It is not too late to make your plans to attend the International Association of Laryngectomees Annual Meeting and Voice Institute in August in Little Rock, Arkansas! You have until August the first to register for the Annual Meeting or Voice Institute and to make a reservation with our hotel and still get the discount rates for both. The dates are August 28th through the 30th for most who plan to come, while those who attend the Voice Institute come one day earlier on the 27th.

Those of us who have attended an Annual Meeting and Voice Institute are convinced that every laryngectomee ought to attend at least one. And many of us come every year, or as often as possible. Even those of us who come every year always feel that we have benefited from coming again and have learned new things and, of course, enjoyed meeting old friends as well as making some new ones. Many of us would never consider not coming if there is any way to do so.

We come for many reasons such as:
• get together with people who understand what we have gone through as fellow laryngectomees. It just feels great to be in the majority for a change, and to feel that natural kinship we have with one another.
• learn about the latest products designed for us. It is not unusual that a major manufacturer will use the Annual Meeting to introduce a new product and you are there to see it up close and perhaps try it out. We also always end up carrying back lots of free samples and literature to use ourselves and to share with others.
• learn just about every development concerning total laryngectomee rehabilitation.
• socialize, celebrate, laugh and eat out
• shop and visit museums, and tourist and historic sites
• obtain help with speaking or other problems we may have
• meet the “celebrities” and “stars” in our field such as the inventors of the products we need and love, the vendors we deal with, and the best medical professionals in the world in the field of laryngectomee rehabilitation
• get together with old friends and make new some ones. No one stays a stranger long at an Annual Meeting
• bring back materials and ideas for our local clubs
• represent our clubs as Delegates who elect those who serve the IAL and shape its direction
• run for election to IAL office
• serve on IAL committees
• enjoy a great learning experience combined with a vacation
• and many, many more

Our hotel this year is the gorgeous and famous four-star rated Peabody Hotel. Those with Internet access can learn more about the Peabody at http://www.peabodylittlerock.com

The room rate we negotiated is more than 40% less than the standard rate, so you will be enjoying truly luxurious accommodations at a bargain price. Our hotel is located in the heart of Little Rock’s
Riverfront Market District. There are lots of very interesting stores, clubs and a great number of restaurants serving a variety of meals and for every budget. Many are within easy walking distance, or you can take the old fashioned electric (but air-conditioned) streetcar. Our hotel is home to the highly rated Capriccio Grill Italian Steakhouse. Treat yourself to a world quality steak.

Little Rock is also home to a number of tourist attractions including the William J. Clinton Presidential library, WW II submarine, Arts Center, Little Rock Central High School library and exhibits, Heifer Project International world headquarters, and many others.

If you drive, ask us about the cheapest place for long term parking. If you fly, the shuttle to and from the airport is free. Your shuttle driver may even give you a quick tour of the major downtown attractions on your way to the hotel.

So let’s make a date to meet in Little Rock in August. Use the information on pages 4, 5, 6 and 7 to register and make your hotel reservations. We can just about guarantee that you will be glad you came!

Remembering Judy Breckon

As we travel to Little Rock this coming August to the Annual Meeting and Voice Institute we are reminded of Judy Breckon who played a major role in helping to organize the last Arkansas meeting of the IAL, which was held in Hot Springs in 1996.

Judy was featured several times over the years in the IAL News because of her excellent esophageal voice and her active lifestyle as an exceptional tennis player. In the 1990s Judy was regularly rated number one or two in her age group in the Arkansas women’s tennis ranking, and in the early 2000s her Super Senior woman’s tennis team (all in their 60s) won the state championship five times, and the Southern Section three times. In 2006 her team was the national championship runner-up losing a close match to Arizona in the finals.

In 2006 Judy was diagnosed with lung cancer, and, while chemo and radiation treatments slowed the process, the cancer had spread and she died in 2008. As her husband Dick put it, “She was a fighter all of her life.”
Little Rock – 2008! Registration Questions and Answers

Question: Should I register for the Annual Meeting, the Voice Institute, or both?
Answer: Register for EITHER the Annual Meeting OR the Voice Institute. Not both.

Question: Which one should I register for?
Answer: Most people have a choice. 

The Annual Meeting runs from Thursday August 28th to Saturday August 30th. It is designed for laryngectomees, family members and others. The Annual Meeting is three days of educational and social programs on most aspects of life as a laryngectomee. Those attending the Annual Meeting may also attend sessions of the Voice Institute on a space-available basis. 

The Voice Institute runs from Wednesday August 27th to Saturday August 30th. It is designed for laryngectomees (in two categories), speech-language pathologists, and students in graduate programs in speech pathology. It is an intensive four days of lectures and hands-on experience on all aspects of laryngectomee rehabilitation. There are four categories of Voice Institute attendees:

Voice Institute Pupils (VIP) are laryngectomees who attend primarily in order to improve their speech, learn more about laryngectomee rehabilitation, and to serve as demonstration subjects for others in the Voice Institute. They are welcome to attend all four days, but are only required to attend from Thursday to Saturday. 

Laryngectomized Trainees (LT) are laryngectomees who attend from Wednesday through Saturday. If they wish, they may take a test at the end of the week. After passing the test and completing a one year internship under the supervision of a trained speech pathologist, they may elect to be listed in the IAL Directory of Alaryngeal Speech Instructors.

Speech Pathology Trainees (ST) are speech-language pathologists who attend from Wednesday through Saturday. If they wish, they may take a test at the end of the week. After passing the test and completing a one year internship under the supervision of a trained speech pathologist, they may elect to be listed in the IAL Directory of Alaryngeal Speech Instructors.

