IAL Board urges Medicare to change Rules on Reimbursement of Indwelling Prosthesis

The IAL Board of Directors passed a resolution to communicate with Medicare and members of the United States Congress expressing concerns about the significant negative impact on laryngectomees of Medicare rules on the reimbursement for the indwelling TEP prosthesis. The Board urges all laryngectomees and other members of the laryngectomee community to join us in working to change these rules. (See pg 3).

The Medicare Ruling

About a year ago Medicare made a ruling that it would reimburse for the indwelling type of voice prosthesis (the kind that a speech therapist or ENT MD installs, HCPCS code L8509) only if it was ordered and inserted by the clinician. Companies such as ATOS Medical and InHealth Technologies can no longer directly bill Medicare, and laryngectomees could not bring their own indwelling prosthesis to be installed unless they completely paid for it themselves and agreed that neither the clinician or patient would seek Medicare reimbursement. (The policy does not effect the patient-changed prosthesis, hands-free valve, etc.)

Why This is a Problem

Many smaller and medium sized clinics will not be able to order and prepay for a minimum stock of different brands and sizes of prostheses to keep on hand. We are already seeing this spreading. The cost of a bare-bones stock to meet the needs of individual laryngectomees estimated at between $1000-$2000.

Many clinics will also not be able to lay out this kind of money since the maximum Medicare will reimburse for any indwelling prosthesis is approximately $99. The cost of the most common indwelling prostheses is $177.40 up to $350 (and this excludes the most expensive required by some laryngectomees). Many of these smaller clinics cannot make up for the loss on the cost of the prosthesis through other charges.

For laryngectomees who get their indwelling prostheses changed at these clinics they will have to pay the entire cost out of their pocket with no way to get Medicare to reimburse us for any fraction of the cost.

Some clinics will have to stop providing this prosthesis service and are already doing so. This will force many laryngectomees to travel greater distances to find a clinic that can afford to stock indwelling prostheses. And some clinics will not be able to give laryngectomees any choice on brand or type of prosthesis because of these reimbursement and stocking problems.

Laryngectomees also need a way to obtain and get reimbursed for a spare prosthesis in case of a sudden leak or other emergency (especially while traveling).

Many laryngectomees may feel forced to switch to a patient-changed prosthesis whether this is the best option for them or not. A high percentage of laryngectomees are not good candidates for the patient changed prosthesis. There are many reasons including that their puncture is in a difficult location, they lack the eyesight or manual dexterity to change it themselves (and there is no one at home who can do it), they need the longer life of the indwelling because they live some distance from their clinic, and other restrictions.

Some clinics will require that laryngectomees bring their own prosthesis with them. This may put the laryngectomee in the position of also having to make what ought to be a professional medical decision about the best prosthesis for them. Also, if the laryngectomee has to buy and bring the prosthesis with them and it turns out that the length of prosthesis needed has changed their clinician may not have the proper size in stock. This could result in temporarily placing a catheter in the puncture to keep it from growing closed and sacrificing the ability to speak until the correct size can be obtained, and the extra cost and time.

One of the worst possible outcomes would be if a patient dislodges a prosthesis. Unless they can quickly place something in the puncture to keep it open they could grow shut requiring another puncture surgery. The cost of the re-puncture surgery is very expensive.

An even greater risk for laryngectomees having to pay the entire cost of their prostheses is that they will change them less often in order to save money. This (Continued on page 3)
Introducing the New
Blom-Singer® Dual Valve
Voice Prosthesis
6mm Size Now Available

Our new dual valve Indwelling voice prosthesis uses leading-edge design to deliver on a very simple, but powerful benefit: two valves are better than one!

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Included with the Dual Valve Voice Prosthesis is a unique pop-through insertion system, designed to assist the clinician in the deployment of the esophageal flange during placement.

The Dual Valve voice prostheses are offered in non-sterile 20 Fr. indwelling packages, in five lengths:

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<th>LENGTH</th>
<th>20 FR DIAMETER</th>
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will inevitably result in laryngectomees keeping leaking prostheses in longer and risking developing aspiration pneumonia. This is both a very expensive hospital treatment and is a potentially life-threatening illness.

Current Medicare reimbursement rules for the indwelling prosthesis are clearly detrimental to laryngectomees. There is no benefit to laryngectomees in enforcing this current Medicare rule.

We Can Make a Difference

As the patients being effected by this rule the laryngectomee community can be THE most effective voice in getting it changed. Since there are relatively few laryngectomees in the U.S. the more of us who will speak out the more likely we are to be successful. There are a number of ways to speak out on this issue:

(1) Contact members of the House of Representatives and Senate who serve on committees that oversee Medicare (the names and contact information and a sample letter are on the IAL web site: http://www.TheIAL.com)
(2) Write a letter to Human Health and Resources personnel (names and contact information and a sample letter are on the IAL web site at http://www.TheIAL.com)
(3) Contact your Congressional representatives. To find the contact information for your member of the House of Representatives go to http://www.house.gov Click on “Find your Representative” by entering your ZIP code.
To identify your Senator go to http://www.senate.gov Click on “Find your Senators” and click on your state
(4) File a complaint by calling 1-800-MEDICARE

Working together we can make this change.

SLP Candy Moltz joins the IAL Board

IAL President Bob Herbst nominated and the Board of Directors approved the selection of SLP Candy Moltz to join the IAL Board. Candy replaces Dr. Phil Doyle who resigned from the Board when he was named as permanent Director of the IAL Voice Institute.

