

WebWhispers

Sharing Support Worldwide
Throat Cancer and Laryngectomy Rehabilitation

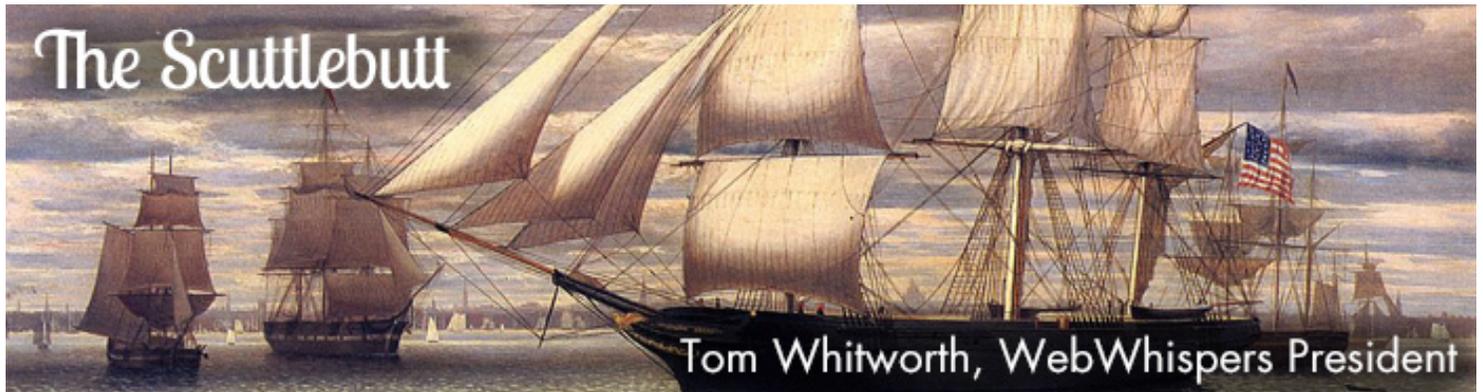


February 2018

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Bloom Where You Are Planted!

If I could think of ten things to write about here or even just one, this would be it. I've never thought of myself as a salesperson and that has been confirmed a number of times, at least that's what I thought until I learned of the criteria that changes that. I am more easily persuasive when fueled by passion, true, unbridled passion. When empathy kicks in at the same time, I become uncontrollably energized. Yes, though I've had disappointments, as have we all, life has given me a number of things about which I care very deeply. Julie and I are approaching our 40th wedding anniversary. Obviously, there is some serious passion there, but I can't say I blame her. Lol! Both of our daughters are people anyone would be proud to be a parent of. One is Fine Arts Director for a private school and the other, a Social Worker and Child Therapist in the foster care system. Don't even let me start on our three grandchildren. As any of you who know me at all can attest, there is enough passion there to light up the world in a universal blackout.

Then there is being a lary. I actually love being a laryngectomee because without that, I can be nothing else. WebWhispers is a true love of mine as I enjoy seeing so many people get the help they need from the same source and people that helped me and still do. It was my first friends through WebWhispers who easily convinced me that attending my first IAL Voice Institute would be a good thing to do. Broke in more ways than one, and still healing from surgery, I somehow managed to attend my first one and I haven't missed one since. I will always remember calling Julie during the first break on day one to share my joy. I recall telling her "I can't imagine having not come here and then learning how wonderful it would have been for me. This is something I now will always do."

A couple of weeks ago, there was an Annual Meeting/Voice Institute announcement on the International Association of Laryngectomees (IAL) Facebook Group. Here is the comment I made that day and I mean it just as sincerely today as I did then.

Tom Whitworth I feel similarly from the laryngectomee perspective. Nothing, absolutely NOT ONE OTHER THING, has made the positive difference in my life as the IAL and the four Voice Institutes I've been privileged to attend. Priceless! ❤️

The Voice Institute this year is being directed by none other than Dr. Caryn Melvin, PhD., who hit the ground running upon accepting the role. The faculty in place for this event is truly astounding! If you are a throat cancer patient or survivor, caregiver, Speech Language Pathologist who works with us, or an SLP student planning to or even considering it, there is no better place for you to be than the IAL Voice Institute in Orlando FL, June 6-9, 2018.

Yes, you will hear more from me on this but for now, just go register using the link below. WebWhispers scholarship funding has not yet been determined but go ahead and apply for that, too.

Dr. Melvin has used the expression "Bloom where you are planted". To that, I say plant yourself where you

can BLOOM!

