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* Orange Emergency Window Stickers (English)
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"First Steps” Available to download from the IAL website
Order From: IAL in Atlanta or email: theialoffice@gmail.com

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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.

Contact Allison Reber Wurz, theialoffice@gmail.com, for all updates to the IAL website, club postings, changes to club contacts and professionals, in addition to resources you may need from the IAL office.

Thank You!
What do you think about when people call you a “Survivor”?

By: Mike Greco  6/6/2021

I wrote this about my survivorship awhile back. I thought I would repost it here on National Survivors Day. I hope it serves to get a discussion going about your personal feelings of survivorship. Not what you tell your “non-cancer” friends in the outside world where they really don’t have a clue, but what we share with each other here in the real “post cancer” world where we live.

Being a Survivor
Someone asked me what it feels like to be a cancer survivor, how I felt about being known as a cancer survivor. It’s a complicated question because being a survivor is not what I volunteered to be, it is a label bestowed upon me because I fought the battle of my life to obtain it. I was involuntarily drafted into this cancer thing, it was not a choice I made. I never asked to become a survivor. Like most other head and neck cancer patients I was physically and emotionally drained by the end of my treatment. My treatment was probably much like yours; 34 radiation treatments that cooked my skin, scarred my throat, ruined my teeth, nuked my thyroid and salivary glands, two kinds of chemo that caused constant nausea and mucositis, a stomach tube for nutrition, a port for ingesting drugs, and finally a partial neck dissection that left a giant zipper scar. I was left shell-shocked and in a drug induced haze. At that point, treatment abruptly stopped and without any fanfare I woke up the next day as a survivor. The root of the word survivor is from the Latin word “viv”, which means “to live”. My after-cancer living began as a one day at a time struggle back to some kind of life we survivors call “the new normal”.

Now, almost 16 years later, people look at me and say awkward stuff all the time like, “I can hardly tell you had cancer”, or "at least you still have some of your voice", or “Wow, you made it!”. As survivors, most of us have become accustomed to these insensitive remarks by well meaning people.

But please accept this; being a survivor is not what I really wanted. What I really wanted is not to have experienced cancer at all. Once you have it, it lives with you forever. It's always just one check-up away. Every bump, every sore throat, every strange ache that "normal" people shrug off are potential life-ending events for me, sometimes causing days of angst and sleep-disturbed nights. Simple daily acts like eating, a joy that most people take for granted, are a constant struggle for me, requiring intense concentration and constant throat manipulation to avoid choking or aspiration.

My least favorite comment goes something like this. “16 Years, wow you are definitely cured”. I don’t feel cured. I feel alive, but my existence comes with recurring emotional ups and downs resulting from living with a genetic time-bomb in my DNA that could go off again at any moment. For me, that faint ticking in the background of my day to day existence will never go away. One bad check up and my flimsy survivors badge will have to go back in my junk drawer in the kitchen.

A person regarded as resilient or courageous enough to be able to overcome hardship, misfortune, etc.

The definition of a survivor is a person who copes with a bad situation and who gets through, or a person who manages to live through a situation that often causes death.

A person or thing that survives; specifically; a person who has survived an ordeal of great misfortune.

One who survives; one who endures through disaster or hardship.
Laryngectomees and Hot Weather

Hot weather is generally easier on a laryngectomee because of the increased air humidity. However, similar to non-laryngectomees it is important to take precautions and stay well hydrated (preferably by drinking cold drinks), avoid direct sun exposure, wear light lose clothes, cover the head, and stay indoors if the quality of air is poor.

Those at greatest risk of heat-related illnesses are people aged 65 years and older. Exposure to extreme heat has particularly adverse effects on people with chronic illnesses such as respiratory, cardiovascular, and renal diseases, diabetes, obesity, and mental illness. Medications including blood pressure and heart medicine (beta-blockers), water pills (diuretics), antidepressants, antipsychotics and anticonvulsants (seizure medication) and antihistamines (allergy medications) may also affect how the body reacts to heat.

The recommend daily consumption of fluids for adults is about eight 8-ounce glasses, which equals about 2 liters, or half a gallon. However, this may vary depending on environmental conditions (i.e., hot weather, low humidity), individual’s needs and medications.

Laryngectomees are required to drink fluids for these reasons:

• Enhancing swallowing
• Maintaining moisture in the mouth to compensate for not having enough saliva (xerostomia)
• Maintaining adequate respiratory tract moisture especially in low humidity
• Maintaining adequate fluid volume in their body (preventing dehydration, and orthostatic hypotension)
• Allowing adequate perspiration (especially in hot weather)
• Enhancing urine excretion

Those who speak using trachea esophageal speech and experience persistent leakage of the voice prosthesis into the trachea when liquids are ingested face a challenging situation in hot weather. It is important to stay well hydrated despite the leakage. If the leak is through the lumen of the voice prosthesis it can be stopped by inserting an adequate plug into the prosthesis whenever consuming fluids or it can be left until the prosthesis is changed. Consuming viscous fluids that generally do not leak (i.e., yogurt, jelly, soup, oatmeal, etc) can enable maintaining adequate hydration. Avoiding fluid losses in hot weather through perspiration by staying in an air-conditioned environment and ingesting liquids in a way that is less likely to leak are helpful. Drinks that contain caffeine increase urination and should be avoided.

Usually, humidity levels are elevated in the summer months and lower during winter. The ideal, home humidity for neck breathers should be between 40-50 %. Humidity that is too low or too high can cause medical problems. The best way to test humidity levels in one’s house is by using a hygrometer.

• Low humidity can cause dry skin, irritate ones nasal passages and throat, and make one’s eyes itchy.
• High humidity can make the home feel stuffy and can cause condensation of water on walls, floors and other surfaces that enhances the growth of molds, bacteria, and dust mites. These allergens can cause respiratory problems and trigger allergy and asthma flare-ups.

Laryngectomees should keep in touch with friends and family, as they may be their lifeline in case they need assistance. Wearing a heat and moisture exchanger (HME) reduces water loss through the lungs that can contribute to dehydration.

Itzhak Brook MD, MSc.

Dr. Brook is a physician and a laryngectomee. He is an Infectious Diseases Specialist, and a Professor of Pediatrics and Medicine at Georgetown University School of Medicine. He is the author of “My Voice: A Physician’s Personal Experience with Throat Cancer”, “The Laryngectomee Guide”, “The Laryngectomee Guide Expanded Edition”, and “Laryngectomee Guide for COVID-19 pandemic”. All these books are available for free download at https://dribrook.blogspot.com/
Karen White - Board Member, Rescue Champion, Mother, Neighbor and Friend

I'm sad to have to announce the passing on March 23rd, 2021 of our dear friend, Laryngectomee Club of Montgomery County (LCMC) board member, and IAL Board Member, Karen White.

