



Whispers on the Web

A Monthly Online Newsletter for WebWhispers

April 2023



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Greetings to our WebWhispers community,
And a warm welcome to those who may be visiting our site for the first time.

We are at it again this month with a particularly unabashed plug for the International Association of Laryngectomees (IAL) and Voice Institute meeting. This year's meeting will take place in May in St. Louis.

As the largest IAL affiliate club, WebWhispers has been a strong supporter and physical presence at the annual IAL meeting since the inception of our organization. Our annual banquet, one of the most highly anticipated events of the year, gives us an opportunity to meet up with each other in person and put a name to the faces that we encounter online each week.

Curious to learn more? Tom's column features all the details you need to sign up for the meeting AND banquet. Kevin shares his own story of what he discovered about himself when he attended his first meeting 10 years (!) after his surgery, and I believe many will relate. We also had many positive comments from members about the IAL meeting in What Do YOU Say.

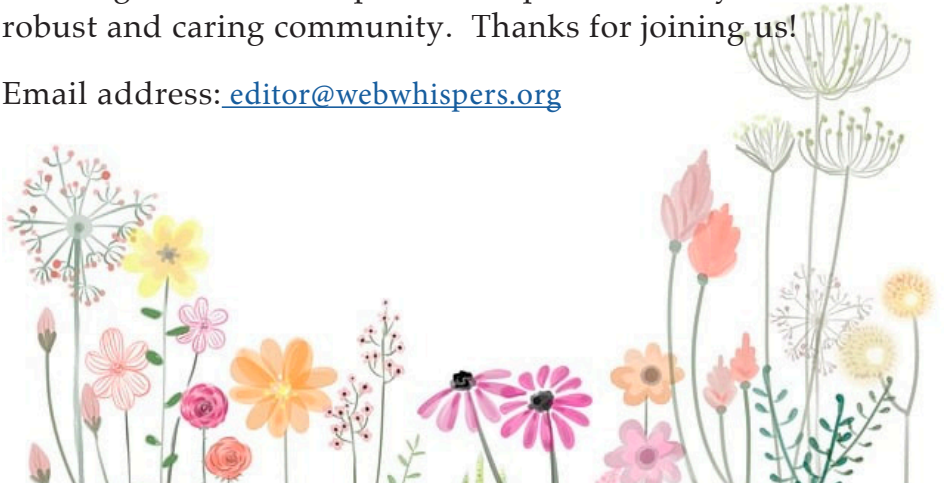
Keep reading for all of this and more, including an interview with radiation oncologist Dr. Kaitlin Christopherson and reflections from Brooke, our newest contributor.

Please reach out and let us know what you enjoy best about this issue. We welcome member contributions and feedback, and we are grateful for the positive impact each of you has on our robust and caring community. Thanks for joining us!

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*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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Our Most Wonderful Time of the Year

Deadlines are fast approaching!

If you haven't made plans to attend the IAL Voice Institute, do so now! Register here:

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

With a WebWhispers membership (see below), there may be scholarships available to help get you

to the meeting. The link for the IAL Voice Institute scholarship is found here:

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

WebWhispers membership brings many benefits and you can join today! All services are free and there are never any dues, though donations are welcome. In addition to applying for IAL Voice Institute scholarships, members enjoy the Email Digest, Members Only section of the website, use of our Electrolarynx Loan Closet, and attendance at the WebWhispers Awards Dinner.

Join WebWhispers here: <https://webwhispers.org/join-us/>

WW Awards Dinner – May 12, 2023

The WebWhispers Dinner for members and guests is held each year during the IAL Annual Meeting and Voice Institute. This year, our dinner takes place on Friday evening, May 12, 2023, at the Sheraton Westport Chalet Hotel.

It's a big event for us and we look forward to seeing many of you there. We take a moment to honor those who have gone before us and we also present scholarship checks and awards who have been of help to WebWhispers during the previous year.

It is our moment to be together face to face and rejoice over everyone, including those who receive awards and recognition.

The WW Pre-Dinner reception will begin at 6:30 with dinner seating at 7:00.

More details, including the menu, cost, and how to make reservations are on our website:

<https://webwhispers.org/activities/ial-dinner/>

Come and 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

Radiation After Total Laryngectomy

A conversation with Dr. Kaitlin Christopherson, Radiation Oncologist, and Robin Neary, Speech Language Pathologist

Kaitlin Christopherson, MD, is a radiation oncologist with Orlando Health Cancer Institute. She specializes in the treatment of genitourinary, hematologic, and head and neck cancers, and works together with each patient's care team to develop a targeted, individualized treatment plan. She is skilled in advanced radiation techniques including volumetric modulated arc therapy, image guided radiotherapy, stereotactic body radiotherapy, and proton therapy.

