

# Spikes & Spasms

The Tremoraction.org Newsletter

DECEMBER 2006

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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

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

## Holidays, Oh My

By Mona Reeve, PhD, MPH, LCSW

Having the strength and fortitude to withstand all the holidays that come upon us in the fall of each year is a sign of sound mental health. And having moments of feeling down, distressed, depressed and anxious is part of that mental health. If we go around thinking we have to "handle" everything without having emotional tugs of war, then our expectations of ourselves is outside the realm of how people feel and think.

To wit, I both love and hate the holidays. Duality is common and coexist as do many of our emotions. My family is pretty large. We have five children, eight grandchildren and three great grandchildren that come from a mix of original and blended families. Each year each family unit makes choices about where to go for Thanksgiving Dinner and Christmas and Hanukah that may or may not include our house. In-laws, tradition, distance, friends, etc., may impact where our children and grandchildren end up for family dinners. Does this mean that I have taken this in stride and say internally, that's ok? Actually, my feelings range from acceptance to anger with everything in between. I may feel abandoned, left out, betrayed, annoyed, angry, disappointed, freaked out, and even have desire to divorce my family or - at least some of them. Then I find that acceptance takes over and we make plans accordingly recognizing that in today's world, change is a guiding principle. And every year these decisions may change. That is the realist coming to the fore. And I recognize that these decisions may have more to do with demands upon them, then whether or not they love us or want to come to our home for the day.

One of the ways in which we started dealing with this is to not get in their way, and have an event on another day to which they may or may not attend. We take care of our desire to have family dinner in this manner. Sometimes it

works, and sometimes it doesn't. It took me a long time to learn how to deal with these stresses so that I don't succumb to them such that it makes me miserable or out of sorts except for fleeting moments. If I were to succumb, who would get hurt? We always invite friends to celebrations to nourish our own spirits and relationships regardless of family attendance.

Fall brings with it so many expectations of family togetherness. And with that, the assumption that on these special days, everyone will be nice to each other and behave civilly and everyone will have a grand time. Yes and No! Sometimes these events bring forth all the anxieties of our original upbringing, with competition for parental attention, or any attention from anyone. Sometimes, we bring with us our fantasies of what we wanted our families to be. And sometimes we bring along our wishes for the future of how life will turn out for them and us. The journeys into the past and future through these fantasies, assumptions, expectations, and wishes, take us completely out of the experience of

**Celebrations are one of the ways in which we can nourish and cherish our relationships and serve good purpose as a result.**

being in real time - the present - to enjoy as possible, the actual interactions we can have in the time we spend together.

In many ways, Fall for me is the best time of year. Perhaps because I was born at the end of September. The leaves are changing color and from the host of greens and browns and florals we have seen through the summer, we come to the myriad of hues that denote the ending of one season and the beginning of the quiet of winter. Life tones itself down for the future regeneration.

Fall provides us with shorter work weeks as a result of many national holidays. As we move towards winter, holidays bring celebrations of many kinds. We are provided opportunities to spend time with family, friends, neighbors and people from work who may or may not be friends, just as family members may or may not be friends.

During this time frame, we can assess obligations, desires, and responsibilities that can provide us with direction about how we spend our time, and more importantly - with whom. Choose wisely, and allow yourself to enjoy these relationships in the context of the celebration. Celebrations are one of the ways in which we can nourish and cherish our relationships and serve good purpose as a result. They are the medium by which we can practice using our emotions of understanding, compassion, love and pathos by which we enhance our bonds with co-workers, friends, and family.

I take this opportunity to thank you for the time we have spent together this year. I have spent time thinking through ideas I have written about, and how they might be of use to all of us. You have read what I have put in writing. For those of you who have written to me, thank you, and I look forward to more commentary, critique and assistance. For these are the ways I can think through more clearly ideas and emotions that we all have, and transmit them in useful words.

And so I wish you and yours a most Happy Holiday Season with best wishes for a Happy New Year. And in our ever hopeful human song, may the **NEW YEAR** bring **PEACE, HEALTH AND JOY!**

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### About the Author

Dr. Reeva's quarterly column focuses on mental health issues. She has worked in the field of mental health and human services for over 40 years. Readers are invited to ask questions.

Contact Dr. Reeva at [mreeva@comcast.net](mailto:mreeva@comcast.net)

Her interests include photography and jewelry making. An avid traveler, her photography is exceptional. You can view her photographs at

<http://www.flickr.com/photos/drmona>

Her Trompe l'oeil photos of a wall in Lyon, France are "photographic art."