Candy Moltz is from Midlothian, Texas and has worked for the past 20 years at the Dallas Veterans Administration Medical Center as a speech/language pathologist. She earned her bachelors degree at Baylor University in Speech/Hearing Therapy/Education, and her Master of Science in Communication Disorders from the University of Texas at Dallas.

Her duties at her VA Hospital include diagnosing and treating neurogenic speech and language disorders, voice disorders, swallowing evaluation and management, and providing complete pre and post operative care of head and neck cancer patients and their rehabilitation. She also supervises graduate speech interns and lectures at the University of Texas at Dallas and Texas Women’s University.

Candy is a member of the American Speech Language Hearing Association, Dallas Lost Chord Club, and planning board of the Texas Laryngectomee Association. She has been involved with the Texas Laryngectomee Association since its founding. She also participated in five IAL Voice Institutes including when the IAL’s Annual Meeting was held in Dallas in 1989.

She has also received the American Cancer Society’s Sword of Hope Award in 1990 and has been listed in the IAL’s Directory of Alaryngeal Speech Instructors since 1989 after completion of a practicum under the direction of her mentor, Jessie Hart. The IAL Board of Directors is grateful to Candy for her willingness to serve.

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 health care 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 U.S. 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.
Chest compression-only cardiopulmonary resuscitation (CPR) can be performed by a laryngectomee on anyone else. The reason is that no separate rescue breathing is required.

Another videotape on performing chest compression-only CPR is available at the University of Arizona College of Medicine at http://tinyurl/2fx8r59.

Our IAL Sponsors

The IAL Board of Directors has established a Sponsorship Program to support the continuation of the work of the IAL.

Individuals, clubs, organizations, foundations and non-laryngectomee product businesses are invited to contribute in any amount. Donations are tax-deductible under U. S. laws. Contributions are cumulative over time with the category increasing by the total amount given. An example is that an individual could start with a donation of $5. When donations from that person reach $50 they would be designated as a “Bronze” level donor.

Please join those who are committed to the continued existence of our nearly 60 year old organization by sending a check today to The IAL, 925B Peachtree Street, Suite 316, Atlanta, GA 30309-3918.

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Hands-Only CPR

Chest compression-only cardiopulmonary resuscitation (CPR) can be performed by a laryngectomee on anyone else. The reason is that no separate rescue breathing is required.

Another videotape on performing chest compression-only CPR is available at the University of Arizona College of Medicine at http://tinyurl/2fx8r59.

3-Drug Chemotherapy Better at Preserving Voice Boxes

Larynx cancer patients who were given a three-drug chemotherapy combination were more likely to keep their voice boxes than those who received a two-drug combination. This was the result of a controlled experiment reported in a recent issue of the Journal of the National Cancer Institute.

Patients in the study were those who had locally advanced larynx and hypopharynx cancers and were treated with either two drugs (cisplatin and 5-fluorouracil), or three (adding docetaxel). Both groups had radiation following chemotherapy if the chemotherapy was successful. Where it was not successful the patient would undergo laryngectomy surgery.

With an average follow-up of three years, the larynx preservation rate was 70.3% with the three drug treatment compared to 57.5% for the two drug alternative. Overall, 80% of the three drug treatment group responded to the drug therapy compared to 59.2% of those treated with the two drugs.
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The Colonel’s Book
By David Blevins
Which laryngectomees, living or dead, have done the most to help their fellow laryngectomees?
Anyone who gives much thought to this question would be seriously remiss if they did not include the name of Lieutenant Colonel Edmund Lauder. And what would so clearly earn Lauder a permanent place on this short list is his book, “Self-Help for the Laryngectomee.”
“Self-Help” has played such a major role in the rehabilitation of generations of laryngectomees it has been referred to by some as “The Laryngectomee Bible”. Copyrighted in 1972, it has continued to be revised and published. At the time of Ed Lauder’s death in 1991 his son Jim had taken over revision and reprinting the book, and it continues to be available today.
The title “Self-Help for the Laryngectomee” was clearly not casually adopted as the title. This is made clear by the fact that, other than information about the author, the first words in the book were written by SLP Jim Shanks, Ph.D., who devoted his life to helping laryngectomees learn to help themselves. Shanks defined the concept of laryngectomee rehabilitation as to “restore to a former capacity.” And the word restoration implies the highest level of completeness.
This goal of restoration is found in the enduring concept within the laryngectomee community of “Total Rehabilitation of the Laryngectomee.” It means that the goal for every laryngectomee should be to recover as fully and completely as possible all that he or she was and could do prior to becoming a laryngectomee. Dr. Shanks listed these areas as restoring physical and psychological well-being, returning to work and speaking as intelligibly as possible.
Put another way, this goal of total rehabilitation is to minimize to the greatest extent possible for each individual any improvable handicapping side effect resulting from becoming a laryngectomee. When the goal of total laryngectomee rehabilitation is combined with the concept of “Self-Help” a major responsibility is clearly placed on the shoulders of the laryngectomee to work hard to achieve his or her highest possible level of healing in all areas.
This means that, while we may receive lots of help from medical professionals and others in our healing journey, this assistance can never be enough without our own full cooperation and hard work. Rehabilitation can never be complete if it relies only on just what others can do for us, but cannot be fully achieved without our best efforts.
Describing what Total Laryngectomee Rehabilitation is not also helps to more fully grasp the ideal. If a laryngectomee is capable of doing something for him or herself, they have an obligation and duty to do so and not ask anyone else to do it. This requirement is not a standard imposed on us by others, but is established by the laryngectomee community as a whole upon each of our members.
At a recent IAL convention an elderly laryngectomee who was more than a year removed from his surgery mentioned that his wife shaved him. When asked why he said that she had done it right after surgery at the suggestion of his doctor and no one said that this would not continue. He was fully capable of shaving himself.
While not the case with this couple, some people can get into what has been described in psychology as “co-dependency” where the giver of help and receiver both benefit from the continuation of what ought to be something the receiver can do for themselves. The receiver of the service benefits by being cared for, and the provider of the service feels needed. This can be destructive and work against our independence. This is also reflected in the concept of “tough love.” We should want our loved ones to take care of themselves if they are capable of doing so. It is in the long term best interests of those receiving the care and those providing it (and of society).
A broader interpretation of the “self-help” idea is to think of it as going beyond the individual and applying to the laryngectomee community as a whole. Our providing help to fellow laryngectomees has always been needed since there are so few of us in the general population, and the level of knowledge and
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experience of the professionals who assist us has never been uniformly adequate and available to all.

