

Spikes & Spasms

The TremorAction.org Newsletter

DECEMBER 2009

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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
Tremor Action Network and Sponsors.

Take the Natural History of Essential Tremor Survey

Esther Baldinger, M.D.

http://www.surveymonkey.com/s.aspx?sm=lpvMp1kdSlCmthyjD4hzeg_3d_3d

Don't miss participating in Dr. Esther Baldinger's second survey that Spikes & Spasms featured in October. The information from Dr. Baldinger's 2007 Survey of Essential Tremor led to more questions and new ideas.

This online multiple choice questionnaire is easy to use and has been designed for individuals with hand tremors. The 45 questions are listed on 2 pages. The "Thank You" 3rd page completes the survey.

The benefits in completing this survey include a greater understanding of the causes and progression of essential tremor. 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. As always, all responses will be kept absolutely confidential and will not be associated with any one individual.

What follows are same or similar survey questions located at:

http://www.surveymonkey.com/s.aspx?sm=lpvMp1kdSlCmthyjD4hzeg_3d_3d

What is your age?

Are you...gender?

What is your racial background?

How far did you go in school?

How would you characterize your body type?

In what body part did you first notice your tremor?

At what age did this tremor begin?

Has your tremor become worse?

If your tremor has become worse, how many years did it take for you to notice that change?

Did a tremor develop in a second part of your body?

Did a tremor develop in a third part of your body?

Do any of your living and did any of your not living biological relatives have a tremor? Check all the living and not living biological relatives that apply.

What is the approximate number of living and not living biological relatives who have or had tremor?

Where did the tremor begin for your affected living and not living biological relatives? Check all body parts that apply.

Do you have Parkinson's Disease?

Do any of your living or not living biological relatives have or had Parkinson's Disease?

Do you have dystonia?

Do any of your relatives (living or deceased) have dystonia?

Are you...dominant hand?

If you have a hand tremor, which hand shakes more?

If you have hand tremors when do your hands shake?

Did a medical doctor give you a diagnosis for your tremor?

What diagnosis were you given?

Have you noticed a change in your balance?

Do you have hearing problems?

Do you have memory problems?

Do you get frequent headaches?

Do you have neck pain?

Do you have back pain?

Do you have motion sickness?

Do you have an urge to move your legs when sitting quietly or in bed at night (Restless Legs Syndrome)?

Do you have other health conditions? Check all that apply.

Do you have any disorders? Check all that apply.

Do you have any joint diseases? Check all that apply.

Do you smoke or use tobacco?

Do you use alcohol?

Do you drink caffeinated drinks such as coffee, tea, cola?

Thank you for your participation and your time in completing Dr. Baldinger's survey.

Disclaimer: Information in this survey should not be taken as medical advice or endorsement of any treatment.

About the Author

Esther Baldinger is a practicing neurologist in Brooklyn, New York. 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.

Eye blink, therefore I am

... MegaBee, an assisted communications device for technophobes

By Lyndon Owen,

Managing Director, E2L Limited, United Kingdom

There are many wonderful high technology communication devices that use some form of eye-tracking to spell out letters and words, and then speak them with a voice synthesizer. Whilst for many this is a dream come true, for others it's a nightmare with a complex plot. As high technology drives itself into unnecessary sophistication it leaves a large minority without applicable or affordable technology to fulfill their needs.

Over the past two years a new device ("MegaBee") has been developed which fills the void between super high tech wizardry and the cumbersome procedures of low technology reading frames. The main reason for this device being so innovative was that the requirement was placed on a product design company rather than an established company 'in the business' and consequently it was designed from a fresh starting point. What I want to do is tell the story of its development, and then demonstrate how it enhances lives of a huge range of users including those with Parkinson's, ALS, Cerebral Palsy, Strokes and ventilated or intensive care patients.

The need

Our company is based in a small town in Wales in the UK. About four years ago, a young woman of 19 had a severe automobile accident on the main highway. She had severed her skull from her axis bone, resulting in 'Locked-in Syndrome' - a condition where she is fully cognizant but is completely paralyzed from the point of fracture downwards. This means that she cannot swallow, talk, move her tongue, breathe or perform any other bodily functions below her top lip level. What she can do is hear and move one of her eyes. In her particular case she lost one of her eyes in the accident and the remaining one has some level of visual impairment.

A year later her parents walked into our office and told us about their problems with high technology communications devices. Essentially, eye-gaze systems all required too high a level of eye movement accuracy, which made her quickly tired. The need to go through calibration was also a major problem. If the first question is 'do you need anything?', it is obviously frustrating to spend 3 minutes or so calibrating the device, especially if the answer is 'my nose itches' or 'I have something in my eye'. Unfortunately her parents had purchased a high technology eye-gaze system without fully exploring the implications and wasted about \$9000.

The only solution that seemed to work was very low technology alphabet boards or frames. Naturally these devices didn't need calibration and their facility is instantly available. However, they are laboriously slow and require a level of skill from the reader. Often the user has to write down the conversation which means taking their hands off the frame frequently. Also, if the reader is trying to remember the letter sequence then it is extremely difficult to delete letters in reverse sequence from the human mind.