## Whole-Food Nutrition: Fruits and Vegetables

### Juice Plus+® Excerpt

Experts agree: the best way to prevent our most prevalent diseases is to eat healthier. Almost every day, another piece of research or another news story touts the disease-fighting power of our dietary choices -- especially the benefits of eating more fruits and vegetables.

You've heard it all your life: "Eat more fruits and vegetables." Now, medical science is telling you, too. But knowing is easy. It's doing it that's hard.

People often turn to vitamins and other nutritional supplements to improve their diets. Unfortunately, vitamins alone can't begin to replicate the thousands of different nutrients found in fresh fruits and vegetables.

You see, Americans don't suffer from a vitamin deficiency; we suffer from a whole-food deficiency. And this deficiency is creating health problems of epic proportions for young and old alike.

Juice Plus+® is the simple, convenient, and inexpensive way to add more nutrition from fruits and vegetables to your diet, every day. Juice Plus+® contains the nutritional essence of **17 different fruits, vegetables, and grains**. Each ingredient is specially selected to provide you with the broadest possible range of nutritional benefits.

### Juice Plus+® Clinical Research

The many healthful benefits of Juice Plus+® have been demonstrated through numerous independent clinical research studies conducted in leading hospitals and universities by investigators in the United States, England, Australia, Austria, Italy, and Japan



## Health Professionals Speak Out!

### Richard E. DuBois, M.D.

**Home:** Atlanta, Georgia.

**Medical Specialty:** Infectious Diseases.

**Most Recent Position:** Chief of Internal Medicine, Atlanta Medical Center.

**Health Advice:** Scientific studies involving isolated, high-dose, and often synthetic vitamin and mineral supplements have shown conflicting and sometimes even harmful results.

### Why he recommends Juice Plus+® to patients:

Studies have proven that whole foods are the best source of micronutrients, in part because antioxidants and other micronutrients work together in ways we've just begun to understand. Whole foods also have thousands of yet-to-be identified phytochemicals that will prove beneficial for human nutrition. I tell my patients: Eat whole foods and take Juice Plus+®.

**20 - 35 grams of dietary fiber per day are recommended for consumption.**

**The American consumption of dietary fiber is well below experts' recommendations.**

### Marla Friedman, Ph.D.

**Home:** Glen Cove, New York.

**Specialty:** Psychology and Nutrition.

**Education:** MS in Early Childhood Education, MS in Clinical Mental Health Counseling, and Ph.D. in Psychology. Dr. Friedman is also a Certified Nutritionist.

**Current Positions:** With 25 years of clinical experience, she currently combines psychotherapy and nutrition in her private practice at the Center for Integrative Wellness.

**Philosophy of Healing:** "Nutrition affects all parts of us, even the brain, especially the brain. Good nutrition affects memory and focus, concentration, your mood. A lot of the people I see who are depressed are also nutritionally depleted. When they begin taking care of themselves with good nutrition, it makes it much easier for them to deal with their emotional struggles."

**How she uses Juice Plus+® in her practice:** "Juice Plus+® has become a foundation product in my practice because there is such a broad range of ways that it can help people. Improving peoples' nutrition with Juice Plus+® helps empower them to make their lives better. It helps them see that - through nutrition - their bodies can heal and improve in ways that they did not know were possible."

The message is clear: we need more of the healthful whole food nutrition of fruits and vegetables in our diets, every day.

## About Juice Plus+®

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Readers may send an email to [tremor@tremoraction.org](mailto:tremor@tremoraction.org) for information on local distributors.

### Spikes & Spasms Note:

*The publication of **Whole-Food Nutrition: Fruits and Vegetables** does not imply endorsement of Juice Plus+® by Tremor Action Network (TAN). The article is for reading only. Neither TAN nor Juice Plus+® express or imply that the Juice Plus+® excerpt supersedes the physician-patient relationship.*

*Dietary fiber includes fruits and vegetables. 20 - 35 grams of dietary fiber per day are recommended for consumption. The average consumption is 10 - 20 grams per day. There is concern that the American consumption of dietary fiber is well below experts' recommendations.*

## Symptom as a Messenger A Change of Perspective

By Ann Bennett Sturgis, Ph.D.

She was a child of eight, when trauma in her family caused a trembling of her hands. Fear triggered the onset and then anytime she was fearful, the trembling would occur. During those turbulent years, fear was a frequent companion. Growing up in a fundamentalist religious environment, she heard tales of "the original sin," in which she and everyone was born, and a fiery hell for sinners.

