

NSDA Southeast Region Newsletter
December 2006
Mel Dubovick, NSDA SE Regional Coordinator and
Chairperson, US

Preface: I am always on the lookout for interesting articles from 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 meldubovick@comcast.net Thank You.

I ATTENDED MY FIRST SUPPORT GROUP MEETING

(comments from a first-time Support Group attendee)

I really enjoyed my first time joining in the Support Meeting Group. This was the first time that I had ever been around with others that sound just like me. I felt so welcomed and I had such a clear and better perspective on this unusual condition. Everyone was so nice and friendly and made me feel like I belonged. I believe that after hearing a lot of speaking from the group it really helped me to understand more and I appreciate that more than you know, especially the real communication of open talking. I spoke on a few subjects with questions and I got the info that I needed. I enjoyed the questions and direction with the meeting. Up to this point I had only been able to read about SD and I need to be honest and say a lot of folks out there have no clue and even describe the illness incorrectly with no real updates. I would like to send a special thanks to everyone for the invite and I will follow and join in again. I need this guidance and mostly the true insight to what really happens with this voice crippling disorder.

LETTER-WRITING CAMPAIGN and MOVEMENTS DISORDERS PATIENT SUMMIT

RESULTS IN AWARENESS ON CAPITAL HILL

The NSDA would like to thank all who participated in the Life in Motion (LIM) Congressional letter-writing campaign designed to raise awareness of movement disorders. More than 4,000 Americans from every state reached out to their Congressional representatives and educated them about movement disorders via this Campaign. Eighteen member organizations of the LIM Coalition, including the NSDA, elected to participate in the Letter-writing Campaign. Of the total 4,000 letters generated, these 18 organizations accounted for 2,729 of the letters sent to Congressional representatives. The organizations that drove the most letters were:

1. Tremor Action Network
2. Spastic Paraplegia Foundation
3. National Spasmodic Torticollis Association

In recognition of our organization's efforts, the NSDA received an educational grant reflective of the number of letters generated by our membership. We hope in the future more members will participate in these types of activities!

In addition to the Letter-writing Campaign, the first-ever Life in Motion Movement Disorders Patient Summit was held in Washington, D.C. on September 14. It was attended by more than 50 patients, advocates, organizations, health care professionals, media and congressional representatives.

Participants came to discuss ways of improving care for the more than 40 million Americans affected by movement disorders - that is more than twice the number of people with diabetes and more than four times the number of those surviving cancer. Congressman Danny Davis (D-IL), the keynote speaker at the Summit and sponsor of legislation to designate October as National Movement Disorders Awareness Month, spoke about the struggles people with movement disorders experience while seeking a diagnosis. He also noted that the Summit and Movement Disorders Awareness Month is meant to call attention to these devastating conditions and demonstrate why resources are needed to help people receive faster diagnoses and effective, up-to-date treatment.

UNIV. SEATTLE-WASHINGTON RESEARCH STUDY ON SD

The NSDA presents information on this research study in order to further the scientific understanding of Spasmodic Dysphonia, but the NSDA does not endorse or recommend participation in this or any other medical research studies.

This is an online study of SD being conducted by investigators at the University of Washington in Seattle. They are studying the impact of SD on involvement in life activities, i.e. speaking in different situations in this case. Participants will be asked to complete three questionnaires and one on background information about themselves and their SD history. It is estimated that participants will take about 60 minutes to complete the questionnaires (I finished in half that time). If you are interested in participating or need additional information, please contact Carolyn Baylor, contact info shown below. (if you choose to use e-mail, please be aware they

cannot assure the confidentiality of information sent by e-mail):

Carolyn Baylor, Ph.C., CCC-SLP

Email: cbaylor@u.washington.edu

Phone: 206-755-2247

note: The deadline for completion of this questionnaire is 12/31/06

(this study has a lot of questions but they are sort of repetitive and can be answered quickly.)

A GOOD THOUGHT

(sometimes we need to be reminded)

A well-known speaker started off his seminar by holding up a \$20.00 bill.

In the room of 200, he asked, "Who would like this \$20 bill?"

Hands started going up.

He said, "I am going to give this \$20 to one of you but first, let me do this.

He proceeded to crumple up the \$20 dollar bill.

He then asked, "Who still wants it?"

Still the hands were up in the air..

Well, he replied, "What if I do this?"

And he dropped it on the ground

and started to grind it into the floor with his shoe.

He picked it up, now crumpled and dirty.

"Now, who still wants it?"

Still the hands went into the air.

My friends, we have all learned a very valuable lesson.

No matter what I did to the money, you still wanted it

because it did not decrease in value.

It was still worth \$20.

Many times in our lives, we are dropped, crumpled,
and ground into the dirt

by the decisions we make and the circumstances that
come our way.

We feel as though we are worthless.

But no matter what has happened or what will happen,
you will never lose your value.

Dirty or clean, crumpled or finely creased,

you are still priceless to those who DO LOVE you.

The worth of our lives comes not in what we do or
who we know,

but by WHO WE ARE and WHOSE WE ARE.

You are special - Don't EVER forget it."

Count your blessings, not your problems.

"And remember: amateurs built the ark ..

professionals built the Titanic.

If God brings you to it - He will bring you through it.

TAX BENEFITS OF DONATING STOCK TO THE NSDA

Based on an article from *Dystonia Dialogue* magazine, Winter 2006

There is a potential tax benefit to donors of appreciated stock to a 501(c)(3) not-for-profit organization such as the National Spasmodic Dysphonia Association (NSDA).

Let's say you are interested in donating \$10,000 in cash to the NSDA. This cash donation would provide you with a charitable deduction based on your tax bracket. If you were to sell \$10,000 worth of appreciated stock purchased one or more years ago for \$2,000 and write a check to the NSDA for the appreciated amount (\$10,000), you would generally be required to report and pay 15% capital gains tax, as well a state tax on the \$8,000 profit.

On the other hand, if you give the stock directly to the NSDA, you will receive the same \$10,000 and you are EXEMPT from paying any capital gains tax.

There are of course, a few caveats. I recommend you consult your tax advisor before making a stock donation to the NSDA.

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.

Merry Christmas and/or Happy Hanukkah!!!

Save the Date: May 5, 2007 NSDA Symposium