

Spikes & Spasms

The Tremoraction.org Newsletter

DECEMBER 2007

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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
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Deep Brain Stimulation for Essential Tremor

By Diana Herring, MN, ARNP



Did you know that four percent of individuals older than forty have essential tremor? No one knows exactly why. Risk factors include age, family history, and possibly ethnicity (the condition is more prevalent in Caucasians).

This kind of tremor, which is defined as "kinetic," usually occurs with movement of the arm or leg. "Postural" tremor occurs when holding the hands and arms in a fixed position, like in an outstretched position, and is a component of more advanced essential tremor. Tremor can gradually lead to functional disability, requiring great effort to eat, perform daily activities such as dressing and grooming, as well as hand-writing. It often leads to social discomfort for the sufferer. Some people avoid applying for job promotions, and severe tremor may require early retirement.

The most common areas involved in this kind of tremor are the hands. The head, and rarely, the legs can also be affected. The voice can be involved. Also tremors can occur in the chin, the mouth and the tongue.

The pharmacological treatments (medications) available often are ineffective, waning in benefit, or come with side

effects intolerable to the person.

When medications do not work, Deep Brain Stimulation (DBS) surgery can be considered in people with essential tremor. It is safe and effective, although not without risks. The decision whether this kind of surgery is appropriate for the person with essential tremor needs to be weighed carefully with a qualified, experienced neurosurgical team.

Newer and improved imaging techniques allow for the accurate placement of the DBS lead into targeted area of the brain, the thalamus, the area of the brain involved with this kind of tremor. The person remains awake for the

surgery, although comfortable. During surgery, while placing the frame (used in stereotactic surgery) on the head and the MRI scanning, the anesthesiologist may give medications to reduce tremor, to induce a mild and light sleep state, and to reduce discomfort. The neurosurgeon places the DBS lead, about the gauge of a violin string, into the thalamus on one

side of the brain, using stereotactic guidance equipment.

The surgical team then tests the stimulator to confirm proper placement right in the operating room. The patient is awake. The DBS stimulator is temporarily turned on and the voltage increased slowly. The neurosurgical team evaluates the placement of the lead by watching for benefits (tremor reduction) and making sure there are no side effects.

At our center at Northwest Hospital & Medical Center, located in Seattle, we implant the lead on one day, and then about three days later implant the battery. The battery is placed beneath the collarbone, under the skin.

An implant to one side of the brain treats the opposite side of the body. So for example, if the tremor is worse on the right, the left brain is implanted. If subsequent DBS is

"The greatest benefits from DBS are achieved with a team that has plenty of experience, accurate targeting, and good, solid DBS programming experience."

desired to treat the other side, then consideration of implantation on the opposite side for a later date would be considered.

Most people are amazed at how quickly the tremor can be brought under control with DBS. When the lead is accurately placed, in the appropriate candidate, then the next step is programming the DBS. This often can be accomplished in just a couple of sessions, but sometimes requires more time. Tremor of the hands and arms is the easiest to control with DBS to the thalamus. Head and neck tremors are more challenging, although some people have reported a reduction in head tremor to us by forty percent after unilateral DBS to the thalamus. Leg tremor reduction may take more sessions, but we've seen people with both leg and arm tremor that have had about ninety-eight to ninety-nine percent control of the tremor after DBS.

Below is a description of the experience one of our tremor patient had with DBS surgery here at Northwest Hospital & Medical Center:

My condition, Familial Tremor, was evidenced by head shaking, I could not get food from a plate to my mouth without falling off the fork, I could not put a screw driver into the slot on the head of a screw, and I could hardly sign my name legibly.

A friend, with Essential Tremor, told me about a procedure he had done, with great results, called Gamma Knife at Northwest Hospital in Seattle, WA by Dr. Ronald Young.

I consulted with my Neurologist and she said "yes" to the procedure as long as Dr. Young performed the procedure.

I met with Dr. Young and discovered another procedure known as DBS (Deep Brain Stimulation) which is more invasive than Gamma Knife and the results more immediate. Based on my own decision I decided to have the DBS procedure performed.

To my friends and family the idea of drilling a hole in your skull and implanting a Lead (wire) into your brain and then running the Lead under your scalp and skin to below the collar bone and

attaching it to an implanted neurostimulator seemed frightening. My response has been, "It was an absolute Breeze."

