Spikes & Spasms

The TremorAction.org Newsletter

OCTOBER 2010

IN THIS ISSUE

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WELCOME TO THE OCTOBER ISSUE!

- Movement Disorders Awareness Month -

Paraphrasing author Cary Cook, *"It's so amazing that we know **so much less** than we assume we do."*

The October issue introduces readers to Cary's emphasis on health care education, Peggy Deras' BTX experience, Melissa Gaskill's knowledge of physical therapy for tremors, Dr. Rob Lamberts' advice on dealing with doctors, and what TremorAction.org has been up to - exhibiting at annual neurology meetings, reviewing **cutting edge** movement disorders poster abstracts, participating in the Member of Congress meeting, getting involved in advocating for the passage of H.R. 1362 and S. 1273, and attending the 9th consecutive St. Rose Health Fair.

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Health Care Education

By Cary Cook, RN

Health care is a huge issue in the United States right now. Healthcare and our healthcare system are always important, but with the political fight over reform, it is news constant. There are more websites than ever with information on just about any illness you can think of, and tons of disinformation alongside them with scams to bilk people out of their money.

Part of the problem with our system is that the majority of U.S. citizens do not have a basic grasp of anatomy and physiology. They don't know how their bodies work, so they don't know how to take care of them. We are born without owner's manuals, and most of what we learn comes from our parents. If they are not educated about their bodies, how can they teach us?

> "Suddenly you have this problem and you don't understand anything about the mechanism that caused it."

Basic knowledge of anatomy and physiology is critical to staying healthy. It is an important dynamic of healthcare spending, because if you don't understand how your body works, you don't understand why treatments or testing may be required when you are ill. You don't see the need for preventative healthcare or screening tests. Lack of healthcare education may cost you money, or even your life.

I know a man who does not have insurance. His doctor ordered a colonoscopy but he waited years to have one because it was too expensive. This man is not uneducated. He was born in the U.S., he is a tradesman who completed a four-year apprenticeship and he runs his own contracting business, but he did not know what or where his colon was. He had heard the word, but that was it.

Because he didn't understand his body, his diet was poor. His health was not great. He did not understand why it was important to have an expensive screening test when he felt fine. He thought he couldn't afford a colonoscopy so by the time he had one, he already had cancer. He paid far more than the price of a screening test. He paid with a foot of his colon and a hospital stay, weeks off of work that meant weeks without income. All because he didn't have a basic understanding of anatomy and physiology.

I'm sure some of you did not know a thing about tremors until you developed one. Suddenly you have this problem and you don't understand anything about the mechanism that caused it. How do you sort out what treatments might be effective and what are a waste of time and money? How do you know whether you have a good health care team, or one that wants to use you as a cash cow to buy unnecessary treatments, testing, or supplements? You are behind as soon as you start because you have to teach yourself about nerve function and the healthcare system.

I answer questions from strangers every day on a women's health website. These women do not know how to care for themselves, how the menstrual cycle or pregnancy work,or where to look for information. Every child should know the difference between a vagina and a urethra, but many of them don't. We really need to improve basic health information in this country, so that as adults we can be responsible participants in our own healthcare. Our lives depend on it.

About the Author

Cary Cook, BSN, RN, has experience in medical/surgical, orthopaedic, neuro/neurosurgery, and psychiatric units in hospitals along with ortho/spine clinic, home hospice, psychiatric home health and case management experience as well. She is a member of Sigma Theta Tau International, the Honor Society of Nurses, and the Case Management Society of America.

Cary contributed a chapter to Leave No Nurse Behind: Nurses Working with disAbilities, by Dr. Donna Maheady. She shares that she has rheumatoid arthritis and bipolar disorder.

Cary is a contributor and guide for **EmpowHER**, and writes on occasion for **LiveStrong**. You may contact her at **CaryJCook@gmail.com**. Her website is **CaryJCook**.

Botox Injections for Essential Tremor?

Proceed with extreme caution

By Peggy Deras

I want to share my experience with Botox injections to treat essential tremor in my head and right hand to help others avoid what could be a lengthy and disabling experience.

I have had ET since childhood. I am 67 now, and for the last several years I have been actively seeking treatment to diminish my tremor enough to allow me to keep working in a rather public job. I have tried various medications and supplements with varying degrees of success. I was diagnosed with Type 2 diabetes two years ago. Deep Brain Stimulation is farther than I want to go as a diabetic. The dangers of infection are just too great.

A year or so ago I began to hear and read about other ET sufferers who had good results with Botox injections. This seemed interesting to me so I researched further. It seemed to me at the time that there was a possibility that Botox injections just might be the "magic bullet" treatment I had been looking for. Therefore, in the early part of this year, during a regular checkup, I asked my Movement Disorder Specialist (MDS), at UCSF Neurology Department, about possibly trying Botox injections.

My MDS told me he did not do or recommend Botox injections for ET. However, he said, he could refer me to the UCSF Surgical Movement Disorders Department for evaluation if I liked. I said I would like to explore the treatment further, so he agreed to make the referral.

In April 2010 I went in for the evaluation appointment with Dr. Galifianakis. We met for an hour or so. He did the usual tests to evaluate my ET and an interview. He said he thought I might be helped with Botox injections in my neck for my head tremor. However he felt that injections for the hand tremor were unlikely to have any positive effect, based on previous studies and results.

He told me about the possible after effects I might expect: tenderness at the injection site for a few days after the procedure; transitory flu-like symptoms; and, somewhat frightening, the remote possibility that I wouldn't be able to lift my head from a forward hanging position. He emphasized that their clinic had never had this kind of result, but that they had heard of patients elsewhere with such results. What he said gave me pause, but, I thought: "I am an out-patient at UCSF Surgical Movement Disorders Department. The likelihood of such bad results should thus be very small." We scheduled the procedure for the following month. I was given nothing, no reading material about Botox injections, no disclaimer forms to sign, at this assessment appointment.