Graduate Students (GS) are individuals enrolled in graduate speech pathology programs. They attend from Wednesday through Saturday. If they wish, they may take a test at the end of the week, and after passing it and serving a one year internship under the supervision of a trained speech pathologist, they may elect to be listed in the IAL Directory of Alaryngeal Speech Instructors.

All Annual Meeting and Voice Institute sessions are conducted in the English language.

Annual Meeting Registration - LITTLE ROCK

Voice Institute Registration - LITTLE ROCK

Answer: Register for EITHER the Annual Meeting OR the Voice Institute. NOT BOTH see page 4

Step 1

Step 2
| **2008 IAL Annual Meeting/Voice Institute Schedule** |
|-----------------------------|-----------------------------|
| **Annual Meeting** | **Voice Institute** |
| **WEDNESDAY AUGUST 27** | **(Note: all Committee and Board meetings of the IAL are open to all.)** |
| 8:00-5:00 | 8:15-9:00 | Surgical Overview of Laryngectomy |
| 12:00-5:00 | 9:00-10:00 | Artificial Larynx Training |
| **THURSDAY AUGUST 28** | **10:15-11:15** | Esophageal Speech Training |
| 9:00-10:00 | 11:15-12:15 | Tracheoesophageal Speech Training |
| **FRIYDAY AUGUST 29** | **11:15-12:15** | Artifical Larynx Speech Evaluation Process |
| 9:00-10:00 | 11:15-12:15 | Hands-On Clinic I |
| **SATURDAY AUGUST 30** | **11:15-12:15** | Hands-On Clinic II |
| 9:00-10:00 | 11:45-2:45 | Hands-On Summary, Q & A, Presentations |
| **TENTATIVE SCHEDULE** | **3:15-4:30** | IAL Test-Optional |
| | **5:30-6:15** | Esophageal Speech Refinement |
| | **7:00-9:00** | WebWhispers Dinner |
| **8:00-5:00 IAL Committee Meetings** | **8:00-1:15** | Joint Sessions for Annual Meeting and Voice Institute Participants |
| **9:00-10:00 Dental Issues & laryngectomy/radiation** | **9:00-10:00** | Keynote Address – “30 years of inventing Medical Devices to Restore Voice and Human Dignity” (Dr. Eric Blom) |
| **9:00-10:00 Dental Issues & laryngectomy/radiation** | **9:15-10:15** | TEP Troubleshooting, Complexities |
| **8:00-9:30 Caregivers Continental Breakfast** | **5:30-6:15** | Esophageal Speech Refinement |
| **8:00-9:00 Hearing Issues** | **5:45-6:30** | Artificial Larynx Refinement Issues |
| **8:00-9:00 Hearing Issues** | **6:00-9:00** | VI Reception (VI registrants only) |
| **6:00-9:00 WebWhispers Dinner** | **7:00-9:30** | AIOL Test-Optional |
| **7:00-9:00** | **9:00-10:00** | Swallowing Disorders |
| **10:00-10:30** | **9:15-10:15** | TEP Troubleshooting, Complexities |
| **10:30-12:00** | **10:15-11:15** | Esophageal Speech Evaluation Process |
| **11:15-12:15** | **11:15-12:15** | Hands-On Clinic I |
| **11:45-2:45** | **11:45-2:45** | Hands-On Clinic II |
| **2:45-3:15** | **2:45-3:15** | Hands-On Summary, Q & A, Presentations |
| **3:15-4:30** | **3:15-4:30** | IAL Test-Optional |

**Hotel Info:**

**Peabody Hotel**
Statehouse Plaza
Little Rock, Arkansas
Phone: (501) 906-4000
Fax: (501) 865-6670
Toll free: (800) 732-2639

Our group discount rate for this luxury hotel is $110/room/night (single or double occupancy).

This rate is available from Sunday, August 24 through Sunday, August 31 if you would like to come early or stay late.

The deadline for making reservations to get this rate is August 1st.

(Mention that you are with the IAL meeting when making reservations.)

You may also register online at
http://www.larynxlink.com/littlerock/
or http://www.peabodylittlerock.com/

**Being Understood on the Phone**

Have trouble being understood on the phone? Find yourself spelling things out?

One suggestion is to keep a copy of the phonetic alphabet call signs near your phone:

A  ALPHA AL fah  N NOVEMBER NO vem BER
B  BRAVO BRAH voh  O OSCAR OSS car
C  CHARLIE CHAR lee  P PAPA PAH pah
D  DELTA Dell tah  Q QUEBEC KWEENI keck
E  ECHO ECK oh  R ROMEO ROW me oh
F  FOXTROT FORKS trot  S SIERRA SEE air RAH
G  GOLF GOLF  T TANGO TANG go
H  HOTEL HOH tell  U UNIFORM YOU see FORM
I  INDIA INN dee AH  V VICTOR VIK tah
J  JULIETT JEW lee ETT  W WHISKEY WISS kee
K  KILO KEY loh  X X-RAY ECKS ray
L  LIMA LEE mahn  Y YANKEE YANG kee
M  MIKE MIKE  Z ZULU ZOO loo
Annual Meeting

“Our annual attendance at the convention is a pilgrimage to rededicate ourselves to the cause of the laryngectomee who needs assistance. It is also an avowal to help those who are now going through the same experiences to which we were subjected, the temporary frustration, the uncertainty of the future that too often follow laryngectomy. We come to help others to help themselves, to inspire those who have recently undergone the ordeal of laryngectomy to the extent that they too, in their turn, can be of help.”

