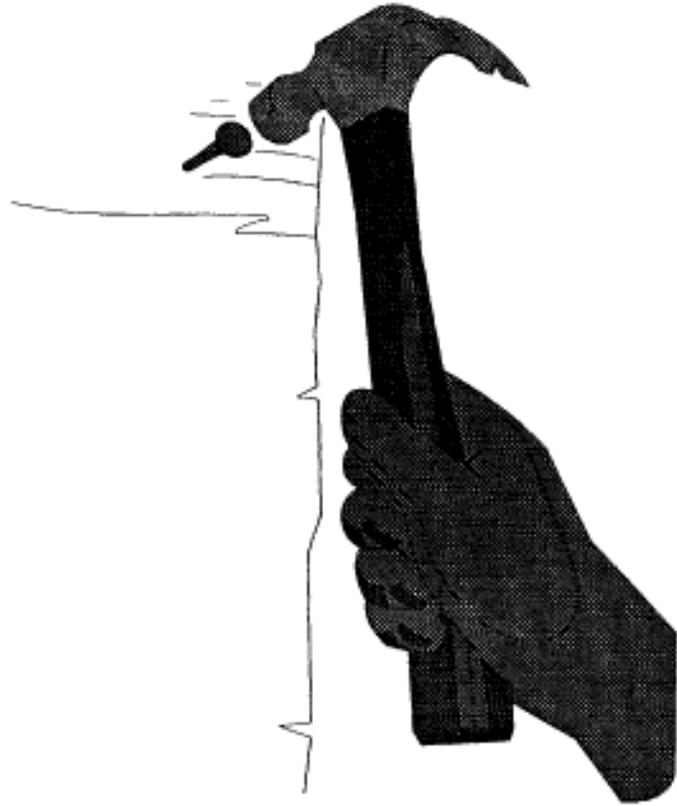


**BUILDING  
A  
SUCCESSFUL  
LARYNGECTOMEE  
CLUB**



by  
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Atlanta, GA

Published by the American Cancer Society - April 1989.  
Revised - June 1993  
Reissued by the International Association of Laryngectomees - January 2001  
Web OCR Edition by IAL Webmaster, January 2001

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# ***CONTENTS***

## INTRODUCTION

WORKING WITH THE AMERICAN CANCER SOCIETY.....	1
INVOLVING PROFESSIONALS.....	2
PUBLICIZING YOUR CLUB .....	3
MEMBER PARTICIPATION AND DEVELOPING LEADERSHIP .....	4
MEETING STYLE .....	5
HOSPITALITY .....	5
MEETING TOPICS .....	7
NEWSLETTERS .....	12
CLUB PROJECTS .....	13
INTERNATIONAL ASSOCIATION OF LARYNGECTOMEES .....	14
PUBLICATIONS .....	15
AMERICAN CANCER SOCIETY DIVISION ADDRESSES .....	16
SUGGESTED CLUB PROGRAMS	
LOAN CLOSET .....	21
PUBLIC SPEAKING.....	22
VISITATION .....	25

# INTRODUCTION

What is a laryngectomee club? In fairly formal language, you could say it is a voluntary, non-profit association dedicated to the total rehabilitation of laryngectomees. And that's true. Some call a laryngectomee club a support group. By some definitions that too is true.

To the laryngectomee club, the word "support" means caring about, helping, encouraging, listening to and involving laryngectomees and their families in the rehabilitation process. It means being there when a laryngectomee needs information, reassurance and guidance during the life crisis that a laryngectomy represents.

So when a few dedicated people get together for the purpose of helping the new laryngectomee and family adjust to living with laryngectomy surgery, a great deal of energy is represented. When this energy can be "harnessed," so to speak, and organized, it can grow and attract new energy. A small support group can become a functioning laryngectomee club whose members become a positive force in a community while never losing that one-to-one involvement with each other.

This book was written to help you build a successful laryngectomee club. These are not some high-flown concepts that you have to translate to fit your needs, but some down-to-earth, nitty-gritty suggestions that you can use.

It takes hard work and dedication to keep interest in any kind of club at a high level these days. With so many distractions and time filled with other

activities, it is sometimes difficult to get people to make the effort to come to a meeting or take part in club activities. It is my earnest hope that the ideas presented here will help you to develop your club and make it more effective or to start a new one within your community.

It is my firm belief that a good laryngectomee club is a mix of laryngectomees, family members, and professionals, such as physicians, speech pathologists, social workers, nurses and others who are interested in the total rehabilitation of laryngectomees.

When starting a new club or expanding an existing one, the American Cancer Society (ACS) can help. Contact your local Unit or state Division and seek their advice. They have contacts with professionals who can help. They can often provide meeting space, office supplies, or perhaps limited postage. Since the National Office of the International Association of Laryngectomees (IAL) is sponsored by the ACS National Home Office, ACS Units and Divisions will have access to IAL literature and videos.

In the many years that I have been involved with laryngectomee club activity, I have observed that successful clubs are the result of laryngectomees accepting primary responsibility for the club. So, be enthusiastic and Build A Successful Laryngectomee Club !!

Jane Del Vecchio, Author

# WORKING WITH THE AMERICAN CANCER SOCIETY

The American Cancer Society's National Home Office has sponsored the International Association of Laryngectomees since 1952. ACS Divisions and Units around the country sponsor individual laryngectomee clubs. The relationship between the ACS and laryngectomee clubs is mutually beneficial. While the ACS is "in the business," so to speak, of helping cancer patients, it is an organization of volunteers, and your club and its members can contribute volunteer service in return for the sponsorship of the ACS.

