Thank you for hosting the 66th IAL Annual Meeting and Voice Institute

Peninsula Lost Chord Club

Tidewater Lost Chord Club

Welcome and Attractions in Virginia
On pages 12 & 13

Registration and Hotel info on pages 16 & 17

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About The IAL News

The IAL News is published four times a year by the International Association of Laryngectomees. Information provided by the IAL News is not intended as a substitute for professional medical help or advice, rather as an aid in understanding problems experienced by laryngectomees and the state of current medical knowledge.

A physician or other qualified healthcare provider should always be consulted for any health problem or medical condition.

The IAL does not endorse any treatment or product that may be mentioned in this publication. Please consult your physician and/or speech-language pathologist (SLP) before using any treatment or product.

The opinions expressed in the IAL News are those of the authors and may not represent the policies of the International Association of Laryngectomees.

IAL Items Available

- IAL Brochures
- IAL News order/change of address cards
- Orange Emergency Cards (English)
- Orange Emergency Window Stickers (English)
- “Laryngectomees Loving Life” DVD (35 mins) ($10 donation requested) (May also be watched on website)
- “First Steps” Available to download from the IAL website

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Have a good idea or a helpful hint?

We welcome laryngectomees and caregivers to submit ideas that would be helpful for other laryngectomees.
From the Nominating Committee

My fellow laryngectomees,

This is a plea to all laryngectomees!!! Please consider stepping up and taking a seat on the board of directors or running for an elective office in the IAL.

Over the years we have seen people come and go. Some went because their term expired, some because they could no longer fulfill their duties, and some who had their feelings hurt. Since we are all volunteers, we hope to be respected for taking a leadership role and giving of ourselves, our talents, and our time. When we feel we are not getting that respect we tend to back off and just let someone else do the job. Please, don’t let what happened in the past keep you from taking an active role now. We cannot change or make improvements to our organization without the aid and assistance of all members.

Unfortunately, we are at a place where our president, Tom Cleveland, took that position because if he had not, there was no-one else willing to do it. Thank you, Tom, for caring about all of us and stepping in to keep our organization on track.

I, too, am a new volunteer. I told Tom I would take the Treasurer’s position and Tom asked if I would also step in as Vice President, which I accepted. I just accepted the role of chairman of the Nominating Committee and I am pleading with everyone to consider taking an active role in the IAL. As you can tell I am new to this, I admit that I do not know a lot about the IAL as a whole but I do feel my experiences in both my work and my pre and post op visits with others helps me to be the best I can be. We are all valuable and worthy to make decisions concerning an organization that aims to help each of us. All of you have hidden or not so hidden talents that can help keep us ever improving the IAL. I beg of you to please share those talents by filling a vacant position.

My group, the Tidewater Lost Chord Club, and the Peninsula Lost Chord Club headed by Tom Olsavicky, are working together to host the IAL Conference in June, 2017. I am looking forward to meeting many of you there and hope everyone who can will come and enjoy the fellowship and gain information invaluable to all of us.

If you have any questions, comments, or concerns about accepting an office or a seat on the board, please feel free to contact me by text or email at the following:
Phone 757-285-2992 Email: Agrath3004@aol.com.

Thanks for your consideration and for saying “I will.”

Sincerely,
Helen Grathwohl, VP, IAL Board of Directors

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Board Member
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Getting to Know Your Board Members
By Barb Nitschneider

Each board member was asked to complete a questionnaire. Each question will be followed by the answer of each board member.

What position do you currently hold on the Board?
Tom: President
Helen: Vice President
Barb: Secretary
Candy: I am a Member at large on the Board of Directors, and help solicit articles and edit The IAL News.
Dr. Mitchell: Medical Director
Susan: I am the IAL Administrative Manager starting in 2007.

Where were you born and where are you now living?
Tom Cleveland: Born in Mason, MI and now live in Kalamazoo, MI.
Helen Grathwohl: Born in Lavelle, PA, and now live in Chesapeake, VA.
Barb Nitschneider: Born in Chicago, IL and now live in Trout Valley, IL
Candy Moltz, SLP: Born in Aberdeen, MD while my father was stationed at Aberdeen Proving Grounds in 1951. Although my family was from Texas, we moved around a lot until I went to college at Baylor University in Waco, TX. Right after graduating college in 1972, I married and lived in the Metroplex ever since.
Dr. Brian Mitchell, DO: Born in Peoria, IL and now live in Spokane, WA.
Susan Reeves, SLP, Administrative Manager: Was born in Iraan, TX, and grew up in McCamey TX. I left home and my parents moved to Clyde, TX. My husband and I now live in San Angelo TX.