Register and get more information:

<http://theial.com/ial-voice-institute-and-annual-meeting/>

Apply for assistance:

scholarship@webwhispers.org

Suggestions for WebWhispers:

tmwhitworth@gmail.com

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



**"How does weather/climate, etc., affect you as a laryngectomee?
If it doesn't we like to hear about that also."**

These last couple week have been bad with the mucus and coughing. I run a vaporizer daily but with the heat running more due to cold weather I had to run 2 vaporizers and it defiantly helped! Been a lary for going on 2 years. I live in Philly

Susan Belz – Philadelphia, PA

I live in East Tennessee; it's been seasonally cooler than normal so far this year. I run a humidifier by my bed at night and one by my chair when watching TV. Still get quite a bit of thick muck, especially in the early morning, use saline solution to loosen it up. It's been so cold and dry I haven't been able to get outside much

and exercise. Of course there's not much yard work either, very depressing.

While taking down the Christmas decorations I experienced some difficulty breathing, my HME was freezing up. I walk when the temperature is above 50. When it's really dry I don't go very far cuz I can feel the dryness in my windpipe. On foggy days it's much better and I can go further.

Another concern is pollen in Spring. It's severe here in ETN and will plug up your HME in a heartbeat if doing any work outside for an extended period.

David Sherr – Tennessee

I have found for me hot and humid doesn't affect me much. However cold and dry does so I take precautions when I go out into the weather. I would not think about going out without a HME in place and a few spares in my pocket, I usually wear a ski mask or wrap a scarf around my neck.

I try to slow down so air has a chance to warm, instead of rapidly inhaling, I fish and hunt in all kinds of weather. I just prepare beforehand. I also keep weather related supplies in my cars, in case they are needed.

**Joe Hilsabeck – Edelstein, IL
6/2009**

I live on Cape Cod in Massachusetts so it has varying degrees of humidity in warm weather months and less so in the other months. I use the Xtra Moist HMEs. Breathing is a little more restricted with it than when my stoma is exposed but I am used to it so my breathing is satisfactory. Sometimes an unexpected cough can push mucous onto the HME which restricts breathing. I always carry 3 extra HMEs and a cleaning kit for my Activalve with me.

**Dick Spiers,
Class of 2015**

I just can't take cold air anymore. I live in FT LAUDERDALE and the warm humid air is so nice. I breathe great with high humidity.

**Paul Winkle Sr. - Ft. Lauderdale, FL
1990**

Hi everyone. I, like you, have and dealt with the same issues. Mucous, swallowing, breathing etc. especially in dry winter months. After 8 years here's what I do. First you Must humidify your home! A little room humidifier is NOT enough because you don't live in one room. Get a whole house humidifier. They are effectively rated in square feet of your home. So if your bedroom is 400 square feet BUT your home is 2000 square feet , DUH ! Do you get the idea? It's no good if too small.

The buildup of mucous, loose or dry, restricts your esophagus so swallowing can be affected. So now what???? I have 2 spray bottles. One is very fine mist. The other is a coarser mist. Believe it or not each mist has a better or different effect, so use them how it works for you best. Both are small so I can easily carry them with me when I'm on the go.

I fought several times a day using forceps and coughing like crazy to rid the mucous. What a task!!!! So now here's what I do. I still use humidifier and spray misters . I few shots with a mister and get your coffee or whatever. The mist will quickly soften the mucous!

Then the best part.... I got a Devilbus suction machine. WHAT A GREAT DEVISE. No longer coughing and hacking till your stomach and back gets sore. Your relief comes very very quick! Try it you'll love it. The bonus is obvious but by quickly AND effectively removing the mucous you should notice a easier swallowing experience. WHY? Because you removed the restriction between esophagus and windpipe! Good luck to all.

Ron DiBartolo – St Louis, MO

Happy new year every one! You have heard the slogan "Don't leave home without it"? I wish I would have remembered to take a humidifier with me on a recent trip to North Carolina. I spent 2 days looking at beach property near the ocean and I was fine. However, when I got to my sons in Durham the difference in humidity was a big problem. Thankfully I packed many saline bullets that helped me for 3 days until I returned home. Now I make sure a humidifier is with me when I travel. Stay well everyone.

**Ed Kuszajewski. Pittsburgh, PA.
Class of 2014**

My laryngectomy surgery was done on August 4 , 2017 . Around Christmas time the temperatures around here were in the teens . I was exposed to these low temperatures twice when we went out to eat. Each time, I could barely breathe once I got out of the car till I quickly entered the restaurant. Under warmer conditions, my breathing gradually got back to normal. I was wearing warm clothing but no scarf over the adhesive and the filter. Since then I am reluctant to go outside in the cold weather. That was a terrible experience. A scarf around the neck seems to give me shortness of breath.

**Raj Phansalkar - Ponca city, OK
August 4 , 2017**

I had full laryngectomy April 2016. I live at bottom of South Africa 34 degrees S. and daily weather is warm and humid about 24c and 60 %. Occasionally up over 80%. Our currency makes use of HME and tubes, etc. too costly so my daily use is a wet bib of which I have a homemade stock - made of a sort of perforated cotton. Very easy to manage. If % drops below 50 then I wet it and wear it damp so breathing through the wet cotton. It's an easy life and very cheap.

