



Whispers on the Web

A Monthly Online Newsletter for WebWhispers

May 2022



From The Editor's Desk

See You at the VII!

If you plan to attend the International Association of Laryngectomees Voice Institute in Charlotte, NC June 15-18, 2022, now is the time to make any arrangements you haven't already handled.

Tips on making the trip more affordable:

1. Drive if you are close enough.
2. Share a room.
3. Apply for a WebWhispers scholarship to defray part of the cost of your trip.

Details are still being worked on but now is the time to apply. Priority is normally given to first time Voice Institute attendees, but others are also eligible depending on who applies and how much money we have to work with.

Requirements include: 1) registration for the Voice institute, 2) be a member of WebWhispers, and 3) complete a scholarship application at the link provided below.

Membership Application: <https://webwhispers.org/join-us/>

Scholarship Application: <https://webwhispers.org/scholarship-application-form/>

Please note: The WebWhispers Dinner will be held on Thursday night, June 16. Final details will be posted in the next few days to the list and to Facebook, including information on purchasing tickets.

We hope to see you in Charlotte!

Enjoy, Laugh, and Learn,

Tom Whitworth
WebWhispers President

Whispers on the Web May 2022

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Voice Points is written by professionals for the lary community and is coordinated by Kim Almand M.S, CCC-SLP and Erin Guidera, M.S., CCC-SLP. Please contact them with contributions or questions at Kalmand@uthsc.edu or Erin.Guidera@moffitt.org

Better Speech & Hearing Month

Better Hearing and Speech Month (BHSM) is celebrated every May. BHSM's goal is to bring awareness to various communication disorders and the professionals who make it happen. In this article, we focus on some of the roles of speech-language pathologists who work to facilitate improved quality of life and communication for those with head and neck cancer.

According to the American Speech-Language-Hearing Association (ASHA), "Speech-language pathologists (SLPs) work to prevent, assess, diagnose, and treat speech, language, social communication, cognitive-communication, and swallowing disorders in children and adults." SLPs can work in a variety of settings such as but not limited to: hospitals, skilled nursing facilities, schools, and outpatient clinics. To be a licensed SLP an individual must obtain a bachelor's degree, a master's degree in speech-language pathology, and complete a clinical fellowship year.

A medical SLP works in a healthcare setting, often in nursing homes or hospitals. These SLPs assess and treat areas such as speech, language, cognitive, and swallowing. In the medical setting, SLPs work closely with doctors, nurses, occupational therapists, physical therapists, and a variety of other healthcare professionals to develop treatment plans that best support their patients and their needs. Swallowing is an area often assessed and treated in the medical

setting, often at the patient's bedside and/or with instrumental swallowing evaluations such as a modified barium swallow study (MBSS) with radiology. The SLP evaluates the patient's swallow to make necessary diet recommendations based on the results of the swallow and patient's current medical status.

SLPs are also heavily involved in evaluating and treating individuals that undergo a total laryngectomy. The SLP is involved in a pre-laryngectomy evaluation. During this appointment, the SLP explains what the surgery is and how the anatomy and physiology of swallowing and breathing will alter. How to properly take care of the stoma and options for communication and voice restoration are also reviewed during this appointment. The SLP will explain what a tracheoesophageal voice prosthesis (TEP) is, and if the patient is a candidate for a primary or secondary puncture. After the total laryngectomy, the SLP will visit the individual during their inpatient hospital stay. These visits involve checking in on how the individual is recovering after surgery, reviewing the components of pulmonary rehabilitation, and practicing using an electrolarynx. Once the patient is discharged from the hospital, they will be evaluated and treated in an outpatient setting. The first outpatient post-surgical appointment involves how to order necessary total laryngectomy supplies (and TEP supplies if applicable), reviewing swallowing changes,

and practicing with the electrolarynx. If the patient received a primary TEP puncture and medically cleared by the surgeon, the patient will practice using their TEP to talk. An SLP will also periodically see these patients as necessary on an outpatient basis for ongoing therapy for voice, communication, and swallowing. If the patient has a TEP, the SLP will change their TEP as needed.

Tiffany Povlak, BA, is a student in the University of South Florida Speech-Language Pathology graduate program completing an externship clinical rotation at Moffitt Cancer Center in Tampa, Florida under supervision from Erin Guidera, MS, CCC-SLP, BCS-S.

