

Whispers on the Web

A Monthly Online Newsletter for WebWhispers

Photo CC by HMBq.com



Contents

Column	Author	Title
From The Editor's Desk	Donna McGary	An Oasis of Support
The Scuttlebutt	Tom Whitworth	Does It Ever End
VoicePoints	Kim Almand, MS, CCC-SLP	A Virtual Reunion
My Neck of The Woods	Don Renfro	Quite a Challenge
This Lary Life	WC Baker	Portugese Interlude
The Agony & Ecstasy	Dr. Branton Holmberg	Chapter 10: No Voice
From The Archives	Donna McGary & Members	On The Lighter Side

From The Editor's Desk

Hello all,

Remember back in the “old days” when certain words were unacceptable for print? Well, this is how I would describe things lately, what a @#\$\$%^& . I am pretty sure you could add a few choice descriptors yourself!! And while it is true that what 2020 has presented us with so far has not impacted us all equally, we are all equally bombarded with “stuff” to process and it’s hard work to sift through. Some days I feel like my head will explode just trying to separate the wheat from the chaff.

So, in the interest of sanity, yours and mine, I offer you an oasis, Whispers on the Web. Guaranteed no news, fake or true ripped from today’s headlines, no conspiracy theories, partisan politics or nasty name calling and mean spirited retorts. Just an oasis of support, information, anecdotes, insight, escapist travel and memoir...all written by fellow members of our exclusive by fate, yet inclusive by choice, little club.

VoicePoints from SLP Kim Almand not only highlights the recent IAL/Voice Institute webinar but gives both clinicians and patients valuable information about telehealth, something we can all expect more of moving forward. Although it poses unique challenges for us and our providers vis a vis lary issues certainly other health concerns could be easily and adequately addressed this way. Tom Whitworth writes/vents about another challenge we pose to the medical community, one that appears to be never-ending.

As the editor of a volunteer army of writers it has not always been easy to find recruits over the years, especially those who are willing to muster up month after month. So I am especially happy to have three talented writers, all with different perspectives, on the WotW team. WC Baker provides us with great escapist travel tales, all true from his adventures over the years (being a laryngectomy didn’t stop him one bit). Don Renfro is so thoughtful, by that I mean honest and insightful,

about our human condition and Doc Holmberg shares his amazing life journey (and in the future some of his more fanciful tales he wrote for his grandchildren after he lost his “second” voice). Plus we have included a bit of levity from a 2016 Speaking Out column about “Funny Lary Experiences”.

It’s a pretty darn good line-up and a true oasis, IMHO. Please let me know if you agree.... Or disagree, that’s okay, too...just let me know what you think!

Stay safe and stay connected,

Donna McGary





Does It Ever End?

It seems like a zillion years ago now, but I remember that prior to my first post-laryngectomy procedure, I could not yet communicate on the phone very well at all. I understood me but they didn't. The laryngectomy had only been 2 or 3 weeks earlier. Though I had a primary puncture with a voice prosthesis placed a week later, the voice was faint at best, so I could not be understood on the phone. The valve was too big to begin with, my "party wall" and the rest of me for that matter, was too messed up from the reconstruction with radiation damaged tissue. Surgery had been so recent that I coached my wife in limp language exactly what I wanted her to say and to ask of the nurse on the phone, similar to our dress rehearsal for communicating with the health insurance carrier. (Julie is too nice, unlike her retired Navy Chief husband who doesn't mind being a total ass when he perceives it as necessary and is fully capable of enjoying that immensely.)

We wanted to be sure the staff in the operating room would know -you guessed it- how to handle a laryngectomee and get assurance that they knew to put the mask on the stoma, not the nose and mouth. We all know the drill. Of course, we were assured everything would be hunky-dory. The rest of the story is all too familiar for many of us. The anesthesiologist came and talked to us once I was stripped, gowned, and on four wheels with strong liquor in the IV, I believe. He wanted to assure us that they did know what to do and he was totally convincing. I guess he had to go play golf or something. In the operating room, a very senior, white-haired anesthetist nurse began to place the mask over my nose and mouth.

The Jack & Coke was really kicking in by then and my voice was extremely faint anyway. I groaned, grunted, and voiced the best I could with a thumb to the stoma, until I got the attention of the physician, who explained to the nurse that he would need to get an infant mask and administer oxygen at the stoma. The nurse did as he was told but was shocked at the instructions saying something like "in nearly forty years at this I have never heard of that!" on his way out the door. He was so horrifically embarrassed that I felt sorry for him. Later, I wondered how experienced clinicians go through so many years of exceptional job performance and yet do not know how to work with us. That needs to change.

With my next two procedures, one at my gastroenterologist's office, and another at the V.A., the story is almost exactly the same. With the first one, an experienced, wonderfully kind and brilliant nurse came to my side. I asked in detail if she knew what we needed to do. She didn't. She said she would check with someone on that and come back to me, which she did. With the V.A. event, two nurses sat with me and told me without being asked that they had done this before and knew what to do. "This ain't our first rodeo" one of them said. I felt special.

Again, in the O.R., here comes the one who said that with an adult mask to my nose and mouth. Again with thumb to stoma, almost in lah-lah land, I managed to point at the stoma and get out "that goes here". She looked at me as if I had just turned into a real live unicorn before her very eyes. This time, the two surgeons from Emory, turned around, grinned at me and said "he's right", then told her

what was needed. After making such a point of telling me she knew what to do, she did not know either. The next day, now sober, I could only think of her, how embarrassed she must have felt, and how her employer had failed her.

Fast forward about seven years to this past February. I could tell one of my bronchial infections was trying to cramp my style so I made an appointment at the neighborhood medical center I use for such simple things. I was a little ahead of the game, but the Z-pack moved slower than the infection and I had to follow it with something else. That was actually in very early March. (hmmm?) As I approached the counter that afternoon, the receptionist handed me a mask saying they were asking all to wear one in the building. "There is so much stuff going around", she added.

