Charlotte, North Carolina is a city on the rise. It has been recognized as the top travel destination in the Carolinas. The No.1 “up-and-coming city in America” by Yelp and is also one of the fastest-growing major cities in the U.S.

From Olympic-Level whitewater rafting at the U.S. National Whitewater Center to high-speed fun at the NASCAR Hall of Fame. Charlotte offers exclusive experiences only found in this ready-to-be-discovered urban city. Charlotte is continually garnering attention for its ever-evolving cityscape, diverse culinary scene, star-studded sporting events and more. With all the excitement and growth happening in the city. Charlotte continues to boast hometown pride along with friendly and welcoming attitudes that make visitors and newcomers feel instantly at home.

- We hope to meet you in Charlotte!
Better Nights

New nighttime solution designed to help you prepare for better days

Provox Luna has been designed to help you have better nights and prepare for better days.

The Provox Luna HME provides superior humidification compared to other HMEs and it has a low breathing resistance for easy breathing at night.*

The Provox Luna Adhesive is soft and smooth, and can help to soothe and cool your skin while you sleep.

Use Provox Luna at night to sleep comfortably, and get ready for an active day.

Experience the difference!

Call 800.217.0025 TODAY for a FREE sample
The IAL News is published four times a year by the International Association of Laryngectomees.

Information provided by the IAL News is not intended as a substitute for professional medical help or advice, rather 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 (SLP) 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.

IAL Resources
- IAL Brochures
- IAL News order/change of address cards
- Orange Emergency Cards (English)
- Orange Emergency Window Stickers (English)
- “Laryngectomees Loving Life” DVD (35 mins) ($10 donation requested) (May also be watched on website)
- “First Steps” Available to download from the IAL website

Order From: IAL in Atlanta or email theialoffice@gmail.com

Table of content
Our Valued Advertisers
ATOS HME ....................... 2
TruTone Emote ................. 10
Griffin Sonovox .................. 16
InHealth ......................... 20

Contents
Grandpa is going on tour .... 4
A special shout-out to my wife ................. 6
Nathaniel Rankin ............. 7
Visiting a Head & Neck Cancer Conference in the UK .......... 8
Carla Gress ..................... 14
President’s Message .......... 15
Participant registration .... 17
Vendor registration .......... 18
Scholarship Fund .......... 19

We thank all our vendors for their support. Please contact them with your questions/comments and ask if they have any special offers for IAL members. Order from them whenever you have a need.

Contact Allison Reber, theialoffice@gmail.com, for all updates to the IAL website, club postings, changes to club contacts and professionals, in addition to resources you may need from the IAL office. Thank you!

Have a good idea or a helpful hint?
We welcome laryngectomees and caregivers to submit ideas that would be helpful for other laryngectomees!
Grandpa is going on tour

Dealing with cancer is hard. You go through all kinds of treatments, surgeries, visits to doctors, specialists, maybe speech therapy, and physical therapy. It is also hard on your family and friends to watch you undergo this.

The hard part for me was the radiation, 35 treatments, every day for 7 weeks. One hour drive each way, to and from the hospital. Sitting in the waiting room, then going to the treatment room, getting a mask put over your face and having that strapped tight to the table. It scared the hell out of me. BUT, I got through it and finished all the treatments.

My mask was made of plastic and I never had the chance to take it home with me. Never even thought about it.

Now a days, the masks are made of some kind of thermal plastic with little holes in it, they shape it around your face, neck and head. Not that it makes it feel better being strapped to the table though, you have the prints in your skin after.

The “good” part is, that after you are done with radiation, you get to keep it.

And that is where my story starts. I visited the International Head and Neck Cancer Conference in Brighton, England this year. Walking in the room where the event was, I noticed different masks. One was a Lion, there was King Tut, a totally green one and so many more. I was amazed by it. At first I did not realize what they were until it dawned on me. They were radiation masks! All decorated in a beautiful form of art.

The one that stood out for me, was a mask, all covered with blue and white pieces of paper. I could feel it had to have a special story because it was so different from all the other masks in the room. I was right, it was, and it still brings tears in my eyes.

It turned out the mask belonged to a man who battled head and neck cancer. He underwent radiation, but sadly lost his life. After he passed away his family kept his mask under the stairs and never thought about it. Some time later, they heard about a special program, “The Mask Art Program.” They decided to take the mask from under the stairs and planned a weekend to decorate it with the whole family. They all gathered around the table and the stories about their beloved husband, father, and grandfather all came up. They decided to decorate his mask in PNE colors, Preston North End Football Club, his beloved Football team. The team he used to go cheer on as a life time season ticket holder. The family worked on the mask over the following weekends, decorated it in the blue and white colors of PNE while telling each other stories remembering the good times and honoring the life of this beloved man. It was not just a project, it bonded the family.

