

WebWhispers

Sharing Support Worldwide
Throat Cancer and Laryngectomy Rehabilitation

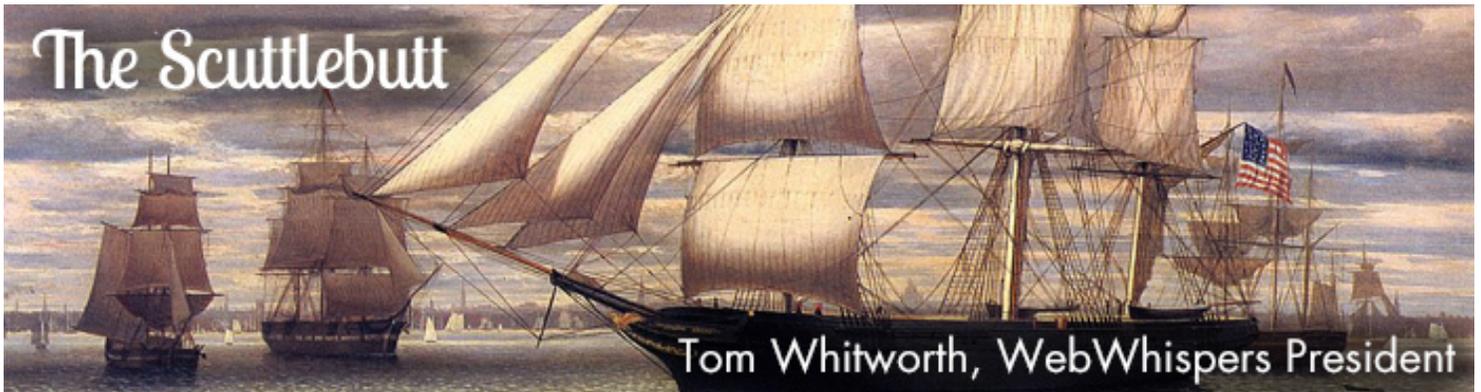


October 2017

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I'm Okay, You're Okay

Most of my life I would have been considered reserved, introverted and just plain shy. Maybe I am all of those and maybe I'm none of them. I used to walk into new situations where I didn't know anyone and I tended to feel self-conscious about something, even though I had absolutely no reason to feel that way. Ultimately, when I would get to know people, they would not think of me as shy at all, but that was around those with whom I felt comfortable. Generally, I stayed in my box and in part, for good reason. I've always been of the mindset that I learn more from listening than I do from talking. Growing up, my mom had a little plaque in the kitchen right next to our single, wired telephone. It read "If the good Lord intended that we talk more than we hear, we'd have two mouths and only one ear." Maybe that's where the quiet nature came from.

As an adult, I eventually started trying to attend certain networking events to benefit my business career, especially after I lost my job due to cancer. I had been attending such groups before and most of the time was the quietest person in the room. I tended to gravitate toward the people I already knew, if any were there, as that kept me comfortably in my box. Oftentimes, I would manage to make good connections anyway but I will always wonder if I could have done better. During recovery and rehabilitation from throat cancer and laryngectomy, I attended no such functions for reasons that most would consider obvious. Eventually, I started trying these things again with my HME generally behind a buttoned collar and tie. Though I was never, ever ashamed of myself in any way, I surely was self-conscious. How many times would I have to leave the room to clear my trachea? Will I have to step out because my voice gets stuck? Will they even be able to hear me (at more crowded events)? Do I look pitiful? I think you get the picture. For a while, if I could even convince myself to attend networking functions, I would consider the experience successful as long as I didn't pass out or blow mucus all over my shirt or worse yet, all over someone else. Incident free I viewed as an accomplishment. How sad! I was like that for the first year or more post-laryngectomy and then something in me started to change. Gradually, I became better and better at getting out of my box, not only the old box but the even smaller one I had crawled in and sealed up from the inside.

I began to recognize this change a little along the way but wondered sometimes if it was simply my imagination. In particular, the past month I have come to realize that I'm not only okay, I am way better at this than I was without a hole in my neck and have become a serious networker. This month, there have been four such things for me to attend; the most recent event was earlier this week. Something happened as I arrived for the event. I'm not even sure if it was conscious or subconscious but it took hold and directed my behavior for the evening. It was a more casual kind of thing with people of all ages and walks of life. At this particular monthly gathering, wearing a tie is pretty much a nerd label so I wore an oxford dress shirt with an

open collar. There it was for all to see. In order to speak, I was occluding with the HME. Knowing that the event would likely be loud and crowded, a hands-free device was not even considered. Yes, it was crowded and as the crowd grew, so did the volume. It seemed like most were having to yell to be heard, even out on the patio. I had been to an earlier event at lunch time that day so my voice actually was a little strained but so were all the others! Most were leaning to hear one another, so I didn't even stick out. Of course, the "button" made me unique but I continued for two hours without the slightest hint of self-consciousness or shyness. Our field of work at this is identified by name tag color. Two people actually walked up to me specifically needing my services. Since I presented myself without reservation, I was accepted that way. I spoke to at least half of the 75-100 or so people there and managed to have productive business conversations with many of them. At least fifteen are additions to my business referral network.

The experience was surely my most enlightening since surgery and all that jazz that failed me before it. I have become a serious networker. Anyone who can't accept me the way I am will just have to settle for someone else.

"You gain strength, courage, and confidence by every experience in which you really stop to look fear in the face. You are able to say to yourself, 'I lived through this horror. I can take the next thing that comes along.'"
– Eleanor Roosevelt

Enjoy, laugh, and learn,
Tom Whitworth
WebWhispers President



Tell us about yourself. What was your primary occupation and your favorite job?

