



WebWhispers

Sharing Support Worldwide

Throat Cancer and Laryngectomy Rehabilitation

Whispers on the Web

A Monthly Online Newsletter for WebWhispers

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April 2017

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FEEDBACK

The Scuttlebutt

Tom Whitworth, WebWhispers President

Just Do It!

Attending my first IAL Voice Institute soon after my treatment and laryngectomy was the greatest thing I ever did after being told I had cancer, (short of the treatment and the surgery). It may be the best thing I ever did - period. With more time and space, I could write a book but I'll spare you that. You can thank me later. My response in "Speaking Out" is the short version. I will add that I truly cannot imagine ever missing an IAL Annual Meeting and Voice Institute. Aside from what there is to learn about lary care, and all communication options, there is simply no substitute for meeting other laryngectomees, caregivers, and SLPs face to face. The highly-accomplished presenters do an amazing job at providing information to enhance our rehabilitation, recovery, and quality of life. They are amazing! You'll also find truly caring representatives from our suppliers, with new products to display, but just as much interested in being helpful to each and every one of us.

This issue is filled with information about the IAL event in Newport News, VA this June and some great stories from past meetings. WebWhispers is proud to promote the information we have on events for those in our community. If you know of one or a group of them, not currently listed on our website, please let us know.

Important links I invite you to see and use:

The International Association of Laryngectomees (IAL) Annual Meeting and Voice Institute, June 2017, Newport News, VA. How to register:

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

Need help getting there? We are still gathering information on scholarship funds available and will have that finalized soon. Meanwhile, click here to complete and submit the WebWhispers Scholarship Application:

https://webwhispersinc.formstack.com/forms/webwhispers_scholarship

For scholarship questions, email us at <mailto:scholarship@webwhispers.org>

While there, join us on Thursday evening for our annual reception and awards dinner:

<http://webwhispers.org/activities/2017WebWhispersAwardsDinner.asp>

Information on other events:

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

For more information, read on!

Hope to see you in Virginia!

Enjoy, laugh, and learn,

Tom Whitworth

WebWhispers President



Voice Points

Written by Professionals

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

Resource Roundup

Many thanks go out to all those who took the time to answer our VoicePoints survey originally posted in January. The survey will be open for one more week and we welcome responses from as many professionals as possible. You do not have to be a member of WebWhispers to participate. Please take five minutes to respond to this anonymous survey if you have not already done so: <https://www.surveymonkey.com/r/Z9ZJ36Y>.

This month, VoicePoints features some preliminary feedback from the survey and you will hear how your responses and comments are being used to shape our column over the next several months. We have also rounded up some helpful links and resources, below, for your clinical use that you might not yet have discovered.

What's new with VoicePoints: We're spreading the word! The recent survey shows that our professional readers are involved in a range of clinical practice, research, and teaching in hospitals, outpatient clinics, private practices, universities, and home health settings. As per your requests, VoicePoints along with WebWhispers will highlight upcoming national and regional meetings and training workshops on an ongoing basis, and regularly feature current clinical case studies along with discussion relevant to all methods of alaryngeal voice restoration. New contributors to the column are always welcome. I encourage you to keep checking in with VoicePoints and webwhispers.org each month for the latest information. Please share this information with your colleagues, patients, and caregivers. If you have a favorite resource that is not listed here that we could add to the list, please connect with me via email: kbalmand@gmail.com.

For the rest of 2017, VoicePoints has teamed up with some of our doctors and professionals in nursing, speech-language pathology and other allied health to bring you a fantastic lineup for the rest of the year. Topics you can look forward to hearing more about in upcoming issues include: a review of treatment options including proton therapy; considerations for establishment and managing nu-voice clubs and head and neck cancer resource groups; emerging research applications for head and neck cancer rehabilitation; additional meeting updates and patient education resources...and more.