The result of the mask is amazing but the story behind it even more. And what really hit me was that this mask is going all over the UK and maybe, one day, around the World. “Grandpa is going on Tour.” The Mask tells it’s story and he will never be forgotten. His memory and legacy will always be there, for as long as the Mask is there, thanks to his beloved family and their decision to decorate it and donate it to the art project. I can see how they all worked on it, sitting around the table, laughing, crying, bonding. Their loved one might be out of sight, but he lives in their hearts forever.
Stories like this touch me very deeply and that is why I decided to write this article. As a tribute to Grandpa Preston, and all the others that we lost. To show the world that they are gone but not forgotten. They still have a story to tell, even after they passed away. I hope this inspires other families to work on projects like “The Mask Art Project” or maybe something else.

Thank you Preston Family, for the story behind the Mask

Marianne Kooijman

PLEASE share your ideas!

All too often people speak among themselves and talk of things they would like to hear about and see more of at our AM/VI. If you have any ideas about what you would like more discussion on, topics that may not be covered, or just your own personal feelings about our conference, please be sure to share those with any board member. This is the only way we can know and do what someone would like to see. If there are changes you would like to see, please let us know.

We are here to help each other, in any way we can. It is very heart warming to see a laryngectomee come for the first time and discover that he or she is not alone. Many come very depressed and leave with a much better feeling, knowing that this is not the end of their life or the world as it was. It does make a big change in our lives but we have learned to adapt and know we can live a full, new-normal life.

I urge all of you to come to our conference, encourage others to come and you will leave feeling much better about yourself, knowing that life goes on.

Planning Ahead for Future Conferences

Would your club be interested in hosting the IAL Annual Meeting during the summer of 2021? Please submit your application to the IAL Board of Directors!

Can YOUR club help bring the IAL to your neck of the woods?

There are complete directions on the IAL website at www.theial.com
This was a Facebook post from Marty O’Brien and he has given us permission to share it with everyone.

I want to give a special shout-out to my wife, Allison Downer O’Brien, for attending the Lost Chord Club’s Christmas party in Norfolk while I covered the Maury-Stone Bridge football state championship game in Hampton for the Daily Press and Virginian-Pilot.

I planned on going to the party until I was asked early in the week to cover the game, something I correctly felt would give me a sense of normalcy after being out of work nearly two months following vocal chord cancer surgery.

For those of you wondering what the Lost Chord Club is, it’s a support group for folks like me who have had their vocal chords removed because of cancer. I’m told we’re a fairly select group as there are only about 50,000 laryngectomees (people who’ve had their vocal chords removed) in the country.

The first time I ever heard of the Lost Chord Club was in August, when a surgeon told me my cancer might have returned (despite 28 radiation treatments from August-October 2018) and there was a 50-50 chance I’d have to have my vocal chords removed.

I recoiled in horror when the surgeon suggested I attend a Lost Chord Club meeting. My thought was, “I’ll never be one of THOSE PEOPLE and I don’t even want to know what they are like.”

As a journalist who’s written for many years about athletes and others who’ve experienced injury or illness, I’m ashamed of that gut reaction but it was my original feeling.

By September, however, it was confirmed that the cancer had returned and that my best option was to have my vocal cords removed. After a week of bitterness and exploring treatment options – neither of which had a better than 33-percent chance of saving my vocal cords – I called Tom Olsavicky, the local president of the Peninsula Lost Chord Club.

Much to the chagrin of his (terrific) wife, Tom, speaking clearly through an Electrolarynx (an electronic device he pressed under his chin to produce sound) spent two-and-a-half hours on the couch at my house telling me what to expect and what he’d been through in the decade since his surgery.

A light went on in my head.

“If this guy, with his upbeat personality, was able to survive the surgery and loss of vocal chords with his positive attitude intact, maybe there’s hope for me.” His inspiration was one of the reasons I assented to the surgery rather than gambling on saving my vocal chords via radiation that had little chance of totally curing the cancer. Now, two months post-surgery, I am healthy, back at work, eating like a horse and have developed an attitude about life similar to Tom.

It would’ve been nice to celebrate my recovery with the Lost Chord Club folks I so admire now, but, to be honest, as a sports writer I have no regrets about choosing to cover a state championship football game.

Still, I couldn’t wait to get home and hear what Allison had to say, and was particularly pleased to hear of two guys who had surgery about the time I did and are improving after some bumps in the road. Their triumphs are my triumphs because “THOSE PEOPLE” are me.