I politely suggested she give me two masks so I could cover my mouth and nose with one and my stoma with the other. I wasn't in bad shape but I certainly wanted to avoid picking up someone else's cooties, too. She abruptly replied that she could only give me one mask. I said "that's okay, but I breathe through here", pointing at my stoma. The look on her face indicated that she also was looking at a unicorn (me!).

Just last week, I had to be COVID tested three days before having my voice prosthesis replaced. After two days short of a year, my Blom-Singer Dual Valve was like a 45 year old NFL quarterback. It was time to throw in the towel. I casually attempted to confirm with my absolutely fabulous SLP, Christina Huffman-Shipp of the Atlanta VAMC, that the testers would know to test me in the nose and also in the stoma. She told me who would be ordering the test and thought the doctor would ask for both. I agreed because this doctor had confirmed for us online (via me) both on the list and Facebook, that we should be tested at both places.

There was a three hour window for the test from our vehicles and I didn't want to sit in a traffic line for that long so I got there early and was the second victim in line. In a most friendly tone, I mentioned to the first tester, who was doing the interview, that I would need to be tested at both the nose and the stoma and that the test should have been set up that

way. "I don't know what you're talking about" she said, "we just do the nose." I don't think she hallucinated anything; I am not even sure she saw me. I doubt if she gave a rodent's derriere about much of anything. "You'll have to ask her" she said, referring to the tester at the next stop, the one actually doing the test. The tester was ever so pleasant. She smiled and presented as a reasonable clinician with a brilliant mind. "She said to tell you I am supposed to be tested in the nose and from my stoma", I said. At least this person did not see any unicorns. She saw a hundred flying monkeys from "The Wizard of Oz", each laughing hideously.

When I shared about this last happening on the WebWhispers list and on our Facebook group, I received an almost immediate reply from Elizabeth Finchem, which began with "Tom, does it ever end?"

To be continued in the August issue of Whispers On the Web.

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





Voice Points

Written by Professionals

Coordinated by Kim Almand M.S., CCC-SLP

kbalmand@gmail.com

A Virtual Reunion

Even though we were not able to meet up in person this year for our annual WebWhispers banquet at the International Association of Laryngectomees (IAL), we still have opportunities to be in touch with each other online through Facebook, the WebWhispers email list and chat group. On Saturday, June 13 and Sunday, June 14, 2020 WebWhispers members had another opportunity to “gather” together as the IAL met virtually for a special one-day event hosted and moderated by Atos Medical. While not quite the same as an in-person hug or shared meal, this was yet one more opportunity for us to simultaneously take part in coming together to share information and support. Almost half of the participants were first-time attendees of the IAL and many of our own WebWhispers members contributed during the weekend to make the online meeting a success.

Jennifer Karkenny from the IAL Board of Directors kicked off the meeting with opening remarks. The first talk of the day was by Shrenik Shah, laryngectomee and motivational speaker, and subject of the newly-released book, “ShahenShah: Story of Shrenik Shah, the Cancer Conqueror.” In his talk entitled, “There Is A Beautiful Life Even After Cancer”, he discussed how cancer taught him how to live and love, and he emphasized his Elixir Life After Cancer, based on the 4 pillars of acceptance, courage, confidence and troubleshooting, along with generosity and mindfulness which is living without fear. Our virtual meeting platform enabled Mr. Shah to join in to the meeting all the way from his home in India.

Next, speech-language pathologist and board-certified swallowing specialist Erin Guidera discussed how our bodies are all quite sensitive to changes in weather, climate, and environment. She discussed tips for caring for the respiratory system, stoma, ears, and nose, and tackled the ever-present issue of mucus in her talk entitled “The Unique Effects of the Aerodigestive Tract and the Effects of Weather on Stoma Health.”

Dr. Greg Carter, a psychiatrist and laryngectomee, provided his own unique perspective of what it is like to live as a laryngectomee, giving voice to some of the topics discussed each day here at WebWhispers including nutrition, oral/dental health, jaw/ear/neck pain; chemotherapy and

radiation, and swallowing. He encouraged laryngectomees to keep engaged in their lives by finding new ways to adapt to the physical and emotional changes by asking for assistance when necessary, engaging in daily exercise and time outdoors, conserving energy, and being aware of fall risks. Telling family and friends, “Don’t ask me questions when I am eating!” or “Don’t ask me a question in a loud room!” may go a long way to help avoid putting yourself in a “vocal frustration” situation.

In “Laryngectomy Assessment and Management During COVID: How I Do It,” speech-language pathologist Erika Taylor from Columbia, SC shared how her practice has changed from pre- to post-Covid-19. In her detailed outline of the inner workings of inpatient and outpatient speech pathology services, from aerosol generating procedures to personal protective equipment, she reminds that even though the logistics of her practice, like many, have necessarily changed, her ability to provide compassionate care while maintaining a high standard for patient education and training remain.

Linda Stachowiak, speech-language pathologist and long-time IAL faculty member and presenter shared travel tips and disaster preparedness. She reminded laryngectomees that to be prepared for a pandemic may mean holding off on changing a leaking voice prosthesis. To that end, it is always helpful to be prepared to manage a leaking prosthesis with items such as a plug or catheter, thickened liquids, and/or the use of swallowing strategies. A stoma should always be covered and if you are being tested for Covid-19 as a laryngectomee, it is recommended to test in two sites: the nose and the stoma. Linda shared “tricks of the trade” for keeping thin secretions, including tracheal lavage along with a recipe for homemade saline. She also referenced her previous VoicePoints article from December 2018, “Travel Tips for Larys.” <http://www.webwhispers.org/news/dec2018.asp>

Dr. Itzhak Brook, a pediatrician and laryngectomee, has also published a new book entitled, “Laryngectomee Guide for COVID-19 Pandemic,” available as an eBook (free), Kindle Edition, or in paperback through Amazon.com. During his interview and live discussion, he discussed this book as well as many of his other publications which highlight his experience

with his own personal journey as a head and neck cancer survivor. He encouraged laryngectomees and caregivers to explore the many resources out there as they learn to talk, eat and breathe in a new way following surgery.