Website Update: Ron Mattoon-along with the rest of our hardworking tech support personnel-works tirelessly to make our website as user-friendly as possible. We are updating the Current Events sections and the WW library. In case you missed last month's column or need another reminder to make plans for CEUs, we have compiled a list of some of the premier opportunities for continuing education and training workshops held around the US. It can all be found in the WW library in General Information under Meetings: <http://www.webwhispers.org/library/Meetings.asp>. In addition, more detailed information on various upcoming events for clinicians and laryngectomees may be found in the About Us/Current Notices section of the website. Listed here include some important 2017 meetings that might be of particular interest, including the Clinical Laryngectomy Conference (AHNCR), 3rd Annual All-Chicago Laryngectomy Symposium, 3rd Annual California Laryngectomee Conference, and the IAL Annual Meeting and Voice Institute: <http://www.webwhispers.org/about/currentnotices.asp>.

Additional Online Resources: One of the most frequent survey requests we have already received is for access to more patient education materials. I am pleased to share with you below some of the most practical, clinically-relevant, and fascinating sources for further information related to head and neck cancer and laryngectomy rehabilitation. Many of these organizations have further links for even more information and printable resources. You may find it helpful to bookmark these sites and refer to them often, as specific contents within each website may change.

American Cancer Society. Basics of oral head and neck cancer for patient education. Includes a link to materials in Spanish. Includes "easy reading" pages for patients recently diagnosed with cancer wondering what questions to ask their doctor.

<https://www.cancer.org/cancer/oral-cavity-and-oropharyngeal-cancer.html>

Head and Neck Cancer Alliance. Nonprofit organization dedicated to advancing prevention, detection, treatment and rehabilitation of oral, head and neck cancers. Formerly the Yul Brynner Head and Neck Cancer Foundation. The Oral Head and Neck Cancer Awareness Program sponsors free head and neck cancer screenings year round and during a special world-wide OHANCA Awareness Week each year in the month of April.

<http://www.headandneck.org>

The National Association of Laryngectomee Clubs (NALC). A UK-based association of laryngectomee clubs. Links to meetings and educational programs, NALC publications, and other web-based resources for throat cancer and laryngology. For patients and professionals. Includes a link (at bottom of page) to a Club List of member clubs across the UK.

<http://www.laryngectomy.org.uk/useful-links/>

NIH National Cancer Institute. Overview of head and neck cancer; current treatments and research studies; statistics; and links to "Coping with Cancer" appropriate for patient education. Pages for both patients and health professionals.

<https://www.cancer.gov/types/head-and-neck>

Support for People with Oral and Head and Neck Cancer, Inc.

A nonprofit organization with a mission dedicated to raising awareness and meeting the needs of oral and head and neck cancer patients through its resources and publications. Local chapters throughout the US; monthly newsletter for members; website includes extensive links to resources, clinical trials and national survivor volunteer network.
<https://www.spohnc.org>

Suppliers. Check out this link for all your laryngectomy and throat cancer supplies. Contact information to the invaluable suppliers who help support patients and clinicians throughout our community.
<http://www.webwhispers.org/suppliers/suppliers.asp>

Audio Recordings. A favorite among the many helpful tools in the WW library: multiple links to alaryngeal speech samples, including esophageal, artificial larynx, and TEP voices. A valuable go-to for speech pathologists in preoperative laryngectomy teaching and evaluation.
<http://www.webwhispers.org/library/talking-again.asp>



Lary Camp

Back in 2013 I wrote a column looking back at how my experiences at the IAL annual meetings had changed over the years. Jack references it this month in his wonderful recollection in “My Neck of the Woods” about the significance of these meetings to him. As we get ready for our 2017 meeting in Newport News, Virginia, I wanted to do another review of what these get-togethers have meant to me. I attended my first IAL annual meeting in Boston, September 2005. It was a revelation. I wrote this for my column the next month:

... It was a bit of a shock to walk into the Park Plaza in Boston and hear that distinctive buzz and rasp all around me. I heard myself at every turn. I saw myself and I was nonplussed. You could have knocked me over with a feather. And yet I was strangely disquieted. I couldn't possibly sound like these people. Face it, Donna, we have seen the enemy, and it is us! I still was hearing my old voice in my head and it was very hard to accept that wasn't me anymore. I knew it...but sometimes it was just too much sitting in a class with all those terribly well-meaning SLP's...I mean no disrespect - you all were great - but we have lost our voice and trying to learn to speak again is a mighty task and one I hope and pray you never have to learn. It was hard for me to be the center of all that concern and well-meaning pity.