I worked construction all my life. Primarily as a Mechanical Engineer, designing HVAC and Fire Suppression Systems. My love, though, is in the wood shop. I feared that being a neck breather would make woodworking a hazard because of the sawdust. But it hasn't stopped me! I figured out a way to cut a face mask to fit my HME and off I go to work (really play) in the shop.

Jody Ann Black -Tooele, Utah
9-11-2007

Retired USAF Colonel, most of service in the Reserve. Served in Viet Nam and Desert Storm. 33 years total service.

Retired Corporate pilot for Ford Motor Co. 28 years service.

Continued flying after regaining qualification about 3 months after surgery. Only required to demonstrate the ability to communicate effectively on the radio.

Built 3 experimental homebuilt aircraft, performed with a formation flight demonstration team.

Still flying today privately at 74 and also enjoy activities with a 1934 Ford Street Rod.

Dutch was a great positive influence for me with our similar backgrounds; I always thought if he can do it so can I.

I have no remaining issues from radiation (did lose thyroid gland), a very good voice, and neck flexibility thanks to a great medical team at the University of Michigan.

I am also a prostate cancer survivor and underwent brain surgery in 1993 to remove an acoustic neuroma, fully recovered from both.

Richard Sipp – Midland, MI
Class of 2000

When I got out of the Air Force in 1958, I enrolled in a pre-med program intent on becoming an MD. I was a medic during my service tenure (January 1955 to Sept 1958 when I took an early out to go to college) and loved every minute of it. Physics, Organic Chemistry and Advanced Algebra and I didn't mix very well and I dropped out of pre-med and majored in Psychology. That was one of the best decisions I ever made. After completing a Master's degree in psychology I was hired as an Instructor at Pacific Lutheran University where I'd enrolled when I got out of the service. I loved teaching in higher education and went on to get my doctorate in psychology. In the mid 1970's I left university teaching and became a business entrepreneur. My wife and I owned a nursing home for several years and I started a business consulting practice, as well as a couple of other small businesses.

I stayed with my love of teaching and was an Adjunct Professor at several universities during the rest of my career. I was also Director of a doctoral program in psychology, and Dean of an off campus program during that time. One of my favorite jobs (I had many) was as a sensitivity trainer during the mid-1960's to the late 1970's. Those were very exciting years. The country was in turmoil and the field of psychology was trying to find ways to address that turmoil. During that time I conducted hundreds of workshops concentrating on opening better communication channels for people in virtually every walk of life. People are amazing when they find themselves in an environment where they can openly explore their inter-personal communications, and those of others.

Regarding the question of special skills, I like the one I've found most recently and that's writing. After I lost my larynx in 2010 I was really down on myself because I wasn't communicating the way I had throughout my career. I decided I'd try writing fictional adventures containing fantasy as well as science fiction elements. WOW, what a breakthrough for me that was. I've written dozens (more than 4 dozen) of what are now called short read books (around 100 pages or so) and have loved every minute of it. I sincerely hope each of you use your special skill to bring the sunshine into your life that writing has brought to mine again. I know Len Hynds, our speechless poet will agree with me on that.

Dr. Branton Holmberg – Wauna, WA
Lary class of 2010

My profession was a biomedical engineer that worked on all kinds of medical equipment from Radiation therapy equipment. MRI and CT systems, but my specialty was the imaging equipment for cardiac catheterization and angiography equipment. I was in a support position that worked with the design engineering team and the field personnel to do whatever it took to make the equipment meet the customer's needs. It was a challenging but fun job and I got to work with many very highly qualified people at all levels.

I have many hobbies including wood working, building custom cars and many outdoor activities. The outdoor activities include fishing, hiking and spending time in the mountains of Idaho and Washington states.

My family consists of two sons that have families that include my 5 grandkids that range in age from 19 years to 9 months old. Of course that includes my wife of 44 years that many of you have met at IAL and on cruises. They are the most important thing in my life.

In 2005 I was diagnosed with laryngeal cancer and had two laser surgeries, a partial laryngectomy. Then in 2010 I had my total laryngectomy and that is when I found WebWhispers. In a few short years I went from having 2 surgeries in my life time to 23. There was no support group in my area so I wanted to start one. I was new at this and had a lot to learn, so I attended my first IAL and a WW cruise. My life was changed by all of the great friends I made and the help I got. People that helped me were many but I will always owe special thanks to Pat Sanders, Ed Chapman, Cliff Griffin, Tony Talmich, Jim Lauder and Tom and Dorothy Lennox to only name a few. I started the local club and started doing patient visits with John Hudlow and everything has grown from there.

It is said that when one door closes in your life another one opens. This one was a whole new chapter in my life and one that I am so glad for, because it has made me a better person. I also cannot say enough about all the special people in my life as a part of this.

I did not want cancer but, I have survived cancer 5 times now. My journey with cancer has given me new challenges, one of which is being the webmaster for WebWhispers, which I had never done before. It has taught me so much and given me so many new special friends. It has enriched my life in more ways that I could have imagined.

I was told once that there was a question that could not be answered. The question was "Who are you really"? My answer was that it was easy to answer because, to know who I am, you only have to look at my family and friends. They reflect and shape who I am.

Thank you to all of you!

**Ron Mattoon - Seattle, WA
2010**

I was a mechanic for a couple of Crop Dusters. I worked on Piper Pawnee's, Weatherly's and Air Tractors. I enjoyed the round engines the most. This gave me the opportunity to work on unique aircraft. Like Beechcraft Staggerwings, Homebuilt aircraft. And crazy helicopters. I still get to get my hands dirty from time to time. I enjoy doing annual inspections on friends planes. and I taught myself how to TIG weld.

