What a great time in St. Louis!
at the
Annual Meeting and Voice Institute

Also IAL Members, see page 5 for two important notices
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Information provided by the IAL News is not intended as a substitute for
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The IAL does not endorse any treatment product that may be
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IAL Resources: IAL Brochures, IAL News order/change of address
cards, Orange Emergency Cards, Orange Emergency Window Stickers
(English), “First Steps” Available to download from the IAL website.
Order from: IAL in Atlanta or email: office@theialvoice.org
Who were the greatest IAL Presidents?

By David Blevins

For those who know much about the history of the IAL, who would you say should be listed as in the top five or ten IAL Presidents? These would be those who did the most for the IAL.

These individuals would have provided leadership during critically important turning points in the organization’s history, provided exceptional leadership, have served in many selfless ways over time, and otherwise supported the IAL in many unique and significant ways.

As a former editor of the *IAL News*, the IAL obtained all of the issues of the newsletter we could find (the first issues were printed in 1955), and I read a fair number of them.

In my list I would include two members of my own local laryngectomee support group. The first one who would be on anyone’s list is Joe Marasco, who served as IAL President from 1996-1998. He lead the Board of Directors to unanimously reject a proposal by the American Cancer Society, which had financially supported the IAL from its beginning in 1952. The ACS proposal would have cancelled our Annual Meetings, dissolved our Board of Director, and taken the funds from our treasury. They offered, in exchange, a seat on their Patients Advisory Committee.

The other member of my club who I would list as among the top Presidents was Helen Grathwohl, who completed her journey through hospice care at home on July 14, 2023. She was surrounded by family at the end of her life and showed her character and strength to the very end.

Helen was Catholic and a member of the Pythian Sisters. The sisterhood has four principles:

*Purity* is the stage reached through honorable motive, action and thought and should be a goal we seek to attain.

*Love* represents service

*Equality* requires sharing with each Sister all rights and responsibilities. As Pythian Sisters we work together for the good of all.

*Fidelity* means being faithful, steadfast and loyal to God and to each other.”

Helen lived by these principles and served fellow laryngectomees from our region of the State of Virginia though her work through our local club, The Tidewater Lost Chord Club. Through the IAL, she served laryngectomees and their caregivers throughout the United States and beyond. Helen simply could not turn down a request for help from a laryngectomee, caregiver or organizations helping laryngectomees if that help was possible.

Helen served as IAL President from 2020 to 2022. On several occasions there were not enough people who were willing to serve as officers, so Helen served as acting Treasurer and helped host the Annual Meeting in Newport News in 2017, VA; President and acting Treasurer and later Secretary until 2020, and edited the *IAL News* from 2016-2022.

This is an extraordinary service. She would ask people to step forward and help. But if she could not find anyone she would volunteer to take on that task even as she was already serving in other offices. One her most extraordinary decisions to serve came when she could not find an editor for the *IAL News*. It didn’t surprise those of us who knew her that she taught herself how to do it and edited the News herself for six years.
By Eric Glass

After visiting my primary care physician a few times and two other specialists, in 2017, I was assured I was fine and told to stop worrying. Actually, my Vietnamese doctor charmingly used the phrase “stop kvetching” and suggested I not obsess about my persistent sore throat that I’d been complaining about for months. She even offered to give me a referral to a mental health specialist in the area, implying, I believe, that my concern was bordering on the neurotic. I asked if she would refer me to the best E.N.T. doctor in central Florida and she reluctantly did. He was two and half hours away and I made an appointment for the following week.

I was ushered into his office; he asked why I was there. I told him about my sore throat and the specialists I had seen over the last year. He shoved a scope down my throat, and he immediately said something that was not comforting. He said “Jesus Christ, how did they miss this!”

I asked what it was that they apparently missed, fairly certain I was not going to like his answer. He replied, “There’s a large growth on your larynx and I don’t like the looks of it. I’m sending you for more tests and a biopsy.” “Biopsy,” I learned on the spot, is definitely not a word that inspires confidence nor is it a word you want to hear from your doctor in the course of an examination. If he didn’t like the looks of it I was pretty positive I wasn’t going to like it much either.

When the tests came back his office called me to come back; I drove the two and a half hours to his office and his first words were “sit down.” I immediately translated “sit down” to mean “I have some very bad news for you.” I was correct.

He said I had stage 4 cancer and because this had gone unchecked for at least a year, the cancer had spread from my larynx to my pharynx, my thyroid, all my lymph nodes and part of my tongue. He referred me to the Orlando Cancer Center, “the best around,” he said.

The only good news concerning all this was I lost 42 pounds while on the feeding tube and I hadn’t looked this good since sophomore year in high school when I played on three varsity teams. With the exception of my horribly swollen face, I looked fabulous!

