

NSDA SUPPORT GROUP MANUAL



**National Spasmodic
Dysphonia Association**

Research and Education for Our Voice

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INTRODUCTION

We are very pleased to welcome you into the ever-expanding network of the National Spasmodic Dysphonia Association and to assist you in forming a Support Group.

The National Spasmodic Dysphonia Association (NSDA) originated in 1989 and was founded by Larry Kolasa and Daniel Truong M.D. They financed the NSDA until it received a seed money grant of \$5,000 from the Million Dollar Round Table Foundation in 1990. The first year was spent developing the newsletter, establishing the non-profit status, recruiting volunteers and working with support groups.

The first of the annual NSDA Symposiums was held in 1991. After receiving the first national media coverage about SD in 1991, the NSDA responded to the many inquiries for information and support groups and grew in the process. The administrative functions started with a small office setup in Michigan in 1993. Then, the Dystonia Medical Research Foundation managed the NSDA from June 1997 to the end of 2004. As of January 1, 2005, the NSDA is newly independent again.

The NSDA membership has grown to thousands. We continue to promote public awareness of spasmodic dysphonia and to promote the care, welfare, and rehabilitation of those with spasmodic dysphonia through education and research. Through our annual patient symposiums, media mailings, research contributions, award-winning video and updated DVD, we strive to increase awareness, membership, and support opportunities for our members.

We are pleased with your interest in starting a Support Group and will do everything we can to assist you in the formation.

Ideas for achieving public awareness and giving patient support are infinite. With compassion and available medical knowledge, the staff and volunteer leaders will assist Support Groups in helping its members to find hope and a better tomorrow. Members can help with campaigns and events to fund medical research grants so that some day there will be no need at all for the NSDA as it presently exists. The NSDA will continue with its work until the cause of and the cure for spasmodic dysphonia are found.

Please understand that not everyone is comfortable in attending a Support Group. An individual may prefer to contribute in other ways such as by donating and raising funds for research or by attending one of the annual symposiums. Or, they may be content with receiving the latest medical news through the publication of the Association brochures or the NSDA Newsletter *Our Voice*. Others may keep in touch with NSDA activities through participating in forums provided by the Internet Support Group. People do want to receive announcements, updates, and invitations to events held locally. The NSDA has a place for everyone. We welcome everyone's interest.

CHAPTER ONE:

How to Organize an SD Support Group

A. Understanding the Goals

The goals are to:

- Encourage a better life for people with Spasmodic Dysphonia (SD) who strive to live as fully as possible while coping with a chronic voice disorder.
- Promote public education to generate better awareness and understanding of people with SD.
- Stimulate increased access to and availability of information and resources for people with SD and their families.
- Promote professional education and research which seeks to uncover the causes and improve the treatment of SD.
- Facilitate communication with and provide support for people with SD, as well as to provide information, treatment options, and a better understanding of SD.

B. Materials

Each new group at no charge will be given all basic medical information brochures and DVDs, such as "What is Spasmodic Dysphonia?" as well as copies of the National Spasmodic Dysphonia Association Newsletter, *Our Voice*.

C. Personnel/Assistance

Depending on the circumstances, a regional coordinator may be available in person to assist with the formation of a new Support Group.

In all situations, the NSDA staff at our Headquarters office and leadership volunteers will assist with giving telephone and e-mail advice and encouragement and will act as liaison with various medical persons.

In turn, the Leader will be expected to furnish to Headquarters a list of the Support Group attendees so that they may be added to the mailing list to receive the NSDA Newsletter.

D. Finding Like-Minded People

1. Leadership Attitude

The Leader should be excited about what he/she is doing and personally optimistic and not easily discouraged by a fluid and changing membership.

Most support groups are informal. The leader is responsible for orderly and pleasant meetings while encouraging others to participate. The leader should recognize that people come and go as their interests and needs are met. The leader should make attendees comfortable with flexible membership requirements and should operate an "open door" policy for members and their families.

2. Sources of Membership

Enlist the cooperation and assistance of local speech pathologists, otolaryngologists, and voice treatment centers and neurologists and their staffs. These voice specialists will know of others who are interested in sharing common feelings and perceptions. Since names of patients are confidential, it may take time initially for these medical professionals to ask others of their interest. However, very soon, people will respond.

To locate professionals in your area, first check the NSDA website under "Healthcare Referral." There are listings by state of healthcare professionals who treat SD.

