



IAL

news

International Association of Laryngectomees

Vol 45 No. 3 May 2000

Music City 2000

HEAR OUR VOICES

Imagine an elegant Southern manor located on a hilltop and surrounded by 23 beautiful landscaped acres. Inside is a magnificent lobby elegantly appointed with period furnishings. As you cross the lobby you will spot the Veranda Piano Bar, which is adjacent to a large outdoor patio area. During the evening songs of many genres will float softly from the piano accompanied by beautiful vocals.

This is only the beginning, the setting for something much more spectacular. Because amidst the beauty of this grand hotel, the mouth watering Southern cuisine, and warm gentle Southern nights you will "Hear Our Voices." You will hear the voices of some of the best speech and medical professionals in the world dedicated to laryngectomee rehabilitation. You will hear the voices of extraordinary survivors who have met the challenge and now devote their energies to helping others overcome the silence, the fear and the uncertainty of their future. You will hear new voices that speak for the first time, as well as voices that will undergo tremendous improvement during this magical week and the weeks to come. When you hear our voices you will experience the sounds of victory, and the voices of courage that have met the dragon head on with the determination not only to win, but to help others as well. All of this takes place in Music City USA. But, all the music ever produced will not compare to the sweet sounds of success and the victories over the sounds of silence when you hear our voices.

The IAL Clubs of Tennessee and Hopkinsville, KY invite you to join us in this celebration of the laryngectomee as we move into the new millennium. The 2000 IAL Meeting and Voice Institute will be the first of the new century and that's something that shouldn't be missed. Do you need help with your speech or would you like to learn how to help others with their speech? Then register for the Voice Institute as a Voice Institute Pupil, a Laryngectomee Trainee, or a Speech Thera-

pist Trainee. Want to meet fun and interesting people from all



over the world who have shared the same experiences as you? Then register for the Annual Meeting and you will make new friends for life while listening to superb speakers who will teach you various rehabilitation skills and techniques. There will even be time for lots of fun while staying in Music City. The Grand Old Opry is just minutes away from the hotel for all you country music fans. Opry Mills, a brand new country theme park and mall

will be opening just weeks before our meeting. Historic music row, resplendent with honky tonks that feature tomorrow's stars are just a short trip to downtown Nashville. If you're into tours a wide variety can be arranged right there at the hotel. Tour the historic downtown Nashville area, the Country Music Hall of Fame, see the homes of the Country stars and legends, visit the Hermitage, home of Andrew Jackson, the Jack Daniels Distillery, or get a group together and create your own tour.

For those of you who have attended in the past there are a few changes this year. The Voice Institute will start on Tuesday, Aug 15 and will run through Saturday, Aug. 19. Only those who register as Speech Therapist Trainees (STs), or Laryngectomee Trainees (LTs) are required to be there the first two days. Voice Institute Pupils (VIPs) are those that need to improve their speech, and they start on Thursday morning, Aug. 17. The Annual Meeting portion also starts on Thursday morning but it is preceded by the always-fantastic Meet & Greet reception on Wednesday night. Something you don't want to miss. IAL committee meetings will also be ongoing all day Wednesday and anyone is welcome to sit in if they desire. Everything will culminate Saturday afternoon with the ever popular fun show and then the Grand Banquet Saturday evening.

The host clubs are working hard to make this an event to remember. Let's help them by making this the biggest turnout out ever. If you've never been to an Annual Meeting make this your first. If you're a seasoned veteran come back again and bring a first timer with you. Join us as we invite the world to "**Hear Our Voices.**"

Acupuncture etc.

Several Laryngectomees have related their experiences with alternative forms of treatment for various conditions. The following letter from Ned Bienemann of Pasadena MD relates his experience with one of the more credible alternatives. Note that such treatments should be pursued only with the knowledge and approval of your doctor.

"After my laryngectomy and esophagectomy (which "omy-ed" a lot of other parts of me too, including stomach, shoulder muscles, etc.) I was plagued by all sorts of pain. With the nerves all scrambled up after so much surgery it was hard to tell what was causing what.

