International Association of Laryngectomees

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

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Order From: IAL in Atlanta or email: theialoffice@gmail.com

We thank all of our vendors for their support. Please contact them with your questions or comments. They are always ready and eager to help with any problem.

Newsletter Editor
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Table of Contents
Our Valued Advertisers
InHealth Technologies……..2
Atos Medical……………….20

******************************************************************************************
Meet Me in St. Louis………………….4
Crab or Creeping Ulcer………………5
Damage to Carotid Artery Following Radiation……………………………..6
Beatitudes of a Laryngectomee………7
Head and Neck Cancer, A Hard Thing to Swallow……………………………..8
My 10th. Anniversary………………9
Oh No……………………………..10
Shift in Focus for Head and Neck Cancer Treatment………………………..12
Biggest Threat to Lary Health and Safety (part 3)……………………………..14
Editor’s Story……………………18
Lary’s Speakeasy…………………19

We thank all of our vendors for their support. Please contact them with your questions or comments. They are always ready and eager to help with any problem.
Me in St.Louis

The International Association of Laryngectomees will be holding their Annual Meeting/Voice Institute

May 11 thru 14, 2023
Sheraton Westport Lakeside Chalet
191 Westport Plaza
St. Louis, MO 63146

Look for registration information on our website (TheIALVoice.org) after the new year.
Crab or Creeping Ulcer

By: MacKayla Jean LaPlante

What is cancer? If you search it on Google, you will find: “Cancer refers to any one of a large number of diseases characterized by the development of abnormal cells that divide uncontrollably and have the ability to infiltrate and destroy normal body tissue. Cancer often has the ability to spread throughout your body. Cancer is the second-leading cause of death in the world.” This is how The Mayo Clinic defines it.

Cancer is different for everyone despite that basic, wide ranged definition. All I really know is that cancer doesn’t care. You could be the happiest you’ve ever been and it will sneak up on you. It will rob so many little moments.

It doesn’t really ever go away. It’s kind of like when someone says they have to talk to you LATER. That sense of anxiety. It never goes away.

For me cancer is wondering if I’ll get to watch my children’s lives unfold. That fear that if you don’t win, that nobody could ever care for them exactly the way you would. For me, cancer is wondering if every little pain in my head and neck area is a tumor coming to take me away from all the things that matter most.

Cancer. In Latin it means crab or creeping ulcer. It’s said the veins around tumors resemble the legs of a crab. To me it means the death of who I used to be. The death of relationships that took on too much strain from how unhappy I was. Either way, I’ll always find it ironic that my zodiac sign is cancer. Kind of like I’ve had a warning all my life of what would one day unfold.

Don’t Quit

When things go wrong as they sometimes will, when the road you’re trudging seems all up hill.

When the funds are low but the debts are high And you want to smile, but you have to sigh, When care is pressing you down a bit, Rest if you must, but don’t you quit. Life is strange with its twists and turns As every one of us sometimes learns And many a failure comes about When he might have won had he stuck it out; Don’t give up though the pace seems slow— You may succeed with another blow. Success is failure turned inside out— The silver tint of the clouds of doubt, And you never can tell just how close you are, It may be near when it seems so far; So stick to the fight when your hardest hit— It’s when things seem worst that you must not quit. John Greenleaf Whittier
Damage to the carotid artery following radiation treatment (RT) for head and neck cancer

Damage to the carotid artery (CA), can cause narrowing (stenosis) and stroke, CA rupture, and CA baroreceptors damage leading to blood pressure problems.

**Ischemic stroke** can be a late complication of neck irradiation. Many factors can contribute to the increased risk of stroke in patients with head and neck cancer, including CA stenosis (see below) and increased deposition of plaque, as well as other preexisting risk factors for cerebrovascular disease, particularly smoking.

**Carotid artery stenosis and carotid artery rupture:** The CAs in the neck supply blood to the brain. Radiation to the neck has been linked to CA stenosis or narrowing, and rarely to CA rupture; representing a significant risk for head and neck cancer patients, including laryngectomees. Screening ultrasound within the first year since completion of radiotherapy, followed by repeat ultrasounds every two to three years and whenever CA stenosis is suspected can lead to early diagnosis. Smoking increases the risk of CA stenosis. The incidence of CA stenosis ranged from 18 to 38% in patients who underwent RT for head and neck cancer among not irradiated patients. CA disease can cause strokes and transient ischemic attack, though it does not always cause symptoms. It is important to diagnose carotid stenosis or impending rupture early, before a stroke or severe bleeding has occurred.