I did not experience any pain or discomfort, of any significance, during or after the procedure or since. I would compare any pain or discomfort to having a cavity filled by the Dentist.

The results of the DBS procedure were immediate. My eating and writing hand is as steady as a rock. My head Tremor is none to slight.

The whole Surgical Team at Northwest Hospital are very skilled. Dr. Young is an authority on both DBS and Gamma Knife. Diana Herring, MN, ARNP, the program director, who pretty much guides you through the whole process and programs the neurostimulator, is very skilled, positive and very encouraging.

It has been a great experience for me and has changed the quality of my life in a profound way. - Milt Lowe, Redmond, WA

The risks and benefits of DBS should be carefully reviewed with the neurosurgeon, and do include the very rare risk of bleeding. There is a risk of infection when any device is implanted in the body. A small risk of other side effects also exists in some cases which must be balanced against therapeutic benefits during programming sessions. The greatest benefits from DBS are achieved with a team that has plenty of experience, accurate targeting to place the lead in the specific area of the brain, and good, solid DBS programming experience.

About the Author

Diana is the program manager for the Deep Brain Stimulation Department at Northwest Hospital & Medical Center, located in Seattle, Washington. She enjoys working with DBS and people who have various movement disorders.

For further information on the Northwest Hospital DBS Program and Team, please view the web page:

http://nwhospital.org/services/neuro_deepbrain_stim.asp

Survey of Essential Tremor

By Esther Baldinger, MD

Spikes & Spasms Note:

Dr. Baldinger's Essential Tremor Survey is located online at:

http://www.surveymonkey.com/s.aspx?sm=7yBDntiGTekKkhN6gVvBVg_3d_3d

This online survey is easy to use, and has been designed with the survey participant in mind. Multiple choice questions include Comment fields which allow participants "the Option to add Other choices," and to also make comments.

"Some questions will require only a Yes or No, or straightforward answer, but others will allow you to express your own ideas...No information will be used; shared or published that identifies any individual...Please fill in the survey only once."

Dr. Baldinger's article provides same or similar survey questions for those willing participants who do not own computers or whose computers may not allow them to access an online survey. To participate in the survey offline, please print and complete the questions and then mail to: Esther Baldinger, M.D., 8118 21st Avenue, Brooklyn, NY 11214.

Essential Tremor (ET) is a common problem, but many of the features of this disorder remain unknown. If more was understood about ET then ideally better treatments could be made available and the issues of slowing or stopping progression could be addressed.

A very important question is whether all ET patients have the same disease. Three genes (so far) have been associated with ET, but there is no information about whether people with one type of ET-gene look or act differently from those with another ET-gene. Does race or ethnicity play any role? In addition, we do not know if substances in the diet or environment can produce ET or influence progression. Do lifestyle choices like work, hobbies, sports, and even sleep make a difference?

"A very important question is whether all ET patients have the same disease."

What follows is a survey to help learn more about ET. It may be the first of many if the information leads to more questions and new ideas. Some questions will require only a yes or no, or straightforward answer, but others will allow you to express your own ideas. A summary of the results will be published in this newsletter. No information will be used; shared or published that identifies any individual. Your candor is appreciated. Please fill in the survey only once.

We are still recruiting patients for the study of the effect of Riboflavin on ET. Please contact me (Esther Baldinger, M.D.) at (718) 232-1570 if you can make four visits to Brooklyn, New York.

Thanks for participating.
Esther Baldinger, M.D.

1. How old were you when you first noticed shaking of your hands?

2. How old were you when you first noticed shaking of your head? Voice? Jaw?
3. At what age did the tremor interfere with daily activities, or cause embarrassment?
4. Does anyone else in your family have tremor? If yes who? What country did they come from? What is your ethnic or racial background?
5. How far did you go in school?
6. While you were in school what was your best subject? What was your worst? Do you sing or play a musical instrument?
7. Are you good at spelling, grammar, arithmetic, complex math, and reading?
8. What kind of work do you do now or if retired what did you do? If you had different jobs you can list them. Have you been exposed to any chemicals? If so, list them.
9. What do you like to do for fun? List sports, hobbies or whatever you like to do.
10. List a task that you find particularly easy.
11. Consider yourself before the tremor interfered with activities. Some people would describe themselves as "having all thumbs" are you one of those or would you say you were "good with your hands?"
12. Are you left or right handed or use both?
13. Do you exercise on a regular basis? What kind of exercise do you do?
14. Do you smoke? If yes how much daily? Do you drink alcohol? If yes how much daily?
15. How many hours do you sleep? Do you have a problem sleeping? If yes describe.
16. Do you have a food you really like and often eat? What foods do you try to avoid?
17. Do you have allergies? If yes, list allergies such as medications, foods, pollen, dust, insect bites or others.
18. Do you have pain? Where? What is the cause of your pain?
19. Do you get headaches now or did you at some time in your life? Were you diagnosed with migraine?
20. Do you have motion sickness? As a passenger can you read in a moving car?

