

Whispers on the Web

A Monthly Online Newsletter for WebWhispers

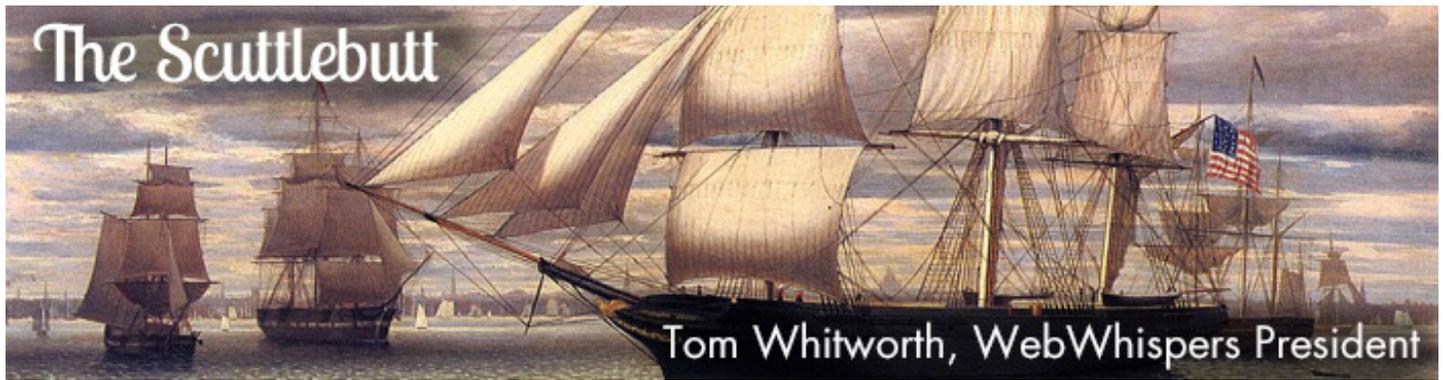
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Fairy Tales Do Come True, It Could Happen To You

Not for five minutes of my entire life have I ever thought of myself as a sales person. However, along the way, I have learned that I can promote anything as well as anyone if I really believe in it and I have no problem doing so. With all my heart, soul, and mind, I believe in the Voice Institute, specifically the International Association of Laryngectomees Annual Meeting and Voice Institute. This event of a lifetime, especially for newbies, is happening next month in Phoenix, AZ.

I attended my first Voice Institute right after starting to speak post cancer treatment and laryngectomy. This one will be my sixth Voice Institute. I will never forget calling my wife Julie about two or three hours into my first event. She would have thought I was crazy had she not realized how deeply serious I was. It was a short conversation as the break was almost over and I did not dare miss the next presenter. Sounding like a kid at Christmas at first, I calmed down and simply told my bride of 35 years at the time "this is something I will never not do. (Yes, I intentionally dropped a double negative.) I don't care where they have it, if I can get there, I will".

As the conference continued, I became an even bigger fan. Lectures I could not have imagined answered questions I did not yet even know to ask. I learned so much that I began to wonder if my brain could hold anymore, but I found room. Auditoriums, hallways, dining areas, and the entire hotel were filled with people using esophageal speech, electrolarynx, voice prostheses and tracheoesophageal puncture, boogie boards, text to speech, pen and paper, and even the Tokyo to communicate. It was not at all unusual to be in an elevator full of larynx and no one else—just us. What a joy it was to interact with other laryngectomees and other patients, caregivers, SLPs, and suppliers of the products we need.

On my way to the airport to return home, I got on Facebook and told my whole world what an amazing, needed, helpful blessing I had just experienced. I told my friends at home that missing the Voice Institute would have been the worst thing I could possibly have done. Yes,

I was still amazed that I got there.

I had looked into the event, the costs and arrangements, with the imagination of a child dreaming of the most grandiose, unlikely thing he could imagine. Things fell into place as I would have never predicted. I did have flight miles to use, so I was covered there. But what about the registration fee and the hotel stay? Food seemed like a good idea, too. How in the world could I do this? - I thought. I made it there with some scholarship money I learned about from Pat Sanders, then President of WebWhispers. I have to admit that a family member handed me some cash to make sure I didn't go hungry and I did not need much of that. The event was so well arranged, that I didn't need to worry about food at all. There were wonderful breaks with refreshments each day sponsored by the various vendors, plus receptions and banquets. The links you need are provided below. Please do yourself a favor and use them! I promise you will not regret doing this for yourself.

Using the first link below, register asap as the special room rate is only available for a couple of weeks OR until the blocked rooms are booked. Below that link is one for WebWhispers members to apply for scholarships. The final link tells you about the WebWhispers Annual Awards Dinner, a separate event held on Thursday of the conference.

<https://www.theial.com/2019-voice-institute-annual-meeting>

<http://webwhispers.org/services/voice-institute-scholarship.asp>

<http://webwhispers.org/activities/2018WebWhispersAwardsDinner.asp>

Come see us in Phoenix!