The signs and symptoms of a stroke or TIA include these sudden features:

- Numbness or weakness in the face or limbs, often on only one side of the body
- Difficulty in speaking and understanding
- Trouble seeing in one or both eyes
- Dizziness or loss of balance
- Severe headache with no known cause

Stenosis can be diagnosed by hearing a bruit sound over the CA, ultrasound, CT, MRA (Magnetic Resonance Angiogram), MRI, and angiography. Treatment of stenosis caused by RT is usually by placing a stent (a small device placed inside the artery to widen it). Other methods include removal of the blockage (endarterectomy), and prosthetic carotid bypass grafting, or a prosthetic carotid bypass grafting.

Evidence suggesting impending rupture can be obtained on physical and radiological examinations. Endovascular stenting is also performed in patients with impending CA rupture.

**Hypertension and hypotension due to baroreceptors damage:** Radiation to the head and neck can damage the baroreceptors located in the CA. These baroreceptors help in regulating blood pressure by detecting the pressure of blood flowing through them, and sending messages to the central nervous system to increase or decrease the peripheral vascular resistance and cardiac output. Some individual treated with radiation develop low, labile or paroxysmal hypertension.

**Low blood pressure:** This can be cause by damage to the peripheral and autonomic nervous system and the carotid baroreceptors. This can lead to baroreceptor failure that is manifested in orthostatic hypotension (intolerance) which is characterized by dizziness when standing up from a sitting or lying down position.

. This can be managed by standing up slowly, wearing of compression stockings, exercising and by keeping well hydrated. Postprandial (after a meal) hypotension can also cause low blood pressure.

**Labile hypertension:** In this condition, the blood pressure fluctuates far more than usual within the day. It can rapidly soar from low (e.g., 120/80 mm Hg) to high (e.g., 170/105 mm Hg). In many instances, these fluctuations are asymptomatic but may be associated with headaches. A relationship between blood pressure elevation and stress or emotional distress is usually present.

**Paroxysmal hypertension:** Patients exhibit sudden elevation of blood pressure (which can be greater than 200/110 mm Hg) associated with an abrupt onset of distressful physical symptoms, such as headache, chest pain, dizziness, nausea, palpitations, flushing, and sweating. Episodes can last from 10 minutes to several hours and may occur in different frequency - varying from once or twice daily to once every few months. Between episodes, the blood pressure is normal or may be mildly elevated. Patients generally cannot identify obvious psychological factors that cause the paroxysms. Direct massage of the CA during Doppler ultrasound can lead to such episodes. Medical conditions that can also cause such blood pressure swings need to be excluded (e.g., pheochromocytoma).

Both of these conditions are serious and should be treated. Management can be difficult and should be...
done by experienced specialists. Correction of CA stenosis (i.e., stent insertion) can prevent or reduce the occurrence of these conditions.

Dr. Samuel Mann from Weill-Cornell Medical Center in New York City is one of the leading experts in treating paroxysmal hypertension. [https://weillcornell.org/smann](https://weillcornell.org/smann). The Vanderbilt Autonomic Dysfunction Center is one of the nation’s leading expert centers in dysautonomia, or autonomic dysfunction. [https://www.vumc.org/autonomic-dysfunction-center/vanderbilt-autonomic-dysfunction](https://www.vumc.org/autonomic-dysfunction-center/vanderbilt-autonomic-dysfunction)

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dribook.blogspot.com/

**BEATITUDES OF A LARYNGECTOMEE**

Blessed are you who take the time to listen to my strange new speech. For you help me to realize that I can be understood.

Blessed are you who never ask me to “hurry up” or say my words for me. For I appreciate the time more than the well intended help.

Blessed are you who do not shout act me when we speak. For you realize that I am not deaf only sometimes a little dumb.

Blessed are you who ask me to repeat when you don’t understand me. For that is more honest and helpful than pretending you understand me.

Blessed are you who allow me new opportunities and challenges to use my speech. For only by doing and succeeding will I grow in confidence and strength.

Blessed are my doctors, nurses, my speech teachers and all my friends and especially my family. For you have given me back my life and made me realize what a fortunate and lucky person I am.

Blessed are you who love me just as I am.
Head and Neck Cancer: A Hard Thing to Swallow

This Spring, individuals battling head and neck cancer will be getting the wider attention they deserve. In April and May, races will be held across seven states to bring recognition to this increasingly common cancer. The events raise funds to support patients and caregivers in the local area; increase community awareness; and provide a fun opportunity for patients, caregivers, physicians, healthcare providers and supporters to interact in a positive and life affirming activity.