21. Do you have hearing problems? Can you listen while on the phone with either ear?
22. Do you have balance problems? Do you get dizzy? Have you fallen? Describe your symptoms and the length of time you have had them.
23. How is your vision? If you have had visual symptoms, describe them and the length of time you have had them.
24. Would you describe your sense of smell as good or poor and if changed when did that occur?
25. Do you have or did you have cancer? If yes where? Did any treatment received for the cancer effect your tremor? If yes in what way? Did anyone in your family have cancer and where?
26. Do you suffer from high blood pressure? High cholesterol? Heart disease? Have you suffered a stroke, or heart attack? How have these conditions influenced your tremor?
27. List any other diseases you suffer from.
28. List the medications you take.
29. List the Vitamins you take.
30. Have your tried Riboflavin for ET? If yes have you noticed any benefit?

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. Dr. Baldinger attended SUNY Downstate Medical College, graduating Magna Cum Laude and AOA in 1977.

Dr. Baldinger's Essential Tremor Survey is located online at:

http://www.surveymonkey.com/s.aspx?sm=7yBDntiGTekKhkN6gVvBVg_3d_3d

Writer's Cramp: Therapeutics Perspectives

By Flavia Quadros Boisson Waissman, RPT

João Santos Pereira, MD

Spikes & Spasms Note:

Tremor Action Network is privileged to feature this international excerpt from the State University of Rio de Janeiro study, "Câimbra do Escrivão: Perspectivas Terapêuticas," courtesy of the Authors. The "full" research paper is available in both Portuguese and English at:

<http://www.tremoraction.org/studies.php>. TAN is grateful to Flavia Quadros Boisson Waissman and João Santos Pereira for granting permission to print the excerpt.

Abstract:

Writer's cramp has been recognized for at least a century, yet its treatment remains unsatisfactory because it doesn't have a specific therapeutic proposal. The use of drug therapy that act in a systemic way like GABA agonists and anticholinergics have not been found to be of reliable pharmacological benefit.

The latest attempt to treat writer's cramp has employed botulinum toxin. The use of splints can bring new results for the motor recovery of writer's cramp.

Writer's cramp:

According to Tsui et al in 1993 [3], writer's cramp is characterized by involuntary muscle contraction and may be painful in the upper limb when the patient writes, despite normal control of the limb in performing other activities. This may be associated with contortion of the wrist, elbow and shoulder.

Clinical Treatment:

Anticholinergic agents are employed in the treatment of this disorder and should be used in low doses. Other medications like GABA agonists, anticonvulsants, and

atypical neuroleptics are part of the therapeutic arsenal [7].

The introduction of botulinum toxin has revolutionized the treatment of focal dystonia. The duration of treatment effect for both botulinum toxin types (A, B) is approximately 3 to 4 months [7].

Non Clinical Treatment:

The first step is to alter the grip of the pen. Another way would be the use of an artifice to write [2].

Tas et al in 2001 [11] initiated physical therapy treatment in patients with claims of functional loss. The use of splints

at rest may be useful as an aid when there is extreme tension in the forearm and hand muscles. Splints can be made to correct hyperflexion of the distal interphalangeal joint [9].

Conclusion:

Due to limitations and variations of pharmacological therapeutics splints have been suggested as an alternative

for plagued upper limbs, especially for focal hand dystonia.

"The use of splints can bring new results for the motor recovery of writer's cramp."

Case Study:

This study was conducted in two phases, duration of four weeks each, two sessions per week for 60 minutes.

Patient shown in Figures 1-3 is of male gender, 24 years of age, occupation lawyer, with claims of 6 years of feeling weakness and tremor sensation in the right hand. In the last three years writing difficulties presented after writing a few hours, however without stopping the writing.