Education/job training. Are you currently working or are you retired? Did you return to work after your laryngectomy
Tom: I returned to work two weeks after my laryngectomy. With other health problems, I was forced to retire in 2000.
Helen: I worked in management for 7- Eleven for 37 years and retired after my surgery in 2002. Went back to work at Toys R Us in 2010 and left there in 2015. I am currently retired.
Candy: I have a Master’s degree from the University of Texas at Dallas. I recently retired from the Dallas VA Medical Center as a speech language pathologist. Since then I occasionally take a traveling job for 13 week contracts.
Susan: I am currently the co-owner of Reeves Rehab Speech Therapy and Safety Training Center in San Angelo, TX. I am a speech pathologist where the majority of my career (31 years) was working at West Texas Rehabilitation Center, a nonprofit agency. I was introduced to my first IAL meeting in the late 1980’s in Seattle.

When did you have your laryngectomy and what method of speech are you currently using?
Tom: April 21, 1995. I use a TEP.
Helen: January 6, 2002. I use a TEP to speak.
Barb: June 10, 1974. I use an Electrolarynx to speak
Candy: not applicable
Dr. Mitchell: not applicable
Susan: not applicable

What is your favorite place to travel?
Tom: Alaska
Helen: Anywhere in the mountains
Barb: The state of Virginia. It has everything I like.
Candy: John and I like to travel and have been lucky enough to travel quite a bit. We really like beaches everywhere (US, Mexico, Caribbean) and that would be the all-time favorite.
Dr. Mitchell: Mountain regions.
Susan: I love to travel everywhere. Probably my favorite travel locations would be places
where there was plenty of water and/or mountains. Spokane and Seattle WA, would be two of my top picks for that reason, in addition to the special people I have been fortunate to know from the area.

What hobbies do you enjoy?

Tom: Working on old vehicles and motorcycles, and being on the computer

Helen: I enjoy reading, crocheting, gardening, sewing and meeting and visiting people.

Barb: Spending time and riding my horse, reading, and volunteering.

Candy: I love to walk, bicycle, read, sew, mow and sing.

Dr. Mitchell: Cycling and skiing

Susan: I love music of all kinds and dancing. My favorite past time would have to be watching my grandchildren play together as well as watching Ben/alias “Pop” play with them.

In one or two sentences, how would you describe yourself?

Tom: Business like and I enjoy talking to people and meeting new people. I guess I’m a people person.

Helen: I have an upbeat, positive attitude and look for the best in everyone. I am open and honest. People often say, “If you don’t want to know the truth, don’t ask Helen.”

Barb: I try to look for the good in people. I learned this over the years, and life is too short to get yourself pulled into negativity and bad energy.

Candy: I am energetic and eternally optimistic.

Dr. Mitchell: I am full of good intentions but often short on time.

Susan: I’m determined, brutally direct and strive to be fair and honest with people. I care about people and their needs and have shared that common compassion with the IAL family, Voice Institute staff, and especially vendors over the years. I feel extremely grateful for this journey.

What are your goals and hopes for the future of the IAL?

Tom: I hope IAL will become more international again and to find more ways to educate the new laryngectomee and care givers. I also would like to see more health students get involved with the IAL to see how we must change and learn how to live with our new voice.

Helen: We need to be International if we are to be known as such. We need to do all we can to keep our list of clubs and speech therapists, current and up-to-date. We need to assist in establishing clubs and, we need a better publication or just post on the web. We need openness and cooperation between our board and all members.

Barb: Being International is important, but with it there comes more expense. We also need to develop a strong website that will educate new/old laryngectomees quickly and efficiently. But our greatest need is to support and educate new and existing clubs. Clubs are the backbone of the IAL.

Candy: I wish to see the IAL fulfill its goal of providing information and support to laryngectomees and their total rehabilitation.

Dr. Mitchell: I would love to see the preservation of a body of knowledge to care for laryngectomy patients, particularly unique information where creative ideas have been used to make things easier when it comes to stoma care and speech rehab, ideally with a network of educated patients who can interact face to face both before and after surgery with those facing a new laryngectomy.

Susan: I hope that all working for the common cause of helping others with alaryngeal needs would see worth in each other and work towards that common goal. I hope the next decade is a decade of coming together doing just that. My goal is to educate young clinicians as to the needs of the alaryngeal population and to help as many laryngectomees as I can. My goal is to support the IAL board, its membership, young clinicians as well as veteran friends and all vendors within the alaryngeal family that I have been blessed to be part of.