## SOME WAYS YOUR CLUB MEMBERS CAN HELP THE AMERICAN CANCER SOCIETY

- \* Serve on Committees & Boards
- \* Volunteer to work Special Events
- \* Participate in the *Great American Smokeout*
- Drive cancer patients to treatment
- ACS's *Road Recovery* program
- \* Become a Laryngectomee Visitor
- \* Speak to school children about the perils of smoking
- \* Help with ACS fund raising
- \* Staff booths at Health Fairs
- \* Be a resource for information on laryngectomee equipment and supplies

## SOME WAYS THE AMERICAN CANCER SOCIETY CAN HELP YOUR CLUB

- \* Furnish a place for you to hold club meetings
- Furnish literature for club activities (Visitation Program)
- Furnish films for club programs
- Help produce club newsletter (Some Divisions provide postage)
- Help you find speakers for your meetings
- \* Possibly contribute financially to the cost of seminars and workshops
- \* Serve in an advisory capacity to club, if asked.

## INVOLVING PROFESSIONALS

**M**ost successful laryngectomy clubs have strong ties with the professional community, especially the medical and allied health professions. This is a mutually beneficial relationship: the club benefits from the expertise of the professionals, and they benefit from the experience gained by working with those in your group or even by just being exposed to laryngectomees. Regardless of how they participate, the practice of including professionals among your membership is a wise one. Here are a few ways professionals can help your club.



**PHYSICIANS:** The IAL Charter Standards require that each club cooperate with the medical community. Physicians often do not have the time to attend meetings but should be relied upon for medical guidance. A good relationship with physicians in your area is important not only to your club but to new laryngectomees as well. ENT (Ear, Nose & Throat) physicians especially need to be aware of your club. They are essential when it comes to establishing a Visitation Program (we will explain this program later). They will often refer patients to your club meetings. You can also call upon them to present programs to your club when their time permits.

**SPEECH PATHOLOGISTS:** Unfortunately not all speech pathologists work with laryngectomees, but those who do are usually enthusiastic advocates of laryngectomy clubs. They have found that when their patients attend club meetings, they are motivated to greater efforts to attain good speech. Speech pathologists gain experience by attending meetings and observing laryngectomees other than their own patients. They can help set up speech programs, participate as faculty advisors during visitation trainings and workshops, and are often asked by physicians to make arrangements for laryngectomy visitors. Some speech pathologists will volunteer their time to offer speech practice sessions at selected club meetings.

**AUDIOLOGISTS:** These professionals are often involved with laryngectomees because of the relationship of hearing to speech. They can provide interesting programs for your club, counseling for club members and their spouses, and can even arrange screening for hearing loss at a meeting or workshop.

**NURSES:** Every laryngectomy learned to appreciate a good nurse while hospitalized for his surgery. Physicians often depend on floor nurses in hospitals to request pre- and post-operative visits for their patients. Nurses can present informative programs at club meetings on topics such as stoma care and other aspects of post-operative physical care.

## PUBLICIZING YOUR CLUB

In order to reach the maximum number of people, your club needs a good publicity campaign. Here are some suggestions:



Send a letter to all ENT physicians in the area informing them of the existence of your laryngectomee club. Be sure to mention your Visitation Program. (ACS might be able to help with this letter)

Ask the ACS to run a story about one of your laryngectomees in their newsletter.



Prepare a brochure about your club and its goals. Distribute it to physician's offices, speech pathologists, hospitals, nurses, social workers, and ACS Units, and don't forget your library.

Speech pathologists in your area should receive a letter inviting them to your club meetings. Inform them of your Loan Closet (if one has been established).



Include local health professionals who work with laryngectomees on your newsletter mailing list. Send the newsletter to all ACS Units in your area so they can refer laryngectomees to your club.

Keep in contact with other laryngectomee clubs in your area and in other states, if possible.



Contact your local newspapers, radio and television stations and try to arrange an interview with one of your well-rehabilitated laryngectomees. This type of story is always of interest to the media.

Include a regular notice of your meetings in your newspaper's calendar of community events.



Seize the opportunity to speak to civic and service organizations about your club's activities.

**Promote...Promote...Promote !!!**

# MEMBER PARTICIPATION AND DEVELOPING LEADERSHIP

Developing leadership is one of the most difficult challenges facing any club. Some people are content simply to attend meetings and make a financial contribution. Others may participate by working on committees or special projects but will not assume a role of responsibility. Occasionally, however, some members will seek out important roles such as president or vice-president.

No matter how large or small your club is, you will find that your members have many talents and they are willing to share them if asked to do so. As an illustration, one club discovered and used the talents of its members in the following ways: two members work as florists and regularly provide centerpieces for refreshment tables at special occasions; a speech pathologist, who also is a semi-professional clown, entertained the club on several occasions; a long-time member is a commercial artist and has designed club awards and certificates; members with gardens frequently bring fresh vegetables to be given away at meetings; another speech pathologist with a beautiful soprano voice can be counted on to lead the singing at meetings and parties.

## ***SOME SUGGESTIONS:***

- \* ASK several members to bring refreshments for the next meeting (don't rely on the same few all the time).
- \* ASK members who sew or crochet to make stoma covers and other neckwear.
- \* ASK all members to contribute items for the club newsletter. Have active members write a biography to be used in a "profile" section.
- \* ASK a member to greet those arriving for meetings at the door.
- \* ASK a member to be responsible for sending get-well cards to ailing members.
- \* ASK different members to become involved in specific club activities: operating the Loan Closet, becoming a Visitor or a Speaker, planning programs, or arranging transportation.
- \* GET to know your members!!! Continue to ASK for help!!!