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



Voice Points

Written by Professionals

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Swallowing Resources Part 2

This month's column features a continuation of last month's list of definitions relating to the anatomy and physiology of swallowing, swallow studies, and conditions of the esophagus and stomach. Please refer to March's VoicePoints column in the archives for additional definitions if you missed the beginning of the list last month:

<http://webwhispers.org/news/mar2019.asp>

For further reference, there are also many excellent online clinical resources for swallowing. For starters, refer to our American Speech-Language Hearing Association (ASHA) website. WebWhispers has published a variety of swallowing articles and helpful tips for swallowing difficulties. If you have a favorite resource or helpful tip for swallowing, please let us know and we can spread the word!

<https://www.asha.org/PRPSpecificTopic.aspx?folderid=8589942550§ion=Resources>.

<http://webwhispers.org/news/may2004.htm> (May, June and July 2004 issues).

<http://webwhispers.org/library/Swallowing.asp>

Glossary of swallowing terms, continued:

gastroenterologist: a physician dealing with disorders of the stomach and intestines.

gastrointestinal (GI): adjective referring collectively to the stomach and small and large intestines.

gastrostomy tube (also called a G-tube): A tube inserted through the abdomen that delivers nutrition directly to the stomach.

gastroesophageal reflux disease (GERD): a condition in which the acidified liquid content of the stomach backs up into the esophagus and irritates it. Symptoms may include a burning in the chest or throat (heartburn).

GERD: gastroesophageal reflux disease.

glossectomy: surgical removal of all or part of the tongue.

H2RA/H2-receptor antagonists: H2 blockers work by blocking the histamine receptors in acid-producing cells in the stomach/suppress gastric acid secretion.

halitosis: bad breath.

hiatal hernia: part of the stomach and/or the section where the stomach joins the esophagus (called the gastroesophageal junction) slips through the hiatus into the chest.

hypopharynx: the bottom part of the pharynx (throat) and the entrance into the esophagus.

intraesophageal: occurring within the esophagus, e.g., intraesophageal pressure.

laparoscopic Nissen fundoplication: also called Nissen fundoplication; a surgical procedure to treat gastroesophageal reflux disease (GERD) and hiatal hernia.

MBS: modified barium swallow.

modified barium swallow (MBS): also called video fluoroscopic swallowing exam (VFSE) or speech swallow exam; a radiologic examination of swallowing function that uses a special movie-type x-ray called fluoroscopy. The patient is observed swallowing various consistencies and textures, ranging from thin barium to barium-coated cookies, in order to evaluate his or her ability to swallow safely and effectively. This exam is often performed with a speech-language pathologist present.

motility: a term used to describe the contraction of the muscles that mix and propel contents in the gastrointestinal (GI) tract.

myotomy: the surgical removal of part or all of a muscle.

neopharynx: a surgically reconstructed pharynx.

NGT: nasogastric tube.

NPO: nothing by mouth.

odynophagia: painful swallowing.

Omnipaque: trade name for Iohexol, a contrast agent used during x-rays.

oropharynx: the part of the throat at the back of the mouth behind the oral cavity, including the back third of the tongue, the soft palate, the side and back walls of the throat, and the tonsils.

peptic: pertaining to or associated with digestion; digestive. promoting digestion of or relating to pepsin.

percutaneous endoscopic gastrostomy (PEG) tube: specifically describes a long G-tube placed by endoscopy. Sometimes the term PEG is used to describe all G-tubes.

pharyngeal: pertaining to the pharynx or throat; the passageway leading from the mouth and nose to the esophagus and larynx.

pharyngeal constrictor hypertonicity: spasm/incomplete relaxation of the pharyngeal constrictor muscles (these muscles contract to propel food through the pharynx and into the esophagus/they shorten and widen the pharynx).

pharyngectomy: total or partial surgical removal of the pharynx.

pharyngitis: inflammation of the pharynx.

pharyngoesophageal segment (PES): made up of the inferior pharyngeal constrictor, the cricopharyngeus muscle and the proximal part of the cervical esophagus.

pharynx: area of the throat connecting the nose and mouth to the esophagus. It is a hollow tube about 5 inches long that starts behind the nose, goes down the neck, and ends at the top of the trachea (windpipe) and esophagus (the tube that goes from the throat to the stomach).

propulsion: the action of driving or pushing forward.

proton-pump inhibitors (PPIs): a group of drugs whose main action is a pronounced and long-lasting reduction of stomach acid production/suppress gastric acid secretion.

pseudoepiglottitis: a fold of tissue coming from the pharyngeal wall into the tongue base, forming a side pocket in which food collects during swallow attempts.

pseudo diverticulum: also called pharyngoesophageal diverticulum; pharyngeal pouch; hypopharyngeal diverticulum; Zenker's diverticulum; a small outward bulging sack of the mucosa of the esophagus, just above the cricopharyngeal muscle (i.e. above the upper sphincter of the esophagus).

pseudoglottis: also called neoglottis, referring to the space between the vocal cords. In total laryngectomy, the pseudoglottis is a vibrating structure that replaces the glottis

in alaryngeal speech.

SES: Standard esophageal speech; also called esophageal speech.

serial dilations: a therapeutic endoscopic procedure that enlarges the lumen of the esophagus using sequentially increasing sizes of dilators to open the obstructed area.

sialogogue: a drug or agent that can stimulate the flow of saliva.