Only issue sometimes is with mucous through the hole in valve stopping full closure, and causing a cough... I

fix that now with an eyebrow brush trimmed with scissors and fits snugly into the valve hole. Twirl and withdraw. BUT BEWARE don't push it more than indicated by the stop flange on your Provox brush.

Why use this? I find the Pro brush too soft and not grabby enough. An indication of a poor closure of your TEP valve is fizzing and popping noises telling you that the flap isn't fully closed. The brush fixes it.

Only other problem is life of ProvoxI examined two old ones right after removal and found tiny buds of candida fungus....so I am taking a large spoon of plain YOGOURT at bedtime or if I go to bathroom in night Getting 5 + months from a Provox....don't think my Med Aid would be pleased if under that.

David Statham - South Africa
April, 201

Perhaps because I do not use HME devices or humidifiers I have built up as much resistance to weather changes that is humanly possible for Lary's and perhaps the fact that my windshield-less Harley is my only means of transportation has also helped in this aspect. Perhaps living in the land of perpetual sunshine (FL) is also a factor.

That being said . . . as I live in Northeast Florida (just a few miles ride to GA border) it do get frosty cold on occasion. As we've had the past couple weeks thanks to the polar blasts that consumed the rest of the country. During those times my mucus does get thicker, but I've good lung power and can usually expel it. Yet there are times when it is brrr-butt cold, do not laugh we've had several hard freezes this past week alone (28-degrees or below for 12 hours), I find that I must use a steamy washcloth to help break it up so I can get better clearance.

I joined this elite neckbreathers club on 10/30/2006. In the beginning years I struggled with excessive mucus, but continued to believe my ENT (a crusty old guy named Nelson Goldman) who told me he believed I could live without the vast majority of do-dads (his words) being sold to most larys.

He also told me to sell my Harley cause my riding days were over. He also said if I decided to ride I would be a 'fair weather' rider complete with windshield and fairing, and I'd never be able to ride in the rain or cold.

On those points . . . I proved the old coot wrong because I am NOT just a rider. I am a biker. Been running with Harley's and Harley people since my teenage years and I be over retirement age now. Tis true, I have been a Christian biker the past quarter-century, but I am still a biker nonetheless.

So there be no windshield nor fairing on my bike, No cup holder or stereo. While I may not leave the house for a pleasure ride if it be raining, if I have some place I MUST be . . . I will ride.

Been in some whiteout deluges and haven't drowned thus far, and have ridden many a mile in cold weather. Some with some nice drenching rain included. And when I get to old to hold up two wheels I pray the good Lord has blessed me enough I can trade her in for a trike and keep on keepin' on!

Troll – Jacksonville, Florida
Class of 2006

I reside in Richmond, VA & I must say any weather or climate change has no effect for me. In our region we experience the gamut of conditions including extreme cold (0 degree temps this month) up to in excess of 100 degree temps occasionally in the summer months. I am 71 years of age & had my surgery in June 2015.

Ron Crenshaw –Richmond, VA
June, 2015

I have never had any problems with the weather changes even with traveling, mostly by flying, to different parts of the country. I think it might be due to the fact that in 2010 I had the soft palette in my mouth replaced due to the cancer returning. That surgery closed off the back of my nose to my mouth which I believe prevents me from getting colds. Plus, I always get the Flu shot at the VA.

Bob Bauer, Hayward, CA
Class '08

I become more and more convinced that we laryngectomees are definitely all a little different. I also become more and more convinced that the passage of time can be both a blessing and a curse. As I am on the verge of my twenty fifth anniversary of surgery and my eighty first birthday I am finding that the New England winter weather is affecting me more than it did ten or fifteen years ago.

In the same way that I am more prone to bruising and more easily breaking the skin on my hands, I now am more prone to periodic bleeding in the bronchea and trachea. This is a winter only phenomena and has been occurring for the past five years or so. It happens even though I have two humidifiers set at 45 percent relative humidity going, sleep with a large volume nebulizer, and use a hands free valve with a HME filter. Four years ago I had a bronchoscopy with no definitive results. So, I simply accept it as a part of ageing.

I also find that even with no infections, my mucus in January and February tends to thicken during the night and many mornings I need to use a saline bullet to clear it out. It seems strange to need to flush clear mucus with saline, but again I simply accept it as a part of ageing.

I don't find any of this more than an annoyance. I have no intentions of moving. It is just a part of being a guy with a hole in the neck. As long as I can still read, drive, eat a normal diet and enjoy my family and friends, life is good.

Carl Strand, Mystic, CT
February 10, 1993

I have a whole house humidifier in my heating and ac system and I live in hilly east Tennessee. We've had pretty cold weather in the last month; many days 6 - 18 degrees. -- I have hiked, lifted weights, and cut and split firewood for many decades, so I've always stayed in good physical shape - never overweight, always pretty strong.