None of the "high-powered" places in Baltimore, DC, UPenn, Mayo were of any solace. I finally tried some holistic approaches including acupuncture. This latter approach for me, in time, has worked almost miraculously, not only in relieving a lot of pretty terrible pain, but also in a sort of reintegration of the various parts of the body into a working entity again.

For awhile after the surgery there was one department working on my stomach, another working on my mind another my throat, and another my teeth, but they didn't work together and one treatment would often offset or negate/distort another. The acupuncture (which is not painful, but a little scary at first) I feel was the primary factor which let me get back to some "normalcy", and physically has let me rejoin much of the athletic activity that the surgeons said would never return. I'm back to black diamond skiing, tennis, triathlons (without the swim) and the like. I don't know if it'll work for anyone else but it sure worked for me which is why I share it."

Ned Bienemann, Pasadena, MD

TRANSPLANT Second Anniversary

On January 4, 1998 Tim Heidler was given a new larynx by Dr. Marshall Strome of the Cleveland Clinic. Tim was not a cancer



Tim Heidler

victim, he was young, in good health, emotionally stable and highly intelligent, the perfect candidate for the procedure.

On the occasion of his second anniversary we find that Tim's voice has continued to improve daily, and Dr. Strome feels that it now sounds perfectly natural. The problems have been small. Tim still has his stoma which he has to occlude to speak. The stoma will eventually be closed, but Dr. Strome has not yet set a time.

Dr. Strome had planned to wait at least two years before attempting another transplant. Now that two years have elapsed, he feels he's almost ready. He hopes to begin searching for a subject in a few months, possibly a cancer survivor. Dr. Strome feels that a cancer survivor who is at least 5 years post op would be a good candidate, as long as he or she is free of disease, and has not had radiation or neck dissection.

Dr Strome described Tim's recovery, his spirit and dedication, and the knowledge that he and the medical community have gained from this noble experiment as "Incredible!"

"The first of any medical procedure is not easy; however, if you are going to move medicine forward, it must be done. This has been a significant moment in medicine, and years from now many people will have Mr. Heidler to thank." However, it is not for everyone. It's for the select patient who, post-laryngectomy,

feels he or she is really missing something." He adds, "it should not just be a rich person's procedure...."

Ron Langseth asked Dr. Strome what he felt was the future of larynx transplantation. "I expect to see many transplants performed in the future. Perhaps primarily at the time of laryngectomy, but also for longtime laryngectomized patients. I'd like to see a replacement larynx for every individual who needs one."

Ron Langseth says, "We agree with Dr. Strome, and feel that in the twenty-first century we will see at least as many larynx transplants as we now see kidney transplants, perhaps more. After all, Dr. Strome and his colleagues have put in a lot of time, risk and effort. Would they have done so to perfect a procedure that they felt would scarcely be utilized?"

ACCIDENT OF BIRTH

Spared by a car- or airplane-crash or cured of malignancy, people look around with new eyes at a newly praiseworthy world, blinking eyes like these.

For I've been brought back again from the fine silt, the mud where our atoms lie down for long naps. And I've also been pardoned miraculously for years by the lava of chance which runs down the world's gullies, silting us back. Here I am, brought back, set up, not yet happened away.

But it's not this random life only, throwing its sensual astonishments upside down on the bloody membranes behind my eyeballs, not just me being here again, old needier, looking for someone to need,

but you, up from the clay yourself, as luck would have it, and inching over the same little segment of earth-ball, in the same little eon, to meet in a room, alive in our skins, and the whole galaxy gaping there and the centuries whirring like gnats-you, to teach me to see it, to see it with you, and to offer somebody uncomprehending, impudent thanks.

William Meredith

LARYNXLINK, IAL WEB SITE ALIVE

David "Dutch" Helms reports that LarynxLink went on line on September 20, 1999 providing the Home Page of the International Association of Laryngectomees, laryngectomee clubs, products and services information, alaryngeal speech therapy, FAQ's on larynx cancer, newsletters, library, and related links.

LarynxLink was turned over to the IAL by its founder, **Jack Henslee**. Among other things, Jack developed the maps on which users click to find Laryngectomee Clubs and Alaryngeal Speech Instructors certified by the Voice Institute.

The IAL website has three major corporate sponsors for it's first year, Bivona, Luminaud, and InHealth Technologies, each have web pages on the site.