> **"If you are considering Botox injections for anything that is off-label from the FDA Black Box Warning, Beware."**

In early May I went for the Botox injections. I took my daughter with me, because I was uncertain about driving. Just in case I had the bad reaction and couldn't lift my head. Dr. Galifianakis was not there. Instead Dr. Landes took me through another interview and assessment. Then she explained to us what was going to happen and the dangers. Her cautions were very much the same as those the previous doctor had detailed; almost verbatim, actually. It was decided that I would receive a 30% dosage, to keep the possibility of a bad reaction as low as possible, then a higher dosage on later injections if we were successful.

I was surprised, actually pleased, that they, or Dr. Landes, had decided to go ahead and inject my shoulder and forearm. There was lots of conversation, even joking, about cosmetic Botox injections since my daughter gets them every three months. She also explained the noisy EMT machine, which was so large it took up the entire center for the room. It would be used in conjunction with the needle to pinpoint the muscle causing the tremor. Then we were ready to start.

Suddenly the tiny treatment room filled with doctors, trooping in to observe. With the EMT machine, the room was packed. Then, as I recall, an office person came in asking me to sign a release form. I remember I had to step outside the room to find a small flat surface to sign it on. I assumed it was a typical Medicare release form saying I promised to pay if Medicare didn't. I signed it and gave it to my daughter so she could print my name and the date. She did not read it either. I received 8-10 injections of 30% Botox in the muscles in the front and back of my lower neck and front and back of my right shoulder and several places in my right forearm. Dr. Landes and our audience left. An office assistant came in and gave me a card with contact information, in case I had any problems. Surprisingly, after my precaution of having my daughter drive me, I was fine, and we went home. I even said to her "I could have driven myself!"

The following day or so, I experienced the predicted tenderness at the injection sites and bruises began to appear on my neck. Four days post-injections I had the predicted flu-like symptoms. I spent the day in bed and by evening felt fine. Five days post-injections I visited my GP doctor for a regular checkup. She asked if somebody had been strangling me? The bruises were that prominent.

Seven days post-injections the pain started. This wasn't injection site pain, instead I felt excruciating pain (pain scale 10) in the back of my head and neck; also, oddly, in my right knee. I had difficulty holding my head erect. I looked like a turtle, my neck was so compressed. I noticed that my cervical bones were grinding together when I turned my head. In short order, I couldn't turn my head at all. After 20 days I faxed in a written report about my situation to the doctors at UCSF Surgical Movement Disorders Department. My report ended with a question for the doctors who administered the injections. I received no response. The pain continued unabated for seven weeks, and then, ever so slowly, began to let up. Everything I did was painful, any movement, any walking, everything.

I was unable to do my usual 30 minutes of cardio exercise each day to manage my diabetes. My blood sugar spiraled out of control and I began to have diabetic complications: gum/tooth abscesses, boils, rashes, neuropathy; this all aside from the pain in my neck, head and knee.

After about six weeks post injections I made an appointment to see my orthopedic surgeon. He ordered X-rays and MRIs of my neck and knee. He told me that Botox injections can damage cartilage. This spurred me to do further research on Botox injections for tremor. What I found horrified me: The FDA had required that Allergan, the maker of Botox, include a Black Box Warning enclosure in all doses of Botox, beginning in 2009:

"April 30, 2009 -- The FDA announced today that it will require black box labeling on Botox and similar products warning of a rare but potentially life-threatening complication when the effects of the toxin spread far beyond the injection site.

The move stems from reported hospitalizations and deaths attributed to botulism poisoning in children with cerebral palsy treated with botulinum toxin for muscle spasms.

Hospitalizations requiring ventilation have also been reported in adults treated with botulinum toxin for involuntary muscle movement and frequent neck spasms. Deaths among adults are suspected but could not be confirmed."

I put in a call to the UCSF Surgical Movement Disorders Department, asking for a faxed copy of the disclaimer form I had signed just before my injections. I called four times and each time I was promised a fax. It never came.

I then contacted the UCSF Records Department and put in a written request for my records. A couple of weeks went by and an appointment was made, July 27, 2010, to review the records at a separate facility. My older daughter accompanied me for the review. The records there were incomplete, so we were given permission to go to the UCSF Surgical Movement Disorders Department to review my actual file.

There we found that the disclaimer I had signed warned of the possibility of death as a complication of Botox injections. Oh silly me! Guess I'd better remember from now on to READ everything given to me in a renowned teaching hospital in a major US city by renowned neurologists. I was incredulous! I had met with Dr. Galifianakis for more than an hour of assessment for my suitability to undergo Botox injections and he hadn't even bothered to mention such a possibility as death. Dr. Landes, who also assessed me and then administered the injections, hadn't bothered to mention it either!

We also discovered that they had diagnosed me with cervical dystonia. I do not have cervical dystonia. I have essential tremor.

Also, just as we were leaving, the receptionist came and gave us a copy of the Botox warning enclosure that is required to be given to every patient BEFORE they receive the injections. The copy they gave us, on July 27, 2010, was obsolete, because it did not contain the Black Box Warning required by the FDA since 2009.

I came away with a complete copy of my file and a much better understanding of what had transpired in my treatment by these doctors. They had deliberately misdiagnosed me, but why? The answer came on September 2, 2010, when I read in the San Francisco Chronicle that Allergan had been fined $600 million by the Justice Department:

"The Justice Department and the company said Wednesday in a statement it will plead guilty to one misdemeanor charge of "misbranding," in which the company's marketing led physicians to use Botox for unapproved uses. Those included the treatment of headache, pain, spasticity and cerebral palsy in children.

Companies are prohibited from promoting drugs for unapproved, or "off-label," uses.