How does climate affect me as a laryngectomee? - First of all, I much prefer to wear a baseplate and HME, but had to stop about 6 mos. ago b/c I've developed an allergy to them. I always get a rash after one day of baseplates. So, I wear a foam bib/stoma cover, and then a nylon mesh (Addvox) stoma cover over the foam bib. Supposedly / theoretically, in very cold weather it would be good to cover one's stoma with say a loose

neck scarf or some covering, to allow the incoming air to warm up a little from your neck heat before it enters your stoma. I do this when I'm just casually walking outside in sub 30 degrees, but I do NOT do this when hiking or cutting wood in cold weather, b/c it restricts my breathing too much. I have a little more mucus with the foam cover setup than with baseplates and HMEs

I honestly can't say I notice any difference in my breathing whether it's 20 or 90. The humidity in TN is usually lower in winter (30%) than summer (90%). Because of this, I often squirt a daily shot of saline into my stoma after very cold hikes, because I figure my lungs might be a little more dried out. Surprisingly, I haven't coughed out blood droplets after all this cold weather and hiking so I must be staying adequately hydrated.

**David Smith – TN
2014**

**Next month's question:
"Tell us about your outdoor activities."**

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

Staff of Speaking Out



Voice Points

Written by Professionals

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

The following is an updated version of an article originally written a few years ago for VoicePoints. HME use and pulmonary function continue to be incredibly significant issues for all of us! Stay tuned into upcoming VoicePoints columns for additional answers to your questions along with a review of more current research and education being conducted in this area.

The Weather Outside Is Frightful, but The Stoma Doesn't Have To Be!

It's that time of year! For the laryngectomized individual, who now breathes via the stoma rather than the

nose, seasonal changes can be particularly difficult.

The change in the weather, cold or warm, can cause changes in the mucus emitted from the stoma. The changes can vary from thicker mucus, thinner mucus, tinted blood (less than a teaspoon amount) in the mucus, mucus plugs and/or increased crusting of mucus around the stoma. This time of year, when most parts of the United States are cold, our heaters may be running full-time. As a result, the air tends to be drier, thus increasing the need for additional moisture to the lungs.

Following a laryngectomy, there are anatomical changes in the respiratory system.

The airway is surgically separated from the nose and mouth and the permanent airway opening is the stoma. Once breathing through the stoma, the nose is not able to “to do its job” of filtering, moistening and humidifying the air. Therefore, the lungs receive all the dust particles, pollen, etc. in the air. The lungs are not made to accommodate these unfiltered particles, and as a result, make more mucus, to clear the foreign particles. To complicate this process, there is no moisture to assist in clearance.

What can you do to help your patients?

It is of the utmost importance that every laryngectomized individual wear a heat moisture exchange filter (HME) 24/7 as soon as possible following their laryngectomy. The filters are available through ATOS Medical, InHealth Technologies and Trachinaze. The filters are coated with Chlorhexidine (anti-bacterial agent,) NaCl calcium chloride salts (helps trap moisture,) activated charcoal (helps absorb volatile fumes,). These are disposable and should not be reused beyond the manufacturer’s guidelines. The filters function to capture the warm, moistened, and humidified air upon exhalation. Upon the laryngectomee’s next inhalation, he/she is receiving his own moistened, humidified, filtered air.

A recent study by Macri et al., 2016, found that for users who never wore an HME before – after 12 weeks of wearing an HME:

72% reported easier to breathe

- 48% thought their appearance was better with HME in place
- 82% reported less tracheal irritation
- 76% reported less need to forcefully cough to clear secretions
- 79% reported less dried mucus / crusting in stoma / trachea
- 90% coughed less

The HME filter can be attached to the laryngectomee via use of an intraluminal device, which may include a Laryngectomy Tube, Barton Mayo Button and/or Lary Button. The filter can also be housed by a peristomal attachment (adhesive adhered around the stoma.)

Keep in mind a stoma cover, laryngofoam filter, bandana, etc. does not benefit the laryngectomee in the same manner as an HME filter. These types of devices are purely a “COVER.”

The speech pathologist should evaluate the patient to determine which type of attachment and HME is best suited for each patient.

In addition to wearing an HME, it is recommended that the laryngectomee utilize sterile saline for inhalation. This consists of “squirting” 3-5cc of sterile saline into the stoma 3-5 times per day. This will make the patient cough... but it adds extra moisture and assists in keeping the secretions thin!

Additional tips include: using a cool mist humidifier, a saline mister, maintaining your hydration and use of

mucolytic medications (i.e. Mucinex.) after checking with your physician.

Jodi Knott, M.S., CCC-SLP

Clinical Coordinator of Speech Pathology and Audiology MD Anderson Cancer Center

Many thanks to Nicole Auton, M.A., CCC-SLP, Territory Sales Manager, Atos Medical, for providing a review of the current literature and reference list to assist with this article. Further references available upon request.

Clin Otolaryngol. 2016 Dec;41(6):652-659. doi: 10.1111/coa.12578. Epub 2016 Feb 15.

