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The Tremoraction.org and Care4dystonia.org Newsletter JUNE 2005

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Through the ET Looking Glass…What Andrea Found

By Andrea Goldstein

When I was a teenager, my great aunt Ethel would sometimes come by to visit. I only knew a little about her past; she was my maternal grandfather's sister, she had come to America from Russia as a young woman, her late husband was the father of the actor who played Zorro on television, and she had been unable to have children. I can see her sitting in the living room of my parent's house. She was tall, wore large rimmed glasses, and was very pretty for her age. I also remember that her head and hands shook.

Back then I didn't know what essential tremor was; I don't think my aunt Ethel knew what it was either. I never thought much about it. Some years later my aunt passed away. By that time, her nieces and nephew (my mother and her siblings) were in their 60's. I was a young adult at the time. As I grew older, I realized that my uncle's hands shook, too. Soon after I noticed my aunt's head shook, as if she was always responding "yes" to unspoken questions. I never thought much about it.

When I first found TAN I came looking for a place for me where I could connect with others with ET.

I was in my 30's when my mother's other sister was dying of cancer. She was my favorite aunt. Widowed as a young woman during the war, she remained unmarried for many years and would spend her winters working in Florida and her summers living with us. Because of our close bond, I saw her often during her illness. On one particular visit, she and my mother were talking in the living room of her small apartment while I cleaned the kitchen. I heard her ask my mother why my head was shaking. I didn't know what ET was.

For many years I felt "different"; shaky inside, sometimes with shaky hands, seemingly nervous, even though I knew I wasn't. My mother would ask "why are you so nervous"? By this time my aunt and uncle were in their 70's, and their shaking, while finally labeled as being ET, was attributed to "old age". My uncle's hands were so bad that cutting his food became a problem. My aunt developed a voice tremor to go with the tremor in her head.

Five years ago, when I was 46, I realized something was wrong. My hands were shaky, I shook inside, I'd been dealing with what I thought was a twitching muscle in my upper back. As a nurse, I knew how to do health research, and at first I thought I had a life threatening degenerative brain disease. I consulted a neurologist, presented him with my family's history, and learned that I, too, had ET. The doctor drew a little chart of my family members, and focused in on my grandfather, who had died in his 40's. He had passed on the ET gene. I was relieved that I wasn't dying, but that was replaced by a growing fear of what the future held for me.

After my diagnosis, I tried a lot of medications before I found one that I could live with that helps, at least somewhat. Thus far, though I'm sure my ET started when I was a young woman, I'm doing ok. I told my cousins that I had ET. I wanted to know if any of them had it. And I wanted to bring the issue out of hiding. It looks as though two of my cousins have a slight tremor. Among my sibling and my cousins there are 13 children, and three grandchildren.

When I first found TAN, I came looking for a place for me, where I could connect with others with ET, share stories and learn to live with my symptoms and the uncertainty of the course of this disease. Once I'd done that, I knew that I had an obligation to try to bring ET into the public eye, to work hard to see that research is done so that better therapies and perhaps a cure might one day be realized. It's easy to get involved with something that touches so many people you love and hope to protect.

I do not want to have ET when I'm elderly, as my aunt and uncle do. My uncle is debilitated by his hand tremor; he is now too old and too sick for DBS. My aunt must carry straws with her in order to drink because her head tremor is so bad, and understanding her tremulous voice is now difficult. I invite you all to join with me in becoming a force to be reckoned with; that force that will lead to a cure for ET, so that generations to come will know it as we know of many other diseases; something that has been eradicated from the face of the earth. It won't be easy, but with the help of every one of us, it can happen.

About the Author

Andrea Goldstein is a RN with over 20 years in the health care field. She has been published in Nursing Spectrum Magazine and most recently worked on a research project to increase prevention screenings in primary care practices. Theresearch findings were published in the Archives of Internal Medicine in March of 2005.

Social Security Disability

By Nancy Muller

The key word in obtaining Social Security disability is PATIENCE. It can be a long involved process and you have to be patient in order to make it through the ordeal. Yes, I do call it an ordeal because it can be both complicated and frustrating, but if you hang in there, it's worth the wait.