Tod Date the 8000 visitors to the site have been presented with information on:

← The International Association of Laryngectomees (IAL): its organiza-

tion, officers, Board of Directors, and committees; its purposes, services and publications.

← The IAL's Annual Meetings and Voice Institutes

← Assistance in locating qualified alaryngeal speech pathologists/therapists

← A worldwide listing of all current IAL-affiliated clubs and regional organizations

← The IAL News and other selected local newsletters of interest to laryngectomees

← On-line forms to subscribe to the IAL News and to update/add club information

← A Directory of Distributors providing products and services of interest to laryngectomees

← A Calendar of Events for laryngec-



Dutch Helms

tomees and associated professionals

← A Library of laryngeal cancer information, inspirational articles and poems submitted by IAL members

← An extensive list of "Laryngectomee FAQ's" Frequently Asked Questions

← Extensive links to other sites that deal with laryngectomy and larynx cancer issues, voice rehabilitation, and other useful laryngectomy-related resources.

← A Guide to Donations to the IAL; financial support and/or services.

The site is set up to provide NASHVILLE 2000 information and registration.

Dutch notes that updating information is a constant and ongoing process. Indeed, he has spent hundreds of hours in the process of updating. The IAL is indebted to Dutch for the excellent job that he has done as the IAL Web Master and to Jack Henslee, founder of LarynxLink.

JOHN G. KLOEPFER, WWII & CANCER VETERAN DIES

John Kloepfer, a former Director of the IAL and a member of the board of the American Cancer Society, died in Buffalo at age 75.

As a sergeant in the 4th Division of the Army John landed at Utah Beach during D-Day and went on to fight in the Battle of the Bulge.

His battles continued as he fought against throat cancer in 1978 and had heart bypass surgery in 1992.

He was a three-term president of the New Voice Club of the Niagra Frontier and edited its newsletter. Like so many of us, he was passionate in his campaign against smoking

IAL SCHOLARSHIPS

THE IAL HAS A SCHOLARSHIP FUND FOR LARYNGECTOMEES TO ATTEND THE ANNUAL VOICE INSTITUTE.

The fund was set up with money donated by Mr. **Frank Batten**, a laryngectomee of considerable geenrosity, is called the Batten Fund.

To be eligible for a Batten Fund Scholarship all you have to do is demonstrate financial need, and not have received a scholarship before. You may use it to attend the Voice Institute as either a laryngectomee trainee who demonstrates good esophageal, TEP or electrolarynx speech and want to learn how to assist with speech instruction, or as a laryngectomee who wants to learn or improve his or her speech.

In order to provide the greatest

benefit to as many as possible the IAL normally will only pay for the room and the registration fee. However, it will consider additional funds for special cases who can demonstrate greater need. If you feel that you qualify, and would like to attend this year's Voice Institute, fill out the application on the back of this page, Page 4.

CORRECTION

In the January issue of the IAL News metntion was made of the IAL film CHECK THE NECK. No mention was made of the part played by **Howard Moore** in the making of the film. The film would not have happened without Howard. We are indebted

Batten Scholarship Application Form For Voice Institute

Please Print Clearly

I would like to apply for a scholarship to attend the Voice Institute as a Laryngectomee Pupil or as a Laryngectomee Trainee. (Laryngectomee Trainees must be well rehabilitated with a good voice and at least two years post-op.) I understand that the scholarships will cover registration fees and up to 6 nights lodging. Travel and meal expenses are the responsibility of the attendee, although some additional limited assistance may be available if requested.

Are you employed? _____ Where? _____

Annual Gross Income? _____ Number of dependents? _____

Have you ever attended an IAL Annual Meeting or Voice Institute? _____ When? _____

Would you share a room with another laryngectomee or pay for part of your room? _____
(This is not a condition of acceptance, but it could allow for additional scholarships)

If you require additional assistance for travel expenses please attach a separate request that clearly states your current rehabilitation status, your expectations from the Voice Institute, and an explanation as to why your financial status prevents you from attending without additional assistance. This information is required to insure that our limited funds are utilized in the best possible manner.