2023 will be the 11th year the “Head and Neck Cancer: A Hard Thing To Swallow” 5k run and 2 mile walk has been hosted by Partners in Care, a not-for-profit oncology foundation. Funds raised from each event stay in that local community and provide financial assistance to those diagnosed with head/neck cancer regardless of when they were diagnosed. This financial assistance includes services and products related to the diagnosis that patients would otherwise go without due to costs.

The 2023 races have a superhero theme. Come dressed as your favorite superhero to add to the fun.

The 2023 race schedule is as follows:

4/15 9am Tri-Cities WA: Columbia Point Marina
4/16 9am Redding CA: Lake Redding Park
4/22 7am Key West FL: Higgs Memorial Park
4/22 6pm Miami, FL: Larry & Penny Thompson Park
4/23 7am Broward County, FL: Tradewinds Park
4/29 8am Cape Coral, FL: Jaycee Park
4/30 8am Sarasota, FL: Payne Park
5/4 6pm Charleston, WV: (Venue To Be announced)
5/6 8am Winston-Salem, NC: Jamison Park-Muddy Creek Greenway
5/7 8am Asheville, NC: Carrier Park
5/7 4pm Greenville, SC: Conestee Park Nature Preserve
5/13 9am Denver, CO: Carpenter Park
5/14 9am Colorado Springs, CO: America The Beautiful Park

Everyone is encouraged to get involved whether it be volunteering prior to or the day of events; walking/running in person or virtually; helping to distribute race information in your community; or many other volunteer opportunities. More information will be coming at [www.yourpartnersincare.org](http://www.yourpartnersincare.org) or contact race founder and chairperson at Sbrill@aol.com.

The races are guaranteed to be a fun time for a great cause. If you are interested in hosting a free oral/head/neck cancer screening at one of the races, please email Sbrill@aol.com for more information.
My Tenth Anniversary

I was lucky enough to celebrate my tenth anniversary on September 18th. It made me stop and think about how important it is to be your own advocate, especially when it comes to your own health.

My journey started late in the summer of 2011 when my voice became very hoarse, and the hoarseness wouldn’t go away. I went to my family Doctor and he referred me to an ENT, which made sense to me. So for the next six months, I saw my ENT every month. She scoped me three different times, sent me to an allergist and tried numerous different nasal sprays, which had no effect. The whole time my voice continued to get worse and I was beginning to aspirate when I would drink something. At that point my ENT said that unless my voice got worse, I didn’t need to come back! I thought “are you kidding me” because I could hardly talk.

So I went back and forth with my family Doctor and the potential side effects of some of the medications I was taking, one of which could be voice hoarseness. He changed one of my meds but still no improvement. At that point he said he wanted me to go back to my ENT. That’s when I put my foot down and said NO! I want a second opinion! He didn’t argue with me and gave me three different options. I chose Johns Hopkins in Baltimore and he got me an appointment as soon as he could.

By now it was almost a year since my symptoms began. When I met with the Doctor at Johns Hopkins he examined me just like my ENT had except for one thing. He said I think we should do a CT scan of your neck and bingo! There is was. A large tumor wrapped around my esophagus. It biopsied positive as squamous cell carcinoma and a T4 size tumor and they recommended that I have a total laryngectomy as soon as possible.

I’m sure you all know the rest of the story. My point is that when you know something isn’t right with your body, be your own advocate. Unfortunately everyone isn’t good at what they do. They may be professional but that doesn’t mean they are proficient. Luckily for me I got to someone that was and they saved me from the “C” monster.

I hope everyone is enjoying the beautiful fall weather that we are having here in western Maryland!

Your President
W. Kyd Dieterich

I will be in St. Louis
May 11 - 14, 2023

Hope to see you there too!
Editor’s Story
By Helen Grathwohl

I have been putting together this newsletter for over three years now. I've had many laryngectomees tell me their stories to put in our newsletters but I have never done a story about myself. That being said, Let me bore you with my own story.

I was born and raised in a very small town (Lavelle) in central Pennsylvania. I was the only girl with three brothers. My Dad was a coal miner and my Mom was a stay at home Mom. She also had rheumatoid arthritis that began in her teens, which caused her to spend the last thirty years of her life in a wheelchair. I had an ideal childhood with two parents that loved each other and their children.

I graduated from school in 1959. I got on the train, and went to the big city of Philadelphia. I lived at the YMCA, and quickly got a job at an insurance agency. I remember my weekly salary was $35.00.

I met my husband on a blind date and we were married less than a year later. He was in the Navy and we went from coast to coast and back. We settled in Virginia, raised two children, and were married thirty years before he passed away from brain cancer.