Saturday wrapped up with a question and answer panel comprised of IAL Board members Dave Ammenti, CindyLee Gordish, SLP and David Kinkead, along with Tarah Huberty and physicians Drs. Matthew Bak and Johnathan Mark. Participants submitted questions on issues related to swallowing; mucus production; nutrition; voice restoration strategies including esophageal voice, COVID-19 concerns, and more. CindyLee discussed the IAL's vision and future plans for the laryngectomee community, which includes exploring different avenues to serve the community. Recognizing that effective change cannot take place overnight, she noted that as service delivery models evolve and the makeup of our community changes, modifications to the traditional platform, such as Saturday's virtual meeting, may be useful to deliver education and support to the international laryngectomy community. She noted that the IAL will remain dedicated to original mission of the organization, including assisting and coordinating educational/support conferences, teaching and supporting all methods of post-laryngectomy voice restoration, and serving internationally.

On Sunday, we were treated to a special screening of the inspiring and brilliant film "Can You Hear My Voice," produced and directed by Bill Brummel, who spoke with WebWhispers about the production in March 2020. He noted on Sunday that this virtual web meeting was not the premier he had envisioned for this film, as it was intended to be shown with surround sound to bring to the audience "giant characters on a big screen." Bill also emphasized that thanks to Atos Medical, distribution of the film is free of charge to laryngectomees around the world and that when it is safe to do so, he encourages everyone to view the film again in a communal setting with other laryngectomees, friends and caregivers.

Over the course of Saturday's meeting, the issue of telepractice was mentioned several times. What does this mean for our laryngectomee community? Medical appointments and therapy services via telepractice will surely depend on individual considerations such as one's place of residence and type of medical insurance, as well as local hospital or outpatient clinic regulations and provisions. However, the general consensus is that telepractice is a viable and useful component to service delivery for the head and neck cancer population. A few summary points to consider:

What is telepractice? Interchangeable with the term "telehealth," the American Speech-Language Hearing Association (ASHA) defines telepractice as: the application of telecommunications technology to the delivery of speech-

language pathology and audiology professional services at a distance by linking clinician to client or clinician to clinician for assessment, intervention, and/or consultation." ("Telepractice." American Speech-Language Hearing Association, 2020, <https://www.asha.org/practice-portal/professional-issues/telepractice/>)

How might I use telepractice in my clinic? Some head and neck cancer patients may be too medically fragile and/or may be concerned about going out in public. For those undergoing chemotherapy and/or radiation, staying at home may be the best option if possible. In many situations, telepractice may ensure continuity of care for head and neck cancer patients when they are not able to come in to the hospital or clinic, because of concerns over exposure and/or limited/reduced availability of clinicians, speech pathologists and/or physicians to provide in-person services.

Some issues that may lend themselves well to telepractice include education and teaching/monitoring of swallowing strategies; pre-op counseling and discussion of voice restoration options (can even include use of audio-visual demonstrations); and education regarding pulmonary rehabilitation and caring for the stoma. Telepractice may be a useful tool to support patients when troubleshooting their voice prosthesis, e.g., cleaning/maintenance, use of a plug or catheter if leaking is occurring and the patient cannot get in to the clinic in a timely manner. While telehealth may not be ideal for beginning training with an artificial larynx device or achieving first sounds with a tracheoesophageal prosthesis, and not appropriate for changing a voice prosthesis or managing stomal stenosis, with a good audio-visual setup, telehealth may be quite viable for issues such as esophageal speech training, artificial larynx device use, and follow up visits for practicing tracheoesophageal voice. For the foreseeable future, telepractice is here to stay! And ASHA has some helpful resources for clinicians getting started and for patients wanting to know more: <https://www.asha.org/About/Telepractice-Resources-During-COVID-19/>

Have you had success with telepractice? We would love to hear about your experience. And do not forget: our Facebook page and email list are always a way to reach out for information, friendship and encouragement. Have questions and not sure where to look? Need to find a provider in your area? Want to share your thoughts or questions about telehealth? Please visit our homepage or contact: kbmand@gmail.com.

And finally, Save the Date.... June 9-12, 2021 when the IAL aims to reconvene in person in Charlotte, NC for the Voice Institute and Annual Meeting. With a whole year to plan, we may have to reserve two rooms to accommodate all those who will want to attend our WebWhispers banquet!



Quite a Challenge

By Don Renfro

Spread love everywhere you go.

~Mother Teresa

What a fitting quote for the times we are going through now. As I was cleaning my kitchen I used the time to just think about all we are going through today. One of the things I pondered was that there is no one issue or belief that commands a universal agreement or consensus among everyone. For every issue there is an opposing view. I understand there is a school of thought or belief that debates the practically universally accepted fact that the world is not flat.

So I must believe that somewhere out there someone would argue the opposite position of what Mother Teresa was saying. I am very happy to say that I am not one of those that dispute her words shared in this quote.

John Lennon wrote a song "Imagine" that suggested we all imagine living in a world like the one described by Mother Teresa, where the people "Spread love everywhere we go".

Spreading love everywhere I go sounds like a task that is too enormous to even begin to tackle.

I bought a webcam for my computer so I could participate in Zoom meetings. Everybody in the meeting could see me fine but no one could hear me. After hours of working to identify the problem I found the problem was the microphone in my web cam did not work. I went back to the Walmart website where I made the purchase and found I could return the item for a refund in the store. On the web site I was directed to print a store receipt and bring the item with the store receipt to any Walmart for my refund, by June 16. I went to my normal Walmart where I usually shop and was told the printer was down and they could not do my refund because they were unable to print a label to return the product. I was told the printer had been down for six months and they did not know when it would be fixed. Frustrated, I left the store without returning my defective product.