She was sure she must have done something very terrible to have to be punished with the painful problems in her family and her condition. Because the tremor connected to painful events in her childhood, she felt ashamed. The tremor was an "affliction" and a sign of her defectiveness, sinfulness which was visible and could not be hidden. She shaped self images that she would only be able to articulate when she was a woman.

Her mother and others attributed the condition to "nervousness." In school she realized that she would have to work harder than the other kids to keep up. What seemed an impediment in her life, however, began to show itself as a gift. The extra effort took her to the top of her class, skipping two grades and graduating from high school at 15. Because she felt "different," she was shy and observant, developing empathy for others' differences and challenges.

She had to make pilgrimages into many fields of knowledge and experience to make sense of what may have been a handicap had she refused the challenge. Following the symptom of the tremor, each journey provided more clues to the mystery. In order to help her self, she studied art therapy, dance therapy, bioenergetics, religions of the world, various types of meditation, Feldenkrais, biofeedback, neurolinguistics, biochemistry, psychobiology

of mind/body healing.

She worked as a chemist in medical research in psychosomatic medicine, as a mental health journalist, as stress management educator with people who were diagnosed with chronic and emotional illness, and also educator for health care professionals.

This girl's story I have related to you is my story. Only when a journalist friend gave me a copy of a newsletter in 1992, did I understand about this tremor, although I had been diagnosed as having essential tremor years before. Knowing there were millions of people who also had this condition, transformed my perception of myself and of the

tremor. The information in the newsletter has been invaluable in coping with challenges in work and daily life. Realizing how stress exacerbates tremor helped me appreciate the avenues down which the symptom has led me. Without it I would not have developed the career in stress management training. It has enriched my life and brought me satisfaction

and fulfillment, travel to wonderful places to teach and lead workshops.

The idea of the "Wounded Healer" caught my attention many years ago, as I was searching for answers. I traveled to Greece to visit the temple of the ancient Greek physician, Asclepius, the wounded healer. The "Wounded Healer" finds wholeness as healing flows through him or her to others. Many times I have experienced a mysterious cessation of my tremor as I was helping others learn how to manage pain, reduce their blood pressure, or connect to their creativity to resolve problems in their lives.

So often in our culture, we have been encouraged to speak of, or think of ourselves as "victims." Doing so creates resentment. Dr. Hans Selye, the originator of the stress theory of health and illness, maintained that the best way to protect one's self from the stresses of life was

**I am well convinced that this "tremor" that I have has led me to an awareness of the blessing of connection to people and creatures of the earth.**

by cultivating a deliberate attitude of gratitude. This is far from easy. It requires a mindfulness, self awareness, and repeated commitment. He said if we do not endeavor toward this biologically healthy, natural attitude, vengeance and resentment can seep into our lives, harming our health and relationships. Whereas, exploring ways to appreciate our infinite creative intelligence's ability to constellate reality in a way that is sane and serene in our variety of life experiences, awakens a vibrancy all the way down to our cellular level.

In ancient Greece, and now again appearing in some of our literature on mind/body medicine, is the idea of a symptom being a "divine gift," that comes to bring us motivation to harmonize our inner and outer worlds and serve us in unique ways.

I am well convinced that this "tremor" that I have had so many years has led me to a deeper spirituality, reverence for life in my cells, and an awareness of the blessing of connection to people and creatures of the earth. This is a long, long way I have come from being at war with the tremor, thereby increasing it and feeling angry and unhappy with it. It is such a fine signal telling me when I need to manage my thoughts, words, images, and choices with the creative intelligence with which we are all so bountifully supplied.

The poet Rilke expresses this experience:

"Whoever reconciles the many contradictions of his life, gratefully gathering them into one symbol, expels the noisy crowd from his abode and in a different kind of festive mood receives you as his guest on gentle evenings.

You are the other in his solitude, a silent center for his conversations with himself, and every circle drawn around you makes his compass span beyond the rim of time."

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## About the Author

Dr. Ann Bennett Sturgis is an educator, counselor, and founder of the Stress Management Training Institute. She obtained a Ph.D. in psychology and counseling from International College in Los Angeles. One of her most significant achievements as a stress reduction expert has been the development of relaxation tapes - Relaxation Through Awareness and Relaxation For Sleep.

The tapes have been used by various professionals at the Scripps Clinic Pain Clinic, Scripps Memorial Cardiovascular Rehabilitation Center, and the San Luis Rey Hospital.