You may also want to check the following listings in your yellow pages: speech pathologists, speech therapists, speech and hearing centers (sometimes available at your local hospitals and universities), otolaryngologists (ear, nose, throat specialists) and neurologists. Write or call these sources and tell them that you are forming an SD support group. Ask them to recommend the group to their SD patients.

Ask the National Headquarters staff for names, phone numbers and addresses including e-mail of area contact persons.

These are people who have consented to have their names open to calls and inquiries. They may know of other persons in your geographic area who wish to be part of a group.

Headquarters will be pleased to send flyers to patients in your area about the establishment of a local support group. It will also send out a mass e-mail to the people in your area who belong to the On-Line Support Group.

E. Defining the Purpose of the Support Group

After learning who shares your interest in having a support group, the members of the organizing group will want to talk about the reasons they want to start a group, with such purposes as:

- to support one another and guide one another in learning how to cope with their voice problems, interpersonal relationships, changes in self-image, self-esteem, and treatment;
- to call upon medical resources to develop strategies in dealing with this chronic condition of spasmodic dysphonia and to receive information about treatments and therapies;
- to learn what medical advances are being made (and how we can contribute to the fund-raising for grants, collectively raising money for medical research);
- to keep up to date on current laws and government regulations affecting the disabled;
- to increase awareness about spasmodic dysphonia among the medical and lay communities;
- to offer companionship, valuable lessons, adaptive strategies and, thereby, lessen loneliness and isolation, thus giving of ourselves and gaining by giving; for, "We are not alone."

F. Basic and Underlying Issues for Support Groups

Author Linda Noble Topf in her book, "You are Not Your Illness: Seven Principles for Meeting the

Challenge" reminds us to look inside of ourselves for validation and worthiness, not at the illness that has affected us. By doing this, we come to see that everything in our life is our teacher, even spasmodic dysphonia. For some, this can be a turning point in which we want to learn and face the challenge presented to us. Spasmodic dysphonia was not planned, but it has happened; so we must accept it and move on.

This acceptance means dealing with our spasmodic dysphonia voice limitations, our anger, and our grief. We have to honor that our illness is a part of us.

Acceptance is letting go of pretenses and illusions of life the way it should have been before spasmodic dysphonia, and, having the courage to face life as it is now.

Instead of concentrating on the catastrophes of what life has brought forward, we can participate fully in life whether we are healed or not. The end result is accepting and loving ourselves, not in spite of our spasmodic dysphonia but maybe because of it.

G. Guidelines for "Self-Help" Discussions

Some support groups have found that it is helpful to set some general guidelines to aid in group discussions. Self-help discussions may be a very new experience for some members who might be used to the formalities of business meetings or for those who have been in psychotherapy groups. Here are some guidelines that you can consider supplying to new members:

What we share about our personal lives is confidential; what is said stays in the group.

We encourage members to share their strengths, skills, insights, successes and their hopes.

We encourage "I" statements. Everyone speaks for themselves alone.

It is important that we actively listen when someone is talking and avoid having side conversations.

Each person has the right to speak up - or not to participate, especially in a voice disorder group.

We share the responsibility for making the Support Group work.

Each member's right to confidentiality is respected.

The primary responsibility of the group leader/facilitator is to ensure that the group is a comfortable, "safe harbor" for its members to disclose their personal stories, feelings, fears, etc. Secondly, the facilitator holds the responsibility of seeing to it that each person gets a fair chance to participate; to use her/his people skills to cut down on irrelevant discussions, and prevent the domination of the group by individual members.

It is recognized that the leader/facilitator is not the "expert."

We encourage members, having benefited from the help of the group, to offer their own help to others in the group.

We recognize that we are all individuals with various backgrounds, personalities and outlook. It is desirable that we respect these very differences. We will not always be in unanimous agreement about all issues.

H. The First Mechanics: Meetings, Mailings, Telephone, Supplies, and Finance

1. Meeting Locations/Time

It is generally best to enlist the assistance of your otolaryngologist or speech therapist and/or his/her staff members and have meetings in a Conference Room of [the] hospital, thus avoiding any liability insurance which private establishments will require.

You may wish to investigate university and college facilities. Generally, meetings are best held on a Saturday or Sunday afternoon when driving is relatively light and families and/or friends can easily attend with the spasmodic dysphonia-affected person.

2. Mailings

A simple flyer can announce all beginning details; the office will be pleased to prepare such flyers at no cost to you and will underwrite the initial postage to get you started.

3. E-mail and Telephone Communication

Contact can be made by e-mail or by phone.

