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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!
Presidents Message

It was with much consideration and angst that the decision was made to cancel our 2020 Annual Meeting/Voice Institute due to the COVID-19 pandemic. It was agreed upon by the entire Board of Directors after much input from some of the top doctors in the medical community. We further made the decision to hold the 2021 meeting in Charlotte, NC at the Crowne Plaza, June 9-12.

Due to this pandemic and the isolation we encountered by sheltering in place, I think we have learned some valuable lessons and hopefully some good has come of it and will continue after it is over and we return to a new normal.
* We have seen more families out walking with their children and/or pets, waving to friends and neighbors as they go by.
* We have seen neighbors helping neighbors, neighbors checking on the older folks in their neighborhoods and being kind to each other.
* Children are once again playing outside and learning the great outdoors.
* Parents learning what teachers go through every day and learning to appreciate their patience and hard work.
* People working in their yards, doing needed upkeep they have not been able to get done while they were working. The best part is, the children helping their parents.
* People stepping up to make face masks for anyone needing them.
* There are many acts of kindness, food donations, help for the medical community, and many other good deeds reported in the newspaper every day making it a joy to read the newspaper.
* I think we have all learned the value of family, friends and neighbors. Not being able to see, hug and be near those closest to us have made us appreciate them much more.
* We find we are all in this together and we have to work together to stop the spread of this terrible virus.
* REMEMBER: Be Safe! Wash Your Hands!

I do hope and pray that all of our laryngectomees are safe and well. I know it has been a trying time for all of us as we shelter in place and try our best to avoid getting struck by this virus. I am so looking forward to June of 2021 when we can hopefully all be together again in Charlotte, NC.

One last note, due to the fact that an election of officers could not be held due to no annual meeting, the officers and board members have all agreed to stay in place until 2021.

“I Goofed” in the March 2020 edition of the IAL News we published a wonderful story about the UK Head and Neck Cancer Conference. It was attended by David Kinkead and the wonderful story was written by him, but he was not acknowledged as the author of that story. I’m so sorry for this oversight and I want David to know that we are grateful for all he does for the IAL.

Congratulations to
Allison (Reber) and Joseph Wurz
On the birth of their Daughter, Norah
Born May 17, 2020
PREVENTING RESPIRATORY INFECTIONS INCLUDING CORONA AND INFLUENZA VIRUSES IN LARYNGECTOMEES

By Dr. Itzah Brook

Laryngectomees are more susceptible to respiratory infection because the air they inhale is not filtered by passing through their nose. Consequently, they are at increased risk of inhaling respiratory pathogens (viruses, bacteria, and fungi) through their stoma directly into their lungs. Therefore, laryngectomees have to be vigilant and protect themselves from respiratory pathogens.

Respiratory pathogens most commonly spread from an infected person to others through:

- The air by coughing and sneezing and rarely, fecal contamination
- Close personal contact, such as touching or shaking hands
- Touching an object or surface with the pathogen on it, then touching the stoma, mouth, nose, or eyes before washing hands.

Laryngectomees can protect themselves by getting vaccinated (when a vaccine is available) and:

- Wearing HME 24/7 especially when being around other people. HME with greater filtering ability would work better in reducing the risk of inhaling the virus (i.e., Provox Micron TM, Atos Medical's XtraMoist). Provox Micron, has an electrostatic filter and 99.9% filtration rate and it’s cover prevents direct finger contact of the stoma. Wearing it protects other individuals from becoming infected when the laryngectomee is infected.
- Wearing hands free HME (because it does not require touching when speaking) in those using trachea esophageal speech. Those who use a regular HME should wash their hands before touching their HME
- Wearing a face mask (preferably N95) over the stoma (see pictures how to modify the mask)
- Washing hands often with soap and water for at least 20 seconds. Use an alcohol-based hand sanitizer that contains at least 60% alcohol if soap and water are not available. This is especially important before managing their stoma, and touching their HME when speaking using trachea-esophageal speech.
- Avoiding touching the stoma, HME, eyes, nose, and mouth with unwashed hands. • Avoiding close contact with sick people.
- Cleaning and disinfecting frequently touched objects and surfaces.

