

# Whispers on the Web

A Monthly Online Newsletter for WebWhispers

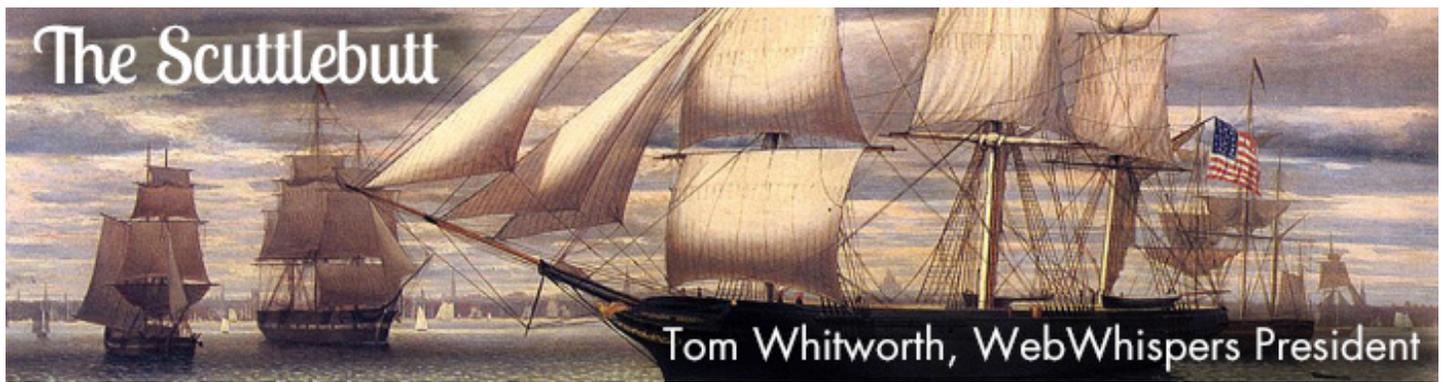
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*June 2019*

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## WebWhispers With the International Association of Laryngectomees

The IALs 2019 Annual Meeting and Voice Institute was as wonderful as one could imagine and then some. I truly believe The Voice Institute, directed by Caryn Melvin, PhD, could not have been any better. The faculty and their presentations were incredible. The VI attracted 70 laryngectomees! Along with them were 33 caregivers/friends, 7 SLPs, a graduate student, faculty of 14, and 17 vendor representatives. The event this year was a huge success! We asked questions, learned, and thoroughly enjoyed being with one another. With several receptions, the IAL Banquet, WW dinner, a museum tour, a Grand Canyon visit for some, and even line dancing lessons on Friday night, socialization could not possibly have been better. Just being together is an integral part of this!

As in each of the previous years, the WebWhispers 20th Annual Dinner, was preceded by a beautiful reception sponsored by Bruce Medical. This year, the reception was held on an outdoor patio leading into the banquet room, providing a nice chance to visit with one another. Our dinner was arranged, as in the past, by Jeff Vanden Hogen and featured an excellent “Little Italy” buffet. The WebWhispers Annual dinner tradition was begun by Pat Sanders as an opportunity to express our gratitude to some of those who have served the laryngectomee community in the past year by working with or supporting Webwhispers in some special way. Several awards were presented, each celebrating a unique contribution.

Others will appear later in the issue but here are two that were awarded at the end of the dinner:

### **Certificate of Appreciation presented to Richard Najarian, Bruce Medical**

*For more than two decades, WebWhispers has provided support worldwide for those affected by cancers of the head and neck and rehabilitation following laryngectomy. Richard Najarian and Bruce Medical have been with us every step of the way, hosting the reception for our annual awards dinner, now in its twentieth*

*year, providing financial and other support, ongoing fundraising efforts with Neckbreather pins, and much more. Now with more than four thousand members, WebWhispers continues to flourish as a direct result of these efforts. For these and countless other contributions, we are truly grateful.*