I think my life career stemmed from my misspent youth! I started working on aircraft at the age of 6. My neighbor had an old Curtis OX-5 engine out of a 1939 WACO biplane. I got to take it apart. At age 11 I help to put it back together and see it run! Found out later it was once owned by Charles Limburg!

**John Haedtler - New Mexico, USA
2001**

I only had 2 real jobs during my working life. The first was with the US Navy where I attained the rank of Petty Officer 2nd Class as an Electronics Technician. After leaving the Navy I was hired by IBM where in my 28 year career I held a number of different positions. I started out as a Customer Engineer serving Keypunch machines, Sorters, collators and tabulators. Soon after I was trained on the larger computers, the 7074 (which would fill a 3 bedroom house) and the 360 Series of computers. From there I became an Instructor at the Ed Center in Chicago. I developed and taught a course for a Telecommunications software program. Last position, before retirement, was as a development programmer creating software tools to help other programmers do their jobs.

I never believed there ever was the best job, but there will always be the one you enjoyed the most. For me, it was when I was an instructor teaching others.

**Bob Bauer - Hayward, CA
Class '08**

I was an auctioneer when I had my laryngectomy. I now make my living as an appraiser. I am still working as an auctioneer/realtor every day.

Richard Crum -Jeffersonville, IN

I have been asked this question many times, and the answers would fill a book. As a matter of fact I spent a great deal of time starting my book. Then someone stole my computer with all my outlines and hundreds of notes. After my laryngectomy a young friend of my daughters asked me some questions. I have led a very interesting and exciting life, and been everywhere in the world that I wanted to go, and a couple of places I

didn't want to.

First of all the job that I really enjoyed the most was being a commercial fisherman, and I fished until I was 76 years old and my eyesight became so bad I could no longer drive my car to the boat. There isn't a night that I don't dream about fishing somewhere.

Johnnie Dondos – Woodway, WA

My profession still is computer programming. I've been in the field since 1980. It took me 26 months to get back to work after my laryngectomy. A lot of that delay, though, was to ensure I was healed enough and my voice was working consistently enough to travel independently to client locations around the country. I elected to use a patient-changeable prosthetic after surgery with the express intention of getting back to work.

My favorite job was teaching programming for a software manufacturer where the audience was other programmers. And yes, it was as much of a total geek-fest as you would imagine. :)

Loyd Enochs - Evansville, IN December 2009

I am an eighty old, twenty-four-year survivor of laryngectomy. I graduated from the United States Coast Guard Academy in 1961 and was assigned as a deck officer on a 255 foot Weather Station Coast Guard Cutter. Twenty-one months later, I was given the command of a 95 foot Coast Guard patrol boat. I kept this command for 15 months and it was probably the most interesting and challenging position I held during my working life.

In April 1963 the boat was transferred temporarily from New London Connecticut to Miami Florida to conduct patrols in the Florida Keys. This was in the aftermath of the Cuban Missile Crisis of October 1962 and was part of the agreements between President Kennedy, Nikita Khrushchev and Fidel Castro designed to prevent the Cuban exile population from conducting raids from Florida to Cuba. We did the patrol on a rotation with two other boats and continued this until I was detached back to New London in early July.

I kept this command until the spring of 1964 when I was assigned to be the commanding officer of the Coast Guard Loran Station in Adak Alaska. Adak at that time was completely military and civil service with about 5,000 persons on the island. It was a family duty for me and my wife and I spent two years on Adak, 1500 miles west of Anchorage.

Following Adak, I resigned my commission in the Coast Guard and returned to Connecticut as a civilian. In the summer of 1966 I began work as a maintenance engineer for Pfizer, Inc. at their Groton Connecticut chemical and pharmaceutical manufacturing facility. Ten years later I was transferred to the power plant as a Utilities Engineer and I retired as a Senior Utilities Engineer in 1997, as a laryngectomee, after 31 years of service with Pfizer. During the years in the power plant I was responsible for computerizing the accounting and budgeting systems for this 7 million dollar a year operation. Probably the most challenging assignment I had during my years at Pfizer was managing the purchase, refurbishing and installation of a 10 megawatt steam turbine driven generator. This was one of four turbo generators in the power plant and was the largest.

In retirement, I continue to be active in community volunteer positions, currently as President of the Old Mystic Fire District. I am also the treasurer of my church. I also have a MBA, obtained in 1975 from the University of New Haven.

**Carl Strand, Mystic Connecticut
Radiation 1991; Laryngectomy February 10, 1993**

I had a 40 year career in the paper industry. All of it was in pulp and paper manufacturing in the mills. I pretty much grew up in the industry since my Dad worked at a local mill and I worked there during my summer years while going to college. Manufacturing processes have always been interesting to me - solving problems, improving efficiency of the operations. Later on, I was manager of a paper converting and warehouse/shipping plant. But my favorite job was when I was shift supervisor in a pulp mill when about 30-35 years old. Leading and working with older guys, I quickly learned how to rely on their years of experience. While I knew the chemical side of the processes, they knew the "hands on" realities.

**Pete Meuleveld - Salem, Oregon
June 2010**

I was a Certified Athletic Trainer, which I thought was the best job in the world, when I was 24! Because, I got paid to watch sports, which I love. After earning my degree from Southern Illinois University at Carbondale, I began working at Cheyney University in Pennsylvania. I worked at the college level and also in physical therapy clinics with outreach to local high schools.

