Let's meet in San Mateo!

Come join us in San Mateo in June! The 2009 Annual Meeting and Voice Institute will be held in beautiful San Mateo, California June 25-27. The Voice institute begins one day earlier at 8:30 a.m. on the 24th.

Many of those who come will want to come early or stay late in order to take in the sights of San Francisco, which is less than 20 miles away, as well as enjoy everything beautiful San Mateo has to offer.

An unusual feature of this Meeting is that it is being sponsored by a number of hosting IAL member clubs. The San Francisco club is being joined with those from San Mateo, Santa Clara, Santa Rosa, and Marin County. These clubs, working with the Annual Meeting Committee of the IAL (chaired by Vice President Bob Herbst) and with Director of the Voice Institute, Dr. Jeff Searl, and Executive Director Susan Reeves promise to make the Meeting and Institute an outstanding and memorable occasion for all.

The headquarters hotel is the beautiful San Mateo Marriott at 1770 South Amphlett Boulevard, CA 94402. You can make reservations using the information found on page 20. Located just five minutes from the San Francisco International Airport, the hotel is a beautiful facility and guaranteed to please. The room rate is $109 per night (plus tax) single or double occupancy. You can make reservations by calling toll-free 1-866-263-1461. The group code to get our discounted rate is: IALIALA.

You can register for either the Annual Meeting or Voice Institute using the information on pages 18 and 19.

For those hesitant to come because of the economy, airlines are discounting their airfares to attract more travelers and, of course, there is no guarantee that the economy will be more favorable next year or even the next. For those on the West Coast, it may be many years before the Meeting returns to your area.

Those of us who have attended an Annual Meeting or Voice Institute are convinced that every laryngectomee should attend at least one. And many of us come every year and always feel we have ben-
When will you need a Micron HME?

PROVOX® Micron HME

A breakthrough in pulmonary protection.
Designed specifically for the laryngectomee, Micron HME couples the pulmonary benefits of a heat moisture exchanger (HME) with an effective electrostatic filter for reduction of inhaled submicron particles like bacteria, viruses, pollen and dust.

Ideal for times when extra protection matters: during hospital visits, in large crowds, enclosed areas, while traveling or at home. Micron HME is a perfect supplement to 24/7 use of a standard Provox HME cassette.

Breathe easy.

www.micron-hme.com  1-800-217-0025

Let's talk about life®
cilfitted from returning again and have learned new things and, of course, enjoyed meeting old friends as making some new ones. We have said it before, but no one remains a stranger long at an IAL Annual Meeting and Voice Institute. It always feels great to be in the majority for a change and to feel that natural kinship we have for one another which comes from shared experiences. You will feel that you have recharged your laryngectomee “batteries” and will begin to look forward to your next chance to attend.

We come for many reasons including:
- spend quality time with people who understand us.
- learn about the latest products designed for our use.
- learn just about every development concerning total laryngectomee rehabilitation.
- socialize, celebrate, laugh, dance and dine out.
- shop and visit museums and tourist and historic sites.
- obtain help with speaking or other problems we may have.
- meet the “celebrities” and “stars” in our laryngectomee world including the inventors of the products we use and love, the vendors we deal with, and the best medical professionals in the world in the field of laryngectomee rehabilitation.
- get together with old friends and make some new ones.
- represent our clubs as Delegates who elect those who serve the IAL and shape its direction.
- run for election to an IAL office
- serve on an IAL committee.
- enjoy a great learning experience perhaps combined with a vacation.
- return with samples and many new ideas.
- and many more

So let’s make a date to meet in early summer in beautiful San Mateo, California! Use the information on pages 18 and 19 to register and make your hotel reservations.

We can just about guarantee that you will be glad you came!

**Dr. Singer is Keynoter!**

The IAL is proud to announce that our keynote speaker for the 2009 Annual Meeting and Voice Institute in San Mateo, California is Mark Singer, MD. Along with Dr. Eric Blom, SLP, Dr. Singer is credited with inventing the Tracheo-Esophageal Puncture surgical technique. Using the prosthesis designed by Dr. Blom, this medical breakthrough added this excellent alternative method of TEP speech to the communication aspect of our rehabilitation.

Dr. Singer was also instrumental in bringing to our community the hands-free valve and attachment system, the “insufflation” test, silicon laryngectomee tube, and many other innovations. Come hear one of our rehabilitation pioneers share his perspectives on the past and anticipate the future. Special thanks to InHealth Technologies for making Dr. Singer’s appearance possible.

Dr. Singer will be addressing the entire AM/VI audience at 9 am on Thursday June 25, 2009. You will not want to miss Dr. Singer’s Keynote Address!

**Attention Non-IAL Member Clubs**

The IAL wants to do all it can to help anyone who is about to become a laryngectomee or who has just become one to be able to find a local support club whether it is an IAL member club or not. With this in mind the IAL intends to publish the name and contact information for all laryngectomee support clubs on its website.

If you would like to have your club information posted, please send this information to our Database Manager Tom Herring at: tomherring@embarqmail.com. Include this information:
1. Location/Area of the club (for example, your city or county, country)
2. Name of club
3. Where and when you meet
4. Name, address, phone number and e-mail address of a a contact person

Thanks for your help in assisting laryngectomees to connect with each other.

---

**IAL News**

The IAL News is published four times per year by the International Association of Laryngectomees.

The information provided in the IAL News is not intended as a substitute for professional medical help or advice, but only as an aid in understanding problems experienced by laryngectomees and the state of current medical knowledge. A physician or other qualified healthcare provider should always be consulted for any health problem or medical condition.

The IAL does not endorse any treatment or product that may be mentioned in this publication. Please consult your physician and/or speech/language pathologist before using any treatment or product.

The opinions expressed in the IAL News are those of the authors and may not represent the policies of the International Association of Laryngectomees.

As a charitable organization, as described in IRS 501 (c) (3), the International Association of Laryngectomees is eligible to receive tax-deductible contributions in accordance with IRS 170.
Neck Cancer - A Physician’s Personal Experience

Editors Note: Dr. Brook is certainly not the first medical doctor to become a laryngectomee. There have been a number over the years, and one, Dr. V. F. Pekarek, served as IAL President from 1978-1980. But most of the doctor laryngectomees did not write about their experiences, or certainly were not so candid in addressing all of the trials they faced in becoming a laryngectomee. His candor on the mistakes made by the medical profession in treating him are particularly refreshing, welcome, and very important to both those facing treatment and for larys).

By Itzhak Brook, MD, MsC

Learning that I had hypopharyngeal cancer shook me to my core. I had to accept for the first time that I am not invincible and that life has an end. Suddenly, I was faced with the potential beginning of the end. Even though the small cancer (T1N0M0)1 in the retro-pharynx was surgically removed and I received local radiation, I was uncertain about my future. I slowly recovered from the radiation adverse effects and gradually believed that I was actually cured. However, after 20 months I had a local recurrence (T2N0M0)2 at a different location (right priform sinus). Unfortunately, my surgeons were unable to completely remove the tumor by laser after three attempts. At that point, I became frustrated and exhausted (emotionally and physically) and elected to undergo complete pharyngolaryngectomy with flap reconstruction at a different medical center with greater experience with this type of cancer. The tumor was completely removed, and no local or systemic spread was noted.

During my postsurgical hospital stays I was able to give my medical caretakers useful input about my symptoms that helped address issues early on. However, this became very difficult once I lost my ability to speak and could communicate only in writing. I prepared a written list of questions, but because some of my surgeons were impatient and always in a hurry, there was rarely a chance for follow-up inquiry. They rarely examined any part of my body except the surgical sites. Nonetheless, I am most grateful to all who cared for me and attempted to help me to the best of their abilities. Although the medical care I received at all institutions was overall very good, I realized that many mistakes were being made at all levels, some minor but some potentially serious. Fortunately, I was able to abort many of them, but not all. I had to be constantly on guard, which was exhausting. Patients without a medical background are most probably unable to recognize and prevent many of these errors.