A face mask with four strings can be modified to fit over the stoma. One of the strings can be extended with extra string; and the lower pair of strings can be tied behind the back. (see pictures)

If worn properly, a face mask can help block large-particle droplets, splashes, sprays or splatter that may contain germs (viruses and bacteria). Face masks may also help reduce exposure of the wearer’s respiratory secretions to others. While a face mask may be effective in blocking splashes and large-particle droplets, it does not filter or block very small particles in the air that may be transmitted by coughs, and sneezes. Face masks also do not provide complete protection from germs and other contaminants because of the loose fit between the surface of the face mask and the skin over the stoma.

Some face masks (i.e., N95) offer greater filtering abilities of germs and small dust particles. However, neck breathers and people with chronic respiratory, cardiac, or other medical conditions that make breathing difficult should check with their healthcare provider before using a N95 face mask because it can make it more difficult for the wearer to breathe.

Itzhak Brook MD, Professor of Pediatrics and Medicine, Georgetown University Washington DC
ENSURING ADEQUATE CARE DURING HOSPITALIZATION FOR LARYNGECTOMEES

Laryngectomees are at a high risk of not receiving adequate medical care when hospitalized. The medical staff is often not aware of their condition, do not know how to care for their airways, and may not know how to communicate with them. It is therefore important to take certain steps to ensure that the care is adequate:

1. Inform the ward’s head nurse and attending physician about the laryngectomee’s general and specific needs. In case of elective admission, this can be done prior to the admission to allow the staff time to get ready and to get adequate supplies and equipment.
2. Inform the dietician about the food requirements of the laryngectomee.
3. Inform and, when possible, meet with the hospital’s speech and language pathologist to ensure adequate care and availability of adequate supplies.
4. Laryngectomees who experience swallowing difficulties should request that the orally administered medications be given in liquid or easy to swallow form.
5. Request specific supplies and equipment to ensure adequate respiratory care, such as saline bullets, humidifier, and suction machine.
6. Keep reminding every staff member caring for the laryngectomee about his or her condition. This can be done by the patient and/or advocate, if allowed by the patient.
7. Inform the head nurse, attending physician, and/or patient’s hospital advocate if medical care is not adequate or if errors are made.
8. Request that signs informing the staff about the laryngectomee are placed in the patient’s room.
9. Wear the hospital patient ID wristband on the same hand that identifies them as neck breathers. Because staff is required to continuously check the patient ID wristband, they will be reminded of the condition.

10. Make sure that the laryngectomee is able to communicate with staff. Those using trachea-esophageal speech may need to use alternative speech methods such as an electro-larynx and/or communicate through writing and speech generating devices, i.e., laptop, smartphone, etc.

11. Prepare and bring adequate supplies required for one’s care (i.e., voice prosthesis and electro-larynx supplies).

Hopefully, these measures will improve the laryngectomee’s care during their hospital stay.

Itzhak Brook MD
Professor of Pediatrics and Medicine
Dr Brook underwent laryngectomy in 2008 and the author of “The Laryngectomee Guide” and “My Voice, a Physician’s Personal Experience with Throat Cancer”.

A PLEA FOR HELP!

By: Ron Mattoon

In consideration of the event we are living in today, we need to leverage the opportunity to help ourselves and others. I have started a project to work with my state officials to help improve the reimbursements for laryngectomy supplies. The main focus of my efforts is the change some of the codes used for Medicare and insurance reimbursements on items especially the base plates and micron filters. As everyone knows they are lumped under a single code for each and do not differentiate for the more expensive baseplates and filters. I have been raising this issue to the state insurance commission office and my senators. As a single person, I doubt I will have much impact however if the inputs come from several states we might have a better chance of making things better.

I urge everyone to send a letter to their state official on this cause, as it will help us all. I sent out my first two replies to the state on the WebWhispers email list. I just sent a clarification to the state insurance commissioner to clarify the issue with reimbursement. If we build some momentum on this issue, it will help. I have been successful in getting a dialog with 4 of our state officials on this and they have started an investigation on it. The micron filters are needed more now than ever, so it gives us an opportunity to be heard.

