Two hundred and twenty registered participants attended the International Association of Laryngectomees 58th Annual Meeting and 49th Voice Institute held from June 24-27 in San Mateo, California. There had been concern that the Swine Flu scare and the state of the economy would keep the numbers down.

Congratulations are in order to Vice President Bob Herbst and the members of the Annual Meeting Committee, Voice Institute Director Dr. Jeff Searl, Executive Director Susan Reeves, IAL officers and Board of Directors, Auxiliary, speakers, vendors and local club sponsors for making the Meeting and Institute a triumph. The Nu Voice Club of San Francisco was the host club this year, and was assisted by the Marin, San Mateo and Santa Rosa clubs.

The Annual Meeting kicked off on Wednesday night with the traditional Meet and Greet reception, sponsored this year by Inhealth Technologies. It was very cool as the breeze blew from the ocean in the evening, but built-in heaters in the patio area let all know that this was common for this Northern California climate.

The opening session on Thursday morning featured co-inventor of the TEP prosthesis and puncture surgical procedure, Mark Singer, MD, as the keynote speaker. Rehabilitation case studies and a medical panel followed. Sixteen sessions were offered in the afternoon including on all three major methods of alaryngeal speech, and topics ranging from swallowing issues to those of special interests to veterans and spouses.

On Friday morning a second general session was scheduled for both AM and VI attendees. It featured Itzhak Brook, MD. Dr. Brook (see article on page 4) is a medical doctor who faced his own battle with larynx cancer and becoming a laryngectomee. Dr. Brook is a new voice speaking out for the improvement of medical care generally, but especially that for larynx cancer patients.

Sixteen additional sessions including one on swimming and other water activities were available on Friday. And the Voice Institute traveled to Stanford University for the hands-on clinic where laryngectomee volunteers received professional care including free TEP prostheses changes, the opportunity to try hands-free valves, etc. Special thanks to ATOS Medical and Inhealth Technologies which provided the clinical materials, product samples and technical assistance.

Friday evening was topped off by a “Fun Evening” featuring karaoke singing, a return of the “California Girls” and more fun activities.

Saturday morning provided attendees with a choice of nine sessions while the Delegates Meeting took place (see article on page 3). Saturday evening provided the climax of the Annual Meeting with the reception, banquet and dance. We had what many remarked was the best DJ ever as many attendees partied and danced late into the evening.

Remembering Beautiful San Mateo

In the pool

Joe “The Pimp” Marasco and the “California Girls”

Saturday morning provided attendees with a choice of nine sessions while the Delegates Meeting took place (see article on page 3). Saturday evening provided the climax of the Annual Meeting with the reception, banquet and dance. We had what many remarked was the best DJ ever as many attendees partied and danced late into the evening.

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Delegates Meeting

Thirty-six clubs were represented at the Delegates Meeting held on Saturday, June 27, 2009. Thirty-one U.S. clubs were joined by those from five other countries. Reports were given by President Tina Long, Vice President Bob Herbst, Treasurer Sapp Funderburk, Secretary Terrie Hall (providing the Auxiliary report), and the chairs of nine standing and special committees also provided progress reports (see the Minutes on the web site, www.TheIAL.com).

Board members answer questions at Delegates Meeting

Four Bylaw amendments were presented. One, which called for the removal of the table of club dues from the Bylaws failed, although another to raise club dues passed. An amendment which sought to remove the immediate past president from automatically serving on the Board passed, while another to reduce the size of the Board to eleven members failed.

Two candidates for Board positions ran successfully for re-election (Tom Herring and Philip Doyle), and two new individuals also won (Torbjorn Bull-Njaa, and Wade Hampton). Bob Herbst was elected to the post of Vice President.

Mary Jane Renner administers the oath of office to Board members Torbjorn Bull-Njaa, Tom Herring, Wade Hampton, Philip Doyle, and Vice President Bob Herbst.

Check your Contact Info

The U.S. club listings are now on the new web site. Please review your club information on www.TheIAL.com under Club Resources and then Club Search. Click on the map on your state. The IAL clubs listing is the method many new laryngectomees use to connect with us all. So please send corrections to: tomherring@embarqmail.com. Thanks to Database Manager Tom Herring and Webmaster Ron Le-Clair who perform this important work.

Breaking News

It’s Louisville in 2010!

Mark your calendars right now and plan to join us at the 2010 IAL Annual Meeting and Voice Institute in the Louisville, Kentucky area. The Annual Meeting will begin on June 17th and goes through the 19th. The Voice Institute begins one day earlier on the 16th.

The headquarters hotel is the Holiday Inn Lakeview in Clarksville, Indiana, which is right across the Ohio River from Louisville. At least one of the hosting local clubs is the Hoosier Anamilo Club.

Plan now on joining fellow laryngectomees, caregivers, medical personnel and vendors in another terrific IAL AM/VI in the heartland of America.

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

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

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

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

As a charitable organization, as described in IRS 501 (c) (3), the International Association of Laryngectomees is eligible to receive tax-deductible contributions in accordance with IRS 170.
Rediscovering My Voice
Itzhak Brook, MD, MSc

I love to teach. As an infectious disease physician for more than 35 years, I have spent many hours with medical students and physicians, making rounds, discussing patients, and reviewing diagnoses. It has been so gratifying to see new and future physicians learn the art and science of medicine.

When I gave my first lecture 30 years ago, I recall being self-conscious of my Israeli-inflected accent. Would I be able to hold the audience’s attention and clearly explain my research? But after delivering scores of lectures, I grew to love the back-and-forth exchange with my colleagues. I became a better physician and researcher by responding to their challenging questions. Most important, I felt like I made a difference in the lives of thousands of patients by discussing my research in ear, sinus, and tonsillar infections. Now, I view lecturing as a critical component of my career, and I try to accept every opportunity I can to share my work.