Allergan said it will pay $375 million in connection with the plea, which includes the forfeiture of $25 million in assets. Additionally, the company will pay $225 million in civil fines - $210 million to the federal governments and the rest to several states - related to the investigation, although the company denies liability for the civil claims.

Allergan, based in Irvine, Calif., also struck an agreement with the Department of Health and Human Services' Office of the Inspector General that requires the company to submit compliance reports, and to post on its website any payments to doctors, such as honoraria, travel or lodging."

Allergan "paid kickbacks to induce physicians to inject Botox for off-label uses and Allergan also taught doctors how to bill for off-label uses, including coaching doctors how to miscode Botox claims leading to millions of dollars of false claims being submitted to federal and state programs," Assistant Attorney General Tony West said."

Suddenly it all came together. I had been misdiagnosed to dupe my insurers, Medicare and Tricare, into paying for Botox injections that they would not otherwise have covered. Had I been apprised of the costs beforehand, and told I would have to pay them myself because Botox injections for essential tremor are "off label"; I would not have proceeded with the injections. The costs were simply too high for me to bear on a continuing basis. The 30% injections I received cost $2,435.00, including $2100 for the Botox itself. Had I gotten good results and proceeded with injections every 3-4 months at 100% dosage the costs would have been $7335 for each round of injections. That's $22,005 to $29,340 per year. An Allergen money machine for the rest of my life!

It has now been 4-1/2 months since my Botox injections. I have made innumerable trips to various doctors to treat the fallout. I am in physical therapy now to try to get back the strength and stamina I had before the injections. My main goal is to resume my 30 minute daily workouts. It's a long, slow and frustrating process.

I have investigated litigation against the doctors, and Allergan, who duped me into this mess. However, I am told by a prominent medical malpractice attorney, quote: *"the cost of pursuing the cases often eclipses any recovery."* Therefore I am left with only getting the word out to others, including my insurers, which may cost me, about what has happened.

Botox is poison, no matter how purified, and some people, like me, will have a bad reaction to it. Some have even died from Botox injections, including children with cerebral palsy. Others have had breathing difficulties requiring ventilators due to migration of the toxin to the breathing apparatus

I was horrified recently to see that Henry Winkler (the Fonz) has signed on as the Botox spokesperson to treat stroke patients. The FDA authorized such use ONLY in the extremities. Please do not be seduced.

This stuff is NOT your "friendly" wrinkle remover folks. Botox kills. To my knowledge there is no way to screen to see who is likely to have a severe reaction to Botox injections, other than a lowered dosage such as I received. That makes every patient who tries it a guinea pig.

If you are considering Botox injections for anything that is off-label from the FDA Black Box Warning, beware. Even those who have the painful afflictions that the FDA has approved Botox injections to treat need to assess whether death is preferable to your pain, because that could be the result of the experiment that is Botox.

About the Author

Peggy Deras, CKD, CID is the owner/sole proprietor of **Kitchen Artworks**. An award winning, independent kitchen and bath designer, she has been in practice in the San Francisco Bay Area since 1983. Her mother, brothers, and one daughter, also suffer from familial essential tremor. She has used computers for design since 1991, to continue working when her tremor precluded hand-drawing and drafting. Peggy authors three blogs on kitchen design: **Kitchen-Exchange**; **Appliance Notes** and **Kitschy Kitchens**. She lives with her husband George in South San Francisco California.

Stable Ground

By Melissa Gaskill

Spikes & Spasms Note:
This article, courtesy of Melissa Gaskill, appeared in TodayinPT.com on Monday, July 19. Tremor Action Network is grateful to Melissa for granting permission to reprint the article for viewing only.

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Often associated with Parkinson's disease, tremor is a common movement disorder with a number of causes. Those causes include multiple sclerosis, stroke, traumatic brain injury, neurodegenerative diseases, drug use, alcohol abuse or withdrawal, and mercury poisoning, according to the National Institute of Neurological Disorders and Stroke, part of the National Institutes of Health. Tremor also occurs in otherwise healthy people and may have no known cause. It appears equally in men and women, most commonly in middle age and after. Tremor can be occasional, temporary or intermittent.

"Tremors are a very non-specific symptom and sign, and can arise from a wide variety of etiologies," says Neal Hermanowicz, MD, professor of neurology, director of the Movement Disorders Program at University of California, Irvine and the Philip and Carol Traub Center for Movement Disorders at Eisenhower Medical Center in Rancho Mirage, Calif. "The two most common are essential tremor, which runs in families, and Parkinsonian."

Therapy Helps Tremor

Hermanowicz often refers tremor patients to physical therapy based on the underlying diagnosis. "The referral is not 'treat this tremor,' but 'treat this disorder,' of which tremor is one of the symptoms," he says. Tremor can make daily function difficult, and physical therapy helps those patients with strategies to work around the tremor or minimize its effect. Therapy can increase function and quality of life, enabling patients to, for example, write, cut food and manage daily hygiene.

Effective treatment depends on identifying the source of tremor, says Kathy Kumagai, PT, DPT, MS, NCS, OCS, CSCS, assistant professor at Azusa Pacific University and clinical faculty of the Movement Science Fellowship at Kaiser Permanente in California. Therapists play a critical role in helping identify the type of tremor, if a patient does not have a definite diagnosis, and designing therapy to improve the patient's quality of life. "We spend a lot of time looking at functional activity, changing positioning, changing alignment, teaching new positions and working on weight bearing to reduce tremor," Kumagai says. Exercises to improve coordination and balance also help.

> **"Computerized neural motor retraining programs also can be quite helpful with tremor."**

Using braces to support affected limbs can make daily activities easier, but braces can increase spasticity, according to the NINDS, and must be used with caution. Some therapists teach patients to brace affected limbs on their own to help gain motion control.