I really didn't have a favorite job, each job had different challenges which I loved. I worked a wide range of sports from football in the fall to baseball and softball in the spring. While I was working people would ask what an Athletic Trainer does. My explanation was, do you watch football? Well, when an athlete is injured on the field, I was the first person out onto the field to see what was wrong and to safely remove them from the field. After an injury occurred, I would work with the medical team to evaluate, treat, and rehabilitate the injury so the athlete could safely return to their respective teams to compete again. Some of my athletes played on the professional level either here in the U.S. or in Europe, several were All Americans in their respective sports, others went on to be successful in their respective professions. I'm proud of each and every athlete who crossed my path, they touched my life in a way I can't explain.

If it weren't for this nasty disease I would probably still be doing this professionally, but, now I'm unable to communicate effectively enough on the field. But, I have gone back to school to begin a new chapter and profession, I will be a Medical Coder. I still get to use some of my knowledge, such as anatomy, in my new profession. I'm looking forward to gaining my new certification in the next year and working again.

Belinda Roddy – Martinsville, IL

My name is Jodene Hilsabeck, I go by Joe to everyone but my mom. I'm 75 yrs. old. Been married to my high

school sweetheart for 56 yrs. We have 2 kids, 1 of each and 6 grandkids, son has 2 girls and a boy, other has 2 boys and a girl, they range from 12 to 18. I grew up with a family of outdoors people, we all hunt, fish, camp and just enjoy being outdoors, whatever the season.

I'm a retired printer, I live in middle of Illinois and in the country, married a schoolteacher, son is a fish biologist and my daughter is a local optometrist. I'm lucky my family lives close. I became a lary in 09. In my spare time I do woodcarvings of birds, mainly water birds, I used to show and sell a lot of carvings, but now I just carve for my pleasure and to pass on to my family. Price always goes up after you pass away. My birds are very finally detailed. My wife has been my rock and my support thru the bad times.

Joe Hilsabeck – Edelstein, II
Lary[09]

In 2005, I retired from teaching art to children in grades K-12. My favorite job, though, was actually a voluntary one which involved feeding, diapering and holding premature infants every Sunday at the local Children's Hospital. Stocking medical supplies in that Neo-Natal Unit and delivering specimens to various labs were some of my additional duties during my 5-6 hours each weekend. What a pleasure it was to watch these tiny people grow and thrive due to the expert medical attention they received. My interest in this area was sparked after I had delivered a premature daughter, who at birth was 3#14oz and is now 45 and works as an artist for Hallmark. She was one of the first patients in that newly formed unit for preemies in 1972.

Barb Gehring - Akron, Ohio
9-2013

I was a sales rep/merchandiser for about 25 years before I retired. I was a Lary for the last 5 years of my employment. This type of work took me all over the country on my companies dime and I tried to always visit interesting places as I travelled. It was how I saw the Statue of Liberty, ground zero, New Orleans two months after Katrina and so many other places.

I always enjoyed the freedom the work allowed me. I was never an office person. I spent my last 10 years in the field working for a premium audio company. So basically I was paid to play with premium headphones, TV sound systems, Bluetooth and computer speakers, among others, all day, every day. Since they were generous with us, I was generous to me and I can "upset" my neighbors from any room in my house. Life was/is good.

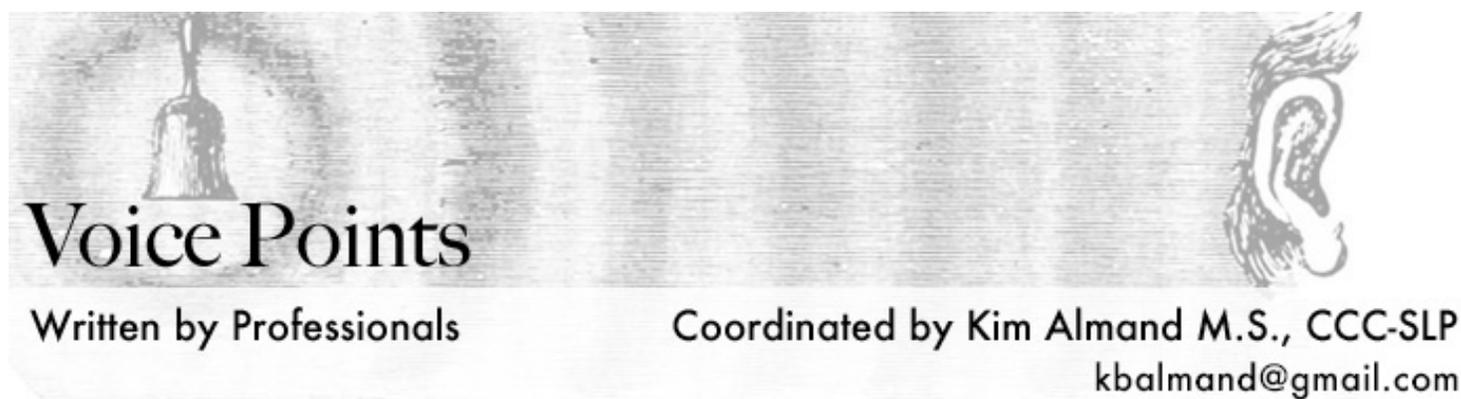
Mike Cohn - Wheeling, II.
10/10

Next Month's question is;

“If an artificial larynx could be transplanted would you do it?”

Thank you for your submissions. Edits are used for length, clarity and to keep comments on subject of the month.

Staff of Speaking Out



More Than Medicine: Surgical Missions Trip

Preparing for a trip overseas can be hard. Picking flights, checking bags, making connecting flights, and coordinating with your fellow travelers can be a challenge. But preparing for an overseas head and neck cancer missions trip? Well that's another animal.

I've been fortunate to participate in one of these head and neck cancer surgical missions trips with Dr. Netterville and a team of surgeons, nurses, and additional support staff from Vanderbilt for the past two years. Dr. Netterville and his team have traveled to the small town of Malindi, Kenya, for the past eight years, completing hundreds of surgeries, developing relationships, and running an outpatient ENT clinic serving the local community for two weeks each year.