Good luck and I hope we are successful,

Ron Mattoon, Seattle, WA 2010

I am including a copy of the letter I sent to the Senators in my state for you to use as a guide.

Hello Senator,

I would like to bring to your attention a situation relating to all of the people in the US that had their larynx surgically removed. There are an estimated 40,000 of us in the US.

You are probably not aware (most people are not) that a person with a laryngectomy does not breathe through their mouth and nose. We breathe through a hole in our neck called a stoma. Our trachea and esophagus no longer connect at all due to surgery from throat cancer or other reasons. Due to this we cannot wear a mask like a normal person and the stoma connects directly into our trachea and the lungs. As a result we have no filtration system like our nose provided before. Here is a link that will help you understand our situation: https://www.inhealth.com/category_s/60.htm

I bring this up because for us, the only filter that protects us from any air born issues is one that is provided by ATOS medical supply called a micron filter. Here is a link to see what the filter is: https://www.atosmedical.us/product/provox-micron-hme/ This filter snaps into a baseplate we wear attached to our neck.

The Micron filters are a single one day use. Insurance only covers a very small part of the cost of them and it should, especially in today’s environment, cover the entire cost. We need them but most people cannot afford them. I purchase a few and wear them on only special occasions when I have to. The problem is actually a medical coding issue. There is one code that covers all Heat and Moisture exchange filter, so the reimbursement is based on the cheapest one. The least expensive ones are about $40 for a box of 30 while the Micron filters that we need are about $250 for a box of 30 so this adds up in a year’s time and that does not include the baseplates and other supplies we use.

There are a lot of special things being done now to help people and this would be a BIG game changer for the Laryngectomy community.
Would it be possible for you to look into this and start the process to give us some help with this situation? This filter should be covered by insurance especially Medicare.

If I can provide any other information to help, please feel free to contact me. I live in the South Des Moines area so I am in your area.

Stay well and thank you for your help,
Ron Mattoon
Email: t23rider@comcast.net

My Journey, From Student to Clinician

By: Sara Fallon, MA, CCC-SLP

Moving from an SLP graduate student to independent clinician was a three year journey. The curriculum in graduate school included the topic of head and neck cancer but there was limited exposure to managing patients with laryngectomies and more specifically managing patients with a TEP.

I was fortunate to complete my last graduate school clinical rotation at an acute care Level I Trauma facility. It was there that I met Cindy Gordish, SLP who mentored me and introduced me to the management of laryngectomy patients and the process of changing a TEP. It was an exciting time but one initially filled with anxiety. As a graduate student, I learned basic anatomy and changes that occur during a laryngectomy. During my clinical rotation with Ms. Gordish I was amazed at how intricate the surgery was and how as a speech therapist we have the opportunity to assist patients in finding their voice again. Learning to change a TEP was rather anxiety producing. Thanks to the knowledge and patience of my clinical supervisor, I was able to learn the process and experience the hands on opportunity to change a TEP. I am thankful to the patients who allowed me to care for them knowing that I was learning. I’m sure I seemed unsure of myself on many occasions but my patients understood and put me at ease. I quickly became very interested in this specialty of speech therapy and found myself yearning to learn more about this complex field. I had the opportunity to observe surgery and work with patients at all points of their journey with a laryngectomy. I looked forward to talking to the patients each day and giving each patient the individualized care they required. My experience in this clinical rotation led me to seek employment in a hospital setting with the goal of working with laryngectomy patients. I achieved this goal by obtaining a position in the same hospital I completed my last clinical rotation.