Allison, though her lovely voice is intact, is one of us, too. She has taken a huge interest in our issues and concerns, and befriended several members of the club.

The spouse of a laryngectomee is called a “caregiver,” and as a guy incredibly well-cared-for these past few months, I can say that description fits her to a tee.

Thanks, Allison, for the care you have given and continue to give.
Kim Rankin, Mother of Nathaniel Rankin shared this beautiful post on Facebook. Knowing how pleased we were to be able to meet this amazing young man and his devoted Mother, I want to share this with all of you and she gave her permission to use it.

We walked to the front of the gymnasium toward the microphone. The tarps covering the hard wood floor were puckered in places, probably from the movement of people and metal folding chairs last Sunday. I half thought about needing to watch my step and half about what was to happen next.

Our family was to read eight verses as part of the Christmas Eve service. Rich would share seven and Nathaniel - one. When I volunteered us, I thought we would practice. But it is December. We practiced for the first time just forty-five minutes before we got in the car to go to the service. We found the words for Nathaniel’s verse on his AAC device, loaded them as a stored phrase, (Hold that Thought feature on Speak for Yourself) and showed him twice where to find the verse, how to add the phrase to the message bar, and then speak the words. It is an operational feature we haven’t used with Nathaniel before. He was as wig-gly and inattentive for our practice as any child when parents want them to rehearse lines for a Christmas service.

At the front now, Rich’s deep voice quickly moved through the first five verses. He then lowered the microphone, placing it near the speaker of Nathaniel’s device. “What will he say?” I wondered silently.

I figured there was equal chance he would say something about Batman and video games as remember the stored words about Jesus. Or perhaps he would say nothing at all.

“My eyes have seen your salvation.” My son’s voice declared Simeon’s testimony through the speakers hung high over our heads.

And this perhaps is Christmas. A mother concerned about the part her child has in the story. The child boldly and confidently fulfilling the role.

Rich’s voice trembled as he finished his verses; his emotions rising to the surface. He was not alone. “Many were astonished beyond measure, saying, “(Jesus) has done all things well. He even makes the deaf hear and the mute speak.”

Merry Christmas, friends. Thank you for traveling this journey alongside us. Thank you for allowing us to share our astonishment that the babe in the manger has offered Nathaniel not only salvation, but also the ability to declare His glory.
Visiting a Head & Neck Cancer Conference in the UK

I had the opportunity in early November 2019 to attend a head and neck cancer conference in Brighton England.

The conference was conducted by The Swallows, a head and neck cancer support group that offers support for all head and neck cancer patients, survivors, and their caregivers in the UK. The Swallows started in 2010 as a small group of patients meeting to discuss how they were dealing with any issues and to share stories. In early 2011 the group achieved full charity status. The stated purpose of the charity is “Supporting patients both locally and nationally, and now internationally”. The name “The Swallows” was chosen because many head and neck cancer patients have problems swallowing during and after treatments. As a patient and caregiver group for those affected by head and neck cancer, we offer 24/7 support for caregivers and patients. The charity is run by patients, caregivers, family and friends so everyone understands the issues you are dealing with.

The conference was a three-day affair starting on November 5th with an evening meeting with Vendors. There were 24 vendors at the conference with everything from dental advice and supplies, feeding supplies, therapy companies, cancer treatment centers, and treatment supplies. I attended a focus group sponsored by Atos. I say Atos since that was the product and company we talked about, however in the UK there is a group called Countrywide Supplies who handles all Atos supply transactions. With the National Health Care system in the UK, all patients must go to a General Practitioner Doctor for all beginning treatment. This GP then writes the script and forwards it to Countrywide and it is filled. I asked a lot of questions about the health care system and was really impressed with how much everyone loved it. They said they had no problem getting supplies and if a prosthesis needed changed it happened right away. Since they are not charged for each visit it seems to work really well. However, they all said it was expensive and their income was heavily taxed for this service. No one mentioned what percent they pay. Back to Atos; they work the same way in the UK as in the US in patient, caregiver, and health care information in that they hold bi monthly meetings for patients and caregivers and visit clinics to educate the health care professional. Just some notes from the ATOS meeting. Most laryngectomees in the UK use valves to speak. I asked if the EL was covered and they said yes but the first choice of the NHS was TEP. The NHS provides home services from nurses to check on products and help the patient on their use.
The Countrywide Company also provides visits in the hospital to new laryngeomies. Remember Country and Atos are synonymous in the UK. All HME’s are covered but it is up to your GP to decide what you need in consult with the ENT and SLP. All types of baseplates, HME, and even hands free are covered. In the UK xtra moist and xtra flow are about even. Now I know I am only talking about ATOS, and there are other companies authorized by the NHS to supply laryngeomies. However, none were represented at the conference. All laryngeomies I talked to used ATOS supplies.