"If patients press down gently with a hand on the thigh when seated at a table, for example, that active movement and slight activation of the arm muscle dampens tremor," says Mary Hudson-McKinney, PT, MS, DPT, NCS, assistant professor, department of physical therapy education, Western University of Health Sciences in Pomona, Calif.

Weights on the ankles or wrists can help, as can adaptive equipment such as special plates and utensils for eating. Weights can cause fatigue, however, so their use must be carefully monitored.

Mobilization and Strengthening

Tremor caused by Parkinson's can be complicated by rigidity. "The disease may create discomfort for patients, so they don't move their arms as much and can end up with reduction in range of motion," Hudson-McKinney says. "I take a careful look at the individual, their range, posture and alignment, and attempt to restore more optimum body positioning and range of motion. The key is not just the arms but the trunk itself, a whole body influence. I look at whether they tend toward a flexed posture, if there is tightness in the pectorals, and so forth."

Hudson-McKinney finds some individuals tolerate a rolled beach towel better than a half foam roll. "If they can tolerate the foam roll, that gives more intensive stretch, but I always make sure they are tolerating it well. I do soft tissue mobilization, and look at gentle thoracic mobilizations as well, often over a stiff ball. The goal is to mobilize them into more thoracic extension. Once we get soft tissue mobilization and posture improved, then we can work on strengthening posture muscles.

With non-Parkinsonian tremor, such as cerebellar, loss of movement or gradations of movement can occur. In those cases, Hudson-McKinney says, weighting the extremity sometimes helps. Use of weights is not typical with Parkinsonian tremor, she adds. Teaching patients to change the way they perform basic tasks in order to bear weight on their limbs can help. For example, she might teach a patient to use a bed lever by putting a hand in a weight-bearing position and moving over that weight-bearing arm rather than reaching straight out.

Computerized neural motor retraining programs also can be quite helpful with tremor. "It's a fun activity that gives them feedback as they manipulate their arms and gives them a new approach," Hudson-McKinney says. "These are kind of like a Wii [video] game, but specifically designed for individuals with weak or limited motor control, or those who need to learn how to grade the intensity of the contraction and movement."

Skill Set Analysis

One of the most important things PTs bring to the table for tremor patients, Hudson-McKinney adds, is skill set analysis. "We can watch an individual move and determine the components of their function," she says. "I start by asking patients to show me the movements they're having difficulty with and looking at the elements affecting their ability to move effectively. Then I go after those elements. It depends on the individual, but I can see definite changes in ability to complete activities of daily living and functional movement." She re-analyzes movement at the start of every session, and may reassess during a session. Generally, patients have exercises to do between sessions.

PTs also can help tremor patients by knowing what medications are out there, Kumagai says. "If a patient comes in and isn't hooked up with a neurologist, we can help get them to one in order to manage their tremor optimally. Physical therapy and medication go together; generally one without the other is not optimal.

"There are things available such as botulinum toxin and deep brain stimulation that people don't know about. We can make sure they understand what types of medications are available for their particular type of tremor. Neurologists who don't specialize in movement disorders don't always know what's out there, so sometimes, physical therapists have to make connections and get patients to providers who can offer them something."

Therapists need to remain on watch for any changes in tremor intensity. Regardless of its source, tremor increases with stress or acute illness, Hermanowicz says. "If someone is fairly stable and then the appearance or intensity of the tremor increases, that indicates the patient is under stress. The source could be acute illness or infection, or a medication that doesn't agree with them. Any change is worth an inquiry."

Hudson-McKinney employs guided imagery, relaxation and deep breathing to help patients modulate a stressful situation and give them specific strategies to help reduce stress.

Melissa Gaskill is a freelance writer.

About the Author

Melissa Gaskill is an independent writer with degrees in journalism and biology. She has written for magazines and newspapers for more than 15 years, specializing in writing about science, travel and nature. Melissa is the author of *Best Hikes with Dogs: Texas Hill Country and Gulf Coast* (Mountaineers Books), and *Lacrosse: A Guide for Parents and Players* (Mansion Grovehouse).

A Letter to Patients with Chronic Disease

By Dr. Rob

Spikes & Spasms Note:

This article appeared in Distractible.org on July 14. Tremor Action Network is grateful to Dr. Rob for permission to reprint the article for viewing only.

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Dear Patients:

You have it very hard, much harder than most people understand. Having sat for 16 years listening to the stories, seeing the tiredness in your eyes, hearing you try to describe the indescribable, I have come to understand that I too can't understand what your lives are like. How do you answer the question, "how do you feel?" when you've forgotten what "normal" feels like? How do you deal with all of the people who think you are exaggerating your pain, your emotions, your fatigue? How do you decide when to believe them or when to trust your own body? How do you cope with living a life that won't let you forget about your frailty, your limits, your mortality?

> **"Keep your eggs in only a few baskets - find a good primary care doctor and a couple of specialists you trust."**

I can't imagine.

But I do bring something to the table that you may not know. I do have information that you can't really understand because of your unique perspective, your battered world. There is something that you need to understand that, while it won't undo your pain, make your fatigue go away, or lift your emotions, it will help you. It's information without which you bring yourself more pain than you need suffer; it's a truth that is a key to getting the help you need much easier than you have in the past. It may not seem important, but trust me, it is.

You scare doctors.

No, I am not talking about the fear of disease, pain, or death. I am not talking about doctors being afraid of the limits of their knowledge. I am talking about your understanding of a fact that everyone else seems to miss, a fact that many doctors hide from: we are normal, fallible people who happen to doctor for a job. We are not special. In fact, many of us are very insecure, wanting to feel the affirmation of people who get better, hearing the praise of those we help. We want to cure disease, to save lives, to be the helping hand, the right person in the right place at the right time.

