

# Spikes & Spasms

The TremorAction.org Newsletter

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SEASON'S GREETINGS!



WELCOME TO THE  
**HOLIDAY ISSUE!**



Warm wishes for

*Holiday Joy*  
and a  
*Healthful New Year!*

Tremor Action Network & Romert

## Accentuate the Positive

By Pat Hill

In an uncertain economy, one thing is certain: people are losing their jobs and people are having a difficult time finding jobs. Another certainty is that it's more difficult to find a job if you have essential tremor, dysphonia, dystonia or a combination thereof.

So what can you do? Your first move is to reinvent yourself. Take an inventory of your skills and interests, no matter how small, even if you don't see any intrinsic value in what you do or like to do. After you have that list, shuffle those skills around and think outside the box so you can consider what type of jobs you may be able to do. It doesn't have to be your ideal job. It can be a stepping stone job to get you where you want to go.

Once you have an inclination as to the directions you can go, start traveling down those roads. You never know when an opportunity may arise or perhaps you might meet someone along the way who gives you an inspiration or a connection. You may even think of another type of job. For everything there is in this world, there is a need for someone to do it. It might as well be you.

No job is beneath you. Just think of it as an avenue. I knew of a popsicle wrapper who became a veterinarian, a pickle packer who became a surgeon, and a waiter who was on his way to becoming an ambassador. "Dream the impossible dream" and go down that road.

Next comes that dreaded interview, where you're in the spotlight and people sit in judgment of you. Curses! It seems like the Apocalypse, but it's not. Keep in mind that you have nothing to lose. Not a fantastic thought, but it's the truth. You don't have the job so you can't lose it. So go into an interview with the attitude that it is just for practice. No sweat! If you mess up, no big deal.

**"Don't think of movement disorders as a disability, but as a door to possibility."**

Before you go into that practice interview, look at yourself in the mirror and talk to yourself about how great you are. "I have a great personality. I'm an organizer. I'm efficient and so forth." Employers love hard working, dedicated people with good attitudes. There is only one you....."be all that you can be."

When you're in that interview, turn the tables a bit. Ask them questions. Put yourself in the king's chair and decide whether they are worthy of you and if you'd want to work for them. Let them talk, then you won't have to work as hard in the interview. Be truthful and tell them what you're like and what you can do. Be very simple and to the point. Either they will like your skills for the job or they won't. If not, you move on.

Which brings us to the next biggie.....rejection. Rejection is rough. With a job interview, it's not a rejection of you as a person, but rather the suitability for the job. If in their eyes, you're not "a fit," then you don't want the job anyway. Why? If you're not qualified or they think you're not qualified, you'll be miserable. If rejection is still an issue, apply for lots of jobs because you increase your chances of being hired.

In the event that someone doesn't like you because of your disability/disorder, you don't want that job anyway because it would be horrible working for prejudicial people. They are in fact the ones with a disability.....a mental one.

So in short, it's all about attitude. Take the attitude that you have a combination of worthwhile skills and traits. Take the attitude that an interview is just that.....an interview. Nothing more than an opportunity to practice. Take the attitude that you too will evaluate whether or not this is the company that you want to work for. Take the attitude that anyone would be lucky to have you and shrug them off if they don't realize it.

Give yourself lots of chances, expand your horizons, and think outside the box. Don't think of movement disorders - essential tremor, dysphonia, dystonia as a disability, but as

a door to possibility.

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### About the Author

Pat Hill has worn a few hats as a writer and special education teacher. She has suffered with the affects of spasmodic dysphonia for 40 years. Her philosophy of life is to take what you have and use those talents for the good of all. Sometimes your disorder can also be an avenue for growth and provide a positive light in your life while opening new doors. It's all about perspective.

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## The Importance of Mind-Body Medicine

By Abby Caplin, MD

My brother is a retired pediatrician. Throughout his career, he was asked almost daily, "Are you nervous, Doc?" "Nah," he'd respond. "It's called familial tremor," he'd say, his hands shaking as he would place the stethoscope over the child's heart. No doubt his tremor was a source of embarrassment, as he weathered the odd glances and false assumptions even from his instructors in medical school. He laughs about it now, but underneath his upbeat attitude, I feel the underlying years of struggle of living with this visible condition.

