

Spikes & Spasms

The TremorAction.org Newsletter

OCTOBER 2009

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WELCOME TO THE OCTOBER ISSUE!

- Movement Disorders Awareness Month -

Advocacy is never-ending.

When one Challenge ends another one begins.

October is National Movement Disorders Awareness Month! Tremor Action Network requests your participation to increase community awareness about movement disorders.

Start by taking [The Natural History of Essential Tremor](#) web based survey. Neurologist Esther Baldinger, M.D., follows up with a second survey of 45 questions that are formatted to help learn more about this movement disorder. "If more is understood about ET then ideally the issues of slowing or stopping progression could be addressed."

Participate in the University of Florida research study on essential tremor.

The October issue also introduces readers to innovative assistive technology designed by E2L Limited, reminds us of Medicare annual enrollment, highlights Mona Reeva's information on donating your time, and pays tribute to movement disorders experiences authored by individuals living with dystonia and essential tremor.

Enjoy reading Spikes & Spasms brought to you by Tremor Action Network and Sponsors

The Natural History of Essential Tremor

By Esther Baldinger, M.D.

Spikes & Spasms Note:

This online survey is easy to use, and has been designed with the hand tremor participant in mind. Some questions will require only a Yes or No, straight forward answer. Multiple choice questions include Comment fields that allow survey participants "the Option to add Other choices."

You are invited to participate in a survey of people with Essential Tremor. In this survey we are trying to learn more about this disease.

1. Why does tremor begin in one part of the body for a particular person and in another part of the body for someone else?
2. Do some people's tremor progress to involve more parts of the body?
3. How long does this take and why does it happen?
4. Does tremor begin in the same way for all those affected in a family?
5. Does the part of the body in which the tremor begins influence how the disease will progress?
6. Do other diseases have an influence on how or whether the tremor worsens?
7. Does gender, race, weight or education play any role?

As always, all responses will be kept absolutely confidential and will never be associated with any individual.

The benefits of completing this survey include a greater understanding of the causes and progression of Essential Tremor.

By participating in this survey, you agree to have your responses collected and compared with the responses of others for the purpose of analysis. The results of this survey will appear on the Tremor Action Network website and may be published in a medical journal once the information has been collected and evaluated.

Thank you for your participation and for your time in completing this survey.

Esther Baldinger, M.D.

Medical Students

Matthew Imperioli, Dustin Monroe, Gracia Mui, Neel Tarneja, Jeff Cloyd

The Long Island College Hospital. Brooklyn, NY

Disclaimer: Information in this survey should not be taken as medical advice or endorsement of any treatment. Please consult with your own health care provider for any discussion or decisions related to your own treatment.

TAKE THIS SURVEY

http://www.surveymonkey.com/s.aspx?sm=lpvM_p1kdSlCmthyjD4hzeg_3d_3d

About the Author

Esther Baldinger is a practicing neurologist in Brooklyn, NY. She is an Associate attending in neurology at the Long Island College Hospital, and an Assistant Clinical Professor of Neurology at SUNY Downstate Medical Center.

Dr. Baldinger is still recruiting patients for the study of the effect of Riboflavin on ET. Please call (718) 232-1570 if you can make four visits to Brooklyn, NY.

"The benefits of completing this survey include a greater understanding of the causes and progression of Essential Tremor."

I can't quite put my finger on it! ... why we need a new alphabet board

By Lyndon Owen, Managing Director, E2L Limited, United Kingdom

Firstly let me tell you how we design: There is a big misconception in the world of product development, and that is "more functionality means 'better'." This mentality is generally driven by the marketing men and not by the needs of the users. It also over complicates the product and, of course, justifies a higher price. Whereas a good product is one which does the job well, and design elegance is the result of what unnecessary features we can take out. To state our design philosophy more concisely "be clever, be simple."