## MEETING STYLE



If possible, and especially if yours is a small club, it is a good idea to arrange your seating in a semi-circle. This gives people an opportunity to look at each others faces, not the back of their heads. It will create a warmer, more intimate atmosphere than theater-style seating.

Be certain that everyone can hear what is going on. Use an amplifier to conduct the meeting or to read reports or

minutes. Usually the laryngectomee is an older person and some hearing loss should not be discounted. If a member cannot hear what is being said, it is hard to sustain interest. Remind your guest speakers that if they choose not to use the amplifier, they should speak at a level that can be understood by everyone. There are many types of amplifiers on the market, and they are relatively inexpensive. If your group does not have one, the acquisition of one might be a good project to undertake.

Many clubs begin their meetings by having each individual introduce himself. For those not yet speaking, an encouraging word from the leader would be appropriate. For those just beginning to speak, an enthusiastic comment on their progress by the leader often inspires a round of applause from the members.

Some clubs do not charge dues and rely entirely on donations for their treasury. In that case, it's a good idea to have a box at the sign-in table so that those wishing to donate can do so. Visitors or guests are often very generous contributors, and frequently members too will make contributions in addition to their yearly dues.

## HOSPITALITY

As your members arrive, there should be a table near the door with sign-in sheets and name badges. Be sure that your officers are on hand to greet people as they arrive, especially the first-timers. Your greeters should be sure to see that everyone signs the attendance register and gets a name tag. (The sign-in sheet will be used by the person who writes the newsletter to name first-timers who attended the most recent meeting). Arrange to have someone else who speaks well to do this if your officers cannot. Laryngectomee visitors should make a special effort to attend every meeting so they can greet new laryngectomees they have visited recently.



Your Hospitality Committee chairman should ask different members to donate refreshments each month. Then, about a week before that month's meeting, the chairman will call the member to remind him of his obligation to furnish refreshments. Where the club is of some size, two or three persons may help each month. People enjoy being involved and will show up if they have an obligation to be there.



Refreshments should be ready when people arrive. Somehow it seems easier to get acquainted over a cup of coffee. Try to have something more than just coffee or cold drinks for refreshments. People will stay around to chat later if they have cookies or cheese and crackers to munch on.

Whenever possible, have something to give away at meetings, and advertise it in advance in your newsletter... stoma covers, pocket emergency cards, windshield stickers, instructions and patterns for making stoma covers, literature about shower shields, artificial larynx instruments, etc.

Sometimes a door prize is a good idea. Members are often willing to donate these. Many IAL clubs have members who have vegetable gardens and could bring in fresh vegetables and fruit to be used as door prizes. Prizes of some value are often raffled off, thus enriching the club's treasury.



Some clubs sing "Happy Birthday" to those celebrating birthdays in the month of the meeting. Perhaps someone in your group plays the piano or guitar and could accompany the singing.

The Hospitality Committee also takes charge of special events such as parties, picnics, covered-dish dinners, etc. Members can be asked to make table decorations and favors, furnish prizes, supervise games or obtain entertainment.

A member with a large patio or spacious lawn may volunteer to have a club picnic at his home. A covered-dish dinner usually requires the use of a stove, oven and refrigerator, so a member's home is often used for such affairs. Also, some communities have meeting places for civic clubs, and frequently these places have a stove, refrigerator and other serving facilities.

It goes without saying that thank-you notes should always be sent to persons or institutions providing meeting space and other facilities. In some cases clubs send a yearly donation to the institution along with a thank-you letter.

## MEETING TOPICS

To keep interest in your club at a lively level, the topics or programs presented at your meetings have to be interesting or informative or entertaining or all of the above. They should be planned well in advance with a back-up in mind just in case a speaker cannot come at the last minute. Good meeting planning can be accomplished by a combination of professionals and laryngectomees on a Meeting Planning Committee. The very best meetings are often those that are presented by the members themselves. Some ideas for this type of meeting are as follows:

**"CAN DO"**: Each laryngectomee talks in front of the group about things he can do that he thought he would never be able to do again, things that he has learned as a result of surgery, new abilities that have been acquired, and, perhaps a change in lifestyle that has been beneficial.

**"LAUGH-IN"**: Members talk about the funny things that have happened to them since becoming a laryngectomee. This is great therapy because it encourages people to laugh at themselves. Sometimes it is a good idea for them to also spout off about things that annoy them. Fellow laryngectomees should be sympathetic encouraging. Be careful not to let the meeting become a gripe session.

**"HEART-TO-HEART"**: February would be a good time for this. Members come prepared to discuss their problems and either ask advice from others about how to solve them or talk about ways in which they have solved problems that might be of interest to others. At this meeting, pamphlets and literature about items used by laryngectomees should be available, i.e., *IAL Directory of Sources of Supplies*, which lists companies that carry stoma covers, shower collars, artificial larynx instruments, etc. You might have some stoma covers, IAL Emergency ID Cards, and IAL Emergency Windshield Stickers available for distribution.

**"LARYNGECTOMY: A FAMILY AFFAIR"**: Line up a panel consisting of a husband or wife, son and/or daughter of a laryngectomee, and perhaps a friend, and have a moderator ask them questions. Each individual should be given the opportunity to answer each question. You will be amazed at the difference in the answers. Sample questions might be:

What was your reaction when told your spouse was going to have a laryngectomy?  
Did you understand what was going to happen?  
What information were you not given that would have helped you understand?  
What has helped you most in dealing with this entire situation?