### **Volunteer of the Year, David Kinkead**

#### **List Manager, Mail Digest Moderator, & Salesforce Data**

*For the past three years, David has been responsible for enrolling new WebWhispers members from all over the world at almost any time day or night. He also serves as one of four regular moderators for our Mail Digest, covering the “west coast” shift the first half of each month. Dedicated to each task, he does not wait to be asked; he sees a need and says, “I can help with that”. In 2018, when we lost our Salesforce Data Manager, David added that work to his list of responsibilities. Also last year, David was elected to the board of directors for the International Association of Laryngectomees where he has served while retaining each of his commitments to WebWhispers. David is motivated solely by a yearning to help others and we are truly grateful for his efforts to serve the laryngectomee community.*

Our scholarship recipients and sources were:

InHealth Technologies (\$200) –Karen White, Arlington, VA  
Mike Csapo, Twentynine Palms, CA  
Atos Medical (\$400) – All first time attendees to the Voice Institute  
Daniel Carlson, Prescott, AZ  
Lorna Larson, St. Louis, MO  
Steve Cooper, Potomac, MD  
Konrad Zeilinski, Warsaw, Poland

I can't wait until the details are rolled out for the event next year! See you then.

**Enjoy, laugh, and learn,  
Tom Whitworth  
WebWhispers President**

# Stand By Me

The Caregivers Journey



Care Giver of the Year Award

Presented to

Jeanette Thomas

**Caregivers take on many roles in our lives, from moral support to physical help.**

**Sometimes their role as advocate can make a life or death difference. Throughout her relationship with Jack Henslee, Jeanette has been a source of support and encouragement but during Jack's latest crisis her expertise as a nurse and unwavering devotion has proved critical in his ongoing recovery.**

**Medical professionals are often woefully ignorant of our unique needs and Jeanette was at his side to translate, advocate and interpret as well as keep family and friends informed.**

**We are all aware that without her vigilance the outcome might well have been very different. She is not unique in her devotion, that is for sure, but she has been a model of loving and informed support under really difficult circumstances ... a true caregiver.**

# Between Friends

Donna McGary

"That which does not kill us makes us strong."

Photo CC by Curack5239

## World Wide Friends

WebWhispers is not just the premier resource for information and advice for the lary community but where we go for support and friendship...where we find camaraderie and comfort...where we are not alone. For me, many of those close bonds have been formed as a result of being a part of Whispers on the Web and getting to know the many writers who have contributed to this terrific newsletter over the years. We don't often get a lot of feedback but every so often, I am heartened by one comment or another and we hear that local clubs print out versions which are eagerly read by folks not online. That is so encouraging.

Today I would like to give a shout out to one of my favorites...I've never met her and she and I live worlds apart. But she writes eloquently and with grace and humility and, perhaps as an editor, I can say thankfully, with reliability. This award was presented to her at our WebWhispers banquet in Phoenix on May16. She wasn't there to receive the recognition in person but here's to you, my friend!

Writer of the Year  
Presented to Noirin Sheahan

**For five years Noirin, from Dublin, Ireland, has been writing "The Mindful Lary".**

**As a long-time practitioner and teacher of mindfulness meditation she brings a unique perspective to the laryngectomee experience. She writes with unflinching honesty, humor, compassion and eloquence about her struggles and triumphs in her new life.**

**Her experiences are shared by us all but her writing helps us to see this journey with fresh eyes. She admits that she, like many of our writers, had to lose their voice to find it.**

**Whispers on the Web truly appreciates her commitment to write her heart out every month, even when it is inconvenient or the muse is unwilling.**

**She is truly a treasure and a treat to read.**



# Voice Points

Written by Professionals

Coordinated by Kim Almand M.S., CCC-SLP  
kbalmand@gmail.com



## International Association of Laryngectomees 2019

The International Association of Laryngectomees held their Annual Meeting and Voice Institute in Phoenix, Arizona May 15-18. This 4 day conference covered a variety of topics about laryngectomy assessment, management and life as a laryngectomee. The returning faculty included Kim Almand, Cindy Lee Gordish, Caryn Melvin, Susan Reeves, Lori Simpson, and Linda Stachowiak.