Correction

The February 2008 issue of the IAL News contained a quote from former IAL President Hazel Waldron which was originally published in the newsletter in 1971. It incorrectly identified Hazel as “the first woman and first electronic artificial larynx user to become IAL President.” That honor actually belongs to Mabel Disenger. Thanks to Mary Jane Renner who spotted the mistake. We regret the error.
Michael Buffer is almost certainly the most famous voice in boxing. His good looks and copyrighted “Let’s get ready to rumble” has introduced the biggest boxing matches in recent years.

Buffer released the following statement:

“The cancer was detected at a very early stage in mid-February and three weeks ago I was operated on by one of the best surgeons in the field. I am recovering well and feel stronger every day. The early detection prevented any spread that would have jeopardized my vocal ability. I am looking forward to being back in the ring next week (Saturday, April 19th) as Bernard Hopkins faces Joe Calzaghe on HBO PPV from Las Vegas. The support and encouragement for a return to good health received from my friends and members of the sports promotion and broadcasting community was overwhelming and greatly appreciated. I was very surprised to learn how many cancer survivors are out there and how they instantly rallied to my support. Hopefully, my circumstances will encourage others to avoid smoking and second hand smoke when possible, and please get regular checkups.”

My physicians are not sure of the cause as many things can contribute to cancer but one very distinct possibility is smoking. After a decade of smoking, I quit 35 years ago but the damage may have begun. Hopefully, my circumstances will encourage others to avoid smoking and second hand smoke when possible, and please get regular checkups.

No further details about the nature of the surgery have been provided, but the best educated guess is that Buffer had laser surgery to remove the tumor since his voice appeared to be close to normal in announcing the Hopkins-Calzaghe boxing match in mid April.
The syndicated television program Inside Edition aired a story on May 8, 2008 about a young woman facing laryngectomy surgery. The narration stated: “It was a heartbreaking final message from a mother to her children,” These are going to be the last words that I’m ever going to say to you?” Cynthia Howell is about to lose her voice forever, but she wants her four children, especially two-year-old Miranda, to remember what her voice sounds like. So Cynthia set up a home video camera and is recording an emotional final message to them: “I just want you guys to know how much I love you. I won’t be able to say it with my mouth, but I’ll show you how I feel it in every other way I can,” Cynthia said into the camera.”

This was followed by: “Now, at the age of only 34, she is facing a lifetime without a voice,” and she said before the surgery, “My son told me last night that he’s really going to miss me telling him that I love him.”

And following the surgery the narration continued, “Six hours later, Cynthia’s voice is silenced or balanced with a story about successful laryngectomy rehabilitation. Some suggested inviting Ms. Norville and the program film crew to the IAL Annual Meeting to do a segment that would be more positive, hopeful, and accurate. However, the skeptics have suggested that the Inside Edition producers might only be interested in an emotional and sensationalized “human interest” story than being concerned with accuracy and balance. Programs like Inside Edition have been described as “info-tainment”—shows appearing to be news programs, but dedicated at least as much to entertaining the audience than educating it.

Among the questions asked by those in the laryngectomee community included how such a misleading story came to be aired to a national audience in the first place? Who was responsible for this negative and distorted message? Some wondered that it was almost certainly the fault of Inside Edition in major part, while others wondered about the competency of her medical caregivers if she had not gotten an accurate picture of speaking options after laryngectomy. Had she received a visit from a local laryngectomee club representative? Had she been told about her chances of speaking again. Was Mrs. Howell in any way at fault herself? What was the cause of her cancer? And I’m really thrilled when anyone pronounces it correctly and understand what it means to be a laryngectomee when I get a negative reaction in a demeaning tone, “What’s wrong with your voice?” But, for the most part, I don’t allow any of the negatives to influence my mood or day. As we all know, life is too short. I take pleasure watching the fun and even quirky ways people reflect their own perception and personality into their own life. All of us have been flattered. As my momma always said, “Imitation is the best flattery.”

As for her medical team, the evidence appears that standard protocol was followed in educating Cynthia about the consequences of laryngectomy and the rehabilitation prospects for voice, etc. She was also provided with a copy of the standard reference for laryngectomy rehabilitation, and the nearest laryngectomee support club was involved. But as those of us who work with patients facing surgery know, they do not always read what is provided, or hear and understand everything said.

Another factor which lead to some skepticism is that, with her husband out of work and they and their four children being recently evicted, Cynthia has actively sought and received financial donations as a result of the publicity. The local laryngectomee support club and others affiliated with the hospital where her surgery was performed have worked to supply her with information about governmental resources for which she and her family may qualify.

are you a laryngectomee?

Before my surgery in 1998, the only laryngectomee I was aware of was Ned, a cartoon character from the TV show South Park. Ned was a Vietnam veteran and spoke with an electrolarynx. Come to find out Ned’s character was fashioned after one of the creators’ uncle. Even now, ten years later, my ears perk up when someone asks if I’m a laryngectomee; it is really thrilling when anyone pronounces it properly.

Most of my relatives, long time friends and colleagues in the Athens and Toccoa Symphonies in which I play my cello pronounce “laryngectomee” correctly and understand what it means to be one. When someone puts his or her finger on their throat or puts their fist up-against their neck and talks in a low gravelly voice I know that person is aware of that phrase. Nevertheless, non-specialists can give a more complete story. Cynthia also stated that “There was so much more to the story than what was shown on Inside Edition. It was mainly supposed(d) to be about medical malpractice.” She also wrote “...there was hours of footage that was cut out” and only “the saddest part of the footage was shown on TV.” She concluded by saying, “It is not my fault that the things I tried to say did not show on TV.”