Three years ago, when a bothersome sore throat led to my diagnosis of hypopharyngeal squamous cell carcinoma, I was shaken to my core. After all, neither smoked nor drank alcohol, two major causes of this disease. But my physicians anticipated that treatment would have no lasting adverse effects and, indeed, I was able to function—and to speak—normally after removal of the tumor and radiation therapy. Unfortunately, a recurrence two years later necessitated more drastic measures. After several unsuccessful operations to remove the cancer while endeavoring to salvage my voice, my surgeon told me that my best chance for a cure was a total laryngopharyngectomy: complete removal of the larynx, including the vocal chords. Speaking—let alone respiration, swallowing, and coughing—would be forever changed. At the time, I didn’t think of what it would mean to breathe through a hole in my neck forever. Even though I might never teach, lecture, or speak in public again, I didn’t hesitate. For me saving my life was more important than saving my voice.

Weeks of convalescence without being able to utter a word were, at best, supremely frustrating. And yet, like many others who have undergone this radical procedure, I attempted to fashion a new “voice” with the help of dedicated speech pathologists and supportive fellow patients who had also undergone laryngectomy. I learned how to force air into a small prosthesis that connected my upper airway to my reconstructed throat, thus enabling it to vibrate, imitating the functions of vocal chords. But the result was disappointing—a rusty whisper that barely resembled my former voice. Speaking became a physical challenge: I had to use my chest muscles and diaphragm to intensely force air into the prosthesis; sudden coughing was an impediment to conversation; and the speaking device easily clogged and became useless. It was difficult to express emotions or alter the intensity of my speech. My lifestyle also changed: I avoided noisy restaurants, large gatherings, and many other social situations. People often hung up when I used the telephone; one person later apologized for thinking I was prank caller.

I badly wanted to use my voice as I did before, but I had serious doubts. I wasn’t sure I would ever be able to speak in public again, let alone return to teaching and lecturing.

I was both elated and terrified when I gave my first talk on respiratory tract infections some ten weeks after surgery. While having a microphone helped, I understood that my lecturing abilities would be forever limited by the quality of my voice, the need to express myself with fewer words, and the ever-present fear that a technical glitch with the prosthesis would render me speechless. I was well aware that, given the choice, organizers will usually select someone else without speaking difficulties. As depressing as this was, I felt unable to change the situation.

Recently, as it happened, I discovered an expertise in an area where my impaired speech is an asset rather than a handicap. Several months ago I was asked to give a lecture about my personal experience with throat cancer. In the audience were the surgeons of tomorrow as well as my fellow patients who had had their larynx removed. No longer the detached researcher, I spoke as a patient with a potentially fatal illness and described the challenges I face every day. I talked about how my impairment made me extremely vulnerable and how the compassion, empathy, and concern of treating nurses, speech therapists, and physicians could make a positive contribution to their patients’ recovery.

The applause I received at the end of my talk was not for the quality of my voice but for the content of my words. The surgeons were grateful to hear what issues are important to those under their care. They told me they felt inspired to meet a patient who has recovered to the extent of being able to present a lecture again. The patients who had undergone my procedure not only benefited from hearing my story, but realized that their own experiences and feelings are shared by others.

Since that time, I have been asked to give similar talks to local and national conferences of medical practitioners and to individuals who have undergone laryngectomy. My new audiences are eager to hear from a physician who has been “on the other side.” Most of all, I feel invigorated by the positive responses to my presentations. I have finally found a new mission that turned my weakness into strength and where a whisper has the impact of a shout.


(Note: Dr. Brook lives in Washington, D.C. and was a featured speaker at the IAL’s 2009 Annual Meeting in San Mateo, California this past June.)
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My 3 and 1/2 Minutes of Fame

By Tina Long, IAL President

This past June our local club, The Greater Atlanta Voice Masters, held a mini voice institute. It was a huge success, by the way, thanks to our President, Janice Hayes, Board member Boris Jovanovic, and our favorite SLP, Alma Owens.

I thought it would be a great opportunity for our club, our members and for the public to hear our different voices aired on our local National Public Radio Station, WABE. Our NPR station has a program called “Atlanta Sounds” which records all the different sounds found in our area.

The producer of that segment e-mailed me and informed me that he was unable to schedule anyone to attend our mini voice institute, but he had forwarded my e-mail to the producer of “Radio Story” aired during the weekday noon hour.

For a month I wrote and Dana edited, and finally we put together a story that could be read in 3 ½ minutes. Then came the day I got to go to the studio and record my own “Radio Story.”

At first I was concerned that my voice would not be understandable over the air, Dana nixed that right away. I also mentioned that I didn’t want the sound I make when I take a breath heard over the air; she explained that hearing me take a breath was part of my “Story.” So I soldiered on.

For an hour I felt like a real radio DJ or recording artist. Dana put me at ease and I quickly became a star, at least in my own mind. I told my story, not unlike many other laryngectomees, well, maybe except for the part about taking up cello since I would not be able to play the bassoon after my surgery.

Now I wait for Dana to do her “producer thing,” and when she is finished she will let me know when I will be on the air. My story and photo, will also be on WABE.org.

I never had any opportunity to be a public speaker until after my laryngectomy. Funny how the universe works!

Speech Program Available for iPhone

An application is available for the iPhone which can speak words, phrases and sentences for those who have difficulty speaking. A free “Lite” version is now available from Apple iTunes or downloaded from other sites. An expanded commercial version is planned which will have additional features.

The name “Locabulary” was chosen since the intention was that the program work together with a GPS program and to provide words and sentences which match your location such as a school, hospital, coffee shop, fast food restaurant, etc.

The idea for the program grew out of discussions between a pediatric rehabilitation medical doctor who teaches at the University of Alabama at Birmingham, and programmers. PUSH, the design firm, is a group of Auburn University-educated engineers and designers. The program was funded by a grant from the Alabama Council for Developmental Disabilities, a division of the Department of Mental Health. WebWhispers President Pat Sanders, who lives in Birmingham, Alabama, has been helping the designers by making recommendations helpful to laryngectomees.

Even though this iPhone-based program will not replace larger and dedicated portable text-to-speech equipment such as the Litewriter, it should be a nice addition to what is available and also a simple and inexpensive tool for those laryngectomees who own iPhones who are temporarily or permanently without voice.

FDA Monitors Tobacco

On June 12, 2009 Congress passed legislation granting the Food and Drug Administration jurisdiction over tobacco products, repealing federal pre-emption of state and local regulation of tobacco advertising, and requiring graphical warning labels on tobacco products.