Fast forward three years and I am still fortunate enough to work with my then supervising clinician, Cindy Gordish. We are now colleagues who collaborate to manage the laryngectomy patients we care for. As a novice clinician, Cindy continued to mentor me and help me grow as a clinician. The opportunity I had in graduate school allowed me to move from student to an experienced clinician who is confident in her ability to provide care to this patient population. Without my graduate school experience I would most likely not have found myself in my current career setting working with an amazing group of individuals dedicated to helping patients by working together and continually learning. I am proud to be a part of an amazing society and will always be grateful for the patience and encouragement of the supervising clinician who led me down the path of student to expert clinician.
**Tru Tone Emote Ad**

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Griffin Laboratories is now part of the Atos Medical brand.
Be the Change

By: Stacey Brill, M.S., CCC-SLP

“Be the change you want to see” has been one of my mantras. What I have found, over the years, is that this often means CREATE the change you want to see. This is especially true in the case of laryngectomy patients and interactions with EMT/paramedics, emergency room professionals and hospital workers in general. Though I have been a speech pathologist specializing in working with head/neck cancer patients for almost 16 years, and have worked in hospital systems for the past 27, I had not realized that, due to the rarity of laryngectomies, many hospital staff were not as well educated as I had imagined.

Several years ago, one of my laryngectomees was hospitalized. When he was discharged and shared his hospital experience with me, I was troubled by the possibility that not all staff were as knowledgeable as I would have liked about laryngectomees. I felt I needed to come up with ways to create change to ensure patient safety.

Some of you reading this may have experienced a lack of knowledge about your or your loved one or your patient’s condition. I hope you have not. Sadly, as the population is small, many health care professionals have not been well educated in how to properly administer care. It was evident there was a need for change. To ensure my and all laryngectomy patients received appropriate care, I felt I needed to increase the background knowledge of those in my hospital system, which consisted of roughly 10,000 employees. The question was, how best to do this? There are many different departments and many different professionals... how to reach them all?

My first step was to meet with the informational services professionals who create educational modules online for our hospital system. I received permission to create a module that would be available to all employees. The module, using pictures and easy to understand language, rather than technical terms, provides information on the differences between tracheotomy and laryngectomy patients; safety concerns related to a laryngectomy and specific information about treatment; as well as how a laryngectomy patient communicates. The module is short, only 12 minutes long, and has a brief quiz at the end. Though I had hoped the module would be mandatory for all departments, due to the number of already required modules, this was not possible. I am still pursuing options and am trying to make it mandatory for at least front-line providers. The module is on the hospital system intranet and available for any employee to watch. It is also part of the nursing yearly education protocol.

Another area where I realized I needed to be the voice and advocate for my patients was in emergency care. After contacting our local EMT/paramedic program, I was able to provide 1-hour lectures to them. The focus is on how to handle a patient with a laryngectomy, including teaching them about neck breathers and how anatomy has changed post-surgery. Sharing patient videos and bringing laryngectomy supplies to pass around (so these professionals get a feel for what they could be seeing in the field) has been very helpful. It also eases my mind about the potential treatment my patients' will receive. Bringing a laryngectomee to address the group has been extremely beneficial in answering any questions the trainees may have. The lectures have received positive feedback and I am working to make them an annual part of the training program.
Another crucial part of training emergency care professionals is educating hospital and emergency room staff. Information about the difference of being a neck breather, how to administer oxygen, where to place IVs and pulse oxygen readers with patients using an artificial larynx, or what to do if a prothesis fell out. This focused me on providing educational training of this group in person, as I had with the paramedics. Two of our four hospitals in town see oncology patients, so training started first with those two facilities. Providing an educational in-service to the respiratory therapists was first on the list. I found there was not always adequate knowledge about laryngectomy patients. Once we had reviewed the basics of laryngectomees, I was able to explain safety precautions, ways of communication and what a TEP is. Attendees were appreciative of the information and have contacted me with further questions. The oncology nurses were also given an in-service as a reminder for them (as they see these patients post-op). The ER departments are next on my list. As emergency departments are extremely busy and members are required to do many varied trainings, it has been more difficult to find a time for staff to meet with me, but I continue to plan for the opportunity. I have walked patients to the ER and stayed with them to explain to the staff they are a neck breather, they have a TEP and what it is and if the patient is using an artificial larynx to please place IV’s and pulse ox on the hand not used for holding the artificial larynx. I have also called the ER to explain to them to x-ray the chest and abdomen if prothesis has fallen out and the patient is unable to locate it. Those with whom I have interacted have always been very receptive to assistance, but I continue to believe department-wide training would be helpful.