The parents challenge to us was: "You are supposed to be product innovators. Surely you can come up with a device that is as simple as this [low technology writing frame] but works a lot better".

The design path

As we are a commercial venture providing a bespoke solution for a single Locked-in Syndrome patient is not a viable option. What the challenge provided was the starting point for inventing a product which fulfilled the niche of users who were unable, or more so, unwilling, to use higher technology devices if they were unable to speak or write legibly.

To explore this used two main methods: Build a picture of the user group (visualization), and draw on the good and bad points of the existing solutions (critique).

Visualization

To illustrate our design needs we looked at various user groups and then visualized (imaginary) key characters who would be users. These imaginary people were based on our research discussions with various support groups, hospitals, day care centers, etc. We tried to extend our potential target users across a wide group, for example:

'Guy': 63 years old. Parkinson's Disease, losing his voice, extreme hand tremor, lives in sheltered accommodation, able to walk short distances. Has family visits at the weekend, and carer visit once a day.

'Cecily': 25 years old. Cerebral Palsy. Young, vibrant girl who leads an active life with electric wheelchair operated by head switches. Computer literate.

'Marjorie': 78 years old. Mild stroke. Lives at home with day visits from carers and family. Reasonably cognizant. Left handed with some paralysis, illegible right handed alternative. Speech slurred. No computer literacy and wants nothing to do with computers. Doesn't want a machine to speak for her.

'Tom': 32 years old. Serious injuries from motorcycle accident. In Critical Care unit on a ventilator. Probably quadriplegic but early stages of diagnosis.

Once you start believing in these people's needs then the design process becomes very much a personal quest for an elegant solution without compromise.

Critique

Effective design should take the positives of previous achievements and build on them. It should also look at the negative aspects and either eliminate them, or more radically, come up with a design where those negatives don't play an active role in the solution. There's an old Indian fisherman's proverb "Trust in God and steer clear of the rocks" - if it's bad, don't go there!

To summarize the negatives for this product group:

High Technology Products

- High level of user accuracy required
- Calibration time to begin conversation
- Recalibration after involuntary movement
- Reliability
- Level of training due to complexity
- Higher user cognizance requirement
- Mobility issues and varying light conditions
- Cost - between \$6,000 and \$17,000
- Battery life issues

Low Technology Products

- Time consuming methodology
- Need to physically write everything down
- A good memory is required if not writing things down
- Listeners guess many words wrongly
- Listeners using memory are poor at deleting characters
- Cumbersome and not ergonomic design (E-Tran frame)
- Very low tech boards are flimsy and difficult to use
- Paper/thin plastic frames are not robust

Having speech output was seen as a positive by some users and negative by others

To summarize the positives for this user group:

High Technology Products

- Nothing to learn for the Listener

Low Technology Products

- Low level of user accuracy required
- No calibration required
- Simple to learn for the Listener
- Simple to learn for the talker
- Reliability (no batteries, low complexity)
- Low cost - typically \$200 maximum

(Please remember this is a critique for our specific user group - both ends of the technology are fantastic when they suit the user).

The solution

The answer is 'MegaBee', an assisted alphabet frame which addressed both the positive and negative issues raised in the critique, and fits the needs of our visualized user group. Sweeping statements like that need justifying so here's how it works:



The 'Writer' is the person unable to talk or write legibly; the 'Listener' operates the device. The 'Writer' is the person in the picture.

To type the letter 'A' the Writer looks at the letter 'A' and blinks. The Listener sees the Writer is looking at the white square in the top right hand corner, so with their right thumb they press the white button.

Now, because the letter 'A' is blue (and is in the top left hand corner of the white block), the Writer looks at the blue block and blinks. Again the Listener sees that focus on the blue block and presses the blue button. The letter 'A' appears on the LCD display.

Essentially each letter is a two stage eye movement based on color and/or location. Similarly for the letter 'U': Look at the letter 'U' and blink; the Listener presses the green button. Now because 'U' is white, look at the white block and blink; the Listener presses white and a 'U' appears on the screen.

Blinking is only one form of protocol; others can be used to suit the user's ability. The left hand buttons perform functions such as spaces and deletes. Consequently we can see that words can be spelled out letter by letter using this method and it is automatically displayed, without the Listener needing any training other than "only when I look at a colored block and blink, you

press the corresponding button".

For many people this is good enough as is as complex as they want the device to be. However, for other users we have introduced abbreviations. This means that a letter followed by a number will display a predefined phrase of up to 20 characters. As we have 26 letters and 10 numbers we can store up to 260 phrases. In the picture for example, our Writer just used 'C5' which is 'Can you get me'. These phrases are under the complete control of the user and can be uploaded via a Bluetooth link from supplied software. For non-literate people or younger children we have developed a method of using pictures instead of characters.

Additionally, because we have a Bluetooth link we can write directly to a computer and everything displayed on the LCD screen is also displayed on the computer screen. This not only allows the user to write and save messages, but also allows the conversation to be more than one to one, as everyone can read what's being written, and the Writer can listen to everyone.

How does this address our visualized user group and solve our design needs?