The FDA is expected to ban the use of flavorings in cigarettes which were designed to attract younger smokers, and also to require that manufacturers list all additive ingredients contained in them.

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**Beauty Queen**

Julie Deleemans of Canada is a beautiful young woman. So it came as no particular surprise that out of thousands of girls from across Canada who applied that she would be among the 45 chosen to compete for the title of 2009 Miss World Canada. The winner goes on to the Miss World competition in South Africa at the end of 2009. The competition was incredibly tough and Julie made it to the top 20 semi-finalists, but that is as far as she got. This time.

What is unusual about Julie is that she is a laryngectomee.

A native of Ontario, Canada, Julie was diagnosed at the age of 18 with a stage four tumor and had to undergo laryngectomy surgery along with radiation and chemotherapy. The cause of her cancer is unknown since she had none of the known risk factors.

Raised on a horse farm, she began riding when she was two years old, and later began to compete. She has been competing in horseback riding events ever since.

Many in the laryngectomee community became aware of Julie when she wrote an e-mail to the WebWhispers group seeking to contact any other young people who were laryngectomees. While we laryngectomees are a small minority within the general population, young ones are an even smaller minority within that group. Julie, like most of us, wanted to connect with people her own age who understood her problems as both a laryngectomee and young adult. Julie later wrote asking members of the WebWhispers community to vote for her in “People’s Choice” part of the Miss Canada competition.

A TEP speaker, Julie is a student at Fanshawe College where she is working towards a diploma in Medical Radiation Technology. This interest in a career in the medical science field is the direct result of what she describes as the life changing experience of becoming a laryngectomee. She believes that her experience in being treated for cancer and becoming a laryngectomee has helped her discover and direct her passion for helping others in need.

Her love of horses and desire to help others resulted in her volunteering as an Animal Aide, helping with the Therapeutic Horseback Riding for Children and Adults with Special Needs program, and helping out at a veterinary clinic. She also plans to volunteer with the Canadian Cancer Society.

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**“Panic Stations” Down Under**

Colin Bolton from Sydney Australia had a little scare this past July. He tells his story:

“Bit of a panic on the home front last week. I was nebulising when suddenly I went into a really bad coughing fit and was struggling to breathe. I staggered into the bathroom ready to signal Wyn (his wife) to phone an ambulance. In the bathroom I saw I had blood coming from my stoma!

I could only think that a foreign object had got down there but could not think what---I always wear a cover and had done nothing untoward (or so I thought).

I had enough sense to lie face down on the bed cross wise with my head almost touching the floor while Wyn gave me a few hearty slaps on the back.

Suddenly midst a coughing fit, things eased and looking down I saw I had coughed up the end of a Ventolin capsule that somehow had got into my nebulisor mask and which I had inhaled.

Why am I telling you this? We hear of (and see) people who won’t wear a cover. This poignant episode reminded me always to wear one and what the consequences of getting a foreign object into the stoma can do.

---

**Easier Lung Cancer Test**

University of Texas M.D. Anderson Cancer Center recently reported the results of a study which demonstrated the effectiveness of testing for lung damage caused by smoking by swabbing the inside of the mouth. Cells lining the mouth apparently reflect the molecular damage that smoking also does to the lining of the lungs.

This test could spare patients and those at risk of lung cancer from more invasive and painful procedures used now, according to Li Mao, MD. Previously it was necessary to obtain the sample through bochoscopy, or going down into the lungs themselves to obtain a sample. The presence of the damaged cells can be detected long before the cancer develops, according to the researchers.

**Quotable Quote**

Actor Michael J. Fox was diagnosed with Parkinson’s Disease in the early 1990s. Despite its continued and growing presence in his life he said, “I give the disease what it needs and get on with my life.”
Sudden Loss of TEP Voice

By Carla DeLassus Gress, ScD, CCC-SLP

When someone has had a good voice and suddenly loses it, or starts straining to talk, the most likely scenario is that the prosthesis is too short or improperly inserted, causing the puncture to start to close on the esophageal side. As the esophageal tissue starts to grow back together, less airflow is allowed through the puncture, so the voice will start to require more effort and will not be as loud.

Eventually the puncture may close on the back side (think of a tunnel that has collapsed at the far end). As the puncture starts to close, it will cause the prosthesis to push forward, so it will start to stick out in the trachea, making you think (incorrectly) that it is too long. If the prosthesis is removed, and the puncture dilated so that the tunnel has once again been re-established and the voice is restored, a very careful measurement needs to take place to be certain that the correct size is determined.

If the dilation is difficult or rushed, it is more likely that you won’t get a good measurement since the puncture isn’t fully stretched. The puncture is dilated and ready for prosthesis insertion when the dilator or catheter, sized 2FR larger diameter than the prosthesis you want to use, slides easily in the puncture tract. If it is tight, it is not ready.

If the prosthesis is replaced with a shorter one because it was thought that the old prosthesis “looked” too long, or the measurement wasn’t taken with a fully dilated puncture tract, or if it is not fully inserted all the way through to the esophagus, the esophageal tissues will once again start to close up the puncture, since the prosthesis is not keeping the puncture open on the back end. The voice will be lost again, usually in a matter of hours.

Why does all this happen in the first place if a person has been wearing the same size prosthesis for a long time, and not had any problems? Sometimes swelling of the tissue occurs temporarily due to an infection, inflammation or trauma. Sometimes granulation tissue can start to grow on the esophageal side. Sometimes it can be a cancer recurrence, but if this is the case, it is unlikely that dilation and replacement of the prosthesis will re-establish the voice.

If you start to lose your voice after having a good voice, see your SLP and/or your MD. It is an urgent problem (but not an emergency) because you may end up losing your puncture and have to be surgically repunctured if the issue is not addressed on a timely basis. If you change your own prosthesis, and have had proper instruction, I think it is a good idea to have a set of catheters in graduated sizes, so that you can get something in the puncture to keep it open if and when things like this start to happen.

