



## Defining a Leader: Types, Qualities and Meanings

*Presented at the 2006 Leadership Day in Schaumburg, IL  
By Mary Bifaro, NSDA Support Services Director*

NSDA leaders are the backbone and lifeblood of the NSDA. Generally, they are SD patients themselves, and they have embraced the mission of the NSDA. They agree to work within our patient-driven organization at the grassroots level, and they demonstrate a passion for helping others affected by SD. These volunteers are on the front lines of representation of the NSDA, and they keep our organization alive and vibrant. National Volunteer Week takes place from 4/23/06 – 4/29/06. Its theme is, “inspire by example”. Volunteers have the power to inspire those they help as well as the power to inspire others to serve. Anthropologist, Margaret Mead said: “Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it’s the only thing that ever has”.

The tiers of leadership in the NSDA go from the Executive Director to Board Members, to Regional Coordinators to Support Group Leaders to Area Contact Persons. The Executive Director oversees communications among all the tiers of NSDA leadership, and the entire NSDA membership. The Board of Directors manages the affairs of the NSDA. The Regional Coordinators help to create a stronger network of information, communication and support within their regions. Support group leaders maintain local communities and provide vital support to those affected by SD. In areas where there are no local SD support groups, Area Contact Persons take inquiries from newly diagnosed SD patients. Each of these NSDA leaders serves an important role within the NSDA. They work interdependently. It is common for leaders to serve in more than one capacity. Fortunately, the tone of NSDA leadership is warm, personal, inclusive and supportive. This has been established because trust is at the core of our foundation.

The qualities of a leader are found in the 6 letters making up the word “leader”.

L: loyal to the NSDA cause, long suffering, longstanding, listeners; learners

E: educated about SD matters; energized by the vital work that they do; empathetic to the needs of those affected by SD; extend leadership roles to others; emotionally intelligent; effective; enjoy their work; enthusiastic

A: able to organize, motivate and coordinate activities and people; articulate about NSDA’s history, objectives and services; aware of their members and their needs; activists as they take on activities and projects in behalf of our mission; ask people to work with them, and ask questions about things that they’re unsure of; appreciative of the community in which they serve; advocates; adaptable; accountable

D: dedicated to the mission of the NSDA; dependable to their members and to the NSDA; developers of trust, ideas and the local communities they lead; direction setters

E: empowered by their acceptance and support within the NSDA community; e-mail savvy (usually); encouraging of others to join the NSDA and get involved with its activities; engaged in the work of the NSDA; examples to others

R: responsible for the activities involved with their role; realistic about the people they are dealing with; responsive to the requests of others; reporters to the NSDA on the activities and contact information of their members; risk-takers in the sense that they are willing to try something that they have never done before; role models

I'm sure that each leader present here today can insert other descriptors of the 6 letters in the word "leader". Overall, the NSDA leader feels connected to the NSDA. They assume responsibility for working in behalf of our organization. They take action and speak confidently in behalf of the NSDA. NSDA leaders feel grateful for the existence of our organization that served their needs. They want to see the NSDA succeed so that it can continue to help others affected by SD. Effective leaders manage themselves and their interactions with others well.

The meaning of the NSDA leader rests in the impact that they have in our community. Whether they step up to writing an article about SD, speaking to a service organization about SD, contacting the media about SD, advocating politically for SD, fundraising to advance medical research, representing the NSDA at a health fair, each action is significant. What matters most is that they serve other SD patients. Developing support group communities takes time and effort. Listening to the members, keeping in touch with them and demonstrating a passion for service are key elements. Acknowledging core support group members is vital. People come and go in support groups. Just when you wonder if people care about your support group, someone calls, writes or shows up with a contribution of some sort.

One of the greatest joys as a leader is seeing members move up in service to others. A highlight of many SD support group meetings is having members reach out to newly diagnosed SD patients with information and support. This happens again and again in our Internet support services. The NSDA leader supports the NSDA mission of raising SD awareness to the professional and lay communities, fundraising to advance medical research into SD and providing support to all those affected by SD. Look into the word "support" and you will find the two smaller words, "up" and "port". Therein lies useful tips for NSDA leaders. Be there to lift people UP and to provide a safe PORT in the storm of daily living with SD. In lifting people up, you will help them realize that they are not alone in their struggle. Some of those you reach will be encouraged to join you in your leadership efforts. Others will feel comfortable in referring others to the safe ports within the NSDA community, such as SD support groups. Booker T. Washington said, "If you want to lift yourself up, lift up someone else".

Effective leaders inspire others by touching their emotions. Effective leaders have emotional intelligence. They handle problems, listen to and connect with others. They understand the issues at hand and are team players. They are motivated and improve their skills over time with mentoring, practice and experience. They build personal relationships and facilitate the success of their groups.

I thank each of you for being here today and for your leadership within the NSDA community. I encourage each of you to find your unique voice within our NSDA community. As the only organization that is totally dedicated to SD, you have much to offer and much to take away from your service. With coordinated teamwork, we can all be going in the same direction. Our NSDA is grassroots and patient-driven. When I think about NSDA leaders, I go back to our acronym – NSDA. Aren't we so very fortunate that NSDA –nothing stops determined advocates!

## **TIPS FOR SD SUPPORT GROUP LEADERS:**

1. Communicate your mission of serving the local SD community.
2. Organize your thoughts and ideas on your role within the SD community.
3. Gather and read the NSDA printed resources, the NSDA Support Group Manual and the NSDA Information Sheet.
4. Familiarize yourself with all the elements of the NSDA website and the NSDA support website.
5. Become a regular reader of the NSDA general bulletin board.
6. Join the NSDA and encourage members to do likewise.
7. Contact local media for announcements regarding speakers and events.
8. Encourage members to participate in SD support group activities by attending meetings, participating in fundraisers, and awareness raising events.
9. “Walk The Talk”. Wear the NSDA lapel pin, awareness wristband, post on the bulletin board, speak to a service organization about SD, contact the media about writing an article on SD, write letters to politicians seeking support of SD research.
10. Encourage members who work for organizations with matching gifts programs to have their donations doubled.
11. Follow up with summaries of meetings and activities.
12. Thank your members for their participation and support.
13. Recognize those who step up and lead.
14. Avoid burnout by taking a break, exercising, and other relaxation techniques.
15. Use the leadership bulletin board for information and support.
16. Learn from other leaders. Mutually support one another and share program ideas.
17. Listen to your members and to your inner voice.
18. Develop relationships with SD patients and healthcare professionals. Consider using them as advisors, sources of referrals and information, and as speakers to your support group.
19. Whenever possible, attend NSDA’s annual symposiums.
20. Ask prospective NSDA members if you can send their contact information to the NSDA.
21. Talk about your local SD support group at Botox clinics and elsewhere.
22. Post your meetings and events on NSDA’s website, support section.
23. SD support groups often focus on providing emotional support, practical information, education and advocacy.
24. Share and delegate the work and responsibilities of the SD support group. Establish officers and committees if the group agrees to this structure.
25. Ask if the SD support group wants an internal contact list for members to be able to get in touch with one another between meetings.
26. Begin with small projects. Work your way up to more difficult tasks.
27. Stay in touch with the needs of your members.
28. Expect your SD support group to experience “ups and downs” in terms of enthusiasm and attendance.

29. Identify “gatekeepers” who come in contact with potential members. They may be otolaryngologists or speech pathologists. Visit them to ask them to refer people to your group.
30. Create a flyer for your SD support group. Carry it with you to give to people, and ask your members to do the same.