For further information, in particular, on how to obtain the tapes that have helped people, including but not limited to relief from pain, tension and anxiety, please email Dr. Sturgis at [asturgis@aol.com](mailto:asturgis@aol.com) , or call (858) 270-1997.

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## The Social Security Disability Process How Allsup Inc. Can help

Are you familiar with Social Security Disability Insurance (SSDI)?

SSDI is a government mandated insurance program, and we pay the "premiums" through our paycheck FICA taxes. It's designed to provide monthly income to people who can no longer work because of a severe disability.

Unfortunately, the road to SSDI benefits is a confusing maze of bureaucratic paperwork. And it comes at the worst time. The last thing you want to deal with when you are trying to adjust to a debilitating health condition is the government's red tape.

What happens if you can't apply on your own? Prior to 1984, and still today if you go to a lawyer, you're usually on your own. Often, a lawyer steps in only after you receive one or even two denials.

There is a way, however, to increase your odds of receiving an SSDI award. At the very least, you can greatly increase your odds of getting an award on appeal.

Get help from the very beginning!

A few companies will take the case at the beginning, and one of these is the industry's trailblazer, Allsup Inc. Jim

Allsup, a former Social Security Administration (SSA) field representative, founded Allsup Inc. in 1984. It was the first private company to handle SSDI cases nationwide, and it is still the nation's premier SSDI representation company.

The SSA allows private companies to charge a fee of up to 25 percent of back benefits, or \$5,300, whichever is least. What does this mean in real-world terms? Let's say you receive your award one year after you became eligible, and your monthly benefits are \$1,000. You'll receive \$9,000 immediately and you pay Allsup \$3,000. The monthly payments of \$1,000 that follow are yours. That means if you collect benefits for the next 30 years, you'll receive well over \$370,000 after cost-of-living increases.

**Allsup will treat you sympathetically and professionally because they know there is a real person behind that Social Security number.**

What can you expect when you deal with Allsup?

Allsup will treat you sympathetically and professionally because they know there is a real person with serious health issues behind that Social

Security number. Allsup's motto is, "You stay at home. We do the work." That customer-first attitude is why the Better Business Bureau presented Allsup its prestigious 2006 Torch Award, which salutes superb customer service.

Allsup designed its system to be hassle-free. Professional claims representatives gather necessary information over the phone, and then mail the appropriate forms for you to sign and return. About 80 percent of Allsup's customers never deal directly with the SSA.

There are five levels in the SSDI application process.

Level one is the initial application. Once you appoint an Allsup representative, he or she immediately goes to work for you. Your representative will complete the necessary forms during a telephone interview so you never leave the comfort of your home. Allsup then develops the claim and

submits all relevant medical and vocational evidence to the SSA.

Sometimes, your condition may not precisely meet the SSA's requirements for SSDI benefits. That's when Allsup puts its experience and resources to work. When your representative presents the evidence in the correct context of other conditions and documents your education and other lifestyle issues, he may be able to prove that your condition meets the SSA's standards. The result is a regular monthly income.

Because Allsup is so familiar with the Social Security process, the award rate for initial claims is much higher than those filed without professional assistance.

Level two is the reconsideration level. If your initial application is denied, Allsup promptly files an appeal. Your representative will review and update your medical and vocational information and stay in regular contact with the SSA.

Level three is the hearing level. If your reconsideration is also denied, an experienced Allsup senior representative takes over. He or she will interview you and complete the necessary forms for an administrative law judge hearing. Allsup pioneered the use of on-the-record decisions at this level—the goal is have an award made without an in-person hearing. Most of the time, however, an in-person hearing is not needed. If one is required, your Allsup representative will accompany you to the hearing.

Level four is the Appeals Council. If your hearing ends in a denial, Allsup will review your case again and may submit an appeal, along with any additional medical information and a written brief, to the Appeals Council. The Appeals Council will review your hearing decision to determine if it was rendered properly according to the law.

Level five is Federal Appeals Court. This level takes you into the federal court system, and Allsup stays by your side.

It can be a lengthy process, but SSDI benefits means increased monthly income and automatic Medicare benefits. That means you'll receive medical benefits, prescription drug coverage, protected retirement benefits, benefits for dependents and return-to-work incentives.

Since 1984, Allsup Inc. has fought on behalf of tens of thousands of people with disabilities and achieved a phenomenal 97 percent success rate. With superb customer service and demonstrable results, Allsup Inc. has done the unthinkable. They made a complicated, lengthy and distressing process of applying for benefits into a process that garners over a 96 percent customer satisfaction rate.