Having a reputation for this approach, we were contacted early this year by the Speech and Language Therapy (SLT) department at Frenchay Hospital, Bristol, part of the UK's National Health Service (NHS). They invited us to enter into a joint collaborative venture to develop a new alphabet board for literate people who were unable to speak and had tremor problems. This may be due to a variety of conditions such as strokes, swallowing difficulties, tracheotomies, MND, ALS, MS, CP, cancers, and many motor control problems, or just 'jittery' hands.

The great advantage of working with the NHS is that they are needs driven, and the products they require come from direct experience of therapists on floor. What they had identified was a problem and were looking for a professional solution in the form of a commercial product.



The problem is this: Printed paper alphabet charts tend not to be durable, they slip about, they pick up dirt, people get messy, they get lost, don't work in the shower, and, above all, people are not very accurate when they point at letters. Add to this a tremor condition, such as Parkinson's, and the task of isolating a single letter by pointing at it becomes an extremely difficult task. What was needed was a solution which addressed all of these problems in the simplest possible way. The result is the FAB (Frenchay Alphabet Board).

The design requirements for the device were defined as:

1) Positive finger location

This is achieved by providing a smooth recessed depression over each of the letters available. A shaking finger stays in this depression because there is a little ridge all around the edge, thus limiting involuntary movement.

2) Non-slip

The non-slip property is a major advantage for the tremor user. Positive finger location is of little use if the chart slides around with your shaking hand. To overcome this, the FAB has a high grip neoprene rubber based (much like a mouse mat but with a stronger bond).

3) Spill proof

It's a fact of life that people spill coffee, drop food and pick up dirt. The use of a single continuous plastic injection moulded finger guide which is bonded to the closed-cell neoprene base ensures that no ingress of dirt is possible.



4) Washable, hygienic design

A health service requirement was that the alphabet board could be washed in soap and water. Choice of materials has achieved this, but we have extended the design to tolerate 1000ppm chlorine solutions and to be resistant to alcohol wipes.

5) Anti-microbial keypad

Not being content to rely on the cleaning regime alone, we have loaded the clear plastic moulding with a nanoparticle silver compound which is antimicrobial. This makes the product inherently hostile to MRSA, E. Coli, Salmonella, Listeria - this is not a coating that can wear off, but an residual property of the material.

6) Choices of layouts

Some people are used to the standard keyboard 'QWERTY' system whilst others prefer a matrix type of layout which lists the letters of the alphabet in order. In considering these layouts the matrix has been designed so that the vowels are listed down the left hand side. Either style has a space bar, a question mark, a full stop, and a positive and negative symbol. We have also provided an up and down symbol which can be used as "more and less," "louder, quieter," "up, down."



MATRIX



QWERTY

7) Choices of sizes

Alphabet boards are generally used in two different environments and as a result two different sizes were designed. "Table Top" is for use in day centres, on hospital wards, libraries, hospices, and places where the board can be placed on a fixed surface such as tables or desks. "Pocket size" is a smaller portable unit which can be easily carried in a handbag. One emerging use of the pocket size alphabet board is as a backup to much higher technology devices. If you use a Lightwriter, Dynavox, PRC, eye tracker or similar system, FAB offers an emergency solution to communication if your batteries go flat or you have a breakdown. Pocket size FAB is much more discrete, yet still offers the positive finger location.

8) Languages

FAB is designed to be rapidly adapted to any language. Already it is available in English, Spanish, German, French, Swedish, Finnish, Danish, Norwegian, and any character set can be supplied on request (Spanish keyboard illustrated).

To conclude, an alphabet board should be simple and fulfill all its design constraints without compromising the end user. FAB is a good example of this. Whilst the underlying decisions are complex, they should be invisible to the user.

Anyone unable to speak but has some hand movement, regardless of the extent of the tremor, can communicate more accurately, conveniently and with increased hygiene due to the rigorous application of design simplicity.



