The 57th Annual Meeting and 48th Voice Institute convened at the end of August in Little Rock, Arkansas. The Meeting was dedicated to the memories of Judy Breckon and Jane Varner; two women who were instrumental in bringing the IAL to Arkansas in 1996 (Judy), and then again in 2008 (Jane). The Annual Meeting and Voice Institute were ably hosted by the members of the Lost Chord Club of Central Arkansas. Lisette and Harvey Black and James and Caroline Kennedy lead the local efforts for their club. The clinical portions of the Voice Institute were held at the University of Arkansas Medical Sciences Hospital.

InHealth Technologies and ATOS Medical hosted the Meet and Greet Reception on Wednesday night, and a combined program for the Meeting and Voice Institute began on Thursday morning. Dr. Eric Blom, SLP, gave the keynote address. Titled “30 Years of Inventing Medical Devices to Restore Voice…and Human Dignity,” Dr. Blom reviewed the progress made since the tracheoesophageal puncture technique (TEP) was developed in 1978 including both products and surgical techniques (see page 23). Among his more recent inventions is the creation of an indwelling prosthesis (installed by a clinician) which features two valves. This design is intended to extend the life of the prosthesis as well as reduce leakage.

A talk on thyroid issues was followed by a panel of medical experts who answered questions from the audience. Afterwards a special presentation was given by SLP and laryngectomee Joanne Fenn on “What Makes a Good Clinician and a Good Patient.” Joanne was then surprised with an IAL award for all she has done in the cause of laryngectomee rehabilitation. She was presented with the first “Shirley Salmon Master Clinician Award.”

The Annual Meeting and Voice Institute then diverged into two separate programs (but with everything open to all who were interested). One feature of this year’s meeting was a “Town Hall” where the Board of Directors addressed...
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.

IAL Has New Executive Director

The IAL Board of Directors is pleased to announce the appointment of Susan Reeves as the new International Association of Laryngectomees Executive Director. Susan will work on a part time basis and can be contacted through the IAL’s new permanent address and our toll-free phone number (see back page).

Susan is a Speech/Language Pathologist and is currently the Clinical Director at the West Texas Rehabilitation Center in San Angelo, Texas. She holds two degrees from Southwest Texas State University.

Susan has had an abiding interest in laryngectomee rehabilitation for most of her career. She first attended the IAL’s Voice Institute in Seattle, Washington in 1988. She has worked as the organizer and coordinator of the Concho Valley Lost Chord Club, and worked with the Texas Laryngectomee Association. She also served for a year on the IAL Board of Directors, and has worked as a consultant for laryngectomees in two hospitals. She also served as a consultant to the International Rehabilitation of Laryngectomees in Cologne, Germany, and has helped to establish and lectured at the Mexico Voice Institute. She also served periodically on the IAL’s Voice Institute staff over a 14 year period.

Susan was interviewed by the Board of Directors at the Annual Meeting in Little Rock and formally selected in September. Among her duties are to plan the Annual Meeting, organize the records of the organization, assist in planning the Voice Institute, respond to all communications, help upgrade the web site, maintain and store the organization’s audio-visual equipment, help identify ways to conserve resources and to find new sources of funding, and others.

The Board of Directors is delighted that Susan Reeves has agreed to lend her considerable talents and lifelong dedication to laryngectomees to the continuance of and improvement to the IAL.
An article in *WebMD Health News* and in *Cancer* reported that people who breathe burning incense over long periods have an 80% increased risk of developing a number of respiratory cancers even if they never smoked tobacco. The research, carried out with Chinese subjects, showed an increase in the development of squamous cell cancers in the nose, throat and lungs. The risk was considered minimal for those who are exposed to incense on a casual basis, but the findings are particularly important for cultures and individuals that routinely burn incense in their homes.

**Notice to IAL Clubs—2009 Dues**

Invoices for the annual dues for 2009 will be sent out by e-mail about November first to those clubs for which we have e-mail addresses. We will continue to send invoices via the U.S. Postal Service to those clubs for which we have no e-mail address.

However, we ask that if the official club contact does not have an e-mail address to please appoint anyone in your club who does to be the receiver of this online invoice who will then pass it to the club officials. Having an e-mail address for each club will also allow the IAL to communicate with clubs between issues of the *IAL News* as well as save the cost of the mailing.

It is urged that all clubs insure that the IAL is aware of any change in their club contact's e-mail address. You can determine whether your contact information is correct by checking the information on your club here: www.larynxlink.com/Main/clubmap.htm. Please send e-mail address updates to Tom Herring at tomherring@embarqmail.com or ialhq@larynxlink.com.

Thank you for your help.