On my first trip, the team completed four laryngectomies and we even completed our first tracheoesophageal puncture. Last year, the team completed two laryngectomies, four tracheoesophageal punctures, and two prosthesis changes in half the time.

Although resources may be limited, we have been able to provide communicative options for our laryngectomy patients through generous donations. Patients are provided with an electrolarynx, and while they learn to use the device, I learn a bit of Swahili, the local language. The patients that have received TEPs have been successful in their voice production and management of their prostheses, and Kenyan surgeons have provided support over the past year to the patients, even changing a prosthesis when necessary.

The mission of this particular trip is not only to provide care to the underserved, but also to provide training to

the ENT surgeons at Kenyatta National Hospital in Nairobi. The our team works together with the Kenyan team to provide pre-operative, operative, and post-operative services so that care may remain sustainable long after the Vanderbilt team leaves.

Outreach over the past several years has grown. Many head and neck cancer surgeons are leading teams to Africa and other parts of the world to care for those who may otherwise be left untreated. Teams donate their skills, time, money, and vacation days to go on these worthwhile endeavors. Additional groups providing surgical care include Dr. William Koch of Johns Hopkins University who works closely with the Pan African Academy of Christian Surgeons and Dr. Chad Zender of Case Western Reserve University who leads a team to the Uganda Cancer Institute, though there are several more.

As we pack for our upcoming trip in October, I'm looking forward to seeing the patients I've worked with over the past two years and the local community members we have built relationships with. Bags are being packed full of surgical supplies and other gear, including laryngectomy tubes, TEPs, cloth stoma covers, and electrolarynges. Although the travel to Africa and back home is tiresome and surgical days are long, knowing we are making a difference makes it all worthwhile.

To learn more or to donate to any of the trips listed above, you may visit MorethanMedicine on Facebook (Vanderbilt) or <https://www.paacs.net> (Pan African Academy of Christian surgeons), or email [:Katrina.harrill@uhhospitals.org](mailto:Katrina.harrill@uhhospitals.org) (Case Western Reserve).

Stay tuned for updates from our upcoming trip!

Jenn Craig Starkweather, M.S., CCC-SLP
Speech-Language Pathologist



Who am I? Depends on which electrolarynx I'm using...

Who am I? Unless you want a laugh, don't ever try to answer that question using a voice recognition system - not with an electrolarynx anyway. Here's two good reasons why.

Me: *Hello, my name is Noirin Sheahan* (pronounced Noreen Sheeyan).

Using TruTone: *A low minors no mean sheen.*

Using Servox: *Yellow eyes Oh easy on.*

See what I mean! I got the idea from another Webbie, Johnie Dentos, who sent me his attempts to pledge allegiance to the United States using his Dragon Dictate voice recognition system. First of all his daughter said the pledge:

I pledge allegiance to the United States of America and to the Republic for which it stands one nation under God indivisible liberty and justice for all.

The Dragon translated perfectly. So Johnnie tried with his Trutone:

I'd like to leave the edge of the United States of America and to the public would disband all one nation under God indivisible with liberty and are all.

Undeterred, he tried again:

I like the allegiance of public one nation under and to the Republican or wicked one nation under God and all with liberty and has all.

Oh dear – the wicked nation! He then tried with his Servox:

I didn't leak in the United States of America and the Republic of week and one nation under God indivisible with liberty and justice for all.

Servox worked better but when he tried to say 'Servox' he got weird stuff including "Email he" and "Milk"! When he tried to say "Milk" the system interpreted it as a command to go to his mail box! At that stage I think he gave up and mailed me his results – giving me the best laugh I'd had in ages – thanks Johnnie!

Thank goodness for those times when the electrolarynx gives us a good laugh. But what about intimacy? I'm trying to imagine what a voice recognition system would make of my attempts to say "I love you dearly"?

"Club you early" ... "Hello Eugenie" ...

This reminds me of one such mistake I made myself many years ago. I was having a drink with an old friend (who had one too many by this stage) when he suddenly announced "I want to make love" and leaned over and put his arms around me in a drunken embrace. This was so unexpected that what I heard was not "I want to make love" but "I want my glove!" I had hidden his glove, it seemed, under my jumper or else I was sitting on it! I also started fumbling around in search of the missing glove, assuring him that I hadn't hidden it or even seen it. After a few moments, he suddenly announced that he was very drunk and needed to go home. I didn't think any more about it till I met him the next day and he apologized profusely for his behaviour.

I kid you not - it was only then that the penny dropped! He looked so miserable, I didn't dare tell him what my ears had made of his amorous declaration. I just accepted his apology and assured him I hadn't taken offence, but inside I giggled for hours!

Sometimes its as well not to be understood perfectly!

