

# Whispers on the Web

A Monthly Online Newsletter for WebWhispers

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*June 2020*

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# From The Editor's Desk

Hello my friends,

This is a great issue but it was not without its challenges putting together. In better days we would have been in Charlotte at our annual meeting of the IAL this past week. Instead we all were pretty much home, being careful and cautiously, in some areas, venturing back out.

I suspect I am not the only one given to much introspection these days. I went to my first IAL/VI in Boston in 2005. I was relatively new to the whole hole in the neck thing and it was overwhelming. We had a pretty big turnout at that time and hearing all those squawking/buzzing/odd voices all at once was, I will admit, a turn-off for me. It took me a while to recognize that these were my people and there was nothing to be ashamed of. We were all there to learn and share.

At the Voice Institute I had some of the best SLPs work with me to try to learn Esophageal Speech. I was hopeless. Scar tissue is a b\*\*\*. But they were so patient and kind and supportive in their expertise and knowledge. THAT is what the IAL/VI and WebWhispers is all about.

I am much more fluent these days with my trusty EL. I am more confident...most days. I am not embarrassed by my voice most of the time but still there are times I can't bear the sound of my voice and it takes all I have to make a phone

call. That's why it is so important for those of us who are different to speak up...ironic that the one thing I can't do is "speak up". We understand what it feels like to have no voice, no place at the table, to be interrupted and patronized, to be unheard, to be less than.

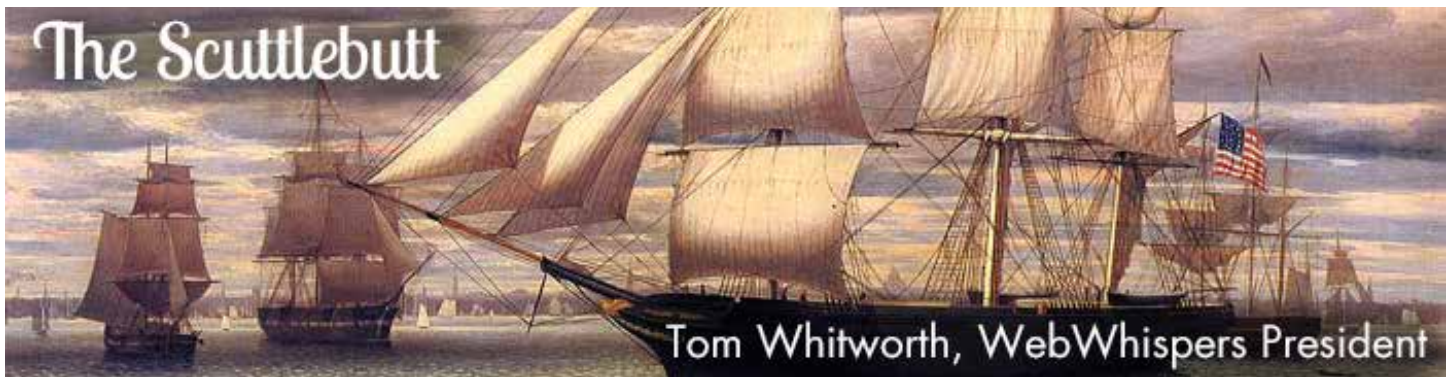
It is important that WebWhispers is a safe and supportive place for everyone. We strive to be inclusive and I think we are. But I also think we need to be aware that for many of us, the first time we experienced being immediately and noticeably different and being looked at and perhaps treated differently because of it was after our laryngectomy. For some folks that is something they have known from the day they were born. I, for one, am taking a hard look at my place in our society. Back in the day we used to say if you aren't part of the solution, you are part of the problem. That is still true.

As we wrestle with these seemingly intractable social problems, Whispers on the Web still has some great reading. Inspirational, educational and supportive....just what we need right now! Please read and let us know what you think!

*Donna McGary*







## Then And Now

Friends,

**I wrote this two years ago on what could have easily been a “bad” day. Instead, it was a time of epiphany and peace, with a few tears. Today, I realize that what happened to George Floyd could never happen to me.**

So many things are different now, clearly unlike they were during the time I refer to as B.C. (Before Cancer). Situations that bothered me a lot B.C. simply do not bother me now. A recent experience brought that to light like never before. I realized that I am truly a changed man and changed for the better. Though a fairly decent guy in the first place, I suppose I am now the new and improved version of my former self. For me, these days are A.D. (After Disease).

A few days ago, I was on my way to a medical appointment on the far side of the city, about an hour's drive. As I was clipping along a familiar stretch of the freeway, my car suddenly died, without so much as a hint of warning. It was one of those totally out of nowhere breakdowns and I suspected my transmission had bitten the dust. I managed to coast up the slight incline of the exit ramp and turned the switch off. Upon attempting a restart, it was fairly obvious that the car was not drivable and would have to be towed. By force, I turned the steering wheel and coasted slightly downhill into the parking area of a gas station/convenience store. I did my best to direct the car where it would not be in the way of customer traffic. I let the doctor know I would be missing the appointment and why then contacted my wife, Julie, to let her know my whereabouts. Next, I called AAA which I have been a member of for many years. They had always responded within an hour but this time the representative said it would be two hours. The tow truck actually drove up three and a half hours later.