We were very fortunate to have physicians and speech-language pathologists from the Mayo Clinic and Banner MD Anderson join our faculty this year. Dr. Michael Hinni from the Mayo Clinic opened the Voice Institute on Wednesday with a talk on anatomy and physiology pre- and post- laryngectomy. He also presented some of his more interesting cases and entertained questions from the audience.

The Keynote Speaker, Dr. David Lott from the Mayo Clinic, presented on Thursday. He talked about his laryngeal transplant and tissue regeneration program. His work is not only fascinating but also gave attendees hope that in the future a diagnosis of laryngeal cancer may not result in a total laryngectomy. Laryngeal preservation may be possible.

Lisa Crujido from the Mayo Clinic gave a talk about tracheoesophageal voice restoration as well as dysphagia following total laryngectomy. She was also presented with the James Shanks award for her contribution to the laryngectomy community. Keri Winchester from Banner MD Anderson gave a talk on TEP troubleshooting. Leah Mackie, Clinical Rehabilitation Manager from Banner MD Anderson gave a talk on pulmonary changes following total laryngectomy.

Stacey Brill, a speech-language pathologist from the Lee Memorial Health System also joined the faculty this year. She has developed a laryngectomy program at her facility that has been recognized not only locally in Florida but nationally by the American Speech-Language-Hearing Association. She discussed ways to build and sustain head and neck cancer programs. This is a particularly important subject as many smaller and rural hospitals do not have the support for laryngeal cancer patients that can be found in larger cities or dedicated cancer hospitals.

Friday was an exciting day for the Annual Meeting and Voice Institute. Bill Brummel shared a sneak preview of his documentary "Segue". Segue is a film that tells the story of Dr. Thomas Moors's Shout at Cancer choir and some of the members of the choir.

There are no words that can adequately describe this beautiful film. Listening to the stories and the music left every audience member tearful and amazed. The preview was a powerful testament to what we already know about life after total laryngectomy. ANYTHING is possible. Life not only goes on but can be better than ever imagined.

On Friday afternoon, conference attendees went to the Heard Museum. The Heard is dedicated to the advancement of American Indian art. The outing was a way for Voice Institute students and Annual Meeting attendees to get to know each other in a more casual setting. The staff at the Heard gave us an informative and entertaining tour of the museum, guiding us through the many exhibits found throughout the building.

The Voice Institute and Annual Meeting wrapped up on Saturday with a talk and demonstration of voice amplifiers by Tom Lennox as well as an opportunity for students and attendees to interact during a segment "What It's Really Like" where persons with a laryngectomy, spouses, and family members share their story one-on-one with students of the Voice Institute. This opportunity to interact and learn from one another is an experience like none other. Students always come away inspired and with a deeper, richer understanding of what it means to be a laryngectomee. Having the laryngectomee community there with them as they learn, willing to answer questions and share their stories is what makes this conference so very special.

The Voice Institute would not be possible without the generous support of our vendors. ATOS Medical and InHealth Technologies provided hands-on HME and TEP learning experiences for conference attendees on Friday morning. This hands-on opportunity would not be possible without them. Jim Lauder, Cliff and Karen Griffin, Matt Griffin, Bruce Medical and Tom and Dorothy Lennox also provided invaluable information and education for attendees.

I am so very grateful to the faculty, vendors, board of directors and all attendees for making our conference successful, enriching and inspiring!

As we wrap up the 2019 conference we eagerly look forward to 2020. We will be announcing the conference location shortly so stay tuned!

Caryn Melvin, Ph.D., CCC-SLP, CPC  
International Association of Laryngectomees, Voice Institute  
Director, 2019

# Dear Lary

Noirin Sheahan

## A Social Networking Kit

I'm very aware of the temptation to withdraw from social life because of laryngectomy. At some level this is Ok because I'm generally quite content when I'm alone. I rarely feel lonely. I enjoy reading and studying as well as listening to the radio and relaxing in the garden. And I have a mindfulness meditation practice which calls me inward for several hours each day, inviting me to learn about life from the moment-to-moment experience of it.