**Correction**

Because of a printing error the sources of two graphics on page 15 of the August issue of the *IAL News* were inadvertently left out of the printed version.

The source of the graphic showing the use of the ultrasound "wand" was West Virginia University. The source of the graphic showing the carotid arteries was Iowa State University.

**Apologies**

We wish to apologize to Griffin Labs and to Servox for errors in this year's Annual Meeting and Voice Institute program. Griffin Labs was left off the back cover as a Silver Sponsor. And Servox was not listed as an "exhibiting vendor" and not credited with sponsoring Voice Institute coffee breaks. We regret the errors and apologize for the omissions.

**Order Postcards Now**

Clubs, clinicians, vendors, etc. should order the number of *IAL News* postcards they think they will need over at least a one year period. Ordering a larger number will save on postage. These new cards should be able to be used indefinitely. These postcards are used to sign up new laryngectomees to get the *IAL News* and to use if there is any change in address for those already receiving it. When these new cards are received you should discard the old ones since these new cards contain the new permanent IAL address. Place your order by email and state the number you want and the mailing address to which they should be sent to ialhq@larynxlink.com; write us: IAL, 927B Peachtree Street NE Suite 316, Atlanta GA 30309; or phone us at (866) 425-1678 (866-IAL-FORU). Thanks.

**When will you need a Micron HME?**

A breakthrough in pulmonary protection.

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

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

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Let's talk about life.

Since there are other pathways for pathogens to enter the human body, Provox Micron HME can never guarantee total protection. Degree of filtration efficiency is dependent upon particle size, shape, surface charge, concentration of particles in the air and inhalation air velocity.
Contributing to the IAL
By Sapp Funderburk, IAL Treasurer

The International Association of Laryngectomees is a tax-exempt 501 (c) (3) organization, therefore, all donations to the IAL are tax-deductible.

Like any organization, we need to have money to get along in this world. Did anyone else hear that prices are going up? Almost everything we buy has gone up regardless of where it is purchased or whatever the source. This is especially true for the IAL. Everything we buy, from postage to computer supplies, has gone up in price over the last few years.

In addition to raising prices the other side of our budget—income—has reacted the other way and gone down. This is somewhat understandable that when times get tough people cut back on donations, travel and entertainment. Companies buy less advertising, go to fewer conventions and cut back on donations, even as the IAL costs continue to rise.

The IAL publishes the IAL News four times a year. The last four editions have cost $25,000 to publish and mail out to almost 8,000 addresses. That is a little over $1.00 per copy. Advertising can only pay a small percentage of that amount. While we do not charge for the IAL News we do ask for donations. Anyone who wants to receive the IAL News can have it sent simply by asking.

The vast majority of our donations are very small. Donations from just ten individuals make up better than 40% of the donations we have received this past year. It is true that in most organizations 10% of the people do 90% of the work. The difference is that it is more like 2% making donations to the IAL.

Those who give $5 per year are a big help, at least they are paying the cost for them to receive the News. There are a few who give $10 a month or $15 a quarter. What is needed is for many people to give $5 a month, $25 a quarter and so on. If only 10% of the people gave $5 a month the News would actually make some money for the IAL. But the reality is that 10% gave $15 a month it would more than cover the cover the entire basic budget including publishing the News.

When we receive donations the money is used for many different purposes. In addition to running our day-to-day operations there are so many worthwhile projects that could use our support. For example, on September 5th there was an hour-long program from Los Angeles sponsored and broadcast by the three major television networks. “Stand Up To Cancer” was a major success. In that one network alone, on September 5th there was an hour-long program from Los Angeles and San Francisco, and the other two were going to be in the area anyway, so the cost to the IAL was almost nothing.

The IAL needs to reprint many of our pamphlets and brochures, both to update and correct them, but also to have a supply on hand to give out. Because of a lack of the necessary funds we cannot do this at this time. Several of the regional laryngectomee organizations have asked for monetary support from the IAL to help their regional meetings and special projects. But, again due to the tight budget, we cannot help at this time. Many members of the Board of the IAL only take part of their per diem, or travel money, for the Interim Meeting and Annual Meeting. Some are able to pay all these costs themselves. Officers and Board members have been recently paying for their travel while representing the IAL at regional meetings. No Board member is paid to work for the IAL.

The Board has considered many ways to save money. We have taken a long look at the Executive Director position and, as of the end of September, hired Susan Reeves as ED on a part time basis. The savings for us will be more than 66% of our previous costs by not including payroll taxes, workman’s compensation insurance and office allowance. Members of the Board have taken on many of the tasks formally done by the Executive Director in order to save money. We will probably be having the Interim Meeting via the Internet with web camera to save the cost of a face-to-face meeting. There has not been a benefit or directory printed this year to save that cost. We recently reduced the per diem from $42 to $35 for official travel to the required biannual meetings. These are just a sample of cost savings we have implemented so far.

