

NSDA Leadership Resources

We asked you how NSDA National could help you in your roles as leaders. Below are answers to your most frequently asked questions. This list will be updated annually as new resources become available.

Question	Answer	
	Go to:	To Find:
Where can I find new content to share with my group?	www.dysphonia.org/merchandise.php (Click on <u>Publications and Videos</u>)	<ul style="list-style-type: none"> • 2014 Symposium Overview: Minutes from the 2014 Patient Symposium • 25th Anniversary Booklet of the NSDA • REAL LIFE: SD and Unemployment: Information on unemployment with SD
	www.dysphonia.org	<ul style="list-style-type: none"> • NSDA News: The latest news and events about NSDA
	www.dysphonia.org/personal-experiences.php	<ul style="list-style-type: none"> • Personal accounts of people living with SD
	e-Voice newsletters (published quarterly and emailed to leaders)	<ul style="list-style-type: none"> • SD Victories
	http://www.dysphonia.org/leadership/	<ul style="list-style-type: none"> • NSDA Support Group Meeting Topic Workbook: Topic ideas and instructions for running meetings around specific topics • NSDA Support Group Activities Sheet: Form to share innovative meeting ideas with other SG leaders
How can I reach out to doctors in my area?	www.dysphonia.org/merchandise.php (Click on <u>Brochures</u>)	<ul style="list-style-type: none"> • NSDA Information Sheet: 1-page overview of NSDA • SD Fact Sheet: Answers to common questions • SD General Kit: Understanding SD: Brochure + newsletter • Understanding SD: Info about causes, symptoms and treatments
	www.dysphonia.org/merchandise.php (Click on <u>Awareness Materials</u>)	<ul style="list-style-type: none"> • Awareness posters • Waiting Room Literature Kit: NSDA brochures and a brochure holder for use in doctors' offices

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	Go to:	To Find:
	www.dysphonia.org/leadership/	<ul style="list-style-type: none"> • Awareness posters • Healthcare Provider Letter: Informs healthcare providers about SD and the NSDA • Healthcare Referral Survey: For healthcare providers to be included in NSDA referral list
Are there resources available that would help me learn more about the leadership role?	www.dysphonia.org/leadership/	<ul style="list-style-type: none"> • Code of Ethics: Ethics standards for NSDA leaders • Defining a Leader: Types, Qualities, and Meanings: Presentation on the characteristics of a successful and effective leader • The Importance of Support Groups in Living with SD: Presentation on why SD support groups are beneficial • Leadership Day Summaries 2007-2010: Minutes from prior year Leadership Days • SGL Committee Self-Intro 2007-2010: List of who is available to help support group leaders • Volunteer Leadership: The Essence of the NSDA: Presentation on the critical role of NSDA volunteer leadership • Support Group Manual: Detailed guidance for how to run support groups
What resources are available to share with those who contact me with questions about dealing with SD?	www.dysphonia.org/merchandise.php (Click on Brochures)	<ul style="list-style-type: none"> • Employment and SD: 2-page sheet with options for working with SD including a list of jobs that have lower voice demands • Insurance Assistance Approval and the Appeal Process: Booklet to assist with insurance approvals for BOTOX treatments • Job Interviews: Overview of options when interviewing for a

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<p>What resources are available to share with those who contact me with questions about dealing with SD? (continued)</p>		<p>job</p> <ul style="list-style-type: none"> • NSDA Information Sheet: 1-page overview of NSDA • Qualifying for Disability Benefits: Article on how to qualify for disability benefits • Resources for Personal Voice Amplifiers: 1-page information sheet on resources for personal voice amplifiers • SD Fact Sheet: Answers to common questions • Three-Fold Wallet Card on SD: Business card sized explanation of SD • Telecommunication Options for People with SD: 4-page overview of telecommunication options including operator assisted and non-operator assisted resources • Understanding SD: Info about causes, symptoms and treatments
	www.dysphonia.org/leadership/	<ul style="list-style-type: none"> • Vocational Rehabilitation: Information sheet on vocational rehabilitation services for SD
<p>How can our group raise money for the NSDA?</p>	www.dysphonia.org/merchandise.php (Click on Brochures)	<ul style="list-style-type: none"> • Tampa Bay Walk-a-Thon Sheet: Template for a pledge sheet
	www.dysphonia.org/leadership/	<ul style="list-style-type: none"> • Elements of the Letter Writing Campaign: Instructions on how to conduct a fund-raising letter campaign • Sample Letter for Letter Writing Campaign • Sample Picnic Raffle Flyer • Support Group Manual