I talk very well using my Servox and love my new T-shirt from Jim Lauder that says “Servox...We have ways of making you talk.” I loved being around people who didn't blink an eye or struggle to understand me, but I was disquieted. And I was disquieted that I was disquieted. I was uncomfortable seeing so many mirror images of myself

coughing and clearing and discreetly and bravely managing while we buzzed and burped and otherwise talked and laughed and flirted and generally carried on as if nothing was amiss. Because something is amiss and it is my voice - it is amissing!!

Although I admit that I bobbed and dodged a bit, the experience was invaluable. I look forward to the next IAL. I suspect I won't be so taken aback by the many mirror images of myself.....

In June of 2006 I wrote this as I prepared to head to Chicago. Clearly my attitude had improved!

*...Make new friends, but keep the old;
One is silver and the other gold.*

When I was a Girl Scout many years ago, I learned that song...meant to be sung as a round. It was best done around a campfire at sleepover camp where you did make many new friends and fortified old ones. I did not love school - I did well enough but always felt just a bit out of place. I was not one of the "popular kids" but I wasn't unpopular, either. Nor, thankfully, was I picked on - which has to be one of the worst fates ever to befall a child. But at summer camp, I was in my element! I was free to re-invent myself...to be bravely non-conformist...even a bit rascally! During the school year I was the Superintendent's daughter, at camp I could be the "Merry Prankster". There is camaraderie in the conspiracy that we feel when we break away from our everyday lives with other people who are doing the very same thing.

Now I have only been to one IAL Annual Meeting, but I have to say there are some similarities! During most of the year, we are in the minority. We, hopefully, aren't being picked on, but we certainly are different from just about everybody else around us. I use an EL [electrolarynx] and just today, while on the phone, I was called "Sir" (repeatedly). Just for the record I am a woman and I think I do a pretty good job with my trusty Servox. Even my son noted recently, after I had been sick, "You sound good, Mom, like you are back to your old self...which is kind of weird to be able to tell, but I can". I have a lary friend who uses ES [esophageal speech], very proficiently, I might add, whose pet peeve on the phone is being called "Ma'am". It is especially disconcerting for him since he is a hunky 6 ft tall construction worker who rides a Harley. Thankfully he has a very well developed sense of humor.

At the annual meetings and in our local support groups and here at WebWhispers we are not in the minority, we are one of many. Each of these groups serves a little different purpose and we each use them differently, according to our own needs. Even that changes over time. In all these places we are free to be ourselves, to re-invent ourselves, if necessary, and to celebrate what is, for many of us, a new lease on life.

If there is one recurrent theme on the WW List (after the ubiquitous mucus, maintaining a proper seal, and prosthesis problems) it is just how tremendously useful and comforting it is to have this "family".

That got me thinking. Human beings are social animals. We need to belong and we need to be with our kind. And while I completely understand the family metaphor, given the size and disparity of WW these days I wonder if perhaps tribe might not be more appropriate. A tribe is made up of many smaller family groups who all share a common bond. They work together for the common good but have separate roles. They have squabbles among factions, power struggles and tribal councils where the elders try to resolve the issues. I KNOW that sounds suspiciously like one of those reality shows, but to my knowledge, we haven't voted too many off the island!! Seriously, we are a very special tribe. We have been marked in a way that sets us apart from the general population. We have our warriors, brave souls who keep pushing the envelope and live to tell us their latest adventures, we have our teachers and nurturers, we have our medicine men and priestesses who keep our spirits strong and we have our elders to pass along our knowledge.....