## Awards

**AWARDS:** An ideal program to be combined with the holiday party at the end of the year. You might select the "Laryngectomee of the Year," the Speech Pathologist of the Year," or simply the "Member of the Year" and present them with a plaque, framed certificate, or some small gift, as appropriate. Be creative with this program. Members will work hard through the year so they might be recognized.

**SPEAKERS PROGRAM:** Your club's public speakers can prepare a program demonstrating the presentations they make to schools, civic groups, professionals, etc. They might cite some of their experiences, i.e., some of the amusing questions that have been asked by school children. These anecdotes will liven the program. A speakers program also informs club members of the efforts being made by the club to enlighten people about laryngectomees, to publicize the club and to help with the American Cancer Society's programs.

**SING-ALONG:** Chances are that a great many of your members loved to sing before their laryngectomy. Why not keep on singing? It's good speech practice, especially in achieving inflection, and it is great fun. You could have a piano or guitar player for accompaniment, but then again that's not even necessary. Ask a spouse, speech pathologist, and any non-laryngectomized person to lead the singing. Have printed song sheets for everyone. You might even discover a laryngectomee who can whistle.

**CLUB HISTORY:** Some of the club's early members can talk about its formation, its evolution over its existence, its programs, its structure, its involvement with the IAL and the American Cancer Society. This serves to inform newer members of exactly how the club works. Too often it is taken for granted that new members just automatically absorb this information. The more members know about the club, the more they will be involved in its operation.

**SOCIAL EVENTS:** Many clubs have social events during the year, not only because they are fun, but because they encourage laryngectomees to return to a normal social life. Events might include picnics, holiday parties, covered dish suppers, a trip to the local museum, or an evening "out on the town."



The professionals involved with your club are a great resource for program topics. You might want to ask them to lead a meeting and present a program covering their area of expertise. Some suggestions might be:

**EMERGENCY PROCEDURES:** This program should feature resuscitation techniques for laryngectomees, especially the proper use of bag-mask resuscitators on laryngectomees. You should provide the IAL/ACS publication *First Aid for Laryngectomees (Neck Breathers)*. You might want to provide IAL Emergency ID Cards and Windshield Stickers.



You can even expand this program to include simple safety information, i.e., shower collars, proper stoma care for cold months, and personal safety.

**AMERICAN CANCER SOCIETY:** A local ACS staff person can be invited to explain the services available to laryngectomees and their families. They can also talk about how the ACS supports the local club and how club members can support the ACS by volunteering to help with crusade speakers programs, driving patients to treatments, office work, etc.

**FITNESS:** A physical therapist should be called on to demonstrate how laryngectomees can strengthen muscles damaged by laryngectomy surgery. They could also include simple exercises for general fitness.



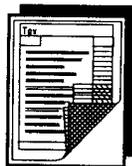
**SPEECH:** This program on speech options for the laryngectomee should be led by a competent speech pathologist. The therapist should cover esophageal, TEP and artificial larynx speech. A demonstration of the different instruments available might be helpful. Members should be encouraged to ask questions about problems, bad habits (klunking), stoma noise, etc.

**PSYCHOLOGICAL EFFECTS OF LARYNGECTOMY:** A local psychologist, social worker, or counselor can be called upon to cover some of the adjustments that must be made in the lives of the laryngectomee and family members. This could be very beneficial to all members.



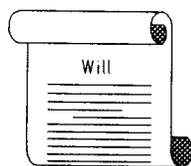
**NUTRITION:** Since nutrition is an important factor in returning to good health, everyone in the club will benefit from this program. Laryngectomees should ask how to enhance the taste of their food without adding excess calories and salt. This program can be expanded to include all topics regarding healthy living.

**CANCER:** Laryngectomees are often interested in all types of cancer having experienced one type themselves. A program featuring a person who has had mastectomy surgery, one who has had ostomy surgery and one who has had a some other type of cancer surgery should be well received. Your local ACS can put you in touch with people who are willing to tell their stories. Information regarding signs and symptoms is always helpful as are the ACS cancer prevention guidelines. Members will gain a better understanding of cancer in its many forms.



**TAXES:** Members do not necessarily want to talk about themselves at every meeting. This program is a good change of pace and will provide vital information during the tax season. You can even have an accountant explain ways to save money on next year's taxes.

**HEARING LOSS:** An audiologist can cover how hearing loss might affect speech. Emphasis should also be placed on the spouse's ability to hear and understand what the laryngectomee is saying.



**WILLS:** Many people have never made a will. An attorney can present a very informative program on why a will is necessary, how to make one out, and the laws surrounding estates.

**PRESCRIPTION DRUGS:** A pharmacist can present a very informative program on drugs, their purpose, their limitations, the hazards of mixing certain drugs, the merits of generic drugs, etc.

**RADIATION:** A radiologist can explain the uses of radiation in treating cancer and can update your club members on the latest advances in radiation treatment

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**T**he topics suggested here are only a few examples of programs your members will enjoy. Providing your members with creative and imaginative programs will keep them knocking at your door.

**REMINDER:** A prompt *THANK-YOU* note should always be sent to those who have presented a program. Some programs are appropriate for repeating at regular intervals, and a speaker will be happier about returning if he/she receives a gracious letter of thanks.