Even though my surgeons explained the procedures and their aftermath, I was unable to digest and internalize the information because I was very anxious at that time. I wanted the cancer removed - all other issues seemed insignificant. I faced numerous and frustrating new realities that included fluid reflux into my mouth; difficulty in swallowing solid food; inability to speak while eating; limited motion and loss of sensation in my neck and left arm; the presence of a “hole” in my neck and a severely swollen neck that looked different without the Adam’s apple; repeated coughing to clear my secretions; continuous maintenance of the stoma and the tracheo-esophageal prosthesis (TEP); ordering equipment and always carrying airway supplies; the fragility of my speaking ability; learning how to speak again using the TEP and all the challenges relating to its repeated failures; difficulties being understood because of a weak voice; and often overt or discreet discrimination from others.

I had to learn and adjust to new realities and limitations and battle depression and despair. I continuously reminded myself that all of these difficulties and handicaps were worth the chance to survive a cancer diagnosis. What helped me overcome the difficult times was my wish to set an example to my children that one should not give in to adversity and do everything within one’s power to fight back.

I coped with depression by gradually getting reinvolved in activities I enjoy, which include teaching, writing, and lecturing. I had the support of my family and colleagues who accepted me as I was. I was also fortunate to have a supportive local laryngectomee club, a dedicated and caring surgeon, and a supportive social worker.

I was slowly able to return to my previous routines. I started with simple challenges such as learning to take a shower without aspirating water, taking walks, and reading medical literature again, and I gradually became able to ride a bicycle and hike. One of my greatest comebacks was fulfilling my commitment to lecture at the Annual Meeting of the American Academy of Otolaryngology—Head and Neck Surgery.

Experiencing firsthand the difficulties and tribulations of a postlaryngectomy experience showed me how dependent and helpless one can be. Being unable to speak, eat, and breathe normally while dealing with a potentially fatal illness make the patient extremely vulnerable, both physically and emotionally. In this difficult and challenging time, a proficient, competent, compassionate, and caring approach that appreciates what the patient is experiencing should be practiced.

I am sharing my personal experiences in an attempt to convey to health care providers the difficulties and challenges a patient faces after being diagnosed with cancer and undergoing extensive surgical procedures. Hopefully, my experiences will encourage these professionals to better understand and to diligently and compassionately deal with their patients.

(Reprinted from Archives Otolaryngology Head Neck Cancer, ©2009)

1 T1N0M0 is the lowest stage for a cancer. It has not begun to grow into the tissues around it. The N0 means that the cancer has not spread to nearby lymph nodes. M0 means that there is no evidence that the cancer has spread. T2N0M0 is the second stage for cancer. It has begun to invade the nearby tissues with still no spread to lymph nodes or other parts of the body.

Itzhak Brook, MD
The TruTone™ Electrolarynx is the only instrument available with natural intonation.

- Single Pressure-Sensitive Button, for Natural Expression
- 9v Battery Operation Means No Custom Mail-Order Batteries
- 2 Years of "Drop & Soak" Coverage with an additional 3 Year Limited Warranty Protection*
- Wide Frequency Range, Allowing for Masculine or Feminine Voice Adjustment

Now Available!
Low Profile Noise-Cancelling Headset Microphone

Specifications Subject to Change Without Notice
*Must return warranty registration card

800.330.5969
www.griffinlab.com
Dr. Brook to Speak in SM

There is an important article on page four by Dr. Itzhak Brook, MD. The decision had been previously made to feature this reprint of the article which originally appeared in a recent issue of a medical journal. And then the IAL was recently informed of the exciting news that Dr. Brook will be a speaker at the Annual Meeting in San Mateo in June. His appearance is sponsored by ATOS Medical.

As you read the article by Dr. Brook on page four you will see a number of themes which we can relate to including how this medical doctor experienced many of the same things we did. His being a doctor didn’t make him immune to all of those feelings and challenges. But he also provides unique insight on a subject of concern to each of us: that the quality of care available to us is far from universally excellent. His own care was lacking and he was in the unique position to fully understand and act on that knowledge.

The IAL is delighted to have many extraordinarily important speakers to share with us at the Annual Meeting and Voice Institute in San Mateo, California. Come join us and learn from Drs. Singer, Brook, and so many more!

Larynx Cancer Facts

According the National Cancer Institute (and based on complete information from 2001-2005):

- About 12,250 men and women (9,680 men and 2,570 women) were diagnosed with larynx cancer in 2008.
- About 3,670 died from larynx cancer.
- The average age at the time of diagnosis was 65 years of age.

<table>
<thead>
<tr>
<th>Age</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 20</td>
<td>0.0 %</td>
</tr>
<tr>
<td>20-34</td>
<td>0.5 %</td>
</tr>
<tr>
<td>35-44</td>
<td>3.7 %</td>
</tr>
<tr>
<td>45-54</td>
<td>15.6 %</td>
</tr>
<tr>
<td>55-64</td>
<td>28.4 %</td>
</tr>
<tr>
<td>65-74</td>
<td>29.2 %</td>
</tr>
<tr>
<td>75-84</td>
<td>18.3 %</td>
</tr>
<tr>
<td>85+</td>
<td>4.3 %</td>
</tr>
</tbody>
</table>

- From 1975-2005 the incidence of larynx cancer had decreased for all categories (race, age) except for a brief upward trend for women in the 1975-1988 period.
- The overall five year survival rate from 1996-2004 was 62.5%.
- Only a little over 1/3rd of 1% of the general population will have larynx cancer in their lifetimes.
- In 1995 there were approximately 93,096 men and women alive who had a history of cancer of the larynx.

Gifts to Honor Both the Living and Those Who have Left Us

The IAL Board of Directors invites you to make a gift in memory of someone who is no longer with us, or in tribute to someone you wish to honor. Gifts in any amount are welcome. In lieu of flowers, you may wish to donate in memory of a loved one, friend, club member, or others.

You may make your donation via regular mail by sending a check along with the name of the person you wish to honor to IAL, 925B Peachtree Street NE, Suite 316, Atlanta, GA 30309; make it through our web site at: http://www.TheIAL.com; or by using the information on page 21.

Each donation will be privately acknowledged with a mailed card to either the giver, for memorials, or to the person honored, and also posted on the IAL web site. Gifts will also be periodically acknowledged in the IAL News by donor (unless you wish to remain anonymous), and the name or names of those who are being honored.

The Board of Directors believes that this program will help the IAL continue to serve the purposes for which it was created more than 57 years ago, and also provide us with a way to publicly honor those each of us believes is deserving of recognition.

These donations are tax-deductible.

by Judy Greive

Larry continued his struggle with fear of water.
Active Members Needed
By Tina Long, IAL President

My local club, The Greater Atlanta Voice Masters, has lost many of our dearest members these past years. Some have passed away, some have moved and others feel, through the support of their doctor, SLP, family and friends, that they are fully rehabilitated, and don’t see the need to be part of a club/support group. After rehabilitation and recovery many people go back to work and get involved with all the activities enjoyed before the surgery. But as I see it, we need the rehabilitated laryngectomees now more than ever.

I can remember my first time attending a club meeting; it was such a boost for me and my husband. I met numerous people just like me, who have gone back to work, maintained a busy social life, and, best of all, these people were able to communicate. Truly it was the beginning of my total rehabilitation. I’m sure everyone remembers their first time hearing a laryngectomee speak, whether it was in the doctor’s office, in the hospital or at a club meeting. We must be available to give all new laryngectomees, and the laryngectomees who have not been contacted by a fellow laryngectomee, the information they need and the opportunity to see that there is life and the ability to communicate after a total laryngectomy.

Even though I am independent and back to “life as usual,” I feel it is an honor to meet our newest members and share what I've learned along the way. So why not discuss with your club members different ways your group can be there for the laryngectomee community?