90 Days in Jail

It’s been 9 years since it happened, but one laryngectomee has not forgotten his a run-in with law enforcement. While traveling in Dooly County, Georgia, a laryngectomee pulled off the highway for a quick nap. A tap on the window by a sheriff’s deputy awoke him and he was asked to take both a sobriety and breathalizer test. He explained to the officer that he couldn’t blow into his breathalizer instrument and he was promptly arrested for refusing to take the test.

To make matters worse the local circuit judge would not be back for 90 days and the laryngectomee did not have the means to bail himself out. When he finally went to court the judge threw the case out, but he had already served a tough sentence over a misunderstanding and by not being able to make bail.

In many states any statement which can be reasonably interpreted by police as refusing to take a breathalizer test is considered a virtual admission of drunk driving and grounds for arrest. The take-away lesson from this story is that laryngectomees never want to give police the impression that they are refusing to take sobriety tests. It is a pretty safe bet that the police officer will not know about your unique breathing system and may interpret any reluctance to take the test as your trying to put something over on him or her. It is therefore good advice to agree to take the test, but explain that you breathe only through the hole in your neck. Some states also allow a blood test as an option which you can volunteer to take. Being completely cooperative is the key to avoiding misunderstandings, tickets, or worse.

A Lary “Souvenir”

We would suspect that virtually all laryngectomees remember the date of their surgeries.

But former IAL BOD member John Ready from California has a daily reminder in the tattoo he got commemorating the day he lost his larynx. John’s club was a sponsor of the 2009 AM/VI.
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Those Gone Remembered

At the WebWhispers Banquet in San Mateo Jack Henslee read a poem by Frank Morgan. The choice of the poem was based on its reflection of the time period when WebWhispers was created by its founder, David “Dutch” Helms. Frank, who was a long time member of the Tidewater (Virginia) Lost Chord Club and WebWhispers, died from lung cancer in 2004.

The Third Voice

By Frank Morgan

Mario Lanza became my idol, when I was very young
I tried to emulate his voice, knew every song he’d sung.
In literature, Keats and Shakespeare I studied very hard,
My voice would swell and passions tell, as I would quote
the Bard.

But reading books and learning much weren’t total education
For music’s art would play its part, I sang with great elation.
In prose or verse, or tenor soaring, my voice was my ID
The accent sweet, the tone unique, told all that I was me.

Then Cancer struck that fragile chord, not just once but twice!
Eating away, eroding, burning. Rewarding the smoking vice.
Cobalt beams would kill it dead, that very first time around,
Second time, the surgeon’s knife, and I’m left without a sound
Desperation, fear and dread filled each day of my new life
As I tried ways to find out how to overcome my strife.
I had to learn to speak again, but how when on ones own
I was a freak, no one to teach, this silent fool...alone

Then slowly, slowly words came out, a drone for sure, it’s true
But language graced these lips again, so how could I stay blue?
I’d used a tool, vibrating source, to imitate a voice,
Then I discovered gulp and speak......I had another choice

Where once I had a single voice, I find I now have three!
The third came with my keyboard “chord” and screen of my PC.
The latest, loudest of them all, gives power to speak to nations,
And sends out notes of hope and cheer to newer cancer patients.

The message that I’ve tried to send, in this short history,
Is one of faith and hope to all who sadly follow me.
The surgeon’s knife will take but flesh, and leave you with your life,
So take that gift and use it well, tell others of your strife...
For we are teachers, you and I, all laryngectomees...
Who’ve proved to all that we have beat the dread Big C disease.

New IAL Brochure is Ready for Distribution

Thanks to the generosity of ATOS Medical and Griffin Laboratories which paid to print them, the newly revised IAL brochure is available for distribution. Clubs, clinicians, and others should order as many as they believe they will use within a 2 to 3 year period.

The full color brochure provides complete contact information for the organization, an explanation of its purpose/goals/governance, description of the Annual Meeting and Voice Institute, and an explanation of the three major forms of post-laryngectomy speech. It also describes the services offered by many clubs and provides a link to publications of the IAL including the draft of “First Steps.” “First Steps” is a booklet that covers most aspects of laryngectomee rehabilitation and is available to download from the IAL web site.
According to the European Alliance for Access to Safe Medications, 62% of medicines purchased from sources on the Internet are either fake or substandard (including those for serious illnesses). By itself, this fact would seem to indicate that the benefits of any lower costs would clearly not be worth the risk.

**Fake Drugs Alert**

There is no uniform program in the United States that supplies electronic equipment to individuals who need assistance in communicating over the telephone (including laryngectomees.) The different state programs vary widely from excellent ones which provide laryngectomees with an electronic artificial larynx and other equipment, to those which provide nothing.

Those readers who live in the U.S. can find out what your state provides at this Internet address: http://www.tedpa.org/interiorPage.php?pageID=1

We also hope that individuals and clubs in the U.S. will use the information contained on the TEDPA page for your particular state to lobby your state agencies and government to work to make sure that no laryngectomie falls through the cracks and is trapped in silence.

What does your State offer laryngectomees?

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Quotable Quote--A Matter of Priorities

Considering the amount and variety of supplies and equipment available to laryngectomees some claim to be “necessary,” Dr. Zilpha Bosone, SLP, stated that “the basic needs for a laryngectomee are a satisfactory method of communication and a stoma cover worn 24/7.” A “master clinician,” Dr. Bosone has served on many Voice Institute faculties. Recently retired from working at a Veterans Administration hospital, she lives in Virginia.

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If your club intends to place an order for the brochures please also request a 2 to 3 year or more supply of the postcards provided to new laryngectomees to subscribe to the IAL News or to use by club members for changes of address. After receiving the new postcards please discard any old ones which have any address other than the new permanent one in Atlanta, GA. Also please discard any copies you may have of the previous brochure since the contact information has changed.

Place your orders specifying the number of brochures and postcards needed by writing to the IAL, 925B Peachtree Street, Suite 316, Atlanta, GA, 30309, phone toll-free at 1-866-425-3678, or e-mail to IALHQ@TheIAL.com

Thanks.

Dr. Bosone

www.TheIAL.com
Local Club in the Spotlight

Tri State Nu-Voice Club

It will probably come as no surprise that the Tri-State Nu-Voice Club of Joplin, Missouri, gets its name from its location. Just a short drive from both Oklahoma and Kansas, it draws members from all three states. Indeed, the current president, Betty Labigang, lives in Oklahoma.