4. Supplies

Generally, the core group shares in the initial costs for such items as nametags and pens, financial and membership record-keeping books, and postage costs for press releases and invitations (flyers) and meeting announcements.

There should be volunteers who are willing to bring light refreshments, such as soda or punch, or coffee/tea and cookies and/or fruit. A small charge is appropriate or reimbursement for refreshments can be paid out of the group treasury.

5. Finances

The NSDA will assume the start-up costs of mailing to prospective members and will provide a supply of basic brochures and a copy of the "What is Spasmodic Dysphonia?" DVD. Additional materials are to be paid for by the Support Group members from the group treasury.

It is appropriate to charge members an annual fee for mailings and/or to collect funds at each meeting.

I. Meeting Topics and Concerns

1. Potpourri of Meeting Ideas:

- Spasmodic Dysphonia Test - make up questions and answers, distribute them before meeting and review answers at meeting.
- Workshops for Assertiveness Training and Stress Reduction - You can design your own workshop or invite a speaker in your area who specializes in these topics.
- Telephone Communications Workshop - Ask a good speech pathologist to give a workshop to help people with SD to deal with the phone. Go over phone attachments available, voice exercises, psyching yourself out, etc.
- Invite neurologists, otolaryngologists, or speech pathologists who are knowledgeable about SD. Invite speakers from a local SD treatment or research centers.

- Hold a discussion on relationships and how they are affected by SD - start with friends, work up to family.
- Meeting the Challenge of Change.
- Dealing with SD in the Workplace.
- Telling people about Your Voice Problem.
- Dealing with Noise.
- Show our award-winning DVD: "What is SD?" or other relevant videos such as the Brain and Tissue Bank video, also available from Headquarters.
- Problems of Dating with a voice problem.
- Problems of Job-Hunting with a voice problem.
- Have a Spouse-Relative meeting at the same time as your regular meeting.
- "Who am I now?" and "Who was I before I got SD?"
- In the warmer weather, plan a picnic in the outdoors with support group members and their families.
- Rebuilding Your Life after SD.
- How my life goals have changed since the onset of SD.
- Things I would like to improve in my life.
- Steps to acceptance of a chronic disorder (good books in the library on this).
- Small group discussions on subjects such as:
 - Members who choose not to have the botulinum toxin treatment - to discuss their reasons with each other.
 - How life goals have changed due to SD.
 - Steps to Acceptance of a Chronic Disorder.
 - Pushing the Boundaries - Set up your group in a circle. As you "go the round" each member gets a chance to speak, if they wish to, about their experiences with the

very real, as well as imagined, limitations that have set in as a result of their voice disorder.

- Choosing Happiness - How do we break through our preoccupation with our voice problem and with its limitations? Are we on a roller coaster of emotions tied to this outer condition of our lives? Who are we other than our voice disorder? To what degree are we able to move beyond the voice disorder and get in touch with the currents of our lives?

2. Meeting the Challenge with Creativity

Group Meetings should be conducted by an individual with SD, where possible, or several people with SD who alternate running the meetings. This serves to empower individuals and the group as a whole.

If you have pretty much exhausted all possible physicians and speech pathologists as possible guest speakers, check out the catalogs of local colleges, YMCAs and adult education programs in your area. Look for speakers on subjects such as: stress reduction, communication skills (public speaking teachers, when fully informed about SD, can help with coping tips for handling telephone anxiety, etc.), assertiveness training, etc. Some of these people may agree to run a workshop for your group pro bono (for free). The leader should brief them about SD and its specific problems and ask them to tailor their workshop specifically to SD needs.

3. Group Discussions on Coping Topics

Try using a variety of specific topics that can bring out many in-depth aspects of a person's experience with their voice problems, in a warm group setting. Having a variety of topics and speakers may help retain the interest of your membership; however, medical professionals who specialize in voice or SD tend to increase attendance at meetings.

Try to set up in a circle, where possible. This is best for seeing, as well as hearing and symbolically enhances a member's feeling of belonging to the group. When you "go the round", each member gets a chance to speak without interruption. It is the facilitator's job to keep things moving tactfully.

If you have a very large group, you can, on occasion, set up a few small groups with different topics and have members choose which topic they prefer. For example, some may choose job communication problems – others, family relationship problems.

Discussion Question: You receive a call from a person who has just been diagnosed with Spasmodic Dysphonia. The caller has many questions. Is he receiving correct treatment? What doctor should she see? Will this get any worse? Where did it come from? Will it be passed on to their children? What medication should he/she take? Life is changing and it isn't fair. One group came up with these suggestions:

Is he/she receiving the correct treatment?