Is there anything else you would like us to know about you?

Tom: I have come a long way in 22 years of being a laryngectomee.

Barb: I am on my 7th horse, a buckskin mare named Amber. I have loved each of my horses and they all have taught me so much.

Candy: I love animals and we have three Maine Coon cats and an 80lb Doberman mix foundling that a patient begged me to take as a 4-month old puppy.

Dr. Mitchell: I have 3 great kids all of whom are growing up faster than I would like.
In Case of Emergency Please Contact SLP

It's 10:05 AM on a Thursday and Speech Pathology receives a phone call from the front desk that a walk-in laryngectomee is here to see them. The clinician goes to gather the patient from the lobby and is surprised to see an open stoma with a coffee straw through the patient's TEP. The man shrugs and writes on a pad of paper, "For some reason the people on the train were looking at me like I was nuts." He smiles and follows the speech pathologist back into clinic for some disaster recovery.

Keeping an emergency kit on your body, in your home, and in the car is important for any laryngectomee to avoid a potentially dangerous situation. Accidents are never planned and you don’t know when a TE voice prosthesis may become dislodged, an HME cassette may become soiled, or crusty mucus may obstruct your airway. Some items to consider including in your "emergency kit" include: Kleenex/paper towels, an extra HME cassette, a mirror, saline bullets, tweezers, a flashlight, red rubber catheters (14 or 16 Fr) or a TE dilator, a larytube if you have stoma stenosis, a stoma cover, and your electrolarynx if you are a TE speaker. A spare battery is always helpful for your speech aid. Like the Boy Scouts, the laryngectomee population must always "Be Prepared," so that way their coffee straws will only have to be used for stirring hot beverages.

By Dana Collinsworth, MA CCC-SLP
Dallas VA Medical Center

The Good Life with Ceredas
A key combination for improved breathing after total laryngectomy

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Caregiving is stressful and that is an understatement. In past columns we have talked about ways to make caregiving less stressful and why it is so important to take care of YOU. I would like to add something to your toolbox, a technique that works when nothing else does. And even better, this tool is free! You can use it anytime and anywhere. You do not need to leave the house. You do not need anything special to utilize this tool. You do not even need to ‘set aside time’ to do this. And you can use this tool, not just for alleviating caregiver stress, but for any condition that is persistent and difficult to live with.

The tool I am talking about is Mindfulness-Based Stress Reduction (MBSR). MBSR was developed in the 1970s by Professor Jon Kabat-Zinn at the University of Massachusetts Medical Center. It was developed to fill a specific need; helping patients cope with illness or pain that could not be helped with medicine or pharmaceuticals. It is a program that helps you learn to calm your mind and body to help cope with stress, pain and illness. MBSR teaches you to focus only on things happening right now, in the present moment. By focusing on the present moment we can stop much of our thinking that contributes to stress. As a caregiver you may often find yourself thinking about what might have been. It is very easy to get stuck in “woulda-shoulda-coulda” mode. You may think about what you could have done differently such as not purchased cigarettes for your loved one. You may engage in catastrophizing, thinking about the future and imagining all kinds of unpleasant scenarios. Playing the “woulda-shoulda-coulda” game does not change anything except add to your stress. Engaging in catastrophizing is also a useless and stressful activity. Most of what we worry about never comes true. I remember seeing a sign in a doctor’s office that very wisely stated, “The tomorrow you worried about yesterday is today.” And likely today, none of what you imagined happening yesterday has indeed happened. Engaging in woulda-coulda-shoulda thinking and catastrophizing only results in the loss of this moment and the stress that comes from thinking about things you cannot change and things that may never be. Mindfulness teaches you to be in charge of your thoughts and mind rather than having your thoughts control you.

The University of Massachusetts Medical School offers a self-paced, on-line, FREE course in MBSR. You can find more information at www.palousemindfulness.com. The course is 8 weeks long but again, it is self-paced. There is also a very good, nine minute YouTube video that is a good introduction to MBSR. The video can be found at this link:  https://youtu.be/mBSO41ZimNsl=PLbiVpU59JkVaWH5kKrkSCIkg0vKLr1p9f

I am interested to know what you think about MBSR or hear any other comments you have about Caregiver’s Corner. Please write to me at carynmelvin@gmail.com with any comments, suggestions for topics of future columns or if you would like to share your caregiving story for an upcoming issue.