- i) There is no calibration; it is immediately available
- ii) Writer accuracy is low; there are only six zones to focus on.
- iii) It becomes extremely quick after a little practice
- iv) It is quick to learn for both parties
- v) The conversation is displayed so no need to write things or remember them
- vi) Robust and ergonomic design. The position of the handles ensures comfort.
- vii) There is a short cut vocabulary tuned to the user's regular conversation needs
- viii) Very low power consumption. Many battery saving strategies but if it fails it still works like an alphabet frame.
- ix) Language can be changed by local distributors (English, Spanish, German, Swedish, French, etc)
- x) MegaBee is made from a silver impregnated plastic and uses microban labels which make it inherently antimicrobial and resistant to infections such as MRSA and E.Coli.
- xi) It is affordable technology c. \$1200
- xii) Whilst it can interface to a computer it doesn't need to, making it widely accessible, especially to an older age group.

The users

'MegaBee' is now being used throughout the world by a wider range of people. The ALS association in the USA has increasing interest as do users with Parkinson's, Rett syndrome, Multiple Sclerosis (MS), Cerebral Palsy (CP) and Stroke.

One particular CP user in Germany uses both MegaBee and a high technology speaking device called 'My Tobii'. When we asked her why she wanted MegaBee her reply was "I use 'My Tobii' to talk to people when I am out in public, but I use 'MegaBee' to communicate with people I know". Its efficiency and facility is a lot more instant, and a lot less effort for her to have conversations with those close to her.

We don't see MegaBee as being competitive with anything else; it is a complementary product and whatever a person's needs, the solution has to be 'fit for purpose'.

The final judges have to be the user's who give this thing value or not. For us the best accolade was from the Treasurer of the

UK MND (ALS) Association in respect of one particular late stage patient:

"It has been the saving of his sanity and of his wife and two children. We all have a great respect for the development of MegaBee™, it has been a life saver. Thank you."

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 recognized in Wales as 'Ambassadors for Innovation' and their unique approach to product development ensures simplicity and effective solutions to a wide variety of problems. 'MegaBee' is distributed in the USA by Shelton Technologies and Resources (FL) and AMDi (NY).

www.megabee.net



Tremor Action Network and The American Brain Coalition

Spikes & Spasms Note:

Tremor Action Network received a lovely glass and wood plaque for winning the 2009 American Brain Coalition Summer Advocacy Challenge Award. We thank the American Brain Coalition, in particular Allison Wainick Kupferman, ABC's Governmental & Public Affairs Director, for giving TAN the opportunity to compete in a worthwhile challenge.

Tremor Action Network is a proud member of The American Brain Coalition (ABC), which is a non-profit organization comprised of some of the United States' leading professional neurological, psychological, and psychiatric associations and patient organizations. Together, we seek to advance the understanding of the functions of the brain and to reduce the burden of brain disorders through public advocacy. The American Brain Coalition is a strong and powerful voice for patients, families and professionals dealing with neurological and psychiatric disorders. This voice is used to advocate for increased support of federal research funding and improving care for those with chronic conditions. We believe that our support for these issues will lead to better treatment, services and support to improve patients' quality of life, and a national commitment towards finding cures.

The ABC's main vehicle for achieving these goals is through Advocacy. ABC sends alerts to associations and patient organizations such as Tremor Action Network about timely legislative issues, asks us to take action, providing us with access to "CapWiz," an online legislative action center where -with a few clicks of the button- our Advocates can send a pre-formulated letter to their

Members of Congress or the President.

The ABC encourages visits to Capitol Hill and even provides "background papers"

(<http://www.americanbraincoalition.org/go/advocacy/position-papers>)

and a "white paper" with talking points for us to use

(<http://www.americanbraincoalition.org/go/advocacy>). The ABC tries

to make it as easy as possible for Tremor Action Network to engage in advocacy on behalf of key legislative issues that affect patients.

Tremor Action Network is pleased to announce that we are the winner of this year's American Brain Coalition Summer Advocacy Challenge Award. TAN rose to the American Brain Coalition challenge and engaged in advocacy activities in conjunction with the Congressional recess, July 31 through September 7.

"The American Brain Coalition is a strong and powerful voice."

Our activities focused on advocating for federal research for movement disorders, personal healthcare concerns stemming from movement disorders, and access to drug

treatments. We also collaborated with other movement disorder groups.

We recruited TAN Advocates, our online support group Tremor, and newsletter readers by posting a special notice on July 27th. We noted the ABC challenge as "perfect timing" to advocate for essential tremor, dystonia, Parkinson's and related neurological movements. We sent an electronic action alert via TAN's "Constant Contact" web page.

We provided guidance and information about how to locate lawmakers through TAN's letter-writing web page. We gave examples of how to contact lawmakers via web forms (e-mails), and directed our Advocates to additional resources on tips and tools for contacting Congress.

In essence, TAN broadened the Advocacy Challenge to include dystonia, Parkinson's and related neurological

movement disorders. We hope our achievement will serve as an inspiration for other patient groups for next summer.

To learn more about The American Brain Coalition, please visit: <http://www.americanbraincoalition.org/>

My Journey In Establishing The New York Essential Tremor Support Group

By Mary Jane Donnelly

As we all know, life is not always a pleasant journey.