# **NEWSLETTERS**

**A** regular newsletter, even if it is only a few paragraphs, is the single most important instrument a club can use to inform laryngectomees and their families, speech pathologists, physicians, nurses and others of the existence of your club and its interesting people, activities, goals and services to the laryngectomee population and community. It is not only a medium of communication but an instrument for publicizing your upcoming meeting or a project you are working on, or providing interesting information about club members.

Ideally, your newsletter should be the effort of several people in your club. You might want to have a writer, editor, and a staff of volunteers who help fold, stuff envelopes, etc. (Your ACS might help with postage if you ask).

If you do not have a name for your newsletter, you can hold a contest or dedicate a meeting to choosing one. You might award a prize for the winning name.

When you update your mailing list you might include a brief information form for submitting items for possible publication. Also, many clubs have reported receiving donations from those who like what they read.

## **BENEFITS OF YOUR CLUB NEWSLETTER**

- \* Keeps members in touch with each other
- \* Notifies members of upcoming laryngectomee meetings (Local, State & National)
- \* Promotes your club activities
- \* Provides useful information, i.e., stoma care
- \* Serves as means for soliciting Loan Closet items.

## **WRITING YOUR NEWSLETTER**

- \* BE ENTHUSIASTIC
- \* Review your last meeting
- \* Encourage members to attend future meetings (*never* scold them for not showing up)
- \* Always recognize member's accomplishments
- \* Recognize members for bringing refreshments, helping with set-up, etc.
- \* Make mention of First-Timers.
- \* Use humor generously
- \* BE CREATIVE

## **Suggestions**

- \* Exchange newsletters with other clubs
- \* Include local professionals on your mailing list
- \* Send a copy to the IAL National Office
- \* Update your mailing list yearly
- \* Compose your newsletter in the third person
- \* Include club location (city) in the masthead

## CLUB PROJECTS

Projects are vital for your club's success. There are programs to be initiated and equipment to be acquired. Keeping members involved in club projects is the surest way of keeping meeting attendance high. Members will feel a sense of contribution to the club.

### SOME PROJECTS INVOLVING YOUR CLUB MEMBERS:

Produce a club brochure to be distributed to physicians, speech pathologists, social workers, hospitals, etc., describing your club, its purposes, meeting time and location, and how to contact its principals.

Establish a safety project. If your community has a 911 emergency number for summoning emergency personnel, members may wish to be listed with a special code indicating they are laryngectomees. This code would immediately alert emergency personnel the call may involve a neck-breather and/or that the caller cannot speak.

Establish car pools. This project would help get members to your meetings and could be expanded to include transportation to other meetings in the area. This helps build good relationships among club members and those from other clubs.

Establish a Sunshine Barrel. Members contribute food items, new toys and other gifts to the Sunshine Barrel. This project is usually conducted during holiday seasons to help needy families in the community.



Acquire an amplifier for use at meetings and by public speakers.

Organize a Road-to-Recovery team. Perhaps there are people in your club available to drive cancer patients to their treatment. The American Cancer Society can give you details regarding this project.

Sponsor laryngectomy rehabilitation workshops. This project involves a lot of organization, plus cooperation with the ACS, speech pathologists and other local professionals. It will entail planning the program, arranging for speakers, obtaining meeting space, hotel accommodations, luncheons and/or banquets and entertainment.



Fund raising projects (**SEE NOTE**). Clubs need operating funds. So occasionally, it will be necessary to raise some money. Some club charge dues. Others depend on member donations, hold raffles, bake sales, or garage sales.

**NOTE. CAUTION!!!** Always check with your ACS Unit or Division before you decide to raise money. The ACS has strict rules governing fund raising by JAL/ACS affiliated groups.

# ***International Association of Laryngectomees***

From the very beginning your club should become associated with the International Association of Laryngectomees (IAL), the national organization of laryngectomee clubs sponsored by the National Home Office of the American Cancer Society. Dues are nominal and are paid yearly.

The IAL acts as a clearing house for information vital to laryngectomees and disseminates this information through its publications, the **IAL News** and/or direct communication with the member clubs, i.e., **IAL HOTLINE**. Thus membership in the IAL is your club's link to all other clubs in the worldwide network of the IAL.

The IAL holds an annual meeting in a different city around the country each year. This event is normally attended by 300-500 people and usually takes the last week in July. Programs are informative and inspirational. Daily speech improvement classes are available and free of charge. The social affairs are lively and well attended. The IAL Board of Directors also conducts its committee meetings during this event.

The annual IAL Voice Institute is the organization's most prestigious program. This five-day session trains speech pathologists and laryngectomees to become instructors of alaryngeal speech. The program includes lectures, daily therapy for laryngectomees, and discussion sessions.

Your club should endeavor to take an active part in the IAL by sending delegates to the annual meeting to observe and report on the proceedings and programs. The delegates are your voice in the IAL.



Periodically your club's contact person will receive important information from the IAL National Office. These items should be shared with your membership. A list of NEW laryngectomees should be sent to the IAL National Office so they can be added to the mailing list of the *IAL News*.

Outstanding members of your club should be encouraged to seek nomination to the IAL Board of Directors. It is a great and rewarding way to be involved in the total rehabilitation of all laryngectomees.

## PUBLICATIONS

The following publications are available free of charge (in limited quantities) upon request. Requests should be addressed to your local office of the American Cancer Society. The telephone number of the local ACS Unit office can be found in the white pages of your telephone book. (The IAL National office is always available to assist in those matters which exceed the knowledge or resources of local or state ACS offices.)

