

Whispers on the Web

A Monthly Online Newsletter for WebWhispers



July 2022



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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

Kim Almand, Managing Editor
Tom Whitworth, Editor

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WebWhispers With the International Association of Laryngectomees

The IAL’s 2022 Annual Meeting and Voice Institute was as incredible as always, despite some major challenges, not the least of which being a three year absence of the event, due to COVID (hereafter referred to as “you know what”). Under the direction of Caryn Melvin, Ph.D., the Voice Institute faculty of experts did not disappoint. Many first-timers were astounded at the experience and learned why so many of us return to the event every year. For laryngectomees, there just is nothing like being with so many with the same or similar journey.

On Thursday, June 16, eighty people attended the WebWhispers 21st Annual Awards Dinner with a pre-dinner reception sponsored by Bruce Medical, as has been the case since our first dinner. The dinner was arranged, as in the past, by Jeff Vanden Hogen, who always does a great job, featuring Debra Sheridan (Faces of HNC) as guest speaker. The WebWhispers Annual Dinner tradition was begun by Pat Sanders as an opportunity to express our gratitude to some of those who have served the laryngectomee community in the past year by working with or supporting WebWhispers in some special way and to present our IAL Voice Institute scholarships. We also use this time together to remember those who have gone on before us in the previous year. This year we honored 94 WebWhispers members who passed away since our gathering in 2019.

Several awards were presented, each celebrating a unique contribution:

- **Certificate of Appreciation** presented to Michael Csapo, Facebook Group Administrator
- **Certificate of Appreciation** presented to Rita Burfit, Facebook Group Moderator
- **Certificate of Appreciation** presented to Steven Cooper, Alert Kit Coordinator

Since Steven took over our Alert Kits, it has become something different altogether. He improved the concept of providing alerts to laryngectomees and vastly improved the process. He

has promoted the kits for neckbreathers and has personally mailed out each one. Because of his efforts, many more laryngectomees have bracelets, decals and more, to tell the world that oxygen goes to the stoma.

Volunteer of the Year presented to Kim Almand, M.S., CCC-CLP, WebWhispers Board of Directors, Editor of Voice Points and Whispers on the Web which reads:

Kim has always shown great leadership, a compassionate heart, and a comforting smile in the laryngectomee community. In the past year, during the illness and following the passing of Donna McGary, Kim in her busy schedule, has managed to help keep our newsletter going, even when faced with great challenges in a difficult environment. This award is presented with sincere gratitude for her efforts.

Volunteer of the Year presented to Sundy Mead, Vice-President, Finance & Administration which reads:

Responding to a request for volunteer help, Sundy was an ideal candidate for the role of Vice-President of Finance & Administration. Bringing to WebWhispers a background in non-profit finance and that of a United States Marine she consistently exceeds expectations and in her first year is already a proven leader on our team.

With help from Atos Medical, InHealth Technologies, and our Buck Martin Fund, WebWhispers presented approximately \$7,000 in scholarships, far more than in any previous year. Awards went not only to laryngectomees but also to laryngectomee/caregiver couples and to SLP graduate students. All except one recipient were first-time Voice Institute attendees.

InHealth Technologies scholarships took the form of paid hotel stays, worth \$650 to:

- Janelle Moser, Reynoldsburg, OH
- David Shockoor, Quechee, VT
- James & Barbara Waring, Yorktown, VA

A \$2,000 grant from Atos Medical enabled two laryngectomee/caregiver couples to attend the VI together:

- Demetrio & Yira Mediavilla, Margate, FL, \$1,000
- Jason & Denise Rosenblum, Kennewick, WA, \$1,000
- WebWhispers' Buck Martin Fund provided \$3,000 as follows:
 - Jay & Elizabeth Sasfai, Dunellon, FL, \$750
 - Debra Sheridan, Mount Pleasant, TN \$1,000
 - Barbara "Suzy" Sullivan, Kennewick, WA \$500
 - Abby Tonos, Knoxville, TN, \$500-University of Tennessee SLP graduate student
 - Cecilee Torres, Conway, SC, \$250-University of South Carolina SLP graduate student

At the IAL Banquet Saturday night, June 18, we helped celebrate the 70th Anniversary of the International Association of Laryngectomees. Congratulations on 70 years! Organizations like ours are always in need of volunteers. If you would like to help the IAL, reach out to its new president, Kyd Dietrich, at kdietrich@myactv.net

Whispers on the Web is always on the lookout for new writers, whether regulars or occasional contributors. Contact us at Editor@webwhispers.org. If you would like to help WebWhispers in some other way, please contact me at tmwhitworth@gmail.com.