I affirm that it would be a financial hardship for me to attend the **Voice Institute** without financial assistance and I have not received a scholarship to attend a previous **Voice Institute**.

Please respond by June 15. Early responses are recommended.

Signature _____ Date _____

Name (Print) _____

Address _____

City _____ State _____ Zip _____

Phone _____ Email _____

Send completed form to:

R.E (Ed) Stone, Jr., Ph.D.
5921 Woodland Hills Dr.
Nashville, TN 37211
(Email: restone@home.com)

JOE MALLON WINS TWO AWARDS



Joe Mallon with 44 foot letter from Willow Glen High School in San Jose

The American Cancer Society recently awarded **Joe Mallon** of Santa Cruz its prestigious **Patient Courage Award**, given to one person each year in California. His accomplishments also earned him the **Hero in Education** award from the California Lottery, which was presented on TV by Melrose Place star Rob Estes in Los Angeles.

In 1994 Joe began volunteering for the American Cancer Society

doing laryngectomee visitations, “showing them how to make lemonade when life gives them lemons”. He served as president of the Santa Cruz ACS from Sept. 1997 to Sept. 1999. Joe has spent about 40 volunteer hours a week, speaking to over 40,000 students as well as adult smoking cessation groups. The Courage Award says in part: “He shares the lemonade with humanity. He instills in the students he teaches

a new understanding of the realism of tobacco use. Sharing his life’s story, he encourages them to make an intelligent decision as to whether they will use tobacco or remain healthy.”

Joe was a smoker for 53 years. After an onslaught of laryngeal cancer, prostate cancer,

emphysema, Raynaud’s disease and diabetes he is still alive and fighting for the lives of young people. The Education Hero Award says in part: “At age 78, long past the retirement age of teachers, he daily visits the classrooms to share with students what happened to him from smoking tobacco. His presentation has great visual and auditory impact.” “He continues his education by attending every available seminar and by religiously surfing the Internet.”

GEORGE ACKERMAN SPEAKS OUT

Some very important developments have occurred this past year. The IAL finally has got with the times, and with the work of **Dutch Helms** and his committee, the IAL has a web page. This web page is full of information that is beneficial for all laryngectomees. If you haven’t yet logged on I would recommend that you do so. You will not be disappointed.

The meeting in Reno was very successful and we showed a profit. This was mainly due to the work of **Jack Henslee** and the hard working group from California.

The IAL has also had some set backs this past year—due to many reasons we found it necessary to close the Indianapolis office. Our thanks is given to **Dr. Hamaker** who granted the space for no charge to the IAL and to **Mary Jane Renner** who ran the office without compensation.

It was with a great deal of regret that I accepted the resignation of our Treasurer Jack Keilsohn. Jack did a lot for the IAL and we do appreciate all the work that he did.

As with any organization we have had some growing



George Ackerman

pains. It was very easy when ACS was doing the bulk of the work. However, I believe we made the right decision to remain a stand alone association. Although we have had some problems there is nothing that we cannot master. As the oppressed have been singing for many years “We Shall Overcome”. We must move forward—Your directorate will do every thing that it can to get the job done and will continue to do the work of the IAL, the total rehabilitation of all laryngectomees throughout the world. We are truly International. We even have a Canadian as President.

The annual meeting in Nashville is going to be a great meeting. This gives us all a chance to learn and to cope with the alaryngeal condition. This is also a chance to meet old friends, as well as making new and lasting friendships. I urge you all to make the effort to be there. You wont regret it.

It is amazing what one learns at these very important functions. I have been to 16 meetings and am still learning and I have also been able to help others.

Hope to see you all there. *George Ackerman, IAL President*

CLASS ACTION LAW SUITS

Just a comment from an attorney about lawsuits. As a warning, this is a generalization and may not be totally accurate.

I have, however, defended against a few class actions.

Bringing a suit against big tobacco is an expensive thing. It takes money to fight money. This is one reason for class action suits. If the class is big enough the return can be substantial and therefore the attorneys get paid. And believe me, the attorneys that can handle this type of suit aren't going to be doing it out of the goodness of their litigious hearts.

Now, you don't necessarily "sign up" to take a class action. If a representative plaintiff or plaintiffs will bring the suit in their names and as class representatives. When and if a class is certified, then notice is given to the class members who can be reached, allowing them to stay in or opt out of the suit.