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How can we increase awareness by utilizing the media and our government officials?	www.dysphonia.org/merchandise.php (Click on Brochures)	<ul style="list-style-type: none"> • NSDA Information Sheet: 1-page overview of NSDA • SD Fact Sheet: Answers to common questions
	www.dysphonia.org/merchandise.php (Click on Awareness Materials)	<ul style="list-style-type: none"> • NSDA Proclamations: Sample proclamation for Dystonia Awareness week • World Voice Day Proclamation: Sample proclamation for World Voice Day
	www.dysphonia.org/leadership/	<ul style="list-style-type: none"> • Suggested Letter from Support Group Leaders: Sample letter to reporter about <i>The King's Speech</i> and SD • Media Interview Tip Sheet: Tips on speaking to a reporter • Support Group Manual
How can we give presentations to speech language pathologist students?	www.dysphonia.org/leadership/	<ul style="list-style-type: none"> • Check-list of Points to Cover in Presentation to SLP: Outline of topics to present to SLP students
What resources are available that deal with employment and SD?	www.dysphonia.org/merchandise.php (Click on Brochures)	<ul style="list-style-type: none"> • Employment and SD: 2-page sheet with options for working with SD including a list of jobs that have lower voice demands • Job Interviews: Overview of options when interviewing for a job • Qualifying for Disability Benefits: Article on how to qualify for disability benefits
	www.dysphonia.org/leadership/	<ul style="list-style-type: none"> • Vocational Rehabilitation: Information sheet on vocational rehabilitation services for SD

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Is there a Support Group Manual?	www.dysphonia.org/leadership/	<ul style="list-style-type: none"> • <i>Support Group Manual</i>
Who would make good speakers for meetings and how can I enlist them to speak?	www.dysphonia.org/leadership/	<ul style="list-style-type: none"> • <i>Support Group Manual</i>
How can I maintain or increase participation in my support group?	www.dysphonia.org/leadership/	<ul style="list-style-type: none"> • <i>Support Group Poster</i>: Template for advertising meetings
Is there a list of medicines that are helpful for SD along with common side effects and interactions?	Support group leaders should refer members to the NSDA when appropriate for medical information. The Support Group should not attempt to provide medical advice relating to diagnosis, treatment, or drugs.	
What are some practical tips for running a support group? How should I structure a meeting? How can I enlist others in the group to volunteer?	www.dysphonia.org/leadership/	<ul style="list-style-type: none"> • <i>Code of Ethics</i>: Ethics standards for NSDA leaders • <i>Defining a Leader: Types, Qualities, and Meanings</i>: Presentation on the characteristics of a successful and effective leader • <i>The Importance of Support Groups in Living with SD</i>: Presentation on why SD support groups are beneficial • <i>Suggestions for Structuring and Maintaining a Group</i>: General tips about leading an SD support group • <i>Support Group Manual, “How to Organize an SD Support Group”</i>: • Notes from May 2011 Leadership Day

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Where can I find information about medical treatments for SD?	www.dysphonia.org/leadership/	<ul style="list-style-type: none"> • Botulinum Toxin Insurance Coverage Information: Guidelines for insurance approvals for BOTOX treatments • Botulinum Toxin Tracking Chart: Table for tracking BOTOX effectiveness
	www.dysphonia.org/merchandise.php (Click on Brochures)	<ul style="list-style-type: none"> • SD Fact Sheet: Answers to common questions • Understanding SD: Info about causes, symptoms and treatments • Treatment Options for SD: Surgical Procedures: Brochure describing surgical options • Treatment Options SD: Botulinum Toxin Injections: Brochure describing typical results of BOTOX for AB and AD patients
	www.dysphonia.org/treatment.php	<ul style="list-style-type: none"> • Explanation of treatment options (click on options on top left side of screen for details)
Is there a directory of doctors and speech therapists?	www.dysphonia.org/healthcare-referral.php	<ul style="list-style-type: none"> • NSDA Healthcare Directory
Where can I find information about current research studies?	www.dysphonia.org/videogallery.php	<ul style="list-style-type: none"> • SD Research Update: 4-part webinar series on current SD research • Research: Video of Dr. Christy Ludlow talking about SD research
	www.dysphonia.org/research.php	<ul style="list-style-type: none"> • Explanation of ongoing and future SD research (click on options on top left side of screen for details)
	www.dysphonia.org/merchandise.php (Click on Brochures)	<ul style="list-style-type: none"> • NSDA Brain Donor Registration Form: Registration form to become a brain donor for SD research