Karen White became a Laryngectomee on June 23rd, 2004. As a result of no prior exposure to any other Laryngectomee and lack of instruction, from the hospital or SLP, on self-care post-surgery, Karen did her best to make sure that that no one else facing this surgery is uninformed. To that end she met with pre-op candidates and make in hospital visits post-surgery. Karen was comfortable discussing life as a Laryngectomee and took the training/certification offered by the IAL to facilitate this. Karen was a dedicated advocate for the Laryngectomee community! She was a board member of the International Association of Laryngectomees and The Laryngectomee Club of Montgomery County Maryland. She was an admin on Larry’s Speakeasy and Larry’s Voice Facebook groups as well.

Karen returned to the work-force only from Exxon Mobil Engineering on July 1, 2015. Her role was supporting 38 refineries and chemical plants worldwide with both phone support and managing the technical website used for operating plants.

When the American Speech-Language-Hearing Association (ASHA) planned a meeting with the policy makers at the Centers for Medicare and Medicaid (CMS) about voice prosthesis reimbursement limits and how to get them improved, I was called upon to be a patient representative by an ASHA.

As so many have said, “Karen was a champion in the rescue world”. One rescue group turned their page “silent” for the day to honor Karen. And I’m told that there’s nothing she enjoyed more than taking care of her animals; except traveling to horse shows with her daughter Lisanne.

At a memorial service at Karen’s home in Alexandria, so many neighbors shared that Karen LOVED the neighborhood children. She was very comfortable with being a Laryngectomee around the children and as a result, the children loved Karen as well. As one neighbor said tearfully: “I want to thank Karen for being so comfortable sharing her disability our children. Because of Karen, my child will never look the other way when meeting someone with a disability, and will always be comfortable in their presence. I cannot thank Karen enough for instilling that set of values in my child”

In addition to her dedication to the Laryngectomee community and the rescue world, there a few things that many do not about Karen. She was an avid skydiver and loved Astrology. However, other than her family, the thing Karen was most proud of was receiving a Bachelor’s Degree in Science at the age of 70, and she walked the stage to receive her diploma. Karen was the oldest person to date to receive a diploma from St Leo University!

My wife, Robin and I met Karen in February 2019 at the LCMC monthly meeting. I will never forget; at the end of the meeting, this petite blonde haired woman all of five foot nothing!, impeccably dressed in purple, (her favorite color) came over to us to what I thought would be to introduce herself. Instead, Karen wagged her finger in my face and said to Robin, almost scolding me "Don’t you do a thing for him in his Laryngectomee care. He needs to learn how to do this stuff by himself". My first reaction was: “Who is this lady”? “I’m having my voice box removed... take it easy on me”. My wife instantly responded to Karen “Oooh...I REALLY like you’!!!. I soon found out, as usual, when Karen speaks out, she is 100% correct.

Karen has held many titles: - Board Member, Rescue Champion, Mother, Neighbor... however Robin and I are honored call her our “dear friend”.

So many posted on Karen’s Facebook page after her passing that: “Karen had gained her wings”.
The reality is that her “wings” were always there... they just unfolded.
Karen is truly missed by everyone that had the pleasure of knowing her.

--Steven Cooper

If you want to, you can find
A million reasons to hate life and be angry at the world.
Or, if you want to, you could find
A million reasons to Love Life and be Happy.
Choose wisely.
I Had No Idea!

By: Tom Whitworth

Forty-four years ago, I enlisted in the U.S. Navy and I retired January 1, 2008 with active and reserve service of thirty years, four days and thirty-five minutes. So many times, being away from my family, I thought of quitting and moving on as a regular person, but I always had reasons to stay. There was the monthly retirement check and medical benefits being earned that would be so important later. That always seemed so far off in the future. Obviously, I stuck with it and I’m glad I did, yet over all those years I had no idea what the best reason to do so would end up being.

At age 56, I was diagnosed with throat cancer and lost my job over it. Yes, I am serious. My retirement coverage would not kick in until age 60. I struggled to pay COBRA insurance payments for a few months and the premium was a goat-choker so I lost that and had no form of healthcare the month following my laryngectomy. Great timing, I know! I had the coverage long enough following surgery to learn that it wouldn’t pay anything to speak of for laryngectomy supplies and I had a very high deductible.

I found myself with a borrowed Servox that needed to be returned and minimal supplies in the form of samples from my SLP. My first two voice prostheses were samples, as well. The future for all this stuff looked more than bleak. What would I do and what was going to happen to me? It didn’t help much at all that I knew basically absolutely nothing about any of this. That is why I fully understand the fear and frustration of many when it comes to getting laryngectomy supplies. I have definitely been there.

Becoming a part of the laryngectomy community has made all the difference in the world for me. I can’t even fathom where I would be without it or what would have happened to me. Only a handful of weeks post-laryngectomy, I found WebWhispers, which would prove to be priceless, and I miraculously made my way to an IAL Annual Meeting and Voice Institute. In one of the Voice Institute sessions, experienced SLPs taught graduate students how to use laryngectomy supplies on their future patients. In need of a nice new baseplate and with very little with me, I eagerly participated as a demo lary.

That same SLP, Carol Stach of the V.A. Medical Center in Houston, realized I was a veteran, and in talking with me, assured me I was eligible for VA health care. I had no idea! I doubted if she was right, anyway. I was in a pretty long stretch of bad luck and that just seemed too good to be true. Of course, she was absolutely correct or I would not be sitting here writing this for a WebWhispers newsletter and I wouldn’t be V.A. health care patient for seven years now. I truly had no idea I was eligible for the help. My V.A. health care has to be among the best in the world for laryngectomees. I don’t have to worry about going broke or even being broke already and I get everything I need. I thought of this because a package came today for which I owe nothing.

I could sing praises of the Veteran’s Administration for quite some time, but the V.A. is not my point. By the way, if you’re a veteran in the U.S. and have any questions, contact me. My point is the value of the laryngectomy community for me. Through WebWhispers and the IAL, I have friends I could not live without and wouldn’t want to try. I do not have to be concerned about my care and needed supplies, and hearing aids and electrolarynges either.

Where would I be without that first trip to an IAL Voice Institute? I had no idea!

Enjoy, laugh, and learn,

Tom Whitworth
WebWhispers President

**YOUNG-STIR**

She’s really cute—this little chick,
Wears groovy jeans and tops.
She uses every beauty trick;
Her dancing never stops.

She’s never square—she swings instead
And always comes in late
Then smiles a lot when she is told,
"Why, Grandma, you look great!!"
A VOICELESS CHOIR DIRECTOR
This article first appeared in the April 2010 Newsletter

By Richard McKinney
I lost my voice ten years ago in February. We celebrate five years out when we’re all cancer free, but we hold our breath, never quite trusting that. I lived in Hawaii when I had my surgery. I had been awfully sick for a while before they could figure out what was wrong. With only two weeks warning, my voice was taken from me. As a singer/voice coach/choir director, this was a particularly devastating occurrence. A laryngectomy is isolating for anyone,

who lack a singing voice. Of course, I have my trusty TruTone, which makes a huge difference in my life. I even do radio interviews prior to concerts.