It's important to support the caller. Tell a story about yourself or a friend instead of giving advice. It also depends on what the treatment is.

What doctor should they see?

Tell them to contact NSDA for a list by state of healthcare professionals who specialize in voice disorders. They may also need to check with their insurance company to see if a doctor is in his/her plan.

Where did SD come from?

Respond that it's a disorder from the part of the brain called the basal ganglia which is responsible for movement. It may affect one or many parts of their bodies. The cause is not known.

Will it be passed on to their children?

Let them know that it may only be passed on if they have a genetic form. Suggest they seek genetic counseling.

What medications should they take?

Botulinum toxin therapy is used with SD. Tiny amounts of botulinum toxin are injected into the muscles of the larynx through the inside of the throat.

Life is changing and it isn't fair.

Reassure them that life evolves and there is life beyond spasmodic dysphonia. Suggest they join a support group to foster better understanding of spasmodic dysphonia and to learn coping techniques.

PART TWO: *Confidentiality*

Confidentiality must be an issue for all support groups. Groups should discuss the need for confidentiality and assume confidentiality as a policy. This means that any information which might individually identify a group member cannot be released outside the group or outside NSDA Headquarters. Since privacy may be a concern of many participants, this policy should be stated as one of the ground rules (along with time for speaking and other rules) at the beginning of every meeting. “What You See and Hear at a Meeting, Leave at the Meeting!”

Examples of confidentiality may include:

1. Not releasing names, mailing or e-mail addresses, or phone numbers of group members to anyone outside the group or outside NSDA Headquarters. Make it clear that no one is required to be listed on the Support Group list and that all members who have copies will not give this information to outsiders. This policy may be especially important to newcomers who may not have shared their diagnosis with others, such as friends and employers.
2. If a news release about a group activity includes pictures or names, a news release permission form should be signed by the group members who will be identified. Furthermore, if pictures are taken or media people attend a meeting, members should be advised beforehand about what is happening and why so they can decide whether to participate.
3. All groups should have a policy that any problems of a personal nature (example, divorce, bankruptcy, etc.) discussed in a group, stay there. It is appropriate for the members of the group to share information about community resources which might be of benefit to an individual. It is up to the individual, however, to contact the resource; no one should do it for him or her.
4. Do not provide names and addresses of group members to any salesperson, no matter how good you believe a product or service is.

Tell the salesperson you will bring the information to the group so individuals can contact the person on their own.

A good rule of thumb: It is all right to tell someone what you said in a discussion. It is not all right to say what someone else said or how they reacted.

If there is any question or situation concerning confidentiality, please contact the NSDA Headquarters.

PART THREE:

Communications within the Support Group

A. Factors

People share their thoughts and feelings in a group both by talking and through body-language or non-verbal messages.

Two special factors appear to be vital in making Support Groups work. One is that all group members must be accepted as equals in dealing with the issues at hand. Each person has his or her own unique experiences and his or her own way of dealing with the issues. A person with a university degree is not necessarily better at handling his or her problem than a person with less education. Members of the group have equal status within the group. Communication within the group will be better if one member doesn't defer to another on the grounds that so-and-so is a lawyer or so-and-so has a Ph.D. in Economics.

A second special communication factor that makes Support Groups effective is the contact between old and new members of the group. The person who has had long experience at successfully dealing with a particular problem can reassure the newcomer that the issue can be managed and will be able to give pointers. Sharing these experiences also reminds the long-standing members of why they originally joined the group. Most importantly, this kind of sharing helps people feel good about themselves and about the group. Some groups have a "buddy" system to encourage communications. The strictly observed rule about confidentiality will encourage members to be more open than they would otherwise be.

B. Asking the Right Questions

1. Opening up discussions:

- a. What do you think about the problem as stated?
- b. What has been your experience in dealing with this problem?
- c. Would anyone like to offer suggestions on facts we need to better our understanding of the problem?

2. Broadening participation:

- a. Now that we have heard from a number of members, would others who have not spoken like to add their ideas?
- b. How do the ideas presented thus far sound to those of you who have been thinking of them?
- c. What other phases of the problem should we explore?

3. Limiting participation:

- a. To the overactive participant: We appreciate your contributions. Would some of you who have not spoken care to add your ideas to those already expressed?
- b. Since all our group members have not yet had the opportunity to speak, I wonder if you would hold your comments until a little later?

4. Moving Along:

Example: Have we gone into this part of the problem far enough so that we might now shift our attention and consider an additional area?