Robin Neary, MS, CCC-SLP is a speech-language pathologist at Moffitt Cancer Center in Tampa, FL. She has worked with the head and neck cancer population for 5 years, providing expert care in post-operative total laryngectomy management.

You've had a laryngectomy. Now your doctor tells you that you should have radiation. You might find yourself asking a lot of questions. Why do I need radiation? What side effects can I expect? What laryngectomy supplies should I use or avoid? I spoke with Kaitlin Christopherson, MD, who is a radiation oncologist at Orlando Health, to get her input.

Q: Thank you for taking the time to answer my questions today, Dr. Christopherson. Many of our

patients have been recommended for radiation treatments following a total laryngectomy. Why might someone require radiation after this surgery?

A: *Every case is unique, and it's important to discuss any treatment recommendations for your case specifically with your doctors. Radiation is very often recommended for patients after total laryngectomy. Locally advanced tumors (meaning a tumor that involves multiple areas of the larynx, invades other areas near the larynx, or involves the cartilage of the larynx) almost always require surgery followed by radiation. Radiation may also be recommended if the cancer has spread to the lymph nodes.*

Q: That makes a lot of sense. Some patients have mentioned proton therapy or have had proton therapy in the past. What is the difference between proton therapy and IMRT (intensity-modulated radiation therapy)?

A: *Both proton therapy and IMRT are radiation. Oftentimes, patients think protons are very different compared to "regular radiation," but they are actually quite similar. The difference between protons and IMRT is how each technique delivers radiation. Protons are weighted particles and we can essentially tell a proton where to stop. They deliver a radiation*

dose as they enter the body, but not as they exit. This feature of protons is a possible advantage. IMRT uses x-rays, which do not have mass, to deliver radiation dose upon entrance and exit of the body. One of the advantages of IMRT is that x-rays are sometimes more “nimble” due to their lack of mass. They can be shaped to turn corners or make specific shapes better than protons, which might help spare a nearby organ. I could go on about the pros and cons of each, but then we will get into the weeds of physics. For patients who undergo laryngectomy, the goal of either type of treatment is to kill any cancer cells that might be left or “hiding” after surgery. Both protons and IMRT are equally good at this, meaning cure rates are the same. After surgery, a radiation oncologist must target any place the tumor initially was, anywhere the surgeon touched, and anywhere the cancer could be hiding. This ends up being a very broad field. Given the size of the field, as well as treating both sides of the neck, IMRT will often be our preferred technique, as protons likely don’t often offer an advantage in this situation.

Q: Thank you for that information. As speech language pathologists, we work a lot with patients in the immediate post-operative period, helping them figure out supplies they need to manage their stoma, including stoma stenting devices, HMEs (heat and moisture exchangers), baseplates, and even TEP products. Immediately in the post-operative period, we recommend that our patients use HMEs to help filter and humidify air entering their lungs. Once cleared by their surgeon, we may introduce baseplates if it’s appropriate. In general, we tend to recommend patients who will be undergoing post-operative radiation to avoid baseplates during their radiation treatment. Our recommendation is two-fold: on the one hand, many patients experience pain and perhaps injury to their skin during radiation, which can be further irritated by the adhesive on the baseplate. Secondly, there may be a risk of inflammation around the stoma, leading

to stenosis of the stoma, and potentially creating airway compromise. We recommend they use some sort of laryngectomy tube instead, to keep their stoma wide open, to attach an HME. Do you have any other recommendations for patients as they undergo radiation?

A: *I will always defer to the surgeon about recommendations for baseplates versus laryngectomy tubes. However, there is a risk of developing what’s called a microstoma, as you described, which means the stoma can become very, very small. This can lead to dangerous breathing issues. Either way, whatever they have in place at time of radiation simulation, we would like to continually have in place throughout treatment.*

We ensure that they have healed well after surgery prior to starting radiation. This usually takes roughly 3 to 4 weeks, and most will start radiation around 6 weeks after surgery. All drains and staples should be removed.