A few suggestions that might help get you started:

(1) Contact all SLPs in your area and let them know your group is available to speak to individuals and their families pre-op and post-op.
(2) Leave information about your club at ENT offices, oncology centers, radiation facilities, dentist offices and even barber shops and salons. (The last two groups are people who could be our “first responders.”)
(3) Let the nurses in the hospital who take care of laryngectomees after surgery know that your group is available to visit a patient. Due to the HIPPA law, a nurse or doctor must get authorization from the patient before a visit is scheduled.
(4) Get involved with the IAL’s Community Outreach Committee to share ideas and learn other ways to get the word out. You will experience the satisfaction of “giving back.”
TEP Topics

By Carla Gress, ScD, CCC-SLP

First off, there are some ENTs who know how to do a laryngectomy, some who know how to do the TE puncture surgery, and some who can do both (and some who shouldn’t be doing either one!) Some ENTs who do the puncture like to do it at the time of the laryngectomy, as long as there are no medical contraindications to it, and some don’t.

That can be a matter of training, or simple physician preference. It doesn’t really matter as far as the eventual quality of the voice is concerned. As a general rule, a patient should never try to convince their physician to do something that he/she doesn’t want to do or feel comfortable about. If your MD refers you to a colleague to have a procedure done, be thankful that they recognize their own limitations and want you to have better care than they think they can provide. Yes, it may be an inconvenience to you, but better than have an MD who is stumbling around trying to figure out what should be done, or what shouldn’t have been done.

I’ve always thought that there are two types of patients who do well with the TEP: those who happen to have the perfect anatomy and physiology for it, and those who are doggedly determined to make it work (read: bull-headed). The worst patients are those who don’t really want the TEP, but whose family members do. My own opinion is that unless a patient is truly dependent upon the spouse, child, sibling, etc. for daily care and/or financial support, the caregiver doesn’t get much of a vote as far as the method of voice restoration. That may seem like I don’t recognize the important role that caregivers serve in the recovery process - not true. A good support system is vital. But I firmly believe that a patient needs to make an informed decision for himself/herself, because when the day is done, it is the patient who has to be able to accept the new voice as his/her own voice.

A large stoma doesn’t mean a larger diameter or a longer prosthesis. To get air to travel through the prosthesis, the stoma must somehow be occluded, by a finger, or the use of a hands-free valve. Large stomas can be tricky to occlude sometimes, but there are almost always methods to get around it. A very small stoma can present even greater challenges, because it can compromise breathing and make for difficulty in cleaning and changing the prosthesis. But then again, there are usually ways to get around it. Dogged determination.

There was a recent post (on WebWhispers) that alluded to trying a larger (diameter) prosthesis when there was leakage around the device. Typically, if there is leakage around the prosthesis, you don’t want a larger diameter prosthesis. The prosthesis isn’t a cork that plugs the hole. A larger diameter prosthesis will usually only cause further enlargement of the puncture, with greater leakage. Often a larger FLANGE on the prosthesis can work like a washer to help seal the leakage (see photo below).

Persistent leakage is a problem that needs to be systematically addressed, not ignored or “tolerated.” It can compromise the patient’s overall health. My rule #1 is “Always sacrifice the voice for the sake of a healthy patient.” If leakage problems cannot be resolved when all attempts have been made, using the collective wisdom of the medical experts who will offer advice and counsel and the veteran laryngectomists, it is my opinion that the puncture should be closed.

The surgical voice restoration procedure of tracheoesophageal puncture (TEP), at least in the United States, is legally performed only by a licensed surgeon. A knowledgeable SLP may place the prosthesis in the puncture, but the puncture itself is created by a surgeon.

There are a few MDs who will perform the TE puncture in an office setting. The overwhelming majority of the experienced surgeons that I know, do not. They prefer to do it in the operating room, such as in an ambulatory surgery center, where they can be certain that there is sufficient anesthetic, adequate visualization, continuous monitoring of vital functions, and the availability of emergency interventions in the unlikely event that should they be required.

Any time there is surgery, there are risks, and that is especially true when you are dealing with the airway. No one gets extra points in my book for trying to take short cuts or being a “cowboy.” Safety is all that counts. That’s not to say that much of the time, possibly even almost all of the time, things will go OK doing it as an office procedure. But I’ve seen a few where things didn’t go alright when it was done in the OR, through no one’s fault, and thank goodness they weren’t in an office or the outcome might have been vastly different.

(Dr.Gress lives with her family in Charlottesville, Virginia)
IAL Incorporates

The IAL is now an official non-profit corporation. Incorporation reduces the personal legal exposure for employees, officers and members of the Board of Directors if there ever were a lawsuit. Incorporation has been recommended for years, particularly by our fellow laryngectomees who are attorneys such as Terry Duga (Treasurer of WebWhispers), as well as others. Thanks to all.

The IAL now is officially "The International Association of Laryngectomees, Inc."

We incorporated in the state of Delaware which is a very popular state for all kinds of organizations including non-profits because of their tax structure. Special thanks to IAL Treasurer Sapp Funderburk who headed the project.

What's Cooking?

The IAL is cooking up a cookbook as a fund-raiser and we need your favorite recipes! The cookbooks will be compiled by volunteers and sold for $10.00 each.

Please send your favorite recipes with your name and club affiliation (if any) to: Susan Reecevs, IAL, West Texas Rehabilitation Center, 3001 S. Jackson, San Angelo, Texas 76904, or e-mail the same information to IALED@ThclAL.com (please put “Cookbook” in the subject line).

Those wishing to purchase a cookbook may order them through the IAL office (contact information is on the back cover). If there are a number of cookbooks wanted by your club members, you can place one order for the group. This will save on shipping costs.

The cookbooks will be pre-sold and money received before the books are printed so that we do not have to spend the money up front in hopes of selling all we print.

If you have questions please e-mail IAL Executive Director Susan Reecevs at IALED@ThclAL.com, or call the IAL office toll-free at (866) 425-3678.

Let's see what we can cook up together!
‘Voice Box’ Transplants Under Scrutiny—Doctors wonder if it’s ethical to do it

By Tudor Vieru, Science Editor
Softpedia.com
27th of February 2009, 14:35 GMT

As stem cell research is currently making impressive headway in the creation of artificial organs, doctors in the UK are starting to ponder the ethical implications of performing voice box transplants. This type of surgical procedure refers to replacing a human larynx, the organ that is responsible for giving each man and woman on the planet their individual voice. Cancer and violent trauma are the main reasons why nearly 1,000 people in the UK lose their voice boxes every year. For them, a transplant is the only way to regain their ability to speak.

On the other hand, a team of scientists believe that they may be able to perform the operation without the patient having to take immuno-suppressive medication to inhibit their body’s natural defenses, so that the transplant won’t get rejected. The trick is to use the patient’s own stem cells for the procedure. The organ that needs replacing is harvested from a newly-deceased patient, and is then stripped of all its own cells. Thus, all that remains is a clean scaffold, on which the patient’s own stem cells are grown, using a bioreactor.

When the organ is ready, it’s simply placed inside the receiver’s body, which has no problem in accepting it, because it’s not viewed as a foreign object. This type of surgery was used successfully on one occasion, when a woman received a new windpipe, constructed from her own cells. She never had to take strong medication to force her body to accept the implant. Other transplant patients, such as those who get a new heart, a lung, or a kidney, need to take them, because, if not, there’s a very high chance that the body will reject the new organ.

As side-effects, these drugs inhibit the immune system, which means that the person is left completely defenceless even against the most harmless bacteria. Countless infections can find their way into the body, left unchecked by the suppressed immune system. Doctors would surely welcome methods that would allow them to bypass this serious issue, and keep the patients out of harm’s way.

