Phoenix was a GREAT meeting!

From the President, Helen Gratwohl

The 2019 Annual Meeting and Voice Institute of the International Association of Laryngectomees is in the books. All I can say is “THANK YOU” to everyone that helped in any way, to all the folks that attended, and our vendors. There is no way we could do this every year without the support of our vendors and the folks that give generous donations to our cause.

Thanks to Caryn Melvin and the professionals she recruited, the Voice Institute was second to none. The doctors from the Mayo Clinic, Dr. Hinni and Dr. Lott, as well as Lisa Crujido, SLP are very devoted and caring. It was reflected in their talks and bragged about by their patients. They made themselves available to answer questions and just chat following their inspiring talks.

Bill Brummel, an award willing documentary producer, director, writer and Laryngectomee showed his latest work Segue. It documents a choir of laryngectomees in England and was extremely inspiring. No-one in the room had a dry eye when it was over. It should be released in late 2019.

Cont. on page 10
Luna™®

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

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

Contact us for more information:
Tel: 800.217.0025 • Email: info.us@atosmedical.com • Web: www.atosmedical.us
**IAL Staff**
Administrative Director
Susan Reeves, SLP
susanr@reevesrehabinc.com

Website: www.theial.com
Email: theialoffice@gmail.com

**IAL Mailing Address**
The IAL
925B Peachtree Street NE
Suite 316
Atlanta, Georgia 30309
866-425-3678

**IAL Board of Directors**
President/Treasurer
Helen Grathwohl
agrat3004@aol.com

Vice President
W. Kyd Dieterich
kdieterich@myactv.net

Secretary
Anne Ammenti
aammenti@sbcglobal.net

Treasurer
Jennifer Malkiewicz
jmalkiewicz@verizon.net

Cindy Gordish SLP
cindyleegordish@gmail.com

Jewell Hoffman
jewells@yahoo.com

David Kinkead
dkinkeadaz@gmail.com

Karen White
kaw1026@aol.com

Susan Bruemmer
sbruemmer3@gmail.com

**The IAL News is published four times a year by the International Association of Laryngectomies.**

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 laryngectomies 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 Laryngectomies.

**IAL Resources**
- IAL Brochures
- IAL News order/change of address cards
- Orange Emergency Cards (English)
- Orange Emergency Window Stickers (English)
- “Laryngectomies 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 Luna .................. 2
TruTone Emote ............. 6
Griffin SoniVox ............ 14
InHealth HME .............. 20

**Contents**

President’s Address .......... 1
Three Things I Learned at the Annual IAL Meeting .... 4
Webwhisper’s banquet ........ 5
It’s never too late to be what you might have been .......... 7
I found my voice in Arizona .................................. 8

2019 IAL Meeting .......... 10-11
Grand Canyon Tour .......... 12
In the pool ...................... 13
IAL Board Information ....6
Obituaries .................... 18-19

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 laryngectomies and caregivers to submit ideas that would be helpful for other laryngectomies!
Three Things I Learned at the IAL Annual Meeting

Nathaniel and I had the privilege to attend the International Association of Laryngectomees’ Annual Meeting and Voice Institute last month. A third party funder, Pythian Sisters of Virginia, sponsored our trip; we could not have participated in this educational week in Phoenix without the financial gift.

Not surprising, Nathaniel was the youngest laryngectomee at the meeting. Konrad, a young man from Poland, was the next youngest. He celebrated his twenty-fourth birthday while in Arizona. Watching Konrad tackle new challenges, like swimming for the first time since surgery, gave me a wonderful glimpse into what life might be like for Nathaniel in the future.

It was very comfortable to be with laryngectomees (larys) and their caregivers. Being in public with Nathaniel can be tricky. Managing his lung secretions draws attention. The cough is often a wet mucus-y sound that I suspect makes by-standers wonder if he is sick. Sometimes one simple cough solves the problem, but usually not. Complete airway clearance often requires repeated coughing or suctioning with a machine. We can be loud, disruptive, and even scary depending on the comfort level of those around us. Children and their parents on playgrounds don’t get it. But fellow larys understand. It was enjoyable to be with people for four days, but never receive that awkward stare or subtle moving away that we get daily. I observed wonderful examples of airway clearance manners. I have ideas on how to help Nathaniel grow in his awareness and responsibility for his own pulmonary needs as he gets older.

The meeting helped me understand the many similarities and differences between our lives and that of an adult laryngectomee. Three topics I have continued to think about include the role of the speech language pathologist, risk taking, and motivation to communicate.

