IAL Launches New Sponsorship Program

At the 2011 Kansas City Annual Meeting the IAL Board of Directors launched a program to keep the organization going financially by establishing a new Sponsorship Program. A system of categories: bronze, silver, gold, platinum and diamond (along with the highest, Lifetime Donor), has been established.

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<th>IAL Sponsorship Program</th>
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<td>Lifetime Donor</td>
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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 reached $50 they would be designated as a “Bronze” level donor. A listing of donors by category will be printed in the IAL News at least twice per year. Donations may also be made anonymously if preferred.

The continued existence of the IAL requires new sources of income. The loss of financial support from the American Cancer Society in the late 1990s, declining number of dues-paying clubs, and the drastic stock market collapse in 2008 and the resulting reduction in interest (and dividend) income, along with a major loss from the Little Rock, Arkansas Annual Meeting; all contributed to the IAL’s financial situation.

Surveyed foundations have indicated that they are not interested in funding the on-going and routine costs of organizations such as the IAL. They, and others, believe that those who benefit from the services of an organization like ours should value it enough to support it financially.

Our vendors are doing more than their fair share through advertising and sponsoring activities at the Annual Meeting and Voice Institute and our publications. Operating costs have been drastically cut and incomes from current operations have been increased. But these efforts have fallen short of making the IAL financially self-sustaining. This leaves members of the laryngectomee community to step up in order to keep our nearly 60 year old organization providing services to fellow laryngectomees into the future.

Please make out a check today and send it to The IAL, 925B Peachtree Street, Suite 316, Atlanta, GA 30309-3918.

First IAL Sponsors

The IAL’s Sponsorship Program is brand new and only those who attended the Annual Meeting are aware of its existence. But even that small group was quick to respond on the spot with gifts.

Bronze ($50)
- Linda Battaglia
- Tom Cleveland
- Julie Crane
- Laurie Gallant
- Logan Grayson
- Jackie Lee Jarmel
- Martin Jarmel
- Walter Josephson
- Cheryl Lee
- Ron Leek
- Ron Mattoon

(Continued on page 3)
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.

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

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HME (artificial nose) Selection Guide

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<th>HME Cassette</th>
<th>Airflow</th>
<th>Humidification</th>
<th>Bacteria, virus, dust and pollen filtration</th>
<th>24/7 capabilities</th>
<th>Antimicrobial hygroscopic properties</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.
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 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.

North Carolina Here We Come!

Mark your calendars now to join our laryngectomee family for the 2012 IAL Annual Meeting and Voice Institute to be held in Raleigh/Durham, North Carolina.

The dates are June 7-9 with the Voice Institute beginning one day earlier on the 6th.

The headquarters hotel is the Sheraton Imperial in Durham. The room rate is $99 + tax single or double occupancy, and there is free parking, Wi-Fi and shuttle from the airport. Plan now to join us!

Kansas City AM/VI is a Major Success

By all measures the 2011 IAL Annual Meeting and 51st Voice Institute held in Kansas City, Missouri in June was a major success. There were 262 total official registrations, and the Voice Institute was among the largest in recent memory. Voice Institute Director Phil Doyle reported that a record 60 graduate students attended the Institute. These students in speech represented more than a dozen graduate academic institutions in both the United States and Canada.

The hosting clubs did an exceptional job of supporting the Meeting and Institute and introducing us all to their famous “City of Fountains.” The Heart of America Nu-Voice Club of Kansas City (Rod Chester, President) and the Tri-State Nu Voices Club of Joplin (Betty Labigang, President), served as our gracious and generous hosts. They solicited donations for many purposes including the auction and table sales, and refreshment break. The “Mary Moerer Family and Friends” group was especially generous in their support of all of our activities including co-sponsoring the annual banquet and dance. The dance featured a live five piece band.

Many laryngectomees and family members took advantage of the free speech and hearing evaluations offered as part of the Voice Institute. A First Timer’s Orientation was again provided on Wednesday afternoon, and the Meet and Greet Reception hosted by InHealth Technologies that night was the first of many social events.