But my preference to keep my life simple and quiet is also because I'm avoiding the challenge of socialising. There isn't the same 'feel-good' in this when I'm struggling to make myself understood, and being too slow to get my tuppence worth in when conversation is flowing quickly. There's disappointment and frustration mixed in with the joy of connecting up with friends. And those emotions are hard to combine! So it's easy to get lazy, to tell myself it isn't worth the bother.

But I know this is a mistake. I know I need friends. They help me see the world in a more balanced way. Their news broadens my horizons. And afterwards, despite the moments of disappointment and frustration, I always conclude it was worth making the effort. So I nearly always say 'yes' when someone asks me to meet up.

A practical problem is that socialising often involves meeting people in public places. With an electrolarynx it's difficult to be heard and understood in a crowded room with lots of other people chatting in the background. I use a portable amplifier but even that doesn't carry my voice when there's a lot of background noise.

A few years ago I came across some technology that helps with this. There are on the market, small pocket amplifiers designed for the hard-of-hearing. The person with the hearing impairment wears an earphone while the person they're speaking with uses a microphone so that their speech can be amplified and fed to the earphone. So that the pair can communicate without anyone having to shout. It's a very simple idea but can help enormously. It

works better than a hearing aid, because only the speech that the person wants to hear is being amplified, whereas hearing aids will amplify all of the sounds in the room which can end up as a cacophony of noise.

My working life had been in the field of Medical Physics and Engineering, which involves the application of science and technology in medicine. It was a year or so post-laryngectomy before I remembered this gadget and realised that I could reverse this so as to help others hear me in a noisy environment. I wear the headset microphone and they wear the earphone. Easy as pie! And when I meet up with a group of friends I connect several headphone sets together using a beam splitter – a device designed to allow a group of people listen via headphones to music from an iPad for example or a computer.

The amplifier, earphone sets and beam splitter fit into a small plastic bag that I keep in my handbag along with a bottle of sanitizer and some gauze pads so that I can sterilise the earphones after every use. I call it my social networking kit! The only disadvantage is that it needs us all to be sitting down for long enough to make it worthwhile connecting up. So it's not suitable for gatherings where people are moving around a lot. Strangers do not always take kindly to being asked to put on headphones, so I haven't used it for casual encounters either.

Despite these limitations, my social networking kit has served me very well. It means I can meet friends in a pub, a café or restaurant, without worrying how noisy the background is going to be. As mentioned earlier I'm often tempted to duck out of social engagements, and easily seduced by thoughts like "What's the point, no one will understand me!" But my networking kit won't let me away with such a paltry excuse!

I'd recommend you try this out if you haven't found some other solution to the background noise problem. I'm very happy to give anyone details on the set-up if they wish to contact me at [noirinsheahan@gmail.com](mailto:noirinsheahan@gmail.com).



## Agony and Ecstasy of Finding My Voice *A Memoir by Dr. Branton Holmberg*

Getting back to my childhood experience with my teacher Miss Light, her humiliation of me drove me deeper into the recesses of the library where my love for reading increased even more. It did put a damper on my creative story telling for a great many years. It was a shame because I'd been very proud of that story. I'd spent a lot of magical moments writing it, and a miserable time reading it out loud. Then for her to tell the class I'd plagiarized it drove me deeper into my desire to be invisible, and get out of her class.

I would have given anything to be what I considered a normal kid who didn't have a funny looking nose with an ugly scar on his upper lip. I wanted to be a kid who could talk normally without people always asking me to repeat what I'd said, especially when they asked me my name which was hard for me to pronounce clearly. I'd even gotten into the habit of saying my name and then spelling it before anyone could ask me to repeat it. I even changed my name to Rex when I transferred to Central Kitsap High School when I was living with my aunt and uncle.

I was glad to finally get into junior high school. I'd done a lot of speech therapy and everyone who knew my sensitivity about speaking was telling me I was speaking clearly. I'm sure now as I look back they were right because I had fewer and fewer problems being understood and the teasing had stopped.

Feeling the air go through my nose when I spoke though was just like it had always been, and my speech impediment was as strong in my mind as it ever was. My face still carried the obvious markings of a harelip. I was sure the world still saw me as I saw myself in grade school.

