

The TremorAction.org Newsletter

DECEMBER 2008

IN THIS ISSUE

- · How to Be a Health Advocate
- Allsup Offers Help with Medicare and Healthcare Costs
- · Dance with Parkinson's
- · Celebrating Persons with Disabilities
- · HHS Ceremony Program
- Deep Brain Stimulation (DBS) for Movement Disorders
- Description of a Functional Stereotactic
 Procedure
- Risks and complications of Deep Brain Stimulation
- DANA Press Books Release: Deep Brain Stimulation
- · BOTOX®
- · Romert Visits Cherry Blossom Enterprises

SIGN UP FOR SPIKES & SPASMS

DONATIONS ARE WELCOME AND ARE TAX DEDUCTIBLE http://www.tremoraction.org/donate.php

Spend time in your favorite armchair! Read new and interesting articles.

To subscribe/receive future issues call 925.462.0111, fax 925.369.0485 or visit: http://www.tremoraction.org/newsletter.php

PS: Let Spikes & Spasms know what you think. Feedback is welcome. Share your personal experiences with Tremor Action Network, PO BOX 5013 Pleasanton, CA 94566



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.

Thank you Dr. Istvan Takacs for your DBS articles!!!

How to Be a Health Advocate

By Mona Reeva, PhD, MPH, LCSW Owner of Green Mountain Artistry

Spikes & Spasms Note:

In Loving Memory...
Linda Victoria Moran
June 15, 1947 - December 5, 2008



Mrs. Moran's daughter, Suzette Moran-Richardson, is the epitome of a "health advocate who more than fulfilled Dr. Reeva's list of importance in having a family member provide peace of mind in a difficult situation. Suzette's presence and intervention made a difference for her mother's daunting medical condition that did not always receive the required care from various providers in a compassionate way. There is definitely a legislative advocacy need for better patient care."

We thank Dr. Reeva for authoring this article

My husband and I usually go to the doctors separately, however there are times that this isn't a good idea and then we tag along with each other. On occasion I share this role with a friend.

As I started to think about writing this article I began doing research on health advocacy which led me first to legislative or policy advocacy which are important roles, however not the subject of what I wanted to write about.

As I worked my way through search engines on the web I began to define my topic to "how a family or friend becomes a health advocate and why this is an important role."

At the end of this article is a list of just a few resources I found on my journey on this topic. But don't jump ahead, you might want to see my ideas first.

All of us know that seeking help for medical conditions can range from easy to daunting. We are required to deal with gatekeepers on the phone and at the front office in order to access care. And this is before we even get to the health provider's office.

We have already seen health care professionals of one kind or another multiple times to get help with our tremors and with other conditions that come along over time. I still bristle when I call for an appointment and have to go through the telephone answering menus, be placed on hold, until I reach a live person, and then it feels as if I have to convince this person who is usually without medical knowledge and experience that I must make an appointment. At times I have not even wanted to call knowing I must deal with a system that is set up to be restrictive. I have told some healthcare providers about the excellence of their gatekeepers. User friendly? Not!

If we are in luck the day of our visit, our provider is not late, and has time to sit with us to hear what is going on. If we are not in luck, it is a rushed experience. I recall one doc who sat across from me behind his desk and gave me 5 minutes of his time and was up and ushering me out of the office. The second time he attempted to do the same. Instead of getting up from my chair as he went to stand by his door, I sat there. I engaged with him until I was satisfied with getting my questions answered. Then I got up and left. I felt it important to ignore his fidgety impatience. Of course then I found another doctor.

Standing our ground during an office visit is not always an easy task, for after all we are dependent upon these

providers to serve us by giving us the best of their knowledge and we don't want to aggravate a delicate situation. And it is exactly for this reason that bringing someone along with us is so useful.

There is a lot said about patient rights and some providers respect that. My internist is one of those doctors who really is concerned, doesn't rush and gives me the time I need. Because of her process she is often late. In this case, I don't mind because she has been doing the same with her other patients. I just remember to leave enough time in my day when I need to see her.

What makes it important to bring someone along who can

be your health advocate? Here is my list. Perhaps you can think of other reasons.

1) Someone to ask questions that we can't think of in the moment. This means that before the visit we discuss what the visit is about, its purpose, and create a list of questions and concerns. Both of us keep a copy and bring it along.

2) Sometimes we are feeling so poorly that to have another person there to intercede on our behalf is both a relief and comforting. We can't think of everything even with a list and at times we can barely muster the energy to be there.

- 3) We need another person to follow up with questions that we didn't think of in advance, but come up as a result of the provider's answers.
- 4) We need someone who has the strength of will to not get up to leave because the provider is rushed. Sometimes we can't do that ourselves and sometimes we don't have the presence of mind to do so because of how we feel.

Having a person come with us can provide peace of mind in difficult situations. Bringing a family member or a friend

along to speak for us can alleviate feelings of being helpless, alone or isolated. Such an action actually gives us more strength to speak up on our own behalf if we need to and at times we can also act as our own health advocate.

It is also good practice to write down what bothers us during our health care visits as a reminder to discuss these issues with our provider. This list enables us to take steps to get the care we need, the care we want, and the care we have the right to have.

Professional advocates abound in the health care industry. And these are important people to call upon in times of special need. Professional care managers can as part of

their job be health advocates and accompany us. Given their professional status their presence can make a difference. They are, however, expensive. In this economic downturn it is incumbent upon us to find alternatives when we can. Call a family person or a friend with whom you are really comfortable and with whom you feel ok about sharing your health

situation. This is a person for whom you could also be a health advocate. Bring her along and see what magic happens in the provider's office. The atmosphere will mostly likely improve and you will get a better chance of getting the care you want. And in the final analysis, if the provider is not giving you the required care in a compassionate way - change providers. Even in this day of fewer providers, there are those who desire to be attuned to their patients.

Resources:

1) Preparing for an Office Visit http://carefirst.staywellsolutionsonline.com/Search/2,615

2)How Should I prepare? Getting Ready for an Appointment

 $\label{lem:http://www.nia.nih.gov/HealthInformation/Publications/TalkingWithYourDoctor/chapter02.htm$

"Suzette's presence and

intervention made a difference

for her mother's daunting medical

condition that did not always

receive the required care from

various providers in a

compassionate way."