Marlene Hayes, formerly of the Wichita, Kansas, club, thought that the story of a relatively new club member, Ron Leek, would serve as a model of rapid and constructive rehabilitation. Below, Ron Leek, who Marlene describes as a “go-getter,” tells his story.

My Laryngectomy

By Ron Leek

On December 14, 2007 I had my laryngectomy. I had lots of time on the Internet beforehand, reading all that I could about my impending surgery. I read about everything that was going to take place and how I was going to be (physically and mentally) after surgery.

Everything went very well. Surgery didn’t last as long as had been anticipated and I was only in ICU 17 hours instead of several days.

Three days after surgery I was trying to learn to talk with my electro-larynx. I was tired of writing everything down for nurses and friends. My doctor and I had decided before surgery that I would use an electro-larynx to communicate with.

After a week I was home, I had learned to feed myself through a feeding tube connected to my nose. A week later I had the staples and feeding tube removed. Getting the feeding tube out was an experience for sure. That afternoon I was driving again, a great feeling, not having to depend on anyone to drive for me.

A couple of more weeks I was in a support group, the Tri State Nu-Voice Club in Joplin, Missouri. I received so much support from Betty Labigang and the great group. I really learned a lot. And then there were the radiation treatments. No chemo. I had six weeks, five days a week of radiation. I did real well until the last two weeks. I was burning inside and out, but I survived. During this period I started going to the Farmer’s Market to get fresh vegetables. While at the market children started following me around to listen to me talk. They all thought it was so cool. So to me the name of “Ronnie the Robot” was born.

The kids wanted to know what happened to make me talk so funny. I explained to all of them and some understood and some didn’t, but they thought it was cool being around me. I also had adults interested in my story and what I had gone through.

In November 2008 I was asked by the American Cancer Society and a TV station here in Joplin if I would be part of a documentary about smoking and cancer. I was very willing to be part of it. I figured that maybe, just maybe, someone would see it and quit smoking.

The video was very well accepted by the public. To this day I still have people coming up to me and saying how much they enjoyed the video. I know a lot of teens have seen it and this really make me feel good; at least they have now seen one thing that can happen from smoking.

One question that is always asked of me by so many people: “Did you ask God why he did this to you?” My answer is: “God did not do this to me, I did this to myself. God brought me through it and gave me a new ministry in life, and I am enjoying that ministry.”

I didn’t lose my sense of humor and I smile and joke a lot. I am 67 years old and so glad to be alive.

Top Ten Highest Larynx Cancer Rates by Country

According to the International Agency for Research on Cancer the highest incidences of larynx cancer four countries per 100,000 individuals:

<table>
<thead>
<tr>
<th>Country</th>
<th>Number per 100,000</th>
</tr>
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<tbody>
<tr>
<td>1. Hungary</td>
<td>181.9</td>
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<tr>
<td>2. Belgium</td>
<td>152.4</td>
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<tr>
<td>3. United States</td>
<td>142.6</td>
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<tr>
<td>4. Croatia</td>
<td>137.8</td>
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<td>5. United Kingdom</td>
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<td>6. Canada</td>
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<td>9. Poland</td>
<td>127.4</td>
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<tr>
<td>10. Czech Republic</td>
<td>123.3</td>
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</tbody>
</table>
If you ever questioned the value of a hospital visitor, local support club, state organization, WebWhispers, or the IAL Annual Meeting, you need to read the quote below. Or if you ever thought that laryngectomees helping laryngectomees is obsolete and no longer needed, you might want to read this e-mail from a new laryngectomee:

“This is all new to me. I just had a laryngectomy March 4th and this has really been an adjustment for me. I have had to deal with loneliness and rejection from friends that no longer want anything to do with me now. They feel uncomfortable around me.

Yes, I am different now, but I am still the same person with the same personality, but they can’t see that. It is like when they were with me they were embarrassed to be seen with me.”

Exercise Reverses the Effects of Mental Aging

According to a recent article from the Wall Street Journal the key to keeping mentally sharp may turn out to include aerobic exercise (the kind that gets your heart rate up).

We often associate the aging process with a long slow decline in our mental abilities such as memory and the ability to learn new things. According to the research, not only has science found something which benefits mental health, but is generally beneficial to overall health.

Before beginning an exercise program we are advised to check with our doctors.

To Stop a Sneeze

We laryngectomees still from time to time feel a tickle in our noses and will sneeze. But it does not work since a sneeze is a forceful and rapid exhalation of air that is meant to blow out whatever caused the tickle in the nose. But now the air is blown out our stomas and not our noses, so the sneeze no longer works.

If you are fast enough you can stop most sneezes by quickly grabbing your nose between your fingers and squeezing it and wriggling it around. This tends to dislodge whatever thing was vibrating in the nose that triggered the sneeze reflex. Try it.
Former IAL President Jack High died June 28, 2009 at his home in Lafayette, Indiana. He was 86. Although he worked as a salesman, Jack was the consummate entertainer. He served during WW II in an Army band and entertainment unit, and while at Purdue University he was a member and manager of the university glee club which sang at the inauguration of President Harry Truman. He was a reed player with symphony orchestras, big bands and many local combos.

He was choir director at his church and founder of the Lafayette Civic Chorus and a performer and musical director for Gilbert and Sullivan operettas. A fan of the Purdue Boilermakers, he worked as an usher/security for men’s and women’s football and basketball for more than 40 years.

Jack became a laryngectomee in 1960. His wife, Dorothy High, stated that Jack lived a long and full life after cancer. He was active in the IAL including as a presenter at a laryngectomee symposium in Tokyo. He served as IAL President from 1980-82.

Former IAL President Frances Stack remembered Jack as “being extremely talented. He could play anything on the piano. He could also act. He always had a lead role in Jan Del Vecchio’s elaborate fun shows. He was also a comedian! He loved to joke and act crazy to make people laugh. He was very talented and played a lead role in governing the IAL. When you think of ‘great guy’ you can remember Jack High!” Dr. Shirley Salmon remembered that he ran the IAL meeting with dignity and accuracy and always in line with the recommendations of the Parliamentarian.