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

What to Expect after Laryngectomy: Communication and Swallowing Rehabilitation

Your surgeon tells you that you have throat cancer and that you will need to have your larynx or “voice box” removed. Your surgeon tells you that you will be able to talk and swallow again. What does that really mean? The following is an overview of communication and swallowing post-laryngectomy and may represent some of the options available to you as you, your caregivers and family and friends navigate the healing process.

An important first step in this process, if possible, is to meet with a speech-language pathologist (SLP) who specializes in working with laryngectomees prior to your surgery. This person will help you understand the changes in anatomy and physiology that will occur following surgery and how these changes may affect your ability to communicate and swallow.

Ideally, you will be educated regarding the use of three different methods of speaking: the electrolarynx (EL) or artificial larynx device, tracheoesophageal speech (TEP) and esophageal speech (ES). Perhaps you will have an opportunity to watch a video featuring individuals that use each of these methods of communication so that you can hear how you might sound with your new voice. You may even have an opportunity to try out an electrolarynx or meet with another laryngectomee who uses one of these various options. It is certainly

an overwhelming time, but it can be a great opportunity to ask lots of questions.

Following the surgery, your speech pathologist will come to see you in your hospital room to provide you with a pencil/paper, a white board and/or an LED board so that you can communicate with your family and health care providers. A text-to-speech app on your smart phone may also be a good option for communication at this time.

In many facilities, a new or a loaner electrolarynx is provided to allow you to communicate immediately following the surgery. This EL can be used via intraoral placement (within the mouth) by placing a straw-like attachment onto the device and placing it in the mouth to create vibratory sound for speech. This placement is necessary due to post-surgery neck swelling and the presence of staples or drains that may not allow for placement directly on the neck.

Your speech pathologist will teach you how to use the device and how to speak as clearly as possible. It will take some time to become proficient with the EL. Don't give up! With practice, many laryngectomees become very proficient communicators with the electrolarynx and it is often a great back-up communication system even if you choose to communicate with the TEP or esophageal speech.

Your surgeon may have placed a voice prosthesis during surgery to allow for tracheoesophageal speech production. You will not be able to immediately use this form of communication following surgery secondary to the need for healing. Your doctor will advise you when you can start practicing this form of communication with your speech pathologist.

This is generally done once you have been discharged from the hospital after you have received clearance from your surgeon. However, during your hospital stay, your speech pathologist may teach you how to clean and manage your voice prosthesis, clean and manage your intraluminal device, utilize your heat and moisture exchange system (HME), and place a plug into your prosthesis for leak prevention purposes.

Once you leave the hospital, you should have a functional form of communication that will allow you to communicate with family and in your daily environment.

During your hospital stay, you may have a tube in your nose that extends through your esophagus or “food tube” into your stomach. You will receive nutrition through this tube until you are cleared by your surgeon and SLP to start eating and drinking again. A swallowing study under x-ray may be completed to be sure that you have healed well from your surgery prior to eating.

When you return to eating and drinking, you will most likely start with liquids and very soft foods. Many patients can swallow easily after they have recovered from their surgery, but it may be a bit more difficult if you have had prior radiation treatment to your throat or if you have had a more extensive surgery. If you are having problems swallowing, do not hesitate to reach out to your SLP to see what can be done to allow you to eat or drink more easily. Maintaining good nutrition and hydration is very important.

Once out of the hospital, you may be cleared by your surgeon to start using your voice

prosthesis. Meeting with your SLP on an outpatient basis will help improve your ability to use your EL (even if it is a back-up form of communication). If your surgeon placed a voice prosthesis at the time of your initial surgery, you may also begin to practice using your voice prosthesis for communication. Your speech pathologist may teach you how to coordinate your air and sound to talk. Lots of practice will certainly make communication better. This may also be a good time to work with your SLP to develop and hone your skills in esophageal speech (ES). A great way to learn esophageal speech is also to work with another laryngectomee who is proficient with esophageal speech and can provide tips and tricks. Do not hesitate to ask your SLP if there is a local esophageal speaker that you can talk to for learning or practice purposes.

Recovering communication and swallowing function following total laryngectomy can be a challenge at times but with perseverance and caring and capable health care providers, it can be accomplished. If you do not have access to an SLP or other laryngectomees to help provide education, training, and/or support in any of these areas, please reach out to WebWhispers through email at editor@webwhispers.org or via our Facebook page. We will connect you with people who can help.

Bretton Jenks, MA, CCC-SLP is a head/neck speech-language pathologist at Cleveland Clinic Indian River Hospital in Vero Beach, 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. She is the coordinator for the Indian River County Laryngectomee Club in Vero Beach.

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What Do YOU Say?

What new thing did you learn or find surprising about the IAL meeting in Charlotte?