5. Evaluating:

Example: Should we take a look at our original objective for this discussion and see where we are in relation to it?

6. Reaching a decision:

Example: Am I right in sensing agreement at these points? (Leader gives brief summary).

7. Lending continuity to the discussion:

- a. Since we cannot reach a decision at this meeting, what are some of the points we should take up at the next one?
- b. Would someone care to suggest points where we need further preparation before we can convene again?

C. Problem Identification

Dealing with difficulties in a Support Group can be similar to problem-solving in a family. Members share common concerns and have one another's well-being as an important goal. Both probably are more interested in compromising a bit and staying together than they are in winning or breaking up the group.

More effective solutions and more feelings of togetherness will result if the problem-solving process is open and creative and if all members take part.

Stages:

1. Identifying the Issues

Are the purposes of the group being met?

Are the goals being reached?

Are there outside pressures?

2. Developing Alternative Solutions

Sometimes totally new solutions come from "brainstorming" wherein all members offer ideas within a few minutes' time without judging, discussing, or editing.

Sometimes solutions can be copied from other groups, or modified, or expanded, or reduced, or substituted, or rearranged, or reversed, or combined.

Other alternatives may arise from reframing an issue or seeing it from a different perspective.

The best solution is the one that's best for both the issue and for the group as a whole. The group will be strengthened if there is widespread, if not unanimous agreement, on the solution chosen.

Decision-making by consensus (rather than utilizing majority vote-taking per Robert's Rules of Order) is a method that is closer to the ideals of most Support Groups. By coming to a solution that has widespread agreement, fewer people have reasons to feel like losers. Consensus is a cooperative effort to find a workable solution that is acceptable to everyone. It is not a competition where the losers are forced to live with a solution they don't agree with.

Consensus begins with developing through discussion a possible solution to which all agree. Alternative solutions are narrowed down until the apparent best solution is identified. The facilitator then asks if there is opposition to the proposal. If there is none, the solution can be adopted.

Objecting to a Proposal without Blocking Consensus:

- Compromise: "I don't agree, but I can live with it."
- Non-support: "I don't see the need for this, but I'll go along."
- Reservations: "I think this may be a mistake, but I can live with it."
- Standing aside: "I personally can't do this, but I won't block others from doing it."

Consensus building takes time but will usually pay off in good will, better decisions, and increased involvement.

Summary:

Effective Group Meetings

The atmosphere is friendly, cooperative, and pleasant, with new members easily fitting into the discussions and the activities.

All members eagerly participate and communicate, not just a few, and there is no fighting for status or hidden agendas.

The group uses the abilities of all members rather than relying on a few.

The group adjusts to changing needs and situations.

The members feel safe in speaking out; neither ideas nor people are ridiculed or belittled. Incidents that block interaction are dealt with rapidly and sensitively.

Leadership is shared. Members are well-informed and up-to-date.

Decision-making is carried out in a consensus-building manner.

Remember, there is a great deal of support for Support Groups from the NSDA!

PART FOUR:

Raising Money for Research

Obtaining help and materials for fund-raising events is relatively easy.

A. The Seven People Rules for Fund-raising Success are:

1. People give to people. Ask in person.
2. The best people you can ask for money are people who already have given. If a person has given at a certain level for several years, it is worthwhile to ask them to increase their donation. Keep complete records of your donors.
3. People cannot respond unless you tell them what you want. Always ask for a specific amount or item. Be enthusiastic, optimistic, and bold. You generally get what you ask for.
4. People who ask for money become better givers. People who give money become better askers.
5. People want to back a winner. Be proud of the organization, what you do, and how you do it. Success breeds success.
6. More people mean more money and more fun. Find a job for every volunteer. Make it more fun to be on the inside and participating than on the outside and looking in.
7. People want recognition. Sending thank you notes is important.

B. Establish a Group Goal for the Year

Our Executive Director and leaders on the NSDA Support Committee, as well as your Regional Coordinator(s), will work with you in establishing goals. They will know how it compares with the goals set by other groups in your region as well as in other regions.

What is a reasonable goal for fund-raising? The short answer is, "More than you think that you can easily raise." If the goal is too low and the effort

required too little, the fund-raising effort will not pick up steam.

We all know that the challenge to achieve a difficult goal is more invigorating than an easy win.

C. Fund-Raising Guidelines

As a condition of using the NSDA name, logo, 501(c)3 tax exemption #38-2918042, literature, and services, all funds raised for research are the property of the NSDA and must be delivered to the NSDA by the individual no more than thirty days after the fund-raising event.