Patients' experiences with HMEs and attachments after total laryngectomy.

Macri GF, Bogaardt H, Parrilla C, Minni A, D'Alatri L, de Vincentiis M, Greco A, Paludetti G.

Just in! For those interested in a fabulous educational opportunity, April 6-7, 2018:

The Association for Head and Neck Cancer Rehabilitation is pleased to announce that the 3rd Annual Clinical Head and Neck Rehabilitation Conference will be held on April 6-7, 2018 on the campus of Michigan State University in East Lansing, Michigan. This year's conference is tailored for students in Speech-Language Pathology, head and neck cancer survivors, and their caregivers. Multiple vendors will also be represented at the conference. For more information, please contact us via email at - AHNCR2018@gmail.com – we look forward to seeing you in April.



To Speak Or Not To Speak ... That Is The Question

My friend Catherine recently suffered a stress fracture in her leg. It means wearing a big plaster boot and using crutches for the next few weeks. She can't drive and as they live in the country and have no public transport her husband (luckily retired a few years ago) is now driving her to and from work. Anyone who's had to use crutches will know how slow and clumsy you become with these, especially in tight spaces. She emailed me to say how conscious she'd become of the need to plan every small task so as to avoid

unnecessary journeys. She said she now had some insight into how I have to plan each communication to get my meaning across.

That made me think. I don't actually plan communications consciously as she is now planning how to get washed and dressed and cook a meal. Certainly my communication patterns have changed, but I haven't consciously planned conversations to best suit the electrolarynx. Unless you could call steeling myself before speaking with a stranger a form of planning. But as I reflect on the changes that have crept in unconsciously, I see that maybe I should try to plan ahead more often.

The main change is that I am now much quieter. Here's an example. As I've been typing this Sharon (one of my mum's carers) came into the house. She called 'Hello' as she let herself in the front door. I'm in my bedroom using the computer, my mum is in the sitting room with the radio on. Neither of us replied – my mum probably didn't hear her, and I didn't bother.

Was I just being lazy? I want to write this Webwhispers column. Saying hello to Sharon would nowadays interrupt my train of thought. Before laryngectomy, saying hello would have happened seamlessly as she walked from the hall door to the sitting room. I would have called 'Hi Sharon' without my fingers leaving the keyboard. She might have replied "Hi Noirin, I'm just going in to your Mum" and I would have responded something like "That's great thanks Sharon" while my fingers typed away. The 'hello's' wouldn't have interrupted either of us from what we were doing.

But what with the time it takes my fingers to get down to my lap and wrap themselves around Ellie (my EL) and then get her up to my neck and into the sweet spot, and by the time my thumb presses Ellie's button so that she squawks in protest, Sharon would have already gone into the sitting room. If she heard Ellie's first squawk she would have to stop and concentrate so as to be able to decipher "Hello Sharon" out of the noise, or knowing how hard Elly is to decipher from a distance, she would most likely retrace her steps to my bedroom door to listen and then give her (totally unnecessary) explanation that she was going in to my Mum. Because she'd made that effort I'd probably also feel I should make the effort of going to the door to say a proper 'thanks'.

The full interaction might have taken only a minute. But it would have interrupted both of us, which would probably have felt a bit irritating. Pre-laryngectomy, a quick 'hello' would have been a brief moment to lift the heart. Post-laryngectomy it would be an effort of some duration which might have felt as much burdensome as heart-warming.

So it's not just laziness. It's also a consequence of the new reality that communication is much harder with Ellie as my spokesperson. I have to make a big effort to get her to say anything, and everyone else has to make an effort to hear and understand her. Hardly surprising that lots of the time I don't engage her services to for small talk like 'hello' and 'goodbye'.

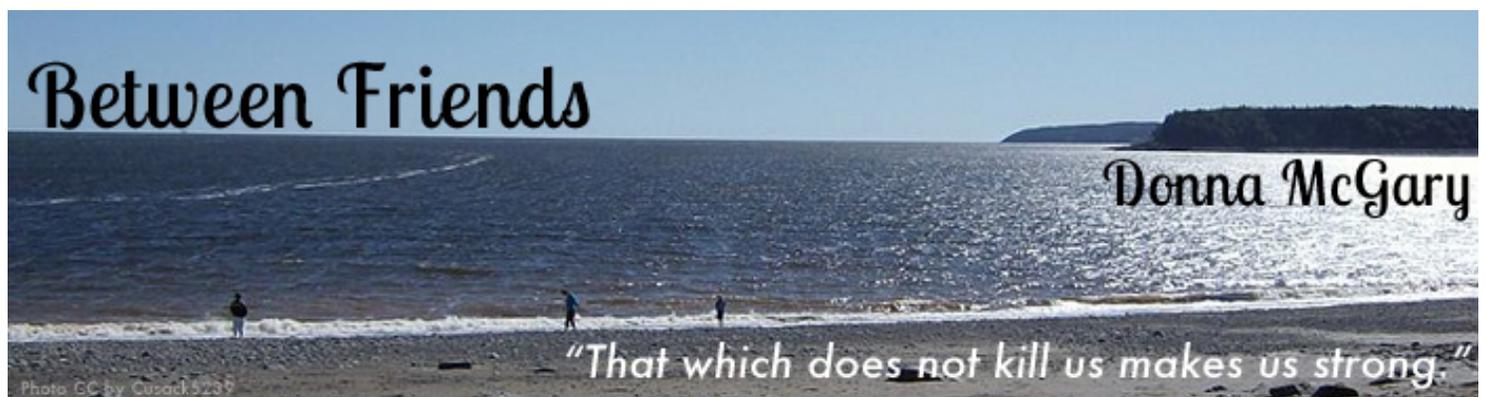
It's not just 'hello' and 'goodbye' either. Sometimes, I'd like to speak up in a conversation but the topic changes direction before I can press Ellie's button. At other times I shrug my shoulders and say to myself 'They'll work it out eventually' when a word from me might have helped someone with something practical. For example, the other day one of my mum's carers was trying to find the 'Off' button on the TV remote control. By the time Ellie could have said 'It's the red button at the top left', the carer had found that same button.