Sjogren's Syndrome: a chronic autoimmune condition characterized by degeneration of the salivary and lacrimal glands, causing dryness of the mouth and eyes.

spasm: a sudden involuntary contraction of a muscle or group of muscles; esophageal spasm is abnormal muscle contractions in the esophagus.

standard esophageal speech (SES): See esophageal speech (ES).

stenosis: a narrowing, closure or stricture of a passage or vessel.

stricture: an abnormal narrowing of a bodily passage, possibly due to scar tissue or tumor. Esophageal stricture is an abnormal narrowing of the esophagus.

sublingual: under the tongue.

supraesophageal: situated above or over the dorsal aspect of the esophagus.

TE: tracheoesophageal; relating to or connecting the trachea and the esophagus.

TE fistula: surgical site creating a fistula, or connection, between the trachea and the esophagus.

TEP: tracheoesophageal (TE) prosthesis.

TE puncture: tracheo-esophageal puncture; tracheoesophageal puncture.

trachea: windpipe; connects the pharynx and larynx to the lungs.

UES: upper esophageal sphincter.

upper esophageal sphincter (UES): a bundle of muscle fibers creating a high pressure zone at the top portion of the esophagus, forming a barrier between the esophagus and pharynx.

XRT: radiation therapy

Between Friends

Donna McGary

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

Photo © by Corack5239

For the Love of Words

(T.S. Lewis "In the End is My Beginning")

Cancer is a thief, a burglar in the night, a terrorist and all too often a murderer. It has ravaged so many lives and despite what I say in my header, those that it does not kill are not always made stronger. For some of us, even if cancer does not strike a fatal blow to our body, it decimates our spirit. I suspect we all know folks who have defied all odds to keep on keeping on being positive inspirations, and others who have just turned bitter and mean-spirited and lost all hope. Why that different response in the face of adversity nobody really knows.

Those who do survive have some type of lifeline during those really bad days and mine has been reading. As a child I was a bookworm. I couldn't play sports....I can barely walk and chew gum at the same time, even to this day. To be honest I was pretty much a pain in the ass know-it-all kid who LIVED at the library but oh, the places I could go...thank you, Dr. Seuss!!

Fast forward to age 47 and cancer. Back to the books... or in this case online information and it took me a while to process all that. But reading got me through those very dark days and it still gets me through the kinda gloomy ones. I just found this today in an article in the New Yorker by Joshua Rothman about the artist Peter Sacks, who has had a notable journey from academic to poet to visual artist.

"Wardsworth writes that a poet is 'someone who is affected more than other men by absent things as if they were present.'

Sacks argues that an elegiac poem doesn't merely describe loss. Instead, like a funeral celebration, the writing of an elegy is 'a symbolic action', a ritual, with two aims: remembering the dead and helping the living return to the stream of life. It's a ritual

describing both loss and revitalization. ...[poets] paralyzed by loss, they are inclined to grieve in silence. They must learn to speak again".

How so much like us, who have lost so much and must in reality learn to speak again!

So over 60 years after I learned to read I still delight in the power of the written word for escape, encouragement, entertainment and inspiration. And I am not the only one whose original voice having been stolen by cancer has learned to "speak again" through writing. It is our elegy to our old selves and our triumphant new voice.

And something to consider before we pass judgement on our dark past there is also this.... Cancer may yet have a role to play.....

"Frodo: 'It's a pity Bilbo didn't kill Gollum when he had the chance.'

Gandalf: 'Pity? It's a pity that stayed Bilbo's hand. Many that live deserve death. Some that die deserve life. Can you give it to them, Frodo? Do not be too eager to deal out death in judgment. Even the very wise cannot see all ends. My heart tells me that Gollum has some part to play in it, for good or evil, before this is over. The pity of Bilbo may rule the fate of many.'

Frodo: 'I wish the Ring had never come to me. I wish none of this had happened.'

Gandalf: 'So do all who live to see such times, but that is not for them to decide. All we have to decide is what to do with the time that is given to us. There are other forces at work in this world, Frodo, besides that of evil. Bilbo was meant to find the Ring, in which case you were also meant to have it. And that is an encouraging thought.'

—J.R.R. Tolkien

Stand By Me

The Caregivers Journey



This first appeared back in 2007 under VoicePoints. I loved it then and still think it is just wonderful. Charlie has since passed away. Nancy received the Jim Shanks Master Clinician Award from the IAL in 2018 after years of service as an SLP within the laryngectomee community.

"I Married One!"

Nancy C Blair MS, CCC-SLP

"I married one!" It's an inside joke and an old one at that. The story behind it is that in a rap session the wife of a new laryngectomee who was struggling to cope listened intently as another member introduced herself and added that she married her husband after his laryngectomy. The struggling spouse exclaimed, "You married one!"

Now I have joined that group not only as the facilitator but as one of the spouses. I married one and learned the practical side of life with a person who breathes through his neck, speaks with a prosthesis, swallows a little slowly and occasionally becomes perturbed that life is not quite as easy as it used to be. I've also been enriched by the opportunity to look at everyday events from a new perspective. I did miss the most devastating features of Charlie's throat cancer. I did not suffer the trauma of my husband having a life-threatening diagnosis. I did not sit in a waiting room unsure of whether or not I would ever have him again. I did not lose the dreams and plans that couples make or just expect from life together. I know these fears and losses because after a few years together he had quadruple bypass surgery after a minimal stroke. He recovered completely and is better than ever!

