



NSDA'S 2007 LEADERSHIP DAY RECAP

Crowne Plaza, White Plains, NY

May 4, 2007

Our 3rd annual NSDA Leadership Day was a great success! Thank you to the 10 Board members, 8 Regional/Assistant Regional Coordinators; 5 Support Group Leaders, 2 Area Resource Persons, 2 Bulletin Board Moderators, 2 Guests, 2 Staff Members, and the Executive Director of Dystonia Australia whose active participation made this day so successful. The relationships that were built and the great camaraderie and information that were shared have strengthened the NSDA's leadership community. Thanks to Karen Feeley for moderating with so much passion, knowledge, skill and grace.

This year's Leadership Day focused on "turning ideas into actions". The goals for the event were to share information on the work being done by NSDA leaders; to build a sense of community among our leaders; and to develop action plans for implementing new initiatives. The following activities helped us achieve those goals:

- Participant introductions enabled us to hear each others' interesting stories, get to know one another, and strengthen our sense of community within the leadership group of NSDA.
- RC Chairperson, Mel Dubovick, gave an informative talk on how NSDA has launched new SD support groups. Mel led the effort over the past year to launch a now-proven model for how to start new support groups. Mel is happy to assist anyone interested in starting or strengthening their support group.
- Assistant RC of the Mid-Atlantic Region, Minerva Gordon, inspired us with her stories about how she has successfully raised awareness about Spasmodic Dysphonia. In talking about how she managed to get SD in six newspapers, on TV, and in front of the government (through Proclamations), she stressed that we need to be persistent, to think of SD as a product that we are trying to market, and to give the media as much information as possible when making the contacts.
- Simultaneous breakout sessions allowed Regional Coordinators and Support Group Leaders to work as individual groups on issues of concern to them. In addition to each group discussing their roles and responsibilities, they prepared for a group discussion of how they could best assist each other. Thanks to Mel Dubovick for leading the Regional Coordinator discussion and to Lylia Bennett and Mary Bifaro for leading the Support Group discussions. The results of these discussions are provided on the attached notes from the flip charts.
- Three panelists spoke of how they implemented new fundraising initiatives. Stephie Mendel showed pictures and explained how she organized the very successful "Golden Gate Bridge Walk" last fall. Laurie C. provided a template and explanation for conducting a successful letter-writing campaign. Mary Bifaro talked about fun and easy fundraising ideas she has conducted, like her eagerly anticipated annual holiday open house/NSDA fundraiser which she has hosted for the past six years.
- Action Planning breakout sessions covered the areas of: membership, awareness, fundraising, support groups and advocacy. Within small groups, participants came up with an activity in one of these five focus areas and determined the goal, next steps, critical success factors, and timelines that are needed to

turn the idea into reality. Each table then reported on its action plans. A summary of the ideas generated has been compiled and is being sent here as an attachment.

- NSDA President, David Barton, briefed us on other activities and events occurring within NSDA, including (1) our involvement in the Dystonia Advocacy Coalition; (2) the establishment of a Scientific Advisory Board for the purpose of advising on research matters and the awarding of small seed grants to attract SD researchers; (3) the proposed establishment of a new SD Validation Study to establish better criteria for the diagnosis of SD; (4) the progress of a new book on living with SD that our Special Projects Leader, Karen Feeley, is writing; (5) the possible sponsorship of several half-day regional symposiums in the coming year and (6) our continued participation in various medical and speech conventions that attract healthcare professionals with an interest in SD. He stressed that NSDA always needs volunteers for this important outreach work. David proudly announced that the 2006 Board Challenge surpassed its \$100,000 fundraising target.

The day closed by acknowledging the special achievements of members of our leadership community. Lylia Bennett received special recognition for her tireless work as Vice-President of the NSDA. Charlie Reavis will succeed her as VP for the coming year. Linda Cannon-Mott and The Dystonia Support Group of Birmingham, Alabama received the Midge Kovacs Annual Awareness Award for their dynamic growth to over 60 members in two years and for their outstanding outreach and awareness activities which include holding monthly meetings, hosting their own website, getting several articles placed in local papers, distributing literature and bookmarks to over 100 public libraries in Alabama, and participating in a health fair which reached over 400 people with information. All Leadership Day participants received Certificates of Appreciation in recognition for all that they do.

Participants received numerous handouts, including articles on public speaking; a list of the 2007 and 2008 Medical and Speech Conventions at which the NSDA will be exhibiting; guidelines for working the conventions; a Support Group Directory; sheets for contacting media; an article on leadership; Tips for SD Support Group Leaders; an article on hosting your first SD support group meeting; the Midge Kovacs Annual Awareness Award Criteria and application; SD Support Group Financial Statement; Healthcare Referral Survey; Support Group Activities Sheet; Dystonia Awareness Week materials; World Voice Day (April 16) materials; SD Fact Sheet; NSDA Information Sheet; listing of current clinical trials at the NIH related to SD; brainstorming ideas from the 2006 Leadership Day; and a sample flyer of an SD Support Group announcement. If you were not with us for Leadership Day 2007 and want to receive these materials, please contact our headquarters for them.

The NSDA is proud of the work of you, our leaders, and wants to continue to help you in your important mission. Feel free to contact the NSDA with any questions and concerns that you may have or any written materials you may need. The NSDA survives on the funding and volunteer efforts of its members; therefore the expansion of the list of paid members is critical to the continued growth of NSDA. NSDA leaders can play a vital role in speaking passionately about the importance of joining us in our NSDA cause. Together, let us continue to propel forward in service. As the only organization that is entirely dedicated to SD, it is up to us to keep the NSDA strong. As we continue to learn from each other, remember that NSDA – Nothing Stops Determined Advocates!