A week or so later, I visited another Walmart to return the item and was told that their printer had been down for six

months and they were unable to print a label and therefore they could not process my return. They suggested I go to another Walmart for my return. I asked to speak to a manager and was told I was speaking to the manager. I asked for her manager and eventually someone came wearing an associate vest, to address my problem. I was eventually told that even if their printer did work that the store would not process a refund as the item was purchased on Walmart.com from a third party, and therefore I would have to seek my refund from the third party and not from Walmart.

That would have been fine with me had I not been told on the website I could get my refund from the store and had I not been told by the first store I contacted that another store could process my refund. Now to be honest by this time my frustration had grown to anger. It is easy to spread love when I am happy but after being lied to and wasting my time and my energy visiting two different stores believing a solution to my problem was in front of me, when it was not, now this is a true test for spreading love.

The reality is though that this is the time when I need to work the hardest to spread the love. I could actually see the final associate I had spoken with in reality empathized with my situation. But due to my anger I was unable to extend this man any gratitude or thanks.

In hindsight I can now see how setting my anger aside and extending this man gratitude or thanks would have been to my best interests. As it was, I left the store feeling angry and bad inside. I went home and disputed the charge to my credit card company and the money was returned to me immediately. I had ended up feeling bad for nothing. My anger did not change any part of the outcome in the store and resulted in me just feeling bad. I will never know if spreading love would have had a more beneficial effect on my outcome in the store. Maybe not but I am sure I would have left the store feeling a lot better. Something I can work towards in the future.



This Lary Life

Portugese Interlude

W. C. Baker

Having left Patricia to find a new home in Essaouira, I flew to Lisbon. Deprived of the opportunity to cross the Straight of Gibraltar, I hoped to at least see it from the air. Perhaps if I had flown to Madrid or Barcelona, I could have, but the flight path to Lisbon was too far west to see it. Ah well, next time.

The Alfama, with its maze of cobbled streets and steep climbs, for was centuries the poor part of Lisbon, but has since become gentrified. Feelings of Falda fill the senses. The pension in which I stayed is on the 6th floor of a building, the first five floors of which are of unknown purpose. The 63 steps to the pension pass unmarked doors to seemingly unoccupied spaces. I climbed those 63 stairs at least once a day during my time in Lisbon, and sometimes two or three times a day, depending on how far afield I might go. But climbing is often obligatory in old cities at the coast.

On this day that started in Marrakesh, after checking into the pension, I headed out and found a pedestrian elevator that saved climbing to a level where I found another elevator to go to yet a higher level. In spite of being saved the climbs, I was quite hot, and was happy to find a vendor of cold water in a jacaranda lined park. I thirstily took a huge gulp of this cold water and promptly got enough of it into my trachea to trigger a coughing spell that alarmed me almost as much as it alarmed others in the park. I'm sure no one knew quite what to do, so they did just the right thing. They asked if I needed help. When I indicated that I did not, they looked on with concern and left me alone. Having been an esophageal speaker for 26 years I had to learn what all TEP users learn; that one has to use some care when swallowing liquids.

Another, higher hilltop on which the Castle of St. George stands was first used as a defensive outpost by indigenous Celtic tribes BCE, then by Phoenicians followed by Greeks and later Carthaginians. The Romans expropriated the space followed by the Suebi, the Visigoths and the Moors. The walls that are visible from almost everywhere in old Lisbon were built by the Muslim Berber forces over a thousand years ago. Pedestrian elevators were not available. It is a worthy climb up, forever up, the winding cobblestone streets. It was another Hot day and after climbing 6 of the 10 towers, each with a different perspective, I was ready for some shade and refreshment. I again took a huge gulp of cold water, and again

leaked a bit into my trachea, and again triggered a coughing spell that alarmed the many tourists within earshot. I had made it through Morocco without incident and, now twice in as many days became the involuntary center of attention. They had to be wondering, Was I contagious? Was I going to die ungracefully in front of their children? It seemed that everything stopped until I completed my performance, then started again as if nothing happened.

Around the corner from my pension is the Sé Cathedral, Lisbon's oldest and most important church: Built on the site of the Moor's main Mosque, which was built on the ruins of a Roman temple. A beggar greeted me on the steps and elicited uncomfortable feelings when I entered the spacious vaulted nave and wandered the ornate apses filled with gold and velvet and marble. The display of wealth in the inside intensified the poverty present outside. Of course the differential today is nothing like the inequality, even oppression that prevailed when the Sé was built, but I still found it disturbing.

I had the same feeling when I visited the National Palace in Mafra. Started in 1717, the palace was an answer to a lot of prayers. King John V promised Franciscan friars that he would build them a friary if his queen gave him a child. When she gave birth to a daughter, the happy king started construction of the friary, a basilica, a library and 665 rooms. All that wealth when there was so much poverty in Portugal, and in Brazil, the source of the wealth. But the building of the palace did provide employment for 45,000 workers over 13 years. I love baroque when it comes to music, all that wonderful complexity woven into a tapestry of sound that lets me know I have a soul. But I find that baroque art and architecture are often overwrought. The best thing about the palace was Christa, a pretty young woman with cerebral palsy who took tickets and explained, in English, the layout.

Into each trip some rain must fall and Porto was the place. With a temporary increase in intensity to deluge conditions, I ducked into a deli for a panini. A sign on the wall read, "Life isn't about waiting for the storm to pass, it's about learning to dance in the rain". A lot of people were waiting for the storm to pass, no one was dancing. The storm did pass and I got on with the business of exploring this city with its Port wineries. Little sail boats line the Dura river,

waiting for their loads of barrels. Porto is also notable for its blue tiled paintings gracing the outside of churches and the inside of public buildings.