She and her husband are reportedly suing their physician who she claims failed to diagnose her larynx cancer at an earlier point. This at least caused some to initially wonder if this played any role in a story that placed so much emphasis on loss and suffering. She stated that her doctor had found a mass on her vocal cords two years previously, but told her there was nothing to worry about. She also wrote, “I was not looking for sympathy or trying to mislead anyone with my story.”

Cynthia concluded by writing that her only personal mistake was to misunderstand what she had been told about her chances of speaking again. “But the truth is that my voice is gone and I will never talk again with my voice. I am grateful that there are other speaking methods out there.” As for her medical team, the evidence appears that standard protocol was followed in educating Cynthia about the consequences of laryngectomy and the rehabilitation prospects for voice, etc. She was also provided with a copy of the standard reference for laryngectomy rehabilitation, and the nearest laryngectomee support club was involved.

But as those of us who work with patients facing surgery know, they do not always read what is provided, or hear and understand everything said.

Another factor which lead to some skepticism is that, with her husband out of work and they and their four children being recently evicted, Cynthia has actively sought and received financial donations as a result of the publicity. The local laryngectomee support club and others affiliated with the hospital where her surgery was performed have worked to supply her with information about governmental resources for which she and her family may qualify.
I talk funny, well different. That is, I communicate with an electronic device called a Servos as I lost my vocal chords to throat cancer back in 2000. I've gone three rounds with throat cancer. First time I was scared to death, second time I lost my vocal chords and hence my natural voice, and the third time it nearly killed me. After I lost my voice I took early retirement. I was a salesman and I decided that the market for salesmen who couldn't talk was small, so to say the least, and would only get smaller. So what else could I do? I started gardening! And boy my life ain't been the same since. I thought about my ability to talk was a life changer; hey, gardening is even more so, but in a good way.

When you've had cancer you're always worried it's coming back or has already come back and you don't know any natural responses to having had the disease. Will I still be alive this time next year? I had thoughts like that a great deal of the time, tried not to let on to my loved ones, but hey, I was scared.

And then it happened, not all at once but slowly, slowly. I kinda got involved with gardening through the backdoor, so to speak. I had a friend who fed birds on his back patio and kinda got involved with gardening through the backdoor, so to speak. I had a friend who fed birds on his back patio and I was feeding me some wild birds and have wildlife come to my yard to visit me (as I interpreted it). Why, I'd have company all the time: birds, squirrels, coons...hey, I'd have company all the time: birds, squirrels, coons...hey, they both looked at me, and the surgical nurse looked at me, and they both looked at each other, and there was all bust out laughing at the same time.

Oh, back to that other thing, cancer and my doctor. So I'm sitting in his office and he comes in with his surgical nurse and the grab my hand tenderly and squeezed it like I might die while I'm sitting there in the chair. Right away I know the news ain't good, and it ain't. Most folks in my situation now have a year, maybe, probably less, but before he has time to tell me anything substantive about what's going on with me I just ask him one question, "Hey doc, give it to me straight, should I plant annuals this year or perennials?"

Well I kinda had a good guess on my face that I have when I said it, and he looked at me, and the surgical nurse looked at me, and they both looked at each other, and there was all bust out laughing at the same time. That was eight years ago. I've been growing perennials all these years and I'm still here. You see I gotta be. I mean, who's gonna mulch the cone flowers. Who's going to weed? And every I got my yearly checkup. I ask the Doc the same old question after he checks me out, "Do I plant perennials or annuals this year, Doc?"

And then we all bust out laughing.

One caveat, some folks aren't as lucky as I've been so far, their situation is grave and the humor I implied in my own situation in no way should belittle the fight these folks have on their hands even as we speak. I wish them all well.

(Paul, his wife Linda, and his mother Martha live with their garden and various wild critters in Piedmont, Alabama. Contact him at Sinai@ mindspring.com).
**Advice on Carrying Medical Information**

By Mike Roenekrans

Four weeks ago I had a very nasty fall while taking out the garbage and ended up in a tangled heap jumbled between the curb, my driveway and a parked car. I could not move or straighten out my tangled legs, and then realized that the moisture pouring down was from my bleeding face and arms.

Larys are not very good at shouting, so there was little point in shouting for help. My EL was hanging around my neck, and my cell phone was clipped to my waist. I used the cell phone to call 911, and because I spoke slowly and articulated as well as I could, I was completely hidden from the street, so the 911 operator acted as a relay between me and the EMS (Emergency Medical Services) unit so I was able to guide them to where I was laying.

When they arrived, the first thing they asked was how old I was, and the second was what medications I was on. I told them the frustrated looks on their faces in anticipation of the answer, but I fooled them. I asked them to reach in my back pocket which I could not reach and pulled out two sheets of paper, listed all of my meds, and the second was my medical history. At the top of the medical history page in bold print was “Laryngectomee – Total Neck Breather.”

Everyone, but especially larys, should carry that information on them at all times, and in this modern day, that goes for a cell phone as well.

There was one silver lining to that dark cloud. I have yet to be permitted to take out the garbage. I know this is only a temporary respite, but I will enjoy it while it lasts.

(Mike lives with his family in Plantation, Florida.)