The Annual Meeting officially opened with combined sessions on Thursday morning. Awards were presented and an important session on recent changes in Medicare funding of indwelling prostheses followed the opening ceremonies (see article on page 4).

Sessions were offered on virtually every aspect of laryngectomee rehabilitation. Once again this year an excursion was planned on Friday afternoon and many took the opportunity to take the free bus to the WW I Memorial and Museum, Union Station and Crown Center, as well as to take in the many sights of Kansas City. As always, the Meeting and Institute concluded with a wonderful banquet and dance on Saturday night.

(Continued) Bronze ($50)
Clyde Simmons
Ellie Tatro
Claire Vaudry
Amie Walsh

Bronze **($100)
Wayne Baker
Marlene Haynes
Lesley Herbst
James Lombardo
Julie Williams

Bronze ***($150)
Sapp Funderburk

Bronze ****($200)
Ron Leclaire

Silver **($500)
Bob Herbst
Medicare Changes Concern to Many Indwelling TEP Users

Medicare has made a ruling that will cause significant problems for many laryngectomees who use the indwelling prosthesis that is installed by a medical clinician (ENT or SLP). Medicare will no longer reimburse for indwelling prostheses that must be inserted by a clinician.

The ruling is that since these devices are installed by the clinician and not the patient, the clinician must provide the prosthesis at the time of service and bill Medicare for it. Many, if not most, medical facilities will not be able to stock an inventory of indwelling prostheses in all of the sizes and styles needed because Medicare reimbursement does not cover the facilities’ costs for stocking them. The facility could lose money on every indwelling installed from their stock.

You can still purchase an indwelling prosthesis out of pocket, but Medicare will only reimburse you for a prosthesis if it is one you can insert yourself such as InHealth duckbill and low pressure prosthesis, and the Provox NID.

Switching to a patient changed prosthesis will be a significant problem for many who use the indwelling. For some, they lack the ability to change the prosthesis themselves and don’t have anyone at home who can do it for them. Additionally, some laryngectomees have a puncture location that makes it impossible for them to change it themselves.

Still another problem is that if laryngectomees have to pay for indwelling prostheses out of pocket some are likely to try and extend the life of the prosthesis and leave them in longer than is recommended. This is likely to lead to leaks and the risk of aspiration pneumonia, which can be fatal.

There are some options. One is to switch to the patient changeable prosthesis, if that is possible. Even if you cannot change the prosthesis yourself a clinician can do it for you. However, since the patient changeable prosthesis should be changed (or rotated) more often, this will require more frequent trips to the clinician and result in more out of pocket co-pays.

Another option is to find a clinician that stocks the indwelling that you prefer. Those living in larger metropolitan areas may be more successful in finding a facility that will provide the prosthesis and bill Medicare.

The last option would be for the laryngectomee to pay out of pocket.

A number of organizations including ASHA (American Speech-Language-Hearing Association) is working to change these rules.

Newly Elected BOD and Officer Sworn in

At the Delegate’s Meeting on Saturday Secretary Terrie Hall was re-elected as IAL Secretary along with Board of Directors members Tom Cleveland, Philip Doyle, Ph.D., Elizabeth Finchem, Tom Herring, and C. W. Moreland. Each was running for re-election except for C. W. Moreland who had been appointed to fill a vacancy that occurred during the year.

Laryngectomee Prayer

Oh, Heavenly Father, I thank you for your sweet gift of speech, the second such gift to me during my lifetime; and for Your help through so many others during my recent and terrible silence. Never let me forget the anguish nor the despair suffered by me while speechless, for only in remembering can I tenderly assist those who unfortunately come after me. Teach me to do so with a clear understanding, a gentle compassion, a deep humility, and with much patience.

(The Laryngectomee Prayer first appeared in the IAL News in 1958 and was attributed to a New Jersey club newsletter).
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Marlene Haynes Survives Tornado and Attends Annual Meeting

Not even having her home destroyed by a tornado in May was enough to keep laryngectomee Marlene Haynes of Missouri from attending the IAL’s Annual Meeting in June. Marlene, then of Joplin, survived a tornado by getting into her bathtub with one of her persian cats. Miraculously, the other returned in two months.

