

NSDA Southeast Region Newsletter
September 2006

JOURNALING

One way to get frustrations and other feelings associated with SD out is to write them down in a journal. One person reports doing that for years and finds it extremely helpful. Nothing fancy, just the use of a black composition notebook bought from the dollar store. Something you might try if the spirit moves you.

SPEAKING OUT FOR SD

Mary Bifaro of the Charlotte, NC Support Group traveled to Birmingham, AL to speak to the Dystonia Support Group. She spoke about her personal SD story and the need for SD medical research. DSG leader Linda Mott mentioned that 37 people attended including out-of-state people from GA, MS and TX.

One of the Charlotte, NC support group members plans to show the NSDA DVD at her sorority organization next spring and invited Mary to join her there in speaking about SD. Mary will also speak at the China Grove NC Rotary Club on October 10, 2006.

Personal note: Mary has Abductor SD and did not respond to Botox injections. She finds it difficult to speak but gains strength when speaking about SD. She found the courage to public speak about SD because she has been encouraged by members of the NSDA community and believes very strongly in its mission.

WALK OVER THE GOLDEN GATE BRIDGE FOR SPASMODIC DYSPHONIA

A Challenge from California

Two support groups in CA are bringing attention to SD with a WALK OVER THE GOLDEN GATE BRIDGE FOR SPASMODIC DYSPHONIA.

The WALK, on Sunday, October 8th, also honors Dot Sowerby, whose dedication to the NSDA has been an inspiration to those of us who have SD.

Hope you will make a tax deductible donation to further research to find a cure for SD; to educate medical professionals, patients, and the public about SD; to support people who daily cope with the frustrations of communicating with everyone we talk to.

Contribution of \$15, \$25, \$50, \$75, \$100 or more if you can. Two anonymous donors have teamed up to MATCH ALL DONATIONS UP TO A TOTAL OF \$2,500. This means that your support will go TWICE AS FAR.

You can contribute online at www.dysphonia.org/join/ ; click on pull down menu and select The Walk Over Golden Gate Bridge or send a check to:

National Spasmodic Dysphonia Association
300 Park Boulevard
Suite 415
Itasca, IL 60143

CHARLOTTE SD SUPPORT GROUP TO PARTICIPATE IN FAIR

Members of the Charlotte, NC Support Group will participate at Bank of America's 3rd Annual Disability Awareness & Education Fair on October 3rd. This celebration of National Disability Awareness Month is sponsored by Team Bank of America Diversity Network and the Disability Affinity Group.

MOUSE STORY ...

A mouse looked through the crack in the wall to see the farmer and his wife open a package.

"What food might this contain?" The mouse wondered -he was devastated to discover it was a mousetrap.

Retreating to the farmyard, the mouse proclaimed the warning.

"There is a mousetrap in the house! There is a mousetrap in the house!"

The chicken clucked and scratched, raised her head and said, "Mr. Mouse, I can tell this is a grave concern to you but it is of no consequence to me. I cannot be bothered by it."

The mouse turned to the pig and told him, "There is a mousetrap in the house! There is a mousetrap in the house!"

The pig sympathized, but said, "I am so very sorry, Mr. Mouse, but there is nothing I can do about it but pray. Be assured you are in

my prayers."

The mouse turned to the cow and said, "There is a mousetrap in the house! There is a mousetrap in the house!"

The cow said, "Wow, Mr. Mouse. I'm sorry for you, but it's no skin off my nose."

So, the mouse returned to the house, head down and dejected, to face the farmer's mousetrap-- alone.

That very night a sound was heard throughout the house -- like the sound of a mousetrap catching its prey.

The farmer's wife rushed to see what was caught. In the darkness, she did not see it was a venomous snake whose tail the trap had caught.

The snake bit the farmer's wife. The farmer rushed her to the hospital and she returned home with a fever. Everyone knows you treat a fever with fresh chicken soup, so the farmer took his hatchet to the farmyard for the soup's main ingredient.

But his wife's sickness continued, so friends and neighbors came to sit with her around the clock. To feed them, the farmer butchered the pig.

The farmer's wife did not get well; she died. So many people came for her funeral, the farmer had the cow slaughtered to provide enough meat for all of them.

The mouse looked upon it all from his crack in the wall with great sadness.

So, the next time you hear someone is facing a problem and think it doesn't concern you, remember -- when one of us is threatened, we are all at risk.

We are all involved in this journey called life. We must keep an eye out for one another and make an extra effort to encourage one another.