I will never get over missing the ability to sing. There’s nothing like it. But I can still make music. My chorus sings for me, and oddly enough, they kind of sound like I used to sing; not perfect, but with lots of heart. And we sing to standing room only audiences.

JUST A LITTLE HUMOR

After some recovery, I continued writing music, something I had done throughout my life. When I had composed a full length cantata, I decided that I must also direct it. I had resigned as director of music at the church and was no longer teaching, but a dozen years as the director of music at a major Honolulu church afforded me the ability to ask the congregation to help me form a special choir that would sing music I wrote for them, starting with my first full length cantata. So with electrolarynx in hand, I asked for their help.

A few years later, I moved back to Missouri where I had done my my graduate work in music. My piano was badly damaged in transport, but the appraiser happened to be the community choir director who was looking to move on. I took over from him and now lead a choir of about 60 voices. I have also started several small ensembles, which are sub-groups of the larger chorus.

Sometimes rehearsals aren’t easy. If only I could demonstrate what I need from them. But we have learned to work together, and we manage. I don’t know any other choral directors

I AM A SEENAGER
(Senior teenager)

I have everything that I wanted as a teenager.
only 50 years later.
I don’t have to go to school or work.
I get an allowance every month.
I have my own pad.
I don’t have a curfew.
I have a driver’s license and my own car.
And I don’t have acne.
Life is Good!
Who in the World of IAL is Ed Myers?

In March of 2019 while visiting Universal and Walt Disney World for two weeks, my wife Cindy and I participated in a Virtual Half Marathon. On the way home I developed a bad cough and had trouble breathing and even staying awake and was later diagnosed with pneumonia. When that cleared up it was about June of 2019 when I realized climbing the stairs in my two-story home caused me to be out of breath and walking to our cluster box for the mail and back – only about 200 yards – I would have severe back pain.

My doctor sent me for neck and back x-rays and the radiologist saw “something” on the scan in addition to some vertebrae issues. At my ENT follow-up he found something that was acting like cancer but in his opinion was not acting like cancer. He then referred me to the ENT specialists at Eastern Virginia Medical School (EVMS). The first biopsy in August was non-cancerous and I was further referred for full Pulmonary and Cardio workups. The Cardio workup found I had a very strong heart (hooray) and so next was a pulmonary workup. The Pulmonary workup also proved unremarkable, and my pulmonologist asked why we felt we needed one. When I explained the situation, he pulled my CAT scan and scrolling through said “Well your lungs are fine, but the cancer is right there and has closed your airway almost 50%.” After he consulted with EVMS on the location of the cancer I went in again in September 2019 for a deeper biopsy on the cricoid bone and a tracheostomy. That biopsy found I had a rare chondro-cricoid carcinoma directly related to my asbestos exposure suffered in the Navy in 1979.

EVMS requested I meet with Cindy Lee Gordish, a speech pathologist (SLP) and Helen Grathwohl with the Tidewater Lost Chord Club. After weighing the options with Dr. Jonathan Mark and my family, I opted for a total laryngectomy in October of 2019.

You can imagine that after 31 years of Naval service, having played softball at some of the highest levels, and 13 years as an umpire this was quite a shock to my system. Speaking of my naval career, during that time I was a finalist for Fleet Master Chief Europe and a semifinalist for Master Chief Petty Officer of the Navy. I also served as the senior enlisted advisor for the Supreme Allied Commander, Atlantic and at NATO Headquarters in Norfolk. My family and I are proud of my naval career. An amusing anecdote started me on that path. While I was offered a full ride at Carnegie Mellon University and a three-year scholarship to the United States Air Force Academy, they weren’t great options for various reasons. Instead, I made an appointment with the local Marine Corps recruiter. When I showed up 10 minutes late, the Gunnery Sergeant had gone to lunch. Not one to miss an opportunity, the Navy recruiter came over and said they covered for the Marine Corps when they went to lunch and “since they’re part of the Navy anyway,” why not just join the Navy?” and 31 years later I re-entered the civilian workforce as a government contractor.

Currently, I work for Cape Henry Associates (CHA) as their Chief Compliance Officer. CHA is an awesome company and has not only supported me during my recoveries but truly recognized and valued my contributions. When my cancer struck, I was the Quality Management Director. When I returned to work 3 months after my surgery, they asked me to take on the additional role and responsibilities as the Compliance Director.

At about that time, I started having some post-op leg problems and was prescribed physical therapy and they were still 100% agreeable to my reduced schedule. Ironically, as my leg improved, and I started walking 3 or more miles each day suddenly I started having intense pains and could barely stand up. CHA allowed me to work from home during the follow-ups to what was causing me so much pain.
Remember that back pain I was having in June of 2019? Well between the cancer and physical therapy it pretty much was an afterthought until I started getting active again. Eventually they discovered I had a bone spur on my C-5 vertebra that needed removed. The neurosurgeon coordinated his schedule with my ENT surgeon, Dr. Jonathan Mark, and on December 1st, 2020, they were able to go in through my original incision for my laryngectomy, move my rebuilt esophagus out of the way, remove the C-5 vertebra, and fuse my C-4 and C- vertebra together. The bone spur caused a lot of damage and required a lot of in-home, and eventually outpatient, physical and occupational therapy.

This surgery had me contemplating my next adventure and I almost retired, but with all the support my company gave me I felt I couldn’t leave them in a lurch and so went back to work – from home – on February 12th, 2021, intending to retire in January 2022. The company was going through a major re-organization in June of 2021. The CEO called me and said are you really retiring, because if not we want to give you a promotion to Chief Compliance Officer and we don’t feel someone outside the company can really set up this position for success. I not only accepted their offer but was deeply honored in their confidence considering all the time I had missed over the last 2 years.

When asked what I like most about CHA I can honestly say, without a doubt, it’s “the fact that, while not always possible in the world of government contracting, they take care of each other as best they can.” The leadership “genuinely cares about their employees” and tries everything they can to keep them employed no matter what. This was truly evident when COVID-19 caused a need to convert to telework.

As a high-risk individual, I was forced to work from home and the transition was seamless.

My family is awesome, and I can’t say enough about their support during the last 5 years. I say 5 years because since October 2016 I had a recurrence of my bladder cancer, rotator cuff surgery, a tooth implant, a tracheostomy, laryngectomy, and spinal surgery; not to mention countless medical appointments, CT scans, MRIs, along with physical and occupational therapy. My wife Cindy, and my daughters Kerrie Lynn and Kayla have been my rock! They have dealt with my highs and lows, my anger and frustration, and mainly just “been there for me! Their support here and during my naval career cannot be measured.

Even my grandkids Jayson and Anna are my joys and kept my spirits up during my recovery. Anna enjoys reminding me when to take medications and checking up on me. Meanwhile, Jayson has stated he will invent a way for papa to have his old voice back. Who can not get better with support like that?