Former IAL President Mary Jane Renner remembered that his love of music “carried over to Jack’s delight in IAL Annual Meeting singalongs and fun shows. One of the roles that I remember was as ‘King of the Road’ in one of the fun shows written by Jane Del Vecchio--she wrote the role with Jack in mind!” Jewell Hoffman wrote, “As President of the IAL, he was a brilliant example of the right mixture of intelligence, leadership, compassion and playfulness.”

Our condolences to Jack’s family and many friends.

Jack High

In flushing your TEP prosthesis use warm (not hot) water instead of water which is cold or room temperature. In addition to doing a better job of cleaning the prosthesis Dr. Itzhak Brook (see article on page 4), believes that it extends the life of the prosthesis.

Tip
What Do You Miss Most Since Becoming A Laryngectomee?

The question about what we miss most since becoming laryngectomees originated as an e-mail exchange among some of the members of the Internet-based laryngectomee support club, WebWhispers. It generated lots of responses including some from larys who insisted on changing the topic from losses to the positive side of becoming laryngectomees, or at least to balance the negatives with positives. Here are some of the responses (edited for length):

- Let’s face it, we all miss talking, eating, and being able to do the things we used to do before our surgery. I am sure that everyone has something they miss, the ability to make speeches, the ability to swim like they used to do, the ability to communicate with others as they did before surgery. (Don Claxton, Chandler, Arizona).
- Laughing out loud! (Carol Matson, Capistrano Beach, California).
- I miss being able to breathe well enough to play golf, or walk up a hill from my favorite fishing pond without gasping for air. (Bob Keiningham, Broken Arrow, Oklahoma).
- I used to sing backup for a local country band, but that’s out. I miss it. (Bill Larson, Las Vegas, Nevada).
- What I miss most is canoeing. I guess it could fall into the swimming category since it is the fear of drowning that keeps me out of my canoe. Last year we rented a cottage on the shore of Lake Superior. With the cottage came the use of a canoe and kayak. It took me three days to get up enough nerve to get in that boat. Once in, I slowly paddled out about 50 feet from shore. There I realized the depth of water was well over my head and the waves made the canoe very unstable. In days gone by, I’ve capsized several times. Usually, I either swim to shore or cling to the overturned canoe until I can correct the situation. Now that I breathe a little differently, I quickly lost my nerve and returned post haste to shore and safety…. (Len Bougie, Minesing, Ontario, Canada).
- What I miss the most is- BEING ABLE TO YELL- at husband, kids, dogs. I still have an Irish temper, but it’s harder to express, but I do pound on the table sometimes! All in all though, I do almost anything that I want to even after cancer again in 2007 that took my right jaw and most of my teeth. (Normal Kuykendall Bowen, Miles, Texas).
- (From a caregiver) My husband is one who rarely opens up about what he misses. When I read these posts it helped me realize that he is glad to be alive, and chooses not to talk about the steak he can no longer chew and swallow, not being able to hike to his favorite fishing spot, etc. I realize that on “bad days,” he is still recognizing his limitations, and trying to accept them. And that maybe that fleeting look of overwhelming sadness is when he knows he can no longer do a certain thing, but the look of joy when he discovers other things that he can (like a big plate of mushroom ravioli at the Macaroni Grill on Saturday night). I have found that as a caregiver that is one of biggest challenges—to replace the can’t do’s with the can do’s! (Debbie Wilson, Atlanta, Georgia).
- I miss shooting skeet because I can’t call “pull” when both hands are on my shotgun. Another thing I miss is being able to work my bird dogs in the field. They finally got to understand my commands in the pen or yard (although as dogs are wont to do, they sometimes act as if they can’t hear), but in the field it is impossible to communicate when the dog is 50 to 100 yards away. I simply have to have someone along who can be heard at a distance and who can blow a whistle loudly to recall the dog from 500 yards off after they chased a rabbit (which they can never catch.) (Joe White, Dallas, Texas).
- I guess I must be a sentimental fellow to say something like this - but what I think I miss most is being able to really laugh - and even cry. Not that I particularly enjoy sobbing; maybe it has happened once or twice since my operation six years ago. And of course I laugh - inside - and maybe utter something like “huh-huh” with my ES voice. But these are also social emotions and you laugh and cry with others in situations, as a way of showing closeness, togetherness and sharing something you experienced. Of course I should have liked to go swimming again - or sing - and drown out my friends in discussions. (Torbjorn Bull-Njaa, Skjetten, Norway).
- As time went on and I recovered more, little things have popped up which I found I missed dearly. I never realized how much I must have attempted to try to control group conversations, and those days are over as even loved ones will talk over you after everyone gets used to you. And I didn’t realize how much I must have enjoyed yelling during basketball games with my beloved Memphis Tigers…but I found out while watching them this year with my son-in-law that as much as I would try, I couldn’t even yell when they lost! And now that the flowers are blooming and everything is turning green, I’ve been in the backyard getting my pool ready for the summer. I taught all three of my kids how to swim, and now with them grown and having kids themselves, I was actually looking forward to acting like a teenager with them and

Continued on P. 16
• doing foolish things off the diving board. I’m determined that we’ll still kick the music on, have everyone over, cook hamburgers and hot dogs, and have fun. But looking at the diving board periodically will cause a little sadness. I never thought I would ever say this, but I actually miss wearing a tie when going to church…. I wore a suit and tie in the business world for 30 years and never thought the day would come when I said I missed wearing a tie. I guess what I miss the most is the amount of talking that consumed my daily life before the surgery…. It just didn’t occur to me how much speech was such a large part of my day to day routine and my daily life. Even though my SLP tells me she thinks I sound great, I am limited in length of speech, or how long I can continuously talk before the speech becomes more difficult and harder to understand. (Mike Smith, North Augusta, South Carolina).

• It’s perfectly healthy to miss things that have been taken from us. I, for one, miss being able to smell and let out a big old hearty laugh - now when I laugh hard I almost faint…. But I think we can all agree that it’s great to be alive and we know things now that we would have never known if we hadn’t had to take this journey - but we’re taking it together and I am so thankful for my life my family and all of you to be with me on this journey! (Lillian Parra, Havasu Lake, California).