“The more time and energy you put into taking care of yourself, the more you will be able to care for those around you.”  — Jane Vock
Recently an article was published by long time friend of the IAL Dr. Jan Lewin and colleagues at MD Anderson Cancer Center in Houston (JAMA Otolaryngology Head Neck Surg. 2017;143(1):65-71). They looked at their experience with voice restoration using TEP (tracheoesophageal prosthesis) following laryngectomy over the past 10 years. 390 patients were followed and it was noted how often these patients required voice prosthesis replacement. In the study, the average time for replacement was roughly 2 months. This is much less than what many of us have quoted patients, typically 3-6 months. The type of valve used or past treatment didn’t seem to have a big impact on the lifespan of the valve. Roughly 70% of the time the valve was replaced for leakage. The reason for noting this recent study is to point out how often patients should expect TEP prostheses to last in the modern treatment setting. It bears mention that many patients will have differing insurance coverage and out of pocket expenses may be considerable if one is on the short end of average when it comes to replacing devices. Potentially needing 6 devices a year is a marked expense. Additionally, there is the act of having it changed often, particularly if one has to travel for health care. When patients are considering choices for voice restoration post laryngectomy, it is prudent to consider these issues in addition to “what’s the best voice”. Practical considerations will often weigh more on patients’ minds in the long term than simply the sound of the voice. A large part of successful voice restoration is finding the right voice for the right patient. This needs to involve a broad discussion that goes beyond what is physically possible for patients. We now try to counsel patients preoperatively as to the different issues that go with TEP including cost over time and device life expectations. This recent article is a good example of what is happening in real life even at the best of health care centers.
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One of many beaches in the area with the Crab Shack Restaurant in the background.

For outdoor enthusiast, the Nolan Trail at the Mariners Museum offers a scenic 5 mile walk.

The Newport News Park offers recreational activities along with several RV campsites.

Next door to your Marriott Hotel is a dining experience that you must have during your stay.

For those who want to shop-til-you-drop, you will enjoy the many outlets in the above areas.

This museum offers fun and a learning experience for old and young alike. Discover the wonders of the Chesapeake Bay. See river otters, bald eagles, endangered red wolves and more of Va.’s wild animals as you stroll on the lakeside elevated boardwalk.
Welcome to Newport News

**THE MARINERS’ MUSEUM AND PARK/ USS MONITOR CENTER**

The Mariners’ Museum connects people to the world’s waterways through engaging experiences. The stories we share are your stories, your history. Find your connection!

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This museum will be our Friday afternoon excursion and is sure to please everyone. It will be a guided tour by experienced docents who provide fascinating stories. The Crabtree collection of model ships is just awesome and will make this tour a memorable one.

Fifteen minutes from Newport News is Williamsburg. Where Busch Gardens, Water Country USA, Premium Outlets, Colonial Williamsburg, the College of William and Mary, and a first class Winery are sure to please if you come early or extend your stay.

Lady Liberty in Yorktown is a must see. Just a short ten minute ride will put you in one of the most historic towns in the area. Visit the Yorktown Battlefield and the Revolutionary Center, with its outdoor encampment, and see for yourself where the British surrendered and Independence was won.

One of the jewels of America’s Historic Triangle is Historic Yorktown, with equal measures of history and charm. Overlooking the York River, this colonial-era village is home to fine antique shops, art galleries and charming restaurants. On the waterfront itself, Riverwalk Landing offers even more shopping and dining fun.
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Red River Valley New Voice Club
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The IAL Board of Directors and staff appreciates every donation to the association. Your gifts will be used to further the cause of the Laryngectomee.
The current donation program listed in the IAL Newsletter was initiated in June 2011. Prior giving was greatly appreciated but not recorded in the totals listed here.

If there is a club interested in hosting the IAL Annual Meeting during the summer of 2018, Please submit your application to the IAL Board of Directors. There are complete directions on the IAL website at www.theial.com. Thank you.

Announcement
Association for Head & Neck Cancer Rehabilitation
2nd Annual Clinical Laryngectomee Conference
M.D. Anderson Cancer Center Houston, TX
June 22-24, 2017 Online Registration
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The Newport News Marriott at City Center will host the 2017 IAL Annual Meeting and Voice Institute from

June 14-17

(757) 873-9299
740 Town Center Dr.
Newport News, VA 23606

Call our reservation system at 866-329-1758 and ask for the IAL Annual Conference group block. Reservations must be made by May 11, 2017, to guarantee group rate of $104.00 or select the link for online reservations. Make sure to tell them that you are with the IAL so you can get your group rate.