The particular stretch of town is not among those anyone in their right mind would think of as a desirable location to have a car breakdown. For that matter, I doubt anyone would consider living there if they had any choice in the matter. The area has been declining for decades and is known for its frightening crime rate. It is home mostly to the indigent, many of whom are immigrants from African nations where their lot in life was even worse.

In this situation B.C., concern for my own safety would flood my mind and most people would think rightly so. I would hope

to not panic and would pray for myself if I did. Scenes of my impending demise would likely have flashed through my head. My thoughts would have been a narcissistic love fest: Why has yet another unfortunate thing happened to me? I don't deserve this! I wasn't doing anything bad; I was only going to a doctor appointment. Why in the world do I always seem to catch hell? Good grief- the crap just seems to never end! I must really be the reincarnation of Job. Woe is ME. The incident would be all about me and only ME.

A.D., my reaction could not have been more opposite. There was no panic. I thought of myself for about 10 seconds, then realized if something happened to me I would most likely not have to deal with it for very long. At that point, I was done with any semblance of fear. Almost immediately, I considered how good I have it. Fresh coffee, ice cold water, lary supplies, and any medications I might need were within arm's reach. If my expensive voice prosthesis got temporarily stuck and I needed to speak quickly, my electrolarynx was right there with a newly charged battery. I had just been able to contact all the people I needed to from my iPhone and those needing to could contact me. Much of the time passed as I got caught up on email, texts, and social media accounts, using the phone. An occasional vehicle pulled into the store mostly from off the freeway to buy gas. Many customers were walking as I sat comfortably in a car, albeit inoperable. Many of those on foot probably don't have access to an automobile in the first place, I thought. My car would eventually get towed to the shop and I would spend the evening comfortably in my home. I could be certain of that. I'm a cancer survivor with a hole in my neck. So what? Big deal. I had been en route to a Veteran's Administration source of health care where I get everything I need as a laryngectomee and then some. It was safe to assume that most of those in my midst that morning do not have access to decent healthcare. If they developed throat cancer or anything similar, would it even get diagnosed in time to save them? If so, would they have funding for lary supplies, prosthetics, and such? Probably not and that should not be!

If I had any fear that day, it was not for me, but for the people who live in that neighborhood and others like it. In total humility, I knew that I am a lucky man and richly blessed.

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



# Voice Points

Written by Professionals

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## Can You Hear My Voice?

There were times I wanted to give up. After having my laryngectomy, I was unable to speak for three months. I had a feeding tube for half of a year. Physical recovery was awful. Worse yet, I was saddled with insecurity, fear, and doubt.

I soon learned that these emotions are common among people who have had their voice boxes removed. A laryngectomy alters some of the most basic human functions such as speaking, eating and breathing. I now speak with the aid of a voice prosthesis and breathe through a surgically created hole in my neck called a stoma. Because of the drastic changes in our appearance and a radical change in the way we speak, laryngectomees can easily lose self-confidence and retreat from society, withdrawing into a world where we don't have to speak, eat or be seen in public. But when we self-quarantine, loneliness and depression are sure to follow. There were times when I found it easier to isolate rather than navigate.

I was forced to have a laryngectomy as a result of long-term damage from radiation treatments I received in 1998 for tonsil cancer, however, a majority of people have the surgery as a treatment for active throat cancers. Whatever the reason, it is a life-altering event. It took me more than a year to adjust to the physical changes, and longer to work through emotional and mental hurdles.

In 2017, my doctor and surgeon, Uttam Sinha of Keck Medicine of the University of Southern California suggested I make a film about how to cope with the psychosocial obstacles of living with a laryngectomy, and creating a quality of life that's abundant and joyful. I knew I was not alone in my harrowing recovery experiences, or in the fact that my medical team, family, friends and support groups encouraged me and helped me gain a quality of life better than before the surgery.

But I was in a unique position as a laryngectomee and a filmmaker to tell this story.

I went in search of a perfect story to illustrate the topic. I found the *Shout at Cancer* laryngectomee choir in the UK- a singing group made up of people with no voice boxes. Now, after two and a half years of development, independent fundraising and production, "Can You Hear my Voice?" is complete.

Through the film, I want to encourage people who are struggling through dark periods of recovery of any kind to hold on. The theme is universal. It's a story of survival and empowerment with a message that will resonate with people combating other diseases, disabilities, or personal struggles, which –when you think of it– is all of us.

Bill Brummel

Producer/Director – CAN YOU HEAR MY VOICE?

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View the official trailer:

[https://www.youtube.com/watch?v=Uc\\_Dt358meI](https://www.youtube.com/watch?v=Uc_Dt358meI)



*This Speaking Out column first appeared in May 2011. I thought it fitting to reprint since we couldn't get together this year. In WC Baker's column below - This Lary Life - he writes about his IAL/VI experiences and shares some great photos from years past, including some you'll recognize as contributors to this SO. It's nice to see their smiling familiar faces."*

### **How Many IAL Meetings Have You Attended ? What is Your Favorite Memory?**

#### **Jack Henslee - 1988**

For many people the first IAL event they ever attended was and always will be their favorite. After all, if it didn't make an impression on you then, you probably wouldn't have gone back for more. I hope that the accounts you read below will encourage you to also attend one day.

I have now attended 16 Voice Institutes/ Annual Meetings so it's probably obvious that my first meeting in Winnipeg was my favorite. That was way back in 1991 and today I still see some of the people I met back then at today's IAL meetings. Laurie Gallant from Toronto, Jessie Hart and Susan Reeves from TX, are a few that come to mind, plus there are so many that have since passed but returned every year for many years.