Over the last few years there has been a decrease in donations to the IAL. I believe that there have been several reasons for this. Included are laryngectomee dying, people moving and no longer getting the News (which would remind them to send in something), and clubs becoming inactive. These are some of the reasons for the falling donations. The greatest reason, I believe, is that there has been no real effort to ask for the donations. I learned a long time ago “if you don’t ask for it you probably won’t get it.”

In order to continue to do all that we do the IAL needs your financial support. We need to find a way to get the full amount of our costs. The amount is too small. Do what you can if it is $5, $10, $100 or $10,000, it is much needed and will be deeply appreciated.

There are several ways that you can help by giving your TAX DEDUCTIBLE gift to the IAL. The fastest and easiest way is to simply write a check and mail it in. For those of you outside the U.S. please be sure your donation is in U.S. funds. The bank charges us to convert foreign currency into U.S. dollars. Most banks can set it up so that a check is sent to us automatically each month or quarter. If you go to the IAL web site (www.larynxlink.com) there is a link to donate. This goes through PayPal, a secure web site, and you don’t have to have an account with them. Just fill out the information along with your credit or debit card information and everything will be taken care of. If you don’t want to go through PayPal simply write a check to the IAL (P.O. Box 6025, Belhaven, NC 27506) giving your card number, whose name that the card is in, expiration date and three digit security code on the reverse. If none of these is acceptable you can call me (864-268-9719), at a reasonable hour of the day, and give me the information on the phone.

Thank you for remembering the IAL.

IAL Web Site: www.larynxlink.com
Mailing Address: IAL, 9218 Peachtree St. NE, Suite 316, Atlanta, GA 30309
My home phone number: 864-268-9719

Danny Viveiros, a laryngectomee, and a surfer. His family lived just two blocks from the beach when he was growing up and his father taught him how to surf from the age of 9. He came to love it.

But when he developed larynx cancer in his early 40s he was told his days of surfing were over. He freely admits that he became depressed after the surgery, had feelings of self-pity and guilt, and could no longer tolerate even looking at the ocean. Friends took him fishing, but he had become afraid of the ocean and the thought of water rushing into his lungs. But his dreams continued to be filled with images of him surfing again. He would wake up thinking that he just had to find a way. He couldn’t let it go. He remembers saying, “I knew I had to do something or I’d bomb. I couldn’t function.” He was dying to get back in the water.

What he did in 1987 just six months after his surgery was to purchase a “Larkel” (no longer available for sale in the U.S.). It is a device that consists of a mouthpiece that connects with a tube that fits into the stoma. Inflating a rubber ring that goes inside the stoma creates an airtight seal.

But the Larkel had not been designed for the power of a pounding ocean surf and he had to abandon it. Not one to quit on his dream of returning to the water, Danny set about to design his own device. Through trial and error he combined pieces of a diver’s wetsuit, mouthpiece and tubing from scuba gear, valves and rubber tubing. Although it shares some resemblance to the Larkel, a major difference is the additional support provided by the part made from a wetsuit. He reported that it was a little painful to use at first, but has gotten used to it. Danny used it successfully for the first time when he wiped out on a particularly large wave. It knocked the device off and him onto the rocks. Danny, who never surfs alone for safety reasons, had his friend to help him get the water out of his lungs. He said the experience made him not afraid to drown, “You just sort of go numb and relaxed. The idea of drowning used to worry me just thinking about it.”

Danny hopes his experiences can help others to make the decision to have the surgery and believe they can recover to do the things they love. He said, “You can adapt and have a normal life.”

Danny stated “I’ve been in about four or five (surfing) contests since the operation, and they (his family) always come and yell and scream and embarrass me. I feel lucky in a way. I’m not a religious person, but I feel like I’ve been given a new life.”

(Compiled from stories from the Los Angeles Times and Union-Tribune. Photos from Danny Viveiros, the Times and Union-Tribune).
Some new uses have been found for a substance that has previously been used for a number of cosmetic surgical procedures. One of these is Cymetra. It is an injectable natural material and has the benefit of rarely being rejected by the body as a foreign substance. Used cosmetically as wrinkle filler and to enhance lips, it is now being used for several applications in laryngectomees.

One use is to inject into the stoma area to even out an irregular shape. This may permit some laryngectomees to use a hands-free valve with a Barton/Mayo Button (available from InHealth) or ATOS lary tube. Using the hands-free valve in a lary tube or button requires that there be a good airtight seal around the stoma.

