOR MEDS	RIBOFLAVIN DOSE	BASELINE TREMOR	TREATMENT EFFECT
63	F	None	400	Mid	Yes*
74	F	None	600	Mid	Yes*
85	M	None	400	Moderate	No
88	F	None	800	Moderate	No

*Yes=Reduction of Tremor Score 1 or More Grades

Patient Response to Riboflavin by Hand Tremor Severity



- Mild - No Improvement
- Moderate - One Grade Improvement of Both Hands
- Severe - No Improvement
- Severe - Improvement of One Grade in Both Hands
- Severe - Improvement of One Grade in One Hand

Live Life to the Fullest on Myobloc®

By Nancy Muller

Just because you have received a diagnosis that you have Cervical Dystonia, doesn't mean your life is over and you're destined to become an invalid. It's really quite the opposite in my book.

I have had Cervical Dystonia for about 18 years now and have done everything I have ever wanted to do before I was diagnosed. The most important aspect of living with this disorder is your attitude, and the key is being positive. You have to realize you don't have a terminal illness and for the most part you can live a relatively normal life with proper treatment.

The first step is to be diagnosed by the right physician, and I am a big advocator for going to a neurologist who specializes in movement disorders. Your general neurologist can diagnosis the disorder, but the movement disorder specialist has the expertise to treat it the best way's possible so you can live a normal active life.

There are different routes that can be taken to treat CD, but I have found the best treatment that has given me the most relief from my symptoms. I am currently taking injections of Myobloc® every three months, and have found if I didn't have this available to me, I wouldn't be as active as I am. I truly owe a lot to the drug (Solstice Neurosciences) and my physician that knows just how to administer it. There are many oral drugs on the market to help further enhance control of the symptoms, but I have found Myobloc® to be my savior. I was on Botox®, which is botulinum toxin Type A, but became immune to the drug and there to save the day was Myobloc®, which is botulinum toxin Type B. I can't even imagine what state I'd be in today if Myobloc® wasn't available to me after I found out I was immune to Botox®.

I thank Myobloc® for giving me the ability to do a lot of activities I couldn't do if I did not have it available to me.

As an example of my activity level, I have just recently started to take golf lessons, and have found I can do it, despite my ST. As a matter of fact there is a pro golfer by the name of Doug Sanders that has ST, and he states he used to play in tournaments and he used to bite his shirt collar to keep his head steady to make his shots. He won a number of major tournaments.

There is absolutely no reason to feel your life is over just because you have been diagnosed with CD. It's all about having a positive attitude and going out there, doing everything you can to make life more enjoyable.

You can drive a car, even with tremor. I have found if necessary I use the sensory trick if I'm driving and happen to find myself getting uptight or trembling, or my neck getting stiff or twisting, or whatever your neck decides what to do. If you're not familiar with the sensory trick you put your index finger lightly on your cheek and you'll be surprised how it alleviates

the symptoms. One thing I have found important is to work on not getting uptight when in traffic. You have to work on relaxing your muscles and sort of go with the flow of things. Stress is the biggest hurdle we have to overcome when dealing with everyday occurrences. I know it's not easy, I have my own issues, but I again take that positive attitude and make sure I don't let CD take over my life.

I've had CD for some many years and if I would have given up years ago and not gone forward with activities I love I think I would have become a recluse with no life. Instead I have taken the bull by the horns and tried everything I can try to make my life more enjoyable. I don't let this disorder take over my life, I control it. I do everything I want to do. If I find I can't quite make the grade, then I'll go on to something new.

I'm a big advocator of support and education regarding

dystonia and this is something all of you can do. By teaching others about the disorder, you can educate those people that are ignorant about it and at the same time you educate yourself even further.

A couple weeks ago I got a call from a professor that was just diagnosed. She told me her students were more understanding about the disorder than her colleagues. I told her she needs to be up front and educate her colleagues. She's a professor, that's what she does for a living, and what a difference she can make letting others know about the disorder so they can further understand what she is going through, and have a little compassion for her. Pretty sad when her students love and respect her and her colleagues give her a hard time.

Many of us can work still and be a productive member of society, and this is what you should do. Don't sit back and feel sorry for yourself, get out there and do whatever your heart desires. I let nothing stop me from trying things that I've always wanted to do, like golfing. I'm having a wonderful time. It's a great sport and gives my muscles a good workout. Make sure you get an instructor that can work with your disability so you can adapt to the way you play your game. I found that when I'm putting, I'm very focused and do really well and that my neck doesn't bother me because I'm so focused on the ball. But once again, I would like to thank Myobloc® for giving me the ability to do a lot of activities I couldn't do if I did not have it available to me.

Go out and try bowling or tennis, or bike riding, as the sky's the limit. There is nothing wrong with the rest of your body and the self satisfaction you'll receive from being able to accomplish these things alone will make a big difference in your life and your attitude.

About the Author

Nancy Muller would like everyone to know she is available to all of our readers if you have questions or concerns about CD, Myobloc®, Botox®, Social Security Disability, or even if you just want to talk because you're having a bad day or you're scared and just need some reinforcement that there is life after CD. You can reach Nancy at her e-mail nmuller406@aol.com or her home phone at 951-926-3677. She is here to be your dystonia advocate and anything she can do to help. Please don't hesitate to get in touch with her.