The opening day of the conference was geared toward the health care professional and was attended by around 200 people. There were patients, SLP, Doctors, along with several patients and caregivers. The conference started with a humorous look at the city of Brighton. Brighton is located on the shore of the English Channel in the south of England about 70 miles south of London. It is a town of around 400,000, so a fairly large town. The conference was held at a beach front hotel but it was a little chilly to enjoy the beach. The biggest tourist attraction in Brighton is called the Royal Pavilion. It is an over the top “castle” built by George the IV in 1823 as a getaway place to indulge in his tastes in art, music, and dining. While taking a tour of this palace, it was fun to see the decadence with which it was decorated. Along with the grounds being so beautiful it reminded me a little of the mansions in Newport RI, or the Hearst Castle in California.

The speakers on the first day included dentists, surgeons, survivors, oncologists, and radiation therapists. I will not spend a lot of time on what everyone talked about and names are not real important, but let me say I was impressed with the lineup of speakers. There were speakers from all over the world. To list a few obviously the UK, the US, Czechoslovakia, Romania, India, and Scotland. The topics included: early detection of H&N cancer, restoring form and function in surgery, new surgical techniques in reconstruction, Survivorship, role of caregiver, multi-disciplinary team, proton therapy, carry on smiling (dental care), and two very inspiring talks from survivors of mouth cancer and larynx cancer.

Some of the interesting things I heard were:

- Survivor isn’t just a title, it’s an attitude
- Focus on what we have, not on what we lost
- Cancer is not a character flaw
- When there is hope you can persevere
- Cancer is a family affair
- It’s not about the length of your life, it’s the breadth of your life
- When I is replaced by WE, Illness becomes WEliness

One of the overriding themes was early detection. If something doesn’t seem right get it checked out. Do not let your doctor send you home and tell you to watch for changes. They are the professional and we should not have to do self-diagnosis. Another thing I noticed is that the Swallows spend a lot of time on caregivers which I believe is lacking in the US. They have a 24/7 hot line and all support group meetings include caregivers. There are also several caregivers only meetings held monthly in the country. Granted they are a relative small country and can have fewer meetings to reach a lot of continues on page 11
Introducing the **TruTone EMOTE®** Speech Aid

Finally, an innovative electrolarynx that is actually easier to use, with an ergonomic design that feels great and provides a better grip. Still proven to have the capability to help you...

**Be Better Understood!**

- **Published University Study for Proven Intelligibility**—
  Not just marketing hype—actual proven results
  Our exclusive *Emotion™ Button* is easy to use

- **Comfortable, Ergonomic & Sleek Design**
  Hourglass design for better grip

- **Simple & Easy to Use**—
  Intuitive adjustments—no tools needed
  Easy-set modes for push-button simplicity
  **Quick & Easy monotone modes**— and check out the
  Exclusive *Whisper™ Mode* for monotone users

- **Up to Month-Long Battery Life & USB Charging**—
  Ultimate Convenience—charges just like your phone!
  Most test users experienced 25-35 days between charges

- **The only Drop & Soak® Warranty**—
  Even the battery has a warranty!

The **TruTone EMOTE** provides you with everything a person wants—Simplicity—Intelligibility—Comfort—Durability! Get started right away—also includes: oral adaptor and oral tubes, USB charger, and an Extra Sharp™ Sound-head cap for hard, radiated neck tissue or for an extra loud voice.

Griffin Laboratories, Inc.: Manufacturing rock solid speech aids for over 20 years! Now our latest premium device raises the bar even higher. It sounds great and feels great in the hand. You will appreciate our premium products and reputation for superior customer service.

**Contact us for special assistance programs!**
people. There have been semiannual focus groups with caregivers to learn what they need. They try to get down to the specifics of each cancer, especially the more common types. One doctor from the US talked about a care center in Massachusetts that uses a multi-disciplinary approach to cancer care. All professionals from doctors to oncologists and social workers to radiation people. I am very familiar to this approach since the hospital where I had my original surgery worked the same way. I had meetings with all professionals involved every two weeks for two months before my surgery and every week after surgery for two months. I realize this is used in a lot of places, however in the UK you must meet with your GP then go to another office and even another. I’m sure some of you went through this in your treatment. This talk was well received in the UK. All of the presenters talked about the HPV virus. The UK just recently approved the HPV vaccine to be given to all children in their 13th or 14th year. I think it is getting more play in the US and I gave this group an article last month on it.