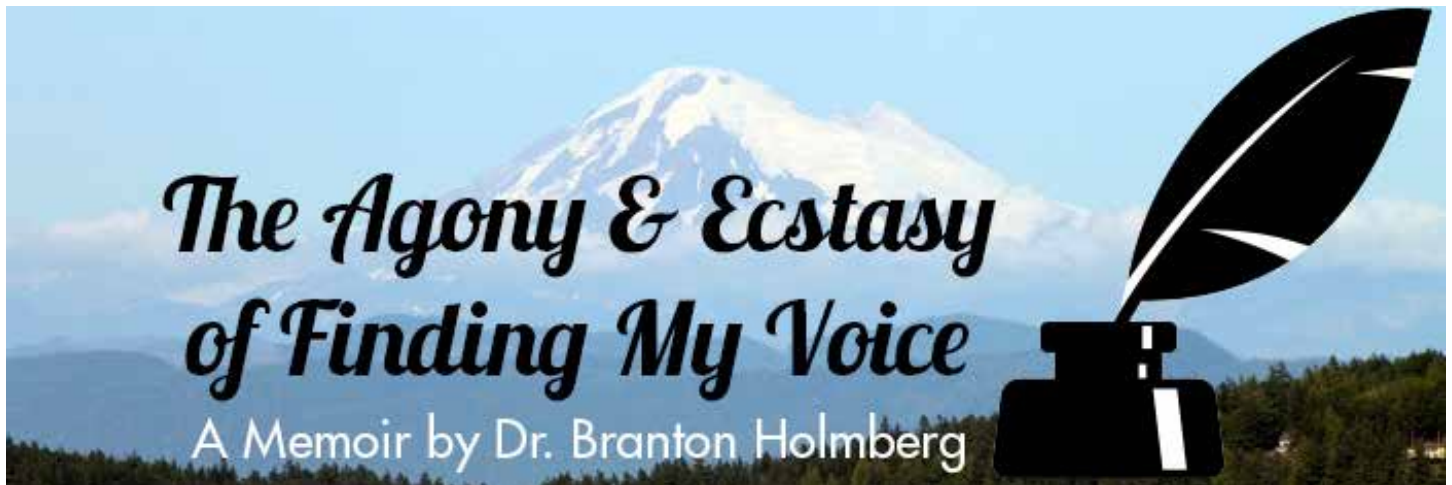
When I had been at Mafre a couple of days before, It didn't occur to me that Christa might be interested in communicating with some people in the U.S., so when I

got back to Lisbon, I made another trip to Mafre to get her email address which I gave to some former students with cerebral palsy. They still communicate with her.

The trip to Mafre for Christa's address was short enough to get me back to Lisbon in time to spend four more hours at the Calouste Gulbenkian Museum. With over 10,000 works of art ranging from ancient Egypt, Greece and Persia to twentieth century European, CBM is regarded by many, including me, as the best art museum in Portugal.

I was able to make a quick trip to the ostentatious Disney-esque Pena Palace at Sintra. Recently named one of Portugal's "Seven Wonders", Pena Palace was ordered by King Ferdinand II in 1838 on the lofty ruins of an old monastery. The palace rolls together many historical styles from Moorish to Renaissance. It was while visiting Pena that I got word from Patricia that she had completed her moving to a new place outside Essaouira and was driving up to Spain. I got a bus the next day to Sevilla to meet at the world's largest cathedral. Other than my coughing attacks I had no other problems in Portugal.





Chapter 10 “No Voice”

In the spring of 2010 my voice noticeably deepened and there was a rapid rise in my thyroglobulin level which is one of the blood indicators used to detect the presence of thyroid cancer. My otolaryngologist, after a thorough examination including scans of the remaining lobe of my thyroid, scheduled me for surgery to remove what was left of my thyroid gland. The cancer had come back. So much for the 5 year rule.

When I woke up from surgery, the surgeon came in to tell me they'd found cancer cells on my larynx and trachea and he wanted to put me through another surgery the next day to take out my larynx and part of my trachea.

Holy cow, I was going to lose the voice I'd so lovingly found all those years ago. After his explanation of the necessity to get it out as soon as possible to prevent the further spread of the cancer, there was no question I wanted to go ahead with it.

The next day I was on the operating table again and when I woke up from surgery this time I was speechless, I mean really speechless. Margaret, my children and grandchildren had gathered around me as I went through this terrible ordeal and were the first to see me with no voice.

The few days of recovery in the hospital went fine with me writing to communicate, and learning to care for the huge stoma, the hole I now had in my neck which made me a neck breather. This is what anyone with a laryngectomy is called.

My stoma is unusual given the fact the surgeon had to remove 4 inches of my trachea which also

showed signs of cancer, and create the recessed hole in my neck with what was left. The result is that instead of my stoma appearing on the surface of the neck area, where stomas appear on the majority of laryngectomees, mine is located two inches behind my sternum resulting in an ominous recess in my neck with the stoma about the size of a quarter at the bottom of that recess. The inside of my trachea is visible when I look at my stoma in the mirror.

The result of that condition has limited me to the use of what's called an electro-larynx, or artificial larynx (AL) which is a battery operated device one holds against what's called a “sweet spot” on the neck where the vibrating disk of the AL turns your utterances into recognizable words, albeit they sound very robotic.

As might be guessed, the ability to effectively use an AL takes a good deal of practice with many frustrating disappointments along the way. There are still many consonants I have difficulty with even now after years of using it. That always triggers responses from those I'm talking to like, “What did you say?”, or, “I didn't catch that”.

When that happens it takes me back to my childhood where trying to be understood was a constant part of my life and each time it happened I felt like a freak of nature, especially when my peers mimicked me by over dramatizing my speech and mocking me with what they thought were clever renditions of it.