Reasonable expenses, depending on the event, are allowable for such items as printing and duplicating, postage, decorations, entertainment, unusual telephone tolls and/or faxes. (In-kind donations by local businesses and/or member underwriting can minimize these expenses.)

If clerical help is needed for large events, such temporary hourly pay is deducted from the gross receipts. In order to be cost-effective, the NSDA authorizes no salaried positions and/or persons who receive permanent hourly pay except at the NSDA office.

D. Service Club Donations

Service clubs-such as, Soroptimist, Lions, Kiwanis, Rotary-consistently help individuals and charitable groups. They also welcome speakers on subjects that inform. Spasmodic dysphonia is an ideal subject. As most club members readily admit, they have never heard of spasmodic dysphonia and want to be informed.

Ask an articulate member of your group to prepare a 15- to 20-minute presentation on spasmodic dysphonia: symptoms and treatments.

You may also contact the NSDA office to receive a copy of a speech concerning SD to be presented on such an occasion.

Be sure the presentation includes several concrete examples, as well as a concise version of the argument for medical research. Utilize visual

materials (e.g., overheads, poster boards, and portions of the NSDA DVD).

These help in focusing the audience's attention and in increasing retention of information. Brochures about spasmodic dysphonia also help.

E. Letter-Writing Campaigns

It's easy to write a letter to relatives and friends asking for money for spasmodic dysphonia.

Here's how it works:

The first step is to inform the NSDA Executive Director that your group will be conducting a letter-writing campaign. This is the most important step of the campaign so that the NSDA staff can keep track of your donors and send you updated lists.

Use the samples of fund-raising letters or write the letters yourself- short letters that explain Spasmodic Dysphonia in a very personal, anecdotal way and that state the need for research into the causes of and treatments for SD. The letter should ask for a donation to support SD research.

Order your donation envelopes from the NSDA office. Prepare an invitation to go to all your members, explaining that each member is invited to meet at someone's home on a certain day for the purpose of writing letters to relatives and friends.

Explain that you know it's more likely that lots of letters will get written and mailed if they do it all together. Ask for a commitment to be there.

Make this a social event. Provide snacks or baked goods or have a potluck supper.

Arrange for copies of your donation letter and envelopes to be available in sufficient quantity. Encourage members to provide their own stamps, but have a supply on hand.

Just before the day designated for letter-writing, call those who signed up and remind them to bring pens, address book, and stamps.

When people arrive on the designated day, hand out copies of the letter.

Explain that people should include a personal greeting on each letter, such as, "Your donation each year means so much to me and my family."

The personal touch makes a big difference - people give to people.

At the end of the day, be sure that all letters are placed in envelopes along with inserts and donation envelope. Apply postage and mail the letters.

Remember, everyone can participate in this event, whether they write letters or help apply postage or provide refreshments.

Donation envelopes will be returned to the NSDA office. When the donations are received they will be properly credited and reported to your support group. The NSDA office will issue a receipt to all donors.

In addition, a personal thank you note from the individual who wrote to the donor should be sent. Thank you cards are also available from the NSDA office. Past campaigns have shown this to be a crucial step to ensuring success and repeat donations in following years.

Keep a list of your donors that you receive from the NSDA office. Be sure to write to these individuals in successive years. Most people will give on an annual basis if asked.

This letter-writing activity is likely to yield high returns in relation to the small amount of time and effort involved.

F. Grocery/Hardware/Pharmacy Store, Etc. Shopping Days

Merchants in your community may be willing to share some of their profit on a day designated as "Spasmodic Dysphonia Shopping Day."

By agreement, each participating merchant contributes a percentage of purchases made by people who identify themselves as members or friends of your group.

First, decide on a preferred shopping day (probably a Saturday)-not several different days for each merchant because that will confuse potential shoppers.

Then, a designated chairperson visits each merchant to explain the proposal and obtains a written agreement from that merchant about the

percentage to be donated to the NSDA for spasmodic dysphonia research.

The chairperson points out that business on that day is likely to increase; he or she also explains how support group members and friends of people with spasmodic dysphonia will identify themselves at the time of purchase. A badge or ticket printed on card stock and clearly designating the name of your group may be the easiest.

Publicizing the shopping day well in advance is essential - through flyers, neighborhood newspaper stories or whatever method the merchants agree is suitable.