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**The Last Lecture**

For many years professors have been asked what would they speak in a lecture to their students if they knew they were dying and this would be their final lecture. The idea was to impart the important truths they could to their students about their subject fields, or about life in general.

Recently a Carnegie Mellon University professor, Dr. Randy Pausch, who is terminally ill with pancreatic cancer, was asked to give this lecture. But instead of talking about his field, computer science, or life and death, his last lecture was entitled “Achieving your Childhood Dreams.” The lecture has been turned into a book and a videotape of the lecture was placed on the Internet YouTube website. Millions of people have watched it. Those with computer access can watch and listen to the inspiring lecture here:

http://www.youtube.com/watch?v=ajs_MqixcSo
Keeping stuff out of our stomas and lungs

**Lubricants**

There are so few of us laryngectomees (just 55,000 out of a total population of 303 million in the U.S.) that it should come as no surprise that there are not many products made specifically for us and the unique problems we face. So laryngectomees often improvise and attempt to use products made for one purpose in the general population for some other problem we have. This can cause problems. A case in point is using lubricants in, but also close to, the stoma.

A problem we have is that our stomas can dry out and hard dried mucus crusts form on the rim of our stomas. Unfortunately, some have attempted to deal with the problem by using products like Vaseline inside or around the edges of our stomas. The most knowledgeable experts warn us against doing this since even small amounts which end up going down into the lungs can accumulate and eventually cause problems.

There is actually a name for a disease which results from oil based products getting into the lungs. It is called Exogenous (coming from outside the body) lipoid (resembling fat) pneumonia. And according to an article published on the respected MedLine Internet web site, the problem can be particularly troublesome since it can produce a CT scan image which looks like lung cancer. This can lead to further wasted medical tests and even unnecessary exploratory surgery.

It turns out that the lungs are not at all designed to easily get rid of things which end up in them which don't belong there. This is in major contrast to the digestive system which has lots of ways to get rid of unhelpful things. And it is also not just petroleum based products which can cause the problem. “Natural” oils such as olive oil, cottonseed oil, cocoa butter, etc., are no safer.

The evidence is pretty solid that oil based lubricants should not be used inside the stoma or so close that they can migrate into the lungs.

Still another kind of lubricant to avoid, at least using inside the stoma or for an extended period of time, are products like Neosporin or Bacitracin creams. In addition to containing oils, if they are used for extended periods of time they can produce antibiotic-resistant bacteria in the area of use.

**Tap Water**

Some laryngectomees will squirt some tap water into their stomas as a way to loosen mucus. Others may hope to save the hospital it is no accident that sterile distilled water is used which is free of anything dissolved in it.

The problem is that tap water contains a great many things. A major contaminant is dissolved minerals, but a laundry list of other chemicals and contaminants commonly find their way into tap water, although the amounts are often quite small. The scientific research on potential harm from using tap water in any amount in the lungs is not solid. But below Dr. Carla Gress, SLP-CCC provides an opinion: “This morning I found myself pressing my daughter’s dress and my son’s shirt, so that all would be nice to join the neighborhood Easter egg hunt. Whenever I iron any clothes (and I try to buy clothes that don’t require it very often), my memory goes back to my days growing up on a farm in assistant discount. We didn’t have Nintendo, Xbox, soccer teams, computers, etc., to occupy our time - we had chores. Mine, as soon as I was old enough, was to iron the clothes for the family. There was no ‘permanent press,’ and very few knits, either. Mostly everything was 100% cotton, which resulted in lots of wrinkles. I remember how thrilled I was when we got a steam iron, one that also would shoot out a fine mist to dampen the clothes, which meant I didn’t have to dampen the clothes with a sprayer bottle ahead of time.

After a couple of years, the iron started to look pretty grungy, with lots of crusty deposits on it, almost like barnacles, particularly at the top where you would fill it with water. My mother explained to me that we really were supposed to use distilled water in the iron, but since we couldn’t afford to buy it, we used tap water. These were mineral deposits from the water that would build up over time. Eventually we would have to buy a new iron, because the deposits were also on the bottom of the iron where the steam came out, and they would stain the clothing in such a way that nothing would remove them, and it would ruin the clothes.

When I think about what tap water did to the iron, I have a hard time believing that it is harmless when it goes into the stoma. It ‘might be’ - to my knowledge there are no scientific studies that demonstrate a definite link with any particular disease - but then again, there aren’t any studies that show that it is harmless either.

Those of you who know me, that I never buy into the argument of “Well, I’ve done it for years and I’ve never had any problems because of it.” That would be like saying that I know someone who smoked for 20 years and hasn’t had lung or head cancer, so cigarettes must be safe. The reality is that all sorts of ill health effects can be occurring that you are not acutely aware of. I won’t tell you not to use tap water. That is your decision. But you should understand the potential risks involved. I’ve seen too many steam irons in my life to think that is a good idea”.

(“...with the iron...”)

Dr. Carla Gress

...with the iron..."

In concluding, it is pretty solid that oil based lubricants and tap water can cause problems. The evidence is pretty solid that oil based lubricants can cause problems.

**Humidifier Fever**

Dirty humidifiers and air conditioners can make you sick. The American Medical Association, the Environmental Protection Agency and other organizations involved with the prevention of disease warn against a respiratory illness they call “humidifier fever.” It is caused by breathing in mold, mildews, fungi, viruses, bacteria and dust mites that can be distributed by humidifiers and air conditioners. Exposure to these contaminants in the air we breathe can cause allergies, respiratory irritation, excess production of mucus, and even infectious diseases of the eye. The symptoms range from mild fever with headache, to a generalized feeling of not feeling well — to serious illness similar to the flu with high fever, cough, muscle aches, chest tightness and breathlessness.