If the attorneys are operating on a contingency, they will get a percentage of the judgment or settlement. The percent that they take will typically vary depending on how far the suit progresses. Often the amount will start at 30%, go to 40% if there is a trial and jump to 50% if there are appeals. The process may be long and drawn out. When you are talking big money, you are talking big defense.

The fact that the lawyers are taking the matter on contingency does not necessarily mean that they are fronting the costs of the litigation. They are just postponing their fees. Costs include hiring experts, who aren't cheap, depositions, discovery, copying costs, all of which can run into some big bucks.



Terry Duga

LARYNGECTOMY ADVANCES

Actually things HAVE changed a lot in the last 40 years. The last 40 years has seen more aggressive attempts at using nonsurgical

treatments, such as radiation or combination radiation and chemotherapy, to avoid surgery completely. Also, there are now partial surgeries in which they can remove only a single vocal cord (hemilaryngectomy) or by which they remove only the epiglottis and other structures above the vocal cords (supraglottic laryngectomy). Both of these procedures are designed to avoid having a stoma, if all heals well and the patient learns how to swallow safely with the reconstructed mechanism.

If we have a little anatomy/physiology tutorial, maybe it will help to understand what the surgeon faces when trying to develop a viable alternative to total laryngectomy. Essentially what you have in the throat is two long tubes, or pipes running in parallel. The tube in the back is the esophagus that leads to the stomach for the passage of food. The tube in the front is the windpipe or trachea, which leads to the lungs for transport of air. The larynx or "voicebox" sits at the top of the windpipe and works as a valve. It is open to let air move from the mouth or nose down into the windpipe and to the lungs and then back out. But the larynx (the valve) has to be closed to keep food and liquid out of the windpipe when you swallow. (If you look at any of the BEFORE surgery anatomy drawings on the WebWhispers site or the InHealth site, it will help your understanding of what I'm talking about.) If the valve doesn't close properly and food or liquid falls into the larynx or the windpipe (aspiration), usually a person starts coughing or



Carla Gress

"choking". If too much food or liquid gets into the lungs you can develop pneumonia, airway obstruction, and you can "drown". For voice production, the vocal cords close, the air comes up from underneath them as you exhale and that sets the vocal cords into vibration. The vibration then makes the voice.

So for the various functions of breathing, swallowing, and voice production, the larynx has to open and close. When the total laryngectomy is performed, the larynx is "cut off" from the top of the windpipe. But it can't just be left it as an open passageway to the mouth or nose. You have to have a valve at the top of the windpipe to replace the valving action of the larynx - otherwise food or liquid would just fall into the airway. As you might imagine, it is very difficult to reconstruct or rebuild the valve. It has to be open for breathing, completely closed to prevent aspiration of food or liquid, and closed to produce voice.

The first concern is always to remove enough tissue to provide the best chance for cure of the disease, and this is done at the sacrifice of the voice and creation of a stoma. If they can perform a partial removal safely, maintain safe swallowing and a decent voice, and avoid the stoma, that's great. But if the entire larynx must be removed, the only way (currently) to allow you to safely swallow again, is to disconnect the windpipe from the mouth by taking the windpipe and ending it in the neck (stoma). That way you can never "choke", because there is no connection between the mouth and the windpipe.

There are many bright minds around the world who are trying to find a better way, but the complexities of the larynx and conflicting demands for respiration, swallowing and speech make it an extremely difficult organ to rebuild or replace.

Dr. Carla Gress

Registration Form
IAL Annual Meeting or Voice Institute
Hear Our Voices
Music City -2000

NAME(s) _____

STREET ADDRESS _____

CITY _____ ST _____ Zip _____ COUNTRY _____

HOME PHONE _____ WORK PHONE _____ EMAIL _____

Please check below. Please DO NOT register for both the AM and the VI unless attending with VI registrant

Annual Meeting Registration: _____ Laryngectomee: Yes _____ No _____ \$60 per attendee

OR

Voice Institute Registration: ST: _____ LT: _____ VIP: _____ Student: _____

Voice Institute Fees: \$400 (ST's) \$75 (LT's) \$75 (VIP's) \$100 (Student)