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	Go to:	To Find:
What resources are available that offer strategies for dealing with SD?	www.dysphonia.org/leadership/	<ul style="list-style-type: none"> • <i>Making Public Speaking Easier:</i> Tips on public speaking • <i>NSDA Support Group Meeting Topic Workbook:</i> Topic ideas and instructions for running meetings around specific topics. • <i>Toastmasters Speech by Gwen Pongracz:</i> One woman's experience living with SD
	www.dysphonia.org/merchandise.php (Click on <u>Books</u>)	<ul style="list-style-type: none"> • <i>Easier Done than Said: Living With a Broken Voice:</i> Ideas from SD patients for how to live with SD
Are there videos of speakers and webinars available?	www.dysphonia.org/videogallery.php	<ul style="list-style-type: none"> • <i>Video Gallery:</i> Collection of videos of speeches and webinars on SD topics
	www.dysphonia.org/merchandise.php (Click on <u>Videos/Tapes/CD</u>)	<ul style="list-style-type: none"> • <i>Understanding SD DVD:</i> Patient and healthcare provider interviews to discuss diagnosis, treatment, and research. Includes voice samples • <i>2008 Symposium DVD:</i> 2-disk set of the 2008 NSDA Symposium in Salt Lake City, Utah
Are there books available?	www.dysphonia.org/merchandise.php (Click on <u>Books</u>)	<ul style="list-style-type: none"> • <i>Speechless: Living with Spasmodic Dysphonia:</i> Biography of NSDA Board Member Dot Sowerby's experience with SD • <i>Easier Done than Said: Living With a Broken Voice:</i> Ideas from SD patients for how to live with SD • <i>My Day has Spasmodic Dysphonia:</i> Illustrated children's book by Mary Keller about explaining SD to children. • <i>Prince Bear and Pauper Bear:</i> Illustrated children's book based on the author's struggle with SD • <i>Bare Branches:</i> Poetry book including poems about having SD

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	Go to:	To Find:
Where can I go online to interact with others with SD?	www.dysphonia-bb.org/forums/sd/	<ul style="list-style-type: none"> • NSDA Bulletin Board: Moderated website for people with SD
	www.facebook.com/pages/National-Spasmodic-Dysphonia-Association/83870472487?ref=br_tf	<ul style="list-style-type: none"> • NSDA Facebook Page
What resources are available to help me to encourage others to become NSDA members?	www.dysphonia.org/members.php	<ul style="list-style-type: none"> • Why should I join the NSDA?
	www.dysphonia.org/about-nsda.php	<ul style="list-style-type: none"> • NSDA History, Mission, and Vision
	www.dysphonia.org/leadership/	<ul style="list-style-type: none"> • Benefits of Membership: 5 reasons to join NSDA • How the NSDA Delivers Support to Its Members: Presentation on ways NSDA helps its members • NSDA Overview: Contact information and key NSDA website URLs • NSDA Regional Structure: List of regional representatives and others who help support group leaders
Other than information contained on the NSDA and NSDA Leadership websites, how else does the NSDA help me lead my SD support group?	<ul style="list-style-type: none"> • “e-Voice” Electronic Newsletter • Leadership Day Meetings • Mentoring Support – colleagues, support committee, Leadership Bulletin Board, Regional Representatives • Patient Symposia • “Voices of Support” Newsletter 	
Where can I find a list of NSDA support groups?	http://www.dysphonia.org/support-groups.php <ul style="list-style-type: none"> • Select a state from the drop-down list. • Click the Search button 	Contact information for support groups and Area Contact People in a state