Role of a Speech Language Pathologist

The Voice Institute programming portion of the meeting provided educational sessions for SLPs. They play a significant role in pre and post- laryngectomy surgery care for adults. They help with voice recovery whether using voice prosthesis, electrolarynx, or esophageal speech. They work in an ENT’s office and change the voice prosthesis for patients. They also help with swallowing concerns, humidity, and stoma care. For adults, it seems an SLP is their go to professional.

Nathaniel’s care is managed differently. An ENT and nurses manage the anatomy and stoma. A pulmonologist and nurses manage Nathaniel’s humidity, lung, and airway clearance concerns. This care can also include home visits from respiratory therapists and representatives from equipment companies. Speech language pathologists monitor his general language development, instruct on the use of his augmentative alternative communication (AAC) device, work on oral motor development and placement for using the electrolarynxx, and provide intensive support on a feeding team along with a dietitian and psychologist. However, the therapists’ expertise is often so narrow that Nathaniel has been seen by three different SLP’s in a week to have all his needs addressed. With so many professionals involved, care coordination is vital.

Risk Taking

Seeing Konrad and the other larys swim conceptualized my understanding that at some point, Nathaniel may chose to take significant health and safety risks. For now the risk assessment responsibility belongs to us as his parents. There is an assumption that we will keep Nathaniel safe through the things we allow him to do. This is inherent in the parent-child relationship. It is intensified when a child is living with medical conditions. There was a time when I didn’t take Nathaniel to the grocery store because of the risk of contracting a virus and what that illness meant in his life. Watching the swimmers, I wondered if I would make different decisions for myself personally than I do on Nathaniel’s behalf. I likely tend to be more cautious with someone else’s safety than my own; I suspect we all do. I anticipate transferring ownership of risk taking from parent to child will look different with Nathaniel than it did with our other children. I am thankful to have observed the swimming portion of the meeting and to begin thinking about this important topic.
Motivation to Communicate

During the caregiver’s breakfast and discussion, a woman shared that her husband relearned to speak after his laryngectomy by turning on their TV’s closed caption setting and reading the programming aloud. Others talked of their loved ones’ determination in using an eletrolarynx or TEP and the varying techniques that helped them succeed. As I listened to these stories, it occurred to me that I can only provide external motivation for Nathaniel to speak. That internal drive or ambition to speak I heard about in the adults isn’t something that a parent or speech therapist can magically create in a child. We can offer opportunity, model speaking with his device or an eletrolarynx, redirect a poor communication choice like a melt down, prompt for more communication when he offers just a bit, and incentivize with stickers, preferred activities, and toys. But that internal drive to just do it? No one can flip a switch and turn that on for someone else. I sense it is especially difficult to motivate a child, but that might be self-pity that I have a hard job.

There are days when Nathaniel works hard at using his device to communicate and there are days he doesn’t. There are times when his persistence to get his message across amazes me. There are times when he stays quiet. I saw bits of the same in the adult larys at the meeting. For Nathaniel and most individuals I’ve met who have a laryngectomy, communicating is much harder than it is for me. More than once, someone waved a hand, a “forget it” gesture, when I was struggling to understand them. They decided the end result wasn’t worth the labor. And as much as I wanted to keep trying harder and harder to hear what they had to say, they were done. I am still learning how to show respect and honor someone when they chose to be quiet. I am learning what silence communicates and how to be present in those moments. I can not provide anyone the internal motivation to keep trying when talking is hard, but the Phoenix trip solidified my motivation to improve my listening skills and to be at peace with silence.

The trip to Phoenix was a milestone reached for Nathaniel and me. It was our first time to fly with him. Our first time to rent medical equipment away from home. Our longest trip both in distance and time without Rich or a second caregiver. Navigating the airport portion with medical conditions and equipment should be a blog post all its own. I will likely write more on the Phoenix trip. But for now, thank you to those who provided the opportunity for us and to those who welcomed us into their world of living as a lary.

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!

* Limited Warranty; call for details. Copyright 2017, Griffin Laboratories, Inc. TTE171022
Growing up in the Sixties, I could croon, not well but I still gave it my best. My aspirations consisted of singing along to the Beatles, Smokey Robinson and the Temptations, mostly in private. No need to scare people. I never dreamed that one day I would be known as one of the best singers in the world without vocal cords.

My early life was typical. I finished school, got a job, got married and had children. Life was simple. Then, in the Fall of 1996, my uneventful life was turned upside down. A diagnosis of squamous cell cancer involving the larynx and esophagus would change my destiny and transform my ordinary life into an extraordinary journey.

My surgeon and I discussed Plan A. Everyone loves plan A. That’s the good plan. Plan A consisted of surgery to remove the tumor, maybe shave the vocal cords but keep my larynx. Plan A would result in a normal existence. Plan B on the other hand was something called a total Laryngectomy: a surgical procedure that involved the complete removal of my voice box (larynx). Plan B involved having a permanent hole or “stoma” in my neck. Plan B involved a physical transformation, one that would take my voice and my identity.