My "first tremor" appeared in late summer of 1984. I inherited ET. My maternal Aunt had essential tremor, and my paternal Grandfather had Parkinson's.

At the same time I also took a fall backwards down a flight of stairs. I felt my spine and the back of my neck twist. The fall contributed to the symptoms of ET. The onset (first tremor) started as a head tremor. In 2006 my left hand decided to join in.

So "Why" did I start a support group you may "Ask?" I spent many years trying to deal with the fact that I had a head tremor. I had people at work whispering, laughing, ignoring me, or asking if I was okay. I was passed up for a promotion. The reason given, "You do not look like a manager."

I became very depressed. I cried day and night. I begged to understand "Why?" I knew in my heart and soul I had not lived my purpose. My husband said to me, "Mary Jane why don't you see if there is anyone else with tremor?"

One day I used my computer to search for the key words: head tremor, and was amazed at what I found. I did a little research and located a Foundation that offered support groups, but only one group Downstate that was inactive.

I submitted a news article and asked if there was any interest in a support group for individuals with essential tremor. To my surprise 30 people called and came to the first meeting in March 2005.

Needless to say I was shaking like a leaf, but it was then that I realized I was not alone in how I felt!

Meeting others diagnosed with ET was a turning point in my life. I became stronger. I had found my purpose. I hosted monthly meetings, contacted medical professionals to be guest speakers, to share their expertise on essential tremor. I didn't stop there. My group members and I held a fundraising BBQ to spread awareness of ET.

I guess my -high energy to do more- led to the down fall of working with the Foundation. The Foundation's termination of my support group leadership turned out to be a True Blessing, as it brought me to Tremor Action Network.

TAN encouraged me to spread my wings. I immediately clicked and partnered well with the Tremor Action Network Board, TAN Advocates and Kathleen, who was generous in providing everything I needed to keep advocating. TAN inspires their volunteer Advocates to be spirited and creative. TAN is supportive of outside the box ideas versus boxed in controlling agendas. Tremor Action Network has a true understanding that Advocates are the backbone of patient advocacy organizations.

I revived my support group, getting my group members to create and implement awareness seminars for local government agencies. We participated, exhibited at well known NY community health fairs and events. We collaborated with other patient oriented organizations. We held a successful BBQ where Wal-Mart matched our fund raising.

Taking the awareness seminars to a higher level was next on my to-do list, but on December 24, 2007 I lost my infant grandson. It took a lot out of me. I had very little desire to do any thing. BUT, I kept researching, emailing my group members, staying in touch.

My husband and I moved to Central NY from the Finger Lakes area in September 2008. The relocation and being

closer to family renewed my energy. Since my move I have had numerous people call to request information. Unfortunately, not everyone can make it to my meetings, as the distance may be too far. I have been in contact with people from as far west as Buffalo, and east to Rochester, Syracuse, Albany, north to Ticonderoga, NYC area including Manhattan, Brooklyn, Bronx and Long Island.

I am blessed to say, many of my original group members are now part of the second, combined group. They are like teachers for the new members. Thank You from my heart!

Having ET or any type of movement disorder or disability IS a challenge. It is also an opportunity. If everyone would just take the time to learn and understand about the disability we could teach, advocate and support one another. More importantly, work together for the ultimate goal!

Personally, I may not be the healthiest I may have been without ET, but, we will all have some ailment in our lifetime. AS difficult as it is having ET, as challenging it is to advocate, I will keep trying. I will not accept defeat.

Everyday of my life, I am reminded of what my dear Dad once told me:

"Life may not always be easy. Sometimes it will be cruel. But, you must find a way around, under, over or through the obstacle. Never give up."

Take my hand. We will walk together on this journey we did not ask for. We shall show the world how strong we are.

About the Author

Mary Jane Donnelly is the essential tremor extraordinaire advocate! Her Journey chronicles her passion for advocacy. Wayne County Health Services Lyons, NY support group meetings are scheduled for the 3rd week of each month. Meeting days and times are subject to change. For more details call Mary Jane at 315-626-3758 or send an email mtdonnelly@frontiernet.net.

"Take my hand. We will walk together on this journey we did not ask for."

DBS Treatment: Part II Turning On The Equipment

By Edwin Yager

In late August this year I underwent the first phase of DBS treatment at the Loma Linda Medical Center, Loma Linda, CA. This involved the placement of electrodes, and a controller that assist in reducing the effects of my tremors.

On September 22 the second and equally important part of this process took place. This involved the activation of the control device to determine the effectiveness of the installed equipment. I went to my neurologist's office (Dr. Kenneth Jordan) in San Bernardino, CA where I met with the representative from Medtronic (equipment supplier). The representative explained that each of the implanted electrodes was divided into four sections, and these would be important in obtaining the best treatment results. I was frankly amazed at the involvement of the representative in my case, until I found out that he was present during both parts of my surgery. He was there not just representing the manufacturer but he was the one who was talking to me during the surgery, testing me after the electrodes were implanted. This team approach between the neurologist, neurosurgeon and the Medtronic representative allowed for the best individualized treatment for me and every patient undergoing the procedure.