Once a patient has been cleared by their surgeon and speech pathology team to begin eating and drinking, we encourage patients to continue to take as much nutrition by mouth as possible. During radiation this will become challenging due to pain with swallowing, and we may rely on a feeding tube more at that time, if needed. Radiation is not a diet! It is very important to maintain your weight throughout radiation so that you heal well afterwards. If you are struggling to maintain your weight during radiation, it is very important to address this with your doctors as well as a dietitian if possible.

Q: You make an excellent point! Many of our patients who have had a laryngectomy have also had radiation before. Many patients may know what to expect, but many do not. Swallowing after you’ve had a laryngectomy is already very different from before the surgery. For some patients, swallowing might be safer. For others, swallowing may prove to be more difficult, as the muscles that helped push food through the

esophagus have either been removed or have been altered after surgery. Nutrition is a very important part of healing post-operatively and during radiation.

Q: Some patients may have opted to have a tracheoesophageal prosthesis (TEP) placed at the time of their laryngectomy surgery. Can this impact their radiation at all?

A: *I really defer to the head and neck surgeons regarding the TEP. At Orlando Health, we completely rely on the speech team to decide if a TEP change needs to happen. The TEP will very likely be in the field of radiation, but it's small. For us at Orlando Health, it doesn't really affect the radiation plan, but I recommend the patient speak with his or her physician if a TEP change is appropriate during treatment.*

Q: Thank you for your input. From a speech pathologist's perspective, I will add that sometimes achieving a TEP voice during radiation may require more troubleshooting because of possible swelling and finding a good seal around the stoma without using baseplates. We thank you, Dr. Christopherson, for taking the time to answer our questions today! As always, we recommend patients speak with their personal physicians about post-operative laryngectomy and radiation treatment management.



Why I Go To The IAL/Voice Institute Kevin Berry

My first IAL/Voice Institute was about ten years ago. I had already been a laryngectomee for a decade and I was doing fine. I spoke well. I ate well. I had rebuilt my life, and I was already a poster boy for laryngectomy rehabilitation. What on earth could I gain from the journey? Well, that year the conference was being held in Kansas City which was just slightly over 1000 miles from my home in Central Ontario. It just so happens that 1000 miles is the exact distance one must travel in 24 hours on a motorcycle to get your Ironbutt certification which is something I had thought about for years. I took that as a sign and loaded up my ancient and weatherworn Honda CX650 Turbo and set off for Kansas City.

It was an inauspicious start to my journey. When I set off at 6:00 am, it was below freezing and snowing. Forty-five minutes into my trip the snow had turned to freezing rain, and I was having second thoughts. I won't give all the details of the trip, but the highlights included a 90-minute wait at the border followed immediately by being hit by half a seagull which had just been severed in two by a semi truck just ahead of me. Welcome to America! By the time I eventually rolled into Kansas City, the temperature was in the triple digits. I went from hypothermia to heatstroke in 24 hours and in the same clothes. To top it all off, I didn't manage to get my Ironbutt certification. The rain had soaked into everything and destroyed my gas receipts which I needed to prove my route.

Thankfully the rest of the week went a little

better. After cleaning myself up and getting some sleep I went down to the hotel bar. The place was full of laryngectomees. The music was turned down and everybody was talking to each other like regular human beings. This was eye opening. I hadn't been able to socialize at a bar in over a decade. Family functions were often hard enough, and here I was meeting new people in a public social environment.

Over the next few days, I attended countless presentations and met more people than I could count. I got to put faces to the names of all the people I had communicated with only via email, and I gained some valued new friendships. I met some very talented and dedicated speech pathologists (SLPs) and doctors, and I was inundated with more information than I could possibly ever need.

There were sessions for laryngectomees and other sessions for caregivers. There were sessions mainly for SLPs and sessions for everyone combined. If I got overwhelmed with the information, I could visit the vendors that provide products and services to our community, or I could just find a place to relax on my own or possibly meet someone new to chat with. There was a swimming demonstration which everyone was invited to join in on and a trip to the local teaching hospital where we had a chance to play Guinea Pig for the SLP students.