The TremorAction.org Newsletter

- 3) How to Talk to Your Doctor

 http://www.aarp.org/health/staying_healthy/prevention/a20
 03-03-13-talkdr.html
- 4) How to Talk to Your Doctor or Nurse http://www.4women.gov/tools/howtotalk.cfm
- 5) Health Advocacy http://en.wikipedia.org/wiki/health_advocacy

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. The result is a beautiful collection of crafts and photographs that demonstrate her life long experience and keen eye. These individually one of a kind items are available in her online store, Green Mountain Artistry, at http://greenmountainartistry.com."

Allsup Offers Help with Medicare and Healthcare Costs

Two new services-Allsup Medicare AdvisorSM and discount program-offer True Help to people and their families

Allsup (http://www.Allsup.com) offers services that support the financial well-being and healthcare needs of people with disabilities, including representing tens of thousands of people in the Social Security Disability Insurance (SSDI) process each year since 1984.

Earlier this year, Allsup two new services:

- · Allsup Medicare AdvisorSM: This new personalized service educates clients about Medicare, identifies the best options and guides people through the process start to finish. Go online to: http://www.allsup.com/Medicare-Advisor.aspx.
- Health Discount Program: This new service offers up to 50 percent savings on medical services and healthcare products. Go online to: http://www.Allsup.com.

These programs are among the new financial and health-care-related services Allsup has introduced for people with disabilities to complement the nationwide SSDI representation services it has offered for nearly 25 years.

Continue reading to find out more about the programs, or call (888) 271-1173 to get answers to your questions.

Allsup Medicare Advisor

This new service provides objective, unbiased and personal Medicare selection assistance.

"There are dozens of Medicare plan options, but all are not created equally," said Paul Gada, personal financial planning director for Allsup's Disability Life Planning Center.

The TremorAction.org Newsletter

"There are particular challenges for individuals with disabilities when selecting the optimal plan to meet their specific needs," Mr. Gada said. "They can spend hours on their own poring through information on the different plans and still make a less-than-desired choice simply because they don't understand the complexities of the Medicare program or how their disability could impact their choice."

Allsup Medicare Advisor significantly cuts an individual's time and effort throughout the regular Medicare enrollment process.

Clients work directly with an experienced Allsup Medicare specialist from start to finish. The first step

is gathering initial information from the client concerning healthcare coverage requirements, including choice of physicians and prescription needs. Based on this information, Allsup researches the available plans and uses a specially designed rating system to identify plans that best match the client's needs and offer the highest quality and satisfaction.

"Two new services— Allsup Medicare AdvisorSM and discount program—offer True Help to people and their families."

These findings then are delivered in a comprehensive, customized, plain-language report that highlights the best plans for the individual and provides details on costs such as premiums, co-pays and coverage limits.

The Allsup Medicare specialist walks through each program with the client so that he or she understands all their available options. Once a final decision is made, Allsup helps the client enroll in the selected plan.

"Our service uses Allsup's expert Medicare knowledge to help clients make informed choices when reviewing and selecting from potentially dozens of local Medicare Advantage plans," said Mr. Gada. "The unbiased analysis we offer of the options based on their personal preferences and needs, and the support we offer throughout the enrollment process ensures our clients

receive the Medicare benefits they deserve."

Health Discount Program

This program is designed to help millions of people with disabilities gain access to discounted healthcare and medical services.

"The Health Discount Program provides the opportunity to further support the needs of individuals with disabilities, particularly those who are uninsured and do not yet qualify for Medicare," said Mr. Gada. "We offer a way to reduce healthcare costs so they will be more likely to seek the health and medical services they need."

About one-fourth of the 2.5 million individuals in the SSDI application process each year do not have health insurance, according to Allsup research. Either they have no health coverage available to them through their former employer or a spouse, or they cannot afford the high cost of COBRA coverage or private health insurance. They are not eligible for

Medicare until 24 months after their date of entitlement to cash benefits from the Social Security Administration.

The Health Discount Program offered through an agreement between Allsup and OptumHealthSM Allies helps make affordable quality healthcare possible by offering these individuals and their families access to a network of more than 500,000 physicians, practitioners and facilities nationwide, as well as online and mail-order providers.

The program includes savings for certain medical, behavioral health, dental, vision and hearing care, as well as prescription drugs and health supplies, long-term care and alternative care services. Examples of potential savings include: a \$72 savings on a \$235 doctor's office visit; \$5.40 savings on a \$12.90 Amoxicillin prescription;

\$26 savings on a \$70 dental cleaning; and \$17 savings on a \$57 eye exam.

"We know from speaking with people with disabilities that their health often suffers while they are awaiting SSDI because they have to choose between paying for food or electricity and getting the medical attention they need," said Mr. Gada. "It's an incredibly difficult position to be in and anything that can be done to help ease the financial burden is something we want to be able to offer to our customers."

This is underscored by findings from the Kaiser Disability Survey (2003), which concluded that two-thirds of uninsured individuals with disabilities reported postponing care and almost as many reported splitting pills, skipping doses or not filling a prescription to save money.

Mr. Gada pointed out that the Health Discount Program is not a traditional health insurance product. It is a cost-savings program. Allsup anticipates the program will be of greatest interest to individuals awaiting Medicare eligibility. Some also may choose to use it to complement their Medicare coverage once they become eligible, helping to further reduce out-of-pocket costs.

To Learn More about the Programs

Find out more about both programs by visiting http://www.Allsup.com or calling (888) 271-1173 to talk with an Allsup specialist.

About Allsup

Allsup, Belleville, Ill., is a leading nationwide provider of financial and healthcare-related services to people with disabilities. Founded in 1984, Allsup has helped more than 100,000 people receive their entitled Social Security Disability Insurance and Medicare benefits. Allsup employs more than 500 professionals who deliver services directly to consumers and their families, or through their employers and long-term disability insurance carriers. For more information, visit http://www.Allsup.com.

About OptumHealth Allies

The OptumHealth Allies health discount program provides access to healthcare savings to more than 15 million members nationwide. Based in Glendale, Calif., OptumHealth Allies is part of OptumHealth, one of the nation's largest consumer health services companies, and an affiliate of UnitedHealth Group (NYSE: UNH). More information about OptumHealth Allies can be found at:

http://www.optumhealthallies.com.

OptumHealth Allies is administered by HealthAllies®, Inc., a discount medical plan organization located at 505 N. Brand Blvd., Suite 850, Glendale, CA, 91203, 1-877-426-2559.

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.

Dance with Parkinson's

By Michelle Gillett

Spikes & Spasms Note:

This article courtesy of Michelle Gillett, appeared special to The Berkshire Eagle on Thursday, November 27, 2008. Tremor Action Network is grateful to Ms. Gillett for granting permission to reprint her article for viewing only.