Charlie impressed me from the moment I met him standing outside one of our meeting rooms at the Florida Laryngectomee Association Annual Meeting. He pretended to have questions about his prosthesis

and I pretended to only be interested in how he could best communicate. A courtship of several months followed and then a wedding. He was a sneaky fellow who seduced me with unimagined intimacy. Dancing with him turned into sharing not only the rhythm of his step but the vibration of his voice rumbling in his chest. He was clever enough to take my hand and hold it in his as he covered his stoma to speak with his prosthesis. The effect was electric! There are songs and poems written about sharing the beating of hearts but I found it more intimate to share the vibrations of his voice. We incorporated that unique experience into our wedding vows. He held my hand in his as he covered his stoma to recite "I Charles.....do take thee...."

Now I share the nitty-gritty, day-to-day concessions required by someone who has to eat slowly and needs a lot of liquid to push the food along. The table is always set with a large glass for water or iced tea and the pitcher is nearby. Snacking at the fair or sampling at the grocery store has to be avoided unless there is a drinking fountain or bottled water nearby. When Charlie decides to forget the whole business and just take the offered sample of fajita he walks around chewing during the entire shopping trip! The server in the restaurant is tipped according to how empty the water glass stands and for how long. Attention has to be given to the selection of food. Only extremely tender steak is acceptable. Seating is arranged at dinner so Charlie is in the midst of the group where he can be heard but with a close enough exit in case he needs a major cough! Meals last longer. So long that sometimes I read part of the newspaper or begin some clean up while Charlie finishes. The conversation is largely up to me when we are out with friends unless Charlie has had time to swallow thoroughly, avoid a gurgle and jump into the conversation before the topic changes. These are all small annoyances. He eats almost anything he wants and

never opts out of a dinner engagement. That's a blessing because it could have been different.

That loud, strong voice with the animated Charlie behind it just does not carry in noise or out of doors. I am the one who steps up at the ballgame and orders the hotdogs and beer. I lean across the driver to order at the drive-thru window and yet again take the lead in talking through the window at the ticket counter. But at times we let the listener puzzle for a moment. Some people seem to assume they will not understand Charlie and look to me to interpret! No. That doesn't work. I'm silent and they have to turn to him and quickly realize his voice is easy to understand and that he makes a lot of sense. I'm allowed a few pet peeves and here is one. Charlie defers telephone conversations to me because he thinks he will be hard to understand but he stands in the background and tells me what to say! Funny thing is that his voice is so loud and clear that the listener hears him say "tell him.....". I end up holding the phone while Charlie talks a few feet away and then I tell him what the other speaker says. Now that is just crazy!

We also have the territory issue. The bathroom, bathroom closets and dressing area should be mine. That is not even questionable. But Charlie has all this stuff! Stoma covers, extra prosthesis, magnifying mirrors, long tweezers, hands-free valves, stoma buttons, stuff to clean everything, Alcohol pads, adhesives, hydrogen peroxide, suction machine (you never know!), spare artificial larynx, batteries, "how to" pamphlets, prosthesis changing kit, samples of every stoma cover available and extras of all the above. Our cupboards are full of his things. This was the most unkind cut of all! Even the linen closet took on the laryngectomee look. Charlie has stacks of white washcloths and hand towels so he can wipe his neck, dump it in his designated dirty towel receptacle and not worry about me picking up the towel to dry my hands or face and finding a less than inviting surprise. The white allows for bleaching. This arrangement also makes me happy. I do have extra duty cleaning the mirrors where an unexpected cough spreads farther than he has thought and sometimes the handles of the sink where wiping his stoma has transferred from his hands-yuck!

I have forgotten many times that Charlie lives with different requirements for breathing and speaking. That loud, shrill cough first thing in the morning is always shocking. My first reaction is alarm. I don't immediately recall that he has no way to muffle it- that

the sound is "normal". I've been known to be offended when he goes silent during a phone conversation only to discover that he had a momentary lapse of voice for one of several legitimate reasons. I still have not learned to ask anything other than "yes or no" questions when his hands are occupied with tools, dirty while working in the garden, covered with chemicals while spraying the lawn or warding off our playful puppy. I'm surprised when the clerks at our local stores recognize him. He doesn't spend that much time shopping! It only occurs to me later that his manner of talking makes him memorable.

Charlie has not forgotten that he is a laryngectomee. He has adapted to the changes. He absolutely never complains about any part of it except the neck dissection and radiation that left him with a tight and sometimes painful neck. He only regrets that he cannot participate in "small talk". He can't seem to get into a conversation quickly enough. The slight delay in voicing allows others to jump in ahead of him. He does think he would have bought a boat and still might have if I could have survived the fear of him being on the water! He does swim with his thumb plugging his stoma but water sports have never been very important to him so that is not much of a loss. He blows bubbles for the grandkids by holding the bubble wand in front of his stoma—a real treat for all of us! The little ones have each in turn tried to talk like grandpa by putting their fingers on their necks and growling out a few words. We use sign language in our family and Charlie's name sign is an index finger to the throat.

I know a lot about rehabilitation for persons who have had their larynx removed. I know about stoma care, prostheses, amplification, stoma buttons, artificial larynges, and breathing, modified telephones, swallowing problems and I know the myriad variations of each. Now I am learning what they mean to the person who lives with them.