Several years after my husband passed away I remarried. My second husband and I were doing well and traveling when we could. My son was living with us and I am forever grateful that he and my husband were good friends. The worse thing in the world happened in 1995. My son was electrocuted at work and passed away. It was the worse thing I ever went through or ever will go through. We were both crushed and had a very hard time adjusting to his absence.

In 2000 my husband was diagnosed with colon cancer. He had surgery and ended up with a colostomy, meaning he had to wear a bag attached to his stomach, much the same as a laryngectomee wearing a base plate. It was something we just had to learn to live with.

In December of 2001 I was diagnosed with stage 3 cancer on my larynx. I was not offered any options, so on January 6, 2002 I had a total Laryngectomy. I was not as scared as most because I already knew someone that had been down that road. He was doing well and running his own business.

I had 39 radiation treatments and was burned from my ear lobes to below my stoma. I was using an EL with an oral adapter, doing well and I got involved with Joe Marasco and the Tidewater Lost Chord Club. I enjoyed the meetings and was there every week. At that time we had a lot of laryngectomees in attendance at the weekly meetings and we were a very close knit group. A year after my initial surgery, I got my TEP. I had a wonderful voice, and started doing pre and post op visits with new laryngectomees. I found visiting to be very fulfilling and it was and is, such a delight to be able to offer others “Hope.”

In May of 2002 I was diagnosed with breast cancer. I had a mastectomy in June of that year and have not had another problem with breast cancer since.

Life went on, I went to work at Toy’s R US as a money counter and worked in the store. I loved answering children’s questions about the way I talked and they always wanted to know why I had to put my hand on my neck when I spoke. I enjoyed telling them I got that because I smoked and it was unreal, how many children turned to a parent and said “see smoking not good for you.”

In 2019 when Covid hit, it changed the world for all of us. I got the immunizations and made it through Covid without a problem. My daughter, her husband and my grandson moved in with me. It is wonderful to have someone here with me.

Toward the end of 2021 I developed problems swallowing and speaking. I had several esophageal stretches and it was not improving. In February 2022, I found a lump on my neck. I immediately went to my doctor, had a biopsy, and pet scan. My cancer had returned and I opted to have surgery. On May 30, 2022 I had a 10 hour surgery to remove the cancer and have my esophagus rebuilt. I declined another round of radiation as I am a firm believer in “Quality” over “Quantity” of life. Today I am doing fine and hope to see many of you in St. Louis in May 2023.

12 Things to Always Remember
1. The past cannot be changed.
2. Opinions don’t define your reality.
3. Everyone’s journey is different.
4. Things always get better with time.
5. Judgements are a confession of character.
6. Overthinking will lead to sadness.
7. Happiness is found within.
8. Positive thoughts create positive things.
9. Smiles are contagious.
10. Kindness is free.
11. You only fail if you quit
12. What goes around, comes around
From the Editor,

I sure hope all of my readers will read this column and respond to it! The IAL Board of Directors is considering taking this newsletter totally digital and not mailing out any copies. I do know that would be a big change and some of our community would be unable to access it.

The reason the board is considering this is, the ever rising cost of printing and mailing the newsletter. Unfortunately, we only have two vendors advertising in our publication due to the fact that some of the companies providing products for Laryngectomees no longer exist.

Covid hit many hard, they were unable to hang on and did not have a choice.

Several ideas are being tossed around: asking for donations, charging a subscription fee, seeking other companies for ads. If any of you know of a company we could ask to take an ad in our publication, please pass that information on to me at: helen.grathwohl@theialvoice.org

If you have any ideas for fund raisers I would appreciate those ideas as well. If you have any type of solution in mind, I would be happy to hear it.

Please remember this newsletter goes out to Laryngectomees, SLP’s and doctors. It is published for your information, with articles to offer hope, to share in the latest cancer treatment advancements for our community, and tips on our own personal care.

We always ask for your stories and would love to hear from you about anything you would like to see more or less of, and all comments, good or bad are appreciated.

Please remember, this publication is written for the pleasure and usefulness of our readers. I would personally appreciate your filling out and returning the second half of this page. Just fill it out, cut the page in half, fold it in three, tape or staple, put a stamp on it and drop it in the mailbox.

Thank You
**Texting 911**

Laryngectomees may find themselves in a situation where they need emergency services but are unable to speak and call 911 for help. One option for many across the United States is to use your smart phone as you would any other number, type 911, but select “send a message.”

Any text should be limited to 160 characters and include the location and nature of the emergency. The system works in partnership with Verizon, AT&T, Sprint and T-Mobile. Other systems may add it. We are asked to only use a text message if we are unable to speak.