Creative Job Hunting Tips for people who have Dystonia

By Terri Sterling, MA

During the last year I have been job hunting. I have emailed endless applications on Career Builder, Monster, and other web sites. If you use these job sites be aware that the way your resume looks to you may not be the way it is received. If you have been using different style type and size type it may look disorganized by the time it reaches the intend person. When I received my resume back attached with a response, I noticed how disorganized and how hard it was to read. The solution for uploading a resume on Career Builder or other job bulletins is to use the same type, style and size, and to left justify everything. It is important to use a cover letter which can be quickly made in Microsoft Word, and pasted into the application site. I have found the most useful job site to be Indeed.com, which pulls employment opportunities from other sites.

Employers are now receiving hundreds of job applications and resumes for each job they post on job bulletins or in the newspaper; therefore, each of us needs to be creative and stand out among the applications being submitted. The perspective applicant needs to market and sell their talents and abilities. I decided to engage in a marketing experiment because it is an employers' market, and I needed to find a unique way to grab an employer's attention.

I took my resume format and created a brochure. I also discovered that in office supply stores you can find magnetic sheets to print a business card on. Most employers will take the magnet and stick it on their filing cabinet in their office. This gives the job hunter the advantage of being noticed in the future even if the employer does not have the right job for you now. You can come up with a special slogan and use bright colors to make the magnet stand out. The brochure and magnet business

card can be created using Microsoft Publisher and Word. I place my resume brochure, magnet business card, a regular business card and a brief cover letter in an envelope. I also include a thank you card and Magic Cards. Magic Cards are a deck of trick playing cards. For my slogan I use, "Hire Terri and watch the magic begin." I suggest taking a break from their stressful job and have some fun with their team using the Magic Cards.

Another creative job hunting technique which is presently being used is to create a web site about yourself, your talents and abilities, and your resume. You can even add a picture of yourself. Some employers are looking for web sites featuring perspective talented employees. There are several free web sites and I have used freewebs.com, which does not cost anything and is easy to use if you follow their directions. All you need to do is create two to three pages about yourself and then you can upload your website free onto search engines by following the directions. If you are afraid of computers or creating web sites then ask a teenager to create a

I recommend using a sense of humor and using your disability to connect with others in a positive way.

site for you!

Employers are reluctant to hire the disabled if they need to provide the disabled person with accommodations. One way to avoid this issue is to ask the Vocational Rehabilitation Office to have a technology assessment done, which would provide you with a clear idea of what you will need in order to be successful at work. They may even provide you with all the necessary technology, which offsets the cost of accommodations for perspective employers.

Another issue is that employers are not allowed to ask if you are disabled, but you can volunteer, which you may feel is necessary if you have an obvious disability. I usually educate the person who is interviewing me by telling them what I have because otherwise they may think I am nervous and not confident. However, I recommend you

think hard about the pluses and minus of engaging in this act. The plus is that both parties have a clear idea of what you can offer the company and what you will need from them. The negative side of disclosing your disability is that they may not hire you. Each person needs to weigh the effects of disclosure for themselves.

I also recommend using a sense of humor and using your disability to connect with others in a positive way. One example is that I am a psychotherapist and I notice that clients will open up to me sometimes when they will not open up to another therapist. Part of the response from clients or prospective employers is they decide that I can relate to them on a personal level. Each of us has difficulties in our lives whether we are able bodied or disabled, so people believe that I can relate because I too have problems. I once worked at a printing place where the on going joke was that we should start a baseball team because I could fool the other team into believing that I could not hit the ball. I had developed a sense of humor about my condition and really thought that was funny at the time. I think we each need to be able to laugh at ourselves and we need to be able to help people relax around us. If this is not your style then communicate to them just how smart you are by using your intellectual abilities and knowledge to knock them off their feet, distracting them from your disability. After you have known someone for a few months or even just a few weeks, they will forget that you are disabled and begin to treat you like anyone else.

Remember that your job is to market yourself to prospective employers. Your first line of action is a cover letter highlighting what you can do for the employer, and then create a professional resume. If you want to be creative, try a brochure, magnet business card, or even a web site. Think about how you can stand out from the crowd and do not expect an employer to know how to react to your disability.

I think it is the job of every disabled person to help able-bodied people feel comfortable around us. It will help if you can laugh at yourself. If you have tried everything else

and still do not find a job then try to increase your experience by volunteering a few hours a week, which will help you network with people to find a job. In addition, if you have a dream and want to fulfill it then try writing a grant and create the job you want. I wish you the best of luck trying to find your dream job!

About the Author

Terri Sterling can be reached at terricreativity@yahoo.com. Be sure to include in your email that you are a reader of the Tremoraction.org newsletter. Terri has a masters in psychology, 14 years of experience, and is a trained Creativity Coach.

Finding Our Way through Loss and Grief

By Mona Reeva, PhD, MPH, LCSW

I've been thinking about losses and grieving recently. I believe that these thoughts come especially as we get older since there seem to be many more losses to absorb and integrate. That isn't to say that at any age there aren't many losses that we can experience. For example recently the following has come to my attention.