The fact that Charlie doesn't have a larynx doesn't count for much. It is just one of those things that is particular to my husband. The laryngectomy does not define the person. The person defines the laryngectomee. I won in all respects when "I married one".

Nancy C Blair MS, CCC-SLP works as a Speech-Language Pathologist for the Barrett Outpatient Rehabilitation and Sports Medicine Clinic of Morton Plant Hospital in Clearwater, FL. Her BS is from Purdue University and MS is from University of South Florida. She has worked with "FLA" for 20 years.

Dear Lary

Noirin Sheahan

Cooking up a Storm!

While I was on retreat earlier this year, I spent a week as 'retreat assistant' which meant cooking breakfast and dinner for ten people every day. Knowing my tendency towards perfectionism and how that can make a misery of any little mistake, I gave myself a pep-talk at the start of the week. Noirin, I said, it doesn't have to be perfect. Do your level best, but above all, don't lose the cool. If it all goes wrong, keep reminding yourself not to make things worse by panicking. And don't start blaming yourself or the cooker or the potatoes or anyone who crosses your path.

Having set myself straight I was pleasantly surprised to find myself cool and calm and good humoured even when, with twenty minutes to go, the risotto rice was still crunching between my teeth. Though I might not have won any cookery competitions, I gave myself five Michelin stars for equanimity!

But pride comes before a fall ... Last week I met up with a group of old friends to cook a meal together. We've been doing this for years – over four decades in fact – meeting in one or other of our houses to cook and eat a meal. On this occasion I'd offered to do the shopping and kick-start the cooking, and the others would arrive later.

I was looking forward to the evening and enjoyed the shopping and getting started with the chopping and cooking. Crucially though, I forgot to give myself that initial pep-talk. Forgot to prioritise above all else to keep the cool if things went pear-shaped. I was sailing on a magic carpet of pleasant feelings to do with affection for old friends, anticipation of a happy evening, completely oblivious to the fact that the magic carpet was heading towards a very bumpy touch-down.

Basically I had overestimated the amount of food needed, underestimated the preparation time and forgotten altogether about the limitations of Ellie (my electrolarynx). As people arrived they started chatting and laughing. I've been a lary for almost six years so I should have been prepared, but it never-the-less came as a surprise to find I couldn't join in. With my hands occupied stirring or chopping, my fingers wet or greasy from cooking, Ellie had little or no chance to join in the buzz.

Perhaps because of this crash landing into sad reality, I started to get stressed by the food preparation. We were supposed to be eating at 7.30, but by 7pm there were still cucumbers, garlic, avocados and a plethora of other ingredients on the table all awaiting someone to

peel and chop. As I'd taken the lead in organising the evening, people were looking to me for guidance but by now the room was buzzing with chatter and even when I put down my knife or spoon to get Ellie into gear, no one –not even me– could hear what she was saying!

At one point I was frying mushrooms when a friend asked how he could help. I said "squeeze lemons for lemonade". When he looked blankly at me, I grimaced internally. That fleeting grimace ... it was shorthand for 'Why the hell can't people just read my mind ... why do they expect me to put this damn machine to my neck to buzz out nonsense that no one can hear?' Oh that I had taken proper notice of the grimace and the nonsense thoughts it represented! If I had, I might have remembered, above all, not to let myself lose the cool.

But no, my cool was well and truly lost as I abandoned the mushrooms, walked over to the table, and grimly pointed to the lemons and lemonade bottle and read out the lemonade recipe even though his face told me plainly that he couldn't hear a word. With a feeling of despair, I turned away and plodded back to the cooker. Of course the mushrooms were now burning! But luckily I had woken up to the fact that I was letting frustration sour the evening for myself and others. With a heavy heart I started rowing back from the flood of bad humour that was threatening to drag me under.

It was as simple (and as difficult) as reminding myself that the evening was about reaffirming friendship, and everything else was incidental. Though I still felt sad and frustrated, awareness kept these from escalating as I threaded my way through the melee, pointing towards vegetables and knives and dishes in an attempt to orchestrate a dozen hands into making dinner. In retrospect I can see I did well and we were soon sitting down to a delicious meal. Most important of all – I resisted the pull towards bad humour, apologised for my earlier frustration and managed to cheer up.

What I hope I've learned from this is the importance of that initial pep talk to ensure I have my feet on the ground and am not floating on a cloud of happy memory and false expectation. I need to remind myself that Ellie is not a party-girl! And that I don't want to let frustration at her shortcomings lead to bad humour. Ellie needs to be made welcome. Otherwise she'll start cooking up a storm!



First IAL

Last month's article by Donna in "Between Friends" rekindled some fond memories of my first IAL meeting that I'd like to share with all of you. I had my total laryngectomy in 1988 after 9 yrs. with a partial laryngectomy. I had attended a California Association of Laryngectomees meeting in Sacramento in 1990. The Sacramento meeting was very informative but there were probably no more than 25-30 of us there. Registration was "at the door" and in a hallway. The conference took place all in a fairly small conference room and the only vendor there was a young Jim Lauder with a single table and a book to sell. He may have had some audio tapes also but I don't recall them. While at that meeting I learned about IAL meetings but based on the Sacramento experience I wasn't inclined to spend a lot of money traveling to another meeting to hear the same thing from different people.