As life would have it, my path took me down Plan B. Surgery was a success and after 36 radiation treatments, my recovery and transformation began. I was 41, with four children, two still in diapers. I had to get back to work to support my family. The process was slow and painful. I had to learn to speak again for the second time. The thought of raising four kids without a voice was not an option. I would speak again. I would be heard.

A fistula was created between the stoma in my neck and my esophagus. A prosthesis was placed to shunt the air from my neck into my mouth. At first, just a whisper. After endless hours of practice, the whisper turned into a grunt, the grunt turned into connected speech and the connected speech eventually turned into song. Adversity was replaced by opportunity. My new voice was not the same, but it was my own. I could communicate at work. I could read to my children at bedtime. I could speak with my wife. I was back.

Fast forward to February 2012 and my first Sin City Laryngology Conference. It was there that I witnessed my first laryngeal karaoke contest. The singers were passionate and talented. They also had something that I would never again possess: vocal cords, those magical oscillators that transform the air in our lungs into celestial harmony. A friend and colleague suggested that I sing in the contest the following year. “You’ll bring the house down!” he said. I dismissed his suggestion without a second thought. Laryngectomees don’t sing. We are vocal cripples. I should be content with simple communication.

(continue on page 15)
“I Found My Voice in Phoenix Arizona”

My Laryngectomee surgery was on February 25th, 2019. I heard about the 2019 International Association of Laryngectomees (IAL) conference and the Voice Institute (VI), from several Facebook groups, particularly WebWhispers. It was late March and I was only 1 month post-surgery however was feeling great and started wondering if I could attend the conference which was only 6 weeks away. After hearing how valuable the conference was from several other Laryngectomees that had attended in the past, I reached out to my surgeon. He said if I felt up to it, he would clear me to fly “as long as I brought my suction machine... and make sure it’s fully charged”!

My plans were set in motion!

I flew to Phoenix on Tuesday May 14th, exactly 11 weeks after my surgery. Getting through TSA was my first concern. I had a carry-on suitcase full of medical supplies and my trusty suction pump. I looked at the TSA rules online in advance but still wondered if they would allow this? I still had not mastered the Electro Larynx (EL), did not have a TEP and was still using a white board. I did bring a note explaining that I was a Laryngectomee, could not speak and that I had the medical supplies in the carry-on bag. TSA was very appreciative that I had the note in hand and with a little extra screening of the medical supplies I was on my way!

Fortunately, on the plane was our territory manager from Atos, Kathryn Flynn, so the flight and getting to hotel was a breeze.

The conference was held at a Doubletree by Hilton. As it turns out, Hilton has an app that allows you to check in from your phone and even get your room key on your smartphone. Since I was only able to communicate in writing I downloaded the app. I did stop at the front desk first however it took only seconds to present my ID and credit card. The hotel staff was so accommodating and fully prepared for our group. The hotel even used text messaging for any guests that wanted it so that was an added bonus for me. The entire process was easy and went off without a hitch. I checked into my room, plugged in my portable mini humidifier (did I mention the Laryngectomee conference was in the desert where it was less than 20% humidity!!), and proceeded directly to the registration desk for the IAL.

The first person I met at the conference was Helen Grathwohl, President of the IAL. She was at the registration table. Although I had my EL on a string around my neck, it was hard for anyone to understand me. I pulled out my whiteboard and started to write my name. Helen’s heartfelt and warm greeting was: “PUT THAT DAMN THING AWAY AND START USING YOUR ELECTRO LARYNX” as she shook her head and wagged her finger at me. I knew from the first minute that I was in a place where others understood what we are going through and were not pre-judged by that odd hole in our necks! Needless to say, Helen and I bonded! I was given a name tag that said “First Time Attendee AND Delegate”. Both were very rewarding to me!

Immediately, I was reading name tags and meeting people that I had talked to on Facebook over the last several months. Many of them had helped me with advice as I was a “newbie”. It was great finally being able to meet face to face!

Additionally, several members of the Laryngectomee Club of Montgomery County (LCMC) were at the IAL as well; Kyd Deitrich, Karen White and Mark Reichenbacher. Kathryn Flynn, our local Atos territory manager was there as well so I never felt like I was alone!

