



## How the NSDA Delivers Support to Its Members

*Presented at the 2008 Southeast Regional Symposium in Tampa, Florida*

*By Mary Bifaro, NSDA Support Services Director*

Good afternoon. My name is Mary Bifaro. I am delighted to be here today at the NSDA's Southeast Regional Symposium. I lead The SD Support Group in Charlotte, NC and serve on the NSDA Board as Support Services Director. I've had abductor spasmodic dysphonia since 1987. It is a joy and a privilege to be involved with the NSDA community. We are making great strides under the capable leadership of our Executive Director, Kim Kuman. You in the SE Region are in good hands under the expert leadership of Regional Coordinator, Mel Dubovick, who also serves as the NSDA's Regional Chairperson. The NSDA is most grateful for its hundreds of volunteers who work tirelessly for our cause. We appreciate the dedicated involvement of many healthcare professionals who treat SD patients, including otolaryngologists and speech language pathologists. The Tampa area is quite fortunate to have local faculty at the University of South Florida who are experts in spasmodic dysphonia.

I've been asked to speak on the topic of how the NSDA delivers support to its members. I'd like to begin by quoting Donna Collins who serves the NSDA as its Midwest Regional Coordinator: "The NSDA has always been there for me throughout my experience with SD. I believe that attending support groups can help patients learn what treatments are available and how to cope with the disorder. The NSDA has given me empowerment to overcome the obstacles associated with SD. I hope to encourage others that they can live a good life with SD as I have."

The patient-driven NSDA was founded in 1989. It is the only organization in the world that is entirely dedicated to spasmodic dysphonia. Our mission has three parts: (1) to advance medical research into the causes of and treatments for spasmodic dysphonia (2) to promote physician and public awareness of the disorder through outreach and (3) to sponsor support activities for people with SD and their families through educational materials, annual symposiums, support groups and Internet resources.

The NSDA community consists of people with SD, healthcare professionals, dedicated volunteers, friends and families. Together, we work to grow our non-profit organization in pursuit of our mission. The NSDA realizes that impaired communication caused by SD symptoms may have an impact on personal relationships and careers. This is why the NSDA works hard to minimize the impact of SD and to help improve the lives of people with SD through outreach and support.

The NSDA's Internet Support Group reaches thousands of people and offers access to a network of individuals with SD from around the world. E-mail updates are sent to members to keep them informed about developments and events. The NSDA hosts the popular Spasmodic Dysphonia Bulletin Board in which members share their experiences, ask questions, and seek advice. Archive and search functions are also available. The NSDA website has information on SD

symptoms, diagnosis and treatment. There are sections on: healthcare referral, support contacts, publications, and events. There is an AOL Voices Chat group as well.

There are many ways that members of the NSDA community support one another. Hundreds of people gather for our annual symposiums which are full of camaraderie and information-sharing. The NSDA has nearly 50 SD support groups throughout the US plus others internationally. Our support group leaders list their contact information and events on our website. Local leaders work hard to develop SD communities. Some also take on fundraising, advocacy and awareness projects. They bring in speakers from the healthcare professions which treat SD and from other areas of interest. They represent the NSDA as speakers and advocates.

Our support network is ever-expanding. The NSDA has the staff and volunteer resources as well as the printed materials to help people wanting to serve the NSDA as a support leader. The NSDA support volunteers are SD patients who serve the NSDA community as: Board Members, Regional Coordinators, Support Group Leaders and Area Contact Persons. The NSDA is represented at various medical and speech conventions each year. Next month, the NSDA will host its fourth Leadership Day in conjunction with its annual symposium. This event allows our leaders to network and support each other. A quarterly newsletter called "Voices of Support" is sent to our leaders.

In addition to hosting its annual patient symposiums, the NSDA sponsors regional symposiums, such as this one in Tampa today. Regional symposiums are half-day events which provide another opportunity for the NSDA community to come together to learn and support one another. The NSDA will have hosted two regional symposiums between its 2007 and 2008 symposiums. The NSDA rotates its events geographically to allow its members to drive in from various parts of the US. It held a regional symposium in the Plains Region last fall and will hold another one in the South Central Region next June.

The NSDA membership has grown to thousands. The NSDA has funded several significant research projects. In 2007, the NSDA launched a new research program and established a Scientific Advisory Board. A listing of the current clinical trials on SD at the NIH is shown on our website. The NSDA has developed a partnership with the NINDS (National Institute for Neurological Disorders and Stroke) and the NIH (National Institutes of Health) in order to support SD research. The NSDA will continue with its important work until a cause of and the cure for spasmodic dysphonia has been found.

The NSDA staff at our headquarters office in IL works with hundreds of volunteers and acts as a liaison with various medical persons. Together with other movement disorder organizations, the NSDA is part of the Dystonia Advocacy Coalition. Healthcare professionals who treat SD are welcome to have their contact information put on our website. The NSDA has brochures, books, an award-winning DVD, and other educational materials. In addition, it sends out an official newsletter entitled "Our Voice" and other mass mailings to its membership. A new book on living with SD will be launched shortly. Hundreds of NSDA members contributed to an on-line survey giving input for the book.

The personal contact afforded by local support groups can decrease the loneliness and isolation that an SD patient might feel. Local support groups and NSDA events, such as their symposiums, allow SD patients to bring their families, friends and health care providers together to learn more about SD. The NSDA's Internet Support Group is convenient and always available, and

numerous mass mailings are educating thousands of people about SD. Whether on-line or real-world, support groups are vital communities. They are vehicles for people to share information and accomplishments as well as commiserate about shared problems. Without its dedicated volunteers, the service of providing support to the NSDA community would be impossible to accomplish.

Spasmodic Dysphonia can provoke a desire to isolate socially in order to avoid embarrassment. However, reaching out to others is the best way of dealing with SD. To facilitate this, the NSDA offers a voice and a caring environment to its members. It works hard to keep its membership informed and connected. In word and in deed, the NSDA tries to make sure that support is there when it is needed. The NSDA support volunteers are the front lines of NSDA representation. They encounter SD patients worldwide. They are the key players in awareness, education, fundraising and providing support. The NSDA's support volunteers are the backbone and lifeblood of our organization. I have the privilege of interacting with many dynamic support volunteers within our NSDA community. I can tell you first-hand that our acronym NSDA suits them well because **n**othing **s**tops **d**etermined **a**dvocates!

In closing, I urge everyone here to support the NSDA and get involved in our cause. Our grassroots, patient-driven NSDA needs our help. Together, let's soar by meeting our goals which are found in the letters of the word soar: **s**upport, **o**utreach, **a**wareness and **r**esearch. Together, let's "speak out for spasmodic dysphonia." In the words of Mahatma Gandhi, "The best way to find yourself is to lose yourself in service." Thank you for your kind attention.