

Whispers on the Web

A Monthly Online Newsletter for WebWhispers

March 2023

Welcome, friends, to the March 2023 issue of Whispers on the Web! We are glad you are here. In recent years, we have literally lost five of our regular writers, which has made holding things together quite a challenge at times. That's where you come in and that is why we need you! If you have something to share, please let us know at editor@webwhispers.org. We will review all submissions and decide which ones fit each issue best, with any necessary edits.



For many laryngectomees, sharing our story may seem a little awkward at first, but no two of our stories are exactly alike. When we read about one another, we identify with the similarities that resonate with us and are just as likely to learn from what is unique about so many of our journeys. We want to hear about life beyond being a laryngectomee, as well. We were already people before boarding the lary train. The most important thing is that we get to know you! We get to know one another and that is what makes us a family.

In this issue, as I do this time of year, I talk about something truly near and dear to my very soul, the International Association of Laryngectomees Annual Voice Institute, which takes place in St. Louis in only a couple of months. Links are provided on registering for the conference and also for applying for scholarships available to members of WebWhispers. Joining WebWhispers is easy and free.

In Voice Points, Erin Guidera, MS, CCC-SLP, BCS-S of Moffitt Cancer Center in Tampa, FL, provides in-depth information on the causes and management of Xerostomia. There is more to xerostomia than just a dry mouth.

We also meet a new writer, Brooke Elkan-Moore of California. Brooke is a great example of one who kept on moving on post-laryngectomy. We look forward to more from Brooke in the coming issues of WotW.

I hope you enjoy the issue. We always welcome your comments, suggestions, and submission for the newsletter. ~ Tom Whitworth

Whispers on the Web March 2023 Contents

From The Editor's Desk
We're Back!

The Scuttlebutt
Meet Me in St. Louis!
Tom Whitworth

VoicePoints
Xerostomia: Causes
and Management
Erin Guidera, MS, CCC-SLP

Member Contributions
Life as a Laryngectomee
Brooke Elkan-Moore

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
Kim Almand, Managing Editor
Tom Whitworth, Editor

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



Meet Me in St. Louis!

Some things we just have to do. They are deeply ingrained in us and we just can't help ourselves. For me, lary nerd that I am, it is talking about the *International Association of Laryngectomees Annual Meeting and Voice Institute*. This is a topic I've written and spoken so much about that not only would I be remiss in not doing so, but some in the community who know me best would wonder if I had bitten

the dust. I haven't and I'm excited about being in St. Louis for the 2023 Voice Institute. I guess I may be the quintessential IAL Voice Institute "groupie".

The effect my first Voice Institute had on me as a new laryngectomee can never be forgotten because the benefits were truly that profound. The VI has its own special spot in my brain and in my heart. The short story? Without what I learned there and the overall experience, I know that my life as a laryngectomee would not have turned out as well as it has. Things now would be sadly different and I can't even let my mind go there. I might not even still be here, and I don't say that lightly. Without the VI, there is surely no chance that I, a TEP speaker, would be in my third year as pastor of a church. They actually pay me to talk and that never even happened before!

I learned about the event only a month or so in advance and thought I didn't have enough time to pull it off. To say that I arrived on a shoestring would be less than truthful. My shoestring had three repair knots and was reinforced with duct tape! With knowledge of a little financial assistance and hard-core determination, I did make it to Buffalo for the event.

In the nine years since, I have not missed a VI and the upcoming *IAL Annual Meeting and Voice Institute* in St. Louis, MO May 10-14, 2023 will be no exception.

If you are a laryngectomee or caregiver, there simply is no better place to be in the second week of May this year than the IAL Voice Institute. Director, Caryn Melvin, Ph. D, has recruited an exceptional faculty as always, and I can promise you an education you won't find anywhere else. SLP grad students will benefit and practicing SLPs can earn more CEUs in the amount of time than any other place I am aware of. Suppliers of the products made especially for us will be there, too. Whether you're a newbie or an "Old Salt", this is the place to learn about new products that enhance our quality of life.

I truly hope to see or meet you there, especially those of you who think you can't make it happen! If you haven't already planned to attend, do so now. Click the link here for details on the event

and to register: <https://www.theialvoice.org/-voice-institute-annual-meeting>

Need help getting there? WebWhispers has scholarship funds available for WW members who are recent laryngectomees and other members who have not previously attended a Voice Institute. Additional applicants are considered based on other criteria, but only after newbies and Voice Institute first-timers have been assisted with attending the event. SLP graduate students are also encouraged to apply as are caregivers, along with their laryngectomee loved one.

How to apply:

1. Be or become a member of WebWhispers. Use this link to join or to update your information: <https://webwhispers.org/join-us/>
2. Scholarship applicants must first register for the Voice Institute before applying and all awards are distributed at the WebWhispers Dinner on Friday night, May 12, in Saint Louis.
3. Click here to complete and submit the WebWhispers Scholarship Application: <https://webwhispers.org/scholarship-application-form/>

For scholarship questions or information on ways to reduce your cost, email us at scholarship@webwhispers.org or message us on the WebWhispers Facebook Group.