**HPV Fact**

Human papilloma virus (HPV) is a known cause of cancers including cancer of the larynx and tongue. At least one half of sexually active males and females will contract HPV at some point in their lives. According to the U.S. Centers for Disease Control, almost all cancers of the cervix are HPV-linked. According to some experts, as smoking has declined, HPV-related larynx cancers are increasing as a percentage of all cases.

**“First Steps” being revised**

The IAL publication “First Steps” is being revised. It is a 20 page illustrated guide primarily intended for patients facing laryngectomy, new Laryngectomees and their caregivers. It answers the basic questions these individuals may have. The updated publication will be posted as soon as it is finished and approved by the Board. In the meantime, the older version is still available online at: theIALvoice.org.

The publication is free and can be downloaded from the website and printed out. Many clubs who continue to visit patients facing laryngectomy surgery provide a printed copy to the patient during the very important, pre-surgery or post-surgery visit.

**HIPPA not a Barrier to visits to lary patients**

HIPPA medical confidentiality laws can be set aside if the patient gives permission for a visit by a rehabilitated laryngectomee. Ask your ENT/SLP.
Cindy Stemple was only 27 years old when she received her diagnosis of stage 3 oral squamous cell carcinoma.

Photo by Amy Ann Photo

Shift in Focus for Head and Neck Cancer Treatment
September 20, 2022
Marijke Vroomen Durning, RN
CURE Fall 2022, Volume 21, Issue 03

Years ago, the goal of head and neck cancer treatment was strictly focused on a cure. Now, there has been a slight change in approach to improve survival rates while preserving quality of life.

When Cindy Stemple of Westerville, Ohio, noticed a sore on her tongue, the last thing she imagined was that she may have head and neck cancer. After all, she was only 27 years old.

She finally went to see her dentist when the sore wouldn’t heal. Since Stemple didn’t have any known risk factors for head and neck cancer, the dentist didn’t expect cancer either. After trying several treatments, they decided it was time for a biopsy. Stemple still wasn’t concerned.

“It wasn’t even in the realm of possible things,” she says. “I didn’t even take anybody to the appointment when I got the results and found out it was cancer because it was the furthest thing from my mind.”

She received a diagnosis of stage 3 oral squamous cell carcinoma — which is a cancer that occurs in the mouth and/or throat.

Tremendous Change in Head and Neck Cancer
Historically, head and neck cancer, the seventh most common cancer globally, was predominantly diagnosed in older individuals and was often linked to tobacco and alcohol use. As smoking rates began to decline, so did tobacco- and alcohol-related cases among older individuals.

But head and neck cancer rates began rising in another group — younger and middle-aged adults — driven by HPV infections, predominantly HPV type 16, which has been shown to be a clear risk factor for head and neck cancer as well as cervical cancer.

HPV-positive oropharyngeal cancers in the United States increased from 16.3% of head and neck cancers in the 1980s to more than 70% in the 2000s. Researchers, however, expect an eventual decrease as the effects of the HPV vaccine take hold, but it may take up to three decades to get to that point.

“I’ve been in the field for about 25 years, and it has changed tremendously,” says Adena Dacy, associate director of health care services in speech-language pathology at the American Speech-Language-Hearing Association in Rockville, Maryland. “Most of my patients tended to be older, usually with a long history of tobacco or alcohol use. Today we still see some of that, but we are seeing much younger patients, often (those who are) tobacco- or alcohol-free.”

Improving Survival While Increasing Quality of Life
In most cases, different treatment approaches are used for the two groups. For instance, since many patients with tobacco- or alcohol-related head and neck cancer are often older and have other comorbidities, treatment options are limited.

On the other hand, patients who are younger and healthier are likely better able to tolerate side effects and extended treatment regimens, if deemed necessary. Additionally, HPV-related head and neck cancers are more likely to respond better to treatments, meaning less aggressive therapy may be used.

Mike Jirousek, from Hamden, Ohio, received a diagnosis of head and neck squamous cell carcinoma four years ago at the age of 59. After noticing a rapidly growing lump in his throat, he went to a local urgent care clinic.

The attending physician was so concerned that Jirousek was immediately transported to the hospital by ambulance.

“They were afraid of (the lump) closing off my airway,” he says.
Now, patients are also encouraged to swallow, eat, drink and speak during treatment. Actively participating in these activities may help retain some of those functions after treatment has stopped.

“We learned that if you can encourage patients to learn to swallow, eat, drink and speak throughout their treatment, they’re more likely to preserve (these functions) after treatment,” says Roof.

Jirousek says his first head and neck cancer diagnosis and treatment happened so fast that he was ineligible for prehabilitation, but he notes he met with therapists when his treatment began.