Grades seven through nine went OK. I got into a relationship with a couple of neighborhood pals that brought me as close to the dark side of life in the tenth grade as I ever want to be. I'd become fast friends with Fred and Eddie who lived near me in our neighborhood.

Fred and I were about the same size but he was a year older than me and was the leader of our gang of three. Eddie was a few months younger than I was and a lot smaller. He was like a lapdog to Fred, there wasn't anything he wouldn't do for him.

Even though they taunted me about my speech once in a while, it didn't bother me. It's probably because we had the same inclination for getting into trouble.

Fred's dad was an alcoholic and had no scruples about letting his

kids, or their pals, drink his beer and whiskey. He had no scruples about letting them smoke his cigarettes either. The three of us got to be old hands at smoking and getting a buzz on drinking beer and whiskey. This was when I was fifteen and thought I was master of my own world.

All our parents worked during the boom years after WWII. Fred's mom worked at St. Joseph's hospital, where I was born by the way, as one of the cleaning staff. She found part-time jobs for Fred and me at the hospital after school, and on week-ends. We jumped at the chance to earn our own money.

I got a job in the kitchen washing pots and pans. I got along great with everybody on the kitchen staff and loved the job even if it was a messy one most of the time.

The Catholic priests and nuns who ran the hospital would often tell me what a great job I was doing, which I loved hearing. Mom let me keep everything I earned telling me to use the money to buy school clothes.

My sophomore year in high school was a disaster. Fred, Eddie and I skipped a lot of school days and became experts in developing excuses and forging the signatures of our parents on notes sent from home excusing our absences.

Our trickery finally caught up with us in the spring of 1952 when Fred found out from his mom that our parents had been contacted by the school and knew about the awful mess we'd made for ourselves.

We'd skipped school the day we found out, and had time before our parents got home to figure out what we were going to do. Our solution was to run away.

Fred and I had cashed our paychecks the day before and the money was in our pockets. Eddie had a few bucks too so we decided to head south and try to get to Texas.

All we had time to do after we made our decision was leave notes telling our parents we'd be back to see them when we were rich and not to worry about us. My mother teased me for years afterwards telling me that I'd said in my note I was running away to get a better "Acknowledgement of the world". We left with the clothes on our backs and the money in our pockets.

It was late afternoon when we got out of town headed for Chinook Pass, and eastern Washington. We figured they wouldn't look for us going that way. Hitch hiking we made it as far as Enumclaw the first night.

Being the dumb kids we were we went to a big restaurant and had steak dinners which cost us a bundle. After we left the restaurant we figured we'd get out of town a ways and find somewhere to sleep. It was getting dark enough it was tough to see. We finally spotted an old abandoned farm house and decided to sleep there.

Just after sunrise the next morning we heard a dog barking like crazy outside the house and when we looked to see why, we spotted what we were sure was the farmer who owned the place walking toward the house. We bolted out the back door and ran with him yelling at us to get off his property or he'd call the cops.

Cutting through the woods behind the property, we made it back to the highway well beyond the old farm house. Hitch hiking the rest of that day we made it to Pasco, Washington and decided to stay there and find jobs to replace the money we were going through fast.

Fred, who looked older than he was, went in alone to rent a sleazy hotel room in Pasco. He said the guy at the desk was only interested in giving him a room if he got a week's rent in advance. Fred took it. I'm sure the guy knew he could take advantage what he considered a snout nosed teenager, and had no scruples about doing just that.

Eddie and I would sneak in and out of the room Fred rented. At night the two of us would flip a coin to see which of us got to sleep on the double bed next to Fred. The loser slept on the floor.

That week's rent in advance took almost all the money we had left. At night when I took a shower I'd wash out my shorts and tee shirt and wring them as dry as I could, then put them on and let them dry as I wore them.

The morning after we got to Pasco I found a job setting pins in a bowling alley where the manager paid me after each day's work. It's a good thing he did because it's the only money we had to eat with. Fred and Eddie scouted around for jobs but still hadn't found anything after three days and Fred decided we needed to head for Texas when the room rent was due.