While no one gets over such a life-threatening trauma quickly, Marlene quickly found a house she loves in a neighboring town and is getting on with her life, including joining her many friends (old and new) at the IAL Annual Meeting in Kansas City.

Philip Doyle, Ph.D., Named IAL Voice Institute Director

The IAL Board of Directors has named Philip Doyle, Ph.D., as Director of the IAL’s Voice Institute. He served as Interim Director this past year after taking the place of Dr. Jeff Searl, who stepped down following the 2010 Annual Meeting. Dr. Searl assisted Phil with the 2011 Voice Institute.

Dr. Doyle is currently Professor of Rehabilitation Sciences and Otolaryngology Head and Neck Surgery, and Communication Sciences and Disorders at the University of Western Ontario (UWO) in Canada. Since 1991 he has served as the Director of the Voice Production and Perception Laboratory at UWO and directs the Psycho-Oncology and Quality of Life Laboratory.

Dr. Doyle received his undergraduate degree at Fresno State University (1979), a M.Sc. at the University of California, Santa Barbara (1981), and a Ph.D. (1985) at the University of California, San Francisco School of Medicine and UC Santa Barbara.

The Board of Directors regrettably accepted Dr. Doyle’s resignation from the Board, but is delighted that he has agreed to assume this critically important leadership position for the IAL.

Head & Neck Cancer Rehab. Institute Closes

The Head and Neck Cancer Rehabilitation Institute closed this past June. Services provided by the Institute included providing Neck Awareness Decals (temporary “tatoos” that identified hospitalized laryngectomees as total neck breathers), and an information hotline. The Hotline, ably manned by Mary Jane Renner, social worker and laryngectomee, provided a toll free number where those facing laryngectomy surgery and their family members could obtain information. The Institute was founded in 1983 by the late Ronald Hamaker, MD, and Eric Blom, Ph.D. Mary Jane Renner, Executive Secretary for the Institute, stated that lack of operating funds had forced the ending of this non-profit service. (See story by Mary Jane on page 10).

Fact–The larynx is the most common location for cancers of the head and neck.
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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All my best,
Jim Lauder
Dave Greiwe Finishes 5K Run/Walk

Laryngectomee Dave Greiwe, 61, finished a 5K run/walk in Bloomington, Indiana on April 2, 2010. The 5K was a warm up for his upcoming fourth Mini-Marathon at Indianapolis scheduled for May. In addition to being a laryngectomee Dave also had lung cancer and had his right lung removed.

Hands-Only CPR

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

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

11 Year Old Makes Video About Lary Grandfather

Laryngectomee Hank Luniewski’s eleven year old grandson Benjamin Shenal of Salem, Virginia made a video on Hank’s throat cancer that won his school and district competition.

You can view it here: http://infobot.com/youtube/watch?=4KlmKRp_rXQ.

The Power of a Hug

By Itzhak Brook, MD

I was deeply shaken to learn I had hypopharyngeal cancer. As a physician, I had access to my hospital’s laboratory results, so I took a shortcut: Rather than wait for my surgeon to call me, I looked for my name in my hospital’s pathology laboratory log book.

After my name, the log book stated in no uncertain terms: “mildly differentiated squamous cell carcinoma.”

I could not believe my eyes. Was this possible? Could it be a mistake? In spite of the hopeful questions that permeated my mind, I knew it was not a mistake: Right here, in front of me, in black and white — my own death sentence. Still, to be convinced that the diagnosis was real, I had to view the biopsy specimens under the microscope myself — and there it was.

In that very instant, my whole world changed. I had always had a sense of invulnerability. Now I was left with uncertainty about my prognosis and future.

I was in a state of desperation and disbelief when I left the pathology laboratory and walked into my internist’s office to break the news to him.

He slowly got out of his chair without uttering a word and gave me a big, supportive hug.