About the Author

Lyndon Owen is the managing director of E2L Limited; an electronic product design company and based in Monmouth, South Wales, United Kingdom. He has studied at Sheffield, Wolverhampton and Southampton universities in the UK and since 1984 has been involved with several small, high technology, startup companies. His current venture, E2L Limited was founded in 1998 in order to address product design in a radical new way. The company is nationally recognised in Wales as 'Ambassadors for Innovation' and their unique approach to product development ensures simplicity and effective solutions to a wide variety of problems. The company has a worldwide distribution network including the USA.

www.FAB.uk.com

Allsup Outlines 10 Critical Questions to Answer When Evaluating Medicare Plans

Medicare annual enrollment is around the corner - are you in the right plan?

Belleville, Ill. - Sept. 2, 2009 - If you're one of the more than 45 million people relying on Medicare for healthcare coverage, you may be paying for a plan that doesn't meet your needs or is too expensive, according to Allsup, a nationwide provider of Social Security disability representation and Medicare services. But you're in luck - Medicare annual enrollment starts Nov. 15 and ends Dec. 31, allowing anyone with Medicare to assess if they have the right plan.

"Many people don't seriously evaluate their healthcare needs and Medicare options when they first become eligible, and even fewer review their needs before re-enrolling each year," said Paul Gada, personal financial planning director and product manager for **Allsup Medicare Advisor**®. Allsup Medicare Advisor is a Medicare plan selection service that helps people understand and choose the most affordable and appropriate Medicare plan for their healthcare needs. (Allsup is not a Medicare plan provider.)

Gada added that many people don't understand they have a wide variety of choices when it comes to Medicare coverage.

Allsup recommends people answer these questions before the enrollment deadline:

1. What will work best for me: traditional Medicare or Medicare Advantage?

If you visit the doctor often and take prescription drugs, a Medicare Advantage plan (Part C) may best fit your needs.

If you only require routine medical visits and few prescriptions, traditional Medicare (Parts A and B) with a prescription drug plan (Part D) may work best. There are **many factors** to consider when answering this question, and your response may change over time.

2. Do I need a supplemental plan?

Medicare supplemental insurance can help pay costs not covered under traditional Medicare (Parts A and B). However, not everyone needs this type of policy, especially if they: are eligible for Medicaid or the Qualified Medicare Beneficiary program, have group health insurance through an employer, the government or the military, or already enrolled in a Medicare Advantage plan.

3. What if I have private healthcare coverage - should I use Medicare instead?

If you have coverage through a former or current employer, speak to the plan administrator before making changes.

Consider comparing your private plan to your Medicare options, especially if your private plan is limited or the cost has increased significantly.

4. Can I see the same doctors that I do now?

The majority of healthcare providers (doctors, hospitals, physical therapists, etc.) accept traditional Medicare. While Medicare Advantage plans are available in almost every area of the United States, that doesn't mean all doctors participate. Before you join any Medicare plan, determine if your doctor accepts that plan.

5. Does the plan cover prescription drugs?

Traditional Medicare doesn't generally cover medications unless they're administered in the doctor's office or hospital. You have to purchase a Part D plan for the

"Medicare annual enrollment is around the corner? are you in the right plan?"

coverage. Medicare Advantage plans, however, can offer prescription drug coverage. If you choose traditional Medicare, you'll need to enroll in a stand-alone Part D plan, possibly with additional cost to cover prescription costs.

6. Are my drugs covered?

Each prescription drug plan has a formulary - or list of drugs that it covers. Plans can change which drugs they cover, so you need to review this list each year.

7. Are my prescriptions expensive enough that I could fall into the Medicare donut hole?

Medicare Advantage plans with prescription drug coverage and stand-alone Part D plans may have a coverage gap, referred to as a **donut hole**. Once you and your plan have paid a certain amount for your prescriptions, you'll have to pay the full cost, up to \$3,453.75 in 2009. Only after this out-of-pocket amount is paid does Medicare begin to pay for your prescription costs again.

8. How much will I have to pay?

Traditional Medicare may be inexpensive, but it comes with high deductibles. Medicare Advantage plans may have similar or higher monthly premiums than traditional Medicare, but offer a zero-dollar deductible and low co-pays (e.g., \$20 doctor visit co-pays). Some plans also cap total out-of-pocket costs.