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Better hearing and speech month 2022. (n.d.). American Speech-Language-Hearing Association | ASHA. <https://www.asha.org/bhsm/>

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Medical Speech Pathologist



What Society Thinks I Do



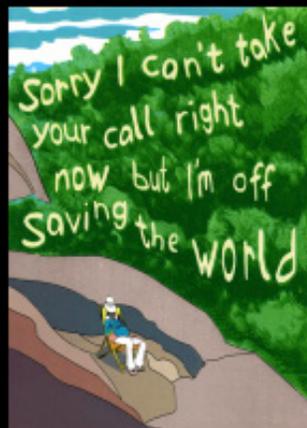
What My Parents Think I Do



What My Boss Thinks I Do



What My Patients Think I Do



What I Think I Do



What I Really Do



Member Contributions

Choices, Challenges and Changes

The Greek philosopher, Heraclitus, is quoted as saying “change is the only constant in life.” I think that all of us in the laryngectomy field – patients, caregivers, and clinicians alike, have come to learn that statement to be very true. I have learned that how we react when faced with inevitable change can define how we recover from or embrace that change. One of the things I have loved most about my nearly 30-year career working with laryngectomees and caregivers is having the privilege of witnessing the incredible strength, fortitude, resilience, and courage that people, when faced with laryngectomy, overcome when challenged by such dramatic life changes. The courage of those I have cared for throughout my career has been my foundation to finding my own center, balance, and perspective when facing far less consequential changes and challenges in my own life.

Many of you may recall that I spent several years fighting to improve reimbursement for indwelling TEPs since Medicare changed the

rules in 2010. From 2010-2018, I worked with many other advocates including TEP vendors, physicians, ASHA leadership, and survivors, attempting to improve coverage and minimize financial burdens on laryngectomy patients and clinics providing care.

In the summer of 2018, our team of advocates met with leaders at The Centers for Medicare and Medicaid at the Department of Health and Human Services outside of Washington, DC. We fought hard, explained the problems in reimbursement, presented evidence, demonstrated TEP speech and care, and discussed changes needed by Medicare to support laryngectomees and allow continued access to TEP products and care. Unfortunately, our efforts were not prioritized by leadership at Medicare, and our many years of hard work stalled out at the highest levels.

Despite a united best effort by all stakeholders, insurance coverage and access to affordable TEP supplies remain issues impacting a patient’s voice rehabilitation choices and access to care. It is my hope that those efforts to make changes

to benefit all were not in vain and that at some point soon, Medicare will hear our call and rise to the challenge of change.

Not long before that meeting at Medicare in 2018, I made dramatic changes in my professional focus as a speech pathologist. I changed jobs and patient populations, and I learned new areas of specialty in the field of Speech-Language Pathology.

Leaving my position in laryngectomy care was a very difficult change for me personally and professionally. Yet, my passion for advocacy for laryngectomee issues has remained at the center of my life's work, despite my professional change in focus. With an intimate understanding of both the financial burdens placed on laryngectomees and the numerous obstacles to TEP voice restoration, I decided to develop something for patients to use as a new voice option.

My goal was to create a non-surgical low-tech affordable voice rehabilitation option that would allow all laryngectomees access to a natural sounding voice, regardless of insurance coverage or socioeconomic status. I didn't have to look far to find such a device, I just had to look backwards and think change!!

Who remembers the Tokyo Speech Aid, a pneumatic device used for speech rehabilitation?

Well, for those of you who have no idea what that is, it is basically like a musical instrument with a reed on the inside and a mouthpiece on the outside that when placed over the stoma, creates a fairly natural sounding voice.

The Tokyo device is no longer available for purchase; and even if it were, the design is very outdated for modern use in conjunction with HMEs, baseplates, tubes, and asymmetrical stoma anatomy from prior treatments or reconstructive surgery.

So...I have been working on a newer, more updated, user friendly, inexpensive, and accessible version of a pneumatic device. I am excited to announce that I was awarded a US patent for my design on December 21, 2021, and I am very close to having a pilot product that is ready for demonstration. Finally, there are long overdue new choices coming soon to the area of voice rehabilitation! In addition to my product, there are several other researchers, developers, and pioneers working on exciting new voice rehabilitation devices as well. I look forward to demonstrating my device for you soon, and I hope that it will offer more choices to those of you who have overcome tremendous change and challenges. Stay tuned!!

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THE SILENT PARTNER

My First Year as a Laryngetomee

Poems by Aaron Wayne

They're all working hard in the hospital's bowels, with kindness and caring and sterile white towels.