This article is protected by U.S. and international copyright laws and treaties. All rights reserved. © Copyright 2008 The Berkshire Eagle.

Tremor Action Network became aware of dance as a complimentary therapy for Parkinson's patients' symptoms of balance and tremor, after viewing Michelle Gillett's reader-friendly creative and positive article; especially, the personal comments by Megha Nancy Buttenheim's class member, Mags Blackwell. Dance "may" be a treatment option for essential tremor and other tremor related neurological movement disorders.

As one of the founders of Tremor Action Network, I was introduced to Nintendo® Wii Sports by Mary and Ann Stovel during a visit to Portland, OR. Ann, founder of the former nonprofit Western Essential Tremor Network shares the dual-diagnosis, essential tremor and dystonia. I noticed that our fine and gross motor skills, impaired by the two movement disorders were not affected by Wii Sports. An avid golf and tennis player for years, I had been forced to give up the enjoyment of both sports because of my neurological conditions. It's amazing that I can once again perform the action of serving a tennis ball as I would if playing tennis for real. The erratic toss prior to my diagnosis telegraphed that my fluid serve was being affected by abnormal movement.

Ms. Gillett's article triggers that millions of people diagnosed with movement disorders, and "approximately 140,000 individuals yearly, living with symptoms of undiagnosed movement disorders," can physically and emotionally identify with this empowering dance therapy -

sensory motor-like training article. Megha Nancy Buttenheim has made TAN aware that the Mark Morris Dance Group is in collaboration with dance teachers in other Cities and Countries. A local partnership is Danspace Studio in Oakland, CA. For more information about Danspace and Mark Morris Dance for Parkinson's, please visit three resources:

http://www.danspace.com/adult/parkinson_movement_classes.html

http://markmorrisdancegroup.org/the_dance_center/outreach#dance
-for-parkinson-s

http://markmorrisdancegroup.org/resources/media/2performances/11-why-dance-for-pd

- Kathleen Welker

RICHMOND - Megha Nancy Buttenheim is on a mission and has the energy and determination to accomplish it. In mid-September she began teaching a Tuesday morning class for people with Parkinson's, their friends and caregivers. The class combines chair yoga, yoga dance, breath work and gentle movement and lively dancing with wonderful, diverse music.

Buttenheim, the director of Kripalu Yoga Dance Teacher training and Yoga Teacher Training at Kripalu Center for Yoga and Health in Lenox, has been teaching for 20 years. Several years ago, she developed and put her own trademark on a program called **Let Your Yoga Dance**, which she defines as "a unique approach to movement, combining the time-honored traditions of yoga, movement, breath, the chakra system, and user-friendly dance" that anyone can do.

She discovered her mission when Ed Rudman, who summers in the Berkshires, started taking her noontime Let Your Yoga Dance class because, he said, "At the age of 71, I wanted to increase my exercise routine." He approached her one day and told her that he had Parkinson's disease and Let Your Yoga Dance was more helpful in addressing his

symptoms than anything he had tried besides his "meds."

Buttenheim found his admission surprising - not because the class was so beneficial to him, but because she had another student with Parkinson's in the class. Ingrid MacGillis, a neighbor in Pittsfield, had called her soon after her diagnosis two and a half years ago. Her doctors recommended staying flexible and focusing on her balance - the sooner the better.

Because Parkinson's disease is a progressive, degenerative disorder of the nervous system, it becomes increasingly disabling over time. People with Parkinson's can have rigid muscles, sluggish movements, and tremors. Their slowed movements make it difficult to write,

speak, change positions, and maintain balance.

MacGillis began taking private yoga lessons with Buttenheim, who convinced her to try Let Your Yoga Dance.

With yoga, "I had to overcome a personal bias," MacGillis said.

The spiritual component of yoga was something she didn't feel comfortable with - but "yoga felt so good," she was willing to go the dance class even though it meant overcoming another bias.

"I am not a dancer!" she told Buttenheim.

But like many who have taken Buttenheim's Let Your Yoga Dance classes, she came away feeling joyful. It's not just what it does for your body, she says, "It's what it does for your spirit. When you have been given a diagnosis of a movement disorder, something like this keeps you from feeling condemned."

It also helps diminish the depression a majority of people with Parkinson's suffer not as a reaction to the disease but

as one of its symptoms and sometimes as a side effect of the medication. Rudman has said Let Your Yoga Dance not only lessens his symptoms, "It makes me smile and laugh. People with Parkinson's don't laugh very much."

The coincidence of having two students with Parkinson's in her class set Buttenheim on her way to develop a Let Your Yoga Dance program specifically for people with the disease. She began educating herself about the disease, and last summer she met David Leventhal, a principal dancer with The Mark Morris Dance Company who has been running a DANCE for Parkinson's class in Brooklyn for six years.

"When Mags Blackwell
takes her medication, she
listens to music, because
"music changes cellular
structure and it helps my
meds to kick in."

In August, she and Leventhal codirected a class in a room donated by Kripalu for Berkshire County people with Parkinson's. The response to the class encouraged her to start looking for a permanent place to conduct weekly sessions of Let Your Yoga Dance for Parkinson's, a place where participants would have "a sense of safety and fun and comfort so they can

create a community," she said.

Mags Blackwell, who lives in Lenox, is one of members of the class. She was diagnosed with Parkinson's 13 years ago.

With Parkinson's, she said, "there's a desire to be secretive." She began distancing herself from family and friends, but "a big turning point came for me when I realized the effect I was having on other people. Family and caregivers need to share the experience."

Now she works to share her experiences with others. Blackwell, who has a long career in creativity and the arts, knew that she had to find ways to deal with the disease.

"Creativity is a quality of aliveness, responsiveness or engagement with life," she said. "I have used everything I know about creativity to cure my Parkinson's."

When she takes her medication, she listens to music, because "music changes cellular structure and it helps my meds to kick in."

She is also writing a book about creativity and how it has helped with her symptoms. When she first attended Let Your Yoga Dance for Parkinson's, during the talking time at the end of the class she shared the positive effects music had on her symptoms.

Ed Maurer, a resident of Stockbridge, asked Blackwell some questions, and when he came back to the class a week later, "he was smiling," she said, "and his movements were more fluid." He had been listening to music all week.

Blackwell finds Buttenheim's design for the class, using yoga and music and breath, "perfect for people with Parkinson's. It's like opening a door - people start coming in."

Rudman is helping open the door even wider.

"I thought if dancing makes me this happy, let's make some other people happy," he said.