Now whenever I'm out in the public and use my AL to talk to my wife, or others, it immediately turns heads. I'm delighted at the looks on the faces of small children as they hear the robot like voice coming out

of me. I enjoy talking with them and telling them my grandchildren think I sound like a robot.

I'm thankful this second problem with my ability to communicate clearly, came at the end of my working career. I could deal with trying to learn to speak again without the pressure of having to try to earn my living with the use of my voice.

I did however begin living with the constant frustration I could no longer verbally communicate with my grandchildren and great grandchildren, and everyone else for that matter, as I could with the voice I'd so lovingly found when I was 26.

Although my children's offspring, and their offspring, most pre-teens and younger, find my robotic voice amusing, any kind of involved communications with them results in many stops and starts. I understand this but it has been a great frustration to me.

That's when the second magic carpet appeared. Writing has been as wonderful to me as getting fitted with my dental appliance, maybe more so.

I felt the communication separation between me and others far more than anyone was aware of and was very bothered by it. I'd done a great deal of writing in my professional career although very little of it was ever published. The things I wrote were developed to help me, and those I worked with in the teaching and consulting activities that were my daily life. I thought to myself why not write adventure stories that would take me and the characters I could create, into imaginary worlds where we faced dangers and intrigue together. This gave birth to the Sam 'n Me series of fictional adventures, and set me free once again from the impediments of speech, at least in the stories I write.

The decision to start writing was just as profound to me as finding my voice when I was a graduate teaching assistant. The thing I became aware of was how much I'd loved reading, going to see western movie serials they showed at the Saturday matinees in the local movie theater, and listening to the radio shows when I was a kid. Images from those early years were still with me and I found them pouring

out of my imagination as I began to write.

My first writing efforts are captured in the Sam 'n Me series which I call short read adventure stories meant to activate your imagination somewhat like going to a Saturday matinee movie which was my favorite thing to do as a kid. As I've said, once I started writing, the fantasy images of my youth seemed to pour out of me like water out of a faucet.

I decided to self-publish my stories to get a copyright protection of them more than with the intent of finding a market for them. Each story runs from 65 to just over 100 pages depending on the adventure. They're printed on 6" by 9" inch pages. It should take about the amount of time I spent watching a Saturday matinee movie to read one. At least that was my hope as I created them. There are 47 stories in that series.

In my second series of books, ones I call the Archeos adventures, I continued the short read format for my books but chose to drop the cowboy lingo style of story-telling and also lower the age range of my main characters. This series follows 3 cousins Sam, Yoder and Mike in their junior year of high school as they use the archeological skills their grandfather, a professor of archeology, has taught them from the time they were toddlers.

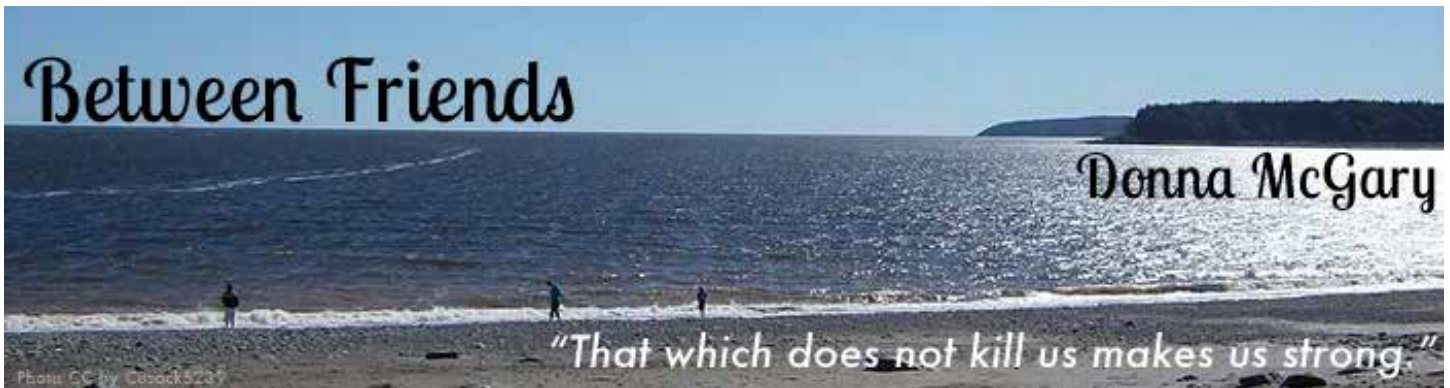
From the second series I transitioned into full length books in "The Quantum Gateway", a novel about a reclusive physicist, and his 3 closest friends who find themselves able to transform themselves first into imaginary beings they'd always dreamed about. As the adventure progresses they must find even more complex beings to transform into to protect themselves from the dark powers of the "God of the Dead".

Then there's the memoir you're presently reading.

I'll give you excerpts of some of my work at the end of this memoir.



–The following two columns originally appeared in our August 2016 issue–



Yuk It Up

It has been my experience that you simply cannot successfully navigate through life without a well-developed funny bone. Folks who can “take a joke” can also “take it on the chin” without going “down for the count” – how’s that for a mouthful of metaphors! Seriously, though, there is a lot of truth packed into that punch. [groan- I promise to stop now - maybe]

I bet you all have heard about Norman Cousins and his unorthodox approach to dealing with chronic illness and pain. “Told that he had little chance of surviving, Cousins developed his own recovery program. His positive attitude was not new to him, however. He had always been an optimist, known for his kindness to others, and his robust love of life itself. ‘I made the joyous discovery that ten minutes of genuine belly laughter had an anesthetic effect and would give me at least two hours of pain-free sleep,’ he reported. ‘When the pain-killing effect of the laughter wore off, [Ellen and I] would switch on the motion picture projector again and not infrequently, it would lead to another pain-free interval.’ [Google him for this citation and more information on his life and writings.]