Each person who receives a badge or ticket should also get a stamped envelope addressed to the support group chairperson or treasurer. The receipts are mailed to the support group chairperson or treasurer so that he or she can return them to each merchant. The merchant sends a check for the percentage of sales agreed on initially back to the chairperson or treasurer.

G. Master File for Each Fund-raising Activity

Include for each fund-raising event the following:

- Who was in charge of organizing and carrying out the activity;
- Mailing list for publicity and/or solicitations;
- Amount of money received, with specific sources;
- Expenses (itemized);
- Net amount sent to headquarters;
- Copies or notations of receipts issued;

- Written evaluation of the activity by the chairperson.

PART FIVE: *Community Relations*

A. Media Relations

The process of encouraging and convincing journalists to do stories about spasmodic dysphonia, your group, and your members, is probably the most powerful and effective way to communicate with the community. One article in a newspaper with a circulation of 10,000 reaches 10,000 households that may include spasmodic dysphonia-affected persons or physicians who see patients with spasmodic dysphonia.

Media coverage gives the group credibility. People are attracted to the stories and information given.

The reporter's goal is to file "newsworthy" stories that may give new and timely information, identify an injustice, tell a human interest story, or describe an event or activity related to a worthy cause. Interest a health writer in doing a story about botulinum toxin injections or some other spasmodic dysphonia issue. The NSDA produces materials for the annual World Voice Day and Dystonia Awareness Week, but good stories are welcome by editors all year long.

B. Physician and Health Care Providers Relations

You may wish to gain visibility for your group by exhibiting at health fairs, displaying materials in hospital areas, organizing public health lectures, and supplying physicians with spasmodic dysphonia information and details about your patient group. You could also invite healthcare professionals to speak at meetings and write articles for a newsletter.

Health care providers include primary care physicians, medical residents, nurses, speech pathologists, dentists, otolaryngologists, neurologists, physical therapists, psychologists and psychiatrists, speech therapists, pharmacists, and the treating physicians - specializing in movement disorders.

C. Midge Kovacs Awareness Award

The late Midge Kovacs was a charter member of the NSDA Board of Directors and is best remembered for launching *Our Voice*, the first newsletter for spasmodic dysphonia. Since 1998, the NSDA has presented a special crystal obelisk annually to the Support Group that has done the most to promote SD awareness. The recognition conferred by this award encourages all of us to keep up the valuable work that Midge Kovacs began in 1988.

Criteria for entering the Midge Kovacs Annual Awareness Award Competition include:

- Newspaper/magazine articles;
- Television/cable Public Service Announcements (PSAs);
- Radio PSAs or other SD related broadcasts;
- Proclamations signings;
- Speaking to speech pathology classes about Spasmodic Dysphonia.
- Poster placings and coffee-can collecting.

Submissions should be sent by December 31st to:
National Spasmodic Dysphonia Association
Attn: Midge Kovacs Annual Awareness Award
300 Park Boulevard, Suite 350,
Itasca, IL 60143
or by e-mail to nsda@dysphonia.org.

There is nothing like the feeling of success in helping to change things for the better. It brings a great feeling of satisfaction to a Support Group.

Here are some things your group can do together to get the word out about spasmodic dysphonia:

Visit a large bookstore or the library to monitor the medical textbooks and home medical books to see whether spasmodic dysphonia is listed, and check whether the information is up to date. Write to the publisher and the editor, sending correct information.

Put together a press release with articles on spasmodic dysphonia and mail this publicity kit to the medical and health editors of all of your local newspapers, radio and TV stations.

Sponsor a booth at your state's speech-language-hearing association's annual conference. You can contact ASHA, the American Speech-Language Hearing Association, by writing to: 10801 Rockville Pike, Rockville, MD 20852, or phoning 1-800-638-8255, or by e-mail to actioncenter@asha.org, to obtain the address of your state organization, if it's not listed in the phone book.

Make an appointment to visit one of your local college or university's speech therapy classes. Contact the head of the department's speech therapy department and suggest that a few people from your group visit the class, and tell their stories about coping with spasmodic dysphonia. Not only do students gain a great deal of understanding about SD that they will always remember. . . but Support Group members gain a feeling of empowerment - or helping to make things better for other people with SD.

Check your local yellow pages for listings under Otolaryngologists and Speech Pathologists. Send them a letter about your Support Group and literature about spasmodic dysphonia. You can do the same for the Ear, Nose and Throat Departments of all your local hospitals.

Important: You and your group are now an important part of the fast-growing National Spasmodic Dysphonia Association. Encourage your members to get on the mailing list of the NSDA and to volunteer to help the NSDA with: fund-raising, writing for the NSDA Newsletter, joining the media, Support Group or education task forces.