“We, as a task force, have to ask ourselves whether we are finally entering the right window where a marriage of technology and of need mandates that we can go forward with this procedure. Before now, the prevailing view has been that the balance has been strongly in favor of not going ahead. But we feel there have been sufficient technological advances to make us seriously revisit the case for developing and making routine this procedure. We have to ask ourselves is it right to subject a patient to the risks of surgery for a procedure which is not life-saving,” University College London professor Martin Birchall, who is a member of the UK task force appointed to clear the dilemma around such procedures, stated. (From Softpedia.Com. Thanks to Jewell Hoffman who brought this article to our attention.)

Larynx and surrounding structures (graphic from BP.blogspot.com)

Tim Heidler was the first person to receive a larynx transplant. He had lost his voice box due to an accident and not to cancer.

The procedure was done at the Cleveland Clinic which has had a difficult time finding someone else willing to undergo the procedure in part because of the hundreds of thousands of dollars needed to control the rejection of the transplanted larynx.

Kits for New Clubs

The IAL Board of Directors has approved a program to provide a customized “Starter Kit” for any new member club.

The kits will contain:
1. Literature from the IAL including window stickers, emergency cards, tips on writing newsletters, “How to Start a Loaner Closet,”
2. Postcards for subscribing to the IAL News or changing address information.
3. Information on the IAL website
4. IAL brochures
5. WebWhispers brochures
6. Visitor Training Program handbook
7. Memorial/In Honor self-addressed envelopes
8. (Upon request) A refurbished electronic artificial larynx to help start a loaner closet.

New clubs will be contacted and sent samples along with a form to order the numbers of items they need.

Existing clubs which do not have these materials on hand (or adequate numbers) are also invited to request them from Susan Reeves, Executive Director, IAL, 925B Peachtree Street, Atlanta, GA 30309-3918, e-mail her at IALED@TheIAL.com, or call her at (866) 425-3678.
Y’all Come See Us

May 8-9, 2009
June 25-27, 2009
September 19-20, 2009
October 2-4, 2009
October 16-17, 2009
Ann Arbor
San Mateo, CA
Philadelphia, PA
Orlando, FL
Fargo, ND
Tri-County Laryngectomee Conference
International Assoc. of Laryngectomees
Mid-Atlantic Regional Conference
Florida Laryngectomee Association
North Dakota Laryngectomee Association
(Free simple repairs on any viable electrolarynx.)

What’s that you said?

Do you find yourself asking people to repeat themselves when others seem to be able to understand the speaker? Did you wonder if your hearing was going bad only to have it checked and the hearing test didn’t indicate any reason why you were having problems hearing?

The answer may not be in the ability of the ears to pick up sound but in our aging brains. The problem is that when there is too much noise, such as background noise, your brain tells your ears to reduce the flow of information coming to them. It is as if there is a dimmer switch in our brains which turns down the sound volume.

According to a recent Associated Press article, it turns out that the brain’s “dimmer switch” deteriorates with age and we are less able to block out background noise and concentrate on the sound we wish to hear. We become more easily distracted.

So it may not be your ears which are the culprit, but the part of our brains which regulate sound.

Scientists continue to work to learn why our hearing deteriorates with age with the goal of slowing down that process.

Support our advertisers! They support the News.
Loaner Closets - Part 1

Many laryngectomee support clubs maintain loaner closets with the items in them which are primarily intended for new laryngectomees, and for these to be loaned for a period of time. Among the most helpful are working electronic artificial larynges (ALs). Frequently clubs are the initial providers of ALs to new laryngectomees. They may be supplied prior to surgery to begin the process of learning how to use them, or, more often, brought by a hospital visitor.

Intraoral ALs such as the Cooper-Rand are particularly helpful in the immediate post-surgery period when attempting to use one against the neck would be impossible because of sutures/stables and swelling. Most other ALs can be fitted with an intraoral adapter for use in the immediate period following surgery.

However, a common problem for clubs is to get loaner ALs back from patients. Often the reason is found in the expression “if it ain’t broke, don’t fix it.” If new laryngectomees have an AL which is meeting their needs they may feel no urgency in finding a source of funding to purchase their own. Some even seem to believe that they can keep the club’s AL as a “back-up” to one they do obtain, or to back up another method of speech such as the TEP/prosthesis.

Keeping good records and making the obligation of the laryngectomee clear to return loaned equipment can help recover these items. Below is a form used by several clubs. A copy is given to the person borrowing the club’s equipment. Good follow-up is important.

(Part 2 on loaner closets will appear in a later issue.)

| (Club Name) |
| (Contact Information including phone number) |

**Equipment Loan Form**

(Please Print)

**Patient Name:** ____________________________  **Date:** ____________

**Address:** __________________________________

**Home Phone:** ____________________________

**Person Responsible For Item (if different from above):** ____________________________

**Address:** __________________________________

**Home Phone:** ____________________________  **Work Phone:** ____________________________  **Cell:** ____________________________

The ____________________________ (Name of Club) is pleased to be able to temporarily provide you with the following equipment, which is the property of the organization:

| Description: | ____________________________ |
| Serial Number: | ____________________________ |

So that we are able to help all of those in need of this equipment, we ask that you agree to the following conditions:

1. The item(s) provided to you are on a loan basis for ________ days. At the end of this period of time, you should either return the borrowed equipment, or call ____________________________ at ____________ to discuss your needs and renew this contract, if necessary.

2. The item(s) will not be loaned to anyone else.

3. The item(s) will be promptly returned when no longer needed by you.

4. In the event of damage or breakage to the equipment due to improper use or negligence, you hereby agree to pay for the repair or replacement of the item if requested.

I have read and understand the above provisions and I acknowledge that I have received the equipment as described above.

**Signature of Recipient/Responsible Party:** ____________________________

**Date Issued:** ____________  **Date due for return:** ____________  **Date Returned:** ____________

**Signature of Club Representative:** ____________________________

Thanks to the Laryngectomee Club of Montgomery (MD), Tidewater Lost Chord Club (VA), and the Montgomery Laryngectomee Association (AL) for suggestions.
Chemo: the New “Gold Standard” in Treating Head & Neck Cancers?

Researchers at the famous Dana Farber Cancer Institute in Boston published an article in a medical journal this past December which suggests that a new standard of care (“The Gold Standard”) of treatment for head and neck cancers, including of the larynx, should involve chemotherapy given before other treatments are begun, or at the same time as other treatments.

They reported that locally advanced squamous cancers of the head and neck continue to be a major contributor to cancer deaths worldwide. Despite progress made through the use of multiple therapies including surgery, radiation and chemotherapy, they conclude that the survival rate continues to be poor. They also reported that the side effects from treatments continue to be significant and include those from radiation such as soft tissue scarring, narrowing of the esophagus (producing swallowing problems), dry mouth, dental decay, and osteoradionecrosis (the death of bone tissue due to radiation).

Recent studies have shown significant improvement in the survival of patients who were given combinations of drugs including Taxotere along with cisplatin and 5FU. Studies are also under way to determine if this formula for induction chemotherapy (given before other therapies are started) can be made even more effective with the addition of new targeting chemicals such as cetuximab and panitumumab.

Mid-Atlantic Regional set for September 18-19

The Mid-Atlantic Regional Meeting attracts attendees from Virginia northward through New York and beyond. It is set for September 18 and 19, 2009 at the Fox Chase Cancer Center, 333 Cottman Ave., Philadelphia, PA, 19111. A discounted room rate of $99/night plus tax is available from the Four Points Sheraton Hotel. Find out more at: http://somersetmiraclevoiceclub.org/id3.html.

Their “Doctor’s Panel” will have new members joining Dr. Dennis Fuller, SLF, and include Dr. John Ridge and Dr. Miriam Lango, Head and Neck Surgery; Dr. Theresa Gills, Psychiatry/Rehabilitation Medicine; and more. Along with their traditional voice workshops on esophageal, TEP and electro-larynx speech, there will be sessions on “Coping with Change,” dysphagia (swallowing problems), lymphedema, physical therapy, and more. Mark your calendars to attend one of the best regional laryngectomye meetings.
Rosalie Macrae Miles Dies

By Vicky Passingham (daughter)

Rosalie Miles, who made friends from around the world after her laryngectomy operation four years ago, has died at age 74. A retired journalist, Rosey enjoyed a distinguished career in national newspapers in Britain.