It felt so good to know that he deeply cared for me beyond our professional relationship. His embrace moved me — made me feel that I was surrounded by those who truly appreciated my pain and distress, and who shared my personal tragedy. It meant much more at that moment than a thousand words of support or elaborate explanations.

It was the power of a caring, human touch. I knew that I was not alone in my future struggles, that he would be beside me all the way.

I had never been hugged by a medical caregiver. Nor had I given a hug to a patient: I always believed in maintaining a professional distance between them and me. Yet at that moment, I learned there may be situations in medical practice where the power of a hug eclipses everything else one can offer.

In the realm of modern medicine, where machines and tests often substitute for close patient-physician contact, this fundamental art is often forgotten. Even a
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simple pat on the shoulder or a warm handshake conveys genuine care and concern. In fact, there is scientific evidence that human touch can generate oxytocin and endorphins, which ameliorate pain and create a feeling of well-being.

Unfortunately, I had to undergo a total laryngectomy to have my cancer removed. The period after my surgery was very physically and emotionally trying, as I battled numerous medical problems and also struggled to regain my ability to speak. What eased those difficult months was the knowledge that my otolaryngologist’s door was always open to me and that he would act immediately to assist me in any way he could. His dedication, emotional support, sincere care and friendliness helped me overcome many of the difficulties and problems I encountered. They were indispensable on my road to recovery.

I sometimes went to his office several times a week — often just to talk with him and tell him how I was doing. I always felt welcomed. He greeted me with a big smile and hugged me every time I left. This simple act created a bond of intimacy between us and made me feel that I had a friend.

My personal experiences changed my attitude toward my own patients. I am less concerned now about maintaining a professional distance or avoiding a caring touch or hug when appropriate. I have learned that such gestures can significantly deepen the healing relationship between patient and physician.

As a laryngectomee, I have found that speaking is often difficult and challenging. So I am fortunate to have discovered that the “power of a hug” can convey so much more than the spoken word.

(Dr. Brook is a pediatric infectious disease physician at Georgetown University in Washington, D.C. He is the author of the 2010 book “My Voice: A Physician’s Personal Experience With Throat Cancer.” More at dnbrook.blogspot.com; contact Brook at ib6@georgetown.edu. [Reprinted from the May 23, 2011 L.A. Times]).

Life Goes On
By Mary Jane Renner

I need to start with a disclaimer that this article is entirely my own personal opinion. I am aware that every individual’s situation is different, and the extent of surgery experienced by a laryngectomee may vary greatly. Thirty one years after my laryngectomy I am pleased to say that my recognition as a person is not related primarily to my surgery. I am Mary Jane Renner - a social worker, a dog lover, has arthritis, has asthma, wear glasses and I have had a laryngectomy.

When I was diagnosed thirty one years ago, my first thought was how I could continue as a social worker without vocal cords-my voice was my business. My surgeon said that he had someone who could teach me to speak in a different way. What if I had been unable to produce esophageal speech? Be careful what you promise someone!

I began my therapy with great determination to learn esophageal speech a month after my surgery. I began a vigorous practice schedule—fifteen minutes out of every waking hour. At the same time I decided that I needed something to do while waiting to return to work. I had lost some weight (good for me) so I decided to capitalize on that and joined a gym where I worked out every day. In my naivety I didn’t even ask my surgeon if I could do this-I felt so so I did it!

I was able to produce sound, say words, but the speech was strained. Reason, I was working so hard that I was extremely tense! Nevertheless, I kept at it. I was able to return to work with minimal speech to complete some assignments about ten weeks after my surgery. I had an hour each way commute to my job which I used to read road signs, recite nursery rhymes, and sing (even though my closest friends said I could not sing with vocal cords). All my efforts were directed at making my speech as intelligible as possible to the listener-it was my responsibility, I couldn’t expect the listener to strain to understand me! At this point I must chastise my surgeon who did not want his patients to use an artificial larynx. His reason was that it would make them lazy in using esophageal speech. This was an unnecessary frustration to me! I encourage patients to use an AL while they are developing esophageal speech or becoming accustomed to using a prosthesis.