Lastly, I want to say thanks to all the doctors that guided me through this: Drs. John Liu, Ashley Burkholder, Jonathan Mark, Matthew Bak, Rachel Lock, Bonnie Nock, and Ran Vijai Singh; all the interns at EVMS and Norfolk Sentara General Hospital; my speech therapist Cindy Lee Lombardo Gordish; my physical therapists Crystal Barnes and Bethany Labossier; my VA therapist Melda Pol; and the countless Angels (nurses) led by Joy Mendoza who got me safely set up at home after my tracheostomy. “Live for today because Life (and speech) is good!”
A Laryngectomee Story

PORTSMOUTH, Va. — When the classical music starts playing and the paintbrush begins tapping against a glass container, Portsmouth artist Greg Haywood’s canvas comes to life.

The impressionist painter often feels trapped in the wrong era.

“I listen to music when I paint, it brings me into that thing… with my paint brush,” said Haywood. “I’m like a musical director. Every color and every stroke is a miracle of sorts.

That’s because in 2010, Haywood was badly injured when he was hit by a car during a hit-and-run. The former construction worker suffered a broken leg in three different places.

Six months later, he had a stroke.

While it didn’t paralyze him, it numbed the entire right side of his body, including his right hand, which he uses to paint.

“I have to adjust my way of painting because I can’t feel very much,” said Haywood.

Then, three years ago, he was diagnosed with stage four vocal chord cancer. It’s been a challenging health battle for Haywood.

The health issues and loss of feeling in his right hand only urged him to paint even more.

“I lived through all of that, didn’t quit, and I’m still here,” he said.

He told 13News Now his work has only blossomed since then.

“It’s more... a celebration of life,” said Haywood. “Of beauty, of love.”

Now, he’s taking his masterpieces out of his little apartment and sharing that labor of love with others.

Thursday, he went to the Gallery 21 in Norfolk, where he’s holding his first major art exhibition in a fine art gallery.

Inside of the gallery, he looked out in astonishment as he saw his paintings carefully arranged along the blank white walls.

They filled the room with color and overwhelmed the artist.

“I can’t believe how much work I’ve done,” said Haywood.

On July 10 between 5 and 8 p.m., the exhibition will open to the public. The show, "My Trek in Color," will last through August 5.

Each of the paintings inside of the gallery will go on sale.

“My paintings… that’s my legacy,” Haywood said.

Admission into the gallery is free.

AN UNCOMMON HERO

Jay Barbee writes:

My good friend and former coaching companion with Tabb High Baseball for 20 years, Coach Doug Baggett asked me to post this beautifully worded note pertaining to our good friend Daily Press Sports Reporter Marty O’Brien since Doug is not on Facebook! He tried to go through the Daily Press but they refused to print it! I’ll make sure Doug and Vee see all comments! Please share this!

Thanks, Jay

Each day that I read the newspaper, I first go the the sports section. As a coach and sports enthusiast, local sports news just brightens your day. It brightens your day unless your team lost the night before. I am a big fan of Marty O’Brien and always look for his human interest stories as it relates to local sports. I first read an article over 30 years ago that Marty wrote for the Yorktown Crier. The article was unbelievable! I knew that someone with those writing skills would draw national attention. The Daily Press recognized his talent and brought him on board. Coaches on the Peninsula consider him one of the best at his trade They trust him to write a story that lifts the athletes, coaches and community in a positive light. He is as much a part of the sports venue as all games that he reports. He is a Friend and supporter of every team on the Peninsula. Marty has faced cancer and treatment of the dreaded disease for some years. This past year Marty elected to have a Laryngectomy in order to continue a healthy life with his Beautiful Wife Allison. His attitude and love of life never wavered. His victory over cancer was much better than a National Championship. His attitude and outlook on the future is unbelievable. He is comfortable with the changes he’s had to make in his daily life. God took him by the hand and said “There’s more to do”! If each coach and athlete on the Peninsula had the fight in them that Marty exhibits day to day, their program would draw National Attention. Marty’s sense of humor and ability to make you smile still exists. His battle with throat cancer was epic.

Coaches and Athletes Marty interviews should first fight for their team with the same passion and desire that Marty felt fighting for his life.

Wins and loses are important!

Marty~1  Cancer~0

We all appreciate you Marty, never stop writing and come by more often!

Sincerely,

Coach Doug Baggett

Tabb High School
Oral Complications with Head/Neck Cancer Treatment ... a reminder to monitor your oral health       Stacey Brill, MSP., CCC-SLP

Regardless of the type of head/neck cancer and the surgery needed, oral complications are common. Whether a patient suffers acute complications (occur during cancer treatment and then go away after treatment) or chronic complications (continue or appear months to years after treatment has completed) concern with management of oral issues is significant. Since preventing and controlling these complications significantly improves quality of life, patients both pre- and post-surgery need to be vigilant in monitoring oral issues and maintaining oral care. Regular visits to your dentist for routine monitoring are a necessary part of your treatment plan.

Why are there so many oral complications?
Chemo-radiation is designed to be effective in slowing or stopping the growth of new cells. Unfortunately, as normal cells in the lining of the mouth grow quickly, particularity to repair any damage, anticancer treatment can prevent this from occurring. Thus, the ability of oral tissue to repair itself by making new cells is slowed, leading to prolonged time for healing of any oral injury. Additionally, chemotherapy and radiation upset the healthy balance of bacteria in the oral cavity, leading to potential infections. Chemotherapy can cause bleeding in the mouth, as well as nerve damage. Radiation can cause fibrosis in the mucous membranes in the mouth, tooth decay, gum disease, a breakdown of oral tissue, damage to salivary glands and bone, and fibrosis of muscle. Chemo-radiation can lead to inflamed mucous membranes in the mouth, infections in the mouth, taste changes, dry mouth (Xerostomia), and pain.

Things patients should monitor and treatment options:
It is important to closely monitor oral health during and post treatment. This helps to prevent problems, as well as identify and treat complications as soon as possible.

Oral mucositis is an inflammation of the mucous membranes in the oral cavity. It usually appears as red, burn-like sores or ulcer-like sores in the mouth. Mucositis can be caused by chemo or radiation. If it is caused by chemotherapy it generally heals in 2-4 weeks. If it is caused by radiation it typically lasts 6-8 weeks post treatment. Mucositis can cause pain, infection, and bleeding, as well as trouble eating/drinking. There are topical medications, painkillers, zinc supplements and alcohol-free mouthwashes may help with the pain.

Xerostomia (dry mouth) occurs when the salivary glands do not make enough saliva. Saliva is needed for taste, swallowing and speech. It helps prevent infection and tooth decay by cleaning off the teeth and gums and preventing too much acid in the mouth. Radiation can damage salivary glands and cause them to make a decreased amount of saliva. When there is not enough saliva being produced, the mouth gets dry. Symptoms of dry mouth include increased thirst, changes in taste, sore or burning feeling, cuts or cracks in the lips, changes in the surface of the tongue, and/or difficulty wearing dentures. Salivary glands may not recover completely after completion of radiation. Dry mouth and changes in the balance of bacteria in the mouth increase the risk of tooth decay. Your dentist may give you rinses to replace minerals in the teeth, rinses to fight infection in the oral cavity, saliva substitutes and fluoride treatments.