The dystonia consisted in extension of the metacarpophalangeal of the right index finger with upper displacement of distal phalanx on the pen as the patient began to write. The grip of the pen was between the index and thumb, which stayed in extension and abduction. In 2005 used clonazepam and botulinum toxin without other

concomitant therapy.



Figure 1

Proceedings:

In the first phase of the program physical modalities were used, relaxation techniques, body awareness, stretching, motor and sensory training for four weeks. At the end of this phase, protocols were applied to evaluate the dystonia, including functional tests of plagued muscles for evaluation of motor dysfunction.

In the second phase of the program specific splints were used on the plagued hand muscles in association with a hand skills program for writing exercises.



Figure 2

After training program

There was marked decrease in the movement of extension of the metacarpophalngeal joint of the right index finger, which demonstrates evidence of a greater motor control. There weren't dystonic postures in relationship to the extension of the index finger, nor was there pressure to grip the pen.



Figure 3

In a written report, the patient stated that he had 80% improvement in the development of writing in relationship to the quality of writing, due to the awareness of body posture and increased motor control in the handling of the pen. The patient further stated that after he was conscious of his posture, he established a linear relationship between quality of writing and emotional influence. In relaxed situations the quality of writing was better, whereas the opposite occurred in stressful situations.

About the Authors

Flavia Quadros Boisson Weissman is a physiotherapist, completing a Master degree in Functional Neurology at the State University of Rio de Janeiro. Flavia's specialty interest is rehabilitative research in writer's cramp (focal dystonia) at the Pedro Ernesto University Hospital.

João Santos Pereira, MD is an Associate Professor of Neurology, responsible for the Pedro Ernesto University Hospital Movement Disorders Section.

Feedback is welcome. Readers are invited to ask questions or send comments to:

flaviaqbw@yahoo.com.br

jspereira.md@uol.com.br

Finding the Meaning of Dystonia

By Terri Sterling, MSP

Dystonia can be a difficult movement disorder to live with and often causes the victims to question its very purpose in our lives. Some of us redirected our lives as we took our anger and allowed it to create a positive force in our lives, which resulted in a college education, a career in the health field, or a career in the helping profession. However, some people who experience Dystonia become depressed, remain confused, and cannot find a purpose for having this health problem. We ask ourselves: "What is the meaning of Dystonia in our lives?"

In order to answer our life-affirming questions, we first need to acknowledge that behind depression is a "Meaning Crisis." A Meaning Crisis is created by persistent uneasiness, irritation, anger, sadness about unfulfilled dreams, and a lack of meaning or purpose. Learning to think outside conventional wisdom can help you find a purpose and meaning for having Dystonia.

Children dream of becoming doctors, lawyers, nurses, police officers, mothers and fathers. What role did you act out as a child? Did you want to become an artist, writer, or scientist? Perhaps, the Dystonia has stopped you from fulfilling your dreams or dreaming at all or maybe it is the thoughts you have about it. Maybe a well-meaning adult told you it would be too hard to fulfill your dreams and you would starve in the process, so you gave up the essence of your dreams and became compliant. Your inner child can help you become creative and find meaning in your life once again.

Our job is to find how meaning comes and goes, what keeps us going, and why meaning vanishes in our lives. You can force life to mean what you intend it to mean and you can choose to create meaning in your life by changing the way you think. Our inner dialog can lead us to an unfulfilled,

limited life instead of one filled with happiness because we are the makers of our own dreams. You can decide to take life seriously and to make it matter or you can hide behind closed doors in depression and loneliness. The meaning of your life is up to you and you must force meaning into your life. What do you want your life to stand for? What is important to you and how can you incorporate that into a personal creed to live by? Perhaps, your plan is to write deeply about your feelings and experience, or maybe you can passionately paint about it and lead an authentic life. Maybe your Dystonia can motivate you to fulfill your dreams and live life to the fullest. You could take your anger, write about it, turn it into a book, and publish it. Maybe you have been blessed and the meaning of your life is closer than you think.

"Learning to think outside conventional wisdom can help you find a purpose and meaning for having Dystonia."