(Continued on page 12)
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Terrie Hall Receives Outliving Life Award

IAL Secretary Terrie Hall received the IAL’s “Outliving Life Award” at the 2011 Annual Meeting. The phrase “outliving life” comes from a book that describes how it is possible for the good works we do to outlive us and continue to serve others long after we are gone.

IAL President Bob Herbst presents The Outliving Life Award to Terrie Hall

Terrie has had many bouts with the cancer “dragon” over the years and she never let these battles keep her from continuing to serve others. Throughout her surgeries and chemotherapy and radiation treatments she continued to serve as president of her club and to perform before and after surgery visitations at local clubs and in the homes of new laryngectomees when possible.

She has also worked for a decade with the American Cancer Society as a Team Captain for the Relay for Life. She is also an active speaker in North Carolina’s anti-smoking program. She recently was asked to speak in Utah and toured the state’s schools for a week. Terrie is also the recipient of the IAL’s Outstanding Service Award and many other awards that give testimony to to the lasting gifts she has given and continues to give to others.

Telephone Tip

It may be easier for people to understand laryngectomees when they speak on the phone if they hold the mouthpiece above the mouth area at about nose height. The reason is that the mouthpiece will pick up less of the sound of our breathing from the stomas. This is also particularly helpful advice for laryngectomees who use a artificial electronic larynx (AL). The reason is that the mouthpiece would otherwise pick up more of the buzzing sound of the AL and less of the sound coming from your mouth. Try it.

Attention SLPs

If you are listed the IAL’s Directory of Alaryngeal Speech Instructors please check it to make sure your information is current. Report any problems to pdoyle.uwo.ca and tomherring@embarqmail.com. Thanks.
Comprehensive Bylaw Revision In Progress

At the Kansas City Meeting the IAL Board of Directors voted to undertake a comprehensive revision of the organization’s Bylaws. The revision will be submitted to Delegates for their approval with the tentative goal to present the revision for approval at the 2012 Delegate Meeting.

The need for a comprehensive revision was suggested by Parliamentarian Elaine Fulton who served in that role at the Delegate’s meeting. She also volunteered to help with the project at no cost to the organization.

The IAL’s Bylaws date back to a draft prepared by Faber Drakenbrod and presented in 1954 at the Detroit, Michigan Annual Meeting. Over the decades the document has been amended many times and, over time, contradictions have periodically emerged, and in some cases it became very difficult to obtain agreement on the intent of the authors. The hope is to simplify the Bylaws and to make the language less subject to individual interpretation.

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 laryngectomee support club to perform a number of functions, although we can work 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.

Help Wanted!

The IAL is continually in need of volunteers. If you would prefer not to run for election as a Board member or officer you can still serve on one of the IAL’s committees. We are especially in need of people with financial/bookkeeping/accounting backgrounds. Every other talent is needed as well including those who can write, edit, create/manage web sites, do graphic work (including drawing, photography), desktop publishing, etc.

Contact the IAL President Bob Herbst at bobherbst@me.com or use the information on page 22.
New DVD, “Laryngectomees Loving Life,” Available

“Laryngectomees Loving Life” is a new DVD available from the IAL. It is a joint project of the IAL and the West Texas Rehabilitation Center in San Angelo, Texas. WTRC is the home base of the IAL’s Administrative Manager, Susan Reeves, SLP.

Introduced by Susan Reeves and hosted by laryngectomee Dave Ross of Florida, the video is both informative and very inspirational. The primary intended audience is individuals facing laryngectomy surgery, new laryngectomees and their family members. Videotaping for the DVD took place at the 2010 Annual Meeting in Louisville, Kentucky/Jeffersonville, Indiana area.

“Laryngectomees Loving Life” provides the kind of total message those of us who visit with these individuals prior to surgery or while they are in the hospital want to convey – that there is a full life possible after losing your larynx and not much to fear.