She was born and raised in the Highlands of Scotland and began her career as a reporter in Glasgow. After moving to London in 1955 Mrs. Miles started work for the Daily Sketch, where her byline was “Youngest Girl Reporter in Fleet Street.” She then went to work for the Daily Express and Daily Mail. Her nine years with the Express included two years based in Paris as a foreign correspondent.

During that time she was sent to cover the Munich air disaster and was the first British newspaper journalist to visit the hospital where Sir Matt Busby and his Manchester United (professional soccer) players were treated after their plane crashed on takeoff killing 21 people.

Celebrities Rosalie interviewed during her career included Elvis Presley when he was a GI, Paul Newman on his honeymoon with Joanna Woodward and Edith Piaf. Having left Fleet Street (notc: a British term meaning the newspaper business) to bring up her three children in the chocolate-box English village of Coggeshall, Mrs. Miles worked as a freelance journalist, continuing to write under her maiden name, Macrac.

Six years ago she moved to Colchester in Essex, to be nearer her family. She was always a popular member of the community and, despite suffering from throat cancer and having her voicebox removed four years ago, she courageously continued to live an active life using a hand-held electronic artificial larynx to speak.

Rosalie embraced the internet revolution and spent many hours talking to fellow laryngectomee friends worldwide on the web.

Some remembrances from WebWhispers members: “Rosalie shared so much fun and humor as she struggled with many ailments. She let us see wisdom through her delightful perspective” (Libby Fitzgerald). “Rosalie...shared her insights and strengths and helped me find my own” (Steve Staton). “(She) was one of my best laughing buddies and... taught many of us the meaning of keeping laughter in our lives (Diane Davis). “She was such a super lady who had so much I wish I could have had the honor of to have met her” (John Shepley). “Rosalie touched all of us with her humor, compassion and excellent writing” (Vicki Eorio).

The IAL Board of Directors extends our condolences to Rosalie Macrae Mile’s family and many friends including those from our laryngectomee community. We will surely miss her.

What a Year (or Two)!

By David Blevins, Editor

What a year (or two) the IAL Board of Directors has had! You would be hard pressed to come up with another period of time in the 57 year history of the organization when the IAL has faced so many serious problems, but also accomplished as much despite these serious challenges.

There are only two members of the current Board of Directors who were on it in 2007, but part of the workload of the current Board has been to go back and deal with unresolved issues, problems and responsibilities from 2007, and even before that in one or two cases.

In the past two years the organization has had 4 Presidents, 5 Vice Presidents, 2 Secretaries, 2 Webmasters, 3 Treasurers, 4 Executive Directors, 2 Voice Institute Directors, and lots of turn-over among Board members! That has got to set some kind of record for personnel turn-over. The work required to advertise, identify, interview and hire the Executive Director, Voice Institute Director and Webmaster was quite extensive, exhaustive and took many months.

Also, when you have many new Board members they need attention and time to bring them up to speed on the Bylaws, procedures, history and on-going projects.

What the current Board inherited can only be described as continuing turmoil, which it has had to work hard to resolve at the same time it addressed the pressing current needs of the organization.

The list of IAL Accomplishments - 2008 to 2009 which follows on pages 15 and 16 is testimony to what the current Board has managed to accomplish despite the time consumed by dealing with personnel changes and a backlog of unfinished work. It is more than possible that no Board in the history of the IAL has accomplished more, and under more difficult circumstances.

I was appointed to fill one of the Board vacancies last year and was then elected to the Board in Little Rock. As someone who has read every IAL newsletter back to the founding of the organization, I know of no Board which ever accomplished as much, in such a short time, under such adverse circumstances, and with what amounted to having its hands tied behind its back financially.

Quite possibly the biggest single challenge for the Board has been financial. With a decline of laryngectomee support clubs there has been a corresponding decrease in income from dues. There has also been a downward trend in attendance at the Annual Meeting and Voice Institute. As a result of declining income the Board cancelled its usual Interim Meeting which had always been held at the hotel where the next Annual Meeting is scheduled. Despite that, the Board eff-
excursively used a provision in the Bylaws which permits it to
make formal decisions via e-mail.

The Board has looked at every IAL expense and
sought to eliminate or at least reduce each of these costs.
The Board has also tried to set a personal example by making
contributions to the IAL in the form of cash and not re-
questing reimbursement for expenses. Every Board member
contributed, and the total contributed by just these eleven
current Board members is three times the income received
from all club dues; and this support continues climbing.
This Board clearly believes in the mission of our orga-
nization and is willing to show that in the most dramatic
way possible by demonstrating that if you really support
something you “put your money where your mouth is.”

Like virtually everyone else, the IAL has lost money
in the financial downturn. A decision was made years ago
to move out of completely safe investments like CDs and
put part of the organization’s funds into mutual funds. Until
recently when the BOD completely got out of this market, it
seemed like a brilliant idea. But the IAL Board was no more
able to anticipate the economic crisis than anyone else.

The Board has definitely not functioned perfectly.
We were months late posting the minutes from the Little Rock
AM. A new Secretary, no tape recordings of meet-
ings, having to rely on committee chairs to provide their
minutes, illness, and multiple drafts caused the delay.
The Board is also determined that financial audits will be
posted on time. New personnel and missing records were
among the factors which caused delay. The Board regrets
these delays and pledges to not repeat them. There is much
more to be done and the Board is looking to each of you to
help the IAL financially and with your ideas and energy.

IAL ACCOMPLISHMENTS--2008 to 2009

Executive Director

1. Hired a part-time Executive Director who has access to a large staff including persons who have expertise in
fund raising and many other skills (personnel includes a large group of volunteers). Cost: $12,000 per year.
Saved: $30,000 per year (previous full time Executive Director was paid $42,000 per year).

Web Site

2. Replaced the former webmaster with an individual with a higher skill level and the time to work on the site.
3. Web site is being completely redesigned and upgraded.
4. Changed web site name from Larynxlink.com to TheIAL.Com (and protected TheIAL.Org, TheIAL.Net and

IAL Assets

5. Moved all IAL assets into insured accounts that cannot decline because of downturns in stock markets.
6. Retained $50,000 in an insured money market account for contingencies and to possibly later reinvest.
7. Eliminated the position of the Financial Advisor. Saves 1% of the total value of the IAL’s assets per year
which was the fee paid (has varied from approximately $6000/year to less than $3000/year.)
8. Maintained a moratorium on Board travel (see “Represented the IAL” below).

IAL News

9. Eliminated the services of a professional graphics person who had designed the IAL News, AM/VI program,
every. Saved: approximately $9600 per year.
11. Added advertisers and reduced deficit spending on the News from about $8,000 per year to a level of less
than $4000 per year. The goal is to make the News pay for itself.
12. Reduced the size of the News from 28 to 24 pages. Savings: approximately $1000 per year.
13. Reduced the amount of “filler” material.
14. Increased the diversity of articles in the News to better address the interests of the vast majority of readers
who do not attend the Annual Meeting or Voice Institute, or closely follow IAL internal business.
15. Improved relations with vendors.
16. Created a fourth category of advertisements in the News (business card size ad for vendors who also pur-
chase their usual sized ad). Income: estimated at $1000 per year

Voice Institute

17. Reduced the Voice Institute budget by approximately $10,000 per year.
18. Began the process of finding additional and/or alternative funding sources.
19. Continued to re-examine the format and structure, location, schedule and timing of Voice Institutes.
20. Term of VI Director increased to three years to provide continuity