Perhaps Allsup can also help you.

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### About the Author

Founded in 1984, Allsup Inc. is the nation's premier provider of Social Security disability benefits.

For more information on how Allsup Inc. can help you file for the Social Security Disability Insurance benefits, please call (800) 279-4357, or visit the company's Web site at <http://www.allsupinc.com/>.

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## The Dystonic Writer

By Terri Sterling, MSP

I am a passionate writer and artist who craves to learn new words and their meanings faster. I am a painter who paints for hours on end in an obsessive special manic stance that only writers and artists purposely generate. I am a dream sleeper who creatively solves problems, dreams up new innovative ideas, and fully paints in her sleep. I wake up with full paintings completed, in my mind, with multicolored layers of delight. My poetry comes fully formed in rhythmic layers as I move the sleepiness from my eyes. I am a Dystonic writer and I have wonderful stories to tell, articles to write, and a passion for life.

I am a dreamer.

I was not prepared for this thing called Dystonia and its ugly ability to steal the love of my life. I was not ready to have my painting life end or words stop in their tracks between my mind and the paper before me. I was starving for the creative life, that I wanted

filled with writers, artists, and an enthusiastic life. I set my dreams aside for years because of this dystonic life, which stole my ability to write but I painted when I could, left-handed. Only my tremors spread to my left hand too and I could not afford to lose it to the dystonic life, so I stopped painting for years, until one day when I could not stand the ache in my heart any longer; I went back to college and learned to paint with my whole body in gross movements. I found the delight of my life once more but I was a legally blind painter and printmaker for several months when I could not see due to the orbital pseudotumors. The inflammation from some strange unrelated medical condition, the steroids, the cataracts from the steroids, threatened to take my art, my vision and my life.

I moved across the county, back to the Pennsylvania and New Jersey area, because I thought I could get help from

the place where I was first diagnosed. I received the greatest gift, I could ever ask for, I found a doctor who could inject Botox in my arm and give me back the life I craved and missed so badly but my struggle wasn't over. As fate would have it, I lost my job and my medical insurance. I thought I would be going back to an empty uncreative life or at least a compromised one. My friends kept me going, with their encouragement, while I tried to start my own Life Coaching business. As you probably know it takes a while for any business to be successful, so in the meantime I could not afford the Botox. Then fate, stepped in and I applied for the Botox Advantage Program but I felt bad that I a well-educated, independent person would need such a program. After all, wasn't I supposed to make it

with all this education and experience, even if my own body betrayed me? No one can pay for the cost of Botox or the injections alone. I was accepted into the Botox Advantage Program and I will receive one year of Botox and injections because my doctor was willing to help me when I could not do it all by myself. Perhaps, the Dystonic life is not so bad because now I can write,

**The Dystonic life is not so bad because now I can write, paint, dance, and encourage the dystonic community to fill their dreams and delights.**

paint, dance, and encourage the dystonic community to fill their dreams and delights. I have found a purpose in my life, my delight, and some of the best friends I could ever ask for. Luckily, the pseudotumors went away with radiation. I am a Life and Creativity Coach for people with Dystonia, Artists, and Writers, and I help people over the phone. I could use a few more clients, so if you want my help in finding the passion in your life than call me at 215-853-2615 and leave a message or email me at [terriccreativity@yahoo.com](mailto:terriccreativity@yahoo.com). We will work out the fee and I will keep my lights on for you.

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### About the Author

Terri Sterling is the owner of Inspiration, a private coaching business for people who are creative or who have movement disorders. For more information about Terri, visit her website at [http://www.freewebs.com/terris\\_inspiration/](http://www.freewebs.com/terris_inspiration/)

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## A DBS SUCCESS STORY

By Nancy Muller

I would like to pass on a heartwarming success story about a good friend and colleague of mine from my days when I was the former president of the National Spasmodic Torticollis Association. His name is Jim Ruetz, and he has an incredible story that he related to me upon my request so that I could show there is a very positive side to having DBS performed for Dystonia. I have read just too much negative about this in different publications and Jim's story does show the positive side of the procedure and that there can be life after the devastating effects of dystonia through this procedure.

Jim's nightmare with dystonia began at the age of 36, when he was a young man in the prime of his life. He was Vice President of Finance at a health care company, he was athletic and active, which suddenly over a period of months, he started to experience uncontrollable eyelid spasms that left him virtually blind at times. He could not drive, function at work unless he was isolated in an office with low lighting. He was eventually diagnosed with blepharospasm and told the condition was chronic and the only treatment available was an experimental drug, at that time, called Botox, or he could have surgery to keep the eyelids open permanently. He opted to do neither, and after 18 months of changing jobs, he experienced a remission.