***First Steps: Helping Words for the Laryngectomee***, (Code: 4511)

***Rehabilitating Laryngectomees***, (Code: 4506)

***First Aid for Laryngectomees (Neck Breathers)***, (Code: 4522)

***Facts on Cancer of the Larynx***, (Code: 2631)

***Your New Voice***, (Code: 4501)

***Laryngectomized Speakers Source***

***Book***, (Code: 4521)

***Neckwear Pattern Book***, (Available for IAL National Office only)

***Attention Sign*** (for hospital), (Code: 4528)

***Attention Poster*** (for hospital), (Code: 4528.02)

***Emergency Identification Card***, (Code: 4520)

***Emergency Identification Card (T.E.P.)***, (Code: 4525)

***Emergency Windshield Sticker*** (Available for IAL National Office only)

***Laryngectomee Visitor Program Manual***, (Code 4529)

### DIRECTORIES

***IAL Club Directory***: Printed annually, this directory contains the most recently received information regarding member clubs including: club name, location, meeting day and times, availability of speech instruction, and a person to contact.

***Directory of Instructors of Alaryngeal Speech***: A comprehensive list of speech pathologists and lay laryngectomized individuals actively working with laryngectomees.

***Directory of Sources of Supplies***: Published semi-annually, this directory lists companies that carry products of interest to laryngectomees.

# AMERICAN CANCER SOCIETY DIVISION ADDRESSES

The following is a listing of addresses and numbers of the American Cancer telephone Society's State Divisions.

**ALABAMA DIVISION, INC.**  
504 Brookwood Blvd  
Homewood, AL 35209-6802  
(205) 879-2242

**ALASKA DIVISION, INC.**  
406 West Fireweed Ln  
Suite 204  
Anchorage, AK 99503  
(907) 277-8696

**ARIZONA DIVISION, INC.**  
2929 East Thomas Rd  
Phoenix, AZ 85016  
(602) 224-0524

**ARKANSAS DIVISION, INC.**  
901 North University  
Little Rock, AR 72207  
(501) 664-3480

**CALIFORNIA DIVISION, INC.**  
1710 Webster St  
Oakland, CA 94612  
(510) 893-7900

**COLORADO DIVISION, INC.**  
2255 South Oneida  
Denver, CO 80224  
(303) 758-2030

**CONNECTICUT DIVISION, NC.**  
Barnes Park South  
14 Village Ln  
Wallingford, CT 06492  
(203) 265-7161

**DELAWARE DIVISION, INC.**  
92 Read's Way, Ste 205  
New Castle, DE 19720  
(302) 324-4227

**DISTRICT OF COLUMBIA  
DIVISION, INC.**  
1875 Connecticut Aye, NW  
Suite 730  
Washington, DC 20009  
(202) 483-2600

**FLORIDA DIVISION, INC.**  
3709 West Jetton Ave  
Tampa, FL 33629-5 146  
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***SUGGESTED  
CLUB  
PROGRAMS***

***LOAN CLOSET***

***PUBLIC SPEAKING***

***VISITATION***



# LOAN CLOSET



**A** loan closet of artificial larynx instruments and other articles is one of the most useful services a laryngectomee club can offer its members, new laryngectomees and the community. Long-time laryngectomees will no doubt remember when they were discharged from the hospital with no means of communication except writing and gesturing. Nowadays a new laryngectomee is usually given an artificial larynx while still in the hospital, and most speech pathologists now agree that when a patient first learns to use an instrument well, it assists him in learning esophageal speech later. Hospitals which have speech therapy departments usually have a few instruments to lend out but often not enough to take care of discharged patients and in-hospital patients at the same time. Therefore, your club, even if it is small, can provide a valuable service through a loan closet.

## GETTING INSTRUMENTS:

- \* Donations from club members or families of laryngectomees
- \* Appeal for donations at meeting and through your club newsletter
- \* The American Cancer Society may donate instruments they have on hand
- \* Local hospitals, speech pathologists, etc.

## POLICIES AND PROCEDURES:

- \* Appoint a Loan Closet administrator
- \* Establish the borrowing period
- \* Establish lending requirements  
(i.e., no transfer of instruments without a new agreement)
- \* Develop a written agreement to be signed by the borrower (IAL National office can furnish samples)
- \* Develop an inventory system

## GENERAL CONSIDERATIONS:

- \* You will need a central location for storage
- \* Record keeping is essential
- \* Maintenance: repairs, batteries, etc. (usually the club's responsibility)
- \* Publicizing your Loan Closet Program

# ***PUBLIC SPEAKING***

**A** successful laryngectomee club is always engaged in education, whether it be educating its own members or educating the public. Laryngectomees have an important message to bring to the public, and this can be accomplished through your club's public speakers. This club activity led to the development and publication of the IAL/ACS booklet entitled, *Laryngectomized Speakers Source Book*. This book contains a wealth of information for members of your speakers' team. We suggest you obtain one from your ACS Division Office and give a copy to each of your speakers.

## **WHERE DO REQUESTS COME FROM?**

- \* American Cancer Society
- \* Schools
- \* Civic Groups
- \* Churches
- \* Hospitals
- \* Businesses

## **THINGS TO REMEMBER**

- \* Not everyone understands the limits of a laryngectomee's voice, so take along a portable amplifier
- \* You might not be able to speak for as long as you used to
- \* You represent your club and/or the American Cancer Society

**A** good public speaker will be prepared to talk about a variety of subjects. These suggestions are for individual speakers according to selected audiences.