Many of you will remember our "Speaking Out" column by Jack Henslee. It was among our most popular columns in Whispers on the Web. In that same vein, this new column is designed to share member comments each month. If you are a laryngectomee, caregiver, friend, SLP, MD or other professional we want to hear from you!

First, I was happy that my wife could attend the conference with me as she is my teammate on this journey. We were both pleasantly surprised that this conference is unique in that it is a multidimensional approach to learning. We learned so much from this approach as there were fellow laryngectomees, caregivers, doctors, SLPs, graduate students, professors, medical equipment providers, and nonprofits all working together to bring a greater understating and awareness to living our best lives with our own unique medical condition involving a partial or full laryngectomy.

The one thing that I took away was each laryngectomy patient is unique and no two are alike. Everyone that was there was doing the best they could with what they had in front of them, remaining optimistic that the future holds our best lives regardless of our condition. I walked away more knowledgeable than when I came to the conference. I feel empowered to take the next steps of healing and learning to speak again even if it sounds different than pre- surgery! Thank you for holding this conference. It was so valuable to my growth as a new partial laryngectomee. Thank you.

-Jason Rosenblum

I found the near-universal positive attitude of the laryngectomees to be very encouraging.

-Dick Sipp

First, I want to say that the IAL conference was very good, very well organized and informative. The most important thing that I got from this conference is that I need to learn a second way of communication, either with AL or esophageal speech. I didn't know that a lary with a TEP could learn esophageal speech. Also, if you are gutsy enough to swim as a lary, pay attention to who is swimming your way!!! LOL, glad that all turned out OK.

-Janelle Moser

I was surprised at what a lively bunch the other larys were, regardless of speech method. The only thing I had to compare it to were the sad sacks in the YouTube videos I had seen previous to the meeting. I did not witness any of that and am proud to be a part of such a courageous group of individuals!!

-Tyler Stone

I have been a laryngectomee since 07/03/2012 (10-year anniversary coming up). I speak with a TEP. WebWhispers helped me get through the first year! I've always followed and finally decided to get involved and also attend an IAL conference this year.

At first it was overwhelming. I've run into one or two larys in 10 years and now I'm surrounded by many with EL's, TEPs, ES and no voice. Best experience ever. There were graduate SLP students that really wanted to learn and great sessions to learn about the different types of speech and what resources are available. I have never laughed so hard in my 10 years of being a lary!

Biggest takeaway, besides what a great group of people (lary's, SLP's, etc.), was to make sure you have a backup voice and we're all out there and have your back to support you if you reach out!