Unfortunately, at the age of 47, Jim experienced his journey into "full blown" Dystonia. He experienced Meige's Syndrome, which made its way down his body, and developed Spasmodic Torticollis, Dysphonia, trunkal spasms and arm spasms. His Blepharospasm returned, and now he was not only blinded but his speech became unintelligible. Breathing became difficult due to the extremely forceful trunk spasms. His body was being pulled over at the same time his head was being wrenched

**New medical technology,  
positive attitude, and  
the power of prayer  
brought a new meaning to  
my long journey.**

to the rear. He was choking on food, and couldn't drive. The severe spasms caused hyperhidrosis. Soon he was unable to sit for more than short periods of time. He spent half his life lying on a mattress on the floor just so he could breathe.

Jim searched for a cure and relief from his symptoms through every avenue available to him. He not only searched conventional avenues, but also alternative forms of trying to treat his devastating symptoms. He traveled through the US and many other countries to search for the "cure".

Jim had two years of Botox injections but due to two horrific auto accidents directly related to his Retrocollis, he considered having a Cervical Peripheral Selective Denervation surgery, as it would be a way to help relieve some of the torticollis symptoms. At this point, any shot in the dark was worth a try. He did receive some relief, but in his words, he was still "Dystonia Man."

His body continued to pull itself forward and he now needed a walker. His Dysphonia was causing constant choking on food, aspiration during sleep and pneumonia and fungus started to permanently reside in his lungs. The only person that could understand his speaking was his wife, and sitting on the floor became lying on the floor permanently. His whole life was in disarray, and he actually had no quality of life at all. No movies, no dinners out, any social life at all. Then his heart couldn't take the burden and he developed Atrial Flutter, and he was put on heart medication and had to have corrective coronary ablation heart surgery. He was now 56 years old and the destructive effects of dystonia had just taken its toll on his entire life.

After deciding his life could not get much worse he had to go for a last ditch effort, and seriously consider having Deep Brain Stimulation surgery performed. Jim delved into doing his homework and seriously looking into DBS. He

interviewed other patients that had the procedure, met with doctors and even got second and third opinions. He explored everything he could find on the web and every bit of info available on the outcomes of others having DBS.

The ultimate decision was to go ahead with the DBS surgery and the rest is history. Immediately after surgery the hyperhidrosis was gone and he was able to rest and sleep on his back. Two weeks after the stimulator was implanted, it was turned on. Within weeks after the stimulator implant surgery, he was up, walking, sitting, swimming, talking, and eating at the table.

Jim states the sacrifices he made was that things had to be done in moderation. He does take speech therapy, he has some low back pain, that will probably always plague him, but he does stretching exercises in the morning, and he can't engage in any extreme sports. His battery drains and has to be replaced possibly every 18 months, and he will be privately searched by security officers at the airport.

I'd like to share this quote from Jim regarding his feelings since having DBS:

"It is very hard to express the changes that this surgery has made in my life. My self esteem had been crushed. I had become reclusive, avoiding everyone but family. Now I feel like a real husband to my wife. I do some of the driving, I take her out to dinner, and I even help with housework and other chores. I feel Joy in my life again. My faith in God has never been stronger. New medical technology, positive attitude, and the power of prayer brought a new meaning to my long journey."

I have so much respect for Jim and I admire his tenacity to go forward and look for quality in his life rather than so many people I've run into that have a negative attitude even after having DBS, being able to be a productive human being, yet they still continue to complain because things aren't "perfect" for them. Jim is a true inspiration to me and I hope to everyone that reads this, because there truly is life after DBS and it can be a good positive life with so

much more quality, as Jim has pointed out. I also have to admire his wife Jenine, who has stood by his side throughout this journey, and Jenine herself also suffers from Spasmodic Torticollis.

Jim tells me if there is anyone that would like to talk to him about his experience with DBS and his journey; you can contact him at his home phone # (714) 990-0574.

Jim is truly an incredible individual and I have to say I'm honored to know him and have worked with him through the years in trying to educate and support those of us with Dystonia. I would like to thank Jim for sharing his story with me so that I could pass it on to everyone going through the same devastation of living with dystonia, and for Jim being able to point out and stress the positive side of life and not giving up, no matter what.