Taste changes are common with chemo-radiation. Taste changes can occur due to damage to the taste buds, infection, dry mouth or dental problems. For most patients, taste returns a few months' post treatment but, in the interim, do not ignore it as a 'part of effects' issue... seek treatment to manage any damage.

Mouth and neck stiffness can also be a consequence of head/neck cancer treatment. This stiffness is usually a result of fibrosis or reduced muscle use. Trismus is a reduced capability in oral cavity opening. Normal oral opening is 40-50 mm, thus a decrease in oral opening can make it difficult to perform good oral care, impacts speech clarity, causes difficulty with chewing and with obtaining dental x-rays. A Speech-Language Pathologist, Occupational or Physical Therapist specifically trained in head/neck cancer can address your trismus as well as fibrosis.

What can you do to maintain oral health?
Prevention of oral complications includes eating a well-balanced healthy diet (a dietary nutritionist can assist you with this), keeping your mouth and teeth clean, undergoing a complete dental exam and making sure you see your dentist on a routine basis every three months. Everyday oral care should include brushing your teeth (use a soft bristle brush if your mouth is sensitive) after each meal. Use a fluoride toothpaste with a mild taste as strong flavoring can irritate the mouth. Rinse on a regular basis using a baking soda/saltwater rinse to decrease soreness in the oral cavity. Floss gently or use a water pick on a slow speed to decrease the likelihood of plaque buildup. Perform good lip care (routine use of anti-chapping balms) to prevent lips from cracking. For those patients with dentures, make sure to brush and rinse dentures daily, use the denture cleaning recommended by your dentist and make sure to keep dentures moist when not wearing them.

While every patient is different, and the degree of side effects experienced varies, all will encounter oral issues. Making sure you practice basic oral health care and immediately address any concerns is extremely important. The gold standard with all patients should be good oral care during and after cancer treatment, patients should be good oral care during and after cancer treatment.
The Dating Dance

By: Debi Austin (reprint from February 2009)

We have made miraculous discoveries and advancements over the years. We have men/women living in unnamed parts of the solar system, we have made the desert bloom, and we have altered the human life span into triple digits. Yet we still deal with the common cold, acne, and the fear of dating. Not necessarily in that order.

I grew up in the 50’s. My grandmother believed women only went to college to find a husband. Bless her. This is also the same woman that told me “Mark my words, young lady. Your first child will be just like you!” I have no children of my own; she could have been telling the truth.

In those days parents laid heavy trips on their kids; some still do. Women were encouraged to marry young and produce children. After all, mothers wanted to be grandmothers. It was almost demanded of young men to choose a craft or profession in their early teens. Strange choices considering very few knew what the world had to offer them. Pick a husband/wife, choose a job, buy a house, and ask no questions. Simple, or not exactly.

What if...you wanted to see the world, dance in the streets, see life from a different angle, or simply be free to choose your own way. Following in any footsteps can be a rough road. New rules of dating were required for this. For those of us that did not want a husband/wife, honesty was mistaken for irresponsibility. Not wanting children was a sign of deep family secrets or in some cultures—punishment.

Dating was/is a test. How honest are you required to be? What little idiosyncrasies do you hide? Do you eat with your fingers? Do you tell him/her that you want to watch a hockey game instead of some love story? Do you ever tell him/her that you have dreams and adventures to follow? Do you really say you do not want children? When does it get easier? Never. Dive in! All the fears of your teens still exist, you just get older.

Those things seem kind of a moot point when you are dealing with a hole in your throat, a funny voice, and a flippant sense of humor on many levels. No matter what we say or think, there is no way surgery did not effect the way we see life and the world in general. Some things that have twisted our senses a year before surgery are now one more thing to add to the pile, the donut pile—when you do get “around-to-it.”

I think after surgery we confuse what we want with what people think we need. Some want to take care of us. This is a wonderful gift to be appreciated for what it is, a gift, not a way of life. As much as I hate to say this, we are treated how we allow people to treat us. If we see a broken person in the mirror, so will everyone else. Not what we wanted, maybe not fair, and not right, but true. Want to test

It, go to a mall and sit on a bench and watch people for an hour. It will surprise you. “Be all you can be” does not just apply to the Army by any means!

If necessity is the mother of invention perhaps we should mark our calendars every so often to evaluate ourselves. It becomes necessary to reinvent who we are, what we are, and most importantly what we want/need on a regular basis. Some of the other distractions are gone. Most of us do not have to do the children thing. We have our skills even if some alteration is required, and we know where we live. These things should make this little dance easier, right? You just keep thinking like that all the way to the single empty seat at the counter of the coffee shop. Now it is harder than it was the first time if you can imagine. Now we are older, set in our ways, unwilling to settle, and at the same time want to share these carved in stone ways with someone else. We do not want much here, do we?

Many of us have not done the dating dance in so long we have no idea where to even start. People are shocked or surprised by our voice, and we become defensive. The more defensive we become, the more our voices change, usually for the worse. Then frustration sets in, and the next thing many of us are home sitting on the pity pot with a bottle of wine or a bottle of whiskey. And we ask, “What went wrong?” We expected to be taken at face value; and when we were, that is not what we wanted.

We want the world to see the person we were instead of offering the world the opportunity to see who we are. No one can date a memory especially when it is not their memory. We have to discover the new person from the voice down and educate the community in the process. No pressure there. I am a fan of gatherings for anyone looking to date. I am anti-social so this is a challenge for me. I don’t play well with other children and have learned this lesson painfully over the years. But I am OK with it; because after all these years, I finally understand it. I can’t always fix it so I work around it.

For someone new to the dance, exactly what do you want? A partner, a friend, a dinner date, a few evenings a month and your personal space, someone for life, what? You have to have your own guidelines to expect someone to fit, don’t you? Or is that the problem? We want what we had, and we don’t want to settle. That is great, but do you remember how you got to what you had in the first place? You shared with a friend. You discovered that you had some of the same hopes and dreams. You worked at it. Very few people meet someone and say, “I just met your husband/wife” and the dream begins. It is hard work. Maybe because we are discovering ourselves through someone else’s eyes and the view is different, shocking, or disturbing, we stumble and lay blame. We need to relax. Have a plan that can withstand some altering from time to time. But most important we have to understand who we are because this
is the person we want to share with someone else. Our private selves have to be dealt with. I met a really nice laryngectomee who told me he was ashamed because he had done this to himself and how could anyone look at him and not see that? Wow, how heavy a trip is that? I think the first step to healing in many cases is to forgive yourself of the flaws you perceive.