I first attended as a Laryngectomee Trainee at the Voice institute. Things were a lot different then and the Voice Institute (VI) and Annual Meeting (AM) were 2 separate functions. Back then the VI started on Sun and ended on Thurs when the AM started. The hours were long! We started at 8:00 AM each day and sometimes didn't finish until 9:00 PM. Lisa Proper was my "team leader" and she worked our butts off but she also got great results. One of the best things, most of us took away from those experiences, was not only being educated and improving our speech, but leaving with a determination to help others in the future. The Voice Institute was and still is staffed with great volunteers that give their time to make our lives better and it sure feels good to pass that on to others.

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#### **Wayne Baker - 1991**

In 1993, the laryngectomee world was different. There were

clubs everywhere and meetings were well attended. American Cancer Society ran the IAL meetings and esophageal speech was considered the gold standard, representing the epitome of laryngectomee rehabilitation.. Most local laryngectomee groups revolved their meetings around esophageal speech and in many places those who were not able to achieve good esophageal speech were looked down upon by those who had acquired it. This attitude had been changing since the introduction of the TEP, but esophageal speech was still king, In 1993 a landmark for that change occurred at the Rochester, MN Voice Institute with the May Clinic.

A wealthy laryngectomee from New York had made a large enough donation to the event that he was given the privilege of speaking at the Voice Institute Banquet. He related his practice of demanding that non-esophageal speakers should throw their Artificial Larynxes away and rely only on esophageal speech. I don't remember what he said about TEP users, but I suspect that he thought they were cheating, He ended his speech to stunned silence.

The faculty of eminent Speech Pathologists and MD's met in emergency session and announced the next day that the best method of alaryngeal speech was the one that worked best for the individual. I have attended a total of 15 meetings and I imagine there is still some arrogance among some old timer esophageal speakers, but they are definitely in a minority now and the laryngectomee world is better for it.

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#### **Richard Crum - 1988**

I have been to every IAL meeting except one since 1990. I missed the New Orleans meeting in 1992.

The one that stands out in my mind more than most was the meeting in Cherry Hill NJ in 1994. I arrived at the Philadelphia, PA airport late, about 11 pm. I had reserved a car because I wanted to go to Gettysburg the next day. The only car they had left was a big black Cadillac and they let me have it for the same price as the compact that I had reserved. After renting the car it was about 1 am and on the way I missed a turn and ended up in downtown Camden NJ. A white guy in a black Cadillac in downtown Camden at 2



am in the morning. Not a pretty sight. With the help of two NJ police I finally made it to the hotel.

The hotel had just filed bankruptcy. Water leaking from the ceiling of the bathroom. This was the last IAL that lasted 2 weeks. One week for the Voice Institute and one week for the IAL meeting. The first week we shared the hotel with a group of gospel singers. The hats were memorable.

I attended the VI as a student and I had an instructor from Greece. The second week, we were joined by a group of 70 laryngectomees and spouses from Japan. All of the laryngectomees in this group were esophageal speakers. The meeting was very interesting and turned out to be very eventful.

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### **Bob Herbst - 1998**

I have been to eight of the last ten AM/VI's. Nashville in 2000 was my first experience being with over one hundred laryngectomees in the same building. My eyes and ears were opened in amazement. I had spoken to Pat Sanders, Dutch Helms, Herb Simon, Elizabeth Finchem, Jim Lauder and many others via WW but never got to put a face and voice together with my new web friends. I brought my wife Lesley and the president of the New Haven CT Lost Cord Club, Burt Haberfeld, and his wife with me. Burt introduced me to one of his favorite SLPs, a woman by the name of Susan Reeves.

About 7 or 8 years later, I was reintroduced to Susan, who is currently our IAL Executive Director. Shortly after Atlanta's AM/VI Burt's cancer came roaring back, and I was chosen to be New Haven's next LCC President. As years went by, I attended Myrtle Beach, Atlanta, Boston, Burlington, Little Rock, San Mateo and Louisville/Clarksville and now am looking forward to seeing old friends and newbies in Kansas City.

My favorite memories probably revolve around the pools. Getting back in the water was a highlight every year. The usual suspects included Pat S, Elizabeth F, Tony Talmich and others.

I believe it was in San Mateo where Terrie Lynn Hall and Tom Herring were coaxed into joining us at the pool where my favorite memory may have taken place. There were about ten or so laries in the pool and Terrie gingerly got in the water and, after occluding her stoma, went under like a fish and came up so proud of her self that she cried right there. That moment alone was worth the trip.

Every year there are special unforgettable moments and people to meet. Meeting other laryngectomees, their spouses, the SLPs, and our vendors face to face is something I highly recommend to every one of us.

### **Barbara Nitschneider - 1974**

I had my laryngectomy at the age of 27. I learned of the upcoming meeting in Chicago in 1976. It was an eye-opening experience and I have been attending IAL Annual Meetings since then.

It's very difficult to pick any single event or meeting as all were special in their own ways. Some were more difficult than others, but all have shaped who I am today. Having to choose, I would pick the meeting held in Chicago in 1976. I had been a laryngectomee for over a year and had developed a fairly good esophageal speech. I had been able to return to teaching second grade. I was beginning to accept that I would have to spend the rest of my life as a laryngectomee.