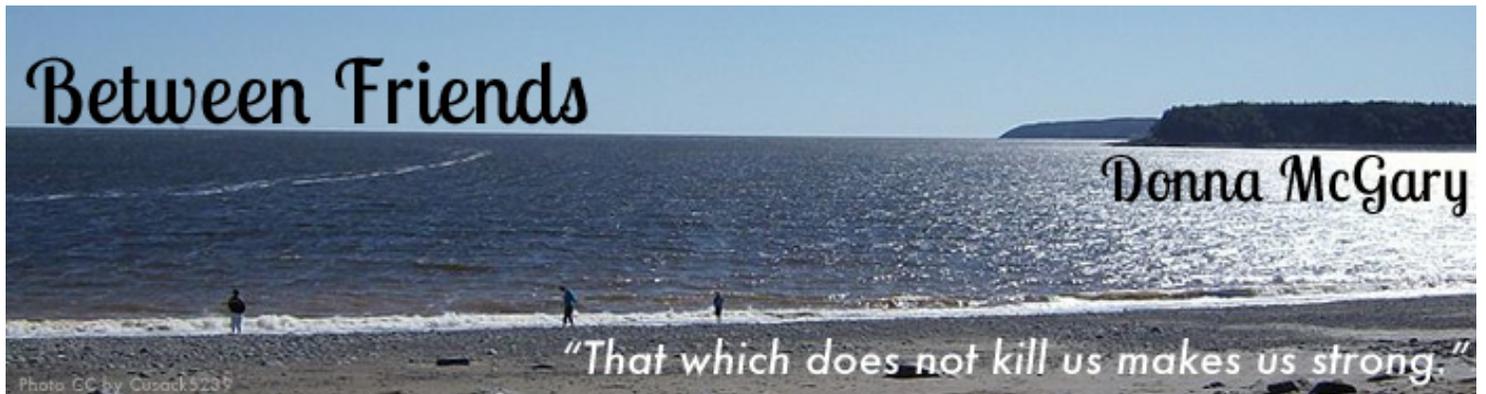
But I can imagine a time where I'll want to say "I love you" and not be misunderstood. I'm not in a relationship or planning on any new romance, but recently realised that I haven't tried to say 'I love you' to my mum or any close friends since laryngectomy. Not that I said it often beforehand, but maybe laryngectomy has made me more appreciative of people and I'm starting to imagine situations where I might want to express this. My mum is now 91, I'm 62, and my friends are mostly in their sixties or over. Sooner or later I'll have to say

goodbye to someone close. My voice doesn't sound like 'me' and, at the moment anyhow, I can't imagine using it to express intimacy.

I'm going to leave it at that for now and try to experiment a bit with this over the coming months. Meanwhile if any of you have overcome shyness and managed to use an electrolarynx in an intimate setting, I would be very grateful if you get in touch.

Than with bees, I lob Ewan early milk.

That was my electrolarynx trying to say: "Thanks Webbies, I love you all very much!"



Our Treasure Chest

We are starting a new column this month which actually proves the adage "everything old is new again". I have been writing and editing in some capacity with Whispers on the Web since 2005 and was a reader before that. Our index has complete copies of every issue since September 2003 and with an average 7 articles a month, 12 months a year that's about 1200 articles contributed by our members, written by us for us: larys, caregivers, professionals, friends and supporters. Now I am a voracious reader but I know I've missed some and forgotten more and I bet you have too.

So with that in mind we're starting a new/old column called, at least for now, "From the Archives" which each month will feature one of these old treasures. For our many newer members these writers will be new and fresh voices; for some of us veterans, it will be like running into an old and valued friend.

This month we start with something in "A Scottish Accent" from Rosalie Macrae. I am especially fond of Rosalie's writing for several reasons. She had a razor sharp wit that took no prisoners but she was as quick to direct it to her own foibles as to those around her. She had a great eye for the perfect detail to make a situation come alive and boy, did she have adventures! Even when her stories included tantalizing bits from her career as a London-based journalist, something about a Sheik in Saudi Arabia and Jackie O in Paris, she always brought us and herself back to earth with a funny, poignant bit about this lary life.

She was the first writer I started "editing" for Whispers on the Web and that was a bit daunting since I really had no experience and she had dealt with some big names. Her style was roughly what my old Lit professor would have called "stream of consciousness" and inclined to lots of dots and dashes. I liked it but that style

can be problematic in an online newsletter. Plus we had the issue perfectly described by some Brit (attribution is tricky), “The United States and Great Britain are two countries separated by a common language”. She and I laughed over that more than once!

We commiserated on our “lost feminine voices” and other vicissitudes of age and infirmity. She became my friend and we were sorely disappointed when our planned visit in person fell through due to her health. I was reminded of her when another favorite, and equally as colorful writer, Len Hynds, passed away recently.

WebWhispers is a treasure trove of talents, personalities, and opportunities. Opportunities to make new friends, discover new strengths, cultivate new skills, and find new purposes. That is really brought home when you read this month’s Speaking Out question of our primary occupations and favorite jobs. We are such a talented bunch. I wouldn’t be here if Pat Sanders had not encouraged (strong-armed might be more accurate) me and for that I am most grateful. I don’t have Pat’s power of persuasion but I would like each and every one of you reading this, even if you think you aren’t a writer and you didn’t have some notable career, to realize you have a story to tell. And we want to hear it. You don’t know who might be touched by your unique journey. I guarantee there is someone out there who needs to hear what you have to say.

I can’t tell you how many times I have wanted to stop writing my column, thinking no one was reading it when I have gotten an email saying how something I had written made a difference in their life. It doesn’t happen often but that kind of thing makes a difference not just to the reader but to the writer.

So I am asking all of you, tell us your stories. It doesn’t have to be a full-on essay but if you have something you want to say, here is your place. Another favorite, to give you an example, is a fellow I met at an IAL meeting as we shared a shuttle bus to the airport. I commented on his good voice and he wrote a brilliant article about how laryngectomy surgery was simply a plumbing issue. You will read that one soon. It’s just another gem in the WebWhispers treasure chest.

Please write to us at editors@webwhispers.org with your stories. We all want to read them.

Bits, Bytes and No Butts!



Frank Klett

Avoid Security Traps, Follow your Credit Report

Recently we were told that one of our larger international companies had a rather significant security breach. This is hardly news anymore since we seem to have one such incident every day to the point we shrug and politely say "please pass the sugar".