I’ve also learned that, as a speech pathologist I, do not have all the answers. I am not a laryngectomee myself. Thus, I have started a program where I offer “laryngectomy buddies” to anyone I see pre-op. It gives them the opportunity to speak with someone that has already traveled the road they are facing and can give them better insight into life as a laryngectomee. The laryngectomy buddy is welcome to visit them in the hospital if they agree and is someone who can provide them with lifelong support. It’s neat to see some relationships that are forged from this. Others prefer online support groups and that information is provided to them as well.

To go back to the beginning of this article … you too can create the change! I hope sharing my journey with you may inspire you to make a difference in your community. Whether you are a healthcare professional, a caregiver, a friend or a laryngectomee, you can offer support to others. You can be a laryngectomee buddy, you can offer training or information to health care professionals, you can ask your doctors or other therapists to consider providing in-services to hospital staff. One person does have the ability to make a difference, one step at a time.

The secret of change is to focus all of your energy, not on fighting the old, but on building the new. Small changes eventually add up to huge results.
KNOWLEDGE IS POWER

By: Susan Bruemmer, M.S., CCC-SLP

The unknown is scary. You can imagine all kinds of terrible things when you are in the dark. Is there a ledge that you can fall over or a bump that you can trip over. But with light you can see what is ahead of you and it is less scary. That is how I see the purpose of pre-operative counseling as well as post-operative counseling.

When I get a call from a physician that he/she has a prospective laryngectomee, I set up a meeting with the patient and any family members that will be going through this life-changing experience. The meeting can be at the patient’s home or my home (since I retired). I also invite one of our laryngectomee club members so the patient can see that there is “life after laryngectomy”. I discuss the present anatomy of the airway for speech, swallowing, and breathing and the anatomy post laryngectomy. It is important to know the differences in breathing after laryngectomy and how vital it is in an emergency situation that first responders apply oxygen to the stoma and not the mouth. I emphasize the fact that although the voice box will be removed, a laryngectomee can still make several consonant sounds that do not require voicing including /p, t, k, f, s, th, ch, sh/. I have them practice making these sounds in isolation and enunciate because this will help their speech intelligibility with EL, esophageal, or TEP speech options after surgery. I have the patient and family members try to use an EL without using their current voice. I have the laryngectomee club member explain helpful tips that have helped them in their journey with life after laryngectomy. Above all, we are there to answer any/all questions the patient and family have about the upcoming surgery. I send home a packet of information about the things we discussed anatomy photos before and after surgery, IAL emergency stickers, cards about neck breathers, Medic Alert ID information, sample of stoma covers, lists of medical suppliers, on-line support groups and our local laryngectomee club.

Of course the pre-operative visit has a lot of information that even with the take home packet can be a bit overwhelming. So I encourage a post-operative visit when there will be a myriad of questions. Again I try to bring one of our laryngectomee members who can answer many of their day-to-day questions about stoma care, swallowing issues with different types of foods, etc. The patient will also be seen by the speech pathologist on staff at the hospital during their recovery. I strongly encourage the patient to join our support group that meets monthly at the Tri-Cities Cancer Center. We are there to support each other, to encourage each other, and applaud their successes. There is no need to be in the dark. Knowledge is power!

“Knowledge is Power” is a famous proverb that states that a person with Knowledge can outwit the physical strength of any other person.
Mom’s Cancer Battle

By: Nicole Oorbeek daughter of Jennifer Malkiewicz

In November of 2016, my brother and I received the news that nobody wants to hear: Mom has cancer. At that time, it didn’t even matter what kind of cancer it was. Our Dad had recently gone through cancer treatment for squamous carcinoma in his neck, and we were all too familiar with the struggles she was potentially going to face. As the details became more clear… tracheostomy… laryngectomy… no more of the voice that we had been so accustomed to since… well, the womb… it just got scarier and scarier. We could tell that we weren’t getting all of the information - our parents’ way of trying to protect us - which only made us worry even more.