**GRADE SCHOOL STUDENTS:** Talk about the dangers of smoking and what happened to you because you smoked. Tell them why you started smoking and remind them that it is usually peer pressure and the desire to look "grown-up" or sophisticated. Involve them in your presentation. Explain, for example, that you no longer breathe through your nose and mouth - then ask them to think about and tell you what you might not be able to do because of that (smell and/or diminished sense of taste). Take along an artificial larynx instrument and ask for volunteers, perhaps a boy and a girl, to come to the front of the class and use it (with help from you, of course).



Remind them that the decision of whether to smoke or not is theirs to make and that you hope they will make a better decision than you did.

**HIGH SCHOOL STUDENTS:** Use the same format as for grade school students, ~ except speak to them as adults. Emphasize the peer pressure aspect of their teen years, and speak of smoking cigarettes and using smokeless tobacco as using drugs. Explain that cancer of the larynx very often happens to young people too, and that they can avoid it by not using tobacco in any form. Make sure you stress it is NOT "cool" to smoke.

**NURSING STUDENTS:** Some student nurses have never encountered a laryngectomee and have never seen a tracheal stoma. Explain why you have a stoma and how you speak. Demonstrate several different types of speech instruments if you have access to them. Show them different types of stoma covers, from the plain crocheted ones to handsome ascots and scarves. Show them the visitor's kit you take with you when you visit patients and briefly go over its contents. Talk about your club and the support it offers new laryngectomees and their families. Remember that nurses usually only see patients when they are in the hospital, that is, at their lowest point. You represent a laryngectomized person who is alive and well and leading a normal life. Nurses want to know what you wish had or had not been done for you in the hospital. Tell them ... this will hopefully make things better for future patients. Above anything else, tell nursing students to educate their patients and encourage them to do things for themselves, to be independent. Suggest that they also try to educate the family of the patient not to allow the laryngectomee to become totally dependent on them. You might mention that some people think a laryngectomized person is also deaf, including nurses!! You may find that nursing students become your favorite audiences.



**MEDICAL SOCIETIES:** Physicians, like nurses, see patients at their sickest and when physical problems are a priority. So talk about rehabilitation when speaking to doctors. Do not talk about medical procedures: they already are schooled in this area. Talk about your club and its Visitation Program. Talk about the emotional support that is needed to return to a full life. Tell them success stories about club members. Tell them about your meetings and how their patients are helped by attending. Ask them to support your activities by referring patients for visits and encourage them to take an active part in the local club.



**EMERGENCY PERSONNEL:** This category could include police, fire departments, and emergency medical technicians. Explain what a laryngectomy is and why it was necessary. Tell them what physical changes were made and how this has altered your way of breathing. Show them the pocket card you carry and the sticker that goes on your automobile windshield. Show them how to adapt a bag-mask resuscitator for use on laryngectomees. Remember to use the infant-sized mask. You can show related videos about emergency procedures for laryngectomees.



**STOP SMOKING CLINICS:** This is a "natural" for a laryngectomized speaker. To begin with, your voice will have a dramatic effect. All you need to do is tell your personal story...how and when you started smoking, how you became addicted, how your cancer was discovered, the trauma of not being able to speak at first, the road back to rehabilitation and especially, that your laryngectomy would not have been necessary if you had not smoked. Take along ACS literature if has not already been provided.



**CIVIC AND SERVICE CLUBS:** This is a wonderful opportunity to talk about your club and about the American Cancer Society which sponsors not only your group but the IAL and other support groups. Acquaint yourself with the other support groups so you can talk about them intelligently. Speak of the services of the ACS to cancer patients, i.e., transportation to treatment, loan of sickroom equipment, pain control efforts in some Divisions, public education programs, support for research, etc. Talk about your club's visitation program, its public speaking team, and its loan closet. Tell them success stories about the people in your club. Let them know that the funds they contribute to the American Cancer Society support all of this. Thank them for their support of the ACS, and by extension, your group and yourself.

**ACS VOLUNTEERS:** Volunteers for any group need to know that they are appreciated. Tell your personal story to such a group, tracing the progress of your rehabilitation and how you have been helped by the American Cancer Society through the sponsorship of your club and the IAL (at the National level), and by ACS's services. Thank them for their efforts in fighting cancer and for helping you as a cancer patient.

## **AMERICAN CANCER 'SOCIETY**

**THERE'S NOTHING  
MIGHTIER THAN THE  
SWORD**

**BUSINESS FIRMS:** As business firms continue to discourage smoking on the job, many of them are looking for speakers to dramatize the dangers of smoking to their employees. For this type of audience, use the format for Stop Smoking Clinics. Find out if your American Cancer Society Unit sponsors these clinics, and if so, cite them as a resource. Provide your audience with ACS literature with tips about how to quit smoking.

# Do's & Don'ts

**DO** organize your talk before you give it.  
**DO** find out in advance how long you are to speak  
**DO** dress appropriately and be well groomed  
**DO** use humor in your presentation **DO** leave time for Questions and Answers

**DON'T** show the stoma!! You will offend someone  
**DON'T** dwell on the "gory details" of your surgery  
**DON'T** eat the wrong things before you speak; i.e., ice cream, ice water, mayonnaise, onions, cabbage  
**DON'T** use off-color language  
**DON'T** tell questionable jokes

# Visitation

**A** well-organized visitation program is one of the most important services of a club and one of its greatest assets. In addition to the comfort and support that trained visitors can give new laryngectomees and their families, your visitors establish a good relationship with the medical community, which brings credit to your club. Your visitors also help build membership as they invite new laryngectomees to meetings and then are there to welcome first-timers when they arrive.