If for any reason you can no longer do your normal work because of your health, and you have not yet reached retirement age, you have the option to file for Social Security Disability, and you will collect your monthly retirement and also Medicare for your health coverage. There are two different directions you can go to file. You can file yourself or go to a lawyer that deals strictly with Social Security Disability claims. I recommend obtaining a lawyer, which is what I did right away. The lawyer you choose should take your case on contingency, which means if you win your case and get a favorable decision, he/she gets a percentage of your retro active benefits. Benefits normally date back to when you originally file your claim.

When filing your claim for disability, you must make sure you have good medical records and a reliable physician that will help fight for you. If you file on your own you must make sure you have copies of all your medical records to submit along with a lengthy form. At some point you will probably need the assistance of an attorney and so I urge people to obtain one to take you through the entire process rather than the added stress of trying to do it yourself.

Once you have filed for disability the Social Security Administration, working with the appropriate state agency, will review your claim. By this, they will examine all your records and sometimes will send you to their doctor at their expense for an examination. In the majority of the cases, and I estimate approximately 90%, a denial occurs.

DO NOT GIVE UP! You then can ask for reconsideration on your own if you file, or your attorney will do it for you. At

this point an impartial examiner will review your application and medical records to determine if the previous decision was correct. Again, the majority of the cases are denied and then you will need to go on to a third round.

In the event you did your own filing and you received a denial on reconsideration, at this point you must absolutely obtain legal counsel before moving on to the third round which is requesting a hearing before an Administrative Law Judge.

Hang tough, by this time the system has probably worn you down, but you can't give up. You can now ask for a hearing. An Administrative Law Judge will hear your case and evaluate the medical history in your life. At this point I would like to add that the system moves very slowly. In my own case it took three years before I received my hearing and favorable decision, so you must prepare yourself for most likely a lengthy process.

You can beat this system, but you have to be patient and not give up!

The judge is not bound by any of the earlier denials and the assigned judge who reviews your case may deliver a completely new decision. This will be your best chance for winning benefits. At the time of your hearing, also present in the hearing room will be a doctor and a vocational expert. Sometimes the doctor will have a phone patch to the hearing room and the proceedings will be presented that way.

I am coming from the prospective of having legal counsel throughout my experience with the system, and I found it was a lot less stressful on me to go this direction. The attorney can only take a certain percentage of your past benefits with a cap on it. The judge will also determine if the amount is fair. You must make sure your attorney is keeping up with your case, and I made sure I called often to check the status. I ended up changing attorneys because I felt my original one wasn't working for me with my best interests in mind, so I changed and the fee was split. This also was according to the determination of the judge.

You also want to have a FULLY FAVORABLE DECISION rather than a partial, because you might have stipulations put on your case and you want to maximize your benefits.

In the event you are denied on the third round you still have other options. The final recourse within the Social Security System is the Appeals Council. You respond to a denial by gathering any new medical evidence along with your file and any additional statements you wish to have considered and send them to the council. The Appeals Council could reverse or uphold the judge or allow you to have a new hearing.

If you still haven't received satisfaction, you can seek redress in the federal courts. You must complete all of the previous steps. If you're still holding a denial at this point, you can file a formal suit in the U.S. District Court in your area. This must occur within 60 days of denial by the Appeals Council and should involve an attorney.

You can beat this system but you have to be patient and not give up. It's unfortunate that those of us with diseases and disorders that are unfamiliar to the examiners and judges, almost always fall through the cracks and its one denial after another. So the importance of finding a good team to fight for you. You must investigate your lawyer and make sure they have a good track record along with a good knowledge of your disorder. The more info you can feed them, the easier to win your case. Also make sure you actually meet with your lawyer face to face and you are comfortable with them and confident they will work hard for you. Call frequently for status reports on your case, because this gets them to keep the wheels in motion.

I would also like to add that if you get a fully favorable decision and you find at sometime down the road you feel you would like to try and go back to work, you can actually

do this for a trial period of 10 months. If you feel you just can't work, you have the option to go back on disability without having to go through the entire process again.

If there is any other way I can assist you in getting through this process please feel free to either e-mail me at nmuller406@aol.com or call me at (951)926-3677.