A brief description of the surgery is provided by SLP Phil Doyle, Ph.D.; and Jim Shanks, Ph.D. provides an overview of the three major forms of post laryngectomee speech. Elizabeth Finchem, Bob Herbst and Joe Marasco provide examples of traditional esophageal speech. Bob, Herb Simon and Tony Talmich demonstrate electronic artificial larynx (AL) use. Tom Cleveland is a featured TEP user who also conveys a powerfully positive message about life after laryngectomy.

Noel Best, Charlotte Liles-Smith and Sandy Olsavicki provide prospective from the standpoint of spouses of laryngectomees. Randy Wienke recounts his adventures skydiving after becoming a laryngectomee, and the video concludes with film clips and still photos of laryngectomees doing a variety of activities including swimming.

Each attendee at the 2011 Annual Meeting and Voice Institute was provided with a copy of the DVD, and plans are being worked out to provide a copy to each IAL member club. Clubs and individuals may choose to make copies of the DVD to provide to new laryngectomees, and a method is being worked on to cover the costs of duplicating and mailing additional copies. It costs about $2.50 to duplicate and mail a single copy.

Dr. Jeff Searl Honored

Jeff Searl, Ph.D., CCC-SLP received the IAL’s 2011 Clinical Excellence Award at the Annual Meeting this past June. Dr. Searl previously served as the Director of the IAL’s Voice Institute and was instrumental in setting up the clinical portions of the Institute at the Kansas City Meeting. Dr. Searl teaches at the University of Missouri.

State help for Larys

Does your state offer any help to laryngectomees to assist them with communicating via telephone? Find out at the Telecommunications Equipment Distribution Program Association at http://WWW.TEDPA.org/directory.

“It all comes out in the end”

Laryngectomee John Shipley was scheduled for his routine colonoscopy exam. The day before the procedure he accidentally pushed his prosthesis into his esophagus and swallowed it.

Before the procedure he told his doctor about the prosthesis and said he hoped the doctor could retrieve it, although he assured him that he had no intention of reusing it! When the procedure was over there the prosthesis was in a container of water. John noted that it looked brand new, having been cleaned by his stomach acid. However, John does NOT recommend this as a method for cleaning a prosthesis!

What’s in a Name?

The Medic Alert Foundation adopted the term “neck breather” based on the recommendation of the IAL’s Safety Committee. (Dec-Jan, 1961 IAL News)
Why Did You Give Me A Balloon?
By Elizabeth Finchem

Why did you give me a balloon? Don’t you know that we can’t inflate a balloon now that we are laryngectomees? These questions have been asked for decades by laryngectomees attending the IAL Annual Meeting and Voice Institute who received a balloon as a gift in their registration bag, or as a party favor.

I was astonished when offered my first balloon as I boarded the riverboat in New Orleans for an IAL excursion cruise during the 1983 Annual Meeting and Voice Institute. My first response was that I couldn’t blow up a balloon before my surgery, and I had no clue how to go about it without lung air. (This was before the TEP was widely used and I was speaking with esophageal voice which I had learned in 1981.)

How could blowing up a balloon possibly help me? Little did I know then that there are many benefits from learning to use “circular breathing”, that is, air drawn up into the nose and sent out of the mouth with tongue movement.

The air is drawn up the nose when the lips are together (around the balloon neck, in this case), and the bottom jaw is dropped creating a bellows affect that moves air in or out of the mouth. Horn players know how this works. Even Didgeridoo players can blow into their tree trunk instruments for 30 minutes using this method of air movement. Go to youtube.com and search for Didgeridoo instructions to see the instrument and method.

When we learn to blow up a balloon using circular breathing we strengthen our tongue muscles. You’ll notice that as the balloon is half full there is a little resistance to pushing another mouthful of air into it. This is a good exercise.

There are other benefits from circular breathing such as the ability to sniff, smell, or reverse this movement to blow your nose. When you can sniff air up the nose and over the olfactory glands you will be able to smell and taste your food much better. No need to go into the relief we can get from blowing our noses when necessary.

Since lung air is for breathing only, in this case, we laryngectomees can use this circular breathing method for speech as well. To improve articulation the tongue needs to be well healed, flat, agile and flexible enough to undulate as sounds and words are shaped in the mouth. This applies to all methods of alaryngeal speech.