My neurologist and the Medtronic representative had me perform several tests to get a baseline from which to measure once the equipment is activated. These tests involved drawing a spiral, printing or writing something, in my case writing my signature.

At this point I got my first look at the calibration / activation computer. It is a hand held unit, and a small attachment was placed over the control device just below

my right collar bone, and held in place by tape. This computer is used to activate the control unit, and tell it what voltage is best to control the impact of the tremors. It is important to understand that the controller only masks the effect of the tremors by interrupting the messages sent from the affected brain area to the hands and other parts of the body. This is not a cure because when the unit is turned off at night (recommended for preserving battery life) the tremors will return. It should be pointed out that the battery will last between two to five years depending on the setting of the controller, and how long it is turned on.

The next step involves determining the level of voltage needed to make the optimum improvements in controlling the tremors. According to the Medtronic representative they look at using the lowest level of voltage and the first segment of each electrode. The effect of the voltage feels like a tingling ideally in the thumb and forefinger on my hand. This sensation lasted about a second, and was not painful. Once the targeted range has been achieved, the testing continues to insure the desired effect is obtained. In my case we moved to doing the other hand, and the whole process was repeated. I should point out that I received a bilateral procedure or one where electrodes are placed on both sides of the brain controlling each side of the body.

Once each hand has been calibrated separately then the final phase is balancing both to operate most effectively. After this is completed and all the tests are finished, the representative then showed me how to use my remote control device to turn on / turn off the controller in my body.

As a result for the first time in many years I finally regained control of my hands. I was finally able to write my name, and be able to read it. I could finally get a drink from a glass without using both hands to control it. In short this

**"In short this medical
marvel gave me my life
back!"**

medical marvel gave me my life back!

Epilogue

I shared this with you so that you can understand that this procedure while somewhat radical in scope should none the less be viewed as a safe treatment possibility. I would urge you to discuss this procedure with your treating physician, and if you decide to pursue it, don't be dissuaded by fear. Ask questions, and be sure that you understand the answers. Be prepared to meet with multiple doctors who will evaluate your situation. In my case I met with two neurologists before meeting my neurosurgeon. I had the benefit of learning much about the procedure from a fellow member (Jeff Ryan) of the Tremor Action Network (TAN) online support group Tremor, and in the end I even watched his procedure being done. I would urge you to take advantage of TAN as an excellent resource in not only dealing with tremor, but also giving you first rate information on treatments, and being able to refer you to people like myself that have done both the medicinal as well as surgical procedure.

I would welcome the chance to discuss this treatment phase if and when you find yourself considering it. You are welcome to email me at calrte66@hotmail.com.

About the Author

Edwin Yager has been dealing with essential tremor (ET) for more than 10 years. As a licensed private investigator Edwin needs to be able to write in such a manner that can be read.

Tremor Action Network is grateful to Edwin for his two articles on Deep Brain Stimulation that provide readers with a better understanding of the DBS procedure. Edwin's first article, *DBS Treatment for Essential Tremor*, is featured in Spikes & Spasms October 2009 newsletter.

Job Discrimination

By Pat Hill

"Can't they do something about your voice?" "Why do you talk that way?" "I don't like your voice." "I don't think you can do your job with that voice." "Perhaps you just need a break from work and then your voice will be okay." "I noticed that your voice seems to be getting worse." "Maybe your voice is just a mental state of mind." "Have you ever thought about going on disability?" "Have you even considered getting another job?"

Then there are our body movement counterparts whose dystonia doesn't affect their voice, but rather their limbs or neck. "What happened to you?" "Do you have Parkinson's?" "Were you in an accident?" "How can you work like that?" "We can't have people see you shake like that." "Is it contagious?" "Were you born like that?" "Does it hurt?"

The worst case scenario is that people in the work place just look at you strangely and don't say anything or talk behind your back. Then when HR (Human Resources) steps in and the work place wants to get rid of you because you are a liability or they're concerned about their image or they don't want to accommodate you, then it can be a job threatening situation. Discrimination can be very subtle, because no one wants to be accused of discriminating.

Michael T. Carr, Attorney At Law is an employment lawyer who specializes in cases such as this, and imparts some information regarding these kind of work place issues.

Ms. Hill: So how can you protect yourself?

Mr. Carr: There is often times legal protection available to you if you have been targeted because you have a disability.

Ms. Hill: "But lawyers cost a lot of money!"

Mr. Carr: Attorneys who practice in this area of law will often take on these types of cases on a contingency basis, which essentially means they will take a percentage of any

settlement or verdict, and will not require any money upfront.

The good news is that the lawyer will probably work harder because he/she wants to win. Aside from the monetary gain, there is the satisfaction that you did what was right in fighting for yourself, which indirectly affects others as well in winning the war against discriminatory practices.

If things are going south at work, there are usually red flags, like they are reducing your hours/work/pay, placing you in another work situation where they are setting you up to fail, or making suggestions for you to retire or go on disability, or worst case scenario have terminated you, which is most typical.

If you suspect that there are inclinations or suggestions at work that you may be being targeted, start documenting what is said or done to you. Lawyers love this. Never underestimate your employer as they may be keeping a paper trail as well, but chances are they probably would not expect it of you.