But chronic unsolvable disease stands square in our way. You don't get better, and it makes many of us frustrated, and it makes some of us mad at you. We don't want to face things we can't fix because it shows our limits. We want the miraculous, and you deny us that chance.

And since this is the perspective you have when you see doctors, your view of them is quite different. You see us getting frustrated. You see us when we feel like giving up. When we take care of you, we have to leave behind the illusion of control, of power over disease. We get angry, feel insecure, and want to move on to a patient who we can fix, save, or impress. You are the rock that proves how easily the ship can be sunk. So your view of doctors is quite different.

Then there is the fact that you also possess something that is usually our domain: knowledge. You know more about your disease than many of us do - most of us do. Your MS, rheumatoid arthritis, end-stage kidney disease, Cushing's disease, bipolar disorder, chronic pain disorder, brittle diabetes, or disabling psychiatric disorder - your defining pain - is something most of us don't regularly encounter.

It's something most of us try to avoid. So you possess deep understanding of something that many doctors don't possess. Even doctors who specialize in your disorder don't share the kind of knowledge you can only get through living with a disease. It's like a parent's knowledge of their child versus that of a pediatrician. They may have breadth of knowledge, but you have depth of knowledge that no doctor can possess.

So when you approach a doctor - especially one you've never met before - you come with a knowledge of your disease that they don't have, and a knowledge of the doctor's limitations that few other patients have. You see why you scare doctors? It's not your fault that you do, but ignoring this fact will limit the help you can only get from them. I know this because, just like you know your disease better than any doctor, I know what being a doctor feels like more than any patient could ever understand. You encounter doctors intermittently (more than you wish, perhaps); I live as a doctor continuously.

So let me be so bold as to give you advice on dealing with doctors. There are some things you can do to make things easier, and others that can sabotage any hope of a good relationship:

1. Don't come on too strong - yes, you have to advocate for yourself, but remember that doctors are used to being in control. All of the other patients come into the room with immediate respect, but your understanding has torn down the doctor-god illusion. That's a good thing in the long-run, but few doctors want to be greeted with that reality from the start. Your goal with any doctor is to build a partnership of trust that goes both ways, and coming on too strong at the start can hurt your chances of ever having that.

2. Show respect - I say this one carefully, because there are certainly some doctors who don't treat patients with respect - especially ones like you with chronic disease. These doctors should be avoided. But most of us are not like that; we really want to help people and try to treat them well. But we have worked very hard to earn our position; it was not bestowed by fiat or family tree. Just as you want to be listened to, so do we.

3. Keep your eggs in only a few baskets - find a good primary care doctor and a couple of specialists you trust. Don't expect a new doctor to figure things out quickly. It takes me years of repeated visits to really understand many of my chronic disease patients. The best care happens when a doctor understands the patient and the patient understands the doctor. This can only happen over time. Heck, I struggle even seeing the chronically sick patients for other doctors in my practice. There is something very powerful in having understanding built over time.

4. Use the ER only when absolutely needed - Emergency room physicians will always struggle with you. Just expect that. Their job is to decide if you need to be hospitalized, if you need emergency treatment, or if you can go home. They might not fix your pain, and certainly won't try to fully understand you. That's not their job. They went into their specialty to fix problems quickly and move on, not manage chronic disease. The same goes for any doctor you see for a short time: they will try to get done with you as quickly as possible.

5. Don't avoid doctors - one of the most frustrating things for me is when a complicated patient comes in after a long absence with a huge list of problems they want me to address. I can't work that way, and I don't think many doctors can. Each visit should address only a few problems at a time, otherwise things get confused and more mistakes are made. It's OK to keep a list of your own problems so things don't get left out - I actually like getting those lists, as long as people don't expect me to handle all of the problems. It helps me to prioritize with them.

6. Don't put up with the jerks - unless you have no choice (in the ER, for example), you should keep looking until you find the right doctor(s) for you. Some docs are not cut out

for chronic disease, while some of us like the long-term relationship. Don't feel you have to put up with docs who don't listen or minimize your problems. At the minimum, you should be able to find a doctor who doesn't totally suck.

7. Forgive us - Sometimes I forget about important things in my patients' lives. Sometimes I don't know you've had surgery or that your sister comes to see me as well. Sometimes I avoid people because I don't want to admit my limitations. Be patient with me - I usually know when I've messed up, and if you know me well I don't mind being reminded. Well, maybe I mind it a little.

You know better than anyone that we docs are just people - with all the stupidity, inconsistency, and fallibility that goes with that - who happen to doctor for a living. I hope this helps, and I really hope you get the help you need. It does suck that you have your problem; I just hope this perhaps decreases that suckishness a little bit.

Sincerely,
Dr. Rob

Post Script: This post has generated a huge amount of conversation and interest (as witnessed by the large number of comments!). I very much appreciate the dialogue it has spawned both here and across the web. I've subsequently written follow-up posts explaining my thoughts in more detail - largely in response to the comments here. One of them discusses in more detail my ***own experiences as a doctor*** *and the second talks of the importance of* ***knowing and being known.*** *Reading these will give you a better picture of my thought process and perspective on this.*
Dr. Rob

About the Author

Rob Lamberts, MD is a primary care physician from the Southeastern United States, board certified in Internal Medicine and Pediatrics. His blog, Musings of a Distractible Mind, are "thoughts of a moderately strange (yet not harmful) primary care physician." As **The House Call Doctor™** for Quick and Dirty Tips, he provides advice for taking charge of your health.

TAN In Action

14th International Congress June 13-17, 2010

Unlike the 13th International Congress, we were the only U.S. advocacy organization in attendance, but quickly made new friends; especially with the neurologists representing **ASOCIACIÓN LEWY BODY ARGENTINA (ALBA)**.

We thank The Movement Disorder Society, in particular Meeting Manager Sarah Smith, for helping to make TAN's participation a success.