In spite of all this, the ordeal never seemed terrible or that I was suffering with something horrible, much to everyone’s surprise. I found out three years later, over some beers with two good friends, that everyone thought I was going to die, a thought that never ever occurred to me. I just plodded on, did what I had to, survived the very real pain, enjoying the wonderful painkillers that were liberally prescribed. Surprisingly, I never even felt sorry for myself or thought that an injustice had been dropped on me or that I had been wrongfully singled out to undergo this experience. I don’t even think I was angry at anyone, with the possible exception of myself for smoking for 47 years, not to assume is close to catatonia. I have no memory of the drive home.

The next week I was admitted to Orlando Cancer Center where I underwent a six and half hour operation, a huge skin graft from my thigh to reconstruct a new throat, followed by six weeks of radiation, five days per week, a puncture procedure in my stoma to accommodate a potential voice prosthetic, four months on a feeding tube, eating nothing but three cans of Jevity per day, a wound machine on my thigh to cover the area where the skin had been removed to make my new throat, rendering me unable to shower for six weeks and causing me intense pain and I had lymphedema so pronounced my face looked like an overstuffed pillow ravaged by angry wolves and thus began my recuperation.

The only good news concerning all this was I lost 42 pounds while on the feeding tube and I hadn’t looked this good since sophomore year in high school when I played on three varsity teams. With the exception of my horribly swollen face, I looked fabulous!

The bad news was I couldn’t speak until the voice prosthetic was installed, a device called a Transesophageal Voice Prosthetic, a T.E.P. for short, a device that would allow me a voice that sounded remarkably like Louie Armstrong with a severe cold. Until the prosthetic was installed, I spoke with an electrolarynx, a device that allowed me to communicate with absolutely no one and even I had trouble understanding what the hell I was trying to say; that voice was remarkably similar to Donald Duck’s!

In spite of all this, the ordeal never seemed terrible or that I was suffering with something horrible, much to everyone’s surprise. I found out three years later, over some beers with two good friends, that everyone thought I was going to die, a thought that never ever occurred to me. I just plodded on, did what I had to, survived the very real pain, enjoying the wonderful painkillers that were liberally prescribed. Surprisingly, I never even felt sorry for myself or thought that an injustice had been dropped on me or that I had been wrongfully singled out to undergo this experience. I don’t even think I was angry at anyone, with the possible exception of myself for smoking for 47 years, not to (continued on page 5)
mention the other toxic substances I had put into my body. I was a little sad that I lived alone, but my daughter, sister and friends flew down to Florida in shifts to take care of me for months, never leaving me alone for more than a day or two. This made me feel so lucky, so blessed to know that these people in my life cared enough about me to do this. One afternoon, sitting on my screened porch overlooking the Intracoastal Waterway, watching dolphins and manatees play near my pontoon boat, I thought about the whole experience. It wasn’t half as bad as it probably should have been. How come I didn’t suffer, feel despondent, sad, morose, angry or have horrible experiences like other cancer patients and survivors? Why wasn’t I depressed and in need of therapy or antidepressants like so many others in similar situations? Why wasn’t I overcome with debilitating sadness?

Two dolphins breached at the same time, leaping a good six feet out of the water like synchronized swimmers and I remembered playing my autoharp and singing for my daughter when she was a very young baby. She would try to sing along, look at me, smile and it would make me so happy and assure me all was right in this world. That’s when I realized I would never sing to my daughter again, never see her smile when I played and sang a song she especially liked. That’s when I cried, for the first time in a year, maybe longer, uncontrollably, for what seemed like forever.

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Mucus Production and Increasing Air Indoors Humidity

By Itzhak Brook, MD

Mucus production is the body’s way of protecting and maintaining the health of the trachea (windpipe) and lungs. It serves to lubricate these airways and keep them moist. Following laryngectomy, the trachea opens at the stoma and a laryngectomee can no longer cough up mucus and then swallow it, or blow the nose. It is still very important to cough and clear one’s mucus; however, this must be done through the stoma.

Immediately after surgery, the patient’s tracheal secretions increases and may be difficult to clear. While hospitalized, tracheal suctioning is done by the hospital staff and the patient and their caregivers should learn how to perform suctioning using sterile techniques prior to discharge. For the first 3-4 months, many laryngectomees require tracheal suctioning as an adjunct to coughing to clear their airways. Over time mucous production slowly decreases. This is enhanced by wearing a Heat and Moisture Exchanger (HME). Over time, most patients are able to produce adequate coughing strength to expel secretions without the need for a suction device.