• In listing all the things we miss it should be remembered that many things stay the same. For instance, when I first attended school I had to raise my hand if I wished speak. Now that I have a TEP that hasn’t changed! (Michael Mac Mahon, Corofin, Ireland).

• Let’s face it, we all miss (many things) but it just ain’t gonna happen folks! We can commiserate about it or we can just accept our condition and move on, making the best of it. I too was a speech maker, swimmer, and interacted a lot with others daily, but just cannot do it anymore and I accept that. I still play golf with at 10 handicap, talk with others in my own way (TEP) and get along just fine. I just thank the good Lord I am still around to hug my grandsons and be with my family. (Don Claxton, Chandler, Arizona).

• After my operation in 1987 my doctor gave me a list of “do’s and don’ts.” I was very active at the time and these new restrictions sent me into a depressed state. After I got over with my radiation, I decided I’d push the envelope a little and see what I could allow myself to do. I found out I could still work the same job, wade in the ocean-but not swim, lift weights, climb, eat what I want ,and basically didn’t have to give up much of anything. So I tell everyone: enjoy the journey.

• It’s better than the alternative. (Bill Larson, Las Vegas, Nevada).

• I don’t miss anything. I’m just glad I’m living and enjoying the joys of every day...my husband...my family...my grandchildren...and my great grand children. I enjoy the sun...the stars...and just plain waking up each morning and knowing that I can see all of this. I thank the good Lord that I am still here and NOT dwell on “what ifs.” You have to move on. (Betty Thompson, Fort Myers, Florida).

• I myself do not miss anything that I had before I had throat cancer and my larynx removed. I am on my new life now after my doctor saved my life for now. It’s almost 3 years since it was done. What I do miss is the friends that I have met in WW that have passed on already. We all know someone who has passed on with cancer. This is what I really miss. I have learned to live without things I grew accustomed to before my laryngectomy was done. This is part of life and should not be dwelled upon. We should be grateful for what we can still do and not what we cannot. (Terrance Gaffney, Piscataway, New Jersey).

• I think I first TRULY realized how precious and good life is when I was diagnosed with lung cancer (in ’97) and when driving to work along this beautiful stretch of US 1 along the back waters of the Mosquito Lagoon and suddenly coming to grips with: “Soon I may never see this again.” How we take for granted our family, our friends, and this wonderful place called EARTH! (Dave Ross, Edgewater, Florida).

• (From a caregiver) I certainly don’t miss the months/years of sleepless nights worrying about his struggle to breathe prior to his laryngectomy couldn’t exhale, and told post-op that it was then sleep apnea! The tumour was closing the airway! The struggle to do anything, for excessive coughing, shortness of breath. Constant vigil to make sure he was still breathing. Apart from the natural process of aging, he is much healthier than before seven years hence, and afraid I don’t always remember that he can’t talk with two hands full, I never notice any scarring, and he looks just as good looking as he ever did! He can do all the things as before, apart from getting under vehicles to work, for obvious reasons. Petrol fumes are a problem, so I insist on filling the car, when possible! Male pride! But appreciate being treated as a lady! So I have to make sure the car filled when he isn’t there! Guess we are lucky that water sports are and have never been our interest. That is probably the main drawback for many others. Being rural folk, I guess you learn early the art of compromise! Positive thinking is an advantage, and negativity never helps! I thought he would miss his fortnightly trip to the pub, but meds prohibit his former social drink-
ing, and he doesn’t seem to miss them at all. He does occasionally, but pays the next day! Food is still enjoyable, although the onset of diabetes type 2, limits that, as well as cholesterol levels, and the occasional problem swallowing some foods. So relative speaking, I guess he is one of the lucky ones! Perhaps all the other medical conditions make his lary incidental! Least of our worries! He certainly makes the most of the time he has, and I admire him so much. I find old friends totally accepting of the few minor limitations he has, and they are very accommodating. One way to find who your friends really are! (Patricia Glassop, Queensland, Australia).

I “miss” coughing myself to sleep each night ... and I “miss” the hopelessness I felt after a couple of ENT’s had examined my throat and said my problems were just scar tissue from previous radiation and nothing could be done. But since last summer I’ve quit missing all that stuff’ because Dr. Zeitels at Mass. Gen. (Hospital) went deep and found cancer in my larynx, and on September 18, 2008 Dr. Jesus Medina at OU MedCenter got it out of me then wrapped a piece of chest muscle around my throat to help me “keep my chin up,” and a wonderful speech pathologist, Tracy Lynn Grammer, taught me how to speak and take care of my new lifeline. I enjoy a lot of wonderful memories, but this procedure has allowed me to celebrate my seventy-fourth year on our bright blue planet with a level of energy and health I thought that I had lost forever ... and I don’t want to spend any of the time I have left thinking about things I can’t do or don’t have. (Bob Keiningham, Broken Arrow, Oklahoma).

**Q & A: What is Granulated Tissue?**

Recently a question was posted on the WebWhispers email list:

Q: “I would like to know what is granulated tissue?”

A: In larys granulated tissue typically forms at the TEP puncture site. It is caused by irritation as the prosthesis moves in the tract, the tissue reacts to the presence of a foreign body (the prosthesis), and also as a result of the puncture trying to heal itself closed.

The tissue wanting to heal closed is a good thing since it is what keeps us from having leakage around the outside of the prosthesis and into our lungs. The attempt to heal itself closed is the pressure which helps maintain the seal.

If they become a problem they are removed surgically (with a scalpel or laser) or and/or with the application of a chemical which works similarly to wart removers by killing the tissue.

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**Mid-Atlantic Regional Conference Set**

The first ever Mid-Atlantic Laryngectomee Conference will be held September 18-19th at the Fox Chase Cancer Center, 333 Cottman Avenue in Philadelphia, Pennsylvania.

The theme of the conference is “To Life” and the program begins with a meet and greet reception on Friday evening at the Four Points Sheraton Hotel, 9461 Roosevelt Blvd. A discounted room rate of $99/night plus tax (call toll-free 866-924-8703 and mention that you are with the Laryngectomee Conference).

A continental breakfast, coffee breaks and lunch are all included in the registration fee. While the $30 registration fee deadline was the end of August, the at-the-door fee is just $35.