This was particularly true during the decades when the preferred form of post laryngectomy speech was traditional esophageal speech. New laryngectomees were at least as likely to learn how to speak esophageally from a fellow laryngectomy than from a speech therapist. Even now we must still count ourselves lucky if we live near and have access to professionals who are fully competent to meet our needs. Laryngectomees helping other laryngectomees is far from an obsolete idea. The needs may be somewhat changed over the decades, but the needs are still clearly there.

In looking at an early edition of “Self-Help” (the 1975 version) it is a remarkable publication at 5 1/2 by 8 and half inches and just 136 pages long.

In addition to including those central ideas of self-help and total laryngectomee rehabilitation that continue as major guideposts the book is also remarkable for how Lauder dealt with the issue of the electronic artificial larynx (AL).

When the book was first published in 1972 there was still a continuing bias in support of traditional esophageal speech and against the use of the electronic artificial larynx. The AL was criticized as an inferior form of speech and a “crutch” that would interfere with or stop the development of esophageal speech. Chapter four of the 1975 edition dealt with the AL and began with ten “good reasons why a laryngectomee would want an artificial larynx.” In the chapter Lauder made it clear that the AL was a viable alternative to esophageal speech.

One of the major contributions of “Self-Help” was and is its sections on esophageal speech including (in the original edition) a ten page chapter on esophageal speech basics and 21 pages of speech exercises. Also available with the book were a number of audio tapes.

The “Blue Book” served as a primer for generations of laryngectomees to learn the basics of esophageal speech. This was especially critical for those many laryngectomees who did not have access to esophageal speech instruction through a trained local speech therapist, lay teacher or support club instructor.

“SoHelp for the Laryngectomee” was and continues to be a classic in the field of laryngectomee rehabilitation and deserves to be in every laryngectomee’s library. It earned its author, Lt. Col. Edmund Lauder, his rightful place on anyone’s list of laryngectomees who made the greatest contributions to fellow laryngectomees.

Edmund Lauder

Edmund Lauder was a retired 25 year veteran Air Force lieutenant-colonel when his larynx was discovered in 1962. He learned basic esophageal speech at the Walter Reed Army Medical Center in Washington, D.C.

He also attended a Voice Institute sponsored by the IAL, American Cancer Society, and Social and Rehabilitation Service where he learned how to teach esophageal speech to others. He then completed coursework and practica at Our Lady of the Lake College (now University) in San Antonio, Texas. He earned a certificate of clinical competence in teaching esophageal speech from the American Speech and Hearing Association (now called the American Speech-Language Hearing Association...ASHA).

Lauder earned a bachelors degree from the University of Maryland, and later a master of public administration degree from The George Washington University in Washington, D.C. He served as a clinical assistant professor in the Department of Physical Medicine and Rehabilitation of the University of Texas Health Science Center in San Antonio and also served a a member and officer of the IAL, and member of ASHA, the National Association of Hearing and Speech Agencies, and the American Academy of Private Practice Hearing and Speech Agencies. For many years he worked full time as a teacher of post-laryngectomy speech and as a speaker for the Texas Division of the American Cancer Society.

Father of three children, Edmund and his wife Lillian lived out the remainder of his years in San Antonio, Texas. He died in 1991.
At Lauder - The ElectroLarynx Company™ our most important goal is to make available the very best speech aids and laryngectomee products to our customers at fair prices.

Our company began when my father Col. Edmund Lauder self-published his book, "Self Help for the Laryngectomee." Col. Lauder was himself a Laryngectomee; thus bringing needed experience and clarity to the project. Throughout the years, this book has become an indispensable guide for laryngectomees and those who care for them.

In 1990, when I was planning to print and update my father's book, I felt I could further serve his customers by offering the best products available today for the laryngectomee.

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- batteries.

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Call us at 800-388-8642 or e-mail me at jklvoice@aol.com.

All my best,
Jim Lauder
WebWhispers Sponsors 15 Day 2013 Panama Canal Cruise

Believe it or not it is not too early to sign up for the 2013 WebWhispers 15 day cruise! The cruise line sets aside a number of cabins for a group, but as time passes and those places are not reserved they are opened up to others. The Internet-based WebWhispers support club is the largest membership IAL club.

The cruise through the Panama Canal and Central America departs on January 3, 2013 from San Diego, California.

It has ports of call in Cabo San Lucas and Puerto Vallarta, Mexico; Puerto Quetzal, Guatemala; Puntarenas, Costa Rica; Conlon, Panama; Cartegena, Columbia; and docks at Ft. Lauderdale, Florida on January 18th. Prices range from $1600-$2390 (per person/double occupancy).