Coughing up mucus through the stoma is the only way by which laryngectomees can keep their trachea and lungs clear of dust, dirt, micro-organisms (bacteria, viruses and fungi), and other contaminants that may get into their airways. It is therefore important to protect the airways from inhalation of these by covering the stoma preferably by a stoma cover or HME filter. Whenever an urge to cough or sneeze occurs, laryngectomees must quickly remove their stoma cover or HME and use a tissue or handkerchief to cover their stoma to catch the mucus.

The best mucus consistency is clear, or almost clear, and watery. Such consistency, however, is not easy to maintain because of changes in the environment and weather. Steps can be routinely taken to maintain a healthy mucus production as shown below.

Tracheal dryness, irritation and overproduction of mucus can lead to the development of mucus plugs. These plugs can cause airway obstruction that can lead to collapse of sections (atelectasis) of the lungs.

Restoring the humidification of the inhaled air reduces the overproduction of mucus to an adequate level and reduce the risk of mucus plugs. This will decrease the chances for coughing unexpectedly and plugging the HME filter. Those without an HME need to cover their stoma with a paper towel or even their hand to collect the coughed mucus. Increasing the home humidity to 40-50% relative humidity (not higher) can help in decreasing mucus production and keeping the stoma and trachea from drying out, cracking and bleeding. In addition to being painful, these cracks can also become pathways for infections.

When adequate humidification of the inhaled air is achieved with a humidifier, the HMEs that provide extra humidity can be replaced with those that provide extra airflow in adequately humidified environment.

Saline bullets are commonly used to provide quick moisture to the lower airways. These plastic bullets contain 3-10 cc sterile saline and after their tip is broken their contents is squeezed through the stoma into the trachea. The insertion of saline induces immediate coughing that facilitates the clearing of secretions. The contents of the bullets is introduced in several insertions. The suction created by the empty saline container enables sometimes to remove a small amount of the secretions. It is generally useful to use saline bullets as needed several times a day or as directed by one’s physician.

Steps to achieve better humidification and healthier mucus production include:

- Wearing an HME 24/7 that provide extra humidity keeps the tracheal moisture higher and preserves the heat inside the trachea and lungs. These include Provox XtraMoistandand Provox Life – Home HMETM, Atos Medical Provox FreeHands HME Moist.
- Wetting the soma cover (or bib) to breathe moist air (in those who wear a stoma cover). Although less effective than an HME, dampening the foam filter or stoma cover with clean plain water can also assist in increasing humidification.
- Drinking enough fluid to keep well hydrated
- Inserting 3-5 cc saline (preferably using saline “Bullets”) into the stoma 3 to 5 times a day (see below how to prepare saline)
- Using a humidifier in the house to achieve about 40-50% humidity and getting a hygrometer to monitor the humidity. This is important both in the summer when...
Voice Preservation Options for Head/Neck Cancer Patients

By Amy Lustig

If you have been diagnosed with a serious head or neck cancer, you are potential risk of losing your speaking voice and/or your ability to form words clearly.

Through voice and message banking, you can capture and preserve your speaking voice to help you with future communication needs.

Voice banking creates a synthesized version of your current voice that will say anything and everything you want to communicate. It takes about 1-2 hours to create a banked voice on a computer or cell phone. It’s always free to create the voice and between $100-1000 to purchase it.

Message banking records your spoken remarks, laughter, and anything else you vocalize. Banked messages can be captured in a few minutes or a few hours on a cell phone, tablet, or computer; or on a digital recorder.

Message banking costs range from free to a few dollars for a recording app, or more for a separate recorder.

Banked voices and messages are both used through text-to-speech applications on your cell phone or tablet. They are intended to be used alongside other voicing options such as electrolarynx, TEP, and/or esophageal speech, and may be desirable in certain communication situations, such as when you need to convey a quick and clear message.

Go to https://preserveyourvoice.com/ to find more information about voice and message banking. The website was created by Amy Lustig, PhD, CCC-SLP, a speech pathologist in the US who is passionate about making voice preservation available to those who desire it.

To contact Amy, email Amy@preserveyourvoice.com or call/text (617) 420-2203.

Mucus Production and Increasing Air Indoors Humidity

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air conditioning is used, and in the winter when heating is used

• Using nebulizing bottle twice daily
• Breathing steam generated by boiling water or a hot shower

A digital humidity gauge (called a hygrometer) can assist in controlling the humidity levels. Over time, as the airways adjusts, the need to use a humidifier may decrease.

Using these measures can lead to healthy mucus and contribute to laryngectomee’s health and wellbeing.

International Association of Laryngectomees
Annual Meeting and Voice Institute
Many loving couples attended the 2023 IALAM & VI
St. Louis was the place to be for the IAL Annual Meeting and Voice Institute