There is no guarantee that having a smoother stoma surface will permit the use of a hands-free valve with a lary tube or button (and thereby avoid having to use the glued on housing). The amount of air pressure each individual needs to get voice is also a major factor in whether this will work.

Research conducted at the University of Pennsylvania Medical School also demonstrated that Cymetra can be injected into the tissue around a TEP puncture in order to help decrease leaking problems. Leaks around the prosthesis are typically caused by tissue around the puncture that is not healthy and firmly gripping the prosthesis to keep the seal. In the study, the injections were successful in four out of five patients.

Still another use for Cymetra is for those who have had a cancer removed from a vocal cord leaving an uneven surface on one or both vocal cords. The injection can even that out and change a breathy sounding voice to a more normal sounding one.

As with so many things, there are a number of alternative procedures and materials that can be used for these purposes and there are advantages and disadvantages to each. Your medical professionals can help you decide if the procedure is desirable in your case, and the best way to go about accomplishing it.

(Note: an article which explains how some laryngectomees can use a hands-free valve without using the glued on housing can be found here: http://www.webwhispers.org/news/aug2002.htm)

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**VOICE CHOICE AND QUALITY OF LIFE**

Is the quality of life a laryngectomee has after surgery influenced by the type of speech they use? This was the question research carried out at the University of Plymouth in Great Britain attempted to answer.

The study surveyed 226 laryngectomees (147 TEP speakers, 42 traditional esophageal, and 37 electro-larynx). While the measured quality of life was lower for laryngectomees than the general population, there were no significant differences among those who used traditional esophageal, TEP or the electronic artificial larynx. The researcher who conducted the study had assumed before the study began that those using the TEP (which he stated produced a “better voice quality”) would have a higher satisfaction level and higher measured quality of life.
While we got there and were heading to claim our baggage I noticed I was at a much higher elevation (Arizona’s elevation, where I live, is around 3,500 to 4,787 feet, and Arizona is 7,000 to 12,000 feet. That’s a huge difference. So I figured I would acclimate in a day or two.

Two days after our arrival we made our way up to Jerome, Arizona, which was even higher than Phoenix, and my breathing was not getting better. By Wednesday, I started coughing more then usual and noticed spots of red. Then I remembered that Arizona was also very very dry. “Ok” I told myself. “I need to drink more water and take longer showers, keep my HME filter moist, keep a damp cloth over my stoma as much as possible and find some saline solution. I can do that.”

By Thursday evening I was miserable. I wasn’t really hungry because I’d consumed more water than most people do in a week. I was coughing up a lot of blood, and my ankles and eyes were so swollen I looked like I was going to pop, and I had to ask my sister to carry my luggage.

By bedtime on Thursday, I was so angry! I was angry that I was a laryngectomee and having to deal with all these issues! Didn’t I suffer enough ten years ago after I had the surgery? Didn’t I suffer enough by having to learn to speak a new way, and suffer the humiliation out in public when some people stare at me like I’m something from outer space?

I was mad at God, myself, cancer, cigarettes and even my sister who slept so peacefully, breathing normally and not coughing. Her pajama top wasn’t all wet from a wet wash around 3,500 to 4,787 feet, and Arizona is 7,000 to 12,000 feet. The situation is better than it was ten years ago, but there is much room for improvement when it comes to having a well-developed swallow and voice. Laryngectomees often represent a very small portion of an SLPs caseload, unless it is a large hospital or cancer center, so there is no requirement for this.

The SLP’s training program must encompass a wide variety of topics, including, but not limited to, normal speech anatomy and physiology, hearing and deafness, childhood speech and language development, articulation disorders, stuttering, mental retardation, autism, learning disabilities, neurologic disorders such as occur after stroke, head injury, Parkinson’s Disease, dementia, etc; voice disorders, swallowing disorders, learning theory, therapeutic methods, and more. It is to say that most often the specialized knowledge that an SLP requires to assist a laryngectomee comes through continuing education programs or on-the-job experience, hopefully with a good mentor.

Language Pathologists are sponsored by professional associations, while still others are sponsored through laryngectomy organizations such as local or state clubs, and the IAL’s yearly Voice Institute. There is not one program better than the other, still others are attended by people who are more than one year post-surgery. Why is it so hard to find a well-qualified speech therapist?
Liebner's initial reaction was that there was nothing he could do about the cancer. But his doctor did mention the names of two other MDs who might be able to help. A plane ride provided by the Kentucky Air National Guard brought him to Chicago to see a prominent specialist, Dr. Paul Holinger. Surgery was performed and his larynx was removed.