Reservations can be made with: Peggy Byron, Cruise Vacations 100 Swan Lake Circle Birmingham, AL 35242 1-205-995-0036, 1-800-844-5785, FAX 1-205-995-2063 Email: Cruise Vacations <peggybyron@bellsouth.net>

Additional information can be obtained from WW President Pat Sanders at Pat@choralmusic.com.

IAL President Bob Herbst does a cannonball dive during the water activities demonstration at the 2011 Annual Meeting in Kansas City. Diving for the first time, Bob was both brave and a good sport since it took a half dozen attempts to get a reasonably good photo.

Free Text-to-Speech Ap

An alternative to writing for those who cannot speak or who have temporarily lost speech is a computer application that will speak out loud whatever you type into it. Many can store commonly used phrases and sentences and can be used on smart phones, iPads, laptops, desktops, etc..

One of the free programs can be found here: http://www.etriloquist.com/Downloads.php

Q & A on Yogurt

Q - I have heard that eating yogurt will help control the yeast (candida) growth in my mouth and throat and keep my TEP prosthesis lasting longer before it leaks. Is this true?

A - It is true, but it has to be the right kind of yogurt. Yeast feeds on sugar so artificially sweetened yogurt is best. The yogurt must have “active cultures” or live bacteria. Look for the NYA’s (National Yogurt Association) “Live and Active Cultures” seal on the yogurt product. Some products will say that they were MADE with active cultures, but may not say that they were heat treated and live cultures destroyed or weakened.

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Host Clubs Needed for 2013 and 2014

We know where we will be having the Annual Meeting and Voice Institute in 2012 — Raleigh/Durham, North Carolina. But we also want to identify locations for the IAL’s 2013 and even 2014 Meeting and Institute. Important considerations are:

- A relatively inexpensive hotel room rate (the more under a hundred dollars per night the better).
- A hotel that has a lot of meeting space.
- Meeting spaces will be free of charge if we guarantee a certain number of room bookings.
- A location that is attractive to families.
- Located within commuting distance of a teaching hospital or other clinical setting for the Voice Institute.
- That is a reasonable distance from the previous AM/VI (a different region of the country).
- Major airline connections.

We need a location with a local laryngectomiee support club to perform a number of functions, although we can negotiate with the local group on what is expected of the club and its membership.

You can get additional information on what is needed at http://www.TheIAL.com and go to “Host an Annual Meeting” under Club Resources, or go to http://tinyurl.com/39ahzpa.

If you have questions, please feel free to contact us through IAL Administrative Manager Susan Reeves, SLP, by calling her toll-free at (866) 425-3678. There are many benefits to hosting an IAL AM/VI, with the major one being to bring this wonderful experience to your local club members and those in your region.

Emergency Cleaning & Care of Electrolarynges

By Tom Lennox, Luminaud Inc.

Since we manufacture and repair artificial larynges, I’d like to offer some practical advice about what to do if your ElectroLarynx (EL) is dropped into water, mud, spaghetti sauce, dishwater, the toilet, etc.

Proper attention on your part may reduce damage and mean that you do not have to send your EL for repair — and even if you do have to send it away, your actions can help keep down the cost of repair or may leave you with an EL that is repairable instead of something that has to be thrown in the trash.

The main thing to think of is the fact that clean tap water does NOT damage an EL unless it is left to sit in it for a period of time — and therefore in an emergency you can use plain tap water to rinse anything water soluble out of your EL. DO NOT USE DETERGENTS, OILS, SOLVENTS OR ANY CLEANING MATERIAL OTHER THAN PLAIN, CLEAN WATER. The exception would be a removable safety cord — it would be OK to wash that part in soap or detergent and water — rinse and dry before reinserting into the EL.

Neck-held EL, immediately remove the battery cap and remove the batteries. Rinse off the batteries and the battery cap, dry them with a towel and set them aside.

If the device has an oral adapter, remove it and wash it as you would occasionally anyway, insuring that there is no food or foreign material in the end of the tube or in the slots if you use a capped tube. Depending on what it’s been dropped into, you may want to discard the tube and put on a fresh one.

Leave the head on the EL, but for the Servox and
Optivox, remove the metal sleeve. Rinse all parts of the unit inside and out with tap water. Then carefully shake as much water as possible from the EL and gently pat everything dry where you can.

Next, remove the head. Be careful not to lose O-rings, gaskets or spacers. DO NOT REMOVE the RUBBER DIAPHRAGM from the top of the body of the instrument. If you find it is DRY under the cap, then wipe the cap inside and out with toweling and set it aside. If the inside of the head IS WET, then carefully rinse with water. Do not use a hard spray of water or compressed air. That could damage your coil assembly. (Big bucks to repair!) After the rinse, gently shake any water that you can out of the hole in the diaphragm. If you have a hair drier that can be set on cool only — no heat — you can help the process along a bit on any instrument by blowing air gently into the parts. (Do NOT use heat. Warm to hot temperatures can damage your EL.)

Set all parts of the disassembled unit in a clean, dry, safe place where nothing will roll off or get bumped off and let them dry for 48 hours.

**Cooper-Rand Pulse Generator** (gold box) - Unplug the Tone Generator and the cord. Take off the back cover and batteries and also take off the front cover. Rinse the circuit board, covers and batteries in clean tap water, carefully shake water off and dry with a towel. Leave all parts disassembled and spread out to dry in the open air for 24 hours.