Book your group rate for IAL Annual Conference by following the online links at:

http://theial.com/ial-voice-institute-and-annual-meeting/

Airports closest to the conference would be Norfolk International (http://www.norfolkairport.com/) and Newport News/Williamsburg International (http://flyphf.com/). Norfolk provides cheaper flights (about $100 less than Newport Airport) but transportation to Newport News would be necessary. Newport News is about $100 more but is closer.

A tentative agenda for the conference is available at:

Registration Fees:
Laryngectomees/ Caregivers/family..$120.00 by May 11  ($150.00 after May 11)
Speech-Language Pathologists.........$400.00 by May 11  ($450.00 after May 11)
Graduate Students ............................$200.00

The recommended method for registration and payment is online at: http://www.theial.com

Mail in registrations: Please use this form

First Attendee (please print)___________________________ Laryngectomee? ___Yes ___No
Second Attendee (please Print) _________________________Laryngectomee? ___Yes ___No
Street Address _______________________________________ 
City______________________ State/Province ___________ Zip_________ Country _______

Check here if you require assistance, have dietary restrictions, or need special accommodations to attend the meeting because of physical limitations. You will be contacted for other information.

Mail in registration forms must have check or money order payable in U.S. dollars to the International Association of Laryngectomees (IAL)

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Mail to IAL, 925B Peachtree Street NE, Suite 316, Atlanta, GA 30309
TLA: 26th Annual Meeting held in Corpus Christi, TX

In Review by Elizabeth Durand

The Texas Laryngectomee Association Annual Meeting ventured out to the previously unvisited bay and beach of Corpus Christi, Texas, on the Gulf of Mexico. Attendees were welcomed warmly from February 16-19, 2017 at the Emerald Beach Hotel where one could enjoy the gentle waves coming ashore and resounding a message to soak in all the knowledge, to be open to meet new friends and to recharge the mind and body with new insights.

The conference was off to a quick start on Thursday with an enthusiastic group of laryngectomies and spouses learning to become trained volunteer visitors to the recently laryngectomized. Then early Friday morning, SLP Jennifer Galysh colorfully recounted the fascinating history and frequently toured sites of Corpus Christi. Matt Steehler, M.D., followed with an enlightening presentation on anatomy/physiology and surgery/treatment options. The audience greatly appreciated the ample time he gave to their questions. It was SLP Jenn Starkweather who gave laryngectomies up-to-date information on the complex area of medical reimbursement issues. Ann McKennis, R.N., stepped up to speak on the importance of advocacy, aging issues, and the power of a positive attitude. Lacey Martins, SLP, effectively explained the necessity of a pre-operative visit and all that it entails.

Everyone gained important information from SLP Betsy Ruiz’s presentation on swallowing concerns, an often-overlooked area in rehabilitation. Other topics as the electro-larynx, esophageal speech, TEP basics and troubleshooting were also highlighted during the academic sessions. Susan Reeves, SLP, skillfully demonstrated esophageal speech with both laryngectomies and attendees much to the delight of the audience. SLP Caroline Nickel on the other hand helped to simplify and demystify the unique complexities that may occur with a TEP. Julie Bishop-Leone, SLP, stressed that the key to better breathing and reduced coughing was through consistent HME use. SLPs Lori Simpson and Lacey Martins lead groups through an informative vendor roundabout in which vendors speed dial information to eager listeners.

Two all-time favorites on Saturday were the hands-on experience with the different forms of communication and the Mix and Match session in which laryngectomies shine telling their stories to inquiring graduate students and SLPs. Nurse Practitioner, Maggie Kramper’s session on allergies: causes, medications and injections, brought about a lively audience discussion. Receiving high praise was a first time Rap session only for laryngectomies conducted by John Ulrich.

Gary Schwantz, the guest speaker at the Saturday banquet, gave pause for thought as he spoke of life lessons learned from his grandchildren. There was much hearty laughter and an occasional misty eye during these precious life reflections. Deores Becho, SLP, gave a strong final session on Sunday by capturing the audience’s interest with her knowledge of cultural variation in healthcare.

Our host club, The Coastal Bend Speak Ez Laryngectomee Support Group, outdid themselves by enhancing the conference success in numerous and immeasurable ways including a fabulous Meet and Greet. Our gratitude also goes to the many other laryngectomee clubs who also supported the raffle and a spirited auction lead by Robert Heckard and Tom Lennox.

All in all, life was good during those few days while immersed in an idyllic setting soaking up the wealth of knowledge and having the opportunity to form new friendships. If you missed it, the TLA will be in the DFW Metroplex in 2018. We hope to see you there!
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