On Wednesday, the VI sessions began. There were experts, primarily Speech and Language Pathologists (SLPs) giving classes and information on the most basic subjects for any Laryngectomee, caregiver or other SLPs. The sessions ranged from; anatomy changes, voice restoration options, EL usage, TEP and Esophageal speech techniques. There were group sessions where I was able to get additional help using the EL. Other classes included HME and stoma care clinics and travel tips. The most beneficial part of the con-
ference was picking up tips and advice from the SLPs and fellow Larys as well. There were several that were almost 40 years out! Also, there was a very interesting presentation by Dr Michael Hinni from the Mayo Clinic in Phoenix talking about ground breaking laser surgery on the Larynx. Based on the results he shared, hopefully it will become the norm, not an exception. It was truly fascinating. There was a swimming session for Laryngectomees however I thought it best to just stay on the sidelines for that one... perhaps next year!

I was encouraged to apply for a scholarship in advance that was offered by WebWhispers.org. The funds were provided by Atos Medical. I was a very lucky recipient and received the scholarship at a presentation at the WebWhispers banquet on Thursday night (see picture page 8). With the tremendous expenses of the surgery, supplies and other items I needed, it helped to make my trip to the IAL possible.

One other event stood out at the conference: Bill Brummel, the maker of the documentary “Segue” gave a talk and played an un cut short version of his film. It’s about a group of Laryngectomees in England that formed a choir. It takes you through their journey, and ends with their final musical production. It was truly inspiring and reinforced to me that there is a normal life ahead for Laryngectomees. Needless to say by the end of the 20 minute film, there wasn’t a dry eye in the audience!

On Saturday morning the IAL had its annual meeting. Although I was only a Laryngectomee for 11 weeks, I was asked by Herb Simon to be a voting delegate representing the LCMC. I considered it an honor. Contrary to my initial concerns, the meeting was very smooth; reports were presented, ballots were cast for open positions, no one got into any disagreements, and the meeting was adjourned early!!!

So why did I say I found my voice in Phoenix?
As I mentioned earlier, I was only 11 weeks into this journey and had been struggling to find my “sweet spot” Herb Simon, President on LCMC had lent me an Servox EL to try out and had worked with me on many occasions. My SLP at Johns Hopkins was working with me as well but I still couldn’t get the hang of it. At the IAL, I met Jim Lauder who I had spoken to before my surgery and had kept in touch with ever since. I had the Servox (which Jim repaired on the spot) but he gave me another unit to try as well. Atos lent me a TrueTone Emote to try out and Tom Whitworth from WebWhispers gave me a basic TrueTone as well. At this point, I was walking around with 4 or 5 Electro Larynxes! Then I met Tony Talmich. He said Steve, put everything away and let’s find your sweet spot… viola we found it... it was right there, hiding under the lymphedema under my chin all the time!!!

Of course Tony was partial to the TrueTone Emote however I was most comfortable with a 50 year old vintage Servox that Jim Lauder gave me to use! What a mensch! Several other people helped me to perfect my speech including Susan Reeves and Tom Lennox and several other SLPs during the breakout sessions. After one or 2 days, I could carry on a conversation. I was so relieved to finally be able to communicate verbally after almost 3 months. So ... now I can say...

“I found my voice in Phoenix Arizona”!

I want to thank everyone that encouraged me to go to the IAL. I also want to thank everyone at the IAL who worked tirelessly to hold such a wonderful event, Tom Whitworth from WebWhispers and Doug Sanchez and team from Atos Medical for their help and assistance, all of the SLPs and every single person that attended the conference that was there to provide unconditional support to me and all of the other fellow Laryngectomees and caregivers. And my wife Robin for encouraging me to make the trip without any hesitation at all and for being my driver to and from the airport!!! The saying it “takes a village” was not just a phrase we use, it was on full display at the IAL.

This was a trip that came at a very fragile stage in my journey and will stay with me for many years (and future IAL conferences) as well.

With best wishes, Steve Cooper
Phoenix was a GREAT meeting! (cont. from page 1)

Our meeting was attended by Nathaniel Rankin and his mother Kim. Nathaniel is six years old and has had a trach since he was born. He is unable to speak but does have a means of communication. It was very inspiring meeting this young boy and his devoted mother.

We also had a young laryngectomee from Poland. Konrad Zielinski came to our meeting having to use a headset with an amplifier to be heard, when using his electro larynx. He was given the opportunity to try all kind of el’s and when he went home he had a new el and a great voice, without the amplifier. He also learned to swim at the conference and really enjoyed himself. He helps other laryngectomees in Poland and is an amazing young man.

Friday evening we had a fun time with our folks learning line dancing on the patio at the hotel. It was a beautiful, cool evening in Phoenix and everyone enjoyed the weather. It was a fun time for all. Saturday evening was our banquet, followed by dancing to a DJ, the closing of our silent auction and saying good-bye to old and new friends until next year.

Last, but not least, I do need to thank the Staff at the hotel, The DoubleTree Inn by Hilton. The staff, from manager to maid went out of their way to accommodate us and help in any way possible. They made our stay very enjoyable.