**Cooper-Rand Tone Generator** (hand held silver colored piece) - Remove cord and tube. Dunk the TG a couple of times in clean water and then shake it hard with the stem (tube connector) of the TG pointed down. Put aside to dry for at least 24 hours.

If you have a hair drier that can be set on cool only — no heat — you can help the process along a bit on any instrument by blowing air gently into the parts. (Do NOT use heat. Warm to hot temperatures can damage your EL.)

BE SURE TO LEAVE UNIT COMPLETELY DISASSEMBLED FOR 48 HOURS FOR A NECK-HELD UNIT, 24 HOURS FOR A COOPER-RAND. DO NOT PUT A BATTERY INTO YOUR EL UNTIL YOU REASSEMBLE IT.

AFTER THE WAITING PERIOD, CAREFULLY REASSEMBLE THE DEVICE AND INSERT BATTERIES.

Of course, I hope you never need this advice. Do anything you can to keep your EL attached to yourself or your clothes in such a way that it cannot fall very far no matter what. But if an accident happens, rinse the bad stuff off right way and good luck!

Cliff Griffin of Griffin Labs recommends these steps if you get a TruTone or SolaTone AL wet:

1. Pull the AL out of the water immediately without delay and drain the water out of it. Most water will go out the volume knob slot, so hold the device level with the volume knob down. DO NOT press the power button "to see if it works."

2. If the water is dirty or is salt water, quickly rinse it in clean tap water. Do not submerge it. Drain again as in step one. DO NOT press the power button.

3. Dry it with a towel or paper towel to remove external moisture. DO NOT press the power button.

4. Remove the battery cap (and battery) and the sound head cap. Do not remove the diaphragm.

5. Dry the AL with one of the following methods. (Do not place in an oven or anywhere it can exceed 140 degrees F.): a. place the AL on the dash of a car in the summer or warm weather for 4-6 hours. b. put the AL in a bowl of dry (not cooked) rice for 14-24 hours. The rice will absorb the moisture. To keep rice out of the unit wrap it in a paper towel.

6. Replace the battery and press the power button (check the volume knob). This process will solve most problems. If it still does not work, send it in for service along with your complete contact information and describe the problem. Be specific.

Tom Dodson who makes the Romet AL (distributed by ATOS Medical) recommends that you send the unit back to them if it is dropped in water. They have a five year warranty including water damage.

**Laryngectomee Pledge**

"I will use every available means to perfect my speech and effect my rehabilitation, and I pledge all my efforts to assist fellow laryngects in achieving this goal."

(From a 1959 issue of the *IAL News*).
New Image Techniques Improve Treatments

“We got it all.” “The tests show that you are cancer-free.” These are the kinds of words those who are being treated for cancer most want to hear. But there often is a major time delay before cancer patients, including laryngectomees, can be declared to be cancer-free. And a major part of the problem is the amount of time it takes for treatments, including chemotherapy (see image below), to show their effectiveness.

A new scanning tool being tested can help provide this feedback much more quickly. The scan is called FLT PET. It combines the more familiar PET scan (Positron Emission Tomography) with the use of a specific radioactive chemical which binds to cancer cells. It shows whether cancer cells are dividing.

Uncontrolled cell division is what active cancers do and stopping that division should be an early result if chemotherapy is being effective.

The planned use is to give a single dose of chemotherapy and, within a day or two, use the FLT PET technology to learn whether the chemotherapy is working.

This will help the patient avoid prolonged expensive treatment and side-effects. If one treatment is not successful a different one can be more quickly substituted. Quick feedback can also save lives since it allows more options to be tried in rapidly advancing cancers.

A standard waiting period for some lung cancers is six weeks before it is known if the treatment is successful. With the new scanning procedure researchers could tell within one week after treatment with 93 percent certainty which patients would eventually respond to a drug and which would not.

There are a number of additional benefits in getting this information quickly. It can let drug companies developing new cancer drugs know sooner if it is effective and therefore save some of the extraordinary amounts of money it takes to bring a new cancer treatment drug on to the market.

One of the hardest aspects of cancer treatment is being in limbo and not knowing whether your treatment is working. Any method that shortens this period of uncertainty can take some of this emotional burden from patients.

Fear of Cancer Recurrence

It is not uncommon for a patient to experience anxiety before, during, and after cancer treatment. Fear of recurrence can be extremely debilitating, or it can be a positive influence in our lives, motivating us to develop a healthier lifestyle and learning to appreciate what we have been given. If anxiety and the fear of recurrence becomes overwhelming, it should be addressed objectively by the health care team like any other medical problem encountered by the patient. Carla DeLassus Gress, ScD, CCC-SLP, Charlottesville, VA.

An Oldie but Goodie

Mr. Lawrence, I am afraid you misunderstood me when we talked about speaking HANDS-free.

By Judy Greive, from November 2000 WebWhispers Journal
Avoiding Dry Air

Depending on where you live in the world, the winter season can be a drying one since colder air cannot hold as much humidity and furnaces can remove the humidity from indoor air.

When the humidity of the air we breath drops to 30% or less an important lung function stops working. What stops is the movement of tiny hair-like cells in our lungs called cilia. Indoor humidity can easily drop below 30%, especially during the winter.

Cilia ordinarily move in a wave-like motion and act like a conveyor belt in moving mucus, and whatever contaminants are in it, upwards to be coughed up.

Whether you wear the most effective kind of stoma cover 24 hours a day or something less effective, some contaminants inevitably get through and into the lungs. If they are not coughed up they reduce lung capacity and put more strain on the individual to obtain oxygen.