I also signed up to attend the Voice Institute which was held on a college campus at that time. It was there that I met all the people whose names I would hear over and over again in the coming years: Colonel Lauder, Jim Shanks, Joe Quigley, and Eric Blom. In fact he was just an SLP at the time and was attending the VI as a student. I learned so much and met so many wonderful people. I met people with similar stories to mine and others with different stories. All of us were special in our own ways. It was the first time since my surgery where I was not in the minority, but was with the majority. I met lifelong friends at the Voice Institute, most of them SLP's.

I was only 27 at the time, which was young in the world of laryngectomees. I also had a good ES voice. I received a lot of attention and that felt good. It had been a long time coming. I'm sure I was not the only one there who had those same feelings. That's the magic of the AM's. I know it was magical for me and would be for a long, long time.

I have only missed one AM since 1976 and that was last year, 2010. I had some significant health problems that kept me away. I do plan to be there this year in Kansas City. I know it will be special, and I know it will be different, as each AM has been. It's the one time of the year where I truly look forward to seeing all the wonderful friends I have met over the years.

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### **Tom Olsavicky - 2008** **Lary from VA**

I have been to the last three conferences and plan to be in KC this year.

I was operated on in April 2008 and the Tidewater Lost Chord Club encouraged me to attend the conference in Little Rock, Ark. that same year. I was amazed that within 5 minutes of personal instruction at the Voice Institute, Dr. Doyle had me saying "cupcake" by using esophageal speech. Up to that

time, I had been unable to make a sound on my own.

Also at Clarksville, Ind. I was moved by a young SLP Trainee who was in a wheel chair because of a birth defect but she was working on improving her/our lives. She even got on the dance floor in her wheel chair and had a wonderful time. She was such an inspiration to us all. She had many more challenges in her life than those of us who had lost our voice.

It made me realize that how we accept our life changing events, is what enables us to enjoy the things that we can do and not to dwell on the things that we can't.

Finally, it is always great to be around people who look and sound similar to us.

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### **Michael Csapo - 2000**

I have been quite blessed with the opportunity and ability to have been able to attend three IAL meetings over the years since embarking on my journey through life as a laryngectomee. In 2004, I attended my first convention in Anaheim, California as a Voice Institute Pupil. Amidst the confusion of running around from one lecture or meeting to another, there were a few brief interludes which allowed for some free time for leisure and socialization. For myself there would have been even more time to socialize had I not been rather consistently prone to losing myself in the confusing corridors, wings and long hallways of the Sheraton Hotel.

It was during one of the brief earlier morning "Break" periods where I exited from a lecture and I caught a whiff of fresh coffee being brewed down the hall somewhere. I shifted into high gear as I chased the aroma down to the Vendor Display room where I grabbed myself a cup of this precious brew. I still had about half hour to consume before I had to return to my room for a "Hands On" session so I casually strolled by the various exhibits and displays. It was during this stroll that I had the very fortunate opportunity to personally introduce myself and shake hands with "Dutch" who many of us know as the founder of WebWhispers. Dutch did not immediately recognize who I was when I offered my name however when I blurted out "AKA Crazy Donkey" I was instantly greeted with the most friendliest of smiles.

There have been so many memorable and cherished moments which have evolved from my attendance at IAL meetings which I have had the privilege to attend. Personally meeting Dutch ranks very high on that list as I am still very inspired by Dutch to this day. The first IAL which I attended was also a huge development in my healing process as I discovered first hand that there were hundreds of others physically in attendance who have faced and overcome the very exact same challenges which I was struggling with. In fact I soon learned that there were others worse off than myself and I learned

to have a better appreciation for my own circumstances. I would urge anyone who has the opportunity to attend an IAL meeting to do so, you will not regret it and you will in fact be enriched and rewarded with knowledge, friendship and proof there is life after laryngectomy.

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### **Elizabeth Finchem - 1978**

My first IAL Annual Meeting was in 1981 and my first IAL Voice Institute was in 1982. (Before I found the IAL I worked on my own rehab at Mayo Clinic's week long Rehab Seminar every June 1979-1983. ) Counting my first IAL, I have attended 25 of them.

My very first one was held in Philadelphia, PA. It was far more than just the help, I hoped to get, in planning future meetings and programs for my local club. I rode to the meeting with a couple from my local club so we would have two Delegates there for the Business Meeting. It was a real eye opener for me as I listened to how well so many presenters spoke with electro larynx and esophageal speech. I was good, but they were better. (TEP was still quite new then.) I also learned about the structure of the IAL organization and what the Voice Institute offered while I attended the AM Speech Improvement classes. It was there that I met a young speech pathologist from Israel, Frieda Friedman, who taught me how to make H sounds by trying to repeat some of the guttural sounds from Hebrew and German languages. It worked for me. I met so many IAL leaders that became close friends of mine over the years as we served together on the BOD and Standing Committees. I miss those we've lost over the years, and value what they did to keep the IAL functioning for the newest laryngectomees that continue to need the support and education the IAL offers each and every year. It makes me wonder who will come forward to volunteer and share their leadership skills?