A paper trail would include your own personal diary of events, emails, and/or snail mail. It's always good to have someone go with you when you talk to administration. Remember that HR (Human Resources) are working for the company, NOT you. They are there to protect the employer.

Watch out for Sneaky Petes.....those are company people who are great at finding ways to get on your good side only to get you to say something inflammatory, threatening, or insubordinate. Don't be fooled by them. Keep your mouth shut. Fellow employees may not be your friends either and their testimony can be used against you.

If an employer has been blatantly discriminatory and you have no witness, write a letter or email to them reiterating

your conversation. Even if they don't answer your letter that is okay, there is an implied admission as to the facts that are documented in the letter.

If a problem arises at work, always go through rank and file. Talk to your immediate supervisor, if that doesn't work, go to the person above them. If your immediate supervisor is the problem, go above them. In this way you are going through moves to be compliant. Collect data along the way, and record everything in writing.

If you need accommodations due to a disability, engage in the interactive process in looking for solutions. This will increase credibility in your favor. Don't ask for anything that dictates against "common sense", as it might cause an undue hardship on the company. Common sense is a very significant factor in litigation or a lawsuit.

If an employer asks you for a letter from your doctor regarding your disorder or recommended accommodations, provide it. This will also show that you are being cooperative. If you had the disorder prior or after the date of hire usually does not any affect on any litigation in this area. Generally at the time of hire, you are not required to disclose your disability as long as you can do the "essential functions" of the job.

If you are in what you would consider to be a hostile work environment that is causing undue stress on you, that needs again to be measured by "common sense." It has to do with the amount of hostility and frequency aimed in your direction in comparison to those around you. People who are trying to get rid of you may be collaborating in that effort. Again document whenever possible and keep your cool.

In conclusion, the Disability Act was signed into law by President Bush Sr. to assure stability in the work force. It is up to the lawyers then to uphold that law and protect you. So be smart, be alert to red flags, stay calm,

"Discrimination can be very subtle. Watch out for Sneaky Petes."

participate in finding accommodation solutions, follow rank and file if there is a problem, don't be insubordinate, don't talk to others, and document, document, document.

Ms. Hill: I would like to thank Attorney, Michael Carr of Monrovia, California for the information he provided. If anyone has further questions, feel free to email him at: mtcarr1@earthlink.net.

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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.

Relaxation Connection

By Marie Lehn, R.N., C.A.P

Relaxation is not a luxury but a necessary element to improvement of health.

What Is...Acupressure?

Acupressure massage is a safe and effective way to reduce such common stress-related disorders as cramps, headaches, insomnia, ulcers and many other related symptoms and conditions. It helps to stimulate the body's self-curative powers. The fundamental distinction between acupressure and acupuncture lies in the use of needles used in acupuncture and the gentle but firm pressure of hands (and feet in some techniques) used in acupressure. Using the power and sensitivity of the human hand, acupressure is especially effective in the relief of tension-related ailments, in self-treatment, and in preventive health care. During a session a person remains fully clothed.

**Relaxation is not a luxury
but a necessary element
to good health.**

What Is...Reiki Treatment?

Reiki is an ancient Eastern healing technique of working with the Universal Life Force/Energy. It is a process which promotes both natural healing and Personal growth. During a "Reiki" session, a person remains fully clothed while the practitioner lightly rests their hands in specific places on the body, giving particular attention to affected areas. A full treatment allows the practitioner to transfer the energy to the person's body. This natural healing energy goes to wherever the body needs it most. "Reiki" is experienced as deeply relaxing and nurturing. It helps to balance the body physically, emotionally and spiritually.

What Is...Massage?

Massage physically relaxes the body, calms the nervous system, lowers blood pressure and reduces heart rate. It relaxes mind, body and spirit to reduce anxiety, enhances self image, provides a feeling of well being and promotes

greater creative expression.

About the Author

Marie Lehn is the owner of Relaxation Connection. She specializes in Reiki, and Pain Management and Stress Reduction using Acupressure and Massage. Marie offers individual and group services. She has spoken to many Support and Service groups over the years, and was a volunteer spokesperson for the Arthritis Foundation in the 90's.

Each session last about an hour. Every modality can be adjusted according to people's needs, conditions, preferences and circumstances. Marie has a website at: <http://www.RelaxationConnection.com> that has a newsletter and further information on how Relaxation Connection can be of help to you. She is available by phone for consult questions and appointments. Please do not hesitate to call her at (510) 783-6594 send an email to marie.lehn@att.net.

When the World Comes Crashing Down There is Hope

By RJ Vasquez

The Purpose:

It has been a wild roller coaster of emotion and false starts with Cervical Dystonia, starting in September 2008. However, there is treatment and there is hope. I am writing this article to share some insights with three main groups.

Group 1: Doctors and others in the medical profession that are the first source who patients turn to for help. In order for treatment(s) to be effective and appropriate, symptoms need to be properly and rapidly diagnosed.

Group 2: Patients who are unsure where to turn when medical professionals have not provided the proper diagnosis. These individuals need to understand what they have, what resources are available to them, and what they can expect in terms of treatment.