As I re-read my first entry back in 2005, it is pretty obvious I was still grieving the changes in my life, but after four and half years of treatments and multiple procedures hoping to salvage my airway or at the least some use of my vocal cords it had become apparent that I was out of options. I had learned in Boston from no less an expert than Dr. Blum that I was likely not a candidate for a TEP due to the radiation damage. Frankly, I was very disappointed and began second guessing myself and all the decisions I had made since my diagnosis. I suspect that I am not the only person to go to an IAL meeting and have mixed feelings. I had come a long way to acceptance by 2006.

Today in 2017, I have no such qualms. I have been to Chicago IL, Burlington VT, San Mateo CA, Spokane WA,

Townson MD, Dallas TX, since then and I am genuinely looking forward to being in Newport News, VA this June. Nowadays, I make a real effort to attend, even though it is expensive and I missed a few because I couldn't afford to but I try to plan accordingly and it is pretty much my one big trip every year. These are my people, my tribe and I treasure their company.

WebWhispers, in conjunction with some of the vendors, offers scholarships to attend the Voice Institute and some financial aid is also available to help defray the cost of travel, hotel accommodations or registration fees. We will be posting complete information on how to apply on the daily list shortly and Tom Whitworth addresses the various options in his column this month as well. Occasionally, in the past we have had fewer applicants than grants available so please, if finances are the primary obstacle to your attendance, let us know, review what we offer and apply.

Additionally, if you are traveling alone and want to share a room, we can sometimes link up folks to room together. I often try to stay an extra day or two since the discounted IAL room rates are available for a full week and that way I can try to catch up with friends and see some of the local sights that I don't have time for during the actual meeting. The best thing is once you get there you have none of the usual concerns we all share when leaving our home territory like what do I do if my prosthesis starts leaking and I need an SLP or need medical attention or my EL decides to go wonky or I blow out my HME & baseplate. We are surrounded by experts and everybody knows the drill!!

In closing I want to share a story from last year's meeting in Dallas. I made a dear lary friend on a WW cruise back in 2003 and we have tried to get together every few years since then. It is not always easy since we live, literally, worlds apart. She and I both love musical theater so in Dallas we went to see Bullets Over Broadway – who doesn't love tap-dancing hitmen? Now the theater was a ways out of town and we braved public transit to get there but having learned that the stop that we had to come back to at 11PM was noted for a particular kind of business, shall we say, we opted for a taxi back to the hotel. Linda and I were talking to the amiable taxi driver and he says, "I hope you aren't offended but what happened to you guys? You sound kind of like aliens." I use a Servox; Linda has a TEP. Of course that meant a whole big conversation but it was fine and kinda funny.

So next morning I go down to the front desk to ask TJ, the concierge, a question and run into Dorothy and Tom Lennox from Luminard. We are chatting and Dorothy asks, "You're from New England, right?" And I reply, "Yes, Maine." The concierge, a terrific local guy who had been so helpful to me earlier, bursts out, "I knew you had an accent, I just couldn't figure out where it was from!" HAH - from being an alien to having an accent....priceless!

The next day as more and more of "us" began to check in I went up to TJ at the desk and said, "Better call the Men In Black, this place is crawling with aliens". He didn't miss a beat and said not to worry, like all good concierges, he had Will Smith on speed dial.

I always come back with new information, new friends, new stories and great memories. Hope to see you in Virginia!



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

This month's question didn't quite meet expectations as far as quantity goes but we did get some good ones. Suffice to say that the IAL has changed over the years with a record 455 attendance in Reno, 1999, to probably less than 100 at meetings the past few years. Many have attended numerous times. In my case this will be my 20th and others have been to many more. Barbara Nitschneider, IAL Secretary, has attended about 40 by my count missing only 2 due to illness.