We believe it is essential to support and promote International clinical research for the advancement of essential tremor and related movement disorders. 74 countries were represented by 4,000 people in attendance. We learned much from Dr. Michel Dupuis of Clinique Saint Pierre in Ottignies, Belgium. Dr. Dupuis shared his abstract, *'Disappearance of essential tremor after stroke.'* He was very kind to spend time taking TAN on a tour of the Tremor Posters, in particular a late-breaking abstract, *'Long-lasting improvement of essential tremor by repetitive transcranial magnetic stimulation of the cerebellum: a pilot study.'* We have highlighted this poster, and selected other abstracts to share with Spikes & Spasms subscribers.

Long-lasting improvement of essential tremor by repetitive transcranial magnetic stimulation of the cerebellum: a pilot study

M. Russo, E. Roze, A.P. Legrand, T. Popa, C. Bonnet, P. Vargas, S. Meunier, M. Vidailhet, E. Apartis (Messina, Italy and Paris, France)

'There is growing evidence for an over-activity of the cerebellum and CTC loops in essential tremor (ET).

Eleven patients with ET underwent 5 daily consecutive sessions of low frequency cerebellar rTMS, targeting the VIII.A cerebellar lobule. Each session consisted of two sequences of 900 impulses at 1 Hz (15 minutes), delivered consecutively over both sides. Tremor intensity was measured by clinical scores (Fahn-Tolosa-Marin Tremor Rating Scale) and physiological quantification of tremor, using polymyography (EMG) and tri-axial accelerometer (PCBPiezotronics, NY USA) recording (Acc).

Clinical scales significantly improved by 25-30% after the fifth session of rTMS. This beneficial effect persisted at +1 week and +3 weeks after the end of the stimulation series. Tremor amplitude, obtained from analysis of the Acc and EMG signals, also decreased significantly. Mean tremor frequency (6.0 0.8 Hz) was not modified by rTMS. No adverse effects of rTMS were observed.

This pilot study further supports that cerebellar dysfunction may be involved in the pathogenesis of ET and modulation of the cerebellar output is a promising therapeutic target in this setting. In a unique previous study (Gironell et al, 2002), a short lasting (<1h) beneficial effect of a single session of 1Hz cerebellar stimulation was shown. Here we demonstrate for the first time, enduring (>20 days) therapeutics effect on ET by repeating rTMS sessions over a week. Further investigations, including placebo controlled designs with chronic stimulation are needed.'

EMG pattern mining for tremor types recognition

P. Palmes, F. Widjaja, I. Seah, L. Tan, W.T. Ang, W.L. Au (Singapore)

Results suggest EMG channels can be useful in helping to identify different tremor types.

Clinical features that best differentiate patients with adult onset dystonic tremor from tremulous Parkinson's disease

C. Lonngren, T. Maggs, V. Gontu, N. Bajaj (Nottingham, United Kingdom)

Adult onset dystonic tremor may not be easy to differentiate from tremor dominate Parkinson's Disease. Similar features seem to occur in both AODT and TDPD.

The influence of age in essential tremor

N. Cinar, S. Sahin, T. Okluoglu, S. Karsidag (Istanbul, Turkey)

The neurodegeneration of the cerebellum may be age related based on spiral drawings and the Fahn-Tolosa scale score (FT) from 3 different age at onset of ET symptoms groups (younger than 30, 30-60, older than 60). There was no statistical significant difference among the 3 groups for tremor frequency and amplitude. The drawings and total score of FT scale were higher in the middle and older age groups.

Percentage of essential tremor patients for whom front-fine medications have been discontinued

N.L. Diaz, E. Louis (New York City, New York, USA)

Suggests that numerous patients have stopped taking primidone or propranolol because of side effects and/or lack of desirable efficacy.

Disappearance of essential tremor after stroke

M.J.M. Dupuis, F.L.A. Evrard, J.G. Philippe, P.R. Gaetane, L.G. Oliver (Ottignies Louvain La Neuve, Brabant, Belgium)

'Locations of strokes interrupting E.T. could be interpreted as concerning afferent and efferent connections between the cerebral cortex and the cerebellum.'

Risk factors for perioperative complications in deep brain stimulation surgery for tremor

J. Fang, E. Presant, F. Phibbs (Nashville, Tennessee, USA)

Patients 75 and over may require a longer period for recovery from DBS for not necessarily long-term complications such as somnolence and dysarthria.

Cognitive and motor functional activity in nondemented community-dwelling essential tremor cases

E.D. Louis, J. Benito-Leon, S. Vega-Quiroga, F. Bermejo-Pareja (New York City, New York, USA)

Authors designed a 37-item mini-mental status test and an 11-item functional activities questionnaire to compare the functional level in ET patients v controls (>65 years in central Spain). Cognitively based activities such as remembering appointments and motor based activities such as writing checks were assessed. ET patients had more functional difficulty than the control population, indicating that lower cognitive test scores in ET have a clear clinical-functional connection.

Parkinsonian features in essential tremor patients

R.P. Prado, L.C. Ferreira, A.G.P. Prado (Aracaju, Sergipe, Brazil)

Data suggests that parkinsonian features were not common in study patients with ET but should be considered during evaluation and treatment of ET.

Hand tremor in dystonic patients

I. Zekja, D. Dobi, J. Kruja, M. Rakacolli (Tirana, Albania)

In study patients, asymmetrical tremor was more frequent, predominating in the right hand.

Tremor profile of a movement disorder clinic

S. Raha, S. Aithal, L. Ebenezer (Bridgend, United Kingdom)

Long term follow up of tremor patients is justifiable for successful management of symptoms and diagnosis. Approximately 20% patients are unable to endure first line treatment, and are in need of second line treatment or combination treatment.