Total Amount: _____ Visa/Mastercard are accepted:

Card Number: _____ Exp. Date: _____

Card Holder Name: _____

Card Holder Signature: _____

Mail Annual Meeting registrations to:

Hugh Hankins
2035 Lebannon Road
Lebannon, TN 37087
(615) 449-2541

Mail Voice Institute registrations to:

Ms. Lisa Proper
(Attn: Ial/Vi Registration)
938 Bayside Bluff Rd.
Switzerland, Fl 32259
Fax: 904-953-2458 (Mayo Clinic)

Registration Information

The **Annual Meeting** dates are: **Thursday August 17- Saturday August 19.**

The Meet & Greet reception will be held the evening of August 16th (Wed) and the Board of Directors will meet the morning of August 20th (Sun). The Annual Meeting registration fee is **\$60** per attendee. This fee enables you to attend all Annual Meeting functions, to include the Saturday banquet. You may also attend Voice Institute sessions as an observer only as long as space is available. This means that you will not receive any Voice Institute handouts or individual speech training.

The **Voice Institute** dates are **Tuesday August 15- Sat. Aug 19 for STs and LTs, Thurs. Aug 17-Sat Aug 19 for VIPs**

The 2000 IAL Voice Institute will accept registrations in four different categories:

- (1) Speech Pathology Trainees (STs): Registration fee of **\$400** for equivalent of 5+ days of instruction and receipt of a demonstration model TruTone artificial larynx.
- (2) Laryngectomized Trainees (LTs): Registration fee of **\$75** (limited scholarships available)
- (3) Voice Institute Pupils (VIPs): Registration fee of **\$75** (limited scholarships are available)
- (4) Graduate Student: Registration fee of **\$100**

These fees enable you to attend all Annual Meeting functions, the Saturday banquet, and /or the Voice Institute

PLEASE NOTE register for the Annual Meeting OR the Voice Institute unless attending with VI registrant.

HOTEL The Sheraton Music City Hotel, Nashville TN 777 McGavock Pike, Nashville, TN.

For hotel reservations call: **(800) 325-3535** or **(615) 885-2200.**

Room rates are \$99 (single or double) and are good from Aug. 12-22. You must tell them that you are with the IAL to get this rate.

A free shuttle service is provided from the airport (You need to call the hotel after 3 PM arrivals). It is strongly recommended that you make your reservations early. The guaranteed rooms in Reno sold out last year because of record attendance. Nashville is expected to be a very popular site as well.

IAL News
19 Tilden Circle
San Rafael, CA 94901

Non Profit
Org.US Postage
Paid
Mail-Com

President: George Ackerman
Winnipeg, MAN

Vice Pres. Jack Henslee
Stockton, CAL

Secretary Barbara Nitschneider
Carey, IL

Treasurer Jack Henslee

Pro Tem. Stockton, CAL

Editor Wayne Baker
San Rafael, CAL

The IAL News is published by
the International Association of
Laryngectomees

IAL OFFICE MANAGER APPLICATIONS

The paid position of IAL Office Manager is being established, and applications are being solicited. The Office Manager will provide services from their home until a permanent site is located.

Frank Morgan will continue to run the IAL office until a permanent office manager is found.

If you are interested in applying for this paid position you may communicate with

George Ackerman
12 Beaumont Way
Winnipeg, MB R3T 0N1
Canada

DUES REMINDER

IAL DUES
CAN BE SENT TO:
JACK HENSLEE
2137 HACIENDA DR.
STOCKTON, CAL
95269

INTERNET SITES

The IAL Web Site:
<http://larynxlink.com>
WebWhispers
<http://www.webwhispers.org/>

IAL BOARD SEEKS APPLICANTS

The IAL is, like the Marine Corps, always looking for a few good people to serve on the Board of Directors. These are working positions which receive no compensation and seldom have expenses paid, but it looks good on your resumé (remember those?). Like any organization, we need periodic infusions of fresh perspectives and new ideas. If you would like to apply you may request an application from:

JEWELL HOFFMAN
105 D'EVEREUX
SLIDELL, LA 70461

We look forward the hearing from
YOU