~Jack

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

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

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

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

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

David Kinkead – Peoria, AZ
Class of 2013

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

Lynn Foti - Akron, Ohio

May 2009

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

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

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

**Linda Palucci – Kissimmee, FL
Sept, 2002**

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

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

**Mike Smith – North Augusta, SC
September 11, 2008**

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

Alyssa Dodd – Lexington, KY

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

R McGrath – San Francisco, CA

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

Richard Crum – Jeffersonville, IN

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

Bob Bauer - Hayward, CA
Class'08

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

John Haedtler - New Mexico, USA
2001

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

Max Hoyt - Lewes, DE

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

Tom Whitworth – Powder Springs, GA

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

Roger & Carol Johnson Richland, WA

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

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

Johnnie Dontos – Woodway, WA

I have been to the last four IAL meetings, and have had a great time at every one. Within fifteen minutes, after I

checked into the hotel, at the first meeting that I attended in Spokane, I met a group of larys who introduced me to the wonders of the Electrolarynx. Being introduced to the EL made a sea change in my life, because, I was finally able to carry on an intelligible conversation for the first time since becoming a lary; my prosthesis didn't work so well for me.

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

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

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

Patrick Kerr – Miramar, FL
Class of 6/11

Next Month's question is:

**“Has your laryngectomee affected your vacations or how you travel?
If so please tell us how. If not can you share a special trip or adventure?”**

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



Dear Lary

Noirin Sheahan

The Growling Ladies (and Men's) Club

Living in Ireland, I haven't yet been to an IAL meeting, but I've attended annual get-togethers of laryngectomees here in Dublin. The most recent happened to be yesterday. What struck me most of all was how easy and friendly it felt. Some new faces and many familiar ones. Some people sit silently, looking stunned, forlorn. Others are chatting

happily. Those who were newbies last year look better and stronger now and most of them have moved from the stunned and silent grouping to the chatty and confident one.

It hasn't always been so easy for me. At my first meeting, the therapist asked a more experienced Lary to tell me a bit about how he had adjusted to laryngectomy. I was delighted to hear that his speech was quite clear and I could even make out his Irish accent! But to my dismay, his wife repeated everything he said, word for word, like an interpreter. I told her that I could understand him perfectly well, but to no avail. It was probably a habit she had developed in his early Lary life when he couldn't be understood. But she had got stuck in her role as interpreter. I resented these patronising intrusions and grew quite frustrated with her. So my first "Lary to Lary (and wife)" conversation didn't give me much pleasure.

Next the therapist introduced me to a lady who had only recently had her surgery. She looked totally shell-shocked. I'm sure we all remember those early days, as our emotions staggered to catch up with our new reality. When I tried to engage her in conversation, she floated the electrolarynx vaguely towards her neck, pressing it now and again at random as she replied. No sounds came from her mouth but her eyes stared into mine in dumb entreaty that I understand the words that her lips were mouthing. It was quite distressing to witness. I could offer her nothing but a few minutes of half-smiles and vague nods of encouragement.

At my next meeting I recognised two men who had been in hospital around the same time as myself. I felt an immediate kinship with them, and would have loved to find out how they were coping and make some sort of connection. But all we did was smile at one another. Was it shyness that kept us apart, or not being confident with our ELs? One way or another, we let this precious opportunity slip away. Instead I found myself sitting beside a woman who was a newbie and had forgotten her electrolarynx. She was keen to connect and mouthed her words enthusiastically. I could only make a vague guess at what she was saying and after several minutes of this found myself getting quite frustrated. Eventually I found some excuse to escape and meet with some other, more experienced Larys, so came away from the second meeting somewhat cheered.