About the Author

Nancy Muller is a Registered Radiologic Technologist with a specialty in orthopedics. She is past president of the National Spasmodic Torticollis Association, West Coast Liason for Care4Dystonia and on the Board of TAN. She herself has had Spasmodic Torticollis for over 20 years, and was in the original Botox trials before it was approved by the FDA. Nancy has a forum in the NSTA Magazine devoted to an up front and personal forum of questions from members. She is an advocate for support and education of both the public and medical profession. She has a published chapter in The Spasmodic Torticollis Handbook, authored by Drs. Pathak, Frei, & Truong.

Animal Tremors: Of Mice and Men……and Marine Life

By Hokuto Morita

For some neuroscientists, it should come as no surprise that one of the avenues for Essential Tremor (ET) research has come from the oceans. The basis of modern neuroscience rests on research performed in marine life. In the 1950s, the scientists Hodgkin and Huxley won the Nobel Prize and launched the field of neurophysiology for figuring out the mechanics of nerve signaling using the squid. The components of nerve to muscle signaling were identified in the torpedo ray. In 2000, Columbia University neuroscientist Eric Kandel won the Nobel Prize for identifying some of the key mechanisms underlying learning and memory using the Aplysia sea snail. The tools that neuroscientists use to study nerve signaling often come from proteins and toxins taken from jellyfish, puffer fish, poisonous sea snails, and a host of other marine life. The ocean's contribution to Essential Tremor comes from one of our furrier friends - and it comes from a place widely considered to be the best aquarium in the country.

In 1997, the researchers at the Monterey Bay Aquarium in Monterey, California noticed that one of their otters, Goldie, began to exhibit a head tremor. The researchers at Monterey Bay took in Goldie in 1984 when she was found orphaned at only 5 weeks old. In many ways, Goldie's tremor resembled that of the type seen in ET patients - her tremor was visible when she extended her neck to reach for food or groom, and the tremor wasn't evident when her head was at rest. Over the years, the tremor progressed to her limbs. A group of researchers at Monterey Bay led by Dr. Mike Murray documented her tremor through regular videotaping until the time of her passing in 2002. They also conducted regular check ups and blood tests and some of the tests would be familiar to many ET patients such as thyroid function tests. Word of Goldie's tremor reached TAN medical contributor Dr. Elan

Louis and neuropathologist Jean Paul Vonsattel, both curators of the Essential Tremor Brain Bank at Columbia University. In collaboration with Dr. Mike Murray at Monterey Bay, they performed a detailed study of Goldie's brain to find the possible cause of Goldie's tremor. What they found was that there was something wrong with the Purkinje cells of the cerebellum. The Purkinje cells are the cells that allow the cerebellum to communicate with rest of the brain and they send the signals that are important for movement coordination, movement timing, and some types of motor learning. Specifically, they found large, clear, blobby swellings, or "vacuoles" in the Purkinje cells. This is an indication that the Purkinje cells were sick or dysfunctional. Preliminary studies by Dr. Louis in human ET brains had similar, but slightly different findings. When Dr. Louis initially looked at the Purkinje cells of ET brains he did not see the "vacuolization" seen in Goldie, but he did see a special type of protein aggregate and swelling called a "torpedo" - a slightly different finding, but another indication that the Purkinje cells in ET brains might be sick or dying. So although the findings are slightly different, it's possible that Goldie's tremor and the tremor in ET patients are both caused by dysfunction of the Purkinje cells in the cerebellum.

Otter studies like this one were almost not possible. In the 18th and 19th centuries, fur traders nearly hunted the Southern Sea Otter to extinction for their very dense fur coats. Since sea otters have no blubber, their very dense fur coats provide the only barrier from the intense cold of the Pacific waters. Their very high metabolism also helps keep them warm and in order to maintain their high metabolism, they must eat a prodigious amount of food, as much as 30% of their own bodyweight. They eat a steady diet of marine invertebrates including shellfish, sea urchins, octopus, worms, starfish, and crabs. Their reliance on these foods may make them especially vulnerable to any toxins that could be present in shellfish, including lead, mercury, and dioxins among some.