I needed Botox® for my Dystonia and my insurance company would not pay for it at that time. The church in my town discovered my plight and anonymously raised the money to pay for the Botox®, so I could continue to help children in foster care. I had the Botox® shots in my neck because of

their help, but I received a much larger gift; an unforgettable gift. I would walk around down town, looking into the face of each stranger, and silently cry because I realized that people really did care and I was important to them. I learned that strangers could bring hope, unconditional love, and that I no longer needed to live in fear of them. I may not have learned this valuable lesson any other way but through this experience. I stopped being so afraid of the world and learned that unconditional love really did exist and that my Dystonia really had a purpose.

I can choose to become depressed over jobs I have lost due to people's fear or prejudice acts, or I can realize its higher purpose. When I lost my job due to a lack of accommodations, I learned to take risks by telling my dreams and to make meaning in my life again. I began to realize that if I reached out, in an authentic way, that people would want to help me fulfill my dreams. My recent

crisis led me to open my business, Inspiration, where I am a Creativity Coach who works with artists, writers, creative souls, and people with movement disorders. I work with people who want to increase their creativity, become unblocked, and find the purpose or meaning in life through authentic creativity.

About the Author

Terry Sterling is the owner of Inspiration, a private coaching business for people who are creative or who have movement disorders. She has a masters in psychology, 14 years of experience, and is a trained Creativity Coach. For more information about Terry, visit her website at http://www.freewebs.com/terris_inspiration/.

Terry can be reached at terricreativity@yahoo.com. Be sure to add that you are a reader of The TremorAction.org Newsletter.

JobEnable: Web Site Links Disabled Job Applicants with Job Opportunities

By Matt Lawrence

If you are searching for employment, make JobEnable.com (www.jobenable.com) the next stop in your internet travels. Recently launched at the World Congress on Disabilities Expo in Washington, DC, JobEnable.com is a new employment web site that connects people who have disabilities with employers interested in hiring them. Candidates can post their resumes, search the database for job openings and apply for jobs online. Employers are able to post jobs and search the resume database for qualified candidates that fit their organization's needs. The service is free to all job seekers, while employers pay a reasonable fee to post their jobs.

JobEnable.com was developed based on Matt Lawrence's vision of assisting people with disabilities in obtaining employment. Matt developed dystonia, a progressive neurological disorder, at the age of 13. It has progressed to affect his speech and fine motor movements. He earned his bachelor's degree in Journalism from Stephen F. Austin State University in Nacogdoches, Texas and went on to graduate school, taking courses in Counseling, Educational Psychology and Social Work to assist him in improving the lives of persons with disabilities.

For Lawrence, every day is about overcoming his own personal disability and using his talent to assist others with disabilities to obtain employment. He joined NetworkIP (www.networkip.net), a communications technology provider, in 2006, bringing with him the idea for this web site. NetworkIP has joined Matt by supporting his vision and is underwriting the JobEnable web site.

"As someone who felt unfairly treated because of my disability while seeking employment, I'm thrilled to be

working at NetworkIP where I am given the opportunity to use my talent and skills for the benefit of the company as well as the disabled community," said Lawrence.

"Thousands of very talented individuals like Matt happen to have a disability," added Pete Pattullo, NetworkIP CEO. "Everyone should have the opportunity to fully participate in the job marketplace. That's why NetworkIP is proud to support Matt's vision of assisting people with disabilities to obtain employment."

NetworkIP has assigned a team of developers to work with Matt and has reached out to prospective employers and non-profit organizations to support JobEnable.com.

"Everyone should have the opportunity to fully participate in the job marketplace."

JobEnable.com has the support of members of Congress, including Rep. Kenny Marchant (24th District, Texas), who wrote, "JobEnable.com is a valuable resource for anyone who feels they are being judged by their limitations instead of their abilities."

About the Author

Matt serves on the Junior Advisory Council and the Dystonia Advocacy Coalition for the Dystonia Medical Research Foundation. He has also spoken to Congress and members of the Senate on behalf of dystonia. He also has been a speaker at The Children and Family Dystonia Symposium.

For more information, please visit www.JobEnable.com.

For more information about NetworkIP, please visit www.NetworkIP.net.

California Telephone Access Program

By Casey Kho

Do you or anyone you know have difficulty using a standard telephone?

If you answered Yes to the question, you can benefit from my coming to your organization and providing **FREE** information regarding our **FREE** services.