On my way to the next meeting I was hesitating in the middle of a busy corridor as I couldn't remember where we were meeting. Then a lady passed by with a distinctive TEP growl. I was relieved that she had solved my dilemma and all I had to do was follow her. But this gave me a weird feeling of both kinship and aversion. There was the thought "We're in the same club" and also the thought "This is a club I don't want to belong to." I was quite disappointed by this reaction as I'd been congratulating myself on how well I'd adjusted to Lary life. It was a let-down to see just how far I still had to go.

Once I got over that bad start, I enjoyed much of the rest of the meeting, especially seeing that the two men who had been in hospital the same time as me were there and looking stronger this year. One still seemed silent, sad and withdrawn. The other was much happier and confident. He was now using a TEP and very pleased with his new voice. I recognised some other faces too. The lady who had been mouthing enthusiastically the previous year was now using her EL quite confidently, and we chatted happily for a while.

This time there was another newbie keen to make connections, but not yet skilled with the EL. From a distance I didn't think she was a Lary at all and presumed she was accompanying her husband or a friend. She was holding the attention of two or three people and appeared to be chatting fluently while gesticulating with her hands to illustrate her words. But then I noticed an electrolarynx in one hand and that she was, every now and again, placing that against her cheek to say a few words. The people around her were nodding and smiling, captured within her delusional pre-laryngectomy communication habits. What a graphic illustration of the shock we go through! This lady was obviously quite sane, bright & cheerful. I could have sworn she was relating some very funny anecdote. The only odd thing was that there were no sounds coming from her mouth.

At the most recent meeting that lady was using a TEP and her communication habits had adjusted to laryngectomy. Though she struggled to make herself understood, she was no longer holding people spellbound with silent anecdotes. That is the happiest aspect of these meetings – seeing how people grow into their new lives. Even the unhappy aspects of the meetings are instructive. The shell-shocked lady of my first meeting helped me acknowledge the depth of the shock we experience in losing our voices. The wife who kept repeating her husband's words showed me how much I resent being patronised and how grateful I am that my friends and family haven't attempted this. The lady who mouthed her silent anecdotes let me acknowledge that this is one burden I hadn't inflicted on others. The distinctive TEP voice that led me to my third meeting clarified the job I have to do – drop the aversion, drop the

regrets, let my heart open to the growling ladies (and men's) club!



My Neck Of The Woods

A Member's Experience

First IAL

I asked the Speaking Out question about attending the IAL meeting in June in hope that some responses would inspire others, or at least nudge them a little bit to try this new experience. For some of us it was life changing and it has kept me returning since my first in Winnipeg, Canada, 1991. You can read about that in more detail in this column from April 2013.

~Jack

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

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

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

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

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

I could ramble on and on about what you may see and learn at an IAL meeting, the friends for life that you may meet, and the very possible and positive effect it may have on you. But instead I would like to share something I started writing as I sat in the Winnipeg airport waiting for my plane. I finished it on the plane before I arrived back in California; a work of tearful joy that I experienced from my first IAL. In 1995 the IAL used the title of that poem as their thyme for the San Francisco Voice Institute and Annual Meeting.

Songs Waiting To Be Sung

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

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

**The horizon frames a vivid red sun
So deceiving without time and direction.
Does it rise with the promise of tomorrow,
Or linger with the light of yesterday's dream ?
Drifting clouds mask its features,
Gently pushed by winds of uncertainty.
Soft shadows float slowly by
Like gentle lullabies caressing the soul....**

**Or the dark silent rage before the storm.
Inside each of us is a song, waiting to be sung.**

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

Jack E. Henslee



Whispers On the Web, and the whole of the organisation is of such great help to Laryngectomees world wide , I wanted to offer my thoughts on the confidence the organisation brings, in the way of a poem. I have written it in the Italian Villanelle Style.

A BEACHMASTER CALLED WHISPERS

By Len A.Hynds

I regarded my life, like 'D' Day,
when we first went ashore in fright.
'Whispers' was there to point the way,
standing so firm, amidst the fray,
so conscious of our nervous plight.
I regarded my life, like 'D' Day.