What made matters worse is that she had recently relocated to Virginia, and her entire family is in New Jersey. Knowing she was largely going to go through this alone was possibly the worst part for us, it was absolutely heartbreaking to know that we couldn’t be there for her in the way that we wanted to, and I think we both really struggled with that. There was only so much we could do from afar. We were both approaching the most exciting points in our lives, on the brink of getting engaged to our partners, buying homes, having babies. We both knew all of that was coming for us, and the thought of our Mom possibly not being here for that was equally devastating.

While those months were some of the toughest we’ve all had as a family, the rainbow that followed the storm has also been the brightest. Our Mom is a fighter and she battled through, even when she felt like she couldn’t. She has been able to experience the happiest moments of our lives with us - those engagements, weddings, home buying, and babies that we were eagerly awaiting all did come. And while it’s not the voice that we grew up hearing, the love behind it hasn't changed, and we are grateful that our kids have their Nana Banana. We are both eternally thankful to her medical team, and to her supporters in Virginia for getting her through that storm.

“Nana Banana”  Olivia  Finnegan
Folks is proud to be partnered with Inspire, the world’s leading healthcare social network. If you are dealing with a health condition mentioned in this article, register and connect with other people who understand and inspire you.

A laryngectomy, the surgical removal of the voice box, creates tremendous difficulties for patients. Firstly, they lose their voice, that vital transmitter of one’s individuality and essence. The procedure also weakens their sense of taste, since they can no longer breathe through their nose. Swallowing, too, becomes difficult. The psychological toll is severe. “The voice is so linked to your personality. If your voice suddenly changes, it has a huge impact on recognizing yourself,” says Dr. Thomas Moors, an ear, neck and throat specialist based in London. Moors, 36, observed the mental anguish that the operation was inflicting on his patients—the loss of confidence, the move towards social isolation, the depression—and came up with an odd remedy. Moors, who in his native Belgium had been a choir boy, had always loved music. His childhood experience in the choir had instilled him with confidence and a sense of camaraderie. “From a very young age I was introduced to the power of music,” he said. He decided this was just what his patient needed. In 2015, Moors formed the Shout at Cancer choir, a choral group made up of laryngectomy patients, i.e. people without a voice box. There are now around fifteen members in the UK, and six in a Belgian offshoot, with a handful of instructors. The group has performed around the world. A documentary on them, Can You Hear My Voice?, premiered in London in February. It was produced by a filmmaker named Bill Brummel, a laryngectomy survivor himself. “I think of the Shout at Cancer choir as a support group on
steroids,” said Brummel. “Through song and spoken word, they reveal the travails and triumphs of living without a voice box in a dramatic and entertaining style. Early on, I saw that and was affected by it. I still am.”

Folks spoke with Moors, whom Brummel describes as, “an ideas man who puts his best concepts into action,” about how he came up with such a strange but successful scheme, how the choir has impacted the lives of its members and what are some future plans they have in store.

**How did this idea first come about in you?**

After starting in medicine, I wasn’t quite sure if I had made the right decision. I wanted to combine my passions and make use of music and art in medicine. I read about laryngectomy and how it turns voices monotonous, how difficult it is to socially reintegrate, how they are affected in their mood. If you read into it, the effect of music and sharing a goal with others like a choir does, helps with social isolation. At the same time they practice on their voice and push each other. And via the use of poetry and spoken word, we have them express their feelings in a different way. When you’re writing in the third person, it’s less personal. You can hide behind the artform, behind the fact that it might not be you that you’re writing about.

**What kinds of people join your choir?**

The choir showcases that throat cancer can affect anyone. You see a huge difference between them in opinions and backgrounds. We have a beautiful range of people: posh members, normal people, a plasterer, bricklayer, secretary, a manager. The beauty of the whole choir is that they found a voice together, people that, perhaps, in a normal setting might not have gotten along. But it’s a very tight group.

**How do you choose songs?**

They are able to select their own songs. It just motivates them to exercise and practice. We often change lyrics. For instance, we completely rewrote the lyrics of “Ain’t Got No” by Nina Simone specifically for our choir group, to really explain the layered impact of laryngectomy on themselves and environments.

**What is the impact, exactly?**

The voice travels with you from birth, grows with you. It is your expression of thoughts. It’s who you are.