9. Will the plan cover additional services, such as dental and vision care?

Some Medicare Advantage plans cover dental, vision and health and wellness programs not available through traditional Medicare.

10. Will I be covered while traveling?

Traditional Medicare provides coverage throughout the country. Some Medicare Advantage plans restrict

coverage to certain areas, but many offer out-of-network coverage if you have an emergency while traveling. If you travel often or live in another area for part of the year, find a Medicare Advantage plan providing coverage in those areas.

Reviewing your needs every year, especially with the experienced help of an independent Medicare plan selection service like Allsup Medicare Advisor, before annual enrollment is crucial to ensure coverage, Gada said.

"There are probably dozens of Medicare Advantage and supplemental plans in your local area, providing a wide range of options," he said. "Medicare is like any other type of insurance; you don't want to be under-insured. But you also don't want to pay for things you don't need."

About the Author

Allsup is a nationwide provider of Social Security disability, Medicare and workers' compensation services for individuals, employers and insurance carriers. Celebrating its 25th anniversary in 2009, Allsup employs about 600 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.

Allsup offers a 'free screening' to help determine if you are eligible for *Allsup Medicare Advisor* at: <http://advisor.allsup.com/>.

Disclaimer: 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.

Confessions of a Volunteer

By Mona Reeva,

Proprietor of *Green Mountain Artistry*

When I think about my formal work history, my volunteer affiliations also come to mind. A parallel path seems evident. I have held paying jobs while concurrently performing volunteer work. I must conclude that I am a volunteer junkie.

We are taught to live according to the dictates of moral codes put forth by religious and health gurus; that addictions in general and specifically to drugs, alcohol, nicotine, food and/or gambling are wrong ... But what about volunteering? This seems to be different from other kinds of addictions. Possibly volunteering can counteract or replace other addictions.

Can I truly say I am addicted to volunteering? Perhaps!

I started volunteering when I was a teen and wanted to try out physical therapy as a profession. Unfortunately that was an awful experience. Not the physical therapy itself, but the practitioner who turned out to be sadistic. He demonstrated an electric muscle stimulating machine by attaching it to my arm muscles and then cranked it up to maximum intensity. I can tell you, that was not a pleasant feeling.

Fortunately my next formal volunteer job was very rewarding. My school required a stint with Traveler's Aid at Penn Station in Manhattan. I found this so interesting that my education kept leaning more and more towards social services. Helping people, who were lost, disoriented, or without a place to stay was exhilarating and satisfying. This kind of work provided immediate positive outcomes.

Over the years, I have participated as a volunteer on

Boards of Directors for non profit organizations, for a group of seniors who put on plays, for my professional organizations, and on advisory boards. I have given talks about loss and grief, midlife and aging, put on conferences, and started academic programs, all as a volunteer. I spent five years working on developing and leading a family advisory group in a nursing home where my mother was a resident.

After retiring a few years ago, more volunteer opportunities presented themselves. I found more ways of engaging in a myriad of cultural activities. What fun! Now I get to hear concerts, see dance performances, watch plays and participate in a not for profit organization that focuses on healthy living through art. I feel the giving of my time and knowledge is a noble action. Giving of one's time and or expertise is an offering to others with a return to you of satisfaction and pleasure.

In the United States, we have the honor of providing the most volunteer time of any country in the world.

Originally when women began to work in large numbers outside of the home, volunteer time dropped. Now, more people give of their time, including men; additionally, many organizations and businesses encourage and sometimes expect their members/employees to volunteer for social causes.

Many organizations support their volunteers with encouragement, honors, formal thank you banquets and informal luncheons and dinners. Those organizations that fail to acknowledge their volunteers often lose these valuable people and suffer high turnover rates.