Database

20. Conducted a major purging of the mailing list eliminating duplicates, changes of address (or unknowns.
verified addresses and converted addresses to the format required by the U.S. Postal Service. Saved: ap-
proximately $800.
21. Conducted research to determine which member clubs are still in operation and purged the list or upgraded contact information on the web site.
22. Conducted research to determine clubs in existence which are not IAL members and worked to recruit them. Added seven new clubs.
23. Began the process of gathering contact information on non-IAL member clubs to add to the web site in order to help laryngectomees to locate a local support club.
24. Designated one individual to be responsible for maintaining all of the databases. **Fund-raising**
25. Obtained over $9,000 in donations (excluding donations from the Board of Directors or memorial program).
26. Revitalized the memorial gift program and publicized donors and honorees via the News and the web site. Obtained over $550 in just over a month.
27. Initiated a cookbook fund-raiser at no cost to the IAL (pre-orders printed only).
28. The current members of the Board of Directors have donated at least $15,000 to the IAL in cash or not requesting reimbursements. Every Board member contributed. Some make automatic monthly donations.
29. Submitted four grant requests from foundations. One is pending. **Publications**
31. Revised and printed postcard mailers laryngectomees use to subscribe to the IAL News or change contact information.
32. Revised *First Steps* (a comprehensive publication on laryngectomee rehabilitation) and posted the draft on the web site where it can be downloaded by clubs and provided to new laryngectomees.
33. Initiated monthly E-mail communication to all designated club contacts. **Represented the IAL**
34. Board members represented the IAL at:
   - American Speech-Language-Hearing Association
   - Florida Association of Laryngectomees
   - Texas Association of Laryngectomees
   - Many local member and non-member clubs
   Cost: all expenses donated by Board members. **Miscellaneous**
35. Incorporated the IAL as a non-profit corporation. Incorporation reduces the potential legal liability of the organization’s employees and Board members.
36. Established a permanent address for the IAL. This will save money by not having to revise publications when personnel or contact information changes, and provides greater stability.
37. Abolished the renting of the IAL’s mailing list to vendors. While this caused a loss of income (approximately $500 for each vendor use) it was felt that maintaining the confidentiality of individual mailing addresses was the right thing to do since those on the list had not given their permission to share their contact information.
38. Completed and posted the 2006 and 2007 (pending) audits.
39. Created “Starter Kits” for new clubs including literature and, upon request, an electronic artificial larynx to help start a loaner closet (see page 10).
40. Made maximum use of e-mails in compliance with the Bylaws to conduct IAL business. Increased productivity by speeding formal decision-making instead of face-to-face meetings of the Board of Directors.
41. Cancelled a face-to-face meeting at the location of the next AM (San Mateo).
42. Considered multiple proposals to save money in all expense areas. Wrote numerous grant proposals.
43. Explored the use of the Internet and other media to conduct business and to save money on face-to-face meetings.
44. Reviewed and revised the Standing Rules of the Board.
46. Began a program to collect, repair, store and distribute electronic ALs to include in Starter Kits and also donate to clubs and other worthy projects.
47. Reaffirmed a Board travel freeze to save money. (Approximate savings: $23,000).
48. Created a program to provide one free Voice Institute registration fee to a graduate SLP student at universities outside the immediate VI area (goal is to increase paid attendance and filling hotel rooms).
49. Stopped publishing the contact information for VI participants in order to protect confidentiality.
50. Began a project to back-up and securely store historic and financial data. And others.
Laryngectomee group gives support

By Jayna Boyle
Tuesday, February 3, 2009 (reprinted from the Go San Angelo.)

After his laryngectomy - the surgical removal of his voice box - John Ulrich taught himself how to speak again by taking walks with his dog and practicing syllables on the pet. “After six months, I learned to speak pretty well,” Ulrich said. “But I’m still working on it.” That was 27 years ago.

He now uses esophageal speech by forcing air into the top of the esophagus and pushing it out of the mouth. The top portion of the esophagus vibrates the throat tissue similar to a belch, and the mouth forms the sounds into words. Esophageal speech is one of three methods of speech that laryngectomees can use. The others involve using an artificial larynx or a tracheoesophageal voice prosthesis.

Tracheoesophageal voice prosthesis requires puncturing the back wall of the trachea to create a passage with the front wall of the esophagus. A prosthesis is inserted into the hole, called a tracheostoma, and as the patient exhales, air is shunted into the esophagus to form speech.

Like most who require laryngectomy procedures, Ulrich had laryngeal cancer. At the time, doctors estimated he would live for two more years. “I guess the Lord gave me 25 extra (years) to help others,” he said. Ulrich, 65, has spent many years helping new laryngectomees adjust their lifestyle.

He is the vice chairman of the Texas Laryngectomee Association and is a member of the Concho Valley Lost Chords support group. Susan Reeves, a speech pathologist and a clinical coordinator at West Texas Rehabilitation Center, organizes the local support group.

She recently was named executive director of the International Association of Laryngectomees, a group that holds annual informational meetings for laryngectomees and clinical professionals. As the executive director, Reeves answers e-mail questions and directs people to resources in their areas. She said about 170 laryngectomee groups exist in the U.S., and about 13 are in Texas. Reeves said the international group tries to get the word out about its resources and support groups because many laryngectomees don’t know whom to turn to for help after their surgery. “It’s not just the talking that’s different,” Reeves said. “Daily life things change.”

Laryngectomees have to learn how to cough out of their necks, learn new ways to blow their noses and smell things, adjust how they taste food and make sure that they adapt their shower routine. “The stuff we talk about at the support group, you don’t get from a doctor,” Reeves said.

The local laryngectomee support group has from two to 15 people at its monthly meetings, she said. “Part of the problem is that people don’t know that we’re out here,” Reeves said. Health-care privacy and security laws in recent years are so effective, it is difficult to find new laryngectomees, she said. The local Lost Chords group depends on doctors’ referrals and word of mouth to spread the word about the club.

Few people have the surgical procedure, and not many professionals are trained to help them, Reeves said. West Texas Rehab in San Angelo sees about five new laryngectomees a year.

Reeves has been helping laryngectomees for more than 20 years and is one of the few speech pathologists in the region trained to work with them. “I’m just trying to pay it forward and pass along my knowledge,” she said.

Ulrich said he saw a speech pathologist twice when he was learning how to talk. At the time, esophageal speech was the only type available. He does nearly all the things he was able to do before the laryngectomy - except deep-sea diving. Ulrich was active duty in the Navy when his cancer was detected.

Ulrich has been attending the Lost Chords meetings for about 25 years, but he now goes to lend support and advice to others more than anything else. His wife also is active with the group. “You get down about it after surgery,” Ulrich said. “I don’t know anyone who doesn’t have a bout of depression.”

(GoSanAngelo.com)
IAL ANNUAL MEETING REGISTRATION
FORM A

San Mateo, California
June 25-27, 2009

If you are a laryngectomee and would like assistance to develop or improve your speech, you should register for the IAL Voice Institute as a Voice Institute Pupil (VIP) and use FORM B, (IAL Voice Institute form).

If you have been a laryngectomee for at least two years, have good speaking skills, and would like in-depth instruction in communication methods and related topics in order to serve as a peer-counselor to other laryngectomees, register for the IAL Voice Institute as a Laryngectomee Trainee (LT) and use FORM B (IAL Voice Institute form).

If you are a spouse, caregiver or a laryngectomee not looking for speech assistance as a VIP or becoming a Laryngectomee Trainee, fill out this form.

All others please complete this form to register for the Annual Meeting.

Registration Fee: $65.00 per person (If mailed on or before June 1, 2009)
$75.00 per person (If mailed after June 1, 2009)

First Attendee (Please Print) __________________________________ Laryngectomee? ☐ Yes ☐ No

Second Attendee _____________________________________________ Laryngectomee? ☐ Yes ☐ No

Street Address ________________________________________________________________

City __________________________________ State/Province________ ZIP ______ Country ________________

Phone Number (______) ___________________________ E-Mail __________________________

☐ Check here if you require assistance or special accommodations to attend the meeting because of physical limitations. You will be contacted for further information. (Note: All sessions of the Annual Meeting and Voice Institute are conducted in English, and if needed, you must arrange for your own translator).