" Get off the beach with no delay,
beneath those dunes, within your sight."
' Whispers ' was there to point the way,
Saying firmly, " Your here to stay."

Encouraging those with faces white.
I did regard my life like 'D' Day.

" Get off the beach" I heard him say.
Bullets, minefields, fearful spite.
'Whispers ' was there to point the way.
Beneath those dunes we safely lay.
He stands there still, a shining light.
I regarded my life ,like 'D' Day.
'Whispers ' was there to point the way.

I have called 'Whispers' him, but of course our leading lights are ladies, so it could be changed easily enough.

[Editor's note- Given that our founder, Dutch, was a military man himself, I think he would have loved this poem and as such, "Whispers" is perfect just the way Len has immortalized him.]

[reprinted from WotW July, 2010]

Bits, Bytes and No Butts!



Frank Klett

How Much Can I Trust Information on The Internet

Since the recent U.S. presidential election many questions have been raised on the impact of technologies on the end result. President Trump has termed much of the internet information and that of the media itself as being "fake news". There are those that agree with him to the point of digging deeper into the sources and credibility of many various news reports. It has also brought to the front the fact that our media news sources are paid for services and thereby prone to report what sells. Of course this should not surprise anyone since we, the consumers, seek information from sources who tend to report on our areas of interest.

I have heard more than one person quote a news item as gospel since they saw it on Facebook. Oh my, seems we have a true issue of credibility here...not with Facebook itself but with the control over the information reported there. Other than paid advertisers we have little to rely on for truth worthiness.

The following paragraph was submitted to Leo Notenboom who is a respected source of technology information and his reply follows it. His reply points to many things to be considered before taking the news as valid.

"I'm a computer science student, and I'm confused about the extent to which I should rely on the internet for the information about computers. For example, if we take the term "IP address," then a lot of information has been provided on (for example, Wikipedia), which is a lot more than what is written in the recognized books. My question is

how much should I rely on the web for such technical aspects?"

<https://askleo.com/how-much-can-i-trust-information-on-the-internet/>

Have our systems of password rules made us less secure?

If you consider that certain (many) websites require that our passwords be structured according to certain criteria then you have already given anyone with the desire to "crack the code" with the ground rules for what to look for in both length and content.

Bob Rankin has written an excellent article on password rules and how most tend to weaken rather than strengthen our online security. Read on to consider your own password structures:

http://askbobrankin.com/are_password_rules_making_us_less_secure.html

Improve your online security by using an alternate DNS

Improving your system speed (actually INTERNET searching) is through the use of an Alternate DNS (domain name service). Your INTERNET provider already provides you with a DNS, however there are other DNS's available which have streamlined the search functions and are more efficient in finding your information. Most are free and install with little effort. While this may all sound very technical and not for the mere human computer user it is actually quite easy to set up and once it is set up you never have to think about it again. Again Bob Rankin has an article to steer you through the process if you feel the change is what you would like to try:

http://askbobrankin.com/you_want_faster_and_safer_internet.html

The WebWhispers Facebook Group is our meeting area along with the Webwhispers Forum. Many of our members are on Facebook, so we knew it was time to have a Facebook home. We invite all our members to join us in our Facebook Group and the Forum.

If you are not a Facebook user then you might enjoy a visit to our Forum. Hosted on Delphi, the Forum is a Members only group which limits the access to only those of our hole in the neck group and is our open area to ask questions and exchange thoughts. There are many categories of interest and you'll find the answers to many of your questions. If you haven't already joined the forum you can simply contact forum managers Bill Cross or Mike Rosencrantz for any questions you may have.

FORUM: <http://forums.delphiforums.com/webwhispers/start>

And for our newest members remember to visit our library for answers to many of your questions. Our Library is one of the most complete collections of information aimed specifically at the Laryngectomy Community...in fact it may be the only one. Taking the time to browse the library and become familiar with the contents will make it even more useful for when you do need to find out a piece of information.

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

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

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

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