Validation of TremAn- A Tremor Analyzing Tool for analysis of tremor frequency from video recordings

E. Ruzicka, Z. Uhrikova, O. Sprdlik, M. Hoskovcova, V. Hlavac, C.D. Nugent (Prague, Czech Republic)

Using accelerometers or electromyography for routine clinical use may be cumbersome and impractical. An alternative method of tremor frequency analysis based on common video recordings with a standard Sony Camcorder

DCR-PC350E, sampling frequency 25 frames per second, has been shown to effectively analyze the frequency of tremor.

Thalamic and subthalamic dbs for essential tremor: What is the optimal location of the electrode

U. Sandvik, L.O.D. Koskinen, P. Blomstedt (Umea, Sweden)

Currently DBS in the ventrolateral thalamus (Vim) is the standard treatment of ET. DBS in the posterior subthalamic area (PSA) has demonstrated promising results. In this non-randomized sequential study, 'tremor/function in the treated hand was improved by 67% in the Vim-group and 92% in the PSA-group.'

Essential tremor: Factors influencing the quality of life

S. Telarovic (Zagreb, Croatia)

The quality of life is affected in a majority of study patients; most notably in younger and still working patients. Authors suggest patients are in need of both medical and non-medical support.

Is botulinum toxin treatment useful in patients with tremor

S. Vohanka, B. Micankova, S. Skutilova (Brno, Czech Republic)

This therapy is considered less effective in tremor disorders patients compared to dystonia or spasticity. Botox Type A treatment may be considered in patients with arm tremor, but in comparison with essential tremor patients (the treatment was non-effective in 24% of the 16 study patients with ET), the therapy may be more useful for parkinsonian tremor (PT) patients (only 1 less effective in 17 study patients with PT).
We are Shaking the World to Find a Cure!

Member of Congress Invitation July 29, 2010

In June TAN received a call from Representative Patrick J. Kennedy's office followed by a letter invitation to come to Washington, DC and participate in a planning and discussion meeting. The meeting was attended by 35-40 professionals representing patient advocacy groups and the fields of neurology and psychology.

American Brain Coalition (ABC) members present in addition to TAN:

- Mike Amery, American Academy of Neurology
- Lyle Dennis, American Brain Coalition
- Alies Muskin, Anxiety Disorders Association of America
- Dr. Nilda Rendino, Benign Essential Blepharospasm Research Foundation
- Ginger Park, Dystonia Medical Research Foundation
- Dr. Paul Aravich and Mona Miller, Society for Neurosciences

Representative Kennedy is retiring, but is committed to raising awareness for research *'to unlock the mysteries of the brain and, to save our veterans.'* Kennedy opened the meeting with objectives set forth in the July 18 invitation, and his *Opinion, 'A brain disorders battle,'* featured the next day in the Boston Globe.

The Congressman recommended a call to action to increase the Department of Defense (DOD) and Department of Veterans Affairs (VA) *funding* to support research into Traumatic Brain Injury (TBI) and Post Traumatic Stress Disorder (PTSD). His advocacy approach to tie brain and neuroscience research to veterans' injuries, TBI and PTSD, would benefit veterans and approximately 100 million Americans that have some form of TBI and, 'millions more Americans and their families living with other neurological disorders.' He suggested getting behind the *translational research* at the DOD and VA, because Congress would most likely support it due to it being a veterans' cause and, also the cause of all those diagnosed with a brain-related disorder.

The rest of the meeting was preparing for Congressional Hearings and legislative initiatives; in particular a Hearing hosted by Representative Dennis Kucinich (D-OH). Kennedy requested ideas and suggestions for Hearing witnesses to talk about research for TBI and PTSD. Kennedy is also interested in a Conference for January 2011, with broad emphasis on neurological and psychological health.

For Kennedy, *'science is a means to an end - which is to protect the ones we love and to be sure we are doing everything we can to realize medical breakthroughs and cures.'*

The American Brain Coalition is working closely with Congressman Kennedy's office, and ABC will keep its members updated as Hearings evolve for TBI and PTSD research and, the possible January Conference.

135th Annual Meeting of the American Neurological Association (ANA) September 12-15, 2010

The venerable ANA hosts a more intimate less populated meeting. There were approximately 800 in attendance, including 22 exhibitors. It was great to attend this San Francisco meeting, in close proximity to TAN. We reconnected with exhibitors In-Step Mobility, Medtronic and NINDS, and made new acquaintances with American Board of Psychiatry & Neurology and National Ataxia Foundation.

We thank the ANA for their complimentary generosity to nonprofit exhibitors.

The ANA poster venue is smaller, but offers interesting movement disorders abstracts.

Functional Outcome after Ten Years in Parkinsonian Patients Having Undergone STN DBS

A.S. Maertens de Noordhout, J.M. Remacle, M. Mouchamps, M. Gonce (Liege, Belgium)

DBS may improve the motor condition in PD patients, but the surgical treatment does not change the natural course of the disease. This study found lower drug intake and dyskinesia, but a higher number of medical visits.

Demographic and Geographic Distribution of Veterans with Parkinson's Disease

E.C. Lai, S. Moore (Houston, TX)

46,024 veterans with a diagnosis of Parkinson's Disease (PD) or Parkinsonism (SP) were seen by the Department of Veterans Affairs health care system (VHA) in 2007 (FY07). The average age of veterans was 76. Distribution was in part based on veterans' period of service: 40.4% WWII, 26.1% Korean War, and 19.9% Vietnam War. The relevance of this study is that a large number of veterans with PD or SP receive healthcare at VHA, and the data collected will assist with the association of military service and PD.