The mold, fungi viruses and bacterial contaminants are particularly known to grow in portable humidifiers if the water in them is left to stand and if the water tank is not thoroughly cleaned and dried. Cleaning portable humidifiers on a daily basis is particularly important for those that are the “cool mist” (impeller) or “ultrasonic” types. These work by breaking down the water drops into tiny particles which are dispersed into the home (along with anything which is in the water). Those which are less likely to disperse these contaminants are “warm mist” (steam) or evaporative humidifier types. With these, only the water is dispersed and the air is kept cool.

Cleaning the humidifier tank should be done with a bleach solution or other disinfectant, 1% solution of hydrogen peroxide, or follow the manufacturer’s directions. Use of products which are added to the tank water can help control for bacteria and other organisms.

Since contaminants also increase in homes with high humidity generally, it is a good idea to make sure your indoor humidity is no higher than 50%. Inexpensive digital humidity gauges can be found in stores like Walmart or K-Mart in the part of the store where temperature gauges are located. Exhaust fans in kitchens, bathrooms and laundry areas should be checked to make sure they are performing as intended. Examining the drip pan on your air conditioner for signs of contaminants can also be helpful to make sure they are not the source of potentially disease-causing organisms.

Interesting Larynx Cancer Numbers from the National Cancer Institute

The National Cancer Institute estimates that 12,250 men and women (9,680 men and 2,570 women) will be diagnosed with larynx cancer in 2008 in the U.S. Of those, 3,670 will not survive. Historically the average age for the diagnosis of cancer of the larynx to occur was 65 years of age. The average age of diagnosis of larynx cancer and the highest death rate is for Black males.

The incidence of larynx cancer continues to decrease, but at a slow pace. It is estimated that about 1/3 of one percent of men will develop larynx cancer between their 50th and 70th birthdays. This reflects that the most common type of larynx cancer, squamous cell, is relatively slow to develop. It is estimated that in 2005 (the latest year for which numbers are available) there were approximately 93,096 U.S. men and women alive who had a history of larynx cancer

Blowing your Nose

Some laryngectomees who use the TEP speech method can blow their noses. Laryngectomee and Californian Steve Statton demonstrated this method: “I occlude my stoma, keep my mouth closed tight, place my index finger on one side of my nose and my thumb on the other. I push air through my T.E.P. at the same time I open and close my nostrils with my finger and thumb. I find it very helpful right after a shower. Steve reported that he told his ENT MD and speech therapist, but they didn’t believe him until he demonstrated his method.

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Then there was CAL, the California Association of Laryngectomees. This was awesome. Being in the presence of people from all over California dealing with situations you may not dream of. I live in Southern California so I had no idea what to do in this regard, other, traveling, and hospitals/doctors. All the stuff that just happens in life. This was mind-boggling, and it was all here in California.

When they started talking about the IAL, I had a difficult time imagining there was more. What did they do? Who were they? And what more do they have to offer than this? One of the things I learned years ago is that there are very few secrets to this life. I often wonder about the answer all too often depends on the ability to ask the question. I was not asking very good questions so I felt I was getting sub-standard answers. DUH. I even sat down with Jane del Vecchio, President of the IAL and tried to understand more by having a one-on-one. I think she answered the questions I asked; but because I was not hearing what I could support it didn't seem to be what was going on. So, for many years there was this void when I would think of the IAL. It was not empty; I just could not connect the dots for myself.

In my crab, I miss much of what the IAL can offer because of my limited ability to travel. But I have been able to attend a few meetings on the West Coast, and they were amazing. The people are always awesome. Our vendors are truly angels. The vendors I have met are always a highlight to me. It is like running into old friends. Yes, we support their business; but I support the Department of Water and Power too, and they don't have a clue who I am, and they seldom smile. Even when I think the subject matter of a particular speaker doesn't apply to me, I am surprised when it is over that I have learned another secret to day-to-day life made easier. We are never too old to learn, but we are often too stubborn.

I recently took a family vacation, and we ended up on the Avenue of the Giants, the redwood forests of Northern California. This is a breath-taking spot of the world. While I was there for a few days, I was truly able to relax and on a local level, I realized the IAL is our giant. The footsteps we are following in are tremendous. The fact that in 1952 a group of people could foresee the monumental need for this information to be distributed worldwide is pretty amazing. I asked David Blevins (IAL, Near Editor) if we had a “history” of the IAL available. Wow! What a read. I sat there and read word for word what they put together, held onto, and fought for.

What does the IAL do? It takes up where local and state conferences leave off. It invites people from all over the world to come together and share what is happening. Sometimes we have to discuss a failure, but more often it is a 3-4 day discussion of progress in our community, and our stories of “our” giants and their missions. We often think there is nothing more the programs have to offer us, maybe that is true. But I really sort of doubt it. There are always new buttons, new devices, and the new and improved models of this and that. They producers end it is from speech aids and oral supplements. Wow! Find that at 7-11 or Stop’n Go. But that isn’t all; that is just the beginning. We have a Voice Institute for all our types of speech. No matter what you use, we need to be understood. These are dedicated people that put this program together to bring the best of the best together. But one step beyond that? The people you meet there. The people who inspire hope, bring peace, the ones who quietly teach by just being. Not all lessons are learned in a classroom. Not all inspiration comes from a master’s degree. Seeing the survival of great warriors will inspire great things in all of us.