In the first few years after surgery we are getting used to who we are, what we are, where we’re at, and where we want to go. This is a difficult adventure to share. Every day is new. I think it takes more honesty than some of us want to admit at first. But there is still a need for companionship and sharing. How do we do this? Join a church, enroll in a class, get out there! The more comfortable you are out in the world; the more comfortable the world is with you. It really is a “Catch 22” situation. Dating is all about sharing, but healing is very personal. You have to separate the two and at the same time make them work together.

If you are not comfortable with the new you, how can someone else be comfortable with you.

“You have to get your act together to take it on the road!” (1992)

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**Can You Hear My Voice?**

By Sara Braden

Can you hear my voice?
It's there for all to hear
It may not be a usual one
Not always very clear
Some days it's hardly there at all
But frustrating as it may.
I have to persevere, you see
As I have something to say.

It's gone
The box, the vocal chords
They took it all away
But can you shut me up?
Well, no!
As I have something to say

One thing is
Is that I am still here
With opinions you can be sure
Equally important
As they ever were before
They may not come across the same
Intonation's not always good
But I ask for you to listen, please
In a way I can be understood.

So here's the thing I know
I look and sound a different way
But I am still me, be patient, please
As I'll always have something to say
So if I'm in mid-sentence
And I stop, it's not by choice
So I'll ask again, in a different way
Can you hear my voice?

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**What is Granulated Tissue?**

In laryngectomees, granulated tissue typically forms at the TEP puncture site. It is caused by irritation as the prosthesis moves in the tract, the tissue reacts to the presence of a foreign body (the prosthesis), and also as a result of the puncture trying to heal itself closed.

The tissue wanting to heal closed is a good thing since it is what keeps us from having leakage around the outside of the prosthesis and into the lungs. The attempt to seal itself closed is the pressure which helps maintain the seal.

If they become a problem they are removed surgically (with a scalpel or laser) or and/or with the application of a chemical which works similarly to wart removers by killing the tissue.

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**Outlook**

By Priscilla Leonard

Forget each kindness that you do
As soon as you have done it.
Forget the praise that falls to you
The moment you have won it.
Forget the slander that you hear
Before you can repeat it.
Forget each slight, each spike each sheer
Wherever you may meet it.

Remember every kindness done
To you, whatever it measure.
Remember praise by other won
And

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**You learn more from failure than from success**

You’re allowed to scream
You’re allowed to cry
But DO NOT give up.
What Do You Miss Most Since Becoming A Laryngectomee?

This article appeared in the September 2009 IAL Newsletter. I am sure many of us can relate to this.

The question about what we miss most since becoming laryngectomees originated as an e-mail exchange among some of the members of the Internet-based laryngectomee support club, WebWhispers. It generated lots of responses including some from laryngectomees who insisted on changing the topic from losses to the positive side of becoming laryngectomees, or a least to balance the negatives with positives. Here are some of the responses (edited for length):

- Let’s face it, we all miss talking, eating, and being able to do things we used to do before our surgery. I am sure that everyone has something they miss the ability to make speeches, the ability to swim like we used to do, the ability to communicate with others as they did before surgery. (Don Claxton, Chandler, Arizona)

- Laughing out loud! (Carol Matson, Capistrano Beach, California)

- I miss being able to breathe well enough to play golf, or walk up a hill from my favorite fishing pond without gasping for air. (Bob Keiningham, Broken Arrow, Oklahoma)

- I used to sing backup for a local country band, but that’s out. I miss it. (Bill Larson, Las Vegas, Nevada)

- What I miss most is canoeing. I guess it could fall into the swimming category since it is the fear of drowning that keeps me out of my canoe. Last year we rented a cottage on the shore of Lake Superior. With the cottage came the use of a canoe and kayak. It took me three days to get up enough nerve to get in the boat. Once in, I slowly paddled out about 50 feet from shore. There I realized the depth of water was well over my head and the waves made the canoe very unstable. In days gone by, I’ve capsized several times. Usually, I either swim to the shore or cling to the overturned canoe until I can correct the situation. Now that I breathe a little differently, I quickly lost my nerve and returned post haste to shore and safety. (Len Bougie, Minesing, Ontario, Canada)

- What I miss most is -BEING ABLE TO YELL-at husband, kids, dogs. I still have an Irish temper, but it’s harder to express, but I pound on the table sometimes! All in all though, I do almost anything that I want to, even after cancer again in 2007, that took my right Jaw and most of my teeth. (Norma Kuykendall Bowen, Miles, Texas)

- (From, A Caregiver) My husband is one who rarely opens up about what he misses. When I read these posts it helped me realize that he is glad to be alive, and chooses not to talk about the steak he can no longer chew and swallow not being able to hike to his favorite fishing spot, etc. I realize that on “bad days,” he is still recognizing his limitations, and trying to accept them. And that maybe that fleeting look of overwhelming sadness is when he knows he can no longer do a certain thing, but the look of joy when he discovers other things that he can (like a big plate of mushroom ravioli at the Macaroni Grill on Saturday night). I have found that as a caregiver that is one of the biggest challenges—to replace the can’t do’s with the can do’s. (Debbie Wilson, Atlanta, Georgia)

- I miss shooting skeet because I can’t call “pull” when both hands are on my shotgun. Another thing I miss is being able to work my bird dogs in the field. They finally got to understand my commands in the pen or yard (although as dogs are wont to do, they sometimes act as if they can’t hear), but in the field it is impossible to communicate when the dog is 50 to 100 yards away. I simply have to have someone along who can be heard at a distance and who can blow a whistle loudly to recall the dog from 500 yards off after they chased a rabbit (which they can never catch.) (Joe White, Dallas, Texas)

- I guess I must be a sentimental fellow to say something like this - but what I miss most is being able to really laugh - and even cry. Not that I particularly enjoy sobbing; maybe it has happened once or twice since my operation six years ago. And of course I laugh - inside - and maybe utter something like “huh-huh” with my ES voice. But these are also social emotions and you laugh and cry with other in situations, as a way of showing closeness, togetherness and sharing something you experienced. Of course I should have liked to go swimming again - or sing - and drown out my friends in discussion. (Torbjorn Bull-Njaa, Skjetten, Norway)

- As time went on and I recovered more, little things have popped up which I found I missed dearly. I never realized how much I must have attempted to try to control group conversations, and those days are over as even loved ones will talk over you after everyone gets used to you. And I didn’t realize how much I must have enjoyed yelling during basketball games with my beloved Memphis Tigers...but I found out while watching them this year with my son-in-law that as much as I would try, I couldn’t even yell when they lost! And now that the flowers are blooming and everything is turning green, I’ve been in the
• backyard getting my pool ready for the summer. I taught all three of my kids how to swim, and now with them grown and having kids themselves, I was actually looking forward to acting like a teenager with them and doing foolish things off the diving board. I’m determined that we’ll still kick the music on, have everyone over, cook hamburgers and hot dogs, and have fun. But looking at the diving board periodically will cause a little sadness. I never thought I would ever say this, but I actually miss wearing a tie when going to church….I wore a suit and tie in the business world for thirty years and never thought the day would come when I said I missed wearing a tie. I guess what I miss the most is the amount of talking that consumed my daily life before the surgery…..It just didn’t occur to me how much speech such a large part of my day to day routine and my daily life. Even though my SLP tells me she thinks I sound great, I am limited in length of speech, or how long I can continuously talk before the speech becomes more difficult and harder to understand.