I changed my mind in 1991 and decided to make the trip to remote, never before heard of, Winnipeg, Canada. I was already trying to help others learn esophageal speech so I signed up for the Voice Institute to be a laryngectomee trainee and was accepted. (Back in those days you had to submit an audio tape for evaluation to attend as a trainee instead of as a pupil or VIP)

The entire IAL program was different back then. SLP's and trainees reported on Sunday and the VIPs reported on Monday. Everyone was divided into teams that consisted of SLPs, trainees and VIPs, and each team was assigned a team leader. My team leader was Lisa Proper a well-known contributor to WW, the Florida Association, and of course the IAL. Laurie Gallant, from Toronto, was also on my team and he is the only laryngectomee that I recall from my team. To this day we still get together at IAL meetings for a mini class reunion. On Wednesday the Annual Meeting people would arrive and they started their own program. (In some years the VI and AM were actually conducted at different locations in the same city. Usually when the VI was held at a university and everyone stayed in dorms.)

Using a current phrase, "back in the day", the VI was a pretty tough course. We would start at 8:00 AM and some nights not finish until after 9:00 PM. For the most part we had separate tracks for the SLPs and trainees while the VIPs studied something different. Some of the classes were co-mingled and we worked on speech with the VIPs several times a day in their rooms. We usually had group meetings in the evening and always had a mandatory sing-a-long. Talk about pressure.... You worked your butt off all day long hoping you could sing at least one verse that night! Oh, and by the way, TEP was very new and everything was geared toward ES! Help was given to AL speakers but the focus was on ES.

For me and many others this was a life changing event. I remember well at one session where we sat in awe as we listened to a lady tell us about her experience. We knew the voice wasn't "normal" and we quietly whispered among yourselves ... how is she talking? It sounded like very good ES but she didn't seem to be talking any air injections and everything was effortless. That was my first meeting with Mary Jane Renner and her wonderful TEP speech. I was also inspired by the many other staff volunteers that I met and stayed in contact with through the years. These are people like Lisa Proper, Susan Reeves, Jessie Hart, Shirley Salmon, Zilpha Bosone and so many others that have dedicated a large part of their lives to helping others and making our lives so much better. Sadly, through the years many volunteers have passed but I have been fortunate to have met and worked with many of them. Some like Lennie Librizzi and George Ackerman I met at my first IAL meeting. Two men that gave so much to help us Larys!

I could ramble on and on about what you may see and learn at an IAL meeting, the friends for life that you may meet, and the very possible and positive effect it may have on you. But instead I would like to share something I started writing as I sat in the Winnipeg airport waiting for my plane. I finished it

on the plane before I arrived back in California; a work of tearful joy that I experienced from my first IAL. In 1995 the IAL used the title of that poem as their thyme for the San Francisco Voice Institute and Annual Meeting.

Songs Waiting To Be Sung

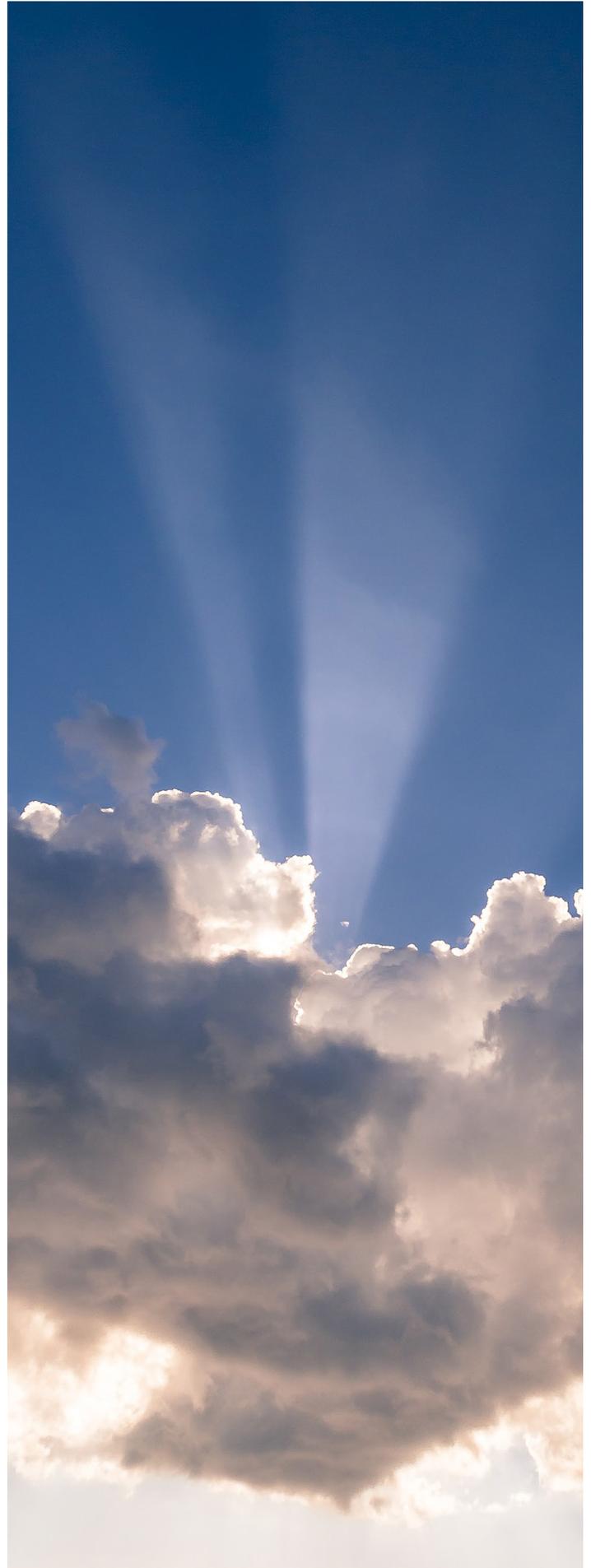
Like the endless tide they arrive,
Survivors of a cruel devastating disease,
Victims of despair and uncertainty.
Hearts once filled with joy
Quiver at thoughts of tomorrow.
Yesterday was an endless delight,
Today... a nightmare of doubt
Fueled by fear of the unknown.
Each heart beats a steady rhythm,
Searching for a song, that's waiting to be sung.