We are currently getting proposals from hotels and searching for our next venue. It will be anywhere from Charlotte, NC to Columbia, SC. A lot goes into the decision and we will announce the location as soon as possible.

We look forward to seeing you at our 2020 AM/VI.

Helen Grathwohl
President
The 2019 Annual Meeting & Voice Institute

Was held in Phoenix, Arizona. It was well attended, we were about 142 in total, including several SLP’s. Many of the laryngectomees attending were there for the first time and were welcomed by Tom Olsavicky and Joe Marasco. There was a welcome reception on Tuesday evening for those early arrivals and vendors given by our president. It was a chance to spend some extra time with friends.

The seminars were well attended. The speakers were some of the best. Doctor Hinni and Doctor Lott from the Mayo Clinic gave fabulous talks and a look into the future for helping laryngectomees keep a voice. Bill Brummel, a noted director, is putting together a great documentary called Segue. It is about a choir of laryngectomees in England. He gave us an early screening and all in attendance were very moved, with most in tears. The documentary should be done by the end of this year.

It is always great to help out with registrations! We get to be the first to greet folks as they arrive, pick up their name badges, programs, information, and goodie bags. Many thanks to Allison for the great job she does for us at registrations every year.

The social part is by far the very best and I would say one of the most enjoyable parts of the conference. It is sharing stories of what we have gone through this journey, encouraging others to not give up and seeing people come in depressed and leaving very happy. It is a great feeling to walk into a room of people that have been on this journey and see how well we are all doing. Sometimes it seems like little miracles happen.

One couple (I will not use any names) came for the first time. This gentleman is a laryngectomee/glossectomee. He really did not want to come but his “clever wife”, made the arrangements and paid all of the fees, with his credit card then told him if he did not come he would be wasting his money, not hers. Needless to say, he came, seemed to really enjoy himself and never missed a dance on Saturday evening. It was so wonderful to see him enjoy himself so much.

Our president was told by one gentleman, that we saved his wife’s life by her being there. She was very depressed and talked of suicide. She came and went away with a whole new outlook on her life. Little Miracles?
On Sunday morning a group of us were lucky enough to go on a Grand Canyon tour, which had been organized by Tom Olsavicky, President of Peninsula Lost Chord Club, Newport News, Va. We met in the lobby of the Hotel at 7 AM and by 7:30 we were well on our way to see one of our Nation’s wonders.

On the trip up we were treated to beautiful Arizona scenery and an amazing amount of information from our tour guide. The farther north we went and the closer we got to the South Rim of the Canyon, the worse the weather got. By the time we got there it was raining and very windy and you could barely see much of the Canyon because of the cloud cover. Our tour guide didn’t give up and kept driving from overlook to overlook, trying to find a clearing in the weather so we could get a good look. Finally, around toward the south eastern part of the Canyon we pulled into an overlook parking area were it appeared there might be some clearing in the cloud cover. We made a short walk to the overlook area and there it was! One of the most amazingly beautiful sights I have ever seen in my life! It was as though we were looking at a beautiful color painting that words just can’t adequately describe.

The clearing in the weather only lasted about 10 minutes and then it started to snow. As short as the clearing in the weather had been, the wait was well worth it. Some day I hope to go back and see it all again!

Attention SLPs
If you are listed in the IAL Directory of Alaryngeal Speech Instructors please check to make sure your information is current. If you wish to be included in this resource, please notify the IAL of your interest to serve as a resource using the same email. There is no cost to you.
Report any problems or interest to: theialoffice@gmail.com

IAL Loan Closet is in Need
The IAL Loan Closet is available to laryngectomies in need of an electrolarynx. The closet is presently quite low on loaner devices. If you have a spare electrolarynx that you are not using or no longer need, please consider donating your device to the IAL using the actual office address at:
18 West College, San Angelo, TX 76903.
The IAL will make it available to a laryngectomie in need.
Laryngectomees in the pool?!

One of the highlights of our conference every year, is the swimming demonstration. Several of our laryngectomees demonstrate their swimming techniques. Capt’n Bob Bauer from California uses a snorkel, some a life vest but many just occlude their stoma and swim with one arm. This activity always draws a crowd and you hear many “ohs and ahs,” “their crazy,” or “I’d never do that” from the bystanders.

This year Konrad, the young man from Poland, learned to swim by occluding his stoma and he was really enjoying himself. We are all too often told we cannot do something and it seems we just have to prove folks wrong by doing what they think cannot be done.

Many new and lasting friendships are formed at our conference.