“I met with the oncologists, radiation specialist, and then the nutritional experts and rehabilitation as well,” he recalls.

The therapists helped Jirousek prepare for potential difficulties with swallowing and limited nerve function in his neck and shoulder.

“During my first time, I was convinced that I would be able to keep eating and swallowing, and I was able to,” he says.

Unfortunately, Jirousek’s disease returned 18 months later, and his treatment was more invasive. He underwent a radical neck dissection — a notable surgery that consists of a significant removal of muscle, tissue and lymph nodes from the collarbone to the jaw — followed by chemotherapy and radiation.

As a result, Jirousek needed a feeding tube, and although he remains on the feeding tube, he is still able to speak.

Feeding tubes are not uncommon among patients treated for head and neck cancer. Data from a study published in 2017 in the journal *Cancer* demonstrated that more than 50% of patients with head and neck cancer required a feeding tube.

Of note, in many cases feeding tubes are temporarily placed during and after treatment. But they are often removed later as a patient’s swallowing function returns.

Stemple, whose disease returned five years ago, says that she didn’t see rehabilitation therapists before treatment for her primary diagnosis. She only recalls seeing them briefly during her radiation treatment.

It was after her treatment was completed that she received extensive therapy.

“I would definitely have been open to doing other therapies before treatment,” she says. “It wasn’t really presented to me as an option at the time.”
Threat to Lary Health and Safety


Parts 1 and 2 can be read at TheIALvoice.org under Publications-The IAL News. Especially if you have not read Part 1, please do. It is important. Parts 1, 2 (and 3) report(ed) on a survey of over 45 speech therapists and a half dozen MDs.

The threat to laryngectomee health mentioned by the majority was: “A lack of basic knowledge of laryngectomees and their changed anatomies and their breathing by medical professionals (such as confusing tracheostomy vs. laryngectomy), and subsequent inability to provide appropriate treatment. These professionals include pulmonologists, respiratory therapists, primary care physicians, nurses, anesthesiologists, SLPs, and ENT MDs.” In one study of 12 hospitals, 26 laryngectomees died as a result.

Part 1 stated that laryngectomees can minimize the chances that medical professionals will injure them and even cause their deaths. Recommendations included:

1. **Identify yourself** through bracelets and necklaces, cards carried in wallets or purses, notifying first responders ahead of time, using car window stickers, and others.
2. **Learn how your breathing worked before you became a laryngectomee and how it now works.** Know that you are a total neck breather. The article also stated that the air reaching our lungs is now dirtier, drier, and cooler.

It described ways to improve our breathing by urging us to wear a stoma cover 24/7, maintain an indoor humidity level of between 40-55%, and listed ways to maintain a good flow of mucus (which is essential for healthy lungs and windpipe.) It concluded with a quote and the advice to never allow medical personnel to put an oxygen or anesthesia mask over your mouth and nose, or a tube down your throat without questioning them on whether they understand you are a laryngectomee and total neck breather and not a trach patient.

It is a sad fact, but laryngectomees (and their loved ones/caregivers) must stand guard and advocate for themselves and loved ones until they are certain that medical personnel who will provide treatment understand our changed breathing systems.

Part 2 discussed the second most frequent answer to the question about laryngectomee health and safety - depression. Clinical depression and less serious forms were discussed and recommendations made.

Part 3, this final one, deals with other important threats to laryngectomee health and safety. This article addresses these other threats. The original question asked in the survey was:

“Aside from (larynx cancer) recurrences and new primary cancers, what do you think is the biggest threat to laryngectomee health and safety?”

**Recurrences of larynx cancer and the development of new cancers are a major threat to laryngectomees.** The chance of larynx cancer returning after treatment depends on the type of cancer, location, stage, and the effectiveness of treatment. Recurrence is most likely to occur in the first two to three years. Being five years free from a recurrence is taken as an indication that a return of the original larynx cancer is unlikely.

The recommended schedule for follow-up visits to your ENT doctor following laryngectomy is once per month the first year. Every 2-4 months the second year, every 4-8 months the third year, and once per year thereafter. Keep those appointments, and report any changes. This is your first defense against a recurrence or new cancer.

The chances of developing a new primary cancer depends, in part, on the cause of the larynx cancer. If the lary was a smoker other parts of the anatomy were also exposed to the chemicals in tobacco. The development of lung
cancer is not unusual in laryngectomees who smoked and/or were heavy drinkers. The combination of the two increases the risk significantly. Many larys who were smokers will be scheduled for an annual chest x-ray.