They march to some distant tune,
Heard by many as sorrowful blues.
Crusaders lead marches with blaring bugles,
To fight a gallant battle
Against the destruction of flesh and spirit.
Others write verse, embracing life's dream,
While some wait for the inevitable, whatever it is.
Each story has a familiar tune,
But the melody is seldom the same.
So many songs, waiting to be sung.

The horizon frames a vivid red sun
So deceiving without time and direction.
Does it rise with the promise of tomorrow,
Or linger with the light of yesterday's dream ?
Drifting clouds mask its features,
Gently pushed by winds of uncertainty.
Soft shadows float slowly by
Like gentle lullabies caressing the soul....
Or the dark silent rage before the storm.
Inside each of us is a song, waiting to be sung.

Across the land they unite in support,
Resurrecting the music of life.
Joyous chords explode in a crescendo
As shadows are blasted by trumpets
Announcing tomorrows rainbow of light.
A symphony of glorious sound
Is orchestrated by victorious dancers,
Rising from the ashes of silence.
Listen to the verses, feel the rhythm,
Life is a song, waiting to be sung...

Jack E. Henslee





Our first Speaking Out column was in April 2011...that's a LOT of questions and answers over the years!! We are going to reprise some of those from time to time since there is some great insight and advice "right from the horse's mouth" so to speak. This month we re-visit the question asked in April 2017 about whether folks planned to the IAL annual meeting which is so relevant since we have the 2019 meeting coming up in Phoenix May 15-18

link here for further info: www.theial.com/2019-voice-institute-annual-meeting

Don't miss Jack Henslee's account of his first meeting back in 1991 and why he thinks they are so important in the previous column, "My Neck of the Woods".

"Will You Be Attending the IAL and WebWhispers Dinner This Year?"

I'll be there and not just because my two clubs are hosting it this year. I have been to eight of the last nine conferences and have enjoyed every one of them. We are doing everything we can to make this an excellent event and I'm sure you will enjoy the location. There are plenty of things to do within a short walking distance which includes movie theater, restaurants, night clubs and just relaxing around the lake. If you have a couple of nights free before or after the conference, there are plenty of attractions to keep you busy for days, like Busch Gardens, Colonial Williamsburg, Historic Jamestown, the brand new Yorktown Revolutionary Center and much more. Please come and enjoy the area, meet new friends, and get expert advice on any Laryngectomee related topic that you can think of. We have scheduled a guided tour of the Mariners' Museum that will inform and enlighten everyone. You don't want to miss the Web Whispers Banquet on Thursday or the IAL Banquet on Saturday. We all hope to see you in June.

Tom Olsavicky - Newport News, VA
Pres. Peninsula Lost Chord Club
2008 Laryngectomee

I am excited to say that I have registered with the IAL to attend this year's conference! I wanted to attend last year but the location and cost was too much for me. I have met another Lary here in my hometown of Deltona, FL. She and I will take this adventure together. So looking forward to meeting others.

Margaret Beck – Deltona, FL
Lary 4\15\15

I will be attending my third IAL Conference. The first one was so informative and fun that I keep going back. I do some online work for Web Whispers and it's fun to get together with the people I deal with every day online. My only wish is that more first timers or early larys could attend. It is so good to hear from others in your position that the cost is worth it. I would not give up this opportunity.

David Kinkead – Peoria, AZ
Class of 2013

I will not be able to attend the IAL convention this year... but, I went to the one in Baltimore Maryland in June of 2015... and it was very nice. I really enjoyed meeting everyone, and all of the Voice institute classes were great, I learned a lot, am so happy I was able to attend. I think it was well worth it, and recommend it for anyone who has never attended one. Still have to give credit to Pat Sanders for all of the help she gave me.. miss her light.

Lynn Foti - Akron, Ohio
May 2009

I had my surgery 9/2002. The following June (2003), I went to the convention in Atlanta GA. I had made plans to share a room with a fellow lary who I met in WebWhispers, that lived in Raleigh NC. One year when the convention was in Boston, not sure which year it was, four of us drove up for the dinner only. Then I was living in Southern CT.

I also attended a convention in NJ, Edison I think. That was a mini one, not the big one. Not sure what year that was either. I drove down to that one. After I moved to FL I went to one in Orlando, didn't stay over since I lived in Kissimmee.