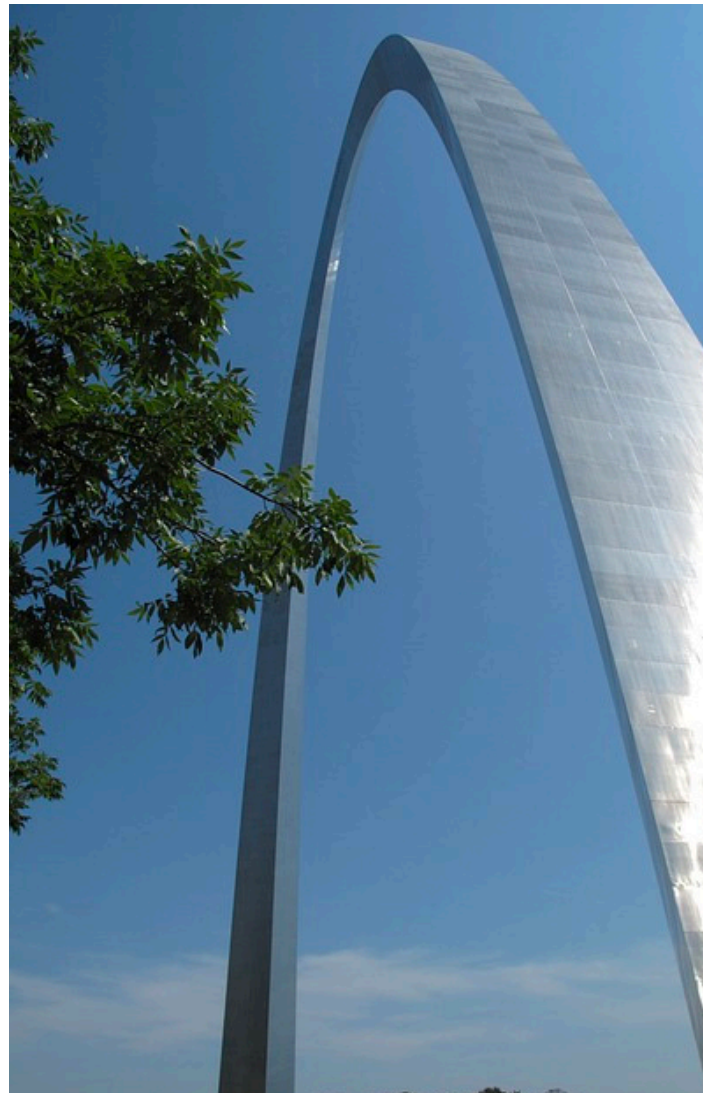
Every day I seemed to witness a small miracle. One individual who arrived barely able to speak discovered a new trick that dramatically improved their TEP voice. Another who was speechless was taught how to use the electrolarynx he was convinced would never work for him. A third person had lymphedema that was so out of control it prevented any speech. By the end of the conference his head and neck were half the size and he sounded like Barry White.

My own personal miracle was much less dramatic. Spending that much time amongst fellow laryngectomees made me realize how much of myself I had shut down post-operatively without ever realizing it. Being my old self for a few days made me realize how much I missed the old me

that I didn't even know wasn't around anymore. That realization changed my life in many subtle ways. I had found my old self again and that old self stayed with me ever since.

I don't go to the IAL every year, but I do try get back as often as I can. The activities and opportunities are a little different each time, but a few things remain the same. There is always a surplus of friendly and caring people to meet or meet again. There is always an abundance of skilled and knowledgeable people willing to share their knowledge and skill. Finally, every time I go, I always seem to witness a little miracle. They are not always big, but they are always miracles.

I hope to see you in Saint Louis, or, if that isn't possible, the first IAL/Voice Institute you can get to after that.





Member Contributions

How I Wish People Would Ask Questions! Brooke Elkan-Moore

In the two years since my laryngectomy, I have been astonished at the complete lack of questions that have been asked of me regarding what caused me to have the surgery, what the surgery is, and why I speak the way that I do. I have had people act reluctant to be around me, to stare or move away from me when I am speaking but have not had anyone just flat out ask me "So what happened?"

Actually, adults are the ones who do not ask. Kids are fully able to just listen, look and then ask what they are thinking. They are concerned that it might hurt to speak, that the button could go into my neck and get stuck. They want to know if it is forever or if it will heal and change. They are totally willing to listen while I take whatever time I need to express myself.

Last fall while working with some 3rd graders on a gardening project, one young girl was clearly worried about my situation. She listened carefully to me and came close to look at my heat and moisture exchanger (HME). She shyly asked if it hurt to talk. I told her no and she said, "Good. That would be hard if it hurt to talk."

The next week she came right up at the start of the class and asked "Is this your real voice?" I replied that yes it was now. She then said "OK, it's a lovely voice." It was the first time since my surgery that

anyone who was not a friend or family member commented on what hearing me was like for them.