By the end of the fourth day in Pasco I saw the hand writing on the wall and knew this was getting me nowhere fast, especially when Fred got curious about how easy it would be to steal money out of the cash register at the bowling alley.

Stealing money was way more than anything I wanted to get involved in. That night after we ate and got back to the hotel room, I told Fred and Eddie I was going out to buy a pack of smokes and that's the last I ever saw of them.

It was still a couple of hours before dark when I started hitchhiking out of Pasco and got lucky when a guy stopped to pick me up saying he was going as far as White Pass. I knew that would get me a lot closer to home so I hopped in.

It was late when we finally got as far as he was going which was out in the middle of nowhere on the pass. He left me on the highway and headed up a dirt road to where he said he lived.

I didn't have a watch but the moon was pretty high so I knew it must be getting late. I walked what seemed like miles trying to thumb a ride from the three or four cars that passed. It must have been about midnight when I heard something on the hillside above me crashing through the brush only a few feet away. At least it sounded that close.

I took off running and I'd never run that fast in my life. Thank God it was a bright moonlit night and I could see where I was going. I'm sure I would've killed myself otherwise.

I ran until I was exhausted. I hadn't seen a car going either direction the whole time I was running from what I was sure was a huge bear, or even worse a mountain lion. I made up my mind to hitchhike either direction because I wanted to get off of that pass and away from the wild animals I was sure would get me if I didn't.

Lady Luck smiled on me when a car stopped and picked me up going the direction I wanted to go. There was only the driver and he said he was going all the way to Tacoma. Lady Luck smiled again.

He was curious about what an obviously young teenager was doing hitchhiking over White Pass in the middle of the night. He seemed like a nice guy and I found myself telling him what I'd been through the past few days. When he found out I was headed home again he took me all the way to within a couple of blocks of my house where I asked him to drop me off.

It was early in the morning and the houses in the neighborhood were still dark but when I got near our house I could see every light was on and when I went in the back door mom and dad were sitting at the breakfast table drinking coffee. When they saw me, they broke into tears. I thought they'd be ready to kill me but instead they couldn't stop hugging and kissing me.

They wanted to know where I'd been. Was I feeling alright? Was I hurt? Mom had me turn around so they could look me over. They kept smothering me with hugs and kisses. I sure felt dumb about what I'd done.

Many years later, having children of my own I realized the terrible agony I put my parents through. I will say there was a positive side to it though. It gave me a greater appreciation of my own children's struggles to find their independence as teenagers and young adults. I bless my wife every day of my life because she was the foundation all of us stood on during the turbulent years with our teenagers.

**To be continued...**

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**Jack Henslee  
Lifetime Achievement Award**

Jack is a true warrior and not just against cancer which he has successfully battled numerous times. For decades he has tirelessly fought to advance the cause of complete laryngectomy rehabilitation.

In California through local and state clubs, through the IAL, WebWhispers and his own initiatives, he has provided inspiration, hope, guidance and practical resources for the laryngectomy community.

Particularly in underserved areas of Central and South America and the Philippines, where laryngectomees are frequently voiceless and without many options he has advocated for donations of ELs and training in ES.

In his writing and his work he has truly given a voice to the voiceless and inspired all of us to follow our dreams and live life to the fullest regardless of the obstacles thrown in our way.

WebWhispers recognized Jack for his years of dedication to the laryngectomy community at our awards dinner at the IAL annual meeting in Phoenix, Arizona on May 16, 2019. We had hoped he might attend but since he was unable to be there his friend, Ron Mattoon, was going to deliver his award in person on his way home. Unfortunately Jack fought his last battle on May 17, a warrior to the end. May he rest in peace.



## Editor's Mailbox

### An Open Letter to WW and the IAL



My Laryngectomy 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 Laryngectomy 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 Montgomery County Laryngectomee Club (MCLC) 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 informative on the most basic subjects for any

Laryngectomy, 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 conference was picking up tips and advice from the SLPs and fellow Larynxes 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 (picture below). 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 uncut 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

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