After a laryngectomy, you sound completely different. And you have to recover from quite a big surgery. Then there’s the radiotherapy that most of them have to go through, which is very painful. That’s a tough period, for most of them the toughest. It gives you burns and all that. It leaves scars. People react strangely to them; they point at them. So they deal with negative experiences outside. It takes a lot to just say, “Listen, why should I change my lifestyle because of people’s reactions?” People who have come to terms with it have found the balance and it makes them stronger. But for a lot of people it just makes it harder and pushes them even further into social isolation.

Also, it’s not just the voice that’s gone. The sense of smell changes because they don’t breathe through their nose anymore. It’s dangerous, in a way, because you can’t smell if there’s fire or a gas leak. That affects your taste. Food is not as nice anymore; it’s like you have a permanent cold, with just the five basic
tastes of the tongue. And it’s harder to swallow, with the whole swallowing mechanism changed. A lot of them struggle with solid foods. They also can’t talk anymore while they eat. That’s very annoying because we are so used to speaking with each other during meals. There’s a huge social link between food and conversation. That’s hard for them. Also, when they’re outside and there’s background noise, the pitch of their new voice is very low, so it’s extremely hard to understand them in a louder environment. Almost impossible.

Was it difficult to recruit members?
That did not go easily. Someone claiming, “We’re going to use singing to improve your voice after you’ve lost your voice.” Yeah, that sounds rather foolish. But I started working with some of them, then more joined. They saw that it made a real difference: in their intonation, the length of voicing, their confidence, their projection. They really could tell the difference, and liked it. Through word of mouth, it grew.

Instructors-wise, it’s not just me. There are a few others. We’ve also worked with opera singers, pro singers, actors, beat boxers, voice-over artists, poets.

It’s co-ed?
Yes, but there’s less women affected by throat cancer than men. It’s about a ratio of one to four.

What are some future plans?
Project-wise, we were lined up to perform in Snape Maltings, a famous music festival started by the composer Benjamin Britten. We also had a ceremony concert at the World Opera Games, which has been postponed until next year. We are also part of research with the development of an implantable larynx through the University of College, London. We are translating that research development into an opera.

This article was originally published in Folks (folks.pillpack.com) Pillpack’s magazine about extraordinary people living with illness or disability.

Folks is an online magazine dedicated to telling the stories of remarkable people who refuse to be defined by their health issues. By sharing the experiences of these individuals, we hope to change people’s notions about what it means to be “normal”.

Editorially independent, Folks is sponsored and published by PillPack. Part of our mission at PillPack is to create healthcare experiences that empower people. We don’t believe people are defined by their conditions. We pay our contributors, and we don’t sell advertising.

If you’d like to partner with Folks, or share a story, let us know at folks@pillpack.com.
Patient & Caregivers monthly online meeting

Coronavirus initiative

We are so proud that since the charity has started, we have never missed a monthly meeting for our patients and caregivers to meet.

In February, this year we celebrated our biggest achievement by hitting our 100th monthly meeting.

The Coronavirus was not going to stop us holding the meeting so in April we held our very first online meeting. We had 40 windows opened throughout the night with patients, carers, health professionals joining us from all over the globe including New Zealand, Australia, USA, India and the UK.

We intend to continue these meetings till December and then review the online meetings in January 2021.

International Online Monthly Meeting

Every 2nd Wednesday of the month ~ 18:30 BST to 20:45 BST

Audience on the night

Patients
Caregivers
Survivors
Head & Neck & Laryngectomy

Health Professionals
Industry Specialists
National Press

40 Windows Open

35 Windows stayed till close
5 Windows left between 20:30 and 20:45

6 Countries

England
Scotland
Wales
USA

Australia
New Zealand
India
Spain
On the night
➢ David Grayson, Clinical Director Otolaryngology Head & Neck Surgery (New Zealand)
➢ Arthur Lauretano, Medical Director - Otolaryngology-Head and Neck Surgery (USA)
➢ Frances Tully, Independent Nurse (UK)
➢ Bruce Carlin, Oralieve (Dry Mouth) (UK)
➢ Paul Burns, Water-Jel (Radiotherapy) (UK)
➢ Laura Mowat, Freelance Journalist (UK)
➢ Julie Lucas, Head & Neck Cancer Support Worker, Blackpool Victoria Hospital (UK)