Relationship of Essential Tremor to Parkinson Disease Compared to Progressive Supranuclear Palsy and Corticobasal Degeneration

R Fekete, A. Davidson, J Jankovic (Houston, TX)

Supports several previous family history studies, showing essential tremor (ET) can occur more frequently prior to the onset of Parkinson's Disease (PD). Study provides additional evidence of an association between ET and PD; in particular, that ET is more common in patients with PD than family member patients with PSP or CBD.

The Fractal Pattern of Hand Motor Activity Is Disrupted in Major Depression

S. Aybek, A. Ionescu, O. Chocron, A. Berney, K. Aminian, F.J.G. Vingerhoets (Lausanne, Switzerland)

Hand activity of depressed patients was monitored with a validated wireless device. Motor analysis suggests major depression interrupts the hand motor area, but the alteration of the spontaneous motor hand activity can be normalized after treatment of depression.

Perioperative Adverse Events of Deep Brain Stimulation

in Early Stage Parkinson's Disease

C.E. Gill, L.A. Allen, A.J. Speranza, T.L. Davis, D. Charles, P.E. Konrad, (Maywood, IL and Nashville, TN)

Early Parkinson's Disease (PD) patients, age 50-75, and on anti-PD medication for less than 4 years, participated in a pilot DBS trial. 12 patients (80%) experienced a range of perioperative adverse events (AE): headache, scalp/facial swelling, confusion, balance difficulty, neck pain, drowsiness, incision site pain, erythema, vomiting/nausea, difficulty speaking, hematoma, dysphagia, intercranial edema, basal ganglia infarct, sensory changes, weakness, fever, sore throat, hallucination and syncope. The average duration of AE was 20 days. None of the AE were ongoing. The safety data collected is important as to whether patients with early PD should consider DBS v. patients with advanced PD.

H.R. Advocacy September 20, 2010

TAN got involved in supporting **H.R. 1362, the National Neurological Diseases Surveillance System Act** in hopes that 'tracking and collecting data on the epidemiology, incidence, prevalence and other factors of neurological disease' will advance research and better treatments, that may one day lead to a cure for essential tremor, dystonia, Parkinson's, Multiple Sclerosis and other neurological diseases.

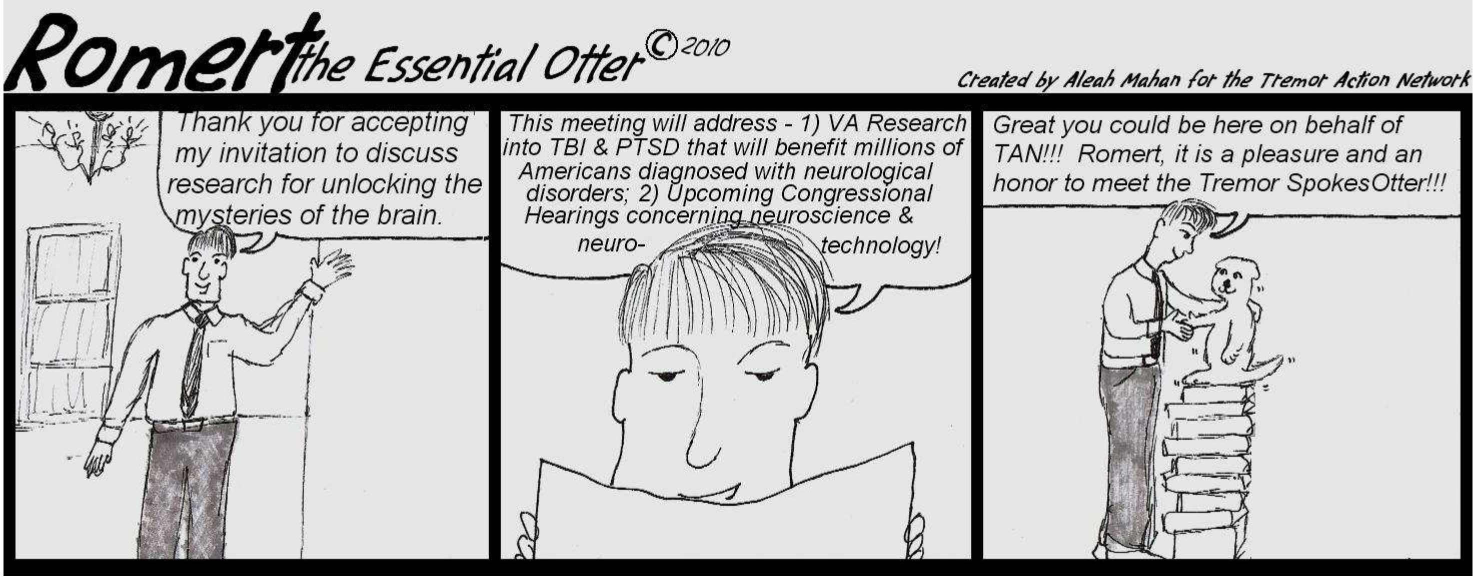
The Act was unanimously passed by the House of Representatives! To make this data system a reality, the Senate must now take action on S. 1273. The companion bill H.R. 1362 was passed on SEP 28. It is imperative that this legislation is passed by the Senate this Congress!!!

St. Rose Hospital Ninth Annual Grand White Tent Health Fair October 3, 2010

TAN has participated consecutively in this event since October 2001. The list of health fair exhibitors has grown to 89! TAN reacquainted with Karen Marshall of Community Resources for Independent Living (CRIL). Karen demonstrated products - a multi-grip bottle opener, a ring pull can opener, weighted utensils and In-Step Mobility cane (ANA exhibitor), that may be user-friendly for those with hand tremors, and difficulty with balance. TAN invited CRIL to author an article for the next newsletter, and also extended an invitation to Abby Caplin MD, MA. Dr. Caplin provides mind-body medicine and counseling for people with chronic illness.

Romert: Spokes Otter goes to Washington, DC - Again!

The Essential Otter Advocate http://romert.blogspot.com



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