D. "What is Spasmodic Dysphonia?" DVD

Made possible through a grant from Allergan, the DVD titled "What is Spasmodic Dysphonia?" aims to explain this vocal disorder to both lay people and the medical profession. Remarkably informative and fast paced, the DVD features explanations from qualified medical and speech-pathology personnel.

There are also plenty of examples of typical SD voices – to aid with diagnosis, understanding of the different types of SD, and to show patients that others have similar symptoms.

FINAL NOTES

Principles

Maintaining a successful SD Support Group requires as much thought and effort as starting one. Remember the following principles to ensure the long life of your group:

Remember to Share

Sharing is central to the maintenance of a Support Group. Sharing helps to develop a cohesive group and allows the members to claim ownership in the group. It sets the tone of the meetings and establishes openness and togetherness. Sharing can be accomplished in several areas: including leadership, tasks, and responsibilities.

Remember to be Realistic

The group will not always be successful in its activities or with each person who may join. Although Support Groups are effective for many people, they are not a “cure-all.” Be realistic about members who decide to leave the group. Members may come in, get their needs met and their questions answered, and then move on. Feel good about this.

Remember to Assess and Reassess

Using typical problem-solving strategies, group members can become actively involved in assessing the effectiveness of the group. The long-term benefits such as increased member participation and goal clarification usually result.

Remember what Support Groups do best

Providing Support Group members with information that will help them address their individual needs. Research shows that the most consistent drawing factor of self-help groups is the emotional support and sense of community which they provide members.

Fund-Raising

Each NSDA Support Group is a vital part of the ‘grassroots’ involvement on which we all depend. The NSDA needs financial resources to stay viable and to continue with our three-fold mission of support, promoting awareness, and encouraging research to find a cure.

How does this affect a Support Group? You start a group with giving support. Next, you raise awareness about SD by fully informing them. Finally, you work toward fund-raising with them. Once your group is together long enough that you are pursuing all three of the NSDA goals, you work toward finding a balance of integrating all three into your activities.

Congratulations!

You're ready to go out and build up a successful Spasmodic Dysphonia Support Group. No one can really tell you how to do it as each group is different. Your best instincts will serve you well if:

- You are honest with yourself and group members;
- You are willing to listen hard;
- You encourage plenty of feedback;
- You enlist others to help you from the beginning;
- You find a few people you can really trust;
- You train others to the leadership role;
- You encourage others to take over one part of a meeting;
- You are not afraid to make errors!
- You avoid leadership burn-out by taking a complete summer off...or skip a meeting altogether and have others run it;
- You remain accessible - remain non-authoritarian;
- You do not have unrealistic expectation of other members' willingness to jump in and be of help;
- And finally – remember to relax and enjoy building up a local community of people with SD.

The therapeutic rewards for you and for the others are ENORMOUS

AGREEMENT TO OPERATE AN NSDA SUPPORT GROUP

The Support Group agrees to:

1. Acknowledge that the Support Group is sponsored by the NSDA.
2. Support the mission of the NSDA.
3. Support and encourage NSDA fund-raising activities, and ask each of its members to pay the annual NSDA membership fee of \$35. This should be sent directly to the NSDA. The Support Group may make a minimal charge to its members for postage and other communication costs etc.
4. Meet regularly (at least twice per year).
5. Provide a list of members with contact information at least once per year to the NSDA so that NSDA has current information for its members.
6. 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.
7. Have an identified leader or leaders provide contact information for the Group to be published in the NSDA Directory and the Support section of the NSDA website.

The Responsibilities of the National Spasmodic Dysphonia Association will be to:

1. Offer advice and guidance in all aspects of operating a Support Group.
2. Supply NSDA materials.
3. Keep the Support Group informed of NSDA initiatives and current developments about SD.
4. Confer the use of its logo to the Support Group.
5. Maintain regular communications with the Support Group leaders through routine and special mailings and regional telephone calls.
6. Assist by publishing meeting announcements on the www.dysphonia.org website, and by mass email when appropriate.
7. Refer new members to the Support Group when appropriate

Group Leader Information *(please note this information will be listed in the NSDA Directory and website):*

Name: _____

Address: _____

Phone: _____ Fax: _____

E-mail: _____

Signed: _____ Date: _____

Authorization to operate a Support Group of the National Spasmodic Dysphonia Association:

by: _____ Date: _____
President or his/her designate



National Spasmodic Dysphonia Association

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