However, if you smoked at least one pack a day for 30 years, or 2 packs for 15 years, are age 55-80, and if you stopped smoking less that 15 years ago there is a different recommendation. The Centers for Disease Control recommend that you have a LOW DOSE CT scan every year until you are more than 15 years since you stopped smoking or you turn 80. CT scans are much more accurate in detecting lung cancer than x-rays in early stages when they are more successfully treated. If you meet the requirements stated above, ask your doctor if you should receive an annual LOW DOSE CT-scan (a yearly regular CT-scan would expose you to too much radiation.)

Lung infections can be very dangerous for laryngectomees. Untreated pneumonia can be life threatening. Wearing the most effective stoma covers 24/7 helps prevent lung infections. The most effective stoma covers are those which cause all of the incoming air to be filtered, such as the Heat/Moisture Exchange filter (HME). Other types of covers have varying degrees of protection. Some larys increase the effectiveness of their square foam stoma covers by doubling them.

The color of mucus can indicate a lung infection. If mucus is no longer semi-transparent but has a green or yellow coloring it probably means an infection. See your doctor immediately. These infections are usually effectively treated with antibiotics.

Although they are fairly rare, a mucus plug is capable of being deadly. Under normal circumstances, mucus moves up from the lungs and through the windpipe (trachea) by microscopic waves of hair-like cilia to our throats/stomas where we can cough it out. But especially if our mucus becomes dried out and thickens the cilia may no longer able to move mucus upwards. If enough mucus accumulates mucus can form a plug which blocks the movement of air. It can cause the collapse of a lung.

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Some new laryngectomees are sent home from the hospital with a suction machine to be used to vacuum out mucus and prevent plugging. Laryngectomees can also reduce the chance of the formation of a mucus plug by keeping their flow of mucus thin and watery. This can be done by staying well hydrated, maintaining an indoor humidity of 40-55%, wearing a Heat/Moisture Exchange filter, squirting sterile saline water into their stomas and then coughing it out. Some use saline “pink bullets” to squirt down into the stoma, others may use a saline spray.

Some laryngectomees experience shrinking of their stomas (stoma stenosis, micro-stoma). If the stoma is too small it can effect the movement of air into the lungs making it harder to breathe. The solution for many is to wear a lary tube or button at least part of the day to stretch out the stoma. An extreme case of stoma stenosis may require surgical revision (stomaplasty) to enlarge it.

Another problem for some laryngectomees is the formation of granulation tissue, especially around.
the TEP prosthesis. The tissue growth is the body’s attempt to heal an unnatural opening. Granulation tissue can be removed by your ENT in his/her office.

Another problem for some laryngectomees is the shrinking (stenosis) of the esophagus (feeding tube) making it difficult to swallow. The solution for many is to have their esophagus stretched (dilated) by their ENT MD. A few laryngectomees can self-dilate using what is called a “bougie.”

For those laryngectomees who were treated with radiation there can be long term complications including the formation of “fistulas” (holes that may not heal on their own). Carotid arteries can be damaged and clogged, and MDs recommend ultrasound scans to determine if they are blocked. In extreme cases, radiation can also contribute to the development of another cancer.

Being unable to speak. Some laryngectomees are unable to speak at all. Others depend on a working battery in an AL/EL or text-to-speech machine, an unclogged TEP prosthesis, or even something to write with or on. Some solutions are to carry a spare battery, a spare AL/EL, a brush to unclog a prosthesis and writing materials. We should also find out if we have the enhanced 911 system in our area which allows us to use a cell phone to write a message asking for help if we are unable to speak.

We laryngectomees need to educate ourselves. There are relatively few of us so we may encounter medical professionals who have never treated a lary and who mistake us for trach patients. There are many things we can and should learn and do to protect ourselves. (Compiled by David Blevins)

**What does the IAL do for me?**

I have been a lary for 25 years and have heard this question asked a number of times about what the IAL does to benefit an individual laryngectomee. Recently it was voiced by a club member. In his case the answer would be “not much, at least directly.”

If I answered the question I would have a long list of things I have gotten from the IAL. Undoubtedly the most important was to get my TEP voice at an IAL Voice Institute. My local ENT and speech therapist had tried Botox injections and myotomy surgery to relax the muscle around my esophagus since I was not getting any sound at all. They gave up on me and said that “some people just cannot get TEP voice.” But as a last resort I went to an IAL Voice Institute and asked for help.

Thanks to SLP Dr. Carla Gress, I made my first sound: (“ahhhh”). I knew then that if I could make any sound I would eventually speak, and be able to keep the job I loved as a teacher.