Each medical condition or illness has its own set of challenges, including the visibility or invisibility of what the body must deal with. As someone who developed an autoimmune disorder, I became acutely aware of the challenges of a mostly invisible illness. I felt ill, but looked great! In cases like mine, it can take years for doctors to take a person's symptoms seriously and begin to investigate. For those with tremors, though, the condition is visible, and one must repeatedly experience the suppositions of others. They may make interpretations and assumptions about visible tremors --- wondering if the person is "nervous" or even a drug addict -- which can create more stress than the actual condition. From mainstream medical journals to patient support groups, it is understood that while stress is not the primary cause of most medical conditions, it often makes symptoms much worse.

For this reason, it's important to understand that the stress generated by self-judgments and perceived judgments of others can be detrimental. Self-judgments can include feeling like you are "damaged goods," "not good enough," and "a loser." Chronically present, these beliefs are especially potent in their toxicity. Those who work in the field of psychoneuroimmunology and its practical

application, Mind-Body Medicine, know such negative beliefs generate inflammatory biochemical compounds that affect the nervous and immune systems, often exacerbating the symptoms.

Every person inherits a set of genes, making each one prone to specific diseases and medical conditions. We cannot change our DNA, but what we can change is our environment, both internal and external. In this way, the expression of disease-causing genes has the potential to be altered. Mind-Body Medicine helps people evaluate what is possible to change and gives them tools to do it. It also challenges people to think differently, find their strengths and lead empowered lives.

**"Mind-Body Medicine  
helps people to find their  
strengths and lead  
empowered lives."**

A competent and compassionate mind-body medicine physician or good psychotherapist, trained in mind-body interventions and energy psychology, is a wonderful resource. Everyone with a chronic medical condition or illness should do whatever is possible to create an internal healing environment.

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### About the Author

Abby Caplin, MD is a physician who practices Mind-Body Medicine in San Francisco, where she helps people with chronic illness find their direction, strength and power. She holds a master's degree in Integral Counseling Psychology.

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## New insights about botulinum toxin A

By Don McSwiney

### Spikes & Spasms Note:

*This article appeared in UTODAY on December 3, 2010. It's a follow-up to Peggy Deras' personal experience with BOTOX® injections, "Botox Injections for Essential Tremor?" featured in the OCT issue of Spikes & Spasms. Ms. Deras corresponded with Dr. Herzog after reading about his research.*

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A new study by researchers at the Faculty of Kinesiology, University of Calgary, is raising questions about the therapeutic use of botulinum toxin A.

The study found that animals injected with Clostridium botulinum type A neurotoxin complex (BOTOX, Allergan, Inc., Toronto, Ontario, Canada) experienced muscle weakness in muscles throughout the body, even though they were far removed from the injection site. The study also found that repeated injection induced muscle atrophy and loss of contractile tissue in the limb that was not injected with the Toxin.

"We were surprised by the degree of muscle loss and atrophy in the limb that was not injected with the Botulinum toxin," says Rafael Fortuna the lead author of the paper will soon be published in The Journal of Biomechanics, "I think it's fair to say that the paper raises some important questions about the long-term therapeutic use of Botox, especially with children and adolescents."

The study used dosages that approximated therapeutic doses used to treat conditions like cerebral palsy where muscle contraction can't be controlled resulting in muscle

dystonia and spasticity. The study follows previous research in Dr. Walter Herzog's lab, which found that botulinum toxin A, easily crosses the muscle membrane barrier, resulting in muscles weakness in the surrounding (non-injected) muscles.

This study shows, for the first time, that over time botulinum toxin A use also results in muscle weakness, atrophy and loss of contractile tissue in non-injected muscles far-removed from the injection site." It may be that the benefits of using Botox for these kinds of therapeutic, medical uses, outweighs these potential long-term consequences," says Dr. Herzog, "however I think this study raises some important issues that need to be followed to ensure the best possible outcomes for patients, in the long term."