There were many other high points that I can recall and cherish from past meetings. Worth mention is finding out that I could blow up a balloon on the riverboat in New Orleans, or having others so excited about swimming with me they jumped in with suspenders and rolled up britches to try it, or passing my written exam at the close of the Voice Institute. Certainly being elected IAL President in Vancouver, B.C. was a very important meeting for me. Oh, how we danced at that banquet!

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### **Dorothy Lennox - Luminaud, Inc. - Vendor**

Our First IAL - 1981 at an old Sheraton (no longer there) in downtown Philadelphia

My first real memory of the meeting was being shown by a hotel staff member how to kick the bottom of the elevator door so that it would close.

This meeting was a “big deal” for Tom and me. It was the first time we had set up as a vendor at a meeting and the first time we felt our “kids” were old enough to be left alone while we went out of town.

The vendor room was small - only about 6 or 8 vendor tables. One of the vendors was Siemens, which was the importer of the Servox back then, and we met Tom Beneventine there - “Mr. Servox.” It was his first meeting, too. There were only 3 or 4 artificial larynges at the time. The Servox Inton, the Aurex NeoVox (now gone for several years) and our Cooper-Rand were being shown at the meeting - maybe one other from Great Britain - I don’t remember it’s name.

The IAL meeting staff and many members were very helpful and friendly - several of them are still coming to meetings - but many things were definitely different. There was no such thing as an oral adapter for the neck-held units. There were very, very few choices in stoma covers and filters. And no TEPs. In 1981, the TEP was probably no more than pictures on a drawing board - an early dream of the doctors who developed it and introduced it several years later. In 1981 there were less female laryngectomees. A woman had never been President of the IAL nor had an electrolarynx user ever been president.

A lot of people really didn’t want to get near any vendors with electrolarynges. If we tried to make eye contact or offered to show them something, many would wave their hands in dismissal. Or they’d say something like, “No - we don’t need things like that!!” If we said, “Well, how about taking some information home to your club?” it would be “No - NO!” and they’d hurry away.

We soon realized that what we had heard from doctors was true of many laryngectomees, too. They felt that ELs were “crutches,” “the lazy man’s way to talk,” “Very inferior to esophageal speech.” Some laryngectomees apparently didn’t want to show the least bit of interest in ELs for fear that someone would think they were lazy, too, and thinking of using the “easy way out.” Some wanted to help their fellow laryngectomees avoid this embarrassment. There was a lady there using one of our Cooper-Rands and another woman actually tried to pull the tube out of her mouth, saying, “What are you using that thing for? You don’t need that!”

The IAL By-Laws in effect then stated that the goal of every laryngectomee should be to learn esophageal speech. Those who had trouble with ES or couldn’t manage it at all were essentially “2nd class citizens” in the organization. How times have changed!!!

Back to the lighter side. The banquet was a very elegant affair. Many of the women brought lovely evening gowns and most

of the men wore suits. In that hotel, getting to the banquet turned into a marathon. The hotel was very tall and narrow and the elevators were small. We were on the 17th floor, I think, with several floors above. Elevators coming from the top would be filled in just a few floors and the people on board would find the doors opening on every floor and would smile and wave to their waiting friends who couldn’t get in. Soon people on the lower floors got smart and began getting on the elevators as they went up, meaning that the higher floor people couldn’t get on. The people on the middle floors found themselves waving at friends twice - once as they went up and once as they went down. I think it took at least half an hour to get everyone down to the banquet.

There was dancing after the banquet in an elegant room - and the band was very loud. That is one thing that hasn’t changed. Whenever there is a band or DJ at the IAL banquet, they apparently have the idea that if people have trouble speaking very loudly, they can’t hear well either so the group tries to be helpful and play at top volume - and are amazed if anyone asks them to play more softly.

The other thing that hasn’t changed is that IAL meetings are usually great fun - like an annual class reunion where you get to spend time with old friends and see new places. We’ve only missed 3, maybe 4, since 1981. One was the 1st one in Kansas City. We’re very happy that we won’t miss KC this year.

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### **David Blevins - 1998**

I attended my first IAL AM/VI in Reno in 1999. After a year of trying the best professionals in my state had given up on my getting TEP speech. SLPs, Dr. Carla Gress and Dr. Dan Kelly at the Voice Institute came to my hotel room and worked hands-on with me.

I got my miracle of speech.

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### **Susan Reeves - SLP IAL Exec. Director**

I have attended 13 IAL meetings. My first was probably my most memorable. It was in Seattle, Washington. I came to the Voice Institute for 5 days and then went to the IAL Annual Meeting for 5 days. Shirley Salmon, Mary Jane Renner, Zilpha Bosone, Frances Stack were my Voice Institute instructors. Speech pathologists and new laryngectomees were partnered up in the Voice Institute for 5 days and twice daily one of my instructors would come into my open-door, hotel room where I was attempting to help my partner with some aspect of the road back to gaining a voice.

I learned so much and met so many wonderful people at that meeting. I met Joann Fenn, also from Seattle and



studying to be a speech pathologist. I met Ellie and Joe Marasco, from Virginia, who's love for life and for helping people was contagious. I met George and Marge Ackerman from Canada who both lit up the room with their laughter. I remember getting into Frances and Hank Scheffe, from Amarillo's van, who drove about 10 of us to the horse races one afternoon while in Seattle.

I saw people swimming, singing, dancing, laughing and truly enjoying themselves. I left Seattle remembering people, not patients. The IAL Voice Institute and its Annual Meeting was truly a life altering experience for me as a clinician, but also as a person.