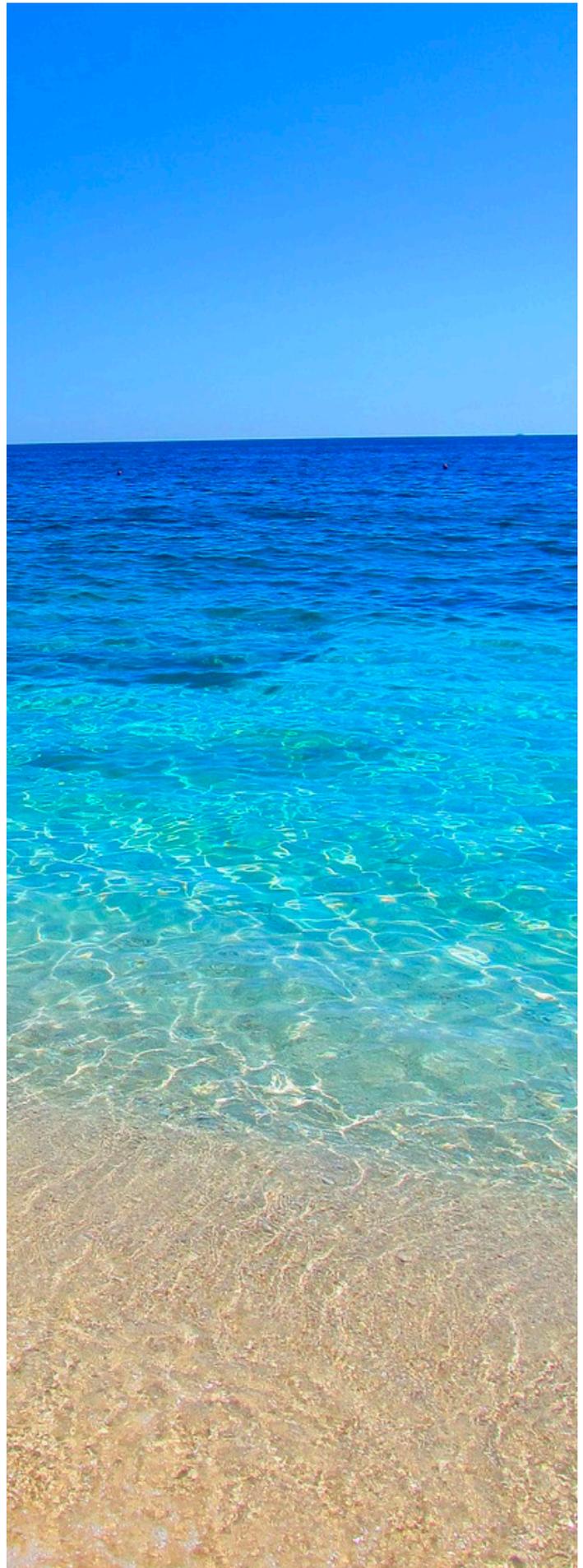
-Sundy Mead

I feel the biggest thing I got out of Charlotte was seeing people I have not been able to see for three years. Also, I enjoyed the first timers. I remember my first time and so many people were so helpful. It is the highlight of my year.

-Dave Kinkead

I got the gift of speech after working with Tony for 10 minutes. I used an oral adapter. After my last session with my SLP, she told me that I will always need the adapter due to lymphoma.

-Jay Sasfai





Member Contributions

The 2022 International Association of Laryngectomees Voice Institute... FINALLY!

The 2022, originally planned for 2020, Voice Institute was held in Charlotte, North Carolina June 15th – 18th. It was great to see familiar faces and meet with many first-time attendees. We had several graduate students attend from the University of South Carolina and the University of Tennessee. Many speech-language pathologists from the area also attended.

The meeting kicked off on Tuesday night with an event for first-time attendees hosted by Tom Olsavicky, Steven Cooper and Jitin Eidnani. The Voice Institute began the next morning with a day devoted to the basic communication options and bodily changes including pulmonary function. We were grateful that many of our regular faculty were able to join us again this year. Susan Reeves, M.Ed., CCC-SLP, Linda Stachowiak MS, CCC-SLP, BCS-S, Stacey Brill MS, CCC-SLP and Cindy Lee Gordish, MS Ed. CCC-SLP presented talks on their specific areas of expertise. Dr. David Estores returned to the faculty presenting excellent talks on esophageal stricture and reflux.

New faculty this year included: Alissa Yeargin, MSR, CCC-SLP, Lindsey Beardsley M.A., CCC-SLP, Della Mann, MSP, CCC-SLP and Kacie Gamm M.S., CCC-SLP. Laura Sprague, OT/R presented information on lymphedema and shoulder issues following total laryngectomy. We hope to make each of them regular presenters at the Voice Institute!

Konrad Zielinsky travelled from Poland to present his research on “The novel bionic communicative interfaces in laryngectomees’ real-life interactions.” He presented and explained the current research and applications that are being developed to improve voicing following total laryngectomy.

Dr. John Sinacori MD was our keynote speaker and presented a talk on humor in medicine that had the audience laughing for the entire presentation. It was great to see everyone enjoying themselves!

InHealth Technologies held their quarterly Virtual Happy Hour during the IAL Meet and Greet on June 15th. Members of the community could log on and experience a bit of the conference right from the comfort of their home.

The annual Caregivers Breakfast and Rap session

took place on Saturday morning. It was good to see some new faces and offer a space where caregivers could share their experiences and support one another.

In addition to the formal presentations and events there was an abundance of fellowship, laughter, renewing of old friendships and the making of new friendships that will last a lifetime. That is the magic of the IAL and the Voice Institute. The community comes together in a manner not seen at most conferences. Persons with a laryngectomy, caregivers, friends, students, speech-language pathologists and other members of the community, learn side-by-side. They learn from each other. They share their stories and offer support and hope and come away renewed and hopeful.

The IAL and the Voice Institute is grateful for all our faculty who give so freely of their time and expertise to make this meeting a possibility. And we are appreciative of our vendors and support clubs who continue to support this event each year. And a BIG thank you to WebWhispers for your continued support of the IAL and the VI.

We have some exciting changes coming to the Voice Institute for 2023. Be certain to check the IAL Voice Institute Facebook page for updates on the 2023 meeting and for our newest Conversations with the Experts that will focus on caregivers.

Caryn Melvin, Ph.D, CCC-SLP, CPC
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Caryn Melvin, PhD CCC-SLP has been a medical speech language pathologist for 31 years specializing in assessment and management of head and neck cancer patients, dysphagia, and adult neurogenic communication disorders. She is a Clinical Associate Professor at the University of South Carolina, Department of Communication Sciences and Disorders and a course Facilitator and Convenor for the Department of Communication Sciences and Disorders at Emerson College. Caryn is the current Voice Institute director for the International Association of Laryngectomees.



*We'll see you
in August!*