We have become numb to computer security news and the problems they bring yet they are truly real life problems that can turn our worlds upside down and even totally destroy them. In this case Equifax lost the lock on the keys to 143 million accounts. The potential losses from this breach could easily exceed any know loss to date...possibly combined totals to date, making it perhaps the most disastrous of all reported hacks.

It involved the encroachment of the Equifax credit reporting agency which is defined by Wikipedia as "a consumer credit reporting agency. Equifax collects and aggregates information on over 800 million individual consumers and more than 88 million businesses worldwide. Founded in 1899 and based in Atlanta, Georgia, it is the oldest of the three largest credit agencies along with Experian and TransUnion. Equifax has US\$ 3.1 billion in annual revenue and 9,000+ employees in 14 countries. It is listed on the NYSE as EFX."

So what is the expected impacted effects on us? Just about a ca-billion more times than getting hit by a bus. A bus would just hit you once, but the loss of your security data can continue to haunt you for the rest of your life. I am sure the lawsuits and ramifications of this breach will last much longer than we would care to believe. Obviously now is the time to get a good grip on your information and to begin a regular system of checking in on it. Most of the commercial banks today offer free credit reports as part of your account service. However they only provide you with the report information not the monitoring or repair of your report.

If you have never taken the time to download your credit report and scrub through it very carefully this is a good time to do it. If you find anything at all wrong, get it corrected. Bob Rankin has put together a quick guide to the whole process:

https://askbobrankin.com/get_your_free_credit_reports_online.html

Plus here is a comprehensive article from the New York Times which is especially helpful:

<https://www.nytimes.com/interactive/2017/your-money/equifax-data-breach-credit.html>

Lately a number of WebWhispers members have been asking about the residual neck pain that we larys often have. After nearly 10 years I have found the neck pain to really suck! It has let up very slightly with no relief from pain meds either prescription or OTC. Back in May 2016 I discussed neck pain caused by computer work and thought I would include it again with some reminders.

Avoiding "Text Neck"

Text Neck is a somewhat new and just recently diagnosed condition...caused by...you guessed it, holding one's head in a downward position for a long period of time...no, not caused by smoking!

There are actual studies being conducted to help identify and hopefully resolve the issues that are arising from our new technologies. The following article from CNET provides more info:

<https://www.cnet.com/g00/how-to/how-to-avoid-text-neck/>

If you are a Windows 10 user then you are well aware of the number of recent changes you are being

bombarded with. I am still a Windows 7 user but I do have a Windows 10 desktop I use for keeping up with things, so I do have an idea of the hurdles you have to jump. I actually find it a royal pain since many times the change process winds up changing my configuration settings (which it is not supposed to do) and I have to spend 30 minutes or more trying to get things back as I had them.

And now a brief message from our sponsors...

All WebWhispers members are invited to join the WebWhispers Facebook Group, our home on Facebook. We are a warm, caring support group of larys, caregiver and SLPs who will help you adjust to life after laryngectomy. Send a friend request plus a message on Facebook Messenger to the FB Page of, John Isler, Anne Rinaldi Ammenti or William Cross at william.cross.752. Tell us you are a WebWhispers member and we will add you to the group.

If you are not a Facebook user then you might enjoy a visit to our Forum; hosted on Delphi, the Forum is a members only group which limits the access to only those of our hole in the neck group. You can read over the questions and insights of other larys as well as ask questions and get answers from our knowledgeable members.

And for our newest members remember to visit the WebWhispers library for answers to many of your questions. <http://www.webwhispers.org/library/general-information.asp> is the most comprehensive collection of information aimed specifically at the Laryngectomy Community, bar none. Taking the time to browse the library and become familiar with the contents will make it even more useful for when you have a new question. The website <http://www.webwhispers.org/library/general-information.asp> offers everything from lary humour to recipes to local support resources.





Editor's Note: Rosalie Macrae wrote for us under this banner from October 2006 until her sudden and unexpected death in February 2009. She was a wonderful storyteller and accounts of her adventures as an international journalist as well as her more recent ones as a lary were always written in her distinctive voice. She took great delight in poking fun of herself and anyone else who might cross her path but always with her trademark sly humor and insight into human nature. Whether Rosalie's Scottish Accent is new to you or like visiting and old friend, I hope you enjoy her now as much as we all did the first time around."

Tijuana At Your Peril

This is Tijuana Day for a repentant Rosalie. Nothing to do with the magical old Herb Alpert Brass. How the young heart soared. No. Nothing uplifting like that. TIJUANA in my 'lictionary' translates as: TryItJustUnwiselyAndNeverAgain.

As a lary and, probably like most of us, a bit of a rebel, I am positive you have had your Tijuana moments. Or else you don't live dangerously. In this instance I salute you and good for you. These moments I can certainly survive without.

I need my Tijuana mantra for occasions like this sunny September morn when I risked having a nice big long bath. Just like in the old days, deliberately not bothering to insert my stoma's custom-built stopper- which someone was probably paid gold troys for inventing. The heck with caution, thought I, sinking down to savour listening to Saint-Saens' 'The Swan'.

Eyes closed. Oh to have a swan-like neck.

Watery underwater silence. Slid right down and thought I was heading into the eternity of that fathomless lake beneath the placid birdie. Swan. Birdie. Perhaps not.

Petrified. Choking. Flailing. Trailing jasmine slid in too, twining around the loofah. Remembered I'd bought it on special offer from Harrods Household Section where I'd been intrigued to find I'd wandered into a walk-in freezer with a television being bought by some sheikh. I told him that I didn't come with it and he laughed. Nervously imagining another harem queen mother. Funny what passes through your mind when you are nearly in extremis; not that light at the end of the corridor they all talk about.