But it isn’t just those who go to an IAL VI Institute who benefit. The Voice Institute trains SLPs and SLP graduate students to learn how to provide help for larys. There are not many of us, and a survey indicated that only about 1% of SLPs in the U.S. could, for example, help us learn AL/EL speech or change a prosthesis.

The IAL Annual Meeting is the only national meeting for laryngectomees. Many larys do not live in areas with a local support club or trained SLPs and the Meeting may be the only contact they have with other larys. Isolation can be very damaging to us. The IAL News is often the only contact many larys have with other larys. We come to Annual Meetings for many reasons:

- spend quality time with people who understand us.
- learn about the latest products designed for our use.
- learn just about every development concerning total laryngectomee rehabilitation.
- socialize, celebrate, laugh, dance and dine out.
- shop and visit museums and tourist and historic sites.
- obtain help with speaking or other problems
- meet the “celebrities” and “stars” in our laryngectomee world including the inventors of the products we use and love, the vendors we deal with, and the best medical professionals in the world in the field of laryngectomee rehabilitation.
- get together with old friends and make some new ones.
- represent our clubs as Delegates who elect those who serve the IAL and shape its direction.
- run for election to an IAL office
- serve on an IAL committee.
- enjoy a great learning experience, perhaps combined with a vacation.
- return with samples and many new ideas.

A better question to ask about the IAL is “what does the IAL do for laryngectomees?” The answer is that it provides unique and essential support for us all, directly, or indirectly.
There are several Facebook Groups you can join. Please See below

International Association of Laryngectomees

WebWhispers.org
Sharing Support Worldwide
Throat Cancer and Laryngectomee Rehabilitation
Opinions and views by members may not represent WebWhispers or its Staff.

Opinions and views by members may not represent WebWhispers or its staff.

Laryngectomy Support

Larynectomy-Glossomectomy Support

Independent Association Of Laryngectomees

Lady Lary’s Lounge

The best portion of your life will be the small, nameless moments you spend smiling with someone who matters to you.

~ Unknown ~
CANCER TAKES VOICES:  
WE GIVE HOPE

Lary's Speakeasy is a 501(C)(3) non-profit organization, founded in 2016 by Lewis Trammell (Louie).
Our mission is to help to provide necessary supplies, education, support, and resources to laryngectomees and their Speech-Language Pathologists (SLPs) throughout the United States, free of charge.

What Kind of Supplies?
Supplies are available on a donation basis. We have provided: HME’s, baseplates, Boogie Boards, electrolarynx, skin care items, stoma covers, shower guards, neck straps, Lary tubes, cleaning supplies, and TEPs. All supplies are new or unopened.

How Do We Give Support?
Our “Lary’s Speakeasy Throat Cancer Support Group” on Facebook has over 3 thousand members. Laryngectomees, SLPs, and caregivers come together and provide their personal experience and expertise in the Lary world. We love to support the development of local support groups and Lost Chord clubs! We encourage you to join our group!

Visit our Resource Center
At https://www.larysspeakeasy.org you will find a wide variety of resources. Here we have a database of SLPs who are trained in laryngectomy care, support groups, medical alert tags, and education for not only Lary’s but also SLPs!

SLPs, Want to Get Involved?
Register with our organization, so that your contact information can be added to our SLP Listing at no cost or obligation to you. If you have a Lary that is in need of support or supplies, email us at larysspeakeasy2020@gmail.com! Join Lary’s Speakeasy Throat Cancer Support Group” on Facebook.

Want to support our cause?
There are several ways to support Lary’s Speakeasy. Contact larysspeakeasy2020@gmail.com or visit https://www.larysspeakeasy.org/donate.html.
1. **Financial support:** monetary donations help us offset shipping costs.
2. **Donate:** We accept new/unopened laryngectomy supplies. These donations are provided free of charge to laryngectomy patients in need of help.
3. **Amazon:** When you shop online thru smile.amazon.com, and select Lary’s Speakeasy, Amazon will donate a percentage of each order to Lary’s Speakeasy.
Provox Life Night HME is designed to improve lung health with the highest humidification of all the Provox Life HMEs

Night is a heat and moisture exchanger (HME) designed to be soft and smooth for comfort. It offers high humidification which helps reduce mucus production and coughing, allowing you to rest while improving lung health.

Night HME is compatible with ALL Provox Life attachments:
- Provox Life Standard, Sensitive, Stability and Night adhesives
- Provox Life LaryTube
- Provox Life LaryButton

Try Provox Life Night HME to experience nights with less coughing and wake up more rested in the morning.

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The testimonials relate to how one individual has experienced the use of Provox® Life™ products and not every person will get the same results. Atos Medical AB does not suggest, imply or make any claims other than those detailed in the product manual.