The WebWhispers Annual Awards Dinner is our only face-to-face event of the year. Details are still being worked out but will be available very soon. Information on the dinner and how to register for it will be posted on our mailing list and Facebook page just as soon as those details are finalized.

Come! Meet us in St. Louis!

***Enjoy, Laugh, and Learn,
Tom Whitworth
WebWhispers President***



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

Xerostomia: Causes and Management

Many healthcare professionals consider the term “xerostomia” to simply mean dry mouth. However, there is a distinction between xerostomia and clinically significant salivary hypofunction. Xerostomia is a subjective complaint of dry mouth, whereas hyposalivation is an objective decrease in salivary flow. The clinical method most often employed for the diagnoses of salivary dysfunction is a sialometry test. Xerostomia is not a disease but rather the result of an underlying medical condition or treatment effect. While there is a common belief that salivary hypofunction is an age-related condition, it is more commonly related to health conditions, hydration and medication effect.

Health conditions that can lead to xerostomia include:

- History of radiation (particularly to the mouth or throat)
- Parkinson’s disease
- Alzheimer’s disease
- Stroke
- Neurosurgical operations
- Brain tumor
- Oral surgery
- Depression
- Dehydration

There are also more than 500 medications that can lead to xerostomia. These are known as xerogenic drugs.

- Common xerogenic medications include:
- Antihistamines (e.g., Benadryl, Claritin, Zyrtec)
- Antidepressants (e.g., Zoloft, Flexeril, Elavil)
- Antiemetics (e.g., Anzemet, Domperidone)
- Antihypertensives (e.g., diuretics, ACE inhibitors, beta blockers)
- Antispasmodic medications (e.g., Dicyclomine)
- Antireflux medications (e.g., PPIs)
- Parkinson’s medications (e.g., Levodopa, Artane)
- Sedatives (e.g., Amytal, Valium, Lunesta)
- Analgesics (e.g., Opioids, Morphine, cannabis)
- Chemotherapies

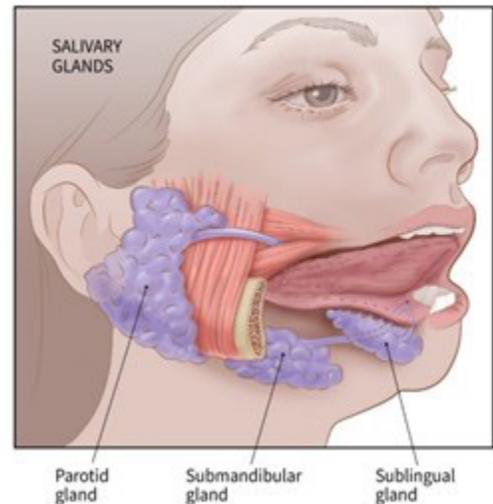
Xerostomia can affect an individual’s overall quality of life in multiple ways. These include difficulty swallowing, alterations in taste, avoidance of foods (e.g., dry, acidic, spicy), poor sleep quality, poor retention of dentures, denture-related sores, altered speech, and oral discomfort. Hyposalivation can also contribute to suboptimal oral care and increasing the risk of dental caries, periodontal disease, and food retention in the teeth/dentures.

Toothbrushing and oral rinsing after every meal is recommended, as are regular visits to the dentist to prevent oral disease.

The treatment of xerostomia depends on the underlying cause. If the issue is dehydration, then increased hydration is needed. If the cause is medication, a discussion with the prescribing healthcare provider regarding dosage and possible changes in medication may be beneficial. Dietary changes can also be helpful including reduction in alcohol, caffeinated beverages and tobacco. Symptomatically, saliva substitute sprays and gels can coat the oral mucosa and reduce frictional irritation. These can also improve oral discomfort during sleep when salivary flow can decrease or cease. Numerous commercially available saliva products are available including rinses, melts, gums, and oral sprays (e.g., Biotene, OraCoat, XyliMelts, Lubricity, Oral Balance). Use of Xylitol gum can also stimulate saliva flow. If the environment is particularly dry, maintenance of optimal air humidification is useful, especially during sleep. There is also some evidence to suggest cholinergic medications (e.g., Pilocarpine) can stimulate saliva production and can be discussed with a healthcare provider. A speech pathologist can also be helpful in guiding patients through xerostomia management, particularly if it affects speech or swallow function.

Erin Guidera, MS, CCC-SLP is a Board Certified Specialist in Swallowing and Swallowing Disorders (BCS-S) and head/neck cancer speech-language pathologist at Moffitt Cancer Center in Tampa, Florida specializing in the evaluation and treatment of patients with head and neck cancer including alaryngeal voice restoration following total laryngectomy and dysphagia management following head/neck cancer.