According to Dr. Mike Murray, neurological disorders are quite common in otters. Researchers are trying to determine how much of this is genetic and how much is due to environmental factors. It could be a little of both. According to the Friends of the Sea Otter organization, the current Southern Sea Otter census is around 2000-2500, making it a threatened species. With such a small population, there may not be enough genetic variability, making otters particularly susceptible to a wide range of disorders. In addition, otters face a number of environmental challenges from toxins and parasites. However, for otters the environmental factors may be more important. "Modeling of the population seems to suggest that the genetic effects may not be significant, but one still wonders about the effects of having such a small population size. However, we have plenty of non-genetic explanations for the high prevalence of neurologic disease," says Dr. Murray.

There are historical precedents for ecological disasters creating neurological disorders in both humans and animals. One such case happened in a fishing town called Minamata, a town that was almost entirely dependent on fish and shellfish as a food source. Between the years of 1932 and 1968, the Chisso Corporation dumped large amounts of methyl mercury into Minamata Bay. The cats of Minamata began to exhibit strange behaviors - dance-like movements, "cat suicides," and some townspeople began to call it the "cat dancing disease." Soon after, the residents began to develop neurological disorders like ataxia, blindness, uncontrollable tremors, slurred speech, and mental illness in what is now called Minamata Disease. For ET research, the exact contributions of genetics and environment are not clearly known. Dr. Elan Louis of Columbia is currently looking at environmental risk factors for ET and has proposed heavy metals, organochlorine pesticides, and plant alkaloids as possible candidates. Research in animals can sometimes help identify common risk factors in animals and humans. The researchers at Monterey Bay continue to look for risk factors that may affect not only their animals, but humans as well. However, Dr. Murray also explains some of the challenges, "We and other marine researchers are looking at the effect that contaminants may have upon the sea otter and

subsequently, human health. The tests are expensive and time consuming, so the going tends to be slow. Also, the results may have far reaching implications, so we want to be certain that any data presented to the public is valid."

What else can studies in animals teach us about Essential Tremor? Therapeutic drug studies often hinge on the presence of quality animal models for a disease. There are many different ways to create an animal model for a disorder. Before the advent of genetic engineering methods, most models were either drug induced or spontaneously occurring mutations occurring in inbred strains of mammals. In the past, many disorders were modeled with drug induced methods. For example, to create mouse models of epilepsy, mice were fed compounds that induced seizures. Researchers would then treat the mice with various drugs, looking for those that curtailed the seizures. A large number of the anticonvulsants used for epilepsy, some of which are being tried for ET, were developed using this kind of animal model. One of the current animal models for Essential Tremor is one such drug induced model. Animals treated with a compound called Harmaline exhibit tremors that resemble the tremors of ET. This has been the approach taken by one of TAN's medical contributors, Dr. Adrian Handforth. He is screening a variety of possible therapeutic drugs in Harmaline-treated mice to try to identify any that may have a beneficial effect for ET. The use of the otter is not quite practical for this kind of drug screening because of their long life span, complexity and expense of upbringing, and endangered status. However, brain pathology studies in Goldie could be useful in looking for changes in the brain that may have caused her tremor.

The ocean's contribution to Essential Tremor comes from one of our furrier friends- and it comes from a place widely considered to be the best aquarium in the country.

In determining how good an animal model for ET is, scientists often ask themselves whether the mouse or other animal model is shaking for the same reason that people with ET shake. It turns out that there are an incredible number of ways to make an animal shake - mice treated with nicotine shake, Huntington's Disease mice shake, Spinocerebellar Ataxia mice shake, but the tremor seen in these mice probably have a different underlying cause than that seen in ET.

So how does Goldie's tremor stack up against ET? Goldie exhibits a postural tremor and the absence of a rest tremor. This is similar to what is seen in ET. Goldie was never treated with ethanol, beta blockers, or some of the anticonvulsants used for ET, so it's unknown whether Goldie's tremor would have responded to these treatments. How about the pathological findings? The findings from Goldie's brain and the preliminary findings from ET brains showed slightly different pathology, but in both cases there were indications that the Purkinje cells, the cells through which the cerebellum communicates with the brain, were very sick. Though it may not be enough to say whether Goldie's tremor is truly "essential," these findings indicate that the underlying causes may be similar. More studies will be required to determine whether Goldie truly had an animal version of ET, but many of the trials and tribulations of her daily life are very familiar to those with ET. As her affliction progressed, Goldie had more difficulty performing certain tasks that required dexterity. "The degree of affliction did escalate over time, and eventually she had difficulty grooming (a catastrophic problem in free ranging otters), and managing her feedings (another catastrophic problem for otter in the wild), as the types of food consumed require some degree of handling and processing," says Dr. Murray. One thing that she did not seem to suffer from that many patients with ET do was the embarrassment of tremors. "There was no observable change in behavior with the other otters after she developed the tremors." Imagine floating on your back, eating meals off your belly with shaky hands…and not being embarrassed about your tremors.