I can also be reached at my home number of (951) 926-3677 or at my e-mail [nmuller406@aol.com](mailto:nmuller406@aol.com). I am here for anyone needing support in any aspects regarding Dystonia. I have experience with Cervical Denervation Surgery, Social Security Disability, and maybe you just need a listening ear and I want everyone to know I'm here for you and will respond to all your calls and e-mails.

I'd like to thank Tremor Action Network for allowing me to contribute information about Dystonia to the public and medical profession to further educate and support everyone on this disorder that is so misunderstood. I also look forward to hearing from our readers and let me know if there anything specific you would like me to write on that has not been addressed.

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### About the Author

Nancy Muller is a passionate dystonia advocate. 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 resides in Southern California with her husband Stuart, their children, and grandchildren. She is a regular contributor to Spikes & Spasms. Her previous articles on Social Security disability, healthcare responsibility, Botulinum Toxin - Type A (Botox®) and Type B (Myobloc®), can be viewed at

<http://www.tremoraction.org/newsletter.php>

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## 50 YEARS OLD!

By William Allen

### Spikes & Spasms Note:

*In memory of William Allen and in honor of his son, Nick Allen of Tunic Software, TAN proudly shares one of Mr. Allen's "selections about his life."*



Borrowing from Nick's eloquent eulogy of his Dad:

"Dad was diagnosed with multiple sclerosis relatively young in life. If there is anything positive to say about this, he did not have a rapidly progressing form of the condition. In fact he lived for decades before its gradual effects, and associated medical complications, eventually took him away."

Through Mr. Allen's "writings" TAN got to know a man we never were to meet in-person, but had the privilege of communicating with through personal correspondence. Through TAN Mr. Allen's Hartlepool Tales became known to the online Tremor support group and Northern California Kaiser Permanente patients; in particular, Mr. Allen's My Favourite Thing. Mr. Allen's tour of his study--his favourite thing, was introduced to Kaiser patients attending a Mind Body Spirit Journey stress management program, led by Pankaj Vij, MD.

Readers of Spikes & Spasms can get to know Mr. Allen too, by visiting his website at two locations:

<http://www.wsallen.com/index.html>

and <http://www.mousecage.org/wsallen/index.html>

The 31st of May started badly with several hefty bills landing on the doormat. The day worsened as it progressed, it was that kind of day. Tomorrow would be the dreaded first of June; my 50th birthday. It was, as I recall, around about teatime that something strange happened. It was as if some Deity had switched on a homing signal. A signal I must obey. I felt its pull as well as the unquenchable desire to be alone with my favourite person. The person I never

have a cross word with. Me!

The mysterious call was pulling only at me, no one else seemed affected. It was irresistible. I put shirt and underpants in a holiday and announced to my long-suffering wife that I had to go. At this time I did not know the exact location of this mystical call, I only knew that it was somewhere in the Yorkshire Dales. It was some call of the past, as if I had been pre-programmed to obey the call and this was the day.

I had been forced to retire from my work with a neurological problem (M.S.) that gave me unreliable legs; therefore the one essential item I could not forget was my walking stick. Even my car was responding to the call and it proceeded up the A1 and circled round to the north west of Leeds. On it sped through Ilkley and on to Skipton. Next was Settle and still it did not stop. The location, to which I was being drawn, was now clearer. It was somewhere on Ingleborough! The car stopped in Clapham, it seemed that it knew we had arrived. It sensed that this was the limit of the assistance it could give. The rest of the journey would have to be on foot.

I soon found an excellent place to stay overnight in Clapham and now knew, because of its close proximity, that my goal was to be found at the top of Ingleborough.

Thirty years ago I had been a potholer and the summit of Inglebrough was a kind of symbol of all my youthful adventures. This was my rationalisation for finding myself sleeping, on the eve of the first of June, in the village of Clapham. I was breathing the clean moist air and listening to the sound of the water outside the bedroom window. The water whose source I must trace on the way to Ingleborough top.

My route was along the lakeside and through the woods towards Ingleborough Cave. The woods were in full flower with bluebells, primrose and rhododendron. Carpets of white garlic flavoured the air. On I limped, leaving Ingleborough Cave behind, away from the maintained pathways, slowly upwards. On through Trow Gill, the path now consisting of muddy boulders and stones. My progress

was slow and people became inquisitive. Other walkers had on Anoraks, woolly hats; strong trousers tucked into thick socks and great boots with complicated laces. They were curious about me as I was out of place. I was dressed as I had left my house, in pinstripe suit, striped shirt with white collar and blue tie. My shoes, being lightweight slippers, were little better than slippers. Proper fell-walkers must have thought that I should not be allowed out, a lame man, ill equipped, struggling on up the hill using his stick as a third leg.