He helped start a Let Your Yoga Dance for Parkinson's class in Waltham at the Jewish Family and Children's Services Agency. Buttenheim supplied the instructor, a former student of hers. Rudman says that Buttenheim and her "boundless energy" have been his inspiration. "It's as if some spiritual being out there put us together."

Wherever she goes now, Buttenheim says, she meets people with Parkinson's and it is clear that many feel isolated and alone, which is one reason she is determined to make the program grow.

Her mission is partly accomplished - she has started a caring community in the Berkshires and beyond for people with Parkinson's. As she takes the program further and keeps expanding her knowledge about the disease and what

can be done to diminish its symptoms, she is also doing what she does best: encouraging people to exercise and remain flexible, to gain strength and support.

And most importantly - she is spreading joy.

If you go ...

What: Yoga and dance class for people with Parkinson's Disease.

When: Tuesday mornings 10-11:15.

Where: Richmond Congregational Church, 2779 State Road, Richmond.

Information: http://www.letyouryogadance.com.

About the Author

Michelle Gillett is a contributing op-ed columnist for The Boston Globe and The Berkshire Eagle, and free-lance editor for other media publications and journals.

She is a writing teacher and an award-winning poet, including but not limited to The Backwaters Prize for her collection of poetry, Blinding the Goldfinches. Her other published works are A Kitchen Gardener's Cookbook, In Celebration of Motherhood, and Rock & Spindle.

The poet Hayden Carruth wrote about Michelle's writing style. "What one finds in these poems is the truth. It's as simple as that. No frills from the workshop, no ostentatious diction or imagery, but only the firm, quiet enterprise of authenticity." Mr. Carruth's praise of Ms. Gillett's work echoes why Tremor Action Network was drawn to Michelle's article.

Celebrating Persons with Disabilities

By Kathleen Welker

Essential tremor extraordinaire Advocate Peter Muller, trumped Andy Warhol's coined expression, "15 minutes of fame," when Tremor Action Network invited Mr. Muller to represent TAN at the United States Department of Health and Human Services (HHS) October 27, 2008 Ceremony to honor the achievements of five award honorees and two certificate of appreciation honorees.

We generally have to know someone to get introduced to celebrities; like Neil Machlis, Executive Producer, inviting

me to visit the set of Grease to meet John Travolta, or Jerry Richardson, Designer/Art Director, letting me tag along to meet up with Kid Notorious -Bob Evans, and his butler, Alan Selka.

On behalf of Tremor Action Network Mr. Muller was able to meet distinguished presenters and the honorees being recognized for their

contributions to persons with disabilities. Mr. Muller described the Ceremony as electrifying, thanking TAN for the opportunity to meet Dr. Alim-Louis Benabid, the world known pioneer who helped develop the surgical technique known as Deep Brain Stimulation. In 1987, Dr. Benabid and his team (Pierre Pollak) "implanted in-depth electrodes for electric stimulation with great frequency for Parkinson's patients who were resistant to medication." Dr. Benabid is Emeritus Professor of Biophysics at Grenoble's Université Joseph Fourier and honorary professor at London's Imperial College.

Source: Alim-Louis Benabid, M.D. Profile http://fr.wikipedia.org/wiki/Alim-Louis_Benabid

Prior to attending the HHS Ceremony which celebrates National Disability Employment Awareness Month, Dr. Benabid received an honorary degree from McGill University on October 5.

Dr. Benabid's presenter was Dr. Ali Rezai, Director of the Center for Neurological Restoration at Cleveland Clinic. Dr. Rezai is also a well known pioneer for "innovative neuromodulation therapies and devices, which include U.S. patents for surgical techniques and neuromodulation devices." He specializes in "neurosurgical management of patients with severe movement disorders such as Parkinson's disease and dystonia, psychiatric conditions such as depression and obsessive-compulsive disorder, chronic pain and brain injuries."

Source: Ali Rezai, M.D. Profile

http://my.clevelandclinic.org/staff_directory/4/staff_3451.aspx

"The opportunity to meet Dr. Alim-Louis Benabid, the world known pioneer who helped develop the surgical technique known as Deep Brain Stimulation." Mr. Muller was disappointed that the HHS Program listed Deep Brain Stimulation for the movement disorders Parkinson's Disease and dysonia, but omitted mentioning the usefulness of DBS for essential tremor. Mr. Muller's primary interest in essential tremor is to increase the federal government's awareness in more research for this neurological

disease.

Tremor Action Network thanks Mr. Muller for his and Mr. Barry Schafer's attendance at the November 17 Fall Membership Meeting of the American Brain Coalition in Washington D.C. on behalf of TAN. Tremor Action Network is part of the ABC Strategic Planning Committee.

About the Author

Kathleen Welker is a movement disorders advocate, who along with individuals diagnosed with essential tremor, dystonia and tremor related neurological disorders founded Tremor Action Network. Kathleen's advocacy passions include the development and implementation of various Programs to promote movement disorders awareness, legislation and research.

HHS Ceremony Program

CLOSING REMARKS

Margaret J. Giannini, MD, FAAP

SPECIAL THANKS TO:

AWARDEE HOSTS

Mr. Richard Campanelli for Dr. Benabid

Mr. Leon Larson for Dr. Joseph Rosen

Dr. Daniel Dodgen for Dr. Phyllis Magrab

Dr. Patricia Morrissey and Mr. Michael Robinson

for Emily Kingsley/Sesame Street

Dr. Robinsue Frohboese for Kyle Maynard

Mr. Jay Merchant for Ms. Dora Ricks

OFFICE ON DISABILITY STAFF:

Lauren Solkowski, Senior Program Analyst Lindsay Mulcahy, Program Analyst Lee Watson, Staff Assistant

HHS FACILITIES AND SECURITY:

Jean Allen, ASAM James Windsor, ASAM Earl Jackson, ASAM London Liebengood, ASPA

SPECIAL THANKS TO OUR PARTNERS THE AMERICAN PHYSICAL THERAPY ASSOCIATION (APTA) AND AMERICAN OCCUPATIONAL THERAPY ASSOCIATION (AOTA). SINCERE THANKS TO THE MANY WHO HELPED MAKE THIS CELEBRATION SPECIAL, INCLUDING THE U.S. MARINE BAND AND ALL ARMED SERVICES COLOR GUARD.



* *

Office on Disability
Office of the Secretary
U.S. Department of Health and Human Services

CELEBRATING PERSONS WITH DISABILITIES

in honor of the President's
National Disability Employment
Awareness Month

OCTOBER 27, 2008 1:00P.M. - 4:00P.M.