**"The results should be valid for any application of the drug."**

Botulinum Toxin A is also used as a cosmetic treatment, where the drug paralyzes small muscles in the face to reduce the appearance of wrinkles.

Herzog notes that while this study was looking at larger doses, the results should be valid for any application of the drug.

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### About the Author

Don McSwiney is Director of Communications & Marketing at the University of Calgary. His news experience includes reporting, hosting and producing at CBC, Canada's national public broadcaster.

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## The Cost of Success

By Dr. Rob

### Spikes & Spasms Note:

*Another gem! Dr. Rob writes what patients think. This article appeared in [Distractible.org](http://Distractible.org) on November 29, 2010.*

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For those of you who didn't know, I entered the [National Novel Writing Month](#) "contest" (which has no winners). I got to the goal of 50,000 words yesterday.

One of the main questions that is asked in my novel (which may or may not ever see the light of day) is this: What would happen if a wonderful cure came along that would take away most, if not all sickness? Remember, it is fiction.

The answer is, of course: utter chaos and collapse of our system.

Our system is designed to deal with sickness. It is designed to fix problems. If a wonder-drug came along, here's what I think would happen:

- Pharmaceutical companies and hospitals would have to oppose it, as they would suffer financial ruin if people became healthy.
- Doctors, especially those focused on chronic illness or treatment of serious problems, would take a huge cut in pay.
- A huge number of healthy people would enter the workforce, disrupting an already fragile economy.

Human stupidity, of course, would remain. There would be some work for those in the medical profession, but only a

fraction of what is there now.

I don't think anyone expects this "wonder drug" to appear any time soon, so what's the point of entertaining this scenario? Looking at the extremes can often give us insight into our current problems. One of our biggest problems is this: our system thrives on its own failure. If we fail to keep people well, the healthcare economy improves. There are more jobs to be had to treat and take care of these sick people. There is more need for new drugs to treat the increased number of sick people. Hospital beds are full, and doctors are busy.

Life is good for those of us in medicine when we fail.

**“What would happen if a wonderful cure came along that would take away most, if not all sickness?”**

I think this truth is not lost on some of those people who are cynical about traditional medicine. They see the motivation to keep people sick, and assume that there is a conspiracy afoot to accomplish this goal. Now, if there is a conspiracy, it doesn't include me. I do see success in keeping people healthier than if they didn't see me, and nobody

has tried to bump me off yet. I'll let you know if they do.

But despite the fact that I don't see a conspiracy to make people sick, I do see a lack of a conspiracy to make people well. It's not an organized conspiracy; it's just a sin of omission. Success of our system, defined as people being kept healthy, comes at a huge cost. Why would people strive for success when the prize would be a pink slip?

Again, I am not saying that this is a conscious decision. I don't think there is a back-room deal between pharma, hospitals, and the government to prevent wellness. No, I just see a total lack of an organized effort to fix things. We are giving absolutely no motivation for success. There is nobody in the healthcare industry who truly benefits from health. If this is our goal (and I think it should be), shouldn't we somehow make it worth someone's while to keep people healthy?

Why aren't we setting goals to shut down hospitals, not keep them profitable? Why aren't we trying to motivate well care and prevention so that sick care and intervention will stop being so profitable? This can't be lost on those whose livelihood depends on the failure of the system. There will be great inertia to the sacred idea of treating the sick, and a reluctance to abandon it for the idea of eliminating the sick (through prevention, not euthanasia).

Would your kids clean their rooms if you docked their allowance for doing it? That's what we are doing. That's how our system is designed. We should not be surprised at failure when success comes at such a high cost.

Until things are changed at the most basic level, success in healthcare will be a purely fictional idea.

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### About the Author

Rob Lamberts, MD is 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."