The second day of the conference was geared toward the patients and survivors. There was over 60 people attending this day. A lot of the speakers were the same but they made their talks more for the patient. By that I mean there was less gory pictures of the operations and easier to understand talks. The day started off with a live link to Australia The doctor is a cancer survivor and his main message was again early detection. If it doesn’t feel right have it checked out. He talked a lot about the HPV virus. Australia like the UK has recently made the vaccine available at no extra cost through their National Health System. He told us that over 90% of the young people between the ages of 12 and 16 are vaccinated. The last figures I saw for the US was less than 50%. We heard about some of the exciting research Australia is doing in the fields of immuno-therapy drugs, skin cancer especially that caused by radiation of the head and neck area, and mask free radiation.

One general theme of this patient day was doctor patient conversations. A lot of the speakers realize this could be an issue with a lot of their patients. The consensus is that sometimes doctors will not give the whole truth. Either because they are worried about unduly alarming the patient or their family or they are not sure how to approach the subject. I have not seen this from any of my health care professionals but a lot of doctors, at least the one who spoke at the conference feel this is a problem. They realize how important complete information is and are striving to get better.

We had a doctor from the Czech Republic who runs a proton beam clinic in her country. As of now there is only one proton beam radiation center in the UK and it just opened in the past year. The doctors in the UK were sending their proton patients to the Czech Republic or France. There is a second center in the works in the UK that should be open in the next few years. She talked about how it works in that it can give a higher dose of radiation without the scatter. Her saying was that cancer forgets the dose received but normal tissue does not. continues on page 12
The survivor in charge of The Swallows gave a talk on survivorship. He is on the hotline they set up a lot and he says he still hears people say “surviving seems to be worse than the alternative”. I personally have never heard a cancer survivor say that but he was talking about the effects of the treatment and the quality of life afterwards. His quote was “Survivorship is not Survivorship without Quality of Life”. He asked the question “What one thing would improve your quality of life?”. There were a variety of answers from survivors of several different types of cancer. Some of what I heard was; eat normally, look better because surgery caused some disfigurement, talk normally, have hair, no dry mouth, get back my natural teeth, and get back the strength and vitality I had before cancer.

One big thing The Swallows do is work with the caregivers. Their mantra is that the caregivers are the unseen heroes. They did a survey of caregivers (they say Carers) in the UK and had several hundred responses. The survey showed that the carers had a life changing experience just as the patient had. Carers highlighted the need for support at the point they need it which is both before and after treatment. They want understanding, someone to listen, support groups, even a buddy scheme. 62% of the carers said they received less advice than needed from their health professionals. 80% said it changed their life forever, 67% have a fear of recurrence, and 65% have a fear of their loved one dying. The Swallows have set up a 24/7 helpline for carers and it gets used on a regular basis. Often the patient forgets that their cancer affects many others rather than just themselves. Carers themselves are under a great deal of stress and undergo major changes to their lives, jeopardizing their own health and well-being.

I had the opportunity to have an extended lunch with the president of the National Association of Laryngectomee Clubs. The NALC looks after the interest of laryngectomees and their families and friends. NALC also supports a wide range of healthcare professionals in the UK and encourages education of patients. They support, educate, communicate, and offer a vital forum for laryngectomees through the network of 60 clubs in the UK. They publish a quarterly newsletter, lead presentations to students, health professionals, and first responders. They have quite an extensive list of publications and information for patients, caregivers, and health care professionals. Informational events are held at least quarterly for laryngectomees and carers. The over 60 lost voice clubs in the UK are supported by this organization. I am at a loss as to why the IAL does not provide this kind of support to laryngectomees and the clubs. Being closely associated with the IAL I know the main reason is money. The clubs are going slowly away because of attendance. I know my local club used to have 20+ attendees now if we get 10 we feel good. They tell me a lot of that same thing is happening in the UK and we were brainstorming as to why. The internet including Facebook is one reason. People can get a multitude of answers to their questions in a few minutes from the many Facebook groups set up for laryngectomees. However, we all agreed that the face to face discussions are very helpful. The NALC has a forum set up for early 2020 to discuss this issue and promised to let me know the results of this forum. I asked why there seemed to be more corporate support in the UK than in the US. There was no definitive answer but the people there feel that their health care system encourages corporate support to health care groups such as those that put on this conference.
I had the opportunity to attend a rehearsal of the Shout at Cancer group. This group was started by an ENT with a background in music. Shout at Cancer is the only charity in the world that uses singing and acting techniques in voice rehabilitation of laryngectomees. Thomas Moors, the founder, says “I became intrigued by voice problems after laryngectomy and the difficulty these patients face in their emotional expression. I wondered if singing would make a difference.” This group was amazing and a lot of fun. They do shows all over the UK and even have traveled abroad.