Some of us are on facebook a lot, just keeping up with the friends we have made and encouraging each other. There are so many wonderful, caring people in our community. Some of us do not see another laryngectomee from one year to the next but by building these friendships we know we are not alone. There are facebook groups listed on the IAI website that you can join and you will never be turned away. It is a great way to stay in touch and share with others. It is a way of reaching out to help each other.
Sonovox
Ad
Then I thought "heck no." I did not come this far to settle for simple communication. I did not survive a terminal cancer to accept complacency. I deserved more, the Laryngectomee community deserved more. After 23 years of surviving, it was time to thrive. It was time to give the voiceless a voice. It was time to sing for the mute.

It took seven years to build enough courage and on February 25, 2019 I agreed to sing in the laryngeal karaoke contest at the Sin City Laryngology Conference. I chose “Mack the Knife” as my song.

Singing without vocal cords is no easy task. The effort required to sing without cords is akin to racing in the Indy 500 on a bicycle. One slip up, one string of mucus obstructing my prosthesis, one unlucky break would be enough to completely derail my performance. To me, this simple, friendly competition was a coming out party for the Laryngectomee community that I represent. If I could win a singing competition without vocal cords, I could prove to all cancer survivors that anything is possible. Failure was not an option.

I walked up to the front of the room, got ready and grabbed the mic. The music started and I gave it my best shot. The lyrics flowed, “Oh, the shark, babe, has such teeth, dear and it shows them pearly white.” I worried that I couldn’t make it through the three minute song. The effort required to vibrate muscles that are not supposed to vibrate and do it in tune seemed insurmountable. I sang like my life depended on it. I crooned with the repressed vocal energy of a generation of Laryngectomees. I soared through the lyrics like Bobby Darin did in the Fifties. The next thing I knew, the audience was on their feet. Three decades of practice and preparation and a survivor had become a “thriver.” I won.

If we now live in an age where people can win singing contests without vocal cords, anything is possible.
IAL BOARD MEMBER INFORMATION

The IAL 925B Peachtree Street NE Ste 316. Atlanta, Georgia 30309
Website: www.theial.com     Email: theialoffice@gmail.com

Helen Grathwohl           W. Kyd Dieterich              Anne Ammenti             Jennifer Malkiewicz          Caryn Melvin
President          Vice-President              Secretary                   Treasurer           VI Director

Jewell Hoffman         David Kinkead             Karen White                   Susan Bruemmer          Cindy Gordis
Board Member          Board Member               Board Member                     Board Member            Board Member

Committee assignments:
• Nominating: Anne Ammenti, All Board Members
• Public Affairs: Jewell Hoffman, Jennifer Malkiewicz
• Speech Standards: Cindy Gordish, Susan Bruemmer, Caryn Melvin, Susan Reeves
• Medical Affairs: Cindy Gordish, Susan Reeves, Susan Bruemmer
• By-Laws: Kyd Dieterich, Karen White
• Finance-Ways & Means: David Kinkead, Helen Grathwohl, Jennifer Malkiewicz
• Annual Meeting: Kyd Dieterich, Helen Grathwohl, Caryn Melvin, Susan Reeves

Use the forms below
to make a voluntary tax deductible donation, subscribe,
change your address, or remove a name from the mailing list.
Send to The IAL, 925B Peachtree Stree, Ste 316. Atlanta, GA 30309-3918

Donation
☐ Enclosed is my tax-deductible gift of $10 or more, with my check or money order made out to IAL

Mailing list
☐ Add me to your mailing list
☐ Remove my info ☐ Change my contact info (as >)
- I am a ☐ Laryngectomiee ☐ SLP ☐ Doctor
☐ Nurse ☐ Caretaker ☐ Other

Please send __ (number) of postcards for others to use so clubmembers can subscribe or change info

Name
.................................................................................................................................

Address
.................................................................................................................................

City, State, Zip, Country
.................................................................................................................................

E-mail
.................................................................................................................................

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-near-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.

Location of Last 30 IAL Annual Meetings
1989 - Dallas, TX
1990 - Cincinnati, OH
1991 - Winnipeg, Canada
1992 - New Orleans, LA
1993 - Rochester, MN
1994 - Cherry Hill, NJ
1995 - San Francisco, CA
1996 - Hot Springs, AR
1997 - Toronto, Canada
1998 - Indianapolis, IN
1999 - Reno, NV
2000 - Nashville, TN
2001 - Myrtle Beach, SC
2002 - Vancouver, BC, Canada
2003 - Atlanta, GA
2004 - Anaheim, CA
2005 - Boston, MA
2006 - Schaumburg, IL
2007 - Burlington, VT
2008 - Little Rock, AR
2009 - San Mateo, CA
2010 - Clarksville, IN
2011 - Kansas City, MO
2012 - Durham, NC
2013 - Spokane, WA
2014 - Buffalo, NY
2015 - Baltimore, MD
2016 - Dallas, TX
2017 - Newport News, VA
2018 - Orlando, FL
2019 – Phoenix, AZ
In 2020, the IAL needs a great location to host the AM/VI. Ideally, the location would have great Club or individuals to offer local support, a convenient airport, a nice hotel with meeting space and room rates between $90-$110. It is always the goal to afford access to laryngectomees from new areas of the country.