Many of us who live with visible tremors may have concerns about volunteering. Some thoughts and feelings may get in the way of volunteering. Here are some questions we need to ask ourselves. Can I put myself in the public view? Can I deal with being seen with shaking hands, arms or head? Do

"Giving of one's time and or expertise is an offering to others with a return to you of satisfaction and pleasure."

I feel shame? Embarrassment? Can I handle and address the problems that come with those who don't know about or understand what I am experiencing or perhaps have no knowledge about my neurological illness?

Each of us can and must answer these questions and then find ways of doing volunteer work that is compatible with our answers.

Why is this so important? Here is a list of benefits that we can derive from giving time, knowledge and expertise:

- 1) Giving of oneself yields fewer moments upon which to ruminate upon our own problems
- 2) Time is used to benefit others in so many ways
- 3) A sense of satisfaction is earned
- 4) Immediate gratification is gained
- 5) Feelings of self goodness are enhanced
- 6) A sense of accomplishment is added to our lives
- 7) We feel useful
- 8) We can gain friendships in new arenas
- 9) There is opportunity to share what we know
- 10) There are many opportunities to learn anew
- 11) Happiness can increase as a result of our activities

If you are not volunteering now and want to, there are a number of companies, organizations, not for profit organizations, hospitals, animal shelters, et al. to contact that can use your help. Start with identifying the kind of organization you want to be involved with. People, books, animals, music, drama, the list is unlimited. Where will you feel the most comfortable? Do some research!

When you have taken the first step by identifying the organization, make the first phone call to find out how to volunteer. Get on the internet and look up an organization that seems right. Ask friends and relatives. Most organizations provide an orientation. That gives you an opportunity to decide if this is the right place for you. If not, move on to another. If it is right, try it out. Remember, you are a volunteer and can leave if the job becomes boring, is the wrong fit or you just don't want to participate any

more. Move on to another. At some point in your quest you will find that there is a perfect fit and will continue for years with the same organization. All along the path, goodness is given and earned. Not a bad arrangement.

Sometimes when I think about my volunteer work and the millions of hours given by all volunteers in this country, I think that without us, this country would stop dead in its tracks. Who would provide the number of person hours for all the work that needs doing that is not paid for if it were not for the large number of us who give and give? Through acts of giving even those who are addicted and suffering could make strides towards healthier and more satisfying living. Everyone benefits.

As you can read, I am an advocate for volunteering. I believe that giving of oneself is valuable and fulfilling. One caveat though that I must offer. Do not overdo. Schedule your hours so that you have time for yourself - time to replenish your energy and time to take care of yourself in whatever way works for you. It is easy to burn out on volunteering. It is hard for many of us to say no, set limits and take care of one's self. However any kind of giving requires replenishment. Stay in touch with your needs. This paves the way for giving with care, pleasure and a fruitful return.

About the Author

Mona Reeva is in her second career creating one-of-a-kind handicrafts in jewelry, knit scarves and photographs, including photo note cards. Mona's catalog is a beautiful collection of crafts and photographs that demonstrate her life long experience and keen eye. Always creative and interesting, her items are available in her online store, Green Mountain Artistry, at <http://www.greenmountainartistry.com/catalog/>.

Internships Pay Off

By Terri Sterling, MSP

If you are looking for more employment experience then Internships can really pay off. There are different types of internships which involve various hours, tasks, and places. Some internships are for students, and others are for people who need experience or are transitioning from one career to another. Internships can be paid or unpaid but almost all of them will provide you with opportunities that you would not normally have, and connections to people you would not normally meet. Internships can be for human services, human resources, social work, grant writing, administration, arts administration or the arts. Just think of something you want more experience in and Google "internships." You will discover 100's of them.