Before we became laryngectomees the air we breathed in was filtered, warmed and humidified by the upper part of our respiratory systems beginning with the nose. The system was automatic and was effective in cleaning the incoming air, warming it to body temperature (98.6 F.), and humidified to 100% relative humidity. Becoming a laryngectomee cuts off the upper part of the system and air directly enters the lungs via the stoma. It is almost always dirtier, cooler and drier.

Getting our incoming air into exactly the condition it was prior to becoming laryngectomees is a practical impossibility. However there are some things we can do to improve the quality of our incoming air. One is to use an HME (Heat/Moisture Exchange) filter to preserve some of the heat and moisture lost when we exhale. The filter catches some of this heat and moisture and returns it when we inhale again.

The use of other types of stoma covers help with cleaning of the incoming air, and moisture can be added to our indoor air, and/or at the stoma level. Whole house and portable humidifiers can keep the indoor humidity in the ideal range of from 40-55% relative humidity (no higher).
Donors Give in the Name of Others
The IAL has a program that invites individuals, clubs and others to contribute to the IAL in memory of those who have left us, and to honor others we feel are worthy of recognition.

DONATIONS

In Memory of:
Ed Colahan
James Hegg
Vicki Metz
Vicki Metz
Vicki Metz
Vicki Metz
Joe Schell

Donor:
Bob Herbst
Erich and Paulie Sender
David Blevins
Richard Crum
Bob Herbst
Susan Reeves
Mary Ann Schell

In Honor of:
Mary Bacon
Paola Franklin
Joy Hesse
Bobby and Jo Murray
Mary Moerer

Donor:
Lewis Trammell
Julie Greene
Melinda VanDer Velden
Clair Lee Overmeyer
Bruce and Julie Williams

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

Each donation will be privately acknowledged and also posted on the IAL web site and periodically acknowledged in the IAL News by donor (unless you wish to remain anonymous) along with the name or names of those who are being honored. Thank you!

IAL Financial Picture has Improved
By Bob Herbst, IAL President
The IAL has just managed to turn the financial corner and move from operating in the red (the last figure was $25,000 in the red) to a small surplus. A recent profit/loss balance sheet from acting Treasurer Wade Hampton showed the organization with an approximate $5000 profit.

This movement out of the red, which had been the pattern for a number of years, is now into the black. This positive movement has been achieved by controlling costs, and raising additional income. This IAL BOD and the VI professionals working along side them are committed to paying for expenses out of pocket, for their own room, board, and travel as much as their finances allow, and all BOD per diems have been eliminated.

While the financial security of the IAL is far from assured, it is heading in the right direction. Our continued financial health continues to depend on vendor support through advertising, attendance at the Annual Meeting, sponsorship of AM/VI events; and on laryngectomees through club dues and the very important individual donation programs including the new Sponsorship Program. Thank you for your support! (See pg. 4).

Check Your Club Listing
U.S. clubs should check their listing on the IAL’s web site. Review your club information at www.TheIAL.com under Club Resources and then select Club Search. Click on the map for your state.

The IAL and other club listings is a method many new laryngectomees, SLPs and others use to connect with us all. Please send corrections to: tomherring@embarqmail.com or IALED@TheIAL.com.

Thanks for your help in keeping the list up to date.

Humidifier Filters
If you use the kind of portable humidifier that contains a replacement filter, be sure to replace it on the schedule recommended by the manufacturer. Several types of humidifiers can distribute bacteria, viruses, minerals dissolved in the water, molds, etc., along with the water vapor and make us sick with a disease called “Humidifier Fever.”

According to the experts, in addition to replacing filters one of the most neglected things users should be doing is to thoroughly clean out the humidifiers following manufacturers directions on how to do it and how often it should be done.

This is the most noble service of mankind—to help his fellow man.

Dr. Warren Gardner, founder of the IAL. 1958.
HPV-caused H & N Cancers Increase

A new study by the National Cancer Institute warns that if recent trends continue the number of (HPV) human papillomavirus-caused cancers among men could rise by nearly 30% by 2020. If it does it would surpass the number of HPV-caused cervical cancers among women, which is expected to decline as a result of better Pap smear screening. HPV is the major cause of cervical cancer.

Researchers found that the incidence of HPV-positive oropharynx cancers (back of the tongue and tonsil area) increased by 225% during a two decade period ending in 2004. If current trends continue more oral cancers will eventually be caused by HPV than smoking, alcohol, and other known agents.

Another study indicated that samples of throat cancer tumors over the past 20 years have shown a 56% increase in those indicating the presence of the HPV virus. According to the U.S. Centers for Disease Control studies have shown that about 25% of mouth and 35% of throat cancers are caused by HPV. HPV is the most commonly caused sexually transmitted virus in the U.S. What has not been ruled out at this point is whether there are non-sexual ways to acquire the virus such as mouth to mouth contact.

Men account for the majority of cases of HPV-caused cancers and the highest prevalence is in men age 40-55. It is not known why men are more susceptible to throat cancer caused by HPV than women. The cancers can show up ten years after exposure to the virus.

Some good news is that throat cancer related to HPV is not as deadly as cancers caused by tobacco, alcohol, etc. The average survival rate for patients with HPV-related cancers is over ten years while other causes average a little over one and half years.

The HPV virus has once again entered the political spotlight in the U.S. since the best known treatment is an inoculation before the individual becomes sexually active. Critics claim the vaccine is or might be dangerous, encourages premarital sexual activity and/or, when the vaccine is required by governments it is an intrusion that interferes with parental rights.