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Debi Austin

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Stoma or mouth odor?

A question was recently asked about mouth and stoma odors. It turns out that laryngectomees are basic to a bad breath due to changes in saliva from radiation treatment as well as from mucus production. One SLP (Speech/Language Pathologist) recommends that in addition to brushing and using mouthwash we might benefit from using either a soft bristle toothbrush to brush the tongue, or a tongue scraper.

We have been told that under ordinary circumstances, there should be no offensive odor emanating from the stoma. If there is an odor it can indicate an infection.

If you are a TEP speaker or traditional esophageal speaker you can get some idea of your stoma odor by rinsing your mouth well, and then try to speak with your mouth closed. If you are a TEP speaker the air will enter your esophagus and come up into your mouth and nose area. Since your mouth is closed the air will exit your nose and you can smell its odor. The same basic idea works for traditional esophageal speakers as well. Just attempt to speak with your mouth closed.
High Flight

Oh! I have slipped the surly bonds of earth
And danced the skies on laughter-silvered wings;
Sunward I’ve climbed, and joined the tumbling mirth
Of sun-split clouds – and done a hundred things
You have not dreamed of – wheeled and soared and swung
High in the sunlit silence. Hov’ring there
I’ve chased the shouting wind along, and flung
My eager craft through footless halls of air.
Up, up the long delirious, burning blue,
I’ve topped the windswept heights with easy grace
Where never lark, or even eagle flew –
And, while with silent lifting mind I’ve trod
The high untrespassed sanctity of space,
Put out my hand, and touched the face of God.

Philip and Patricia Clemmons Perish in Plane Crash

Philip and Patricia Clemmons, 65, along with his wife, Patricia, 64, died in the crash of their single engine private airplane in Ohio on May 12, 2008. They were on a flight from their home in Cullman, Alabama to Montreal, Canada where they had recently purchased an apartment where they intended to live part time. Philip was a co-founder in 1988, along with his brother Terry, of the Elk River Safety Belt Company. His wife Pat was also a co-owner and headed the customer relations department. They had a plant in Canada to which Philip made frequent business trips.

Those in the laryngectomee community knew Philip as an extraordinarily positive, charming, gentle, witty, kind, sensitive, and inspirational individual. He was a role model for the power of positive thinking. A survivor of both larynx and lung cancer, Philip was in too much of a hurry to get back to living a full life to spend much time in recuperation. He was back at work full time after just a couple of weeks of recovery from his laryngectomy surgery. Philip had an excellent TEP baritone voice that, along with his hands-free valve, made him unrecognizable as a laryngectomee to most people. He collected pictures of sunrises, and loved to listen to country music and to dance.

After becoming a laryngectomee Philip decided he wanted to become a hot air balloon pilot, and he enthusiastically thrust himself into that activity. And after becoming enthralled with the view from above he took the lessons necessary to obtain a private pilot’s license. Hometown friends described him as an adventurous man who was determined to live life to the fullest. He drove a convertible and wrote to a friend to whom he sent a photograph of him and his grandchildren in the car, “the top is always down.” In many ways, that was a metaphor for how he chose to live his life—fully exposing himself to the world and everything in it.

In his business life Philip was a member of the Board of Trustees of the International Safety Equipment Fall Protection Group. His business primarily designed and manufactured safety harnesses used in a number of dangerous industrial occupations. He was an innovator and much loved by his employees whom he treated as friends.

He and Patsy were also very much involved in the life of Cullman. She was a driving force behind the town’s Octoberfest activities and Woman’s Fellowship, and both were active in their church. They were also helpful in the creation of a hospital in a very poor village in South America. Philip was also dedicated to animal welfare through his work with the Cullman Area Animal Welfare Association.

Philip was a frequent contributor to the WebWhispers Internet-based laryngectomee support club’s e-mail correspondence group, and could always be counted on to provide wise counsel. His correspondence frequently came while he was on the road as often as when he was in Cullman or Montreal. As an advocate for cancer survivors, he was awarded the Life Inspiration Award from the American Cancer Society in 2001 and was the speaker at the organization’s award banquet.

IAL President Tina Long and Board member Janice Hayes attended the funeral. Married for 47 years, Philip and Patricia were buried together.

Those of us who knew Philip cherish his memory and extend our profound condolences to his family and many friends. Our community (and the world) is the poorer for his loss. There is a quotation from an unknown source (some credit Leonardo Da Vinci) which was printed on the funeral service announcement: “When once you have tasted flight, you will forever walk the earth with your eyes turned skyward, for there you have been, and there you will always long to return.”

A famous poem that is a memorial for all pilots:

High Flight

Oh! I have slipped the surly bonds of earth
And danced the skies on laughter-silvered wings;
Sunward I’ve climbed, and joined the tumbling mirth
Of sun-split clouds – and done a hundred things
You have not dreamed of – wheeled and soared and swung
High in the sunlit silence. Hov’ring there
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Pilot Officer Gillespie Magee
No. 412 Squadron, RCAF
Killed 11 December 1941

Philip receives ACS award

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Pilot Officer Gillespie Magee
No. 412 Squadron, RCAF
Killed 11 December 1941
We laryngectomees need it all

(Part 3)

By David Blevins, IAL News Editor

The first two parts of this editorial appeared in the February and May, 2008 issues of the IAL News. Those with computer access can download and read or print these issues at our web site: http://www.larynxlink.com/Main/newslett.htm

In the first two parts I wrote that I am personally convinced that our laryngectomee community needs all of the resources which currently provide information and support to our brother and sister laryngectomees. I also wrote that I am convinced that every laryngectomee has a duty to support every one of these resources to the extent each is able to do so. The reason is simple. No one but other laryngectomees understand the needs and can and will provide what is needed and which we are uniquely qualified to provide.