You may also register online at http://www.ThelAL.com/SanMateo

Mail check or money order payable in U.S. dollars to: IAL, and mail it to IAL, 925B Peachtree Street NE, Suite 316, Atlanta, GA 30309.

Payment by Credit Card:
Please check ☐ VISA ☐ MasterCard ☐ Discover ☐ American Express (Go to ThelAL.com to use PayPal)

Cardholder Name________________________________________ Card Number __________________________

Expiration Date __________ Security Code _____ Cardholder Signature ______________________

Please register for the IAL Annual Meeting OR the IAL Voice Institute.
Do NOT register for both events. Also REGISTER FOR THE HOTEL using the information below.

San Mateo (San Francisco Airport) Marriott*
1770 South Amphlett Boulevard, San Mateo, CA 94402-2902
Phone: 1-866-263-1461
Fax: (650) 653-6080
http://www.sanmateomarriott.com (Group Code: IALIALA)
Group discount rate is $109/night (1 or 2 people). This discounted rate will run from June 22 through June 29.
Be sure to mention that you are with the 2009 IAL to get this discounted rate.
*There is also a San Francisco Airport Marriott, but it is in Burlingame, CA.
IAL VOICE INSTITUTE REGISTRATION
San Mateo, California
June 24-27, 2009

If you are a laryngectomee and would like assistance to develop or improve your speech, register for the IAL Voice Institute as a Voice Institute Pupil (VIP) using this form.
If you have been a laryngectomee for at least two years, have good speaking skills, and would like in-depth instruction in communication methods and related topics in order to serve as a peer-counselor to other laryngectomees, register as a Laryngectomee Trainee (LT) using this form.

All others please complete FORM A (Annual Meeting Registration form)

Registration Fees check one): On or before June 1, 2009 After June 1, 2009
V Voice Institute Pupil (VIP) $80 (limited scholarships available) $95
L Laryngectomized Trainee (LT) $80 (limited scholarships available) $95
S Speech Pathology Trainee (ST) $400 $425
G Graduate Student (GS) $150 $165

First Attendee (Please Print) Laryngectomee? Yes No

Second Attendee Laryngectomee? Yes No

Street Address

City State/Province ZIP Country

Phone Number E-Mail

Note: All sessions of the Annual Meeting and Voice Institute are conducted in English, and if needed, you must arrange for your own translator.

You may also register on line at http://www.TheIAL.com/SanMateo

Mail check or money order payable in U.S. dollars to: IAL and mail it to IAL, 925B Peachtree Street NE, Suite 316, Atlanta, GA 30309.

By Credit Card: check VISA MasterCard Discover American Express (Go to TheIAL.com to use PayPal)
Cardholder Name Card Number

Expiration Date Security Code Cardholder Signature

Please register for the IAL Annual Meeting OR the IAL Voice Institute. Do not register for both.


There are a limited number of Batten Scholarships available for laryngectomees who require financial assistance to attend. To apply for eligibility please visit http://www/TheIAL.com/San Mateo, or contact
Jeff Searl, PhD., CCC-SLP
The University of Kansas Medical Center
Hearing and Speech Department
3901 Rainbow Blvd MS3039
Kansas City KS 66160
jsearl@kumc.edu
# 2009 IAL Annual Meeting/Voice Institute Schedule

## Annual Meeting

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>8:00-5:00</td>
<td>IAL Committee Meetings</td>
</tr>
<tr>
<td>12:00-5:00</td>
<td>Registration</td>
</tr>
</tbody>
</table>

## Voice Institute

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>7:30-8:00</td>
<td>Registration/Check in</td>
</tr>
<tr>
<td>8:00-8:15</td>
<td>Opening Remarks</td>
</tr>
<tr>
<td>8:20-9:00</td>
<td>Total Laryngectomy</td>
</tr>
<tr>
<td>9:00-9:40</td>
<td>Conservation Surgery</td>
</tr>
<tr>
<td>9:40-10:20</td>
<td>Chemotherapy and Radiation</td>
</tr>
<tr>
<td>10:20-10:40</td>
<td>Question/Answer with Experts</td>
</tr>
<tr>
<td>11:00-12:00</td>
<td>Pre-Op Counseling &amp; Education</td>
</tr>
<tr>
<td>1:00-2:00</td>
<td>Artificial Larynx Basics</td>
</tr>
<tr>
<td>2:00-3:00</td>
<td>Esophageal Speech Basics</td>
</tr>
<tr>
<td>3:15-4:15</td>
<td>Tracheoesophageal Basics</td>
</tr>
<tr>
<td>4:15-5:15</td>
<td>Hands-on Clinic #1</td>
</tr>
<tr>
<td>5:15-6:15</td>
<td>Post-Op Counseling &amp; Education</td>
</tr>
<tr>
<td>7:00</td>
<td>Meet and Greet Reception</td>
</tr>
</tbody>
</table>

## Joint Sessions of AM and VI

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>8:00-9:00</td>
<td>Opening Ceremonies</td>
</tr>
<tr>
<td>9:00-10:00</td>
<td>Keynote Address</td>
</tr>
<tr>
<td>10:00-12:30</td>
<td>Laryngectomy Rehabilitation</td>
</tr>
<tr>
<td>1:30-2:15</td>
<td>IAL Web Site</td>
</tr>
<tr>
<td>2:15-3:15</td>
<td>Body Changes Post-Lary.</td>
</tr>
<tr>
<td>3:45-5:00</td>
<td>Speech Instruction</td>
</tr>
<tr>
<td>5:15-6:15</td>
<td>WebWhispers Banquet (reservations only)</td>
</tr>
</tbody>
</table>

## Joint Session of AM and VI

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>8:00-9:15</td>
<td>Rehab. Process-Perspective of an MD Patient</td>
</tr>
<tr>
<td>9:15-9:45</td>
<td>Caregivers Continental Breakfast</td>
</tr>
<tr>
<td>9:00-9:30</td>
<td>Lary. Panel Hall, Herbst, Long, Simon</td>
</tr>
<tr>
<td>9:30-10:30</td>
<td>Relationships/Sexuality</td>
</tr>
<tr>
<td>11:00-12:30</td>
<td>Swap Sessions (choose 3)</td>
</tr>
<tr>
<td>1:30-2:30</td>
<td>Spech Instruction</td>
</tr>
<tr>
<td>2:30-3:30</td>
<td>Town Hall Meeting</td>
</tr>
<tr>
<td>4:00-5:00</td>
<td>Community Outreach</td>
</tr>
<tr>
<td>5:00-5:45</td>
<td>Swim Demo</td>
</tr>
<tr>
<td>6:00-7:30</td>
<td>Fun Show, Singalong, Who’s Line is It?</td>
</tr>
</tbody>
</table>

## Friday

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>8:00-10:20</td>
<td>Body Changes the SLP Needs to know:</td>
</tr>
<tr>
<td>8:30-12:00</td>
<td>Delegate’s Meeting</td>
</tr>
<tr>
<td>9:00-10:00</td>
<td>Ask a Therapist</td>
</tr>
<tr>
<td>9:00-12:00</td>
<td>Hearing Screenings</td>
</tr>
<tr>
<td>10:30-12:00</td>
<td>Swap Sessions</td>
</tr>
<tr>
<td>1:30-</td>
<td>Delegate’s Meeting (Resumes)</td>
</tr>
<tr>
<td>1:30-</td>
<td>See San Mateo on your own</td>
</tr>
<tr>
<td>6:30-10:00</td>
<td>Cash Bar, Reception, Banquet, Dance</td>
</tr>
</tbody>
</table>

## Saturday

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
</tr>
</thead>
<tbody>
<tr>
<td>6:30-10:00</td>
<td>IAL Written Test (Optional)</td>
</tr>
</tbody>
</table>

<--20-->
Have a Spare AL?