*H. Lee Moffitt Cancer Center & Research Institute
erin.guidera@moffitt.org*



<https://www.cancer.org/cancer/salivary-glands-cancer>



<https://oralscience.ca/en/images/protocols/xeros-duotongue>



Life as a Laryngectomee? I Had No Clue When I Started!

Brooke Elkan-Moore, Lary since 2021

Greetings to all my fellow larys. I have been asked to consider doing a regular piece of writing on the trials, tribulations, and adventures of being part of this gang. At heart I am a writer, photographer and passionate gardener who finds that this life affords many opportunities for expression and for exploration of feelings. In this newsletter I hope to offer support, humor, resources and stories about how our lives are able to be richer than we thought, more challenging than any of us knew and how our part in society has much to be valued. So here is a bit of an introduction to my story with more to come as well as some pieces of a less personal nature.

On the morning of January 4, 2021, I woke up at 4 am, took a shower, let the dogs out, fed them, got dressed, grabbed my bag, kissed my husband goodbye and set off on an adventure that I could not imagine. Covid meant that no one could come into the hospital with me and visiting would be restricted (little did we imagine that the craziness of January 6th would lock down the hospital and I would be totally alone) so my friend drove me and let off in the cold dark morning to take a walk that no one wants to make.

I had been at Montefiore Hospital a few weeks before for the biopsy that would upend my life but also save my life. At that time my husband was camped out in the parking garage waiting to bring me home and wait for the results.

In the summer of 2020, I had several episodes of severe sore throat and loss of voice, had Tele health appointments that were unable to resolve the issue. (Lemon and honey are not much of a treatment for cancer.) It continued into the fall and my ability to breathe was becoming compromised with episodes of extremely low oxygen levels. Finally, I took things into hand and reached out to the ENT I had seen the previous year, after a fall resulted in a broken nose. He saw me the same day, scoped me, and left the room. He came back and said "Get in your car and go to the imagining center. They are expecting you."

I credit him with saving my life. By the time I saw him the next morning he had the results and had already arranged for me to see one of the very best surgeons available. This was the first of many times that I have benefited from the connections of doctors to other doctors.

Things moved quickly after that and the biopsy resulted in a diagnosis of chondrosarcoma, tumor of the cartilage of the larynx. In any other part of the body, this is a simple tumor, you go in take it out and done. Not so in the larynx: the only course of treatment here is a total laryngectomy. This tumor type does not respond to either radiation or chemotherapy. Frankly, I had little knowledge of what that even meant.

On the same day as the diagnosis, we met with a

SLP who tried to give us information and a start on what I was facing. It was a whirlwind. She and my surgeon tried to explain what would be happening and what the recovery process would be, but it was a lot of noise that I really could not take in. As it was now mid-December, I asked for surgery to be after Christmas so that we could have family come and tell them the diagnosis and prognosis in person. By that time, I could barely speak, and breathing was only working by taking steroids. The hospital was on alert that I might come in as an emergency before the surgery date.

Unfortunately, I was not able to connect with a laryngectomee before my surgery. I know that would have been an enormous help. Instead, I searched the internet for information. Most everything was about the mechanics of the surgery, what the surgeon would do, and what the result would be. Little was mentioned about the patient experience.

What an experience it turned out to be! Now I can laugh about the first two days in ICU with a roommate who screamed almost 24/7. He had too much voice and I had none, and my nurse had never before seen a laryngectomy patient. Thankfully, the surgical residents were there all the time making sure that I was safe and working through the shock.

Being in a teaching hospital was such a benefit, from the residents to the interns to the SLP students who were kind, respectful and helpful in so many ways. I was humbled by the care I received and grateful for the help and the support.

That is not to say it was all smooth sailing. No matter how large I made the signs that said, "Cannot respond to intercom", every time I rang for assistance, I got the intercom barking "what did I want?" Somewhere in a hospital in the future there is a call bell system that allows for texting. Maybe we can invent one and fund all the future meetings for laryngectomees.

I also had my first encounter with the problems of phone systems that are deaf to anything but

certain pitches of voice. I wanted to have TV but the only way to get it was by phone and, oh yeah, no voice! And the staff were not allowed to do it as you had to give credit card information. So, it was YouTube and Facebook postings to keep me informed.

Over my 14-day stay I learned to adjust a bit, to manage my stoma and to use an electrolarynx and then finally to speak with my TEP! My first words were heard by my husband over a Facetime call and that was my goal. When I got into my friend's car to go home and said "Thank you for coming," she burst into tears.

The two years since have been a time of ups and downs, of progress and frustration, of great joy and immense pain. In future newsletters I hope to share some of what I have learned, some of what I have achieved, and how so many have stepped up to help me in this life transition.