They fight off our maladies, fevers and curses. They're our guardian angels –

...also called Nurses.



Smoke Gets in Your ~~Mind~~ Larynx

That filthy thing, that cigarette –
I swear it's gonna kill me yet!
But every time I try to quit,
I seem to stop, then have a fit,
And light another dirty weed,
to suck that smoke with hearty greed.
But, that day still fills my dreams,
and oh, so far away it seems –
when I can smile with teeth so clean,
and not a trace of nicotine.
When my breath will smell so sweet
and I can taste the things I eat –
But for now, while I await
arrival of that wondrous date,
I suppose you'll have to let
me bum another cigarette.

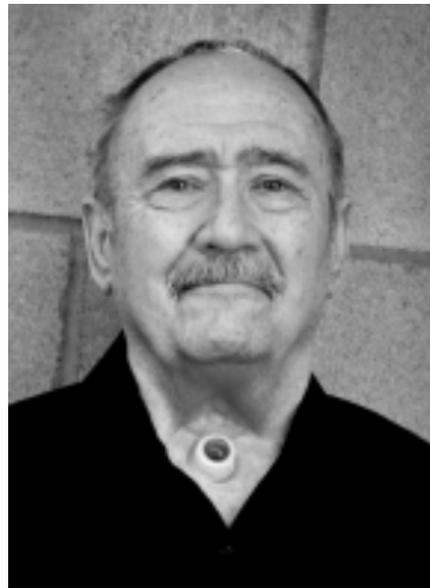


Photo Credit: Chris Russo

About the author:

A retired customs broker, Aaron and his wife Shelley live near Los Angeles with their two rescue cats, Junior Prince Sparky and August I. Aaron does the cooking and Shelley runs the house. The cats run everything else.



You Deserve It

"We accept the love we think we deserve."
– Stephen Chbosky

It has been a while since I have written anything for Whispers on the Web. It seems like forever. I told Kim I would write something last month, but it did not happen. Well, I am back and so grateful to be back.

Since my last article I have been thinking a lot about what I would write when I got back to writing. The one theme that stuck in my mind was about being kind to oneself. That may seem a bit strange to hear as many if not most of you have a significant other, a spouse, sibling or offspring that has trudged this journey into laryhood with you from start to finish.

I have heard from a few of you that the expedition into laryhood has been a solo undertaking. Like my own, there are those of you whom have only your own footsteps to follow on this journey.

My wife died in 2015 prior to my diagnosis of this life changing experience and surgery in 2017. Two women I had dated for a while passed away also. I had cancer and yet I am alive.

It is funny that looking back over my life I never found that I was loved the way I wanted to be. Not as a child, an adult or even as a spouse. My expectations of how I should be loved were always different than my reality.

I have always believed that if I don't like what I was getting in life I need to look at what I am putting into my life. I have also believed for the better part of my life that I can't love anyone else until I can first love myself.

That brings me to where I am today. I read about people struggling with depression because of their new lary life. Or not being able to except this new "normal" and wondering if their survival was a blessing or a curse.

For me, my survival is a true blessing. I have never been happier in my life. One key to this happiness is my ability to accept that "these are the cards I have been delt" now to play them to the best of my ability.

When I was growing up birthdays and holidays, such as Christmas were a big deal. My family was not the type to go through the year saying "I love you" at the drop of a hat, but they said it through gift giving on holidays such as a birthday or Christmas. My mother's birthday was December 23rd and if I or any other family member forgot it or failed to acknowledge it, well let's just say they would not do it two years in a row. Because of her importance of her birthday, she was always very acknowledging of other people's birthdays. I was fortunate to have women in my life as an adult that were just as celebrative of my birthday. When all these women passed away my birthdays would change forever.

For my first couple of years as a lary I pretty much ignored my birthday and Christmas (I was actually in the hospital on Christmas day when I had my laryngectomy). If you can help it, never be in the hospital on Christmas day! I had to call a friend from work to come help me because I could not find any staff.

This all brings me to my quote this month, "We accept the love we think we deserve." And my

belief that to love another you must first love yourself. So, beginning in Christmas of 2020 I began working to make my birthdays and holidays special. That year I did nothing for my birthday, and Christmas I was not planning to do anything special. Before Christmas my thinking changed. I had been shopping at Costco and as usual I always look at the big screen TVs when I first go in. I decided then that was going to be my gift to me.