Planning Ahead for Future Conferences

Would your club be interested in hosting the IAL Annual Meeting during the summer of 2020? Please submit your application to the IAL Board of Directors! The IAL Annual Meeting has been east more than west in the last few years. 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
Gary Lee Miner Sr., 72, died Saturday, July 7, 2018, at UNC Medical Center in Chapel Hill. Mr. Miner was born in Circleville, Ohio; to the late Wayne and Lucille Hickey Miner.

Memorial service was held Saturday, July 14, 2018, at Jones Funeral Home Chapel with Fr. Gregory Spencer officiating.


His fraternal organizations and community involvement included; Master Mason, Scottish Rite (32nd degree). Member of Toastmasters (silver) Jacksonville, NC, Past President (two terms) of the Marine Corps Motor Transport Association. Past Scout Master and District Commissioner for the White Oak River District Boy Scouts of America Jacksonville, NC. Member of and spokesperson for SAVE (Survivors and Victims of tobacco Empowerment). Past president of the IAL (International Association of Laryngectomees). Technical audio/video advisor and member of the Voice Institute of the IAL, President of the Eastern North Carolina Nu-Voice club, Past President (three terms) of the Eastern North Carolina Yul Brynner Head and Neck Cancer Club both of Jacksonville, NC. Chairman for Project Assist Coalition, Onslow County, Member of the Onslow County Asthma Coalition, Onslow County, Board of Director member of CHIP (Community Health Improvement Process) Onslow County. Member of the Community Strategic Plan for Children and Families, Onslow County, Member of the Mayor’s Committee for persons with disabilities, City of Jacksonville, Onslow County North Carolina. Founder of STR2KE (Students Teaching Resistance 2 Kids Everywhere). Onslow County Coordinator for Teen Empowerment School Summit. Member of Onslow County Teen Court. Life member of Jacksonville DAV. Area Ambassador for the American Cancer Society for Celebration of the Hill. Co-Chair for the Onslow County Relay for Life Committee. Board member of the University of North Carolina Otolaryngology Head and Neck Cancer Department. Board member of the North Carolina Alliance for the Community Health Action Council.

Mr. Miner enjoyed raising his children to be good and productive citizens. He was proud of the three great years he served on the drill field. He enjoyed touring the USA with his wife beside him, they would stop at a campground one night and spend the next night in a Walmart, depending on their mood and where they would want to stop that night.

Mr. Miner is survived by his wife of 48 years, Janet Lusk Miner of the home; one son, Gary Lee Miner II and his wife Janie of Richlands; two daughters, Suzanne Miner-Ringham (Anthony Catino) of Jacksonville, Julie Miner and her wife Debra of Jacksonville; three brothers, Thomas Miner and Betty of Circleville, OH, Allen Trego and Becky of Aiken, SC, and Bill Trego and Nancy of Circleville, OH; one sister, Edith Polly of Circleville, OH; 12 grandchildren and three great-grandchildren. He is also preceded in death by his special four-legged friend and companion, “Simba.”

In Memoriam Jack E Henslee

I have been asked and have the honor to write this article about Jack for this IAL newsletter. Apart from my own personal experience, I have used information from articles written about his projects over the years.

Jack was my friend for over 20 years. We both served on the IAL board and shared a passion to help laryngectomees whenever and wherever we could, either on a local basis or worldwide. Jack and I could not always see eye to eye about things; I was the stubborn Dutchy and he the grumpy business man but in the end we always talked it out and remained friends until the day he passed away.

Jack was hired in the late 1990’s as Executive Director. The IAL needed someone outside the BOD to take care of business that was sometimes beyond their own limits and get a financial structure.

Jack worked hard, took care of all the negotiations for hotels etc for the IAL and VI meetings. He made sure all financial agreements worked out the way he wanted and kept track of all the important business that needed to take place. In 2000 Jack Keilsohn, the treasurer of the IAL resigned and Jack, at that time Vice President, stepped in to temporary take over the job. In that same year, at the IAL meeting in Nashville, a new Treasurer was chosen. Leonard Librizzi took over the job and he and Jack worked hard to get the IAL in a financially healthy position.

Jack was a tough cookie to crack in business and in his position at the IAL. People did not always understand him or the decisions he had to make. Especially about the finances: that was always a battle between him and some others. Jack’s goal was to make sure there was money left to help future laryngectomees and when he left the BOD, he had accomplished that goal leaving the IAL in a healthy financial position.
Jack served from 2004 until present in the Board of the Californian Association of Laryngectomées, and was President of the Look Who’s Talking Club, the local voice club in Stockton CA. He wrote newsletters for both clubs. He hosted the CAL annual meeting several times with the local club.