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## Comparing Cost Is Not Enough When Evaluating Medicare Part D Plans

*Allsup outlines key questions when choosing a prescription drug plan*

More than 1,100 Medicare prescription drug (Part D) plans are available for 2011. Most consumers have about 33 plans to choose from in their area during annual enrollment, which is Nov. 15 to Dec. 31. However, Part D plans with the lowest premiums may not be the best match for Medicare beneficiaries' individualized needs, according to Allsup, a nationwide provider of Social Security disability representation and Medicare plan selection services.

"People tend to look at the Part D plan's premium because it's the easiest thing to compare, but it's not necessarily a realistic reflection of the true cost," said Adrienne Muralidharan, senior Medicare specialist for the [Allsup Medicare Advisor®](#). The *Allsup Medicare Advisor* is an impartial Medicare plan selection service that helps people understand and choose the most affordable and appropriate Medicare coverage for their healthcare needs. (Allsup is not a Medicare plan provider.)

"Looking only at the prescription drug premium is like looking at a car's sticker price. The cheapest car could have awful gas mileage, excessive maintenance costs and a design that does not match your needs," Muralidharan said. "The same goes for prescription drug plans. You need to look at all the components that add cost or provide value before you can make an informed decision."

According to Muralidharan, key factors when evaluating Part D plans include:

### What are all the costs involved?

In addition to the premium, these costs can include

deductibles and co-payments. For example, a plan with a \$33 monthly premium may seem like a bargain. However, if that plan has a \$310 deductible and a \$20 co-pay for each medication, the costs for multiple prescription drugs quickly rises. Another plan with a \$50 premium, a lower deductible and no co-pay could actually save you money.

### What drugs does the Part D plan cover?

First, determine that the plan covers your medications. Make certain you also understand if the plan covers the brand name or generic version of a drug. Many people can use generic medications, but others may experience adverse reactions and require the brand name medication.

**"Looking only at the prescription drug premium is like looking at a car's sticker price."**

According to Muralidharan, people often look to the *Allsup Medicare Advisor* service to help navigate the complexity of determining which Part D plans cover which medications. For example, a formulary might cover most of someone's drugs, but if one of the most expensive medications is not covered, this can be a significant cost.

### Does the plan restrict where or how you can purchase medications?

Medicare prescription drug plans contract with certain pharmacies to create a network. Within that network some plans may have preferred and non-preferred pharmacies, potentially requiring you to pay higher rates if you don't go to a preferred pharmacy. Medicare beneficiaries should determine if the plan's network is convenient and cost-effective to them.

### Is having coverage during the gap ("donut hole") necessary?

The prescription drug gap in coverage occurs in 2011 after the individual's and plan's combined costs total \$2,840. After that amount is reached, the person is responsible



for all costs until catastrophic coverage starts, which is when the individual's and plan's combined costs total \$6,448. For 2011, beneficiaries do receive some relief from a 50 percent discount on brand drugs and 7 percent discount on generic drugs bought while they are in the donut hole.

However, not everyone who falls into the donut hole would benefit from purchasing a more expensive Part D policy with gap coverage, according to Muralidharan. "Someone with very high-cost medications could move through the donut hole more quickly to reach catastrophic coverage, where the plan will cover 95 percent of their prescription drug costs."

#### **Do you have comprehensive and objective information on the plan?**

When evaluating plans, it's important to ensure you have all the necessary details to make a fair comparison of Part D plans. Keep in mind that many Medicare plan selection services provided in the marketplace are designed to promote specific plans, including those provided by specific insurance providers. This can be true for Part D selection services offered online and by store pharmacies. Government resources also may not be the most current. These factors can limit your ability to make an informed choice and could mean you miss the opportunity to find a plan that better meets your needs.

"You are going to be able to make a more informed, confident decision on your prescription drug coverage if the information you are using is reliable and comes from an objective, third-party resource," Muralidharan said.

For an evaluation of your Medicare options, please call an *Allsup Medicare Advisor specialist* at (888) 271-1173, or go to: <http://medicare.allsup.com>.