For more information about sea otters, otter conservation programs, healthy seafood choices, and the Monterey Bay Aquarium, visit the Monterey Bay homepage at http://www.mbayaq.org, or the Friends of the Sea Otter page at http://www.seaotters.org. The study on Goldie's tremor is published in the February 2004 issue of the journal Movement Disorders. Special thanks to the researchers at Monterey Bay Aquarium and Columbia University for their time.

Aquariums and Zoos where you can see Sea Otters: SeaWorld San Diego, Long Beach Aquarium of the Pacific, New York Aquarium, Oregon Zoo, Aquarium of the Americas, Monterey Bay Aquarium.

About the Author

Hokuto (Hok) Morita has had ET since he was 5. As a graduate Neuroscience student, he did his research on cell models of Huntington's Disease and has presented his work at many scientific meetings. Hok will begin medical school this Fall at the Penn State College of Medicine in hopes of becoming a Movement Disorder Specialist.

The otter photo by Warren and Leora Worthington, is from the Friends of the Sea Otter homepage

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Ask Linda

Dear Linda:

I was diagnosed with Essential Tremor 10 years ago and experience mild to severe head shaking. My condition can be disabling at times, but mostly I find it to be very embarrassing in that I cannot control the movement of my head. Because of my embarrassment I find myself not wanting to be in public. When I do go out people stare at me, many of them asking me if I have Parkinson's disease. How can I move past this embarrassment and misconception to face the world like Katharine Hepburn did with her essential tremor?

Janet S. – Sacramento, CA

Dear Janet:

I feel many of us are self-conscious about a part of our body whether it is we are not comfortable with our weight, or maybe we don't like the size of our nose or we think we have funny looking feet. At times our obsession with having something perfect may be overwhelming. To overcome and work through this, typically what happens is a more important issue comes about to take the focus away from this negative obsession. We begin to realize, for example, the size of our nose is not important when we are caring for an ailing parent. We shift our energy and thinking to something that needs immediate attention.

In the case of Katharine Hepburn, I feel she had the ability to move beyond the shakiness of her head and focus on the essence of who she was. She may have thought about her tremor, but her energy was focused on her work and who she was as a woman and an actress. She gave the impression that she was comfortable with who she was, tremor included. If she was okay with having an essential tremor, then so should the rest of the world.

I would have to ask "Why do you care what other people think?" You have the right to live in this world no matter

what your body is like. If you find yourself in an uncomfortable or embarrassing situation learn to talk about your Essential Tremor; educate that person or people on your condition and let them know what its like to live in your body. This may help open their minds and be thankful that you had the courage to let them know why your head is shaking.

Be well, Linda Furiate

About the Author

Linda Furiate is a personal coach, mentor, talk show host and author helping individuals with physical challenges move beyond any and all obstacles to live a more satisfying life. To learn more log onto: http://www.portraitsindetermination.com.

If you have a question for Linda email her at Linda@portraitsindetermination.com.

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

Steps to Finding a Movement Disorder Specialist

By Beka Serdans

Your First Task is to:

Get names and phone numbers. Try an Internet search. Several websites list physicians across the country. Scroll to the physician referral link on major medical center/facility websites in your area. An example is:

University of Maryland Department of Neurology:
http://www.umm.edu/neurohome/

Maryland Parkinson's disease and Movement Disorders Center:
http://www.umm.edu/parkinsons/index.html

Post inquiries on the multiple tremor and dystonia Message Boards that exist online today. Many of these Boards have extensive lists of "Who is Who in Tremor and Dystonia." You may need to email others directly to inquire about available medical care in your area.