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### **Charlie Blair - 1993**

My wife Nancy and I have attended 8 IAL Meetings; San Francisco, Indianapolis, Nashville, Myrtle Beach, Atlanta, Boston, Burlington and Clarksville. We were fortunate to have been on the VI faculty for two of these, a great experience.

I never failed to learn something new and make new friends, plus getting to meet the legends of laryngectomy rehabilitation. My favorite memory is San Francisco of 1995, my very first IAL meeting. Nancy and I consider IAL AM's our summer vacation and practically a family reunion. Now where else but Nashville could you get your AM program autographed by Little Jimmy Dickens? (Anyone heard of this guy?)

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### **Pat Sanders - 1995** **IAL, VI, DR, SLP, ES, AL, TEP, and a little BS**

Just arrived home from the 1999 IAL Convention/Voice Institute held in Reno. I attended the VI from 8AM to approximately 6PM every day and my head was, and still is, ringing with voices, voice choices, voice problems and voice solutions. I will share what I remember and can dig up from their literature and my notes as we go along. I saw some interesting voice equipment that I had never seen before. There is a keyboard that speaks the word as you finish typing and hit space or you can set it to wait and speak the entire sentence or it will do both. It has a human voice. For someone, who can't learn to speak because of severe surgery, this is a wonderful device.

Then I saw a pneumatic speaking device and the man who was using it had a superb voice. It must take a lot of time to learn to use one, but if you are living in a place without electricity, the 'no battery' feature would be the way to go. It has a cup that goes over the stoma and a tube that goes into the mouth. Very simple (\$112). There is another that uses a reed (\$69). I tried the pneumatic one and was barely able to get out a recognizable "Hello"

because I couldn't get my timing right and kept doing everything backwards. From watching the expert, I would say it has to be played with practiced timing at the stoma cup, but it would be fun to have one to play with!

I have known very few esophageal speakers (ES) since our thrust here in Birmingham is using the tracheo-esophageal puncture (TEP) and the artificial larynx (AL), but I ran into a lot of ES folks at this convention. Dr. Ed Stone, who is one of the best and most entertaining lecturers you could find anywhere, headed the VI Institute and faculty. The other members of the faculty were excellent lecturers but most were heavily slanted toward ES. This was rather exciting in one way because I would get to learn something new, but, as I listened, I began to realize how many of them put forth the impression that if you didn't do it the ES way, you were copping out. One speaker mentioned TEP as a way of speaking that left you 'one handed'. Another ended her lecture with the comment that you might even decide to reverse your TEP. I found this same attitude among some of the ES laryngectomees.

One man, using an AL, who was there to learn ES told me, "I don't want one of them IMPLANTS!" Did anyone ever explain the puncture to him? I doubt it. A lady ES said she thought either method was fine but it was all about choice and she was bothered that we are not being offered a choice here where I live. True, but I wonder if the TEP was thoroughly explained to her and if she had any more of an 'educated' choice that I did. Our choice of a doctor will indicate which speech-language pathologist (SLP) we use and most SLPs will recommend the brand of AL, or type of speech and prosthesis that they like. Bias will show. A shrug of the shoulder, a facial expression or a tone of voice indicates that something s/he is saying is not worth talking about. This is not necessarily bad, because the SLP that is working with you would do you a disservice if the recommendation were for a method of speech in which s/he is not proficient, unless there were other coaches available.

As I listened and watched at the convention, I heard marvelous speakers but I also heard people who could be barely understood. No matter what method of speech, it seems those who articulated well were the easiest to understand. Timing, phrasing, and enunciation are the keys to any one of these methods.

(Original Report, written for HeadLines) I have attended all since 1999, excepting 2006.



## Speak Out

By Don Renfro

*Limit your "always" and your "nevers."*

*~ Amy Poehler*

My wife and I were together a total of thirty-four years. I was twenty-three when we met and not overly experienced in my insight into relationships. In that time of thirty-four years the both of us matured in our thinking as to our roles and responsibilities in a relationship.

Given that both of us were younger when we met, in thirty-four years we both evolved to be different people by the end of our relationship in 2015 when she passed. Probably our greatest milestone in the advancement of us as a couple was the elimination of the words "always" and "never" all together. Amy Poehler the author of this month's quote says to limit their use. I found that we as a couple we had to eliminate the words from our vocabulary entirely.

We both relied on those words in our description of anything and everything the other person did or didn't do that either of us did not like. It was never they did this or they did that it was they "always do this or they all ways do that". Such an extreme depiction is rarely if ever an accurate description of the behavior of another.

Sad though, it was the only description available to either of us in the early part of our relationship. I have written in previous articles about the problem being my own responsibility and that meant the solution was also of my own making. I exclusively reserve ownership for the problem as well as the solution as I only have control over my part. The reality was that each of us took responsibility to remove the words "always" and "never" from our communication. For us those words created a feeling of strong accusation that then met with a strong defensiveness from the other person. Before long the issue was lost in the defense of how often whatever was actually or not actually done.

Neither person felt heard or validated because the focus was shifted away from the original issue and onto the defense of the frequency of the wrong that was done or not done.

It is absolutely amazing how two little words can have such an effect on the ability for two people to communicate. The bottom line for me is that communication is the foundation or basis for all human interaction. Two people at work, passing someone on the street, interacting with a neighbor, the effectiveness hinges on the ability for the people involved to be able to communicate.