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#### **About ALLSUP**

Allsup is a nationwide provider of Social Security disability, Medicare and Medicare Secondary Payer compliance services for individuals, employers and insurance carriers. Founded in 1984, Allsup employs more than 700 professionals who deliver specialized services supporting people with disabilities and seniors so they may lead lives that are as financially secure and as healthy as possible. The company is based in Belleville, Ill., near St. Louis. For more information, visit [www.Allsup.com](http://www.Allsup.com).

The information provided is not intended as a substitute for legal or other professional services. Legal or other expert assistance should be sought before making any decision that may affect your situation.

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## Lend Me Your Ear

By Pat Hill

Every human being is equipped with two ears and one mouth. Hmmmm, wouldn't that mean that the onus on the human species would be to listen more than to talk? So if you have a spasmodic dysphonia voice, perhaps the ears of the world should make more of an effort to be more attentive to your words. Also, when you consider the number of people who have voice disorders, such as stutterers, stroke, throat cancer, respiratory, and trauma patients, to name a few, the impaired speaking population is immense. Aside from the abnormalities within the speaking world, there are also those who have foreign accents or don't speak English at all. Now that increases our "dysfunctional" expressive population into the millions. Then add to that population all of the people who have a disability with word retrieval problems, autism, language processing, or just those habitually quirky speakers of the world. All of a sudden we are not such a rare and isolated group.

**"Communication is a two way street."**

Then we look at the listeners of the world. How well are they doing? Some people are deaf or hard of hearing, others have attention deficit disorders or auditory processing disorders, and finally there are those others who have selective hearing. The deficits in the skill of listening is not as pronounced as a speaking problem, so again the fault falls on the speaker in any encounter. It would behoove those speakers to think about the listeners' responsibility in these situations. The listener should be listening to the words of the speaker, not the SD, not the accent, not the tone/pitch, and not the breath. Have you ever noticed that some people can understand people with accents better than others? They just cut right through the irregularities. How do they do that? Some people also pick up foreign languages better as well. So there are some people who are blessed with the ability to listen more keenly as there are people who are blessed with

articulation skills.

Since we with spasmodic dysphonia are not in that blessed group of articulators, we can become better listeners, but we can also expect that others will make an effort to be better listeners as well. The burden of communication should not always fall upon the communicator. Communication is a two way street. I would also ask you to consider other forms of communication. About three years ago I attended an educational conference with open seating. I sat down at one of the circular tables, only to discover that everyone at that table was hearing impaired or deaf. It was an ironic situation. I couldn't talk and they couldn't hear. In a way it was a win-win situation. So what

happened? We communicated in every other way that we could think of. I didn't know sign language but it didn't matter. We spent the day together and went out to lunch together. We talked with halting voices, gestures, pointing, facial expressions and posturing. It was a whole new way to communicate that we often take for granted. In all honesty I have to say that it was a fun

and joyous time.

Besides knowing that we are affiliated with the non-speaking world on many levels and also knowing that we can have higher expectations of the listening world, we also are aware that there are many forms of communication that need to be part of our repertoire. Another great bonus of miscommunication is the humor to be found in it. Always be prepared to laugh. It is also nice if the listener shares that sense of humor. I answered my phone one day and my uncle was on the other end calling long distance. I apologized for my voice and he said, "It's all right. I have that affect on all women."

A final aspect to consider is the role that others play in your life and how you can categorize those who are not as accepting. One day my superintendent suggested that I go into administration as a career. I told him that I thought

there would probably be people who would be prejudiced against me because of my speaking disability. His response was, "That would be their mental disability." So there is always two ways to look at situations.

In summary, be an expressive communicator, be a good listener, have a healthy attitude, be selective in your encounters, and develop a good sense of humor. Give that voice a pet name and introduce it to the world out there. Expect people to listen to and learn from you. You are not alone. You are doing this with and for millions.

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### About the Author

Pat Hill has battled the diagnosis of spasmodic dysphonia for 40 years. Actively involved in the NSDA (National Spasmodic Dysphonia Association), she also keeps close ties with the DMRF (Dystonia Medical Research Foundation).

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