Ask family, friends, and co-workers for help. Contact your local support tremor or dystonia group or State and County medical societies, Hospital referral services, other doctors or nurses and word of mouth (relatives, neighbors, co-workers). Don't be shy in asking or learning "Who is Who in Movement Disorders."

Ask yourself "How far can I travel?" Patients with complex conditions will travel any distance to see a good doctor, if they can. Realistically, driving is very hard on some and impossible for others. Think about what you can consistently manage.

Does my insurance restrict who I can see or where? It is easier to work within your insurance guidelines than outside of the network, but consider all possible doctors,

regardless of insurance.

Call to set up an appointment. Call more than one number, if possible. Is there a fee for an interview with a doctor? Generally there is not a fee for so called no-cost interviews.

Share your goals and expectations with the staff after arriving. Sometimes meeting others in the waiting room can clue you in on the office and the quality of care being provided to patients. Tell the receptionist what type of care you expect.

Ask the following Questions:

Is the Physician "Board-certified" in Neurology? Do they specialize in movement disorders? In tremor? In dystonia? Where did he/she complete their medical training? Did they complete a "Fellowship" in movement disorders? What are their credentials? Is the physician affiliated with medical center(s) that are approved by the Joint Commission on Accreditation of Healthcare Organizations?

Post inquiries on the multiple tremor and dystonia Message Boards that exist online today.

You can find this information on the American Board of Medical Specialties website (ABMS): http://www.abms.org and Specialty licensing boards: http://www.abms.org/member.asp.

How many patients with tremor or dystonia does he/she treat on a weekly- monthly basis? How frequently are patients with tremor or dystonia seen?

Is the physician familiar with botulinum toxin therapy? Dosing guidelines? If so, who gives the toxin in the office/clinic (i.e. medical students or the neurologist/ attending)?

Does the physician work with a coordinated team? Is there a neurosurgeon for deep brain stimulation for tremor-dystonia available? If there is no team approach available, are these individuals (dietician, genetics counselor, social worker etc.) easily accessible by referral?

What is the waiting time to get an appointment? Weeks? Months? What is the usual waiting time in the office before you actually see the physician? Are family members allowed to attend appointments? Is there someone on 24-hour emergency call? How easily can you contact them?

Does the office/center carry patient education material about tremor or dystonia? Is the Patient's Bill of Rights posted and visible in the office/center?

Does the physician accept your medical insurance policy? Are there any out-of-pocket expenses?

Will you have access to your medical records including CT Scans, MRIs? Are prescriptions updated on a consistent basis?

Ask as many questions as you need. Ask to speak with another patient who is being currently treated for tremor or dystonia.

Evaluate the office/center-staff:

Was the receptionist/office-center staff courteous and helpful? Was the office/center clean or cluttered? Are OSHA policies in effect?

If paperwork needs to be completed, how difficult was it? Are forms in Spanish or other language available?

Was the waiting room comfortable? Is the office-center handicapped-accessible?

Is there possible assistance with transportation to/from appointments? Is there a 24-hour appointment cancellation policy?

Make your Choice:

If you're satisfied with the Answers, go for it! But, remember "it's your time."

Use your **intuition** when coming to a decision. If you "feel uncomfortable" with the physician or the office/center, they most likely are not the "right" movement disorder physician for you. One basic element to remember is that "**Not all Neurologists are Movement Disorder Specialists; but ALL Movement Disorder Specialists are Neurologists.**" Reread this sentence again. We often don't realize the meaning or importance of this basic element. Bear in mind to trust your gut feeling. Your main goal is to interact with each doctor, checking for a comfortable fit and ability to work together as a team.

Your final task is to begin writing all of your symptoms and questions in a diary/log or in a note pad. Questions can easily be forgotten when visiting a physician. This "diary" becomes your own personal medical record of tremor and dystonia. And it may be prove to be of great value to both you and your chosen healthcare provider.

Good Luck!