Featured speakers include Bruce Horn, a veteran police officer who became a laryngectomee, and Christine Callahan, a social worker for the National Institutes of Health. A doctor’s panel will include SLP Dr. Dennis Fuller, and Drs. John Ridge, Miriam Lango and Theresa Gills. There will also be a nurse’s panel and SLP panel for which continuing education units are available. Other sessions cover most aspects of laryngectomee rehabilitation.

Congratulations to all of the local clubs who have organized the conference and the vendors and other sponsoring organizations.

**Watch Larys Swim**

You can watch a number of laryngectomees swimming at the water activities session at the San Mateo Annual Meeting at this Internet address: http://www.youtube.com/watch?v=c1BOAue3_0

There are also several videos of larys swimming at this Internet address: http://webwhispers.org/library/Activities.asp

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**Larynx Cancer #s Drop**

According to the National Cancer Institute, for the period 1996-2005 (the most current numbers available), both the incidence of larynx cancer and its death rate have fallen (-3/4% and -2.2%, respectively.)
Donors Give in the Name of Others

In February, 2009, the Board of Directors announced the establishment of a program which invites individuals to contribute to the IAL in memory of those who have left us and to honor others we feel worthy of recognition. Since February 40 gifts totaling almost $1300 have been received.

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You may make your 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 our new 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. Gifts will also be periodically acknowledged in the IAL News by donor (unless you wish to remain anonymous) and the name or names of those who are being honored.

The Board of Directors believes that this program will help provide funding to the IAL in order to continue to serve the purposes for which it was created more than 50 years ago as well as provide a way to publicly honor those deserving of recognition.

Please consider donating.

2009 Voice Institute - Another Success Story

The 2009 IAL’s Voice Institute set a modern record with a total of 76 participants. According to VI Director Dr. Jeff Searl, the breakdown was:

- 25 graduate students (of these, three were licensed SLPs who are PhD candidates. One was an undergraduate student while the remaining 21 were master’s degree students. Eleven universities were represented.
- 15 Speech/Language Pathologists who represented six states and Canada.
- 11 Laryngectomee Trainees (LTs) from five states plus Canada and Norway.
- 25 VIPs (laryngectomees who are looking for help or who are volunteering to be research and practice subjects for the SLPs in training). Seven states were represented along with Canada and Pakistan.
Costa Rica - Voices Restored

By Marcos Salazar Chavarria, VP, ALARCORI

Cancer of larynx has not been a priority in Costa Rica, nor institutional or socially motivated, perhaps because the incidence is much lower than other types of cancer. Indeed a high percentage of Costa Ricans are unaware of the existence of this disease. One of them was me. The previous comment refers to a lack of effort on prevention in the absence of strategies for early diagnosis, and lack of services that will help the “laryngectomized” patient in their new life. Although there are excellent surgeons and practitioners in ORL (otolaryngology), you can not say the same about alternative treatments such as radiotherapy (radiation). In this field we do not have the professional skills or schools to sufficiently meet the demand.

For this reason, some of the patients of Dr. Calderon Guardia decided to create ALARCORI (Laringectomizados Association of Costa Rica), an organization that was born to join patients with cancer of the larynx to fight for our rights, but also to fulfill our duties to help others. That’s why we included among our main goals:

1 - Working for a better quality of life for the patient “laringectomizado” and their families.
2 - Join the battle against smoking.
3 - To seek greater disclosure of the symptoms that accompanies this type of cancer to ensure early detection.

One of the first steps we took to achieve these goals was seeking international support from people who knew more about this subject and have more experience in their treatment. That was how we became a club member of the International Association of Laryngectomees (IAL).

Recently, (November 3 to 7, 2008), ALARCORI working closely with the ENT service and Phoniatrics of Dr. Calderon Guardia, Jack Henslee, Barbara Dabul, who personally and on behalf of the Association of Laryngectomees California (CAL) organized a seminar-workshop (Rehabilitation of Laryngectome Patients). This activity was conducted on the premises of SIPROCIMECA (Union of Professional Medical Sciences), which provided much support.

The purpose of the seminar was:

1 - Bring the possibility of oral communication to laryngectomees who can not speak.
2 - Start promoting our Association and the goal “Begin to Speak.”
3 - Integrate as a group and become more aware of our duty to help others.
4 - Improve our quality of life.
5 – Build a foundation for our future struggles.

One by one, all the objectives were achieved, exceeding any expectation. With “laringófonos” (ALs) which were donated by Mr. Jack and Dr. Dabul and, thanks to workshops they led, at the end of the week 14 people were able to go back to talk to their children and their families. Fourteen people managed to use a phone again. Plus they left equipment, supplies and materials that can be used for future ALARCORI partners. The last day achieved television coverage of the event, which was projected to a large part of the country’s population. And as if these accomplishments were not enough, we were also infected by this spirit of selfless commitment and solidarity shown by Mr. Jack and Dr. Dabul, a spirit that will allow us to take forward our commitments as a partnership.

The event was also attended by language therapists, nurses and doctors from different hospital centers in the country, as well as speech therapy students at the University of Santa Paula, and some other friends of the Association who came to give us lectures, workshops, instruction and recreation.

It is important to close this article by publicizing some data on the care of laryngeal cancer in a hospital in our country (there are several hospitals with service ORL):
- 94% of the cases have been treated for cancer Glótico.
- 91% of the cases were men
- The highest concentration was observed in patients with ages between 50 and 70 years
- 88% had a history of smoking
- 73% had a history of alcoholism.
- 67% of laryngeal cancers attended were detected in stages 1 and 2.

This data gave us a direction to plot strategy for channeling our efforts in the future.

ALARCORI, the ENT Service and Speech Therapy Hospital Dr. Calderon Guardia express our sincere thanks to Mr. Jack, to Dr. Barbara Dabul, CAL, and all the below entities and persons known and anonymous that allowed this activity to lead to much success.

Griffin Labs, Lauder Enterprises, Luminaud, Mt Precision, Ultravoice, Look Who’s Talking, Inland Empire Club, Florida Laryngectomee Association, and individual donors.
International Association of Laryngectomees

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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.

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