Speakers on the night
➢ Maureen Jenson, Survivor from New Zealand
➢ Bruce Carlin, Oralieve (Dry Mouth) (UK)
➢ Frances Tully, Independent Nurse (UK)

Open Session
Everyone had the time to chat

Next Meeting Dates
Wednesday, 13th May 2020 Wednesday, 10th June 2020 Wednesday, 12th August 2020 Further dates to be confirmed

Registration
Email chris@THESWALLOWS.ORG.UK

International Online Monthly Meeting
Every 2nd Wednesday of the month ~ 18:30BST to 20:45BST
Committee Appointments

Since we were not able to have a delegate meeting and an election of officers I have appointed two laryngectomees, who have expressed a desire to join our Board of Directors. These gentlemen will be serving on the newsletter committee to assist in gathering articles and other content to appear in our newsletter. I am including their pictures and bios as they will be running for a seat on the Board when next we meet.

Bio By: Steve Cooper

I was born in Maryland on January 2, 1957 and am a lifelong resident. On 2/25/2019 I became a Laryngectomee. Fortunately, I was able to meet Herb (and Sally) Simon President of the Laryngectomee Club of Montgomery County (Maryland) and attended my first club meeting prior to my surgery. I attended my first IAL Annual Meeting, as a voting delegate in Phoenix, AZ in May, 2019 which was just 10 weeks post-surgery. It was in part these experiences that greatly helped in my swift recovery. Additionally, thanks to all of the early help that I received, both in person and from many of the wonderful members of the Laryngectomee community, I have been instilled with a need to assist other Laryngectomees or family members in any way that I can. I soon came to the realization that many of our hospitals, healthcare providers and ENT personnel are not adequately educated in the issues and care required for Laryngectomees. For these reasons, I continually welcome the opportunity to meet with new patients, family members and others, and to be a staunch advocate in the Laryngectomee community. Have met with new Laryngectomees or patients that are about to have this life changing surgery on many occasions and always find this to be a very rewarding experience.

I have had a varied career that would add greatly to provide valuable input to the board of the IAL. I have owned or operated successful businesses for over 40 years, have been licensed in Real Estate, held the National Association of Security Dealers (NASD) Series 7, Series 63 and Series 65 securities licenses. Attended St Joseph’s University Haub School of Business Executive Education Professional Development and Advanced Curriculum Programs in 2007 and 2008.

Currently I am the V-P Finance for WebWhispers, Inc, manage their “Lary Alert Kits” program, and assist in fundraising. I was a member and mentor for the Montgomery County (MD) Corporate Volunteer Council, Co-Chair of the Washington Capitals Alumni Association Annual Benefit for The Children’s Inn at NIH for several years as well as many other volunteer opportunities. I am very active in the Laryngectomee Club of Montgomery County as well.

My hope is to help build on the success, advocacy, education and support that the IAL has provided over its 68 year history.
I'm Martin “Marty” Murphy of Alexandria, Kentucky. I've been involved with the University of Cincinnati Barrett Cancer Center since. I'm on their list of support people that will personally meet with those facing a Laryngectomy.

I have thirteen years experience in the convention/meeting/hotel industry. I worked for the Greater Cincinnati Convention & Visitors Bureau specifically with hotels from 1984 to 1997. After that I spent 19 years with the Cintas Corporation in their Uniform and Fire Protection Divisions.

I would very much like to join the BOD, share my experience and knowledge and receive same in return.

Sincerely,
Marty

These gentlemen come highly recommended by their clubs and we know they will be an asset to our Board of Directors.

SAVE THE DATE
JUNE 9 - 12, 2021
INTERNATIONAL ASSOCIATION OF LARYNGECTOMEES
ANNUAL MEETING AND VOICE INSTITUTE
CROWNE PLAZA HOTEL
CHARLOTTE, NC
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