Useful Websites:

American Medical Association Online Doctor Finder:
http://ww.ama-assn.org/aps/amahg.htm

WebMD:
http://www.my.webmd.com

Doctor Directory:
http://www.doctordirectory.com

Web Guide:
http://www.docguide.com

Interactive website:
http://www.findadoc.com

About the Author

Beka Serdans, RN, MSN, is a strong patient advocate and founder of Care4Dystonia, Inc. She has written about her experiences with dystonia in I'M Moving Two and I'm Moving On... Are U??. Learn more about Beka by reading online excerpts of her forthcoming book: Walk a Mile in My Shoes at:
http://www.care4dystonia.org/about.htm.

What is Dystonia? CERTAINLY NOT ESTONIA!

By Beka Serdans

Dystonia is a neurological disorder characterized by over-activity of specific group of muscles and/or muscle. It is the over-activity of these specific muscles that causes involuntary movements and tremors
sustained muscle contractions
and abnormal postures.

Why is it misdiagnosed?

Dystonia is misdiagnosed 90% of the time by clinicians. The involuntary movements and spasms caused by dystonia sometimes are attributed to stress, stiff neck, dry eyes, tics, or psychogenic disorders. A significant clue to dystonia lies in the fact that dystonia often increases during activity, stress and anxiety; but diminishes during relaxation and sleep. The disorder is touched upon in medical school but not really emphasized.

Dystonia cannot be treated overnight. Treatment may involve one of more multiple options. Have patience!

How often does it occur?

It is estimated that 550,000 people have some form of dystonia in NA alone however, this value does not take into account that dystonia can coincide with other medical conditions such as essential tremor, Parkinson's disease, Multiple Sclerosis, Cerebral Palsy, Wilson's disease etc. The actual number of people identified with dystonia may be over a MILLION, but current funding has not included the distribution of funding towards determining the epidemiology of dystonia.

Who can " get " dystonia?

Anyone can develop signs of the disorder. No one is immune to this disorder.

Is there a cure ?

At present, there is no known cure for dystonia.

Medications

A number of oral medications (pills) have been used to treat and manage dystonia. Sometimes it takes a combination of several drugs to obtain a beneficial effect. These drugs do not work overnight! It often takes a little bit of medication "juggling" to obtain an optimal benefit. Do not get discouraged!

Botox

Botulinum toxin (Botox) is a toxin produced by bacteria called Clostridium botulinum. It causes temporary muscle weakness when injected into muscles affected by dystonia. Botulinum toxin quiets muscle activity.

Botulinum toxin is a temporary treatment. You should expect these injections every 3 to 4 months. More frequent injections with higher doses can result in the formation of toxin antibodies. When antibodies develop, the effectiveness of the toxin is reduced significantly, or stops altogether. Therefore your physician will recommend a conservative dosing program, hopefully to prolong the usefulness of the toxin.

Surgery...DBS

At the present time there are several Dystonia management surgical procedures available. These procedures have helped some people but not all. Generally speaking surgical interventions are considered when medical treatments have failed.

In deep brain stimulation (DBS), an electrode is implanted in the area of abnormal electrical activity and a test stimulation test is done. If there is a beneficial response the electrode is secured to the skull with an "extension wire" that is attached to the electrode which is then tunneled underneath the skin towards the collar bone area

to be attached to a pacemaker. DBS minimizes involuntary movements by delivering mild electrical stimulation to block brain misfiring signals that cause the abnormal movements. The pacemaker is used as a programmer to deliver counteracting impulses. One of the main advantages of DBS is that the effects of DBS are reversible baring any complications.

The risk for surgical procedures include death, bleeding in the brain, stroke, seizures, infections and device malfunctions.

Managing dystonia can be complex and challenging whether it involves oral medications, botulinum toxin injections, surgical interventions, physical therapy and/or complimentary modalities. But with the advent of new treatments developed over the last fifteen years, it has improved dramatically. Dystonia cannot be treated overnight. Treatment may involve one or more multiple options and may affect you differently over a period of time. Have patience!

About the Author

Beka carries multiple " hats " - that of being a patient diagnosed with dystonia; that of being an active healthcare professional. She is the author of Spikes & Spasms article, Steps to Finding a Movement Disorder Specialist. Beka appeared on NBCs Dateline in 1998 with Dr. Mitchell Brin, MD in a story covering the use of Botox for dystonia. Since then she has appeared in multiple media venues, more often writing about her own experiences and battles with the disease. She has developed the innate ability to see all sides of dystonia.