That being said, then how about being a lary? My strength in life up to this point had been my ability to communicate. My communication skills provided me with the ability to successfully navigate life. Now all lary's know that even without a voice we can communicate. We also know it is very different communicating

without a voice. It is even different communicating with a voice that sounds different than what most people are used to hearing. We humans are a strange sort. We like things predictable and easy to determine what will come next. When something interrupts that ease or comfort, there is a tendency to avoid the unknown expectation due to a lack of familiarity.

We lary's lack a familiarity for a large part of the population. So how do we overcome that? That is the million dollar question. When my wife and I removed "always" and "never" from our communication it allowed us to communicate without being distracted by the feelings of defensiveness and allowed us to be able to focus on what the other person was trying to say. In our case as lary's the distraction is how we sound and how do we remove that to allow for effective communication.

Last year at the conference in Arizona I heard someone suggest that when making phone calls to explain to the listener at the beginning of the call that I have an alternative means of speaking (i.e. electrolarynx) and to ask if they can understand me. In doing that it may allow the listener to put aside the "surprise" of how I sound and allow them to focus on what I was saying rather than how what I am saying sounds. I have found that suggestion very helpful. Since I got my TEP replaced and since I live alone, I have actually made many phone calls lately, most of which have been quite successful.

Face-to-face is another story though. Many people decide immediately upon hearing the difference in how I sound that they will not be able to understand me and when they decide they will not be able to understand me they usually won't be able to understand me. It is no easy task to be understood after having had a laryngectomy but I am happy to say it can be done. Different people require different methods or approaches to understand me and I must be open to find the best way I can communicate with them through which ever means is best for them. After all I am the one that wants to be heard.

It is very rewarding to me to experience that I am able to communicate with most people effectively enough to accomplish my objective of why I was communicating with them to begin with. After my surgery the first thing I mourned was the loss of my voice. I had a TEP placed during the surgery but did not know that with it I would have the ability to communicate again.

After the loss of one of my most prized possessions I am truly grateful to of regained my ability to speak and to have a voice that gives me proof of existence. Without a voice and/or a means of effective communication, I can feel very isolated to the extent it is hard to know I even exist. To communicate is to live a life where I am included in it.



## Same Same But Different

W. C. Baker

This S E Asia catch phrase is enigmatic enough to apply to just about anything. It can certainly apply to those IAL annual meetings that I have attended since 1993 along with their Voice Institutes. Each IAL/VI has the same elements, but each one is different. The same general format has different presenters with different materials or perspectives. Laryngectomees, Speech Pathologists Medicos and vendors form a cohort that is the same from one Annual Meeting to the next, sometimes with the same individuals and sometimes not.

As is appropriate for the Annual Meeting of the IAL, it is of, by and for Laryngectomees. At any given meeting most of the attendees have been attending for years, in some cases for decades. Prior to our diagnosis, few of us ever saw or even heard of Laryngectomees. Some of those attending for the first time have had very little or no experience meeting other laryngectomees. We are a rather small community that shares a common trait and tend to become acquainted with others of our ilk within our area. For some, there are no Laryngectomees to serve as role models and mentors. For those, the Annual Meeting is an extra special experience.

The 1993 Annual Meeting and Voice Institute were not run concurrently. I was there to get my certification to provide instruction in esophageal speech so I did not attend the Annual Meeting. The keynote for the Voice Institute was delivered by an esophageal speaker who was given the honor by virtue of a sizable donation that he had made. Unfortunately, his remarks were not reviewed before they were delivered. He forcefully and mistakenly chided those who were not esophageal speakers for not trying hard enough. This caused those conducting the meeting to back track, emphasizing that the best alaryngeal speech method is the one that works for the individual laryngectomee. As Sam Harris said at the time, it was a matter of being given lemons to make lemonade.

For me the most interesting part of the proceedings, and the most different from one year to the next, is the Medical presentation. Two meetings in particular stand out as being of special interest to Laryngectomees. At the Indianapolis IAL in 1998 Dr. Marshall Strom introduced Tim Heidel, the first recipient of a larynx transplanted from another human being. Tim is still living and doing well, but only one other laryngeal transplant has been done. Transplantation is of interest, but offers no hope for those of us whose surgery was necessitated

by cancer. Because the immunosuppressants transplant recipients have to take would put the cancer patients at too great a risk.

Last year at Phoenix, and with greater potential for Laryngectomees, Dr. David Lott of Mayo Clinic announced the incredibly complex process of 3D printing of a larynx. The printed scaffolding serves as a sort of mold in which stem cells can be coaxed to form a new trachea and larynx. Because the stem cells are used to regenerate a larynx, immunosuppressants are not necessary. Dr. Lott and his team have approval to perform two transplants per year over the next five years. The Larynx and Trachea Transplantation Program is the first of its kind. In the school in which I was teaching when I was diagnosed, we had dot matrix printers and Ditto machines were still widely used to make copies. Now Dr Lott and his team are using 3D printing and stem cells to regenerate organs. Amazing! I'd love to see regeneration of prostates.