Group 3: Loved ones and friends who should know how to best love and support the patient with hope and guidance.

What is this?

Being in shape, lifting weights and doing cardio exercises 4 days a week was a part of my identity. There was nothing like listening to my Ipod and hitting the gym.

I started to notice that I had a perpetual stiff neck that I would attribute to either sleeping wrong or hitting the gym too hard. I had the habit of tilting my head to one side and then the other when I would work out. A lot of people who lift weights do this in order to loosen up their necks that feel tight when doing some workouts. However, I started to notice that I was tilting more to my left side. After a few weeks of no relief I decided to go to the chiropractor. I had been to the chiropractor a few times in the past to help me with a stiff neck that I had developed from lifting weights or sleeping wrong. I had no evidence that this time would be any different.

Doctors, Doctors, Doctors

The first chiropractor I saw decided to review the free range of motion of my head. It was then that she noticed that my head did not move as much to the left when she pushed on it, and that my head was tilting to the left. After 3 adjustments in the same week, I started to feel strange. My back and head felt sensitive. It was uncomfortable to stand up. I felt weak and light headed. My eyeballs were affected. The chiropractor would simply tell me, "Straighten out your head," that had developed a noticeable tilt after more adjustments.

Frustrated and uncomfortable, I decided to visit my former chiropractor. I was confident that after he saw me this uncomfortable and strange feeling would go away. I explained my symptoms to him and he did a series of back and neck adjustments. After walking out of his office I decided to start living my life again. I would be terribly disappointed.

That evening I had plans but I started to feel nauseous, dizzy, and felt pressure on my wind-pipe. "What is going on?" "Why do I feel this way?" "What is this?" "I feel worse!" I tried to straighten out my head tilt. When I did, my wind-pipe felt restricted and my eyes felt sensitive. All I wanted to do was to lay down.

I was scared at this point. I needed more help and assumed that I should now see an orthopaedic doctor. The orthopod performed a movement analysis of my head and neck, and took x-rays. He curtly told me, "It's a habit." He was convinced that my head tilt was a habit! I asked for a review of the x-rays. He then said, "You have degenerative disk disease." I didn't know what this meant. I believed I annoyed him by asking for a lay person explanation. He explained there is not much disc cushion between the C7 vertebrae, and that, "Some people are just lucky this way." Translation: "Born with a pre-disposition to this condition." I wasn't prepared for the "labeling" of a medical condition

that was not going to get better.

The orthopod referred me to an ENT (ear, nose and throat) and a general practitioner to check on the dizziness, pressure on my wind-pipe and head tilt. Both doctors were in the same medical building as the orthopod. I went across the hall to the ENT. *While in the waiting room, my world came crashing down.* I had just lost my job. I would lose my health insurance at the end of the year. My worst nightmare was becoming a reality. I would be too sick to work with a curious medical condition, and without a job I would have to move back home with Mom and Dad. I was 30 years old and my world as I had known it was ending.

The ENT did a cursory review of my ears, nose, neck and head. He stated, "You have cervical vertigo, probably caused by the tightness in your neck." He wasn't too concerned about the vertigo or my neck. I was sent downstairs to the general practitioner. She wasn't concerned with my symptoms either, and didn't seem to want to examine or diagnose me. "So,

what the heck was the problem?"

The orthopod had suggested physical therapy at a facility close by. After describing my symptoms to the therapist, she passively re-diagnosed my condition as something having to do with an upper neck vertebrae, as opposed to the orthopod's diagnosis of the lower part of the neck. The therapist explained that my upper neck vertebrae joint was "stuck" and that therapy would provide me with more mobility in that area. I felt less confident after my visit with the therapist. After 6 weeks of physical therapy, I felt only worse. The dizziness started to disappear, but my neck tilt persisted. No one was listening to me, nor taking any additional interest in my symptoms.

I've had It!

I've always believed doctors to be smart human beings, but mortal nonetheless. I felt I had the capacity to study and

"I am happy to be on the right path, and I owe everything to Dr. Lisk!"

understand my symptoms. I visited the UCLA Biomedical Library in an effort to self-diagnose. I Googled "head tilt." At first all that came up was "congenital twisted neck," where babies injure their necks in the mother's womb and had symptoms of neck tilt after birth. Also, animals came up. I saw gerbels and horses with twisted necks, but nothing exactly describing my condition. But Wikipedia.com came up with the term "torticollis" that seemed to match my symptoms. On the right path, I then used this key word to find the term "dystonia" in a few medical encyclopedias.

Without a medical background, all I could do was find a string of medical terms I did not understand. But I began to comprehend through my research that dystonia may be caused by an infarction, tumor, trauma or other causes. The searches also mentioned there was no cure, and that medical professionals didn't know too much about this disease. "Was I to be like this forever?" "Could I not get help?" "Why, God, why?"

I walked out of the Library at least knowing that this condition is neurological. I then found the NSTA website, and was referred to Dr. Jerome Lisk, movement disorders specialist in Pasadena, CA. I later found out that Tremor Action Network had provided the NSTA with Dr. Lisk's contact information and an article he had written for Spikes & Spasms.