And sometimes my input to a conversation makes it all go pear shaped. Recently, three of us were trying to work out the origin of the name Mindy. One person suggested it might be short for Mellissa. Someone else suggested Amanda. I wondered was it related to the Irish name Minnie, and asked what Minnie was short for. No one had a clue what I was saying. "Milly? Do you think Mindy is short for Millie?" asked one. "No" I said "I'm talking about the Irish name Minnie. " Everyone looked blank. "Remember Minnie in The Riordans?" I

said referring to a soap on Irish TV from a generation ago when we were growing up. "Millie Riordan? No, I don't remember anyone called Millie Riordan." ventured someone after a long pause. I wondered whether to go in search of a pen and paper, but it seemed like too much trouble and instead just smiled and shook my head. Luckily they all understood this gesture as me withdrawing in bemusement. There was an awkward pause and then someone started off a new topic of conversation.

Experiences like these make me less willing to put in my tuppenny worth in many conversations. Too much effort for something not all that important.

All this adds up into me being a much quieter person post-laryngectomy. But now, having become more aware of the change because of Catherine's email and writing about it for the February newsletter, I'm thinking that I need to take steps to reverse the trend. Because there is doubtless an element of laziness as well. Ellie's lack of fluency also gives me the excuse to withdraw, to be an observer rather than a participator in life. Participation takes effort! But I see now that this is an effort I need to make. Even if it means interrupting things, and, in one sense, wasting time. So long as I and others can remember that this clunky, slow, awkward communication is an effort at maintaining friendship, then it's not a waste of time.



Out of the Closet.... And into the World

WebWhispers has always maintained a loan closet for members who need an electrolarynx. Some of the loans were short-term while an instrument was in for repairs or to try one out post- surgery or until a new one could be purchased. While technically the loan is for 90 days it has always been renewable indefinitely as long as the individual needs and uses it. It has been a godsend to many folks.

Christmas week 2014 I dropped my Servox as I was getting dressed with my grand-daughter to take her to her first Nutcracker Ballet. It was broken and so was I. My dad was in hospice; I was going the next day to stay with him and now I had no voice. My back-up Servox was packaged up to send to Jim Lauder for repairs and I was 2 hours away from home. I sent Pat Sanders an SOS for a back-up 2 days before Christmas. And she and Roger Johnson, the Loan Closet custodian at the time, came through. I will forever be grateful for that little USPS package that was delivered Christmas morning! I still don't know how or why we had delivery that day but we did! And I was able to go up that afternoon and stay with Dad and have a voice - the one he knew and understood as mine.

So I was honored to have the opportunity to be the latest Loan Closet custodian when Roger and Carol Johnson had to reluctantly step down due to health issues last year. They did an outstanding job for WebWhispers and we all owe them a huge debt of gratitude for their work. They were the unsung heroes for many, including myself.

As it turned out, once we had a chance to assess all the boxes in the loan closet, we realized WW had an abundance of riches from donations here and there over the years. Some “had issues” shall we say, but many more were still working and needed to find a new home. Jim Lauder, AKA The Servox Guru, has been a huge help here, assessing the “wounded warriors”, re-conditioning some and re-cycling others for parts. He has also been invaluable in connecting SLPs and WW to forge new relationships for our community.

As a result, the WW Loan Closet is out of the closet and into the world. We have distributed ELs to SLPs across the country who recently learned of us through Jim or our website for their clients who were discharged from rehab with no voice, folks who have successfully used an EL but now have no access to one and facilities where the need for demo/loaner ELs exceeds the supply. These ELs have been put on “permanent loan” for WW member SLPs to use as they see fit as they serve the lary community.