The other day I learned about the sudden death of a physician in his 40's who left behind a wife and new baby, a partnership that was getting started and his family of origin - mother, father, siblings. A cousin who just turned 60 was diagnosed with stage 4 cancer and is undergoing chemotherapy while caring for her 94-year-old father. One of my friends has a son who, recently separated, became very depressed and unable to work and entered a rehab program. Another friend's sister just passed away in her 40's waiting for a liver transplant. My granddaughter has been diagnosed with hearing loss at age 8 and is now wearing hearing aids and may lose all her hearing and require cochlear implants. I, who love photography, have started noticing that my hands are less steady when I use my camera.

All of these losses bring on grieving. Some losses are the result of the loss of a person, a loved one, and may affect us more deeply than others, depending on a large number of issues such as how close were we to the one who died; how important was that person in our lives? It is not the length or quantity of years of the relationship, but the meaning and quality of the relationship that becomes the important factor for consideration. Other losses may not include the loss of a loved one but the loss of an attribute, place, home, et al, that is quite important to us. How do we accommodate to these changes in our lives?

Through our own emotional struggles we find meaning in our lives in order to make sense of our disabilities, whatever they may be.

Loss and grief are an integral part of our lives, from an early age, although many changes are not always recognized as loss. For example, when we grow and develop as preborns the safety and cushioning of the womb gives way to a completely new experience being in the world where the safety factor becomes far more tenuous than ever. Yet we celebrate this birth as if there were no loss involved, either for the individual or for the mother carrying this life for 9 months within her body. The developmental stages of our infancy is remarkable in the number of changes that take place and as we grow and change we lean into new beginnings, new learning and must give up old ways of being. Remember the tears when you are no longer picked up and carried but must now walk by your self? Remember the parting you make from your parent when you enter preschool or school or are dropped off at the babysitter? When you moved to a new school, or had a new sibling to deal with as you lose your place in your family? When a sibling is diagnosed with an illness and begins getting all the attention? These are small shifts in our sense of our selves as we are growing and changing and finding our way to becoming who we are over the course of our growing up.

Joy and encouragement by family, friends, teachers, and/or neighbors mitigate some of these losses and we weather them as part of our development. However when there are losses that come rapidly and supports are missing or lacking, the impact may become unbearable and we may succumb to various emotional disturbances.

Some losses may be so severe that recovery becomes one of the most critical challenges of our lives. As an example, we have a number of our service men and women coming home from Iraq with a variety of injuries of limb, brain function, post traumatic stress, etc. The level of medical care, health care and emotional support from the military system, the Veterans' Administration and the public health care systems will have an impact on each individual's

recovery over time. How our political leaders deal with these people's losses, as well as the public's support of their bravery and aftermath will have an impact on their recovery.

We recall what happened to many Vietnam Veterans who became homeless and mentally ill in the face of lack of support from the public, the military and the VA. Many of our new veterans will do the same as a result of the myriad problems they seem to be now facing.

Those of us reading this article may have already lost some of our ability to maintain a "normal" steady stance in the world with our tremors, bringing on losses that accompany our participation in the world around us. Emotionally distanced, perhaps even cut off from social relationships, we may become and remain isolated. Depression finds its way into our being and a sense of uselessness, with an increasing inability to cope, as we retreat further and further until our sadness turns into depression and an inability to act on our own behalf increases.

These losses must be recognized and acknowledged for healing to begin. It is not only the difficulty itself, whatever that may be, that creates the most problems. Not being able to recognize that there will be symptoms from intense and or repetitive losses will compound our emotional distress. Such distress requires emotional and psychological assistance from professional people that have the skill and experience to assist us in our walk through emotional turmoil that loss can bring.

I don't know all the possibilities that exist that can lead us to a renewed sense of ourselves, that will take us through our sadness, isolation, depression and/or post traumatic stress. I don't think anyone does. What I do recognize is that through our own emotional struggles we find meaning in our lives in order to make sense of our disabilities, whatever they may be. This struggle is a requirement for our healing process. Recognizing our own levels of distress is a mandate to ask for help along the way. Help may come from friends and family and that may not be enough. We need to

be prepared to say, ok, I can't do it alone any more. Now it is time to seek professional assistance in healing from our losses.

About the Author

Dr. Mona Reeva writes a quarterly column that focuses on mental health issues. Readers are invited to ask questions that will be answered and featured in subsequent newsletters. Topics include but are not limited to mental health concerns that are specific to us with movement disorders. Please email your questions directly to Dr. Reeva at mreeva@comcast.net.

Dr. Reeva "loves photography." Her exceptional and award winning photos can be viewed at <http://www.flickr.com/photos/drmona/>.



Romert invites you to join the online support group Tremor at <http://health.groups.yahoo.com/group/tremor/>.

Explore and learn about essential tremor, and neurological related movement disorders dystonia, Parkinson's and restless leg syndrome that cause abnormal involuntary muscle movements and contractions. Daily discussions offer information and resources. Comfortable environment provides for laughter, tears, and encouragement.

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