That's my history of conventions. The main reason I do not attend, lack of money. Also, I guess, it's not much fun to go alone. At this time I am not planning to go to VA.

Linda Palucci – Kissimmee, FL
Sept, 2002

In the 8 years or so since my surgery, it seems that just about the time where everyone is confirming their attendance, we have had something occur which prevents us from participating. Looking back on the calendar there have been two funerals, a conference requiring my wife's attendance, a wedding of our daughter, and two significant illnesses. Earlier this year I was beginning to believe 2017 was going to be the year we were finally going to attend. We had a very important (and expensive) trip scheduled to Key West, Florida, but it looked like it was going to be a few weeks before the Annual Meeting. Earlier this week I found this was not the case as our Key West trip concludes on the very day the conference begins. I have been assuring my wife for 40 years a trip to Key West which was the site where I joined the military in 1974, so canceling that one was not on the table, and I honestly don't have the drive or stamina to do them back to back. Because of that, we will again be no shows this year.

I have enjoyed the relationships I have developed over the years in the laryngectomee community and look forward to putting faces with names at a point in the near future and to where I can personally thank the people who give so much time and effort to our community of laryngectomees, caregivers, and professionals. 2018 will be the year that Mike and Beverly Smith attend!

Mike Smith – North Augusta, SC
September 11, 2008

I am hoping to attend the IAL event in June in Newport News. A bit nervous as this would be my first time since surgery last November to travel by air and overnight, but I think I am ready.

Alyssa Dodd – Lexington, KY

I will not be attending the conference. I've never been to one, principally because I am still in recovery mode psychologically and physically, but good luck and I look forward to the news.

R McGrath – San Francisco, CA

I have attended every IAL meeting since 1993. This year I will be on a cruise from Rome, Italy to Singapore. I know I will miss not being at the IAL this year but I am looking forward to our upcoming cruise. I will miss all of the friends I have made over the years and hope you all have a wonderful time.

Richard Crum – Jeffersonville, IN

I'm trying to get to this year's IAL. I have been to 4 of them and have always enjoyed them. I always recommend to new Larys that they try to get to at least one of them.

Bob Bauer - Hayward, CA - Class'08

Sorry No! It's too far and way too expensive!!

John Haedtler - New Mexico, USA - 2001

I have hotel reservation confirmed. Sent registration fee today. Waiting for info on dinner i.e. Date, registration info etc.

Max Hoyt - Lewes, DE

My first IAL Voice Institute (Buffalo 2014) was so amazingly helpful, I felt in the first hour that I could not imagine ever missing one. This will be my fourth consecutive Annual Meeting and Voice Institute since becoming a laryngectomee. The socialization is priceless and the information on recovery, rehabilitation, and how to help laryngectomees is second to none. I am registered, have booked the hotel and am searching for flights now. By the way, from Atlanta, some of the direct flights to Newport News are actually cheaper than arriving at Norfolk. This varies by airline and departure point, so don't assume anything without doing your own comparison. If you have never been to an IAL Voice Institute, especially if you are a recent laryngectomee, I assure you that attending is something you will never regret. I hope to see you there!

Tom Whitworth – Powder Springs, GA

We went to the one in Spokane a couple of years ago... and it was one of the most important events of our lives! We would love to do it again.... but travel that far is not in the cards for us this year. Ageing is taking its toll,... maybe when we get younger.... or the IAL gets closer to the NW!

Roger & Carol Johnson Richland, WA

I would dearly love to go I really would, but not only am I a lary, but I am legally blind, and require assistance when in a strange environment. I was shot in the face 70 years ago and lost my left eye. Then in 2004 I woke up one morning and couldn't see my face in the mirror. I have severe macular degeneration.

I live about 14 miles north of Seattle and that is about as far away from Newport News as you can get and still be inside of the of the contiguous states. Don't misunderstand because I lead a great life, and am poetically active. Even at almost 88 I still seem to have most of my marbles.

Johnnie Dontos – Woodway, WA

I have been to the last four IAL meetings, and have had a great time at every one. Within fifteen minutes, after I checked into the hotel, at the first meeting that I attended in Spokane, I met a group of larys who introduced me to the wonders of the Electrolarynx. Being introduced to the EL made a sea change in my life, because, I was finally able to carry on an intelligible conversation for the first time since becoming a lary; my prosthesis didn't work so well for me.

I enjoy the meetings because they provide a variety of social, educational, and discovery opportunities. I like meeting and socializing with other larys, which otherwise doesn't happen. There is always something new to learn in the educational programs regarding head and neck cancer diagnosis, treatment and recovery. Small group discussions about various aspects of lary life, and a support rap group for care givers offer chances to share ideas and experiences, and learn with and from each other. The vendors venue display and introduce attendees to a wide variety of products for up close and personal inspection, comparison, and trial which is an opportunity not available anywhere else.

There are always interesting sightseeing excursions for exploring the new and different cities where the meetings are held. The WebWhispers Dinner is the highlight of the gathering during which everyone has a tremendous time dining, and wildly dancing the night away.

These are a few of the reasons that I am, very much, looking forward to showing up in Newport News. Got me a new pair of danc'in shoes!

Patrick Kerr – Miramar, FL
Class of 6/11

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