I wanted to engage in an arts administration internship, so I applied at the New Jersey State Council on the Arts (NJSCA) where I learned to process grants, helped out with grant panels, and worked at arts and disability workshops. I was blessed to meet people whom I normally would never meet, including the Executive Director of the New Jersey Theaters Alliance, Mr. John McEwen, who is accepting of disabled people and helps theaters become ADA compliant. He goes out of his way to accept all of us. John is humble and sensitive; an unforgettable person. Three disability and arts workshops were coordinated under his direction where he brought in dancers who used wheelchairs or who had other disabilities. I deeply cried quietly through all three workshops when people in wheelchairs were allowed to fulfill their dreams and dance, or act with full acceptance of audience members. I felt I had found my tribe where we were all equal: the disabled and the able-bodied. It was one of the most profound moments of my life because it was so deeply moving. It was a blessing to meet John and was only possible because of the internship.

"Engage in an internship to be supportive of an organization. You can find acceptance regardless of your disability."

During my internship, I met the Executive Director of Arts Unbound, Gail Levinson, and Kathleen Heron, who is the Program Coordinator and Lead Instructor. Arts Unbound is a non-profit community art center for artists with disabilities. One artist has become so skilled at creating art that he now sells his paintings for over \$45,000 in NYC galleries. Last weekend another artist sold three paintings including one for \$650 that was being resold at a NYC gallery. Challenged artists are wonderful people whose ages and disabilities vary. I now have the privilege of teaching printmaking to them for the next four Saturdays. The NJSCA staff introduced me to a number of art organizations that I didn't know about. Because of the introductions my networking contacts have widened. You

can widen your network connections by engaging in an internship. You might find a place like Arts Unbound!

During the last few weeks I became frustrated with a large university whose system is difficult to navigate. The university's disabilities office was very helpful and so was the continuing education department, but other

departments were not willing to have me take graduate classes when I was not a full time officially enrolled student. I networked until I found a connection to a graduate art instructor. I now have a meeting to show my portfolio to her, and to decide which graduate art class I can take. I will be one week behind the other students and will have to catch up, but I am truly grateful to have this chance because non-MFA students are not normally allowed in this program. I networked my way to people that I met during my internship for this opportunity.

I strongly urge you to engage in an internship where you can learn new skills, up-grade old ones, be supportive of an organization in your area, and find new connections to people you would not normally meet. You can even find acceptance regardless of your disability. My internship is over and I don't know what the future will bring, but I know it was one of the best experiences in my life. Go on, engage

in an internship and widen your network!

About the Author

Terri Sterling is a Creativity Coach who helps artists, writers, and designers all over the USA. Creativity coaches are similar to Life coaches but work with creative people. Terri is also a mental health therapist. For more information about Terri and her coaching business Inspiration, visit http://www.freewebs.com/terris_inspiration/, or email Terri: sterlingcoach@live.com.

DBS Treatment for Essential Tremor

By Edwin Yager

I have been dealing with the effects of essential tremor for more than 10 years, and during this time I have seen many doctors and asked them each the same question, "What is so essential about essential tremor?" Most gave me long medical terminology and explanations, but one gave me what I came to accept as the truest of all, "They had to call it something!"

During the course of my treatment mode with this condition I used many of the established medications. I even took part in 3 trials through the VA Healthcare System in Southern California. Treatments and trials were all the same, with limited success result, and also the growing side effects to the medication, namely drowsiness. I decided there had to be a better and hopefully more permanent solution. I learned there was...Deep Brain Stimulation (DBS).

I researched the DBS procedure and discussed it with my neurologist, Dr. Kenneth Jordan. He and I agreed that I was not a good candidate for medication treatment because of the short term benefits and the potential side effects. At the same time I got in contact with an Iowa farmer, Jeff Ryan, whom I met through the Tremor Action Network. Jeff was a DBS pioneer, having undergone the procedure back in the late 1980's. His candor and openness gave me the chance to understand first hand what the surgical procedure would involve.

While my common sense would not allow me to be drilled while I was awake my reality became this was my best option for a good resolution to the matter, so I decided to have it done. Dr. Jordan referred me to Dr. Frank Hsu, neurosurgeon at Loma Linda Medical Center, and after reviewing things with Dr. Hsu he concurred that DBS was the best alternative in my case.