Another reason why I think we realistically have no alternative than to support one another and these resources is that there are so few of us (in the US, just 55,000 out of a total population of 300 + million). With so few to begin with we must come to understand, accept and act on the certain knowledge that if we want to guarantee that these resources continue to exist for us now and for future laryngectomees we must ensure this by supporting them. Those two critically important questions apply: “If not us, who? “If not now, when?”

This idea that laryngectomees need to work to help one another is one of the core ideas associated with all laryngectomee organizations. This is the concept of “self-help.” It simply means that we must help ourselves and one another. It has been a continuous theme of the IAL and of our community as a whole for over 50 years. This concept is, of course, why each of the resources serving laryngectomees rely for their existence in the first place. We had needs that were not being provided by the medical community alone, and these unmet needs are still there. As one ENT medical doctor put it in reference to the need for laryngectomee support groups, “I can remove your cancer, but I can’t assist you and your laryngectomees how to live.” That is the kind of information and example fellow laryngectomees help provide.

I also believe that we should support all of these resources regardless of our individual needs for them when we went through our own primary rehabilitation, or what our needs are now. The question is not whether you or I have a personal need for each of these resources now, but whether ANY laryngectomee does. If any does, then I am convinced we owe it to one another to support them.

The essential laryngectomee services I believe we must have and support are the International Association of Laryngectomees, WebWhispers, our local support clubs, hospital visitors, and (to the extent possible) the medical professionals. These two serve us best. The IAL was needed when we went through laryngectomy. They were going back more than five decades of supporting fellow laryngectomees through these agencies, and nothing has occurred in the area of our rehabilitation that has eliminated the need for our involvement in supporting one another and supporting them. The IAL was needed when it was founded more than 50 years ago (and earlier for some local support clubs), and it and we are needed every bit as much now.

In Parts One and Two I focused on why we need the International Association of Laryngectomees and WebWhispers, the Internet-based support club. In this part I focus on our local laryngectomee clubs that are also the primary source of pre and post-surgery hospital visitors as well as ongoing support for those who need it. In the past two months any local club has had two individuals who were facing laryngectomy surgery come to our meetings. They and their spouses had lots of questions about what to expect from the surgery and afterwards. In addition to seeking information, they needed to meet with people who had been through what they were about to face. Although they may not have fully understood it at the time, they needed reassurance. They needed to hear us speak and joke around with each other. They needed living proof we provided by just being present that there can be a full life after laryngectomy.

While my club also serves other functions including social ones, this is the mission we believe is most important—to provide information and hope to those facing surgery and relieving the pain of feeling totally alone and facing a dreaded disease and the losses that come from the surgery. This is a job we are uniquely qualified to perform. There is no real substitute for clubs and those individuals who perform pre and post hospitalization visitsations to help patients and their families. We have credibility no one else has.

The number of local laryngectomee support groups is declining, but the exact number of clubs is difficult to know with certainty. In 1986 there were 316 local support club members of the IAL. In 2002 that number had dropped to about 150. The best guess is that there are fewer than 100 member clubs now, and appear to be going out of business at a faster rate than new ones are being created.

The “IAL Notebook” section of the September 2002 issue of the IAL News describes the kinds of things the strongest clubs do that have contributed to their staying in business. Those with computer access can download and read or print it out from this website: http://www.larynxlink.com/Main/newslett.htm

The article lists and describes the characteristics of the strongest clubs. Included are making the existence of the club known to all ENT MDs and SLPs in the area and local hospitals where the surgery is performed as well as local ACS chapters; identify and stay in contact with every laryngectomee in the area regardless of whether they are actively involved with the club; meet at least monthly; screen and train hospital visitors; mentor future leaders; distribute a newsletter; and maintain a loaner closet.

There is no substitute for face-to-face communication between a fully recovered laryngectomee and someone facing the surgery. And the best way to sustain pre and post-hospitalization visitations and have an on-going source of information and support is through the local club. Attendance at local club meetings has always been a challenge. In the mid 1960’s during a time when the number of clubs was increasing the IAL News contained this quote: “The (Rehabilitation) Committee believes that a large attendance is greatly needed in the future. It is better that each patient be fully rehabilitated, but if he is willing to re-enter the milieu of his former friends and society and no longer attend meetings, the committee should consider that its work has been well done. However, it is easier to require than to give; hence, a laryngectomee should be reminded that the future laryngectomees need the same encouragement that was given to us.” (IAL News, February, 1967).

In order to guarantee the continued availability of face-to-face communication with laryngectomy patients and new laryngectomees as well as maintain a continuing source of support and information, clubs continue to be needed.

The declining number of laryngectomee clubs may indicate that the rehabilitation of laryngectomees may be standing as a crosstown. However despite early detection and larynx-saving medical practice, laryngectomy surgery continues to be performed. To meet the needs of our brother and sister laryngectomees and to honor all of those who have gone before us in service to one another, we owe our individual support to sustain all of the resources laryngectomees need.

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Information about the IAL. FREE!

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A newsletter that is published four times annual. A $5 a year donation is requested but not necessary.

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Information on how to start a club or make your club successful FREE!

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These emergency stickers can be used on automobiles or on home windows. They are available in English and Spanish. (Send stamped, self-addressed envelope and specify language.)

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