

NSDA Southeast Region Newsletter  
January 2007  
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Chairperson, US/Canada

Preface: I am always on the lookout for interesting articles for the broad audience of SD'er in the Southeast Region and across the US. If you come across something of interest, please send it to me. Thank You.

## **HELPING OURSELVES**

Charlotte, NC Support Group Leader and NSDA Director, Mary Bifaro, reported she and her Husband hosted the sixth annual holiday open house/NSDA fundraiser in December with Greensboro guests Dot Sowerby, Will Blum and local Charlotte members in attendance.

In all, 21 gathered for SD fellowship and a total of \$517 was raised for the NSDA. Please keep in mind the NSDA is the only organization dedicated solely to working with and Supporting the Spasmodic Dysphonia community.

It would be wonderful to see this fine example of 'helping ourselves' repeated over and over in The Southeast Region and across the US and Canada.

## **HELPING OURSELVES - having the right attitude**

This is a recent post from the Spasmodic Dysphonia Bulletin Board hosted by the NSDA. It is an excellent expression of having the right attitude for dealing with adversity.

"I have found the last year very difficult as my SD developed and worsened. I particularly found this holiday season trying. All the socializing, functions etc. Overwhelmed me. It literally became painful to

socialize. I could not grasp the happiness I felt in past holiday seasons and instead felt depressed a lot. I kept comparing how it use to be to what it is now.

Two things happened over the holidays that got me thinking. I met an old friend of my sister's

Who started to go blind several years ago in his early forties. He talked of his experiences.

There was the 'why me' phase, the anger, losing independence, depression and feelings of rejection

From friends. Other friends would talk extra loud to him or make silly suggestions about learning

Sign language. (This is like us learning braille.) He has now adapted to his condition and once again

Is his normal self. He can no longer drive and lives alone. He does not know when and if he will

Become completely blind as they don't know the cause. He has shown great courage moving on and

Resuming his life. It made me think how others suffering losses can teach us valuable lessons.

We are all in this together after all.

The 2nd thing I reflected on was a movie I saw called Rocky Balboa. In one scene Rocky's son is

Blaming his father for his unhappiness and lack of a strong identity. Rocky will not let his son

Get away with this. He tells him that life is full of punches and if you allow yourself to become

A victim and blame others or things for your unhappiness you will never move on but stagnate.

You need to pick yourself up and move forward. On that note, let us not dwell on the past and

What we can not change but pick ourselves up and move forward with courage and confidence to

A new year focusing on what we can still do.

## **(SURPRISING) SOCIAL SECURITY DISABILITY ADVOCATE**

I received the following as part of Newsletter from US Senator Mel Martinez of Florida.

### **Casework Corner**

**Karen, a Gulf Coast resident, had a hearing with Social Security for disability benefits in October 2006.** After not receiving a decision for several months, she contacted the Senator's office for assistance. A caseworker immediately submitted a Congressional Inquiry to the Social Security hearings office. Her file was reviewed and it was found that a favorable decision had already been recommended by the Judge. The official decision was mailed shortly thereafter.

If you have questions about a federal agency, please contact the Orlando Regional Office by calling (407) 254-2573 to speak with a member of the Casework Department. The toll-free number for Florida residents is (866) 630-7106. To find out more about how my office can help you, go to <http://martinez.senate.gov> or stop by one of our scheduled Community Office Hours in your area.

When people are having difficulty getting approved for Social Security Disability Insurance (SSDI), they sometimes follow the tv ads and contact lawyers. It seems that one other source of help may be contacting your United States Senator, at least in the State of Florida. I would have preferred that the Senator's office published an article on how his Casework Department fought for and won an appeals case for an applicant. However, it is encouraging to see that it might be possible to have a US Senator get involved in your case. What's to lose?

## MORE ON HELPING OURSELVES (A popular topic this month)

The NINDS division of the National Institute of Health (NIH) has several SD medical research Projects that need volunteers. Here is an opportunity to help people with SD, including yourself!

NIH pays the cost for all the exams, procedures, tests, etc. They will also pay for travel expenses after your first visit. You must be fairly healthy, not having anything like heart or lung problems, brain disorders, etc which could distort the test results.

Go to the web site, [www.cc.nih.gov](http://www.cc.nih.gov) and select 'Participate In Clinical Studies' in the upper right corner to learn more about it and what studies are available. If you have any questions, you can contact NIH/NINDS research Sandy Martin at phone number 301-402-1109 or email her at [martinsa@ninds.nih.gov](mailto:martinsa@ninds.nih.gov).

## OPEN QUESTION, re; TOPAMAX

An SD'er said:

"My neighbor has an elderly uncle who has had SD. For a number of years, he was treated with Botox. Recently, he saw his uncle and he was symptom free. He claims to be receiving an oral medication "Topamax - 25mg" which has relieved his SD completely. I have googled this medication and it is an anti seizure med usually prescribed for eplipesy. I can't find any references to SD regarding it. Has anyone heard of this course of treatment? Unfortunately, I can't get the name of the physician who is treating this gentleman."

Please send any comments on Topamax to me, re: [meldubovick@comcast.net](mailto:meldubovick@comcast.net)

**Please support the NSDA**

If you are not a member of NSDA, please take the time to join. The cost is \$35. Per year

And it is a way that you can fight back against SD, including the funding of SD medical research

Projects. Go to the NSDA web site, <http://www.dysphonia.org/> and click onto the right hand

Corner box, Join or Donate or write a check and mail to:

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

All contributions are tax-deductible. The NSDA is a non-profit 501(c)3 organization and its U.S. Tax ID Number is 38-2918042.

[www.dysphonia.org](http://www.dysphonia.org)

*Spasmodic Dysphonia (SD) is a neurological voice disorder that involves involuntary "spasms" of the vocal cords causing interruptions or straining of speech that affects voice quality.*