The U.S. Centers for Disease Control has just recommended that boys also be given the vaccine.

Halloween And A Monster

By Len A. Hynds.

It was a Sunday evening, and I was expecting a visit from an old friend, someone who was used to seeing me without my Buchanan bib [stoma cover], and not at all perturbed at seeing an exposed stoma.

The doorbell rang and I walked across the hallway in semi-darkness to open the door expecting to find my friend there, when I was confronted by 6 seven-year old children, all scarily dressed, with their faces painted in a skeletal design to terrify, and each was holding a flashlight, from which shone a green eerie light illuminating those horrid faces.

I had forgotten that this was Halloween, and this obviously was my “Trick or Treat visit.”

I kept my face back in the shadows so that the hole in my neck wouldn’t frighten them. I recognized the obvious ringleader as the grandson of neighbors, a young lad I had spoken to on many occasions. By his body language, I guessed that on approaching my door he had said to them, “A man lives here who can’t speak, but he can get words to come out of his neck.”

He suddenly shone his flashlight upwards, exposing my stoma for all to see, in its green beam, like a magician on stage, and with a flourish said, “There, what did I tell you?!”

The other five green flashlight beams then illuminated my face, and they all moaned in horror, with them all taking another step backwards.

I drew my head back, which must have made matters worse, because my eye sockets were in shadow, and must have looked like the black holes of death. They were all too scared to say “Trick or treat”, and as I fumbled for some coins to give them, the ringleader said, “Can you show them words coming out of your neck?” I duly put thumb to stoma and said, “Happy Halloween, children.”

Another fearful moan of horror, as they all took another step backwards.

I drew my head back, which must have made matters worse, because my eye sockets were in shadow, and must have looked like the black holes of death. They were all too scared to say “Trick or treat”, and as I fumbled for some coins to give them, the ringleader said, “Can you show them words coming out of your neck?” I duly put thumb to stoma and said, “Happy Halloween, children.”

Another fearful moan of horror, as they all took another step backwards with those eerie green flashlight beams all trembling and the young man’s chest filled with pride.

I gave him some coins to distribute, and as I closed the door, I heard him boasting, “Of course he’s a friend of mine. He’s quite good really. Gives Christmas presents.” His reputation must have soared at school.
In Arizona, hospital admissions for asthma dropped by 22% after a year of strong smoke-free legislation (that included bans on smoking in workplaces, restaurants, and bars). In Scotland, there was a 13% annual decrease in childhood asthma admissions after the introduction of a smoke-free law.

The California tobacco control program cost $1.4 billion during its first 15 years, but saved $86 billion in direct health care costs, a 61 times return on investment. (The Lancet medical journal)

Federal government officials predicted that all 50 America States would have bans on smoking in restaurants, bars and workplaces by 2020 based on the current pace of adopting anti-smoking laws. The number of states with comprehensive indoor smoking bans went from zero in 2000 to 25 in 2010.

Dr. Tim McAfee of the Centers for Disease Control stated that it was not a foregone conclusion that this ban would be universal by 2020, but that he was “bullish we’ll at least get close to that number.”

Nearly half of U.S. residents are covered by comprehensive state or local indoor smoking bans and another ten states have laws that ban smoking in workplaces, bars or restaurants, but not in all three.

Asthma Decreases

In Arizona, hospital admissions for asthma dropped by 22% after a year of strong smoke-free legislation (that included bans on smoking in workplaces, restaurants, and bars). In Scotland, there was a 13% annual decrease in childhood asthma admissions after the introduction of a smoke-free law.

95% of people who attempt to stop smoking without the help of nicotine replacement (patches, pills, gum, nasal sprays) and medications such as Chantrix go back to smoking within 6 months.

Asthma Decreases

Lung Cancer Declines

Lead by California and Utah, the U.S. is showing a decline in the rate of lung cancer in women. Smoking rates in the western part of the U.S. have long been lower. 90% of lung cancer cases are attributed to smoking.

Lung cancer rates for men have been declining for years, but the drop among women is more recent. The U.S. Centers for Disease Control reported that the lung cancer rates for women declined nationally about two percent from 2006-2008 (the most recent figures). The rate of drop in western states was double that.
Tobacco Companies Sue FDA Over Graphic Warnings

Claiming that their free speech rights would be violated, five tobacco companies—including the four largest in the U.S.—have sued the federal government over required new graphic cigarette labels. The dispute centers on provisions of the U.S. government’s Tobacco Control Act that requires cigarette packages and advertisements include larger and more visible graphic health warnings.

The Food and Drug Administration issued a ruling requiring nine graphic color warnings to be included on cigarette packages and ads to go into effect by September 2012. These warnings are the first changes in U.S. cigarette warnings in 25 years.

The warnings are expected to have a significant public health impact by reducing the number of smokers, saving lives, increasing life expectancies, and lowering medical costs.

The nine images were chosen to rotate on packs and ads from a group of 36 based on the recommendations of 18,000 people who selected those they believed would be most effective. One of them depicts a laryngectomee smoking. The labels will appear on half of both the front and back of cigarette packs and also be 20% of other advertising. Each also includes the toll-free quit smoking hotline telephone number.

The tobacco companies argue that the warnings will cost the industry millions of dollars and force them to include government anti-smoking advertising larger than their own brand names. The companies also complain that the warnings include a live actor depicted as a corpse and that the lung disease photo was doctored to make it look more dramatic. An organization representing advertisers joined the tobacco companies in the lawsuit.