(Mike Smith, North Augusta, South Carolina)

• It’s perfectly healthy to miss things that have been taken from us. I, for one, miss being able to smell and let out a big old hearty laugh—now when I laugh I almost faint….But I think we can all agree that it’s great to be alive and we know things now that we would have never if we hadn’t had to take this journey - but we’re taking it together and I am so thankful for my life, my family, and all of you to be with me on this journey.

(Lillian Parra, Havasu Lake, California)

• In listing all of the things we miss it should be remembered that many things stay the same. For instance, when I first attended school I had to raise my hand to speak. Now that I have a TEP that hasn’t changed!

(Michael MacMahon, Corofin, Ireland)

• After my operation in 1987 my doctor gave me a list of “do’s and don’ts.” I was very active at the time and these new restrictions sent me into a depressed state. After I got over my radiation, I decided I’d push the envelope a little and see what I could allow myself to do. I found out I could still work the same job, wade in the ocean—but not swim, lift weights, climb, eat what I want and basically didn’t have to give up much of anything. So I tell everyone: enjoy the journey. It’s better than the alternative.

(Bill Larson, Las Vegas, Nevada)

• I don’t miss anything. I’m just glad I’m living and enjoying the joys of every day…my husband…my family…my grandchildren…and my great grandchildren. I enjoy the sun…the stars…and just plain waking up each morning and knowing

• I can still see all of this. I thank the good Lord that I am still here and NOT dwell on the “what ifs.” You have to move on.

(Betty Thompson, Fort Myers, Florida)

• I myself do not miss anything that I had before I had my throat cancer and my larynx removed. I am on my new life now after my doctor saved my life for now. It’s almost three years since it was done. What I do miss is the friends that I have met in WW that have passed on already. We all know someone who has passed on with cancer. This is what I really miss. I have learned to live without things I grew accustomed to before my Laryngectomy was done. This is part of life and should not be dwelled upon. We should be grateful for what we can still do and not what we cannot.

(Terrance Gaffney, Piscataway, New Jersey)

• I think I first TRULY realized how precious and good life is when diagnosed with lung cancer (in ’97) and when driving to work along this beautiful stretch of US1 along the back waters of the Mosquito Lagoon and suddenly coming to grips with: “Soon I may never see this again.” How we take for granted our family, our friends, and this wonderful place called EARTH!

(Dave Ross, Edgewater, Florida)

• (From a caregiver) I certainly don’t miss the months/years of sleepless nights worrying about his struggle to breathe prior to his laryngectomy he couldn’t exhale, and was told pre-op that it was sleep apnea! (The tumor was closing the airway!) The struggle to do anything the least excessive caused coughing and shortness of breath. It was a constant vigil to make sure he was still breathing. Apart from the natural process of aging, he is much healthier than before seven years hence, and I’m afraid I don’t always remember that he can’t talk with two hands full I never notice any scaring, and he looks just as good looking as he ever did! He can do all things as before, apart from getting under vehicles to work, for obvious reasons. Petrol fumes are a problem, so I insist on filling the car, when possible! Male Pride! But appreciate being treated as a lady! So I have to make sure the car is filled when he isn’t there! Guess we are lucky that water sports are and have never been our interest. This is probably the main drawback for many others. Being rural folk, I guess you learn early the art of compromise! Positive thinking is an advantage, and negativity never helps! I thought I would miss his fortnightly trip to the pub, but meds prohibit his former social drinking, and he doesn’t seem to miss them at all. He does occasionally, but pays the next day! Food is still enjoyable, although the onset of diabetes type 2, limits that, as well as cholesterol levels and
the occasional problem swallowing some foods. So relatively speaking, I guess he is one of the lucky ones! Perhaps all the other medical conditions make his lady incidental! Least of our worries! He certainly makes the most of the time he has, and I admire him so much. I find old friends totally accepting of the few minor limitations he has, and they are very accommodating. One way to find who your friends really are! (Patricia Glassop, Queensland, Australia)

I "miss" coughing myself to sleep each night... and I "miss" the hopelessness I felt after a couple of ENT's examined my throat and said my problems were just scar tissue from previous radiation and nothing could be done. But since last summer I've quit missing all that stuff because Dr. Zeitels at Mass. Gen. Hospital went deep and found cancer in my larynx, and on September 18, 2008 Dr. Jesus Medina at OU MedCenter got it out of me then wrapped a piece of chest muscle to my n throat to help me "keep my chin up," and a wonderful speech pathologist, Tracy Lynn Grammar, taught me how to speak and take care of my new lifeline. I enjoy a lot of wonderful memories, but this procedure has allowed me to celebrate my seventy-fourth year on our bright blue planet with a level of energy and health I thought that I had lost forever...and I don't want to spend any time thinking of things I can't do or don't have.

(Bob Keeningham, Broken Arrow, Oklahoma)

"A TRIBUTE TO OUR USA HEROES"

By Francis de Haes Janvier

Cheers! Cheers, for our heroes!
Not those who wear stars;
Not those who wear eagles, and leaflets and bars;
We know they are gallant, and honor them, too.
For bravely maintaining,
The Red, White, and Blue!

But, cheers for our soldiers,
Rough, wrinkled and brown;
The men who make heroes,
And ask no renown;
Unselfish, untiring, Intrepid and true,
The bulwark surrounding
The Red, White, and Blue!

Our patriot soldiers! When Treason arose,
And Freedom's own children
Assailed her as foes;
When Anarchy threatened
And Order withdrew, they rallied to rescue
The Red, White, and Blue!

Upholding our banner, on many a field,
The doom of the traitor they valiantly sealed;
And, worn with the conflict,
Found vigor anew, where Victory greeted
The Red, White, and Blue!

Yet, loved ones have fallen—
And still, where they sleep,
A sorrowing Nation shall silently weep,
And spring's fairest flowers,
In gratitude, strew,
O'er those who have cherished
The Red, White, and Blue!

But, glory immortal is waiting them now;
And chaplets unfading shall bind every brow.
When called by the trumpet,
At times great review, they stand who defended
The Red, White, and Blue!

"IF."

If I were what I wish I were
I'd have no reason to demur;
But I'd be more content and calm
If I wished I were what I am.