The need is more common that you might think both in the United States and elsewhere. We have been able to send a number of ELs to both Peru and the Philippines through contacts Jack Henslee has made with his ongoing work with underserved communities world-wide.

We continue to maintain a loan closet for WW members and are being pro-active in reaching out to the SLP community to give fellow larys a voice. Individual larys reach out through all of the internet/social media platforms where WW has a presence. Applicants first need to join WW through our website:

<http://www.webwhispers.org/join/how-to-join.asp>

Then give us some basic info so we know what you need and where to send it. It is all easy and free.

<http://www.webwhispers.org/services/loan-closet.asp>

Loans are available to any WW member who needs one either on a short and long-term term basis. We operate on the honor system. If you no longer need and use the EL, we simply ask you return it to us so we can get it back out to someone else in need.

Years ago Jim Lauder had a great t-shirt which read, “Servox, We have Ways to Make You Talk”. I always loved that and still have one. The WW Loan Closet has a new slogan – “A Voice is a Terrible Thing to Waste” and we are here to help. Contact at loancloset@webwhispers.org

Bits, Bytes and No Butts!



Frank Klett

But Can It Keep You Warm?

It has finally come to the deepest days of Winter and in a few weeks will only be a memory as we welcome Spring into our lives. We will finally be able to go out and about to enjoy our outdoor pastimes and to visit with friends and relatives. Many of those trapped by Winter's cruel weather antics have spent many hours either with the company of Facebook friends or catching up on re-runs from our TV idols.

Facebook and TV are just 2 of the multitude of wondrous activities we can enjoy in this ever expanding world of technology we have evolved to in the past 30 years (since the invention of the personal computer).

At times like these past frigid weeks I tried to stay sane by getting creative or by fixing something that has been on my mind (but never had the time required to repair it.) I have a stack of old family VHS tapes and quite a few VHS movies we bought for the kids and have since gone unused and I have 8 grand children that could still enjoy them. For kids Disney never gets old! So I got to searching around on-line and found the only place to buy a VHS player today is E bay...as in used. I came across a very helpful guide on how to do just what I was looking for and it was written and put together by none other than Bob Rankin. He has put together a very concise and easy to follow guide on how to convert your old VHS tapes to DVD or to simply store on your hard disk. Bob's article can be found by following this link...

https://askbobrankin.com/howto_convert_your_vhs_tapes_to_dvd.html

Helpful Hint #24 – If you have a PC or laptop with a DVD player hang on to it... they are no longer made so down the road the DVD is going to go the way of the VHS Player, which will leave you stuck with another pile of obsolete technology.

Last month I wrote about "fake News" and "fake Photos". Well as it turns out somethings never go away and now we have a rash of "fake tech support" going around again. You may recall a year or two ago there was a scenario going on that had phone calls at random to folks by someone posing as tech support advisor from Microsoft or some other large software house offering to remove a virus or virus's from your PC. And of course to do this they needed a mere trillion bucks and the left ring finger of your oldest virgin daughter.

The truth was there was no virus and the person on the phone was not a representative of any legitimate software company. So what to do if you get such a call? I personally start speaking in Spanish (I don't speak more than hello and goodbye) or if I am really in the mood I try speaking Russian...I am not very good at that either. Bottom line is to not give the caller any information at all...nothing about me or my PC...just nothing at all. Many /most times these callers are just fishing to gain any info they can from an unsuspecting citizen. The bottom-line is not to be the unsuspecting victim...you can never get in too much trouble by just hanging up.

Read more about this problem written by Bob Rankin ...

https://askbobrankin.com/alert_fake_tech_support_scammers_are_calling.html

And just a thought for the New Year...and a new Super Bowl...

This is from last year's Super Bowl and Lady Gaga's halftime performance...

<http://www.flixxy.com/lady-gaga-super-bowl-2017-halftime-show.htm>

And a Reminder from our sponsors:

Our Webwhispers library <http://www.webwhispers.org/index.asp> is one of best ever sources of any information that a Lary could need...if you have never spent time browsing through it you may want to consider taking the tour. While you're in the browsing mode stop in to our Facebook page and visit with the gang...and if they aren't there they most likely are in the Webwhispers Forum catching up on the latest news.



“Between Friends this month covers some of the new initiatives from our WebWhispers Loan Closet and this article is about a trip Jack Henlsee made to deliver some ELs to the same organization who we will be sending some more to this month. ~ Editor’s Note”

Voices Restored - Travels with Larys

Ever since I was eleven years old, I have dreamed about someday visiting the ancient Maya, Inca, and Egyptian ruins, and more recently the Angkor Wat site in Cambodia. Last year I finally made it to Chichen Itza, and Tulum in Mexico. This year I was supposed to go to the ancient lost city of Machu Picchu in Peru, and while there I planned on visiting with the Peruvian Laryngectomee Association in Lima.