This month’s Speaking Out question asks about

humorous experiences related to being a lary and we had some wonderful responses. Some are sort of sad/scary funny and others are perfect examples of a well-developed humerus bone/nerve or maybe an oft-banged one. And if you don’t get enough funny stuff this month just go to our website and under Library, click on How We Live and there is a section called Laryngectomee Humor with 144 separate entries submitted by our members over the years and guaranteed to make you laugh.

<http://www.webwhispers.org>

Laughter is the great leveler. Humor is no respecter of persons. It is not mean-spirited or bitter. It is a joyous recognition that even with all our faults and foibles we are in this together and human beings are a pretty silly bunch, once you come right down to it.

True humor, the kind that rejuvenates our spirits and expands our perspectives, may be a uniquely human quality. The jury is still out on that but, for now, it is surely one of our best qualities and one we should vigorously cultivate. So don’t just “Suck it Up” – “Yuk it Up”!



“Have you ever had an unusual or funny experience directly related to being a laryngectomee?”

Len Hynds – Newtown, UK

Many funny stories come to mind whilst in the hands of the medical experts.

Whilst awaiting open heart surgery, the Nursing sister was explaining what was to happen, and that two teams would be working on me at the same time. One replacing the Aortic Heart valve with a metallic one, and one on the leg, extracting a suitable long vein to use as a bypass, who would then pass it to the heart surgeon in the second part of the operation. I asked her what would happen if the leg team couldn't find a suitable vein, and she said, "Not to worry, by that time your chest will be opened up with the ribs peeled back, and they will take the memory vein."

After the operation and recovery, and back in my ward, she came to me, and I said, "They had the vein from the leg then, I remember this ward and you," She replied, "You fool Len, it's my Irish accent. I said Mammary Vein."

Another Quickie. On a Pacemaker replacement, lying awake to control my own breathing, and chatting to the two doctors and team, when it was over and sitting on the edge of the operating table waiting for my bed to be wheeled back in, I said to them all busily cleaning up, "Can I have your attention for a moment." All looking up in surprise, I continued. "You have all done a good job. I'm very pleased with it. Have any of you ever thought about doing this for a living." After a stunned silence they all burst out laughing.

Mischievous!

**Jim Fohey – Oscoda, MI
Class of 94 & 2016**

About a year after becoming a lary I went to Ireland to see where my family came from. While traveling I needed gas and at that time they pumped your gas. When I pulled up no one came out so in I went and there was a young woman behind

the counter looking at something. I asked her, using my EL, if I could get gas. Such a scream she let out, turned and looked at me so I told her I come in peace, she said in her wonderful Irish brogue that I had scared to hell out of her. We shared a laugh; they pumped my gas and off I was with a smile on my face.

**Rita in NJ
November 2000**

I have two really interesting and funny stories. Years ago my husband gave me a new laptop computer for Christmas. I was having problems with it...I don't remember exactly what the problem was but I called the help line. At the time, I believe the calls for assistance were taken overseas. Between the accent and my speaking with an EL, you can imagine the problem I was having. The man on the other end of the line just refused to answer my question. He had his list of questions to ask, none of which pertained to the problem I was having. I continue to tell him that he wasn't answering my question. After a very frustrating hour, my husband came home and into the room. I handed him the phone, to see if he could get an answer. The first thing the man on the line said to my husband was, "I've been speaking to a computer." I don't think we ever got an answer to the problem I was having with the laptop, they replaced it.

A few years ago I bought some small bells to put on Christmas packages as decorations. I put them down on the counter for the cashier. She was looking down at them as I said something to her. She said that she didn't realize that they spoke, too!

You definitely have to have a good sense of humor. It is easier to laugh than get upset!

Malcolm Graham - Lancashire, England
Nov- 2014

I had my surgery in November 2014. In November 2015 I had to have a shoulder replacement, partly due to wear and tear and partly to having had lymph nodes taken from my neck.

I attended pre-op with details of medication I was taking, I saw the anaesthetist who was quite intrigued with the laryngectomy not having had contact with a laryngectomee before. I had been told by a member of our group to make sure I asked the doctor and nurses where did they think I breathed from, "the nose and mouth of course", wrong I told them, through the neck to which they replied, "how often".

It is amazing how little medical staff, not involved with ENT know about neck breathers, but, we are trying to educate them, especially in our area, and hope that future laryngectomees benefit from our experiences.

Ian Coates - Bury, UK

I belong to a church in Bury UK. We have a lot of lovely old ladies at the church who know I have been through a rough time with my laryngectomy over the last three years. Some of them still keep coming to me and miming words to me. I do not have the heart to say there is nothing wrong with my hearing but my wife does sometimes and they get very embarrassed.

Martin Mc Dermott – Pearl River, NY
Jan 2015

Hi all. This isn't what you call a funny, funny experience but I laugh at this all the time. I have a small fistula and can't use my TEP yet, so a lot of people when they see I can't talk, think I can't hear as well. I usually reassure them I can hear perfectly fine!!! Also I find funny is that I live in Pearl River, NY and I'm in NYC all the time, but since my surgery I have not met or seen another lary. Are we that few?

David Rankine – Vernon, CT

I've had a few funny moments and some uplifting observations:

At first I used an electro larynx with pitch control, for which I was fortunate enough to have a perfect sweet spot and could enunciate clearly and easily a day or two after surgery with the mouth accessory, and then on my neck as soon as my neck was healed enough for contact.

Since my surgery, I've never been shy about being out and about in public, and I'd always catch children staring in wonderment. With a smile and a nod from a parent, I'd always engage them and explain what was going on. Sometimes I'd buzz them on the arm for a giggle, or let them try it out themselves. They especially

liked the old underarm pumping fart noise. Parents are always very grateful to have learned that we're just normal folks, and for teaching the kids not to be spooked and making them laugh.

Sometimes I'd surprise people by singing. Or hiding the device behind my back in an elevator and giving it a honk, then looking at the guy next to me.