GREAT HALL HUBERT H. HUMPHREY BUILDING

CELEBRATING PERSONS WITH DISABILITIES

PRESIDING

Margaret J. Giannini, MD, FAAP Director, Office on Disability, HHS

OPENING

Presentation of the Colors All Armed Forces Color Guard

NATIONAL ANTHEM OF FRANCE & NATIONAL ANTHEM OF THE UNITED STATES

U.S. Marine Band

PLEDGE OF ALLEGIANCE

Led by John Halverson, PhD, Senior Program Management Analyst Office for Civil Rights, HHS

WELCOME AND REMARKS

Margaret J. Giannini, MD, FAAP Director, Office on Disability, HHS

GREETINGS

Deputy Secretary Tevi Troy U.S. Department of Health and Human Services

PRESENTATION OF THE SECRETARY'S HIGHEST RECOGNITION AWARDS

Health/Service Provider for Persons with Disabilities Award: Dr. Joseph Rosen, researcher, professor and noted plastic surgeon who performs facial and body reconstructions at Walter Reed Medical Center for Returning Wounded War Heroes, pro bono.

Presenter: RADM W. Craig Vanderwagen

Entertainment Industry Award: Ms. Emily Perl Kingsley, writer for Sesame Workshop, who was responsible for the topic of disability on Sesame Street with children with disabilities and Muppets with disabilities appearing on Sesame Street Programs.

Presenter: Mr. Philo Hall

★ The 2008 Certificate of Acheivement: Mr. Jason Kingsley, Author.

Presenter: Dr. Margaret Giannini

★ The 2008 Certificate of Appreciation: Ms. Dora Ricks,

DHHS Mailroom Employee.

Presenter: Mr. Jay Merchant

Pioneer for Persons with Disabilities Award: Dr. Phyllis Magrab, educator, scholar, skilled clinician and champion for children with disabilities nationally and internationally.

Presenter: Dr. Margaret Giannini

Role Model for Persons with Disabilities Across the Lifespan Award: Mr. Kyle Maynard, born with congenital amputation of all four limbs, is a champion wrestler, author, motivational speaker, and advocate.

Presenter: Dr. Duane Alexander

First International Award: Dr. Alim-Louis Benabid, world renowned pioneering scientist and mentor in the area of deep brain stimulation that changes the lives of persons with Parkinson's Disease, dystonia and other movement disorders. Comments: Monsieur Olivier Villey, Counselor for Labor & Social Affairs, French Embassy Presenter: Dr. Ali Rezai

Deep Brain Stimulation (DBS) for Movement Disorders

By Istvan Takacs, M.D.

Division of Neurosurgery, MUSC

Moving a limb in a timely, smooth and exact fashion is a complex task for the nervous system. While one area of the brain comes up with the idea to, let's say, lift a tea cup, a large amount of data have to be taken into consideration before that cup is indeed lifted. Where is my arm now? How far away is the cup? Do I have to bend or stretch my arm to reach it? How heavy do I think it is? All these questions and many more crave an answer before I can lift that cup to my lips and drink without spilling the beverage.

The data come from all the senses, as well as from the memory bank of learned movements. Some muscles have to be relaxed, others flexed, and all at the right moment. All the information is continuously updated and blended together with my original idea to take a sip and an order - much more elaborate than my first craving for tea - is passed on to my muscles.

The information is blended together in three major areas of the nervous system, the cerebellum, the Thalamus and the Basal Ganglia. Simply put, there are three aspects to movement and posture; coordination, fluency and tone. The cerebellum is primarily concerned with coordination; can I find my mouth? The basal ganglia work to make my efforts timely and smooth. All the traffic between my conscious and unconscious minds flow through the Thalamus. Correct directives from all systems are needed to make my movements exact. The muscles, tendons and joints are merely simple tools in comparison but of course their range of motion is important to make my movements perfect. Arthritic hands will not play the piano well, even if the nervous system gives perfect orders. With age, all these systems undergo deterioration to various degrees and it takes the trained eye of the neurologist to sort out which system contributes most to the disability. Some diseases, such as Parkinson's disease, we know stem from a chemical

imbalance in the basal ganglia.

The basal ganglia are a collection of relay stations for nerve signals located deep in the middle of the head. Since the 40s, it has been known that interruption of some of the connections between these relay stations could reduce tremor, rigidity and stiffness. This blocking out of inappropriate signals reduced the symptoms but did not address the underlying chemical abnormality. The connections were disrupted by inserting thin probes into the brain and heating their tips by remote control, thus creating a dot of dead tissue where signals had previously passed. This technique worked well in thousands of patients in the fifties and are still used today. However,

with the arrival of new drugs which seemed to correct the underlying chemical defect, surgery became a rare treatment for 25 years. Time, however, has shown that in many cases the drugs lose their effectiveness and in some instances they do not seem to help much even in the short run. For this reason, the old surgical techniques have been revived with the added

benefit from improvements in X-ray techniques, electronics, engineering and computer technology. We now have the equipment to insert a thin wire to the same position where previously hot probes were placed and send in an electric current that blocks out a signal without cutting the connection permanently. With the lesioning techniques known since the 40s, a defect is created and it cannot be undone. The anatomical target areas are located in the Thalamus and the basal ganglia and all of them fit inside a volume equal to a stack of five nickels. Individually, they are pea-sized at best. If a lesion is perfectly placed and perfectly sized within that pea it will work as well as the new electric stimulation techniques. However, the new technology allows for variations in the current applied, thus changing the size and intensity of the electric field created. This adjustability with minimal tissue destruction is the great appeal of DBS. It is not a wonder cure. It does not address the underlying disease process. It still

requires drilling a hole in the skull and inserting a cannula into the brain with all the risks encountered in deep puncture or biopsy procedures.

The results of DBS applied to the same targets as the lesioning techniques have shown very encouraging results. The effects on pure tremor can be spectacular. The effects on other manifestations such as rigidity, dystonia, akinesia and freezing are less dramatic but 70-80% of patients experience significant improvement in motor function. The thalamus and the basal ganglia are paired organs, located symmetrically in both brain halves. Although there are connections between the two arrays of nuclei, in principle, treatment of a target in one half of the brain will affect symptoms in the opposite side of the body. Thus, a right-handed patient with severe tremor in both hands will typically be operated on the left side of the brain first and return for a second operation some months later to receive an implant on the other side.

On the following pages, the steps of a typical procedure are outlined as an introduction to the practical aspects of a hospital stay for deep brain stimulation.