Calls to the quit smoking hotline doubled the day the media made the images public.
Q & A--  **Question:** I need to have my esophagus dilated (stretched) every so often so I can eat. I am a TEP speaker and after the dilation my voice is poor or nonexistent. What is going on?

**Answer:** To produce a good quality vocal tone, the tissues of the vibrating segment in the pharynx-esophagus must come together. During dilation the tissues are separated by the stretching. So it is not unusual for there to be a decrease in voice ability on a (usually) temporary basis. (Carla Gress, ScD, CCC-SLP)

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The Price is Right

The Internet-based laryngectomee IAL member support club WebWhispers maintains a listing of information and products of value to laryngectomees that are free for the asking at:

http://webwhispers.org/library/FreefortheAsking.asp

Check it out.

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Available from the IAL

**VIDEO/DVD LIBRARY**

*Laryngectomees Loving Life*—(DVD, 35 min.) A $10 donation is requested.

*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.)

**PUBLICATIONS**

The IAL currently publishes and distributes the following:

IAL Brochure (NEW!)

Information about the IAL. FREE!

The *IAL News*

A newsletter that is published four times annually. 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 Breeders**

Available in English and Spanish. FREE!

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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 currently available in English (Spanish will be added later). (Send stamped, self-addressed envelope.)

Publications and the items above can be obtained from:

IAL

925B Peachtree Street NE

Suite 316

Atlanta GA 30309-3918

or call toll-free (866) 425-3678

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FREE Emergency Window Stickers

These emergency stickers can be used on automobiles or on home windows. They are currently available in English (Spanish will be added later). (Send stamped, self-addressed envelope.)

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Send your e-mail address

If you would like to be alerted when there are important announcements please send us your e-mail address. Send it to Tom Herring at http://Tomherring@embarqmail.com. Your e-mail address will not be shared with any other individual or organization.
**IAL Profit/Loss Financial Picture**

Acting Treasurer Wade Hampton prepared a comprehensive profit and loss statement that reflects the current financial picture of the IAL. He presented it to the Board of Directors via email on September 6, 2011. The figures below are a summary of the major categories.

A more comprehensive statement will be made available on the IAL web site.

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**Profit/Loss Statement - Summary**

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**Expenses**

| AM Expenses   | 19,750.06      | 0.00          | 0.00          | 0.00           | 0.00         | $19,750.06|
| General Fund  | 0.00           | 24,245.21     | 12.00         | 0.00           | 0.00         | $24,257.21|
| IAL News      | 0.00           | 0.00          | 21,046.51     | 0.00           | 0.00         | $21,046.51|
| Voice Institute| 0.00           | 0.00          | 0.00          | 17,238.69      | 0.00         | $17,238.69|
| Total Expenses| 20,041.92      | 28,307.26     | 21,058.51     | 17,579.04      | 128.32       | $87,115.05|
| Net Operating | 9,632.66       | -11,844.36    | 4,524.49      | 2,900.96       | -120.67      | $5,093.08 |
| Income Net    | $9,632.66      | $-11,844.36   | $4,524.49     | $2,900.96      | $-120.67     | $5,093.08 |

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**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** _____________________________________________
- **ZIP code** (from billing address) __________ **Credit card number** __________
- **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 Acting Treasurer Wade Hampton at WLHampton@windstream.net
To: IAL  
925B Peachtree Street NE  
Suite 316  
Atlanta GA 30309-3918

Enclosed is my tax deductible gift of $10 or more, with my check or money order made out to IAL News.

Name _____________________________________________
Address ____________________________________________
City, State, Country _________________________________
ZIP/Postal Code _____________________________________
E-Mail Address______________________________

Please send ______(number) of postcards for others to use so club members/patients can subscribe or change News mailing address.

To: IAL  
925B Peachtree Street NE  
Suite 316  
Atlanta GA 30309-3918

☐ Please add my name to IAL News mailing list.
☐ Please remove my name from the IAL News mailing list.
☐ Please change my address as indicated below.

I am a ☐Laryngectomee ☐Speech/Language Pathologist
☐ Physician ☐ Nurse ☐ Other____________

Name ______________________________
Address __________________________________
City, State, Country _________________________________
ZIP/Postal Code _________________________________
E-mail Address (for receipt)____________________________

Please send ______(number) of postcards for others to use so club members/patients can subscribe or change News mailing address.

Use the forms below to make a voluntary tax-deductible donation; or subscribe, change your address, or remove a name from the mailing list.
Welcome two new family members

XtraMoist™ HME comes even closer to mimicking normal nasal function. Humidiﬁcation is improved and good airﬂow is maintained for easy breathing. XtraMoist is recommended for patients who have recently undergone a total laryngectomy, and for those already accustomed to using an HME.

XtraFlow™ HME delivers superior airﬂow. XtraFlow is great to use when exercising, adapting to using an HME, and for those that prefer lower resistance breathing.

XtraHME™ acts as an effective artiﬁcial nose. Many experience the following beneﬁts from using an HME:

- Reduced mucus production
- Reduced coughing
- Improved pulmonary function
- Improved speech
- Hygienic stoma occlusion

Call to request your free sample today.
1-800-217-0025

HME (artiﬁcial nose) Selection Guide

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<th>Airﬂow Resistance</th>
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Provox FreeHands HME cassette is not to be worn at night unless used with an HME cap.

Insurance coverage, payment, co-payments, deductibles and some restrictions apply depending on the individual’s policy and medical need.

www.atosmedical.us