A strong visitation program involves several important factors:

- \* Cooperation of local physicians
- \* Good visitor candidates
- \* Regular training courses
- \* Regular refresher sessions
- \* A good referral system
- \* Good administration

**COOPERATION OF LOCAL PHYSICIANS:** The cardinal rule governing hospital visits to patients who will have or have had laryngectomy surgery is that **the attending physician must always request the visit or approve it**. Professional ethics demand that this rule be strictly observed by laryngectomee visitors. It does become frustrating when an ENT surgeon does not request laryngectomized visitors for his patients.



Some reasons for this may be:

- The physician does not know that trained laryngectomee visitors are available.
- The physician may not recognize the importance of the encouragement a trained visitor offers the patient.
- The physician may simply overlook requesting a visit.
- The physician may have had an unfortunate experience with a previous laryngectomee visitor who was not properly qualified and trained.
- The physician may not know that the visitor may actually strengthen the physician-patient relationship.

Most clubs have a medical advisor, usually an otolaryngologist or ENT. This advisor is the club's link to the medical community. The advisor should actively promote the availability and use of trained laryngectomee visitors for all potential laryngectomees, including patients of other physicians. When a new head and neck surgeon starts practicing in the community, a letter or even a telephone call explaining the purpose of your visitation program is a good idea. The letter might come from the American Cancer Society or your medical advisor.

The club should periodically ask physicians to present a program at a meeting where the physician will meet laryngectomees who have been helped by the visitor program. Your club members should be urged to talk about the program to their own physicians on every possible occasion. Also, your speaker team should actively seek opportunities to speak to local physician organization to promote the program.

**GOOD VISITOR CANDIDATES:** To participate in the laryngectomee visitor program, visitor candidates MUST meet the following qualifications:

- \* Have had a total laryngectomy
- \* Have good, understandable alaryngeal speech (esophageal, electrolarynx, TEP restoration)
- \* Demonstrate physical recovery from surgery (active lifestyle, positive outlook, mature attitude about being a laryngectomee)
- \* Possess good communication skills (including the ability to listen and respond to questions)
- \* Be in good standing with the club and the American Cancer Society
- \* Be approved according to the ACS Unit/Division policies
- \* Be approved by his/her own physician
- \* Have successfully completed training
- \* Be recertified after a specific period (usually every two years)
- \* Possess a sincere desire to help new patients

In some laryngectomee visitor programs, spouses will be encouraged to accompany the laryngectomee visitor. In such cases, both laryngectomee and spouse should attend all training and refresher sessions. It should be emphasized, however, that while the spouse can and should be an adjunct to the visit, the visit should always be primarily conducted by a qualified laryngectomee.

### **TRAINING AND REFRESHER COURSES:** The *Laryngectomee Visitor Program*



*Manual* published by the American Cancer Society is the basis for all visitor training. In addition, some clubs have developed a set of handout sheets covering different topics.

Some examples are: *A set is available by writing the author c/o the IAL National Office*

- \* Emotional Responses to Cancer
- \* Comparative Roles: Friend or Visitor
- \* Visitor Role
- \* Ethics
- \* Laryngectomee Visitor's Guide
- \* Helpful Hints for Visiting

The trainer can be an experienced laryngectomee visitor, and the faculty should include a speech pathologist, an ACS staff person, a physician and a nurse. If it is impossible to obtain a physician, then a nurse with appropriate experience with head and neck surgical patients can substitute. It is always a good idea to have a social worker on hand to monitor and advise during the role-playing portion of the training program.

**REFERRAL SYSTEM:** A good referral system is essential to the success of your visitor program. As stated before, every visit should be requested or approved by the attending physician. Many physicians, as soon as they schedule their patients for surgery, instruct their office personnel to contact the local laryngectomee visitor coordinator and request a visit. This, of course, is the ideal situation. Many visitor coordinators remind the physician's staff on every possible occasion that their referrals are appreciated and that should the physician forget to request a visit, a memory jog by the staff person would be appreciated.

Speech pathologists, social workers and nurses routinely see patients before surgery, and your club's good relationship with these professionals will ensure that they use your visitation program.

**ADMINISTRATION:** To be successful, your program should have a good administrator or coordinator. Usually this person is or has been a visitor and understands what it takes to run such a program. It could be done by the spouse of a laryngectomee or by someone else who is organized and willing to help without being a visitor. If the laryngectomee visits in your area are assigned by the ACS staff people, be sure they know each visitor so that an appropriate choice may be made.

### ROLE OF THE ADMINISTRATOR



- \* Receive calls and record detailed messages
- \* Know which visitors are available at certain times
- \* Match visitors appropriately (age, gender, background should be considered, where possible)
- \* Utilize all qualified visitors
- \* Be fair and don't show favoritism

When calling a visitor, the administrator should provide all the information he has on the patient to the visitor. All visitors should make written reports covering their patients. A visitor who makes a pre-operative visit should wait until after the post-operative visit to file his report with the administrator. Also, a report should be filed with the ACS Unit sponsoring your club. Remember that patient information is confidential; however, names, addresses and phone numbers of new laryngectomees should be given to the membership chairman to be added to your mailing list and roster.

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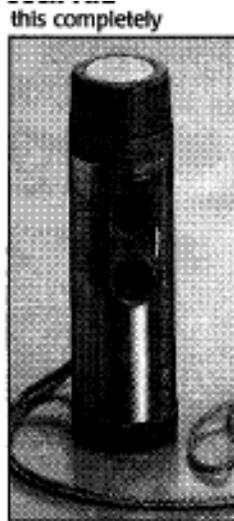
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