The surgical procedure was scheduled in two phases. The first phase took place on August 21, and involved having my

head placed in a metal halo brace. This is a device with spikes on four corners that must be screwed into your head, front and back. Once the placement of the halo was complete I was then taken to the operating room where 2 holes about the size of a fifty cent piece were drilled in my skull, then electrodes were placed in the area most likely to reduce the tremors. Now that doesn't sound too bad, except I may have forgotten to mention I was awake for the entire process. The reality is some sedation is used, but you need to be alert to perform various tests that provide the best opportunity for the neurological team to focus on the prospective target areas. I did not really feel as much discomfort as I had originally convinced myself it might be during this phase of the procedure, but it was still a little scary when the team brought in the halo brace, and began to fit it on me.

The second phase of the procedure took place on August 24, and involved the placement of the controller unit just below the skin. Fortunately I got to sleep through this part which took about 45 minutes. The one thing I noticed was a tightness in the right side of my neck; this feeling was because of the wires from the implanted electrodes to the implanted control unit, are installed behind my right ear.

The final phase is not surgical. Whew! On September 22 a 'techno wizard' from Medtronic, the equipment manufacturer, will help set the level of response of the implanted electrodes by way of the implanted control unit. Now ideally this would happen the first time around, but the reality is it might take several such attempts to zero in on the setting that will provide the ultimate response. Along with the initial setting, the technician will also train me on operating the 'device' that will allow me to turn the control unit on/off.

About the Author

Edwin Yager has been dealing with essential tremor (ET) for more than 10 years. Prior to undergoing the DBS procedure Edwin used a number of established drug therapies, with limited results. He also took part in several ET Treatment Studies through the VA Healthcare System.

As a licensed private investigator Edwin needs to be able to write in such a manner that can be read. His decision process for undertaking the DBS procedure lasted over a year.

Edwin invites patients who are considering DBS or want to know more about his first-hand experience to send an email to:

calrte66@hotmail.com.

"Treatments and trials were all the same, with limited success result."

Blessing in Disguise

By Pat Hill

Music filled the air as hundreds of people wandered about Ventura, California during their famous "Art Walk" festival. The sidewalks swarmed with people as they wandered in and out of stores full of art displays. Business owners happily chatted with people and offered fudge brownies and chocolate dipped strawberries to entice buyers into their establishments.

It was a relaxing and congenial atmosphere on a warm afternoon. I had meandered into a gift shop that also offered a nice selection of ice creams. Not being one to ignore temptation, I ordered and indulged in savoring one of them.

Out of the multitudes, a middle aged woman approached me and asked in a strangled voice, "Is that good?" I was a bit taken aback as she sounded just like me with my ADSD (Adductor Spasmodic Dysphonia). In my surprise, I said that it was delicious and asked her if she wanted a bite. She explained to me that she was not allowed to eat ice cream and then asked me if I'd describe it to her because she wanted to enjoy it through me.

Needless to say this stranger continued to amaze me. This had never happened to me, but I proceeded to explain how the ice cream was coffee-flavored, very creamy, and that it made your taste buds beg for more. While basking in the afterglow of those heavenly spoonfuls, I managed to ask her if she had spasmodic dysphonia. This intriguing woman, Jane, explained that she was a throat cancer victim. She was a eight year survivor and the surgery had saved her life, but she had been left with permanent vocal and throat damage which also restricted her diet. Her husband of twenty eight years had stood by her side through thick and thin. Shortly after her explanation and enjoyment in watching me in my ice cream reverie, she departed, leaving

me in awe.

Why in the world had this woman singled me out of hundreds of people.....this woman who sounded like me, but didn't have SD, but rather had had throat cancer? All I knew at that point was that I was really moved by her introduction and forthrightness in wanting to share in what I was doing.