There are other playful skills we can use such as blowing a cotton ball across the tabletop with mouth air (NOT stoma air). Blowing bubbles with a straw also works.

At some laryngectomee support group picnics they hold watermelon seed spitting contests. Seeds are spit into a trash barrel that is moved further and further away. The person who is the furthest away who gets a seed into the barrel wins. Another version is spouting (spitting) water the furthest onto the grass.

All of these suggestions are just simple fun that are aimed at helping with basic rehabilitation of the tongue for better speech, sniffing, tasting and blowing. Can you blow out a match or candle with mouth air only? Try it. You will probably also smell the smoke and the sulfur from the match.

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.

Free Hands-Only CPR Phone Application

A free application showing Hands-Only CPR is available from the American Heart Association for the iPhone and Android (and soon for Blackberry and Palm Pre) smart phones. It is available from the Apple Store and other websites. You can also preview it at YouTube.com.
New DVD Available to Educate Medical Personnel

Laryngectomee Itzhak Brook, MD., has produced (with the support from a vendor of laryngectomee products) a DVD intended to educate medical personnel in treating laryngectomees in emergency situations. Some of us have had frightening experiences where medical personnel lacked the knowledge needed to treat us, especially regarding how we breathe. Dr. Brook encountered these problems himself when he had to visit an emergency room.

The DVD is designed for use in training Emergency Training Technicians, nurses, doctors and others who may come in contact with a laryngectomee in an emergency situation. A free copy of the DVD “Rescue Breathing for Laryngectomees and Other Neck Breathers” can be ordered by calling toll-free (800) 217-0025, e-mailing Dr. Brook at dribrook@yahoo.com, or downloading a copy in the form of a PowerPoint presentation from his blog, http://dribrook.blogspot.com.

Amendments Pass

Four amendments to the IAL’s Bylaws were passed at the 2011 Delegate’s Meeting. One clarified that the IAL Treasurer has the authority to obtain outside resource to maintain financial records such as a bookkeeper. Another consolidated separately related listed duties of the Treasurer related to the creation of a line item budget to a single sentence. A third made the requirement of a 45 day notice to Delegates of proposed amendments uniform throughout the document.

A fourth amendment added a new category of non-voting membership within the organization. It added graduate students in Speech-Language Pathology, Nursing, Physiotherapy, Social Work and related fields, and established an annual dues rate. The amendment also specifies as eligible non-voting members professionals who hold certification or licensure in areas associated with laryngectomy and rehabilitation in Speech-Language Pathology, Medicine, Nursing, Physiotherapy, Social Work, Counseling Psychology and related fields. It also established an annual dues rate.

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 worthy of recognition.

DONATIONS

In Memory of:

Uncle Alvin  Steve & Carol Bushore
Albert Hoffman  Judy Hoffman
Margaret Blevins Kraus  David Blevins
Margaret Blevins Kraus  Edward Kraus
Margaret Blevins Kraus  Elaine Blevins
Margaret Blevins Kraus  Martha Blevins Thomas
Margaret Blevins Kraus  Susan Reeves
Margaret Blevins Kraus  Montgomery Laryngectomee Association
Margaret Blevins Kraus  Tidewater Lost Chord Club
Milton Matza  Pauli Wertheim

In Honor of:

Tom Herring  T. Eadie & C. Baylor
Joe Marasco  Herman “Red” Noles
Mary Moerer  Marc & Sheri Edwards
Mary Moerer  Mike & Beth Moerer
Mary Moerer  Teresa & Greg Moerer
Mary Moerer  Donna & Patrick Young
Susan Reeves  Shirley Salmon

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!

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.”

(Reprinted in a 1959 issue of the IAL News).
Bob Dlouhy Dies

Anti-smoking warrior Bob Dlouhy, 79, of Riverside, California died this past June. He lost a final battle to another cancer, this time to leukemia. Bob is survived by his wife of over 50 years, Lilabeth, a son and two daughters.