He also served as VP of Finance and Administration for Webwhispers.

Jack was a very active member of the laryngectomee community until his passing. His passion was to help those who could not regain their voice and educating those outside the community. This included training medical professionals about throat cancer and the challenges those who have had a laryngectomy encounter.

Jack wrote a book about how to learn Esophageal Speech in 1990, “Look who’s Talking”, which is still used to this day.

In 2009, Jack founded Voices Restored, One Country at a Time, a Californian Association of Laryngectomées project to provide rehabilitation services to those that lost their voice due to cancer. The primary focus was to provide donated ELs and education to Third World countries. Clinics were held to educate speech pathologists, nurses, students, and laryngectomées on how to obtain speech using an electro larynx or esophageal speech.

Voices Restored donated thousands of dollars in speech aids, medical equipment and supplies to Costa Rica, Peru, Colombia, Mexico, Haiti, Armenia, the Phillipines and Vietnam. Jack made a documentary of the Voices Restored project. This documentary won the Best Documentary Award at the Costa Rica Intern Film Festival in 2010.

Jack had to take a huge step back in 2013 when he developed lung cancer and other health issues. In the years following he still worked hard to help Third World countries. Many laryngectomées all over the world have him and the Voices restored organization to thank for their voice.

His latest project was a movie, “You Don’t Know Jack”, a powerful public service announcement about Tobacco Awareness in which he explained all the physical problems he had due to smoking.

Jack could be tough, was a real business man with a goal but underneath that stern exterior he had a big heart. You just had to know him. Jack was also an incredible poet. His poems came straight from the heart and touched many who read them.

The last 5 months were a struggle for him. He had a lot of health problems and spent a lot of time in hospital. At times his health improved until he got a setback and things did not look so well. But, as always, he kept fighting and seemed to be improving during the last weeks leading to the hope that he might be able to come home. Unexpectedly, the news came that he passed away. As I would say, he had run out of his 9 lives. He survived so many difficulties and this one was too much for his body. He will definitely be sorely missed by those who knew him well. The tough business man, but also a wonderful person with a huge warm heart.

Rest in peace my dear friend
With love Marianne Kooijman

In Memory Of Jack Henslee

We meet Jack when we were on a WebWhisper’s cruise and had cabins next to each other. The cruise was through the Panama Canal so we had a lot of time to get to know each other. This was not long after I became a laryngectomy so I did not know about his involvement before then but have learned some of it. We became friends very quickly.

Jack and I worked on several projects together with WebWhispers as well as spending time at the IAL conferences together. We always had a great time no matter what we were doing. Jack gave a lot to the laryngectomy community with his involvement with IAL and WebWhispers. He was always willing to step up and help or hold a needed position, as treasure of WebWhispers.

Jack was very creative and was good with working on Websites and computers. I learned a lot working with jack beyond being a laryngectomee. He also wrote some wonderful poems and was a monthly contributor to the WebWhisper’s newsletter.

During the Spokane IAL in 2013, my wife and I took Jack and Jeanette to Coeur d’ALene, Idaho for dinner one evening. We had high mountain huckleberry desert and that was the first time they had tried it. They became hooked and loved it. For those that have never eaten the high mountain huckleberries, they are like a wild blue berry but a little tarter. They only grow above 4,000 feet level in the mountains.

Jack also did a lot of work to help laryngectomies in several other countries in Central America and Porta Rico. He would make a trip down to take them supplies and ELs that they could not get within their countries. He also did a lot of teaching to help laryngectomies when he was out of the country. He did this all out of pocket and with donations.

One thing I like about Jack was that you always knew where you stood with him. He was always open and honest with me. That is a trait I always respect. If we disagreed that gave us an open field to discuss the issue and find an agreement.

We emailed each other often, when he was not on the golf course, which he loved. Jeanette and I emailed almost daily while Jack was in the hospital to keep me updated and discuss what was going on with Jack. She would read the messages to Jack so he would know that his friends were concerned for him.

I will miss his friendship very much.

Ron Mattoon
Introducing the new Blom-Singer® EasyFlow™ HME

EasyFlow™ HME has a beige tint and non-reflective surface texture.

MucusShield™ helps protect the foam filter

EasyTouch™ speech button makes speaking easier

24/7 heat and moisture exchange

INHEALTH™ TECHNOLOGIES

We speak ENT

800 477 5969
International +1 805 684 9337

www.inhealth.com

©2016 InHealth Technologies — Manufactured by Freudenberg Medical, LLC (161001.00)