The clinical portions of the Voice Institute will be conducted at Stanford University which is located in Stanford just south of San Francisco. The 2009 IAL Annual Meeting and Voice Institute will be held at Stanford University where the clinical portions of the Institute will be conducted.

The average laryngectomee becomes one sometime after the age of 60, as those who have had a laryngectomy at the age of six will be recently retired. The early symptoms of being short of breath had been noticed by his local doctor, but there have always been the young ones. One of these was Paul Streble. Paul became a laryngectomee at the age of six.

When Paul was going to bed after attending his very first day of elementary school in 1959 he spoke his last words with his original voice when he said, “Good night, Mom. I love you.” His hospital stay had lasted three months and, while his mother stayed in Chicago and his father visited on the weekend, he had already made his third, brother, and extended family visit.

When Paul Streble was 15, Frederick, MD 21705.

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On Supplemental Oxygen?

There are not many laryngectomees to begin with. There are only about 55,000 to 60,000 of us in the U.S., and of this number, only a tiny number must be on supplemental oxygen. But if you are one of those few, you may already know Don Layton of the Inland Empire Nu Voices Association in Riverside, California.

Don became interested in improving stoma covers for those on supplemental oxygen while in the hospital in 1998. An insect managed to get past the large plastic oxygen mask and into his stoma. Later Don and his son figured out how to attach a mesh netting material on the underside of a cloth stoma cover that would hold a nasal cannula or similar device where the oxygen would come out the tube and into the stoma. This delivers oxygen to the stoma, but in a very inconspicuous way since the oxygen tube is threaded under clothing.

Don found out something about the laws of supply and demand when he could not find a manufacturer for his stoma covers. The market is just too small for it to be profitable for a manufacturer. So Don makes them for anyone upon request. He even will make the first one for you for free since he wants to get the dimensions right and a perfect fit before charging for them. He needs your neck size and method you use to speak since the mesh is sewn into the cover low enough that it does not interfere with occluding your stoma for TEP speakers.

You can contact Don at nuvoiceclub@pacbell.net, mallard7@pacbell.net or 4152 Locust Street, Riverside, CA 92501 (951-782-9833).

“I Am Making a List, and…”

IAL Board of Directors member Tom Herring has been “making a list and checking it twice.” It has nothing to do with who’s been “naughty or nice,” it is more than one list, and he checks them many more times than just twice.

Tom has been very busy over at least the last nine months doing the unceasing and tedious work of redesigning and putting our various databases into more usable forms, as well as doing the never-ending work needed to keep them current. Among these important lists is the mailing list we use to send this newsletter.

Tom converted the mailing list to the Access software system for both domestic addresses and those outside the U.S. This system is a standard one used in publication and mailing businesses. He consequently found over 100 duplicate names and addresses, so those were eliminated and thereby saving postage.

The list of over 8,000 addresses also was checked against the U.S. Postal Service system to detect whether the addresses were valid ones or not. All of the addresses had to be edited for machine readable, which means, among other things, that no punctuation is allowed in the addresses other than the dash used if all of the Zip code is used (five plus four). Addresses also had to be street addresses or valid P.O. boxes.

Also among the most important databases is our club database. Tom has worked on identifying clubs which are still active as well as those which no longer exist, and working to make sure the contact information is accurate. The IAL Board is also considering whether it ought to try and identify and list every known laryngectomy support club whether it is an IAL member or not. The reason is that we want anyone looking for a support club to find one regardless of the affiliation of the club.

Tom has also been working with our new webmaster, Ron LeClair, on revisions of the web site. Particularly important in this work is to make sure that our club listings is up to date so that anyone looking for a laryngectomy support club in their area can locate one and make contact.

Meet the new Webmaster

The IAL Board is pleased to announce that we have a new webmaster for our web site. Ron LeClair has been involved in the computer industry for over 25 years including as a software developer. Ron stated “I have kept my eye on the web and web companies since the mid 90’s. It was an interesting technology to watch emerge and then grow both web-wise and stock-wise. I say stock-wise because I bought shares of Netscape stock when it would rise and fall over $20 per share in a single day. What a nerve-racking roller coaster that was.”

Not long after I jumped off the Netscape ride, a friend approached me to put together a fantasy football web site with him for his league. He and I both had zero knowledge of web development back in 1996, but we learned in a hurry and had his league up and running in a few weeks. We continued to learn about the world of web development that was very primitive at that time, but it allowed me to get in on the ground floor.

Soon I was the 90’s and 00’s version of the guy who had a pickup truck that everyone wanted to borrow. A friend in Michigan owned a bar and asked me about a site and from there on in, it was one web site after another.