Now I’ll talk about a little of the fun part of the trip. I had a chance to take a tour out of Brighton to the White Cliffs in southern England. They are fascinating. We spent a lot of time just marveling at them. That trip also included a tour of South Downs, a range of chalk hills across the coastal counties of southern England. Brighton was a great town. I spent most of my time there by the beach. The shore area is just like any beach area in the US. There is a pier with food and games, a nice walking esplanade, and a very wide beach. The unusual thing is the beach is not sand but pebbles. I never got a good answer why. After the conference I spent three days in London. We went to a play in the West End which is London’s Broadway and took a HOHO bus all over the city to see sights such as London Bridge, Tower of London, Buckingham Palace, St. Paul’s Cathedral and others. The highlight of the trip was the tour to Windsor Castle, Stonehenge, the unique town of Bath and finishing with a traditional English dinner in a 15th century tavern. Over all the trip was great. I learned a lot I can bring back to the clubs in the US and the IAL to improve the things we can do for the laryngectomee community. I also had the chance to sightsee around England and see some of the things I have only heard about and wondered if I would ever see. I am planning a trip to Dallas to the Texas Laryngectomee Association Conference in January 2020 to talk up the IAL and our conference in 2020 and also to pick up more ideas to help the laryngectomee community.
There is disagreement among the professionals as to when to change the prosthesis. (The advice to change the prosthesis every six months) is historically correct - in the early beginnings, the prosthesis, as designed, was meant to be changed quite frequently. The devices were “patient Changeable” and they were soft and pliable, making replacement not necessarily as “traumatic” to the tissues as it is with the current “extended wear” that we have on the market today.

The (Blom-Singer) Indwelling Advantage and Provox2 devices are made of stiffer materials, and the esophageal flanges are larger than with the original prosthesis. Some of us feel that we are seeing more problems with granulation tissue on the esophageal side of the puncture, and it is believed that this may be related to frequent traumatic changes of the prosthesis (but it might be some other factor, such as more heavily radiated tissue).

Consequently, it is thought that it might be better to not change the device any more frequently than necessary. Hence, the expression, “If it ain’t broke, don’t fix it.”

If we all agree that we should only change it “when necessary,” the problem becomes defining “necessary.” Certainly when it is leaking, or when there is a change of voicing ability. Those are obvious reasons. But as has been pointed to previously, there can be problems OTHER than leaking and difficulty voicing.

I have seen more than a few patients who waited for long periods to change the device (less than one year) and overgrowth of candida** (yeast) occurred along the shaft of the prosthesis, causing the puncture to expand. In a couple of patients, the replacement device (same diameter as the removed prosthesis) was so loose that it would not seal properly, and we had to wait a couple of days until the puncture shrank. In another patient, I thought the new device was securely in place, but with the first good cough after getting back home, the prosthesis dislodged, though, fortunately, was not aspirated (dropped down the windpipe). This was a patient who was not very adept in self-care, and the result was a lost puncture, necessitating a re-puncture a few weeks later.

I try to learn from my experiences and my mistakes, and consequently, I now tell people that they should have the prosthesis checked every six months or so. You may not be having leakage or voicing problems, but that doesn’t mean “it ain’t broke.” If the prosthesis is having a buildup of candid along the shaft and stretching the puncture, it IS “broken,” whether you recognize it as a problem or not.

Now, other professionals may disagree with me based on their clinical practice. I remember several years ago when I was visiting a very well-known, highly experienced clinic in Europe. A gentleman came in for his regular checkup with the head and neck surgeon. The patient was asked if the prosthesis had been leaking and he stated that it had, occasionally, with liquids. He was asked to swallow a few sips of water and sure enough, you could see a small amount of leakage through the device and he started coughing.

The surgeon asked him if this bothered him, the patient said “no” and he was sent home. Later I asked the surgeon why the prosthesis wasn’t changed since the patient reported leakage and we had verified it. I was told, “Never stop betting on a winning horse. The patient was not bothered by it, so we don’t change it.” OK (continues on next page)
Continued from page 14

I would venture to say that here in the US, most clinicians would have changed the prosthesis at that point. Whatever the reasons, it points out some fundamental differences between clinical practices. I like to think of the prosthesis being like dentures. You can leave them in place for a (long) while, and it may or may not cause you a significant problem. But the nature of the secretions and foodstuff that pass through the digestive tract makes me want to seriously consider periodic removal!

And by the way, I have no financial interest in any device that would be a reason for me to suggest more frequent replacement.