Before my surgery, I had not met anyone who had a laryngectomy. I had seen others using an electrolarynx (EL) over the years on TV or in a restaurant but never up close enough to actually see the situation or interact directly with the person. I had been told about the options for communication, but it was frankly a bit of a blur, and I went along with the surgeon's suggestion to do a primary TEP during the surgery.

While I am mostly happy with the TEP, I am often a bit envious of the freedom that EL (electrolarynx) users have. There is no need to deal with the care, maintenance and funky quality of the voice prosthetics. Some days, I wish I could master the EL and generate a quality of voice that authentically feels like my personality. Some days, it feels like a mishmash of harsh sound and frustration.

In the midst of other's chatter, I often find myself quiet, retreating, not willing to make the effort to speak when I know I will be spoken over or forgotten. The social implications of our surgery are huge and can be so overwhelming.

I wish people would ask more questions about our lives and give us more opportunities to share.



If you have attended an IAL Voice Institute before, why would you recommend it to someone who has not?

I would urge any laryngectomee and their caregiver(s) who have not attended laryngectomee conference to do so if possible. Not only are the conferences educational but also fun. You will make lifetime friendships there.

My first conference was in Anaheim, CA and it was a life-changing event for me. I had never met another laryngectomee and I was deeply depressed after all the treatments and surgery, I felt like a "FREAK!" Once I walked into the hotel lobby to check in, I was overwhelmed with a huge sigh of relief and acceptance as I met others like me. I recall a crowd gathered in the lobby which was elaborately decorated with pools, streams and ponds. All the laryngectomees were gathered around speaking with ELs, TEPs, and even esophageal speech. I made the remark: "It sounds like a huge frog pond in here!" Some turned around and frowned at me while others, however, acknowledged and agreed.

That was two decades ago and to this day I still share a good relationship with many I met there and conferences that were to come.

So, if you get a chance to attend, I urge you not to hesitate. It will be a rewarding experience.

Michael Csapo

I could think of many reasons to recommend attending the IAL. If I had to pick one it would be being inspired by meeting so many others who have a good positive attitude and have found ways to make the very best of their individual situations. "If they can do it, so can I."

Dick Sipp

I became a Lary on August 12, 2005. I had a lot to learn. When I ask WebWhisbers if they thought it was worth going from Idaho to Chicago to the Voice institute, I got a reply from Dutch Helms. He said everyone should go at least one time. He was right: I learned more in that one weekend than I could have on the internet or from anywhere else. If you are new to this Lary Life I would suggest doing what you can to go to at least one of these meetings. The sooner the better.

Dennis Holte

I have been a Lary for 11 years. 2022 was my first ever IAL Voice Institute.

I would recommend going to meet others, share stories and enjoy the company of others. Learn about things that no one told you. Learn of other

resources and be in a public setting without worries of everyone staring at you because everyone is used to seeing a stoma. Build memories.

I can't wait to see you all at the banquet dinner.

Corey Sullivan

Would I recommend attending? In a word YES. We as Larys are in the minority in the medical field. If anyone of us is in need of competent medical care, we have found that most medical people have no idea how to evaluate and treat a Lary.

This holds true with emergency people as well. It is vitally important that we get and pass on advice on how to self-treat and give medical personnel the information they need to take care of us.

By attending the IAL and voice institute convention we can stay abreast of new technology in the field, stay up to date on what would make our lives more enjoyable, and pass on to others what we learn.

The convention is a great way to meet other Larys from around the world, share experiences, laughter, and joy at being able to live a full life as a Lary.

I would urge every Lary and caregiver to attend every year to support the IAL and Voice Institute.

Rich Eisen

A newbie's experience: I had a total laryngectomy on February 25, 2019. Less than 11 weeks later, I flew 2,000 miles from Maryland to my first IAL conference in Phoenix, AZ. I was unable to use my EL yet, had not received my TEP and actually had to take note cards for the TSA that said, "I can hear, but I cannot speak." When I arrived at the hotel in Phoenix, I immediately knew I was among many others who were EXACTLY like me. My fears instantly melted away. It was at the 2019 IAL that I met Tony Talmich for the

first time. Within 5 minutes, he was able to "get me talking" using an electrolarynx. Because of that experience, the invaluable sessions I attended and all the wonderful people that I met, attending my first IAL was truly a life changing trip. I urge anyone to attend at least one IAL/VI conference. If you are like me, you will want to go back every year.

Steve Cooper