About the Author

"Istvan Takacs, M.D., began his neurosurgical career at the Karolinska Hospital in Stockholm, Sweden in 1989. He has completed fellowships at the University of Toronto and at the University of Arizona. Since 2001 he has directed the functional and stereotactic neurosurgery program at MUSC. His practice focuses on movement disorders, epilepsy, and pain. Dr. Takacs has extensive experience in deep brain stimulation, Gamma-knife and LINAC radiosurgery, frameless neurosurgical navigation systems, and other minimally invasive techniques. His research interests include functional imaging of the brain, computer guided surgical techniques, and motion capture technology in outcome evaluation."

Source: Istvan Takacs, M.D. Profile

http://www.muschealth.com/movementdisorders/faculty/

Tremor Action Network is grateful to TAN Advocate Cliff DeCamp for his participation in networking with the Medical University of South Carolina's Functional and Stereotactic Movement Disorders Program for Dr. Takacs' three articles. Cliff has been involved with TAN since his initial DBS surgery in 2002.

Description of a Functional Stereotactic Procedure

By Istvan Takacs, M.D.

Division of Neurosurgery, MUSC

Stereotactic surgery is a technique whereby a target in a highly sensitive organ such as the brain is approached by an exact, mathematically determined aiming technique to ensure maximal precision for a minimum of tissue disturbance. Functional surgery is the term used for procedures designed to change or modulate the function of certain circuits of the brain. Most frequently, these two concepts are united in the treatment of movement disorders such as Parkinson's disease and Essential Tremor.

The mathematical aiming technique involves the fitting of the head in a head ring. Onto the ring are then fitted plastic shields on all four sides of the head, creating a box around the cranium. The walls of the box have markings which show up on the CT or MRI pictures which are then taken of the head. These markings aid the surgeon in aiming precisely his/her approach to the target deep inside the brain.

The ring is fastened to the head with pointed screws that pierce the skin and secure the ring to the underlying bone. This procedure takes only a few minutes and is performed under local anesthesia and with the option of short-acting sedation. Patients initially experience pressure around the head from the ring but this sensation fades within 10-15 minutes after ring placement. The pins hold the ring securely on the head and the patient can move freely without fear of dislodging the instrument.

After frame placement, the plastic shields are secured to the ring. The patient is then taken to the CT or MRI suite and positioned supine on the scanning table. The head ring is secured to a head holder preventing the patient from moving during the scanning, thus ensuring that the pictures

come out clear and unblurred and with the head pointing the same way in every picture of the series. Some procedures require both CT and MRI imaging and the same principles apply to both methods. However, the MRI presents a somewhat noisier, more enclosed environment for the patient and the studies take longer than do CT scans.

After the scans are completed, the shields are taken off the ring. The patient, with the head ring still in place, is transferred to a hospital bed while the surgical team performs the analysis of the films and calculates the surgical trajectory. Once the surgical plan has been completed, the patient is taken to the operating room and

placed on the operating table in a comfortable recumbent position. The head ring is again clamped to the table to eliminate motion and to ensure surgical precision. In a functional procedure for movement disorders, it is desirable that the patient have visible symptoms so the surgeon can observe the effects of treatment directly. This is the most reliable way

to verify correct targeting and detect possible side effects. For this reason, these surgeries are performed with the patient awake and alert as sedation not only prevents the patient from communicating important sensations but also blunts the manifestations of the movement disorder itself.

An area of the scalp roughly the size created when making a circle by putting thumb against index finger is shaved and washed with disinfectant soap and infiltrated with local anesthetic. The rest of the head is covered with a surgical drape. The face is left free as are the arms and legs. When the local anesthetic has taken effect, a skin cut is made to expose the bone. With a power drill a hole smaller than a dime is made in the skull. The drilling creates intense noise as the vibrations travel through both air and bone to the ears. Keeping the mouth open reduces the discomfort from this. The dura, a thick membrane covering the brain is then

opened. An aiming arm is then fastened to the head ring. This arm holds the cannula which will be inserted into the brain. The arm has been fixed into position according to the calculations based on the scans obtained earlier in the day. The cannula is advanced into the brain along the predetermined path. The brain itself, while monitoring everything around it, has no nerves to feel itself. Thus, there is no pain as the cannula is inserted.

Once the hollow cannula is in position, the electric lead wire is fed down through it to the designated target point. The end of the lead wire away from the patient is connected to a hand held stimulator unit and the current is turned on. The patient is asked to perform tasks such as tapping,

drawing, repeating words, etc. Sensations such as tingling, numbness, and visual phenomena are asked about. The current settings and the position of the lead wire tip are modified based on these responses.

When the best combination for symptom suppression has been determined, the lead wire is secured to

a plastic cap in the burr hole, thus locking it into place. The length of the wire hanging out is rolled into a coil under the scalp and the skin incision is stapled shut. The aiming arm is then removed, the drapes are removed, the screws are loosened and the head is freed from the ring. The pin site wounds are cleaned and covered with antibiotic ointment and Band-Aids. This concludes the first part of the operation.

The second part of the operation involves the tunneling of the lead wire under the skin. This part of the procedure needs no patient cooperation and is painful. Therefore, the patient is safely put to sleep by the anesthesiologist. If, during the first part of the procedure, significant symptom improvement has been achieved, the decision is made to implant a permanent stimulation generator. After new surgical scrubbing and draping, an incision is made behind and below the ear and another below the collarbone,

the scalp wound is reopened. A tunneling tool, in essence a hollow steel tube, is pushed under the skin between the incisions. The lead wire is uncoiled and fed through the tunneling device which is then removed, leaving the wire running under the skin from the top of the head to the skin pocket under the collarbone. The generator is connected to the lead wire by an extension cable and placed in the pocket under the skin. The incision is closed with sutures.

If, during the first part of the procedure, it is felt that additional stimulator settings need to be tried over a period of time, the generator is not implanted. Instead, the lead is tunneled out through a small incision on the neck under sedation and connected to a temporary stimulator unit. Over a number of days, various settings are evaluated. When the optimal setting has been found, the patient is returned to the operating room and the generator is implanted as described above. Directly after implantation, the system is in standby mode, not activated. The reason for this is that sometimes the insertion of the lead itself "stuns" the target, creating symptom suppression by its physical presence alone. As this effect wears off over hours to days after surgery, it becomes easier to dial in the correct settings to the generator, reducing the need for readjustments.