A small lifetime later and beautiful, normal breathing was restored. Eyes running, neck aching. TIJUANA! Went downstairs to eat usual porridge soured in heather honey. Heavenly.

But then came the What Ifs which follow Tijuana occurrences. What if I had doused the bath in frankincense?

Not being baby Jesu or his mama I would have suffocated, tubes clogged up.

What if a bee, gorged on heather honey, had nipped into the bathroom and down my stoma. Instant somnolent sting death, like that poor Australian.

Hold on girl. Enough What Ifs. Projection is futile. Que Sera Sera.

Oh and what if I had learned to burp when I had the chance. Laryngectomy life would have been so much simpler without the trauchle (gaelic for 'trouble') of batteries and cords and tone-matching. Esophageal speech sounds like freedom to me... I crave it.

My big burping opportunity was unusual. I was sharing a house back in the Sixties with a stunningly lovely American girl called Lynn who had been provisionally picked to be in the next US Olympics archery team. My male colleagues formed an instant lechery team when she appeared in the office.

Lynn could have burped for her country too. I discovered this gift, apart from the one of Arcadian beauty, after making her some herring, fried in oatmeal, splashed with white vinegar, for breakfast. Something she said they didn't do in her small Colorado town. With that she flexed her back, poised in arrow-releasing mode, and let out a burp of sheer satisfaction.

I asked her to show me how to do it. Never ever dreaming that one day in my future, burping would have been not only a huge asset for esophageal speech, but a good party piece and conversation stopper and/or starter! Lynn went through the burping/breathing pattern patiently in the bedroom, night after night, while our roots were blonding and our toenail varnish setting. Our next-door neighbour, a retired air force captain, complained at the merry shrieks until he saw Lynn, and like most men fell speechless.

My colleagues were wildly jealous. What was it like sharing a bedroom with this icon, they wondered. Did she mention any of them? What sort of books did she like so that they could bring them into conversation? When I told them she was trying to teach me to burp when not reading the thoughts of Mary Baker Eddy to protect her from the London smog--a menace in those days--they burped in disbelief. But I never did get the knack.

If only I had tried harder. This has been underlined to me right now. I am temporarily speechless because I pushed the Servox button too vigorously when joining in Ode to Joy on the radio. It was a moving homage to Leonard Bernstein conducting unrehearsed Berliners celebrating when the Wall came down.

But I jammed the button. Our hospital ENT technicians are recovering from a riotous 'training' weekend. The TruTone needs new batteries; the car tyres need air and I can't bend down as I need air more than they do.

Tomorrow the technicians will have recovered from their hangovers. My son will have done the tyres. I will have bought the batteries. But right now I feel like going to the pictures to see Volver. Alas, without the freedom of speech, phoning for a taxi is impossible. It's a pity Elizabeth Finchem, our WW esophageal expert isn't here to be my personal tutor.

No matter. Inspired by these sweet belching memories I have decided to start learning esophageal properly from a speech therapist. I wager she won't burp as well as Lynn, though. Dammit, I forgot to tell the boys she snored!



Hi Donna,

I believe that you are aware that sadly my father who was a regular contributor to Whispers on the Web, passed away on 23rd August 2017. I have included a copy of his obituary should you wish to use it to notify your members/readers.

Kindest regards,

Len W Hynds Jr.



Leonard 'Len' Arthur Hynds, aged 87 slipped away from us on 23rd August 2017 at the William Harvey Hospital in Ashford, Kent, United Kingdom. Known to many as the speechless poet, Len had been admitted to hospital a month earlier and had undergone an emergency operation. Until the day he died his indomitable spirit never left

him.

Born in March 1930 he was the youngest of 7 children. He grew up in London, through the ravages of the Second World War, and survived the blitz including on three separate occasions when his family home was destroyed by the bombing. Aged 17 he was posted on military service with the Royal Military Police to Egypt; and for 3 years was parted from his true love, Tilly, who he married just days before his posting overseas. Tilly and Len proved to be life long soul mates.

After military service Len choose a career in Policing in London. As a uniform police officer, Len was awarded the Royal Humane Society Award for entering a gas filled building and resuscitating and saving the life of a young woman. Later as a detective with the Met Police's elite Flying Squad he took on some of the most notorious organised crime gangs in the country, including the Great Train Robbers.

During his life, Len proved to be a consummate writer and storyteller, drawing upon his experiences from his childhood, his military service in Egypt, and his crime fighting on the streets of London.

At the age of 73 Len was diagnosed with throat cancer and underwent major surgery removing his vocal chords. To be a storyteller without a voice must have been his ultimate challenge. But he never once complained; instead he committed to reinvent himself, enrolling at Canterbury University where he learnt and refined his craft as a master poet; and using the medium of verse he learnt to entertain us all again.

Len had a palpable sense of fun; and using his abundant creativity and fertile imagination he was never happier than when he was entertaining his loved ones and his wide circle of friends.

Len was a widower for the last 6 years of his life.

The funeral was held at Charing Crematorium in Kent on 20th September 2017. The Royal Military Police Association provided a Guard of Honour and Standard Bearer. Tributes were paid by his children and grandchildren.

From 'child of the blitz' to policemen, to poet, Len's life has been inspirational. Len's family has received kind words of condolence and tributes from all over the world. He will leave a huge gap in our lives but his words will live on.

Here is the link to Len's website, [The Speechless Poet](http://www.thespeechlesspoet.co.uk/home.php), with all the columns he wrote for us as well as all his other poems and short stories: <http://www.thespeechlesspoet.co.uk/home.php>

WebWhispers is an Internet based support group. Please check our [home page](#) for information about the WebWhispers group, our email lists, membership, or officers.

For newsletter questions, comments or contributions, please write to editor@webwhispers.org

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