NEW SUPPORT GROUP FOUNDED IN NASHVILLE

I'm happy to announce that the NSDA has successfully kicked off its first SD Support Group in the State of TN at Nashville. Gwen Davis is the Support Group leader.

ARTANE

Someone reported that their neurologist prescribed Artane, an anti-Parkinsons drug, to see if would help with the vocal spasms of SD. It proved to be only a very slight help and came with side-effects of fatigue and light-headedness.

LIVING WITH DYSTONIA - 12 STRATEGIES

Source: Dystonia Dialogue, Summer 2006, Vo.. 29, No. 2,- DMRF. Author is Mark Groves, M.D., a member of the DMRF's Mental Health Advisory Committee.

1. Increase Your Sense of Control

Become an active participant in your treatment. Do not defer all of the responsibility for your welfare to others. Investigate all treatment options.

2. Build and Maintain Relationships

Confronting an illness requires support from other people. Opening up and sharing your vulnerabilities and fears with friends, family members and health providers, Connecting with others who are living with Dystonia by participating in Support Groups, online chat rooms, and other activities can be tremendously helpful.

3. Seek Out Understanding and Empathy

Unfortunately many patients with Dystonia find it difficult to trust healthcare providers. Find multiple places where you can talk about your experiences and feelings and be understood.

4. Develop Your Sense of Identity

You are not your illness. Do not allow your identity to collapse into that of your Dystonia. Develop a more complex identity by pursuing your interests and striving to achieve your aspirations and goals. Consider counseling or psychotherapy if you need help identifying your goals and direction.

5. Treat Depression and Anxiety

Identify symptoms of depression and anxiety. If symptoms are present, seek treatment.

6. Promote Physical Well Being and Comfort

The body is the victim of Dystonia, not the individual. Sleep well, eat a balanced diet and exercise. Avoid excessive time in bed as it promotes fatigue and depression.

7. Sustain Hope

Find someone or something who motivates and inspires you; a role model, an admired hero, someone whose outlook on life helps lift your spirits. Of your friends and family, who gives a boost when needed? Spend more time with him/her. What activities energize you? Does religion or spirituality invigorate you.

8. Achieve a Sense of Accomplishment

If unable to work or continue highly-valued pursuits, one's self esteem or pride can suffer a blow. A sense of meaning and purpose are important. Be proud of any accomplishments you've made in the context of living with Dystonia. What pursuits give you a sense of achievement? Do more of them and help others if you can.

9. Combat Shame

Booster your self-esteem, and keep your chin up high. You should not be ashamed of your illness. Take advantage of any attention directed towards yourself- be bold and help others. Be a positive role model to others.

10. Break Down Obstacles to Your Freedom

When you find yourself saying I can't, ask yourself, is that really true? Is there a creative way to get it done? Break down the hurdles or

bypass them altogether. Consider assistive devices when they increase your freedom.

11. Partner with an Expert Team of Providers

It often takes a team of experienced professionals to treat Dystonia:

ENT; Neurologist; Psychiatrist/Psychotherapist; Speech Therapist;
Other health care providers;

12. Prioritize Pleasure

Quality of life is the ultimate goal of treatment for Dystonia. No matter how difficult life can be some days, you must seek out pleasure and fun. Antidepressants don't bring happiness (though they can be effective in treating depression). Connection with others, a sense of purpose and pleasure do. Celebrate your accomplishments.

BLUE CROSS / BLUE SHIELD INSURANCE and BOTOX

(as reported by the SD Support Group in the Dallas/Fort Worth TX area)

BC/BS was considering reclassifying Botox injections for Spasmodic Dysphonia as a cosmetic procedure in Texas. Thanks to Dr. Barbara Schultz and others, BC/BS has decided not to class this procedure within that category. So, for SD patients with BC/BS as your insurance provider in TX, this is truly a VICTORY. Last week, all BC/BS reps across the US discussed this matter when the issue was finally resolved. As you think about your insurance provider, this is something to keep in mind.

Scientists discover memory molecule: protein kinase M zeta.

(for those of you with other forms of Dystonia besides SD)

Scientists discover memory molecule: protein kinase M zeta. Finding May Have Applications in Treating Chronic Pain and Memory Loss.

Long term, this finding may some day have applications in treating chronic pain, post-traumatic stress disorder, and memory loss, among other conditions specifically disorders characterized by the pathological over-strengthening of synaptic connections, such as neuropathic pain, phantom limb syndrome, **Dystonia**, and post-traumatic stress.