These were found in an old notebook from 1977 that my mother-In-law passed on to me. The book is full of sayings, stories and poems she cut out of newspapers and magazines and glued in the notebook. I enjoy reading them and wanted to share with you. I find them just as true today as they were back then. Helen
President's Message

As I sit down to write this message, I can't help but wonder if our Board of Directors made the right decision in cancelling our 2021 Annual Meeting/Voice Institute. Then I read our daily newspaper, and read that the governor of North Carolina is now telling his constituents to once again wear masks, due to the rise in Covid cases. Covid cases seem to be on the rise everywhere and it is just not worth the risk. Right decision? I sure feel it is! I hope each of you do too. It is a disappointment not being able to see each other again but we'd rather be safe than sorry.

I want to take this opportunity to thank Caryn Melvin, our voice institute director, and her staff for all of the work they put into getting this together only to have it cancelled. Caryn does so much for us! She works with both Inhealth and Atos to keep us informed of anything new and exciting, while providing needed instruction, and updates. “Thank You” just doesn’t seem enough for all you do for the IAL.

During these uncertain times we have been grateful for the support of our vendors. Because of this support the IAL has been able to stay connected with the laryngectomy community providing education and support during the pandemic. We are grateful to two of our vendors in particular, who graciously provided resources and a platform to connect with laryngectomees, caregivers, speech-language pathologists and students. Atos Medical sponsored our educational webinars and Inhealth Technologies sponsored our on-line support groups. In spite of circumstances that kept us physically apart, these two companies made it possible for us to stay in touch, fulfilling the IAL’s mission of support and education for the laryngectomy community.

We are grateful beyond words for all you have done and continue to do for the IAL.

I want to thank our Board of Directors for their advice and support. We hold meetings once each month via Zoom and discuss our decisions thoroughly. I did appoint two men to fill some open seats on the board. Steve Cooper and John Ready readily accepted these appointments and I am thankful for their wisdom and insight.

Since elections need to be held, and our by-laws updated we will attempt to hold a Zoom meeting with club delegates. More information on this will be sent to each member club within the next six weeks to two months. The information will contain the proposed by-law revisions as well as a list of nominees for all positions on the Board of Directors. If you know of anyone who would like to serve on the board, please pass that name on to us via the nominating committee chairman, Anne Ammenti at aammenti@sbcglobal.net. We need a president! My term is up and with some minor medical problems, I really would like to give up that position. I will continue to work on the newsletter and serve in any way I can. Please consider taking a seat and help with the necessary decisions to move the IAL forward.

I want everyone to know that I am always available to answer any questions you may have. Comments, both positive and negative are also welcomed. If there any suggestions, please send them to me. My email address is agrath3004@aol.com.

What information would you like to see in our newsletter? Do you enjoy the stories of other laryngectomees? Would you prefer medical issues addressed? Would you like a question and answer forum? I am always looking for articles for our newsletter and if anyone would like to send an article, I will be happy to print it. Just send it to my email address above.

While I am talking about our newsletter, I am asking you to go to our website (thelAL.com) and become a member of the IAL. It is only $5.00 and helps defray the cost of the newsletter. We’ve had 65 people do this and I appreciate every one of you. Please take a few minutes and join the IAL today.

Thanks to everyone one of you for your continued support of The International Association of Laryngectomees. We are trying our best to do what we can to support every one of you. Thank You,
Helen

"Optimism is the faith that leads to achievement. Nothing can be done without hope and confidence."
—Helen Keller
Welcome to The Swallows
Head and Neck Cancer Charity

The Swallows Charity supports all people affected by head and neck cancers; patients, caregivers, friends or relatives. The patient is the focus for support, help and signposting. However the role of caregivers and others is vital too, with their own support needs often overlooked. It is our intention for every person affected by head and neck cancer to have access to support at the point they need it, by the method of their choice, on a 24/7 basis. This could be by telephone, email or social media. This is the key growth area for The Swallows and we have expanded our global reach to provide resources, enabling this 24/7 support to be freely available to all people affected by head and neck cancers.

It is a proven fact that early diagnosis saves lives. Hence it is important to educate and inform people globally about a) how to avoid such cancers, and b) how to look for warning signs that allow for early diagnosis and treatment.

Our support groups

Currently we have several Support Groups in the UK and our unique virtual international monthly patient and caregiver meeting. Our aim is to increase the number of support groups over the coming years. The approach we use successfully is to provide a monthly meeting at which both patients and caregivers can attend to discuss their issues. They are given the opportunity to talk about these matters collectively or separately in a safe environment.

Our experience and feedback gathered from attendees is that they value this time spent together to talk about their own specific issues in an open and honest way and to receive support. We find that separating patients from caregivers for some of this time facilitates a more open and frank exchange which results in people in similar situations being able to offer much valued support and guidance. Feedback since 2011 has shown that this approach works very well, and this is the model that we are now seeking to use with all Swallows Support Groups in the UK and overseas.

www.theswallows.org.uk
info@theswallows.org.uk

Our main activities:

- Providing a wide range of patient & caregiver information books to patients, caregivers, relatives, GPs, professors, surgeons, clinical nurses, chemists, and dentists. We have a wide range of material covering awareness of Head and Neck cancer, early detection, signs and symptoms of what to look for, self-screening information and human papilloma virus (HPV) awareness material.
- We offer a unique & dedicated 24/7 support phone line, operated by patients & caregivers for the patient & caregiver. (This is not a call centre).
- Facilitating an annual Head and Neck Cancer Conference at which guest speakers and selected patients and caregivers from around the world can discuss key topics, key innovations in treatment methods, greater cooperation between health professionals and how to improve a patient’s cancer journey.
- We attend overseas conferences to help us raise awareness of our activities to key potential partners in major industries.
- Within the UK we are involved with health professionals at all levels to help them become more aware of the patient and caregiver journeys.
- On 27th July each year we participate in World Head and Neck Cancer Day to help generate awareness to a more global audience.
- We participate at Health and Well-Being events, often providing free oral health checks, in order to highlight the dangers of smoking, alcohol consumption and general lifestyles in the fight against head & neck cancer.
- Our website and social media platforms help to educate patients and caregivers with current and relevant information for head and neck cancers.
- The Swallows Charity shop’s primary purpose is to raise funds. This brings huge value to the local community which in turn supports local volunteers and helps boost the local high street.

Support for all affected by Head and Neck Cancer

24/7 Patient and Caregiver Support Line Service: 07504 725 059

Chief Executive Officer,
Head & Neck Cancer Survivors,
Honorary Senior Lecturer at the School of Health Sciences (UCLan),
The Swallows Head and Neck Cancer Support Charity

Chris Curtis
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JustGiving
justgiving.com/theswallows

Facebook: theswallows_cancersupport
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Provox® Life™ is a complete system designed to improve lung health and quality of life, it includes:

- Six heat and moisture exchangers (HMEs) designed to reduce coughing and mucus production with options to make it easier to breathe when you are more active
- Clover-shaped adhesives designed for comfort and fit that are compatible with all Provox Life HMEs
- SecureFit™ connection between the HME and Provox Life attachments (Adhesives, LaryTube and LaryButton) to provide confidence your HME will stay securely in place

Contact us today to learn how Provox Life can provide personalized solutions for your needs!

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