The greatest difference between my first Annual Meeting and the most recent one in Phoenix is in the number attending. Little has changed in the content, but there has been a significant reduction in attendance. We consistently had approximately 400 in attendance at least until the turn of the century. I imagine that the advent of WebWhispers and other internet access have had something to do with the smaller AM/VIs, but I think that cures with chemo and radiation have reduced the number of laryngectomy surgeries. It appears that there are fewer esophageal speakers, probably due to the establishment of TEPs as the default method for alaryngeal speech and the advent of the hands free valve. In my very personal opinion, a disservice has been done to those Laryngectomees who could acquire esophageal speech, but are never given the opportunity. Having been an esophageal speaker for 25 years and now being a TEP user for 4 years, I can attest to the preferability of esophageal speech.

The IAL is first and foremost, a social event. It is the extra-meeting activities that keep Laryngectomees coming back. The opportunity to socialize, first at the Meet and Greet, on to the City Tour and culminating with the last Night banquet. I missed the Fun Show in Phoenix. When did we stop doing them? These are real motivators that keep me coming back. A virtual IAL just doesn't have the same appeal. I miss you all.







## Chapter 9 "Executor"

Only months after the death of my father in 1992, Velta, Warren's wife, had a stroke that nearly ended her life. She'd been a high school teacher in North Hollywood, California throughout her teaching career. During a leave of absence, just before she was getting ready to retire, she had a massive stroke that paralyzed the left side of her body.

Warren retired from the Vice Presidents position he held at the bank he was working for in the Los Angeles area, and devoted the remainder of his life to her care. Tragically it was to be a short life. He developed lung problems that led to his death in 1997. He was 64.

During the time he was growing progressively worse from his illness he developed a living trust and made me the executor which gave me the responsibility of looking after his wife who lived 16 years after he passed away.

Fortunately our children were grown and doing very well for themselves by the time Warren became ill. I was free from the business responsibilities I'd developed and was able to go to California and spend time with both of them, and help Warren with Velta's care. I finally wound up going to help him with his own care, at least as much as I could before he passed.

After Warren died, Velta wanted to continue to live in their home and I helped her do that for 2 years. After a great deal of urging on my part, I was finally able to talk her into moving to a Masonic care

facility close to us in Washington. She'd suffered a lot of brain damage when she had her stroke and trying to reason with her was very difficult.

After two years of traveling to Los Angeles once a month to work with the live-in care giver my brother had hired to help him take care of her, I made arrangements to move her near us where I could look after her needs better. I then settled into a long routine of finding the best care possible for her for the remainder of her life.

During that time the call of higher education was still vibrant in me and I went in search of a teaching opportunity once more. Northwest Indian College, a Lummi Tribe tribal college fashioned after the community colleges of the State of Washington was expanding its outreach and had a teaching position open. The Lummi reservation is near Bellingham, Washington, and they had a part-time teaching position open at a branch campus they'd established on the Puyallup Reservation in Tacoma. I applied for it and they welcomed me with open arms.

I became heavily involved with them, well beyond my teaching responsibilities. Within months of when I started working for them, the Board of Directors at the college made a decision to start an urban branch campus in Tacoma and located it in the same building the University of Washington had established a branch campus. They called the urban branch campus Northwest Indian College Tacoma Campus and I became Dean of it.

It was set up to serve the urban Native Americans in the Tacoma/Seattle area who chose not to live on their home reservations. I found the complexities of

helping them deal with their cultural norms, which were very different from the urban culture they lived in, very challenging. I worked diligently to create the best marriage possible between norms of the dominant culture they chose to live in, and the norms of the ancestral culture of their tribes in the curriculum the college offered.

It was an exhilarating time in my life and the graduation ceremonies held both at the branch campus, and then at the main campus on the Lummi reservation were very moving to me.

Unfortunately after three years of operation, the Tacoma Campus closed. The Board of Directors at Lummi made the decision to only offer programs on Native American reservations and closed the urban campus. They lost many enrollments. It was with a sad heart I left behind what I knew was a significant outreach to urban Native Americans who were making great sacrifices to try to further their education at an institution that knew their needs.

In 2000 Margaret noticed a swelling on my neck in the area of my thyroid gland. Our family Dr. referred me to an otolaryngologist and he found I had cancer of the thyroid. It was in the early stages of development and by removing the lobe of the thyroid where it was located, along with a radioactive iodine treatment, he thought I should be OK.

The surgery and the treatment went fine although I found the radioactive iodine treatment a little weird.

They injected me with radioactive iodine and put me in isolation where no one could come near me until the radiation levels got low enough. A male nurse with a Geiger counter came to the door of my room periodically to scan me to see how radioactive I was.

They'd covered everything my body would touch in the hospital room with protective coverings, toilet seat and all, and I spent four days having the nursing staff come to the door of my room to check on me, and the kitchen staff come with a food cart and push it in while they kept a safe distance from me.

By drinking large amounts of fluids I was able to flush enough of the radioactive iodine out of me to allow me to go home a day sooner than expected, but not before I was thoroughly checked out with that Geiger counter.

I got a real taste of what all the fears were about during the cold war with Russia where the threat of nuclear weapons was on everyone's mind. Hiroshima and Nagasaki were proof of the horrors.

For more than six years things were fine and there was no sign of more thyroid cancer. I was being monitored regularly with body scans to track whether it was appearing anywhere else in my body since cancer has a nasty tendency to metastasize in other parts of the body. When I got past the 5 year mark, Margaret and I both thought I was home free using the common belief that if you're cancer free for 5 years your worries of it returning are over.



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