Tom Herring, 2597 Penngate Drive, Sherrills Ford NC 28673-9127, or give him a call at 828-478-9705. Thanks to Tom and you for doing your part in keeping us in touch.

Enjoy Dusty Hobbies?

Do you enjoy working with any hobby which produces lots of dust? Then you might be interested in Lanny Kentley’s suggestion for a pretty serious respirator—the Triton Powered Respirator (Model # PRA001). Powered by rechargeable batteries (which work for about four hours per charge), the hood portion and full coverage is what makes it work well for laryngectomees. Filtered air is pumped from the battery and filter unit (which is worn on the waste) and into the helmet. It is appropriate for use with woodworking, metal work and welding. It is not designed to protect the wearer from chemical vapors or other gases.

The respirator is available from a number of dealers. Those with computer access can find a dealer here: http://www.triton.com.au/product.php?id=29, or call their toll-free number in the U.S. 1-888-874-8661.
GETTING
OUT AND ABOUT

There was an interesting exchange of e-mails recently on the WebWhispers web site that began with this e-mail to the group:

“Hi all webbies,
I would like to know how many people still socialize after having their laryngectomies. I used to love meeting people and socializing a lot before becoming a lary. (Please don’t get me wrong, I am not ashamed of what has happened to me.) I still live life very well, but I find going out for dinner with people pretty hard going, I might cough, or have food get stuck, or lose my ES voice during the night out and be wishing I was back in the house. I had my operation 7 years ago so have had plenty of time to get used to being how I am, My wife says that I shouldn’t be so sensitive. Am I the odd one out? I would love to hear some of your feelings on the subject as I think only us larys know how we feel.”

The e-mail sparked many replies. Here are a few of them:

“Wow... that is a pretty heavy trip you have laid on yourself. Didn't you ever cough before surgery in public, didn't you ever choke on food before you were reborn? Didn't you ever lose your voice before? We have an advantage now if we lose our voice, we can have an extra in our pockets. Let a non-laryngectomee pull that one off.

I think you will find there are many people out there that are extremely interested in us as a group and as individuals. You have ‘been, conquered and returned!’ You are an inspiration to anyone facing their own battles, you are an example of the power of human endurance and an amazing example of faith. To anyone facing their own battles, you are an example of the positive influence people to, perhaps, continue smoking and how best to balance their benefits and risks.

This topic comes up frequently. It is a common imagining procedure used by hospitals to get a look at the insides of our bodies. CT stands for “Computed Tomography.” It uses a series of x-rays directed from many angles to obtain the final images. It provides a better and more detailed look at our insides than traditional two-dimensional x-rays.

There have been a number of articles going back several years concerning the use of CT scanners with cancer patients. In brief, the controversy involves three issues. One is whether the routine use of CT scans such as once a year is a good idea for those at risk for developing cancer. Since most laryngectomees were smokers, we are at greater risk than the general public for the development of a second smoking-related cancer such as lung cancer.

First, an article appeared in a major medical journal that reported on research which indicated that CT scans were capable of detecting lung cancers at a very early stage and were nearly 100% effective in doing so. Since lung cancer is frequently not detected until it has spread, this was good news and seemed to suggest that annual CT scans for people at risk for lung cancer was a good idea.

Then a second article appeared in a major medical journal that raised questions about the first one. It pointed out that CT scans expose patients to as much radiation as 100 standard x-rays. And it is known that excessive radiation is also a cause of cancer. The article also pointed out the results of a study that indicated that, despite earlier detection, there was no evidence that patients lived longer.

The article also pointed out that CT scans produced many “false positive” results, or showing something suspicious which turns out not to be cancer. This high rate of identifying changes in the lungs that were mistaken for cancer raised the possibility of unnecessary surgeries and other medical procedures to follow up on the CT indication of possible lung cancer. The article concluded that for most people the possible negative effects and risks of yearly CT scans outweighed the positive benefits of perhaps identifying lung cancer in the early stage.

And the final and most recent disclosure appearing in a medical journal and in the general press. This stated that the first study had been funded by the tobacco industry, but with this information not disclosed in the article. The suspicion was raised that reporting a method for early detection of lung cancer might influence people to, perhaps, continue
Cancer survivors often fail to get follow-up care

(Associated Press)

America's 10 million cancer survivors require customized follow-up care for years, but so few of them are getting it, according to a major study calling for a "survivorship plan" to guide every patient's future health care.

Half of all men and a third of all women in the U.S. will develop cancer, but the number of those who survive has more than tripled during the past three decades because of advances in early detection and treatment.