The joy of that experience didn't come to light until several years later when I too was going to have throat surgery. I elected to have the SLAD-R surgery by Dr. Gerald Berke at UCLA to correct the spasms caused by ADSD. I successfully went through the surgery and was

later in his office for a post-op visit. It was at that time that I had the pleasure of meeting Dr. Scott Howard, who is doing a fellowship under Dr. Berke. It was at that time that Dr. Howard explained to me that they are able to do this surgery in part because of the knowledge they have gained from doing surgery on throat cancer victims.

"Sometimes your disorder can also be an avenue for growth."

This is how he explained it: "Surgical treatment for laryngeal cancer requires a hyper acute knowledge of the structures of the larynx in both a traditional and an "inside-out" approach as we often treat the cancer with lasers from within the throat. In addition to a greater understanding of the structures that provide phonation (vibration), these surgical cases provide an intimate knowledge of the nerve supply to the muscles of the larynx. The knowledge gained by these techniques have benefits to cancer patients to be sure, but are also beneficial to patients with vocal cord paralysis, neck trauma, and spasmodic dysphonia."

To this day, I am amazed that "my" special cancer victim and others like her have inadvertently contributed to medical science that helps SD. It is partially because of their tragedy, that SDers are benefiting from surgery to

correct our SD symptoms. It is that inspirational woman, who has led me to write this and give thanks and tribute to those cancer victims. Their plight has not been in vain and I truly thank them from the entire SD community.

About the Author

Pat Hill is a special education teacher and writer who has suffered with the affects of spasmodic dysphonia for 39 years. She is actively involved in the NSDA (National Spasmodic Dysphonia Association) and keeps close ties with the Dystonia Medical Research Foundation. 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.

Voices

By Rebecca Strecker 7/6/09

You once used to sing and say funny things
that added joy to our marriage.
And then one day your voice went away,
a situation we both disparaged.

We figured it wasn't a permanent thing.
Maybe a touch of laryngitis.
And that it would just run its course,
after your voice took a hiatus.

But that's not what happened and I found myself
saying twice the words that were required.
Maybe I found silence hard to hear.
Talking for us both made me so tired.

The visits to doctors and to a speech coach
did not bring your old voice back to me.
In fact all the worry and running around
pretty much did quite undo me.

Now nothing you say gets short shrift or ignored.
I listen to gain comprehension.
Because I realize each word is a chore
and requires my utmost attention.

Silence is golden but Speech is a gift
nevermore to be taken so lightly.
And each time you tell me you love me so
I hold on to those few words so tightly.

Love, Rebecca

About the Author

Rebecca Strecker has been writing poetry for a number of years, and her work has been featured on several Internet sites devoted to pets and pet adoptions. She has been commissioned by a number of charitable groups to provide her services as a contribution to their fund-raising efforts. Her husband has experienced vocal dysphonia for the past year. Rebecca's poetry is featured on her blog:

<http://poems2order.wordpress.com/>.



RESEARCH STUDY ON ESSENTIAL TREMOR

The Department of Neurology at the University of Miami (Miami, FL) is conducting a research study on the brain mechanisms of Essential Tremor (ET).

You may be eligible if you have been diagnosed with ET and have hand tremors. This research study involves brain imaging using MRI. Participants will undergo a complete neurological examination and psychological testing as a part of the study. In addition, participants will be required to drink one serving of alcohol during the study which may cause intoxication. The study will involve up to three visits lasting a total of up to 9 hours.

If you are interested in participating, please contact Mr. Prantik Kundu at 305-243-5827.

About Fatta B Nahab, M.D.

Dr. Nahab is an Assistant Professor of Neurology at the University of Miami Parkinson's Disease and Movement Disorders Center. He has an extensive clinical expertise in tremor and dystonic disorders as well as a foundation in brain imaging research using functional MRI. At the National Institutes of Health (NIH), Dr. Nahab conducted clinical trials on novel agents for the treatment of essential tremor and also carried out studies using cutting edge functional brain imaging methods to study the causes of various movement disorders.

Romert and Movement Disorders Awareness Friends

<http://www.romert.blogspot.com>



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