People that know me know I do not make impulsive purchases and rarely splurge just for the sake of splurging. But at that time, I decided to make my birthdays and holidays special and something to look forward too. Since I had not done anything for my birthday, I decided I would add the money I did not spend on my birthday to what I would spend for me on Christmas and buy the TV. I am so glad I did. I love sports and movies and this TV allows me to enjoy both as I never did before. This is the type of thing I would have done for my wife when she was alive but never for myself.

I have worked so hard preparing for my retirement becoming very disciplined with my spending and limiting spending on “wants” vs “needs.” It was very good to make that kind of a purchase for something I wanted and not necessarily needed. Most of all it felt good to feel I deserved to allow myself to satisfy a “want.”

This year for Christmas I had not spent much at all on my birthday, so I decided to go to Las Vegas for Christmas and see the Las Vegas Raiders play the Denver Broncos in their new stadium. I sat about 5 rows from the field and stayed in a very nice suite while I was in Las Vegas. For my birthday this year I went to the LA Kings game and again sat close to the ice, and it was the best game I ever went to.

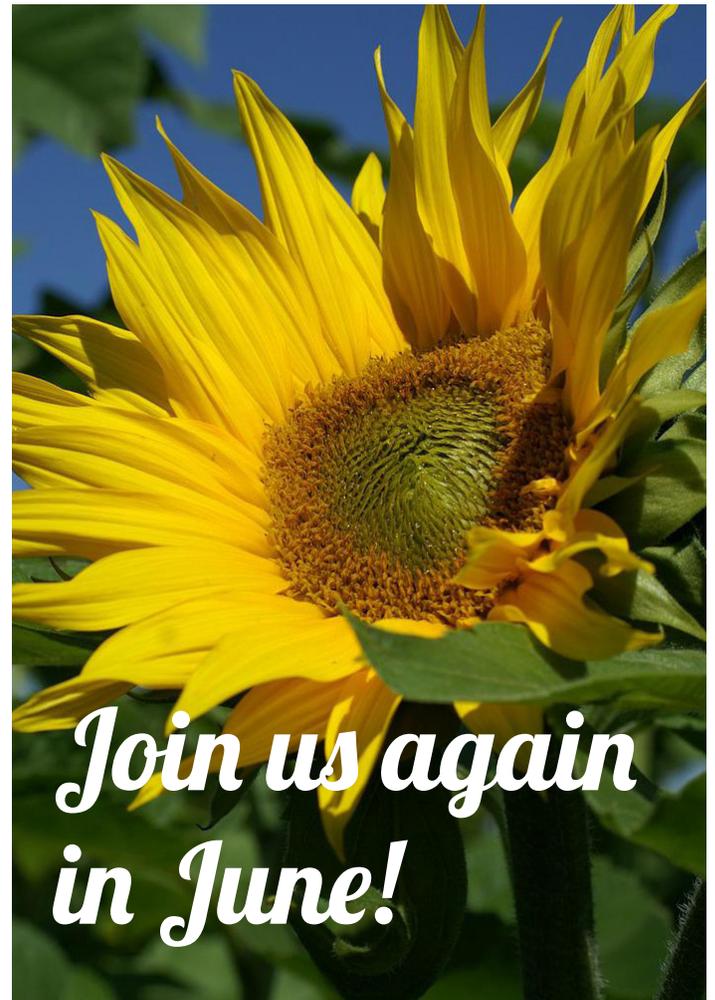
I would encourage anyone to find what makes you happy and do it in a memorializing way and create a live and memories that are fulfilling to you. I do not just recommend this for those by themselves. When my wife was alive, I got so much pleasure out of making her birthday or holiday something special. We were not rich so sometimes the experience was more frugal than

others. But when I could I loved to indulge her with something she would not necessarily do for herself. Now, being alone I am getting the same pleasure out of doing the same thing for myself. And surprisingly it is a challenge to find something that indulges me as much as my last indulgence did. But it is a fun challenge.

The things I shared above are activities that interest me. I have little or no desire to travel the world or even the country. We traveled a lot growing up. But if that is your interest that could be your splurge.

Splurges do not have to be expensive endeavors. When my wife was alive, we engaged in life fulfilling experiences that were many times very inexpensive such as going to a museum or botanical garden.

The important thing is to reward myself for just simply being alive. Enjoy what makes me happy so I have a reason to look forward to my birthday or Christmas.



*Join us again
in June!*