There was an episode when engaging in some poolside horseplay with my nephew, I lost my balance and fell in. Luckily, there were enough quick-thinking young guys close by and they had me up and out in no time. A little sputtering and I was fine. My brother-in-law, before it sunk in, said to my panicking wife, "What's the big deal? Dave knows how to swim".

Since I got my TEP three years ago, I still talk to people I meet in shops and other venues and find that being upbeat and comfortable keeps life cheerful and others always seem to react really positively. Many share stories of friends or relatives who have had laryngeal or throat procedures of various degrees. All you need to do is make them feel comfortable and they light up. I always get a laugh when I say "You're gonna like the way you look, I guarantee it."

Occasionally I get a call from the doc or the nurses at UCONN when there's a new laryngectomy patient, to visit and try to help them see that the future isn't necessarily as grim as they might fear and anticipate. A few shenanigans and some genuine reassurance and questions & answers about aftercare, etc. sure works wonders, especially with the worried family members. My wife (truly the wind beneath my wings – corny as the saying is) being with me is also a comforting presence and helps to validate the positive. Nothing beats the feeling that you've helped to ease some fear and anxiety.

For me, the only significant losses are inability to play the bagpipes and swimming. Both activities I loved. There are however alternatives and solutions to both.

I keep thinking I'd like a job as a spokesman for one of the medical supply companies that specialize in laryngectomy products. That would be fun.

Best of luck to all, and endless gratitude for WebWhispers!

Margo Ziegler - Minnetonka, MN
Trach 1996

I am not a "lary", but do have a permanent trach and about 6 months after getting my trach, I had biked to the bicycle shop and wore my bike helmet in there to pick something up. I do bend my chin down over my trach in order to talk, as I can still talk, and I seem to make a "whistle" noise every time I speak. Well, the sales person and myself were exchanging conversation and finally she spoke up and said "This is the weirdest thing, but every time you speak, your bike helmet WHISTLES!!!"

I really thought it was funny to hear this from her and said that

I had a trach and I bend my chin down to speak and it sort of makes a whistle sound and that it was not my bike helmet making that whistle sound! Her smile left her face and she got terribly serious and apologized about her comment. This was a good time to explain to her what a trach was and how I breathe and talk now and that I did find her comment quite funny! But, she felt very bad and I assured her it was fine.

That was about 19 yrs. ago now and I think about it now and then and still get a chuckle from her comment. She had looked at the top of my bike helmet even to see what was up there that would whistle when I talk. I'm chuckling right now thinking about it.

Kirk Swan – Sherwood Park, AB

My humorous story is while lying in a hospital bed a couple days after surgery I woke up and unable to breath so I pressed the Nurses call button and she came over the Intercom and said "Yes can I help you". Here my poor Larynx was probably in a petry dish somewhere getting dissected. My wife and I still chuckle at that one.

**Linda Shingler – Myrtle Creek, OR
Laryngectomy in 1996**

I was living in Hayward, CA, using an EL on a phone call. He asked, "Are you a machine?" I now live near Roseburg, OR. and I went for an out-patient procedure requiring anaesthesia. When I explained to the nurse that I am a neck breather, she said, "You mean this oxygen cannula won't work in your nose, right?"

**David Hughes – Sun Lakes, AZ
May, 2010**

Not long after my surgery, I experienced difficulty breathing and my wife called 911 to which the local Fire Station responded and took me to a local hospital emergency facility. Convincing the EMS tech that the oxygen mask he was holding over my nose was probably not going to help he quickly moved it into place on my stoma. However, despite that little event there was more to come. The problem seemed to lessen initially but on the 2nd day in the hospital it returned and it became obvious that there was something in my stoma which was moving up

and down with my breathing (mucus plug) although this was not something the med staff were familiar with. After several unsuccessful requests by my wife to get a pair of tweezers, she ended up grabbing the plug with her fingers before I finally choked. The gathered group of med staff seemed quite amazed by this but the final "jaw dropper" was a resident's comment came as he tried to comfort and assure me. "Don't be concerned about the opening in your throat, it will close naturally over time"!!!!

Brenda Jackson - Riverside, Ca.

My Speech Pathologist told me to practice taking deep breaths through my nose. "That's when I decided to learn "ES" on my own..

Noirin Sheahan – Dublin, Ireland

Recently a group of strangers were teasing me about my bad parking - all quite good humoured. When I replied using my electrolarynx most of them looked embarrassed and turned away. I'd say they were embarrassed to find they had been teasing a 'handicapped' person. But one man was really open and asked me what the electrolarynx was and why I was using it. When I told him about cancer and losing my voice box, he became really animated and said "Look at how well you are now. Driving out here on your own and putting up with us lot teasing you - you are an inspiration!" I was delighted and as I was leaving I could hear him telling all his friends my story and what an inspiration I was. I felt really uplifted by his response. It wouldn't have happened without the electrolarynx to break the ice.

**Barbara Nitschneider – Cary, IL
Class of 1974**

It was the Christmas season and my husband and I had been invited to a neighbourhood open house. The people there had just moved here from Arizona. They had met Bob on one of his daily walks. Bob loves to talk and everyone knows "Bob and his dog." I had not met them yet. We drove to their house. As we walked in people and children were there to greet us. I started talking with my EL and a little girl was clapping her hands and said, "Mommy! Mommy! A robot has come to our party!" She was so happy. What a great way to break the ice.

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

Donna McGary Managing Editor • Kim Almand VoicePoints Editor

Disclaimer: The information offered via WebWhispers is not intended as a substitute for professional medical help or advice but is to be used only as an aid in understanding current medical knowledge. A physician should always be consulted for any health problem or medical condition. The statements, comments, and/or opinions expressed in the articles in Whispers on the Web are those of the authors only and are not to be construed as those of the WebWhispers management, its general membership, or this newsletter's editorial staff.