Do you have an electronic artificial larynx (AL) you are not using?

That AL could be put to good use by a new laryngectomee who should begin using one as soon as possible after surgery but who may have no local club which can lend him or her one, or no other means to acquire one. That old AL laying in your drawer gathering dust could be a Godsend to a fellow laryngectomee nearby, or far away.

There are several good things you can do with that spare AL. One is to contact your support club and ask if they have a loaner closet and are in need of one to lend to a new laryngectomee until they can get their own, or to give them permanently if they have no other way to get one. You can find out if you have a local club or a neighboring one along with their contact information by looking at the IAL web site club list here: [http://www.TheIAL.com/ial/index.php?option=com_content&view=article&id=130&Itemi d=131](http://www.TheIAL.com/ial/index.php?option=com_content&view=article&id=130&Itemid=131) (or just to to TheIAL.com main page and click on “Club Search.”

Still another option is to mail that AL (working or not) to the IAL, 925B Peachtree Street NE, Suite 316, Atlanta GA 30309-3918. Volunteers will repair them.

There are several things we will do with them. One is to send one to a new support club to help them establish a loaner closet. Another is to send one to an already existing club which has run out of ALs to lend to new laryngectomees. They may also be used as a source of last resort for someone who needs an AL but who has exhausted other possible ways to get one such as their own insurance, Medicare, Medicaid, the Veterans Administration, state programs which provide telecommunications devices for those with hearing and speech problems, etc.

Another potential use is to send them to parts of the world where they would be a suitable speaking method for that individual (and who can maintain it with spare batteries and local repairs, etc.) In all cases the need would have to be documented by a clinician or club representative and alternative funding sources ruled out. Obviously, if there is an existing program to provide a laryngectomee with a brand new AL under warranty, this would be a better alternative than our giving him/her a used or rebuilt one.

Of particular value to donate to Second or Third World countries would be those ALs which run on 9 volt batteries since they are nearly universally available. Replacement batteries for some other kinds of ALs cost over $20 each, and this could be prohibitively expensive in many parts of the world.

Of particular value in some parts of the world would be the old ALs which carry the names of telephone companies such as Western Electric and AT&T. Most of these run on 9 volt batteries, are simple to use, and are less likely to be kept by laryngectomees in richer parts of the world as back-ups.

Please consider helping out a fellow laryngectomee close to you, or in some distant part of the world, to obtain that precious second gift of speech. Help us to help.

---

**International Association of Laryngectomees**

**Automatic Credit Card Billing Authorization Form**

If you would like to enjoy the convenience of automatic billing for your donations to the IAL, simply complete the information below and sign the form. All requested information is required. Once received, we will automatically bill your credit card for the amount you specify and the charges will appear on your monthly statement. You may cancel at any time by contacting us.

Donor Name ___________________________ Phone ___________________________

PAYMENT INFORMATION

I authorize the International Association of Laryngectomees to automatically bill the card listed below as specified:

Amount ___________________________ Frequency (check one) Monthly _______ Quarterly _______ Yearly _______

Start billing on (date) ___________ End billing on (date) ___________

Unless prior arrangements are made, all donations will go to the general fund.

**CREDIT CARD INFORMATION:**

The International Association accepts the following credit cards (check one):

Visa _______ MasterCard _______ American Express _______ Discover _______

Name on credit card ___________________________ Credit card number ___________________________

ZIP code (from billing address) ___________________________ Exp. date _______ Signature ___________________________ Date _______

Your E-mail Address (to receive a receipt) ___________________________

Mail completed form to:

IAL 925B Peachtree Street NE • Suite 316 • Atlanta GA 30309

or send an e-mail to Treasurer Sapp Funderburk at csfund@bellsouth.net, or call him at 864-268-971
INTERNATIONAL ASSOCIATION OF LARYNGECTOMEES

OFFICERS

Tina Long—President
TLong2051@charter.net

Bob Herbst—Vice President
bobh@2s.com

Terrie Linn Hall—Secretary
th_tfsncc2002@yahoo.com

Sapp Funderburk—Treasurer
csfund@bellsouth.net

IAL BOARD OF DIRECTORS

Kay Allison
whisperingkay@yahoo.com

David Blevins
david6511@aol.com

Tom Cleveland
tcv2137@sbcglobal.net

Philip Doyle, Ph.D
pdoyle@uwo.ca

Tom Herring - Database Manager
tomherring@embarqmail.com

Joe Marasco
smokelessjoe77@cox.net

Sheldon Schultz
schultz_sheldon@yahoo.com

EXECUTIVE DIRECTOR

Susan Reeves, SLP—Executive Director
ialed@TheIAL.com

IAL VOICE INSTITUTE

Jeff Searl, Ph.D—Director
searl@kumc.edu

IAL NEWSLETTER

David Blevins—Editor, Graphics, Production
David6511@aol.com
3558 Shore Drive Unit 601
Virginia Beach, VA 23455-1714

IAL WEBSITE

Ron LeClair—Webmaster
www.TheIAL.com

Available from the IAL

VIDEO/DVD LIBRARY

Check the Neck—14 videotapes available
and 2 DVDs (this video is under
consideration for revision).

Spanish Videos & DVDs
A Una Sola Voz—(1/2” Video or DVD, 35
min.) A $10 donation is requested.

Rehabilitacion de la Voz—(1/2” Video or
DVD, 35 min.)

Videos and DVDs
can now be obtained from:
IAL
925B Peachtree Street NE
Suite 316
Atlanta GA 30309-3918
or call toll-free (866) 425-3678

PUBLICATIONS

The IAL currently publishes and
distributes the following:

IAL Brochure
Information about the IAL. FREE!

The IAL News
A newsletter that is published four times an-
ually. A $5 a year donation is requested
but is not required.

Building A Successful
Laryngectomee Club
Information on how to start a club or make
your club successful. FREE!

Rescue Breathing for Laryngectomees
and other Neck Breathers*
Available in English and Spanish. FREE!

*Out of print

FREE Pocket
Emergency Cards
Emergency cards are available in English
and Spanish. (Send stamped, self-addressed
envelope and specify language.)

FREE Emergency
Window Stickers
These emergency stickers can be used on
automobiles or on home
windows. They are available in English and
Spanish. (Send stamped, self-addressed envelope
and specify language.)

Publications and the items above can be
obtained from:
IAL
925B Peachtree Street NE
Suite 316
Atlanta GA 30309-3918
Introducing the New Blom-Singer® TruSeal® Contour Adhesive Housing

New Addition to HME System

The new TruSeal Contour adhesive housing is the perfect complement to the Blom-Singer HME system and Hands Free Valve (ATSV II).

The new light-weight, malleable material comfortably fits various peristomal anatomies. The TruSeal Contour is offered in three shapes and will stand-up to the rigorous demands of everyday use.

<table>
<thead>
<tr>
<th>REF</th>
<th>DESCRIPTION</th>
</tr>
</thead>
<tbody>
<tr>
<td>BE6070</td>
<td>TruSeal Contour, Round, box of 30</td>
</tr>
<tr>
<td>BE6071</td>
<td>TruSeal Contour, Oval, box of 30</td>
</tr>
<tr>
<td>BE6072</td>
<td>TruSeal Contour, Standard, box of 30</td>
</tr>
<tr>
<td>BE6073</td>
<td>TruSeal Contour Sample Kit, 2 of each shape</td>
</tr>
<tr>
<td>BE1055</td>
<td>Blom-Singer HME System Heat and Moisture Exchange Cartridge, box of 30</td>
</tr>
</tbody>
</table>

Learn more about the Blom-Singer HME System by visiting our web site www.inhealth.com

Call us today to place an order at (800) 477-5969

No Rx Required!

INHEALTH TECHNOLOGIES

30 YEARS

INHEALTH TECHNOLOGIES
THE NAME OF EXPERIENCE SINCE 1978

© January 2009 InHealth Technologies, A Division of Helix Medical, LLC