In an implanted generator, these settings are changed magnetically by placing a transmitter over the skin covering the generator. In the case of an externalized lead, the wire is directly connected to a stimulator unit which fits into a garment pocket. In a beep brain stimulator system, the characteristics of the delivered current can be altered just like dosages of traditional medications. The fine tuning of these stimulation settings as well as any changes in oral medications after the surgery are the responsibility of the patient's neurologist. From a surgical viewpoint, the patient can be discharged the day after an implantation. Stimulator re-settings are done in outpatient neurology clinic. Patients with externalized leads are followed in the hospital. Sutures are removed one week after surgery in the neurosurgery outpatient clinic. Generator battery life varies depending on the required

settings. On average, the unit will remain operational for three to five years. After that time, the skin pocket under the collar bone is opened and the generator is replaced. This is a 15 minute operating room procedure under local or general anesthesia and requires no overnight hospital stay.

About the Author

"Istvan Takacs, M.D., began his neurosurgical career at the Karolinska Hospital in Stockholm, Sweden in 1989. He has completed fellowships at the University of Toronto and at the University of Arizona. Since 2001 he has directed the functional and stereotactic neurosurgery program at MUSC. His practice focuses on movement disorders, epilepsy, and pain. Dr. Takacs has extensive experience in deep brain stimulation, Gamma-knife and LINAC radiosurgery, frameless neurosurgical navigation systems, and other minimally invasive techniques. His research interests include functional imaging of the brain, computer guided surgical techniques, and motion capture technology in outcome evaluation."

Source: Istvan Takacs, M.D. Profile

http://www.muschealth.com/movementdisorders/faculty/

Tremor Action Network is grateful to TAN Advocate Cliff DeCamp for his participation in networking with the Medical University of South Carolina's Functional and Stereotactic Movement Disorders Program for Dr. Takacs' three articles. Cliff has been involved with TAN since his initial DBS surgery in 2002.

Risks and complications of Deep Brain Stimulation (DBS)

By Istvan Takacs, M.D.

Division of Neurosurgery, MUSC

As the name implies, the procedure involves the approach of centers deep inside the brain for purposes of altering their signal transmission characteristics. A center connotes a concentration of functions, whereas outside a center these functions are dispersed. In the brain, these centers are the deep nuclei, which can be likened to extremely complex telecommunication switchboards, where messages of a great variety are relayed through to their destinations. In these nuclei, the information

pathways are thus densely packed. To tap into the specifically intended circuit therefore requires great precision.

<u>Functional complications</u> arise when the electrode is placed so that pathways adjacent to the target fall within the field of stimulation. The circuitry regulating fluency of

movement lies very near pathways carrying information relating to the senses - vision, pain, and pathways carrying information about muscle tension and position. As the electric signal from the electrode "echoes" across to these pathways at certain settings, their signals can become distorted just like a message over a bad phone connection and can lead to misunderstandings at the receiving end. This can lead to involuntary movements, visual disturbances, varying degrees of speech difficulties and various expressions of pain, tension, numbness, tingling etc.

The difference between deep brain stimulation and lesioning techniques is that the latter create a permanent defect in the brain whereas stimulation creates an electric field which can be made greater or smaller, stronger or weaker depending on the side effects noted early or long after the procedure. However, the placement of the electrode itself can still traumatize the neighboring

pathways and create permanent disturbance that is not responsive to changes in the stimulation settings. The risk for persisting complications of this nature is low, below 5%.

The risk of <u>treatment failure</u> is of the same magnitude. Although the basic wiring scheme is the same in all of us, there are individual biological variations which make an individual nonresponsive to stimulation at the normal target sites. In some individuals, the typical manifestations of the disease hide a more complex problem involving several pathways simultaneously. Careful patient selection based on history, clinical examination and brain imaging can detect most but not all of the multifactorial etiologies unsuitable for deep brain stimulation. The

implanted <u>hardware</u> has proven robust and reliable. However, as the technique is only 15 years old and no patients have had their implants for many years, documentation of the durability of the wiring over several years is limited.

Whenever the skin is breached, there is a risk of <u>infection</u>. The overall risk of infection for cerebral implants is 1 -

3%. When infection occurs, it most commonly involves the skin. Wound breakdown with exposure of the hardware is rare but necessitates removal of the implant which has become colonized by bacteria. Spread of infection to the membranes surrounding the brain, meningitis, or abscess formation are also rare but require vigorous treatment and removal of the implanted hardware. Cerebrospinal fluid may leak along the lead wire and collect under the skin. This is harmless. Leakage of the fluid through an incision may require re-suturing. <u>Bleeding</u> from the brain due to the advancement of the lead cannula is a rare but well documented risk of all stereotactic procedures. Depending on the size, location and pressure characteristics of the violated blood vessel, any degree of disability may result, from the unnoticeable to severe handicap and death.

More commonly, there may be bleeding under the skin from the implantation of the generator under the collarbone or

"To tap into the

specifically intended

circuit therefore

requires great

precision."

along the tunnel tract of the wire on the side of the neck. This may give rise to discoloration and tenderness. Any disruption or irritation of the brain cortex can potentially create a local electric disturbance and trigger epileptic <u>seizures</u>. With the minimally invasive techniques used for lead placement, the risk for this to occur is low when compared to other forms of brain surgery. Depending on your individual medical history, presence of debilitating conditions etc, the relative risks may be different from the general outline above. These modifying factors will have been discussed with you prior to the procedure.

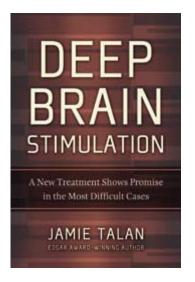
About the Author

"Istvan Takacs, M.D., began his neurosurgical career at the Karolinska Hospital in Stockholm, Sweden in 1989. He has completed fellowships at the University of Toronto and at the University of Arizona. Since 2001 he has directed the functional and stereotactic neurosurgery program at MUSC. His practice focuses on movement disorders, epilepsy, and pain. Dr. Takacs has extensive experience in deep brain stimulation, Gamma-knife and LINAC radiosurgery, frameless neurosurgical navigation systems, and other minimally invasive techniques. His research interests include functional imaging of the brain, computer guided surgical techniques, and motion capture technology in outcome evaluation."

Source: Istvan Takacs, M.D. Profile

http://www.muschealth.com/movementdisorders/faculty/

Tremor Action Network is grateful to TAN Advocate Cliff DeCamp for his participation in networking with the Medical University of South Carolina's Functional and Stereotactic Movement Disorders Program for Dr. Takacs' three articles. Cliff has been involved with TAN since his initial DBS surgery in 2002.