At last the moor was reached and my heart leapt as I recognised at once Bar Pot and recalled my first descent of the Gaping Gill system. In one sense it seemed that it happened to another person a long time ago yet in another way it was as yesterday. The moor was very wet and the sphagnum was like a saturated sponge. The walking stick punching into the bog offered little support. I looked towards my goal. There it was the summit of Ingleborough, shrouded in cloud. This was just as I had so often remembered it. I wondered, could this be the excuse I needed to call off my foolish pilgrimage?

**In one sense it seemed that it happened to another person a long time ago yet in another way it was as yesterday.**

At Gaping Gill I rested and ate the lunch that my bed and breakfast lady, Mrs Snowdon, had prepared. I watched as some potholers came nonchalantly along. They belayed their rope, fitted their prusickers, and calmly descended into the awesome black chasm that was swallowing the stream. They made it look so easy. The technology was simple yet ingenious and somehow I was jealous, remembering the days when I struggled with rope and hickory-runged ladders. I was always wishing I could afford alloy equipment. It was wonderful to see that ladders themselves were now a thing of the past.

Although Ingleborough was in low cloud, Simon Fell was clear and now, rested, I decided to head towards it and tackle Ingleborough's summit from that direction. By doing it this way I hoped to avoid the steeper grassy slopes

and make it easier on my poor legs. It took what seemed an age to reach the path under Simon Fell. This path, much used by people doing the three peaks walk, was stony and easily followed in the mist. By now the cloud was down over the entire moor and visibility was less than 10 metres. It was raining and I was thoroughly soaked. I reached the path and turned towards Ingleborough, pulled by that mysterious call that I now knew needed me to find the stone structure, which marked the summit.

The rock at the top of Ingleborough is millstone grit and I found that if I avoided the grass and walked on the rock, wherever possible, I could make slow yet faltering progress. The wet mist deadened any sound and I somewhat startled a hiker who was resting on a rock. Imagine the expression on his face, seeing a limping man in formal clothing and lightweight shoes coming towards him out of the mist and rain. I too was surprised when he asked me the way to the cairn that marked part of the three peaks walk. I rather wickedly suggested, that, as I was obviously an amateur, he should ask

some one else.

At last I reached the top. I knew the wind direction and used this as a means of keeping my bearings in the mist. I searched for a while before I found the object of my quest. The neatly mortared stones looking almost like a religious object. The act of touching the brass plate on top brought about a feeling of great accomplishment. The spell which had summoned me from more than a hundred miles away, was now broken. I could now resume my normal life.

My tale could easily end here but my return is, perhaps, worthy of some recollection. My legs were now weaker and yet I risked some grassy slopes on Ingleborough's slippery sides. I fell more often than a drunken man but only onto the spongy bog. It was then I remembered something, from all those years ago. Often, before going into a pothole, my friends and I would jump into deep pools of water. The reasoning was that you knew you were to going

to get wet and therefore, rather than get wet gradually and miserably, one did it suddenly and magnificently. Once wet, the condition was accepted as a fact of life and one could then get on with the job in hand. My frequent falls had left my suit covered in mud and I had already become wet, gradually and miserably. As it was impossible to get any wetter and as I could not be seen in public covered in mud, I decided to take the plunge! I approached the fell beck and selected a good pool in the clear running water. Removing paper objects from my clothing, chequebook, money etc., I waded into a pool fully clothed and sat down in the middle. There I sat, rinsing off all the mud from my suit and washing my hands and face. I was adding a baptism and a ritual cleansing, to my pilgrimage. The water was not too cold and the effort of walking had warmed me up. This heat was just nicely cancelled by the cooling effect of the pool. I emerged, restored to some pretence of being clean and well dressed. I then retraced my steps down the hill, out of the mist and down to the village. On my way down a man asked me how far I had been and commented, I thought sarcastically, that I must be the best dressed man on the mountain. I replied that I had been to the top of Ingleborough via Simon fell. I could tell he did not believe me, a limping man in a suit, with slip-on shoes, but that simply gave me more pleasure in telling him my tale.

I had a glorious first of June, a crazy, mad, daft, first of June. It was the best birthday present I had ever had and I had given it to myself. A day to mark my fiftieth birthday. I also believe that I have found the Dales answer to Lourdes. My legs have improved a little. However the curative effect of my pilgrimage cannot be the result of faith. I expected my trip to Ingleborough top to do me no good at all!

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