When treatment ends, these people's special needs may be just beginning. Yet the physical, psychological and social consequences have largely been ignored by doctors, researchers and even patient advocacy groups, often leaving survivors unaware of simmering health risks or struggling to manage them on their own, according to the Institute of Medicine.

"Successful cancer care doesn't end when patients walk out the door after completion of their initial treatments," said Sheldon Greenfield of the University of California, Irvine, who lead the study for the Institute, an arm of the National Academy of Sciences.

These are some of the recommendations by the Institute of Medicine, charted by Congress to advise the government on medical matters.

Every patient completing cancer treatment should be given a customized "survivorship care plan" to guide health care.

That plan should summarize cancer care down to drug and radiation doses, cite guidelines for detecting recurrence or new malignancies, and explain long-term consequences of cancer treatment. It should also discuss prevention of future cancer and cite local psychosocial services and legal protections regarding employment and insurance.

Specialists in primary-care providers should coordinate to ensure survivor needs are met.

Health insurers should pay for this report.

Scientists must improve in some cases create guidelines on what screenings are needed for different cancers and their therapies.

Congress should fund research of survivorship care, to assess their needs and provide evidence for quality care. (from The Washington Post, reprinted in The Voice [newsletter of the Laryngectomee Club of Montgomery County, Maryland.])

Second primary cancers

New research indicates that there is a higher incidence of a second primary tumor in patients who had low stage tumors in the first cancer. This was the preliminary conclusion of a study carried out in Norway and reported at a Chicago meeting of head and neck cancer specialists this September.

A "second primary" cancer is one that is not a recurrence of the first or the result of the cancer spreading from the original site. Instead, it is a completely new one, although the cause may be the same. An example is that one can have a primary cancer in the larynx and later develop a second primary cancer in the lungs. Both may have been caused by smoking, but are otherwise not connected.

The research suggests that patients who had a low stage initial cancer may not be as closely followed as those who had higher stage cancers. The higher incidence of second primary cancers showed up with patients who had the lower stage first cancer, under the age of 66, whose cancers were in the larynx and throat, and who had a good initial treatment of the first cancer.

The results may not specifically apply to laryngectomies, but it reinforces the importance of getting follow-up examinations on the schedule recommended by our doctors. Early detection continues to be a major factor in the effectiveness of successful cancer treatment, and many laryngectomies end up surviving a second battle with cancer.

Nine Cancer Risk Factors

A recent study that focused on the risk factors for developing cancer throughout the world produced a list of nine factors that are associated with the development of various cancers.

The nine were a high body mass index (being overweight), low amounts of fruits and vegetables in the diet, physical inactivity (lack of exercise), smoking, alcohol use, unsafe sex, air pollution, indoor use of solid fuels, and contaminated injections at medical facilities.

As we look at the list some are more likely to reflect the lifestyle of modern, industrialized countries, while others do not. For example, the indoor use of solid fuels and contaminated injections at medical facilities are much more likely to occur in poorer countries.

On a worldwide basis over one third of seven million cancer deaths were directly linked to a combination of the nine risk factors. The risk factors produced twice as many cancer deaths in men compared to women. The largest male-female difference was for mouth or oropharynx cancer, both strongly affected by alcohol use and smoking, was 66% for men and 23% of women. In richer countries liver cancer had the highest difference by gender (59% for men and 37% for women.)

Lung, liver and esophageal cancers have the largest number of deaths in low and middle-income countries. In high-income countries, lung cancer accounted for 52% of all risk factors for causing cancer deaths.
Draft of New Publication Available

A draft of “First Steps” has been placed on the IAL web site. Those with computer access can check it out here: http://www.larynxlink.com.

“First Steps” is a revision of a printed publication distributed by the IAL some years ago when it had the financial backing of the American Cancer Society. It was the revision of a still older publication. It was and still is designed to give to those who are facing the laryngectomy surgery, those who are new laryngectomees, and family members which is particularly useful in the immediate period after surgery.

The publication is currently 20 pages long and contains basic information on larynx cancer; the major ways of speaking period after surgery. The publication is written in clear and simple language, understanding your self as a laryngectomee, showering and bathing; coughing, importance of humidity, using a suction machine, covering the stoma, again, after surgery care at home including keeping the stoma clean, keeping the stoma from shrinking, basic information on larynx cancer; the major ways of speaking period after surgery.

Take care of your 911 needs

by David “Dutch” Helms

After reading several suggestions about contacting the local “911” dispatcher regarding my “condition” as a laryngectomee, I recently decided to do so. Here’s why. After the surgery, I was so commonplace, I was able to walk and run or do almost any activity without any problem. However, as time went on, I noticed that mine was harder and harder to breathe or to do anything that required a lot of energy. This is why I contacted the local “911” dispatcher who was called “911” to get the correct office address. I then drove over and popped in for a visit. They could not have been nicer! They explained my “problem” (being a laryngectomee and a “neck breather”) and asked THEM what information THEY would like to have on hand should I ever call them and be unable to speak. They happily provided me with a short list with which I could deal comfortably with any situation that might arise.