My name is Casey Kho and I am an Outreach Specialist with the California Telephone Access Program (CTAP), a state-funded program of the California Public Utilities Commission that provides specialized telephones and services at no cost to qualified California residents who have difficulty using standard phones. Why are our services and equipment free? This is because our program is funded through a small surcharge that appears on all California residents' monthly telephone bill (California Relay Services and Communication Devices Funds).

To qualify, you **must**

1. Be a California Resident
2. Have existing residential Telephone Service
3. Complete a CTAP Certification Form, including your doctor's signature that certifies that your difficulty seeing, hearing, moving, speaking, or remembering makes it difficult to use a standard telephone.

For a Chinese Certification Form, call us at 1-866-324-8747 (Mandarin) or 1-866-324-8754 (Cantonese), Fax 1-800-889-3974. For English, call 1-800-806-1191 or clip a Certification Form from the coupon section of your Yellow Pages. After you have been approved for your new phone, you can call our Call Center to have the phone shipped to you or you can visit a service center in your area to try out the phones and pick up the right phone for you.

For more information about our program or to arrange a demonstration (English, Mandarin, and Cantonese) for your organization, please contact me.

About the Author

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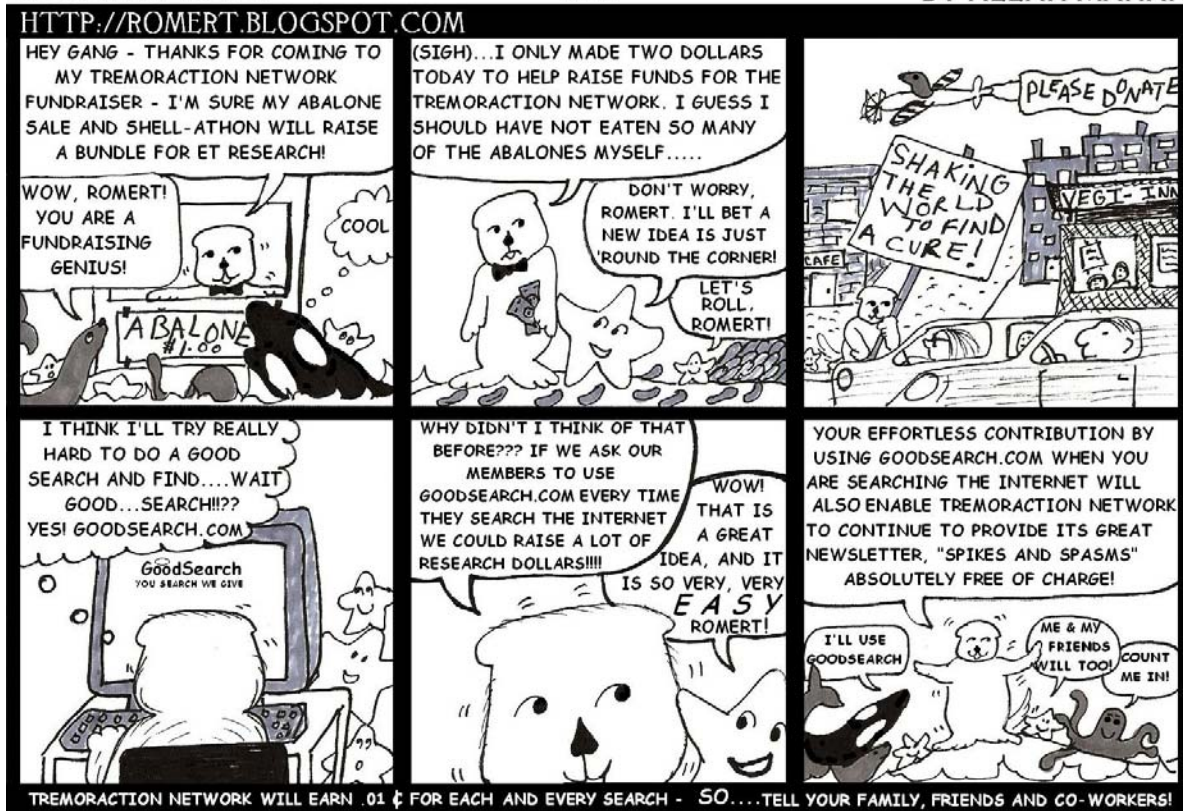
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"Provides services to qualified California residents who have difficulty using standard phones."

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

ROMERT THE ESSENTIAL OTTER ©2007

BY ALEAH MAHAN



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