However, due to some concerns about my ability to handle the altitude and the extensive walking at this time, the plans had to be changed. So I made a reservation for a 15 day cruise from Chile to San Diego, CA, with plans for visiting the Chile, Peru, Ecuador, and Costa Rica associations at their respective stops. Plus the price was fantastic at only \$849 per person for 15 days.

Even though I had four different email addresses for Chile contacts, plus two knowledgeable sources for both Chile and Ecuador, I was unfortunately not able to make contact with anyone in those countries. Chile was just plain frustrating because they have or had a laryngectomee organization at one time, but in Ecuador's case there simply may not be any type of organization. It is a fairly small and poor country.

Peru was not a problem because I had made contact with Dr. Mariella Poblete, Peruvian Cancer Hospital, who is in charge of laryngectomee rehabilitation in Peru. Mariella and I have been communicating for 4-5 years now and it was great to finally meet her. Earlier this year I had sent 6 donated electrolarynx units to her (it is not an easy task to mail things of value to Peru), and on this visit, I hand carried 6 more units.

Mariella and her daughter Laura (who served as a great translator) met me at the Port and we proceeded to the hospital to meet with her group. Due to our late docking which was caused by swine flu concerns, we had a very tight schedule so sightseeing was limited to what we saw while driving. Lima appears to be an interesting city with a staggering population of 7 million which is 1/3 of the country's population. The streets appeared to clean and well maintained but traffic basically turned it into a giant parking lot.

The hospital is only 9 years old, clean and modern. Our meeting area was very small and we were greeted by twelve laryngectomees and an equal number of medical students. They provided a nice snack of "typical Peruvian food and drinks" which we all enjoyed during a Q&A session that lasted 2 hrs. There were several excellent esophageal speakers, 4 used an EL, and one used TEP. That person was Dr. Victor Repeetto, MD, who had his laryngectomy 9 years ago and was one of the first TEP speakers in Peru.

One lady, María García Tarazona, had received one of the donated TruTones sent earlier. Before her laryngectomy, she had been a swimming instructor, and with the loss of her income and her voice she had become a recluse. She is now a very active member of the organization and her speech is great. The next step is to somehow find her a Larkel so she can resume swimming and maybe become employed again.

On the way out, we stopped for a short visit with the Deputy Director of the Peruvian Cancer Hospital, Dr. Raúl Cordero. Dr Cordero, as with all the people I met, was very appreciative of the donations and stressed how much they are needed. Unfortunately, Peru does not provide free medical and as a result there are not a lot of laryngectomees in Peru. They either die from no treatment, or survival is short term because it's diagnosed too late. The late diagnoses also leads to difficulties with speech rehab and swallowing because a lot of radical, extensive surgery is involved, such as with the Peru Association's Treasurer, Ana María Matushita, who has no tongue. A good perspective is a comparison to Costa Rica. Peru has triple the general population but probably less than half the number of laryngectomies!

On the way back to the ship we made one last stop for a late lunch at a Peruvian buffet. That was just what I needed... More food just in case I wasn't getting enough on the ship! Turned out to be an excellent lunch however with about 20 different "local" dishes to pick from.. all you can eat of course!

The next stop was Ecuador, where I had no agenda other than some limited sightseeing. It is very poor country and not a lot to see. At least not in Manta where I was. Manta is famous as the home of Bumble Bee and Star Kiss Tuna, and near where the famous Panama hat is hand woven. I'm sure that they have a need for some laryngectomee assistance but that will have to be another mission. One interesting fact though is that "voting" is mandatory in Ecuador. If you don't vote, you are fined, cannot have a driver license or passport, things that are taken for granted elsewhere.

Finally, I got back to my home away from home... Costa Rica. I was met at the dock by my friend Marcos and his daughter. They took me to a restaurant several miles away and we joined about 10 other members of ALARCORI for a nice lunch and visit. I had also hand carried another 6 donated ELs for them which as always were much appreciated. This was a great visit but it was more social than business. We briefly

discussed their quest for some office space, the status of those that had been taught to speak last year, and their quest for a donated laryngoscope. Dr Ana Vilalobos wants a scope so they can concentrate on early detection and prevention, which of course is the best cure. If any of you have any known sources for a used system please let me know. The ALARCORI members have also started a school visitation program, and they are working on their second Lary Conference for this November.

As with most trips, or even local patient visits, there is one thing that stands out and reinforces your commitment to help others. In this case, they gave me some bittersweet information about two of the men we gave voice to last year. Both of these men had recently died, and one of them was relatively young. After their deaths their family returned the donated ELs so others could use them, and they told the club how important it was to them and their lost loved ones to have been able to speak with the family before they died. They did not die in silence with unknown feelings, and that pretty much says it all.



Jack Henslee, Marcos Salazar and Dr Ana Vilalobos'

The Radiance of the Seas is in the background.



A shot of the CR group at lunch in CR



Jack Henslee, Mariella Poblete, Laura Poblete , Ana María Matushita (clockwise)



Medical Students and 2 Lary's



Jack with Members of Peru Association

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