* Granulated tissue is tissue which may grow at the TEP puncture site as a result of irritation and the body’s tendency to reject foreign material. Sometimes it becomes enough of a problem that it has to be removed surgically.

** Candida is yeast which grows in our mouths and digestive tracts. It can grow into the silicon of a prosthesis and cause the valve to not close completely. It is the major cause for the TEP prosthesis to eventually leak and need to be replaced.

President’s Message

I want to begin by wishing one and all a very Happy and Healthy 2020. As we begin our new year, please be sure to plan on attending the Annual Meeting and Voice Institute, June 10 - 13, in Charlotte, NC. We are planning a great program and our Voice Institute will prove, as always, to be outstanding. It is a wonderful way to share your journey, from your surgery through your recovery, and the “new normal” we all hope to achieve. One may think that they cannot gain anything from attending these conferences, but in fact, your presence and experience may help someone else. “There is nothing better than that great feeling of helping someone.” We always look forward to seeing our old friends and making new ones along the way, all the while, we are in a majority of people that speak a bit funny.

I am among the many that can count my blessings as I celebrated 18 years as a laryngectomee on January 6th. I must say, I personally, have enjoyed my life more following my surgery, by becoming involved with my local Lost Chord Club. I have never been one to sit on the sidelines and even though I did return to work after my surgery, I volunteered to be a visitor for newly diagnosed patients. I find that by helping others, we really help ourselves more. There is no greater feeling than being able to offer the feeling of “HOPE” to that newly diagnosed person who is so very scared of the future. We all know that feeling, we have been there. Very often, just your presence, your ability to speak and function is enough to allay their fears of the unknown.

If you happen to be in an area that does not have a support group, simply start one! I know you are thinking easier said than done! But, it really is not so hard. Talk to your speech therapist or your doctor to find other laryngectomees in your area. Your efforts will pay off many times over.

Helen Grathwohl, President
Introducing the Latest in Voice Amplifier Technology!

- 15 Watts*, Highest Clarity
- Integrated Micro-USB Charger
- Ultralight Design---Only 8oz.
- Reduced Feedback
- Carry Case with Belt Loop
- AUX input for Music

**Includes:** Travel Case, Lanyard, USB Power Supply, Slim Microphone

**Teacher**

**Coach**

**Musician**

**Business**

---

*Calculated using competitors measurement method*
INTERNATIONAL ASSOCIATIONS OF LARYNGECTOMEES

Registration form

Annual Meeting and Voice Institute
June 10-13, 2020

The recommended method for registration and payment is online at: http://www.theial.com

For mail-in registrations use this form

Send to: The International Association of Laryngectomees, 925B Peachtree Street NE Suite 316, Atlanta, Georgia 30309

<table>
<thead>
<tr>
<th>Registration fees</th>
</tr>
</thead>
<tbody>
<tr>
<td>Laryngectomees / Family / Caregivers</td>
</tr>
<tr>
<td>Speech-Language Pathologists / Clinicians</td>
</tr>
<tr>
<td>Graduate Students</td>
</tr>
</tbody>
</table>

First Attendee (please print name)  
Laryngectomee?  
(Y) (N)  

Second Attendee (please print name)  
Laryngectomee?  
(Y) (N)  

Street Address  
City  
State/Province  
Zip  
Country  
Phone  
Email  

Check here if you require assistance, have dietary restrictions, or need special accommodations to attend the meeting because of physical limitations. You will be contacted for other information  
(Y) (N)  

Mail in registrations must have check or money order payable in U.S. Dollar to:  
The International Association of Laryngectomees (IAL)

Fill out for credit card  

Please check one: 

Cardholder’s name  

Address (if different from above)  
City, State  
Zip  

Card Number  
Exp date MM/YY  
Card security code  

Cardholder’s signature:  
Total amount approved for charge  

Send to: The International Association of Laryngectomees, 925B Peachtree Street NE Suite 316, Atlanta, Georgia 30309
# Vendor Registration Form

## Annual Meeting and Voice Institute

**June 10-13, 2020**

Please return this form to: Susan Reeves, 18 West College, San Angelo, TX 76903

### Company

<table>
<thead>
<tr>
<th>Address</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>City</th>
<th>Zip</th>
<th>State/Province</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Contact Name</th>
<th>Email</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Phone Number:</th>
<th>Fax:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Requirements & Donations