(1) Name, address, telephone number, DOB, and that I live alone.

(2) That I am a laryngectomee (no vocal cords), speak via a voice prosthesis, am a total neck breather, have had a single coronary bypass operation, and have O Negative blood type.

(3) Name, address, & phone of two emergency contact persons. (An out-of-state primary family contact and one local good friend).

(4) Name, address, & phone of my primary physician & ENT.

(5) Listing of the medications that I take daily.

(6) Preferred local hospital for emergency care

(7) Name & Phone of my medical insurance carrier

(8) My Medic-Alert ID number they can use to contact Medic-Alert. (I wear a Medic-Alert ID bracelet)

Needless to say, the experience was painless, short, and, I must admit, LONG OVERDUE. I certainly feel a lot better now about calling “911” if necessary. That I would recommend that ALL of us do this or something similar is a clear understatement. While I am sure each “911” office may [Note: Dutch Helms, who died in 2006, was the much beloved founder of the WebWhispers Internet-based laryngectomee support group. Membership is free and you can join here: http://www.webwhispers.org/join/how-to-join.asp].
In 1978, Mark I. Singer, M.D., F.A.C.S. and Eric D. Blom, Ph.D. pioneered the surgical method of Tracheoesophageal “Puncture” and the valved silicone voice prosthesis that over the past 30 years has become the international standard for voice restoration following total laryngectomy.

InHealth Technologies and their worldwide network of distributors salute Drs. Eric D. Blom, Mark I. Singer, and the late Dr. Ronald C. Hamaker for their historic record of achievement.

Surgical Procedures
Post-laryngectomy surgical procedures developed and pioneered by Mark I. Singer, M.D., F.A.C.S., Eric D. Blom, Ph.D., and Ronald C. Hamaker, M.D., F.A.C.S.

1978 Secondary Tracheoesophageal Puncture Technique
1979 Secondary Pharyngeal Constrictor Muscle Myotomy Technique
1982 Primary Tracheoesophageal Puncture Technique
1982 Primary Pharyngeal Constrictor Muscle Myotomy Technique
1985 Primary Pharyngeal Plexus Neuroectomy Technique

Medical Devices
Tracheoesophageal voice prostheses and related medical devices invented and pioneered by Eric D. Blom, Ph.D., Mark I. Singer, M.D., F.A.C.S., and Ronald C. Hamaker, M.D., F.A.C.S.

1978 “Duckbill” (Slit-Valve Design) Tracheoesophageal Voice Prosthesis (Blom and Singer)
1980 “Hands-Free” Tracheostoma Valve and Adhesive Attachment System (Blom and Singer)
1982 Tracheoesophageal Voice Prosthesis Measurement (Sizing) Device (Blom and Singer)
1983 “Low Pressure” (Flap-Valve Design) Tracheoesophageal Voice Prosthesis (Blom and Singer)
1985 Esophageal Insufflation Test System (Blom and Singer)
1990 Tracheoesophageal Puncture Dilator (Blom and Singer)
1990 Fenestrated Silicone Laryngectomy Tube (Blom and Singer)
1991 Tracheoesophageal Voice Prosthesis “Safety Insertor” (Blom and Coe)
1991 “Hands-Free” Adjustable Tracheostoma Valve (Blom and Singer)
1992 Tracheoesophageal Voice Pressure Manometer (Blom)
1994 “Gel-Cap” Tracheoesophageal Voice Prosthesis Insertion System (Blom)
1994 Tracheoesophageal Puncture Surgical Set (Blom, Singer, and Hamaker)
1996 Tracheoesophageal Voice Prosthesis “Valved Insert” Device (Blom)
1996 “Enlarged Esophageal Flange” Tracheoesophageal Voice Prosthesis (Blom)
2007 Indwelling “Dual-Valve” Tracheoesophageal Voice Prosthesis (Blom)
2008 Combined Tracheoesophageal Puncture Stent/Dilator (Blom)
2008 “Automatic,” Voice Prosthesis Retention Flange Confirmation System (Blom)
To: IAL
925B Peachtree Street NE
Suite 316
Atlanta GA 30309

Enclosed is my tax deductible gift of $5 or more, with my check or money order made out to IAL News.

Name __________________________________________________

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City, State, Country ________________________________________

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Thank you for helping to share hope!

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