DANA Press
Books Release:
Deep Brain
Stimulation

A New
Treatment Shows
Promise in the
Most Difficult
Cases

By Jamie Talan

"This book tells the story of

how deep brain stimulation unfolded as a potential therapy for many disparate brain diseases. It is a cautionary tale of successes, failures, and life somewhere in the middle of all this technology. . . . It's also about the scientists who are fighting to study this surgical technique in the right wayand with the right patients-to make sure that deep brain stimulation is not abused as a treatment. . . . It is about hope and caution." -from the Foreword

Dear Reviewer.

More than 40,000 people worldwide have undergone deep brain stimulation, most for Parkinson's disease and tremor but recently for other disorders. Scientists speculate that this new medical technique, similar to a pacemaker that implants electrodes in the brain, might relieve chronic pain, ease intractable depression, enhance memory, alleviate chronic and debilitating headaches, and even help people lose weight.

Through compelling profiles of patients and an introduction to the doctors and scientists who pursue pioneering research, award-winning science writer, Jamie Talan describes in this book the ways in which deep brain stimulation has produced promising results in the experimental treatment of an unusual range of diseases including depression, obsessive-compulsive disorder, and dystonia-as well as the ethical challenges that have arisen in the course of this research.

Deep Brain Stimulation is for all readers fascinated by cutting-edge science, but especially for patients, family members, and health practitioners who have seen the growing number of news reports about deep brain stimulation and wondered if it could treat the intractable disorders with which they are coping. Talan reveals how deep brain stimulation is unfolding as a potential successful therapy but also tells a cautionary tale of failures and areas where more research is necessary

A fascinating and timely investigation, Deep Brain Stimulation reveals the exciting possibilities for restoring a richer life to the sufferers of diseases long though to be incurable. Please contact me for more information on this March 1, 2009 offering from Dana Press.

Yours sincerely, Leticia Barnes Marketing Director (202) 216-2768

lbarnes@dana.org

"A New Treatment Shows Promise in the Most Difficult Cases."

About the Author

"Science writer Jamie Talan (with co-author Richard Firstman) won the 1998 Edgar Award for best nonfiction for The Death of Innocents, a gripping account of forensic science that was also a New York Times Notable Book of the Year. Talan, who covered neuroscience for Newsday for more than twenty years, is science writer-in-residence at The Feinstein Institute for Medical Research in New York."

Source: Jamie Talan Profile

http://www.dana.org

BOTOX®

By Terri Sterling, MSP

I am a strong believer in the power of Botox to help victims of Dystonia. I have received Botox off and on since 1992. My personal experience is that Botox can help reduce muscle spasms but not tremors. In fact, my tremors became worse the first few times I took Botox. It does help reduce the pain of Dystonia.

I used to be a person whose Dystonia left them so disabled that my chin was almost sitting on my left shoulder, but then along came the power of Botox. After my first set of injections my head turned back to its natural position and I could see again; what was on my right side. For years I could not see anything on my right side, and if you were standing there then I could not have seen you.

I receive Botox injections in my arm and neck. The injections in my neck are placed on four of the main muscles in my neck, and along the bottom of my skull. Some are placed in my shoulders, and there are approximately 16 shots given each time in my neck and surrounding area. The Botox needles are thin and are not that painful because it

is over quickly. My arm receives 3 to 4 painful injections, because the injections penetrate 3 to 4 muscles that go deep past the lining of my muscles. I receive Botox injections every 3 months, and they hurt less if I get them before the previous set of injections completely wears off.

As far as I know, BOTOX® has always been billed as a surgery procedure because the doctor must be specially trained, and a nurse cannot administer Botox. Some insurance companies are better then others and I have found Aetna to be the best, because they are cooperative when working with my doctor and they have their own pharmacy. I never have to pay a co-pay when I use their pharmacy, and the Botox is always delivered on time. Aetna has never given me a hard time and I highly recommend them.

About the Author

Terri Sterling is a trained Creativity Coach with 14 year of experience. She is the owner of Inspiration, a private coaching business. For more information visit Terri's website at

http://www.freewebs.com/terris_inspiration/.

Terri is an artist and writer. Her artistic creativity, Creative Souls, can be viewed at http://creativesouls.wordpress.com/.

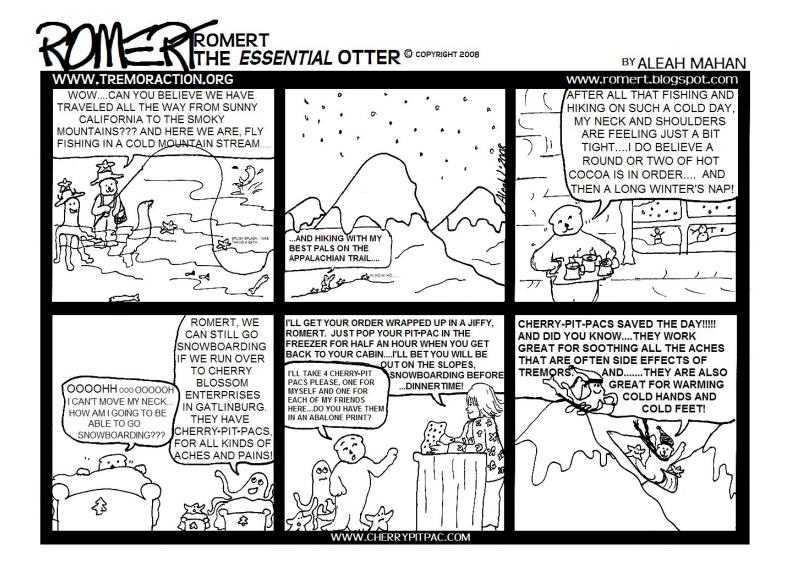
"Some insurance companies are better than others and I have found Aetna to be the best."

The difference between receiving

Botox and not having it is tremendous. When I do not have Botox, the pain from the Dystonia in my neck can leave me in bed for 24 to 48 hours, and I am unable to function. My head will twist to the left and the pain will not stop with aspirin. Without Botox I cannot write, and therefore cannot work in my profession. I am forever grateful for this medication. It is worth whatever pain I go through during the injections because the outcome allows me to work and engage in joyful activities.

The Essential Otter Advocate

http://www.romert.blogspot.com



Disclaimer

Articles are for reading only. Spikes & Spasms does not replace advice from healthcare professionals. Neither TAN nor Authors express or imply newsletter content supersedes the physician-patient relationship. TAN is not liable for information of any kind.

Help keep Spikes & Spasms a free resource by making a donation to offset publishing costs. Any size contribution is welcome and is tax deductible.

Spike & Spasms logo and newsletter layout Copyright © Whitney Chavis http://www.whitneychavis.com