Bob was profiled in the November 2010 issue of the IAL News in an article by Don Layton as he approached his goal of speaking to 100,000 school age children about the dangers of using tobacco, alcohol and other drugs. He reached that goal on September 17, 2010.

Bob, who became a laryngectomee in 1999, was a member of the Inland Empire Nu-Voice Association. The club is in what is called the Tri-County area of California, and it covers more than 31,000 square miles and includes fifteen separate school districts. In addition to his speaking to school children he was also active in his club and with the American Cancer Society.

Bob would often drive over 80 miles and speak to as many as five school assemblies a day for four or five days in a row while camped out in one of the area’s campgrounds.

Our condolences to Bob’s family and many friends. He will be missed.

Bollywood & Smoking

“Bollywood” is the term used to describe the filmmaking industry in India. A recent study showed that young people are influenced by exposure to movies showing smoking and are more likely to take up the habit. These results are the same as studies showing the influence of smoking on Western youth who view it in movies.

Spare AL?

Please consider donating it to the IAL using the information on the back cover. We will give it to a needy laryngectomee. Thanks!

Title Change

At her request at the Kansas City Meeting, the IAL Board of Directors changed Susan Reeves, SLP, title from Executive Director to Administrative Manager. Susan felt that this title was a more accurate description of her duties and would help avoid confusion.

Vocab. Stomaplasty - Surgical revision of the stoma (usually to make it larger).
Menthol In Cigarettes

In March, 2011 the U.S. Food and Drug Administration’s Tobacco Products Scientific Advisory Committee concluded that “Removal of menthol cigarettes from the marketplace would benefit public health in the United States.” The committee noted that the availability of menthol cigarettes reduces smoking cessation, especially among African-Americans. It reported that “menthol cigarettes are marketed disproportionately to younger smokers” and “disproportionately marketed per capita to African-Americans.” Other research reported that people who smoked menthol cigarettes found it harder to quit.

Menthol cigarette makers R.J. Reynolds and Lorillard, which sell the Kool and Newport brands, have sued the FDA, charging that its committee was biased. Under the authority it was given in 2009 to regulate tobacco, the FDA has already banned chocolate and other flavored cigarettes that are attractive to children.

Cartoon Rango Sets Record for Smoking

The cartoon movie Rango opened on March 4 and grossed close to $40,000,000 through the weekend. According to anti-smoking authorities, it has the most tobacco incidents of any animated film since 101 Dalmations (1996). Rango delivered nearly 300 million tobacco impressions to theater audiences across the U.S. and Canada in just its first three days.

The American Academy of Pediatrics, Campaign for Tobacco-Free Kids and Legacy jointly stated that Rango posed a health risk for children.

“The American Medical Association (AMA) is gratified to see progress in the effort to remove smoking from youth-related films by Disney, Time Warner and Universal.... We urge the remaining studios to reduce smoking in their films, and we call on the Motion Picture Association of America to follow the CDC (Centers for Disease Control) recommendation and give movies that depict smoking an ‘R’ rating.” (July 13, 2011)
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.

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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**
- **End billing on**

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 30309-3918

E-mail: http://TheIAL.com

Phone toll-free: (866) 425-3678

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**International Association of Laryngectomees**

**Automatic Credit Card Billing Authorization Form**

Please order the number of items you believe your club can use within at least a year or two.

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<td>Orange Emergency Cards (English)</td>
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**IAL Materials**

**Club Order Form**

Please order the number of items you believe your club can use within at least a year or two.

- **IAL Brochures**
- **Postcards to order copies of the IAL News (or change address)**
- **Orange Emergency Cards (English)**
- **Orange Emergency Cards (Spanish)**
- **Orange Emergency Window Stickers (English)**
- **Orange Emergency Window Stickers (Spanish)**

Mail to:
IAL
925 Peachtree Street NE
Suite 316
Atlanta GA 30309-3918

E-mail:
http://TheIAL.com

Phone toll-free:
(866) 425-3678

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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.)

Videos and DVDs can 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 (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 Breathers*
Available in English and Spanish. FREE!

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

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○ Physician ○ Nurse ○ Other_____________________

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

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