Dr. Jerome Lisk, Neurologist | Movement Disorders Specialist

I called Dr. Lisk's office and was given an appointment two weeks out. I couldn't wait that long. I started to have anxiety attacks. "Did I have cancer?" "Did I have a tumor?" "Did I have some other degenerative condition that would not go away?" "Why did it feel like a "magnetic" pull?" I had to know. I contacted Dr. Lisk's office a week later and asked if I could be seen that day. Dr. Lisk thoughtfully stayed after hours to see me. I felt comfortable as soon as he walked into the room. I asked him, "Dr. Lisk, can I tell you my story, because no other treating professional seems to be listening to me?" He said, "Go ahead," and he

listened intently and did not interrupt. Once I finished telling him my story, about how the neck stiffness first appeared and how the other professionals I had seen didn't really listen nor were they getting it right, he said, "It is probably dystonia." He confirmed my research. I was frightened and relieved at the same time. I finally knew that there was a treatment - botulinum toxin injection therapy, to stop the innervation of the dystonic muscles.

Normal Again!

Since December 2008, Dr. Lisk has determined the proper network of muscles in my neck to inject to get my head straight, back to normal, and get me to living life again. I am so thankful! I see Dr. Lisk once every three months for the botulinum toxin injection therapy, and he always takes the best care of me. He has allowed me to not only look normal again, but more importantly, his botulinum toxin injection treatments have relieved my neck pain. I am happy to be on the right path, and I owe everything to Dr. Lisk!

About the Author

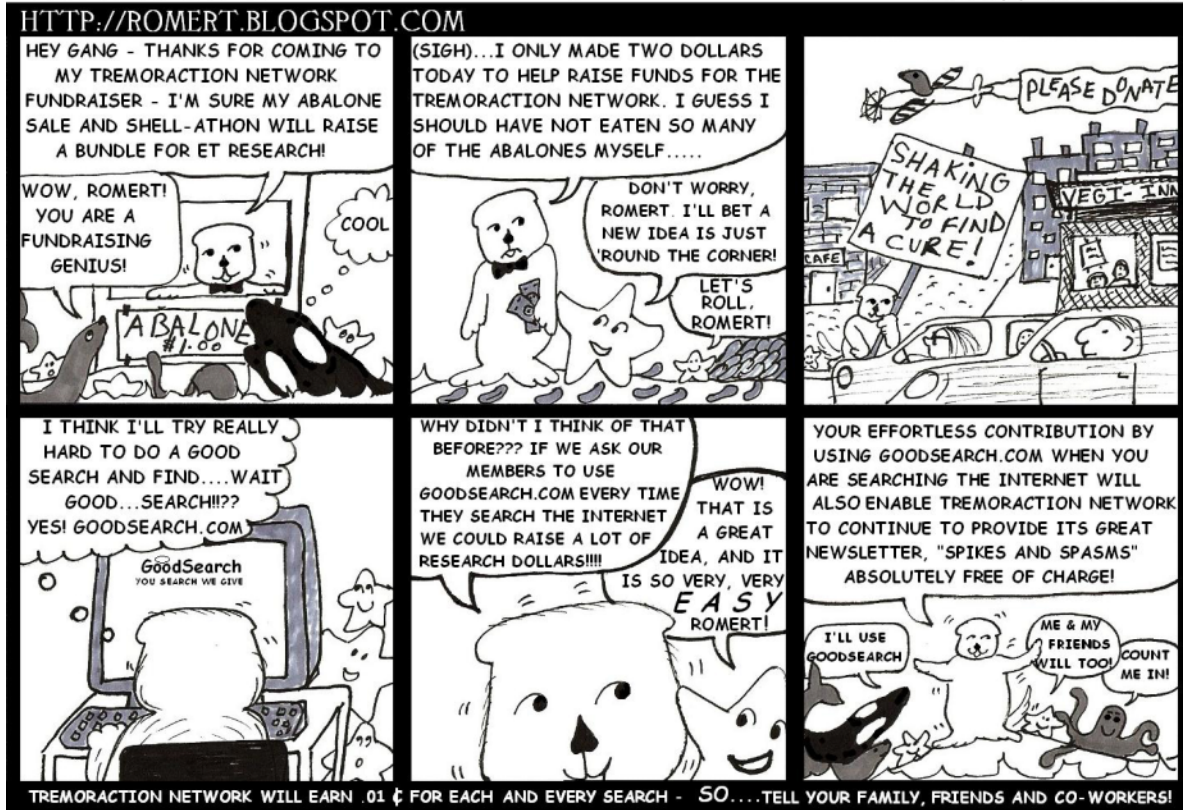
R.J. Vasquez lives in the San Gabriel Valley, 10 miles outside of Los Angeles, CA. He wrote this article to share his experience with a movement disorder. RJ has willingly exhibited the onset of his symptoms, shared his frustrations of being mis-diagnosed, his search for knowledge, and his ultimate happiness in finding movement disorders specialist Dr. Lisk to provide the accurate diagnosis and effective therapy treatment to relieve his neck pain.

How to Raise Funds for the Tremoraction Network - Without Spending a Penny!

<http://romert.blogspot.com>

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BY ALEAH MAHAN



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