<table>
<thead>
<tr>
<th>Requirements</th>
<th>Amount</th>
<th>#Pcs</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exhibit fee (includes 1 attendee, 1 Table, 2 Chairs)</td>
<td>$400</td>
<td>1</td>
<td>$400</td>
</tr>
<tr>
<td>+Additional chair</td>
<td>$10</td>
<td></td>
<td>$</td>
</tr>
<tr>
<td>+Additional table</td>
<td>$100</td>
<td></td>
<td>$</td>
</tr>
<tr>
<td>+Extra attendee</td>
<td>$100</td>
<td></td>
<td>$</td>
</tr>
<tr>
<td>+Electrical hook-up (one time fee)</td>
<td>$50</td>
<td></td>
<td>$</td>
</tr>
<tr>
<td><strong>Donations - you will be thanked at the meeting!</strong></td>
<td></td>
<td></td>
<td>$</td>
</tr>
</tbody>
</table>

**Subtotal** $-

### Program advertising

<table>
<thead>
<tr>
<th>Program advertising</th>
<th>#Pcs</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Full page*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Back Cover</td>
<td>$450</td>
<td>$</td>
</tr>
<tr>
<td>Inside Front Cover</td>
<td>$450</td>
<td>$</td>
</tr>
<tr>
<td>Inside Back Cover</td>
<td>$450</td>
<td>$</td>
</tr>
<tr>
<td>Other inside pages</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full</td>
<td>$400</td>
<td>$</td>
</tr>
<tr>
<td>Half</td>
<td>$250</td>
<td>$</td>
</tr>
<tr>
<td>Quarter</td>
<td>$150</td>
<td>$</td>
</tr>
<tr>
<td>Banner</td>
<td>$100</td>
<td>$</td>
</tr>
</tbody>
</table>

*Full page 7/1/2" x 10", for other details contact us

**Subtotal** $-

**Total** $-

### Name of attendees:

<table>
<thead>
<tr>
<th>Name</th>
<th>Title</th>
<th>Phone</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

|          |       |       |
|          |       |       |

|          |       |       |
|          |       |       |
Scholarship Fund in Honor of Ed Chapman
By Susan Bruemmer, M.S., CCC-SLP, retired

Ed Chapman became a laryngectomee in 2005. He had been a fire chief, a farmer, a plumber, husband, father and friend to many. Ed once told me that he was so grateful to me for the pre-op visit we had so that he was prepared for his surgery and life after laryngectomy. Ed decided to pay it forward for ten years by being the beacon for other people who would face a laryngectomy. He would accompany me to pre-op visits at their homes and answer all their questions based on his experience.

Ed was an excellent TEP speaker and that encouraged people facing their surgery that they could have a new voice after surgery too. Ed wanted to reach more people so he decided that our local club should be the local host for an upcoming IAL annual meeting in the Pacific Northwest.

Ed enlisted the support of his surgeon and friend, Dr. Brian Mitchell, and myself and we embarked on making this meeting in our neck of the woods possible. We worked monthly for a year coordinating the resources in our area to get the approval for an annual meeting in Spokane, WA. We succeeded in getting approval from the IAL Board to host the 2013 meeting in Spokane. Our team also spearheaded the template for the Emergency Actions for Laryngectommes aimed at EMT’s and all first responders who would have to deal with a neckbreather in an emergency situation.

Ed’s knowledge of EMT/firefighter protocols and personal knowledge of issues faced by laryngectommes made him the perfect liaison with the Spokane County Fire Chief to design and implement a 4 hour course which included interactions between laryngectommes with different voices (esophageal, EL, and TEP), different physical appearances, and a free BBQ (food donated by a local grocer). Ed was integral to the IAL and WebWhispers for many years. He was the most excellent advocate for the laryngectomee community.

Sadly, Ed Chapman passed away almost 4 years ago, 4 months after becoming a paraplegic from a burst spinal tumor. Although he cannot continue to support laryngectommes in person, I am proposing a Scholarship Fund in memory of Ed Chapman so that more people can attend an annual IAL meeting. These meetings are so inspirational especially to new laryngectomees. New friendships are formed and continue. This support is so vital in a laryngectomee’s journey. Please consider a donation today.

Send donations to the IAL, 925 Peachtree Lane, Suite 316, Atlanta, GA 30309 or through the IAL website (thetial.com) and specify the Ed Chapman Scholarship Fund. Thank you from the bottom of my heart!

Visit our FaceBook page - and use the resources on our Website!
INHEALTH
TECHNOLOGIES®

TOTAL Solution for Your HME Needs

A new and complete line of options to address your HME attachment needs

Order online at www.inhealth.com

1110 Mark Avenue
Carpinteria, CA 93013, USA
Toll Free: 800.477.5969
Toll Free Fax: 888.371.1530
©